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Social Workers' Experiences With Interventions for Clients With Congenital Heart Disease

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Abstract

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MSW, Western New Mexico University, 2015

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Project Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Social Work

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Abstract

Many adults born with congenital heart disease (CHD) face long-term psychosocial issues related the disease. The purpose of this project was to better understand social workers' experiences with interventions for clients who have CHD and experience psychosocial problems. Bronfenbrenner's ecological theory was a basis for the research questions, which focused on clarifying social workers' experiences with interventions and identifying the ecological levels to which the interventions align. A narrative design with nonprobability sampling was used. Six social workers who counsel adults with CHD from 6 of the 109 U.S. CHD clinics participated in individual interviews. Interviews were transcribed, coded, and categorized using thematic analysis, then analyzed for new information, similarities, and differences. The most significant clinical and nonclinical interventions used by participants were financial assistance, health insurance support, and modalities for treating anxiety and depression. Social workers counseling adult CHD patients may benefit by having information from experienced CHD social workers that they can incorporate into their work with clients. Recommendations include (a) bolstering the number of social workers in private practice who specialize in adults with CHD to address the ongoing mental health needs of this population and (b) encouraging social action and awareness to adjust the guidelines set by government agencies so this population can qualify for better financial, health, and disability benefits. Implementation of these recommendations may have a positive social impact for adults living with CHD.

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Dedication

This is dedicated to my mother, Anita Smorra; father, Patrick Smorra; and brother, Patrick Smorra Jr., who have been at my side during this lifelong journey with congenital heart disease. I am so pleased that I can now show them there are positive results from providing long-term, never-ending support to a child and sister.

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First, I would like to thank my love, Marc Seguin, for his unending support during the 3 years it took for me to obtain this degree. He came into my life at the very beginning of this endeavor and consistently provided unwavering encouragement. I am looking forward to our life together postdoctorate.

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Christa Hope, you have helped me through so many isolating days by staying in touch with me and getting me out of the house for walks during the day. Your company has been a beacon of light through this sometimes grueling and frustrating process; you have also been a friend who has celebrated the positive milestones. Thank you from the bottom of my heart.

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Section 1: Foundation of the Study and Literature Review

A congenital heart defect is a complication with the structure of the heart when a child is born. A congenital heart defect is referred to as congenital heart disease (CHD). Today, approximately one in 100 newborns has a heart deformity; between 2 to 3 million adults, adolescents, children, and babies in the United States have CHD (Adult Congenital Heart Association [ACHA], 2018). Over the past several decades, notable advances such as innovation in diagnosis, less invasive surgical interventions, specialized CHD clinics, medications, clinical research, monitoring, and advanced imaging techniques have been made in medically treating this disease, enabling more infants to live to adulthood and making the current number of adults with CHD approximately four in 1,000 (Bouma & Mulder, 2017; Eslami, Sundin, Macassa, Khankeh, & Soares, 2013).

Researchers studying CHD have identified psychosocial issues as an area needing further research. This is because mental issues have been found to commonly occur among those with CHD (Goossens, Moons, Fleck, Canobbio, & Harrison, 2012; Kovacs, et al., 2015). CHD requires lifelong care. Multiple surgeries, which can be repeated trauma, as well as limitations on energy coupled with the increased demands of advanced schooling, full time employment, and living independently as these clients mature into adulthood, are causing this population to experience depression and anxiety (Eslami et al., 2013). Wilson, Smith-Parrish, Marino, and Kovacs (2015) stated that more research is needed regarding the psychosocial needs for this population, particularly for adults. According to Wilson et al., research for psychosocial needs on adults with CHD is approximately 10 years behind that on children.

The social work practice problems are limited information and research regarding social workers' experience with the CHD population. For example, there are 114 CHD clinics internationally, of those 109 are located in the United States (ACHA, 2019). Of the 109 clinics in the United States, approximately 40 have a designated social worker (ACHA, 2019); hence the number of social workers currently practicing with this specific population is limited. Furthermore, research regarding interventions such as cognitive behavioral therapy (CBT) as a modality for treating anxiety and depression, which are common psychological symptoms from CHD in adults, is not fully established (Ferguson & Kovacs, 2016).

I conducted this project study to address the gap in research on the psychosocial concerns of clients who have CHD (Wilson et al., 2015). *Psychosocial* is defined as an individual's psychological development in his or her social environment, as well as his or her interaction within the social environment (National Alliance on Mental Illness [NAMI], 2019). For this study, psychosocial was further clarified as issues adults with CHD are experiencing psychologically (e.g., anxiety and depression) as well as sociological issues such as securing health insurance coverage, finding employment, and obtaining mortgages.

The literature review reveals that the majority of articles are from a psychology context versus a social work one. This is a concern because social work and psychology are two different fields. Social workers look at the person as a whole, considering biological, psychological, sociological, and spiritual aspects with a focus on improving the individual's quality of life (Social Work License Map [SWLM], 2018). Psychologists are focused on diagnosing a disorder, assessing the problem behavior, and helping the person adapt to changes (SWLM, 2018).

I conducted this qualitative research study using the narrative approach to provide more information about the psychosocial needs and issues of clients with CHD. Findings from this study may enable social workers to learn from others' experiences and apply these experiences to clinical interventions with other CHD clients. Knowledge about successful interventions to help clients access proper health insurance, for example, may help social workers in their clinical practice and effect positive social change for individuals with CHD. As Atlas (2014) and Hellander (2015) discussed, CHD patients may lack the ability or knowledge necessary to see a specialist or may encounter difficulties obtaining health insurance that provides adequate care for CHD.

In the next subsection, I will discuss the problem in more detail. The purpose, research questions, nature of the project, significance of the study, theoretical framework, and the National Association of Social Workers (NASW) Code of Ethics applied to the project will also be presented. I also review the professional and academic literature related to the study topic. Section 1 concludes with a summary of key points and a transition to Section 2.

Problem Statement

The social work practice problem is the absence of information regarding the experiences of social workers counseling adult clients who have CHD. There is insufficient knowledge about the psychosocial issues faced by adults with CHD (Wilson et al., 2015). Psychosocial issues concern an individual's psychological development in his or her social environment, as well as his or her interaction within the social environment (NAMI, 2019). Preliminary research demonstrates there is limited information regarding care for the adult CHD population from a social work context (Leon, Wallenberg, & Holliker (2013). Assimilating psychological care with medical care for clients with CHD has been demonstrated to be helpful (Ferguson & Kovacs, 2016). CBT has also proven to be useful for clients (Ferguson & Kovacs, 2016). Nonetheless, this is a developing field, and there is a need to gather more information about psychosocial services such as education regarding the disease or CBT for this community (Ferguson & Kovacs, 2016).

Lack of knowledge regarding interventions for treating those issues is problematic because patients are experiencing continual psychological and sociological issues from the consequences of this lifelong chronic condition (Goossens, et al., 2012; Kovacs, et al., 2015). Psychosocial issues such as depression, anxiety, and uncertainty about the ability to obtain health insurance and mortgages have been found to commonly occur among the CHD population (Goossens et al., 2012; Kovacs et al., 2015; Waskowsky et al., 2015).

Behavioral and social difficulties for CHD patients are not always related to physiological characteristics or intensity of heart disease (Chiavarino et al., 2015). Environmental aspects such as unpleasant medical procedures and hospital stays contribute to difficulties (Chiavarino et al., 2015). Emotional struggles such as challenges with peer relationships due to limits in physical and social activities, body image issues due to surgery scars, and inhibited personal growth due to parental overprotection are also prevalent (Chiavarino et al., 2015).

Goosens et al. (2012) identified some of the most important areas for further research regarding CHD as patient knowledge and education about their diagnosis and challenges living with CHD. Quality of life while coping with the effects of CHD and experience from living with a chronic illness requiring consistent cardiac observation along with treatment are all difficulties faced by these patients (Luyckx, et al., 2014). Treatments for psychosocial issues such as depression and anxiety and challenges with health insurance, employment, and securing mortgages are additional challenges these patients may face. According to Page, Kovacs, and Irvine (2012), patients with CHD would like the following interventions: individual and group therapy, mentorship programs, peer interaction patient conferences, education, and connection with other individuals who have CHD. These interventions may help clients cope with interpersonal challenges, such as social isolation, conflicts of social expectations, and difficulties talking about the disease as well as feeling different (Page et al., 2012).

CHD clinics are now located in health systems globally with a vast majority located in the United States (ACHA, 2018). However, of the 109 in the United States only about 40 have dedicated social workers (ACHA, 2018). Therefore, not only is there a gap in research, there is also a paucity in social workers who are specialized in CHD. Understanding the experiences of social workers who currently counsel CHD clients can help close the gap in research regarding the psychosocial issues these clients experience, as well as the interventions implemented to help alleviate some of the problems such as depression, anxiety, social isolation, and health insurance issues. Psychosocial issues are defined as an individual’s psychological development in his or her social environment, as well as his or her interaction within the social environment (NAMI, 2019). this study focused on social workers based in U.S. CHD clinics who work with this population. Participants provided information about their experiences with interventions for CHD clients who experience psychosocial problems.

Purpose Statement and Research Questions

The purpose of the study was to use basic qualitative research to understand social workers' experiences with interventions for clients who have CHD and experience psychosocial problems. The practice problem was a lack of social work knowledge regarding treatment related to psychosocial issues for CHD clients (Wilson et al., 2015). The research questions (RQs) for the study were

RQ1: What are social workers' experiences with interventions used when working with adult clients who have CHD and experience psychosocial problems?

RQ2: What successful and unsuccessful interventions have been used by social workers when working with clients who have CHD and experience psychosocial problems such as anxiety, depression, healthcare, health insurance challenges, employment issues, and difficulties obtaining mortgages at the micro, mezzo, and macro system levels of Bronfenbrenner's (1979) ecological theory.

Social worker's experience with clients with CHD is the general concept I explored in this doctoral study. I explored experiences social workers have in implementing interventions to address psychosocial problems that occur at micro, mezzo, and macro levels (Bronfenbrenner, 1979). Attributes at the *micro* level included anxiety and depression, which are personal issues; attributes at the *mezzo* level were the CHD client’s family, community, friends, and caregivers including healthcare professionals. Last, attributes at the *macro* level were the company of employment, mortgage or rental company, insurance companies, hospital systems, and government agencies providing services and benefits to CHD clients.

Nature of the Doctoral Project

The study was a basic qualitative design as I sought to understand the phenomenon related to social workers’ experiences with interventions while counseling adult clients who have CHD and experience psychosocial problems. Narrative inquiry provided the best way to understand these experiences because it enabled social workers in the study to speak freely about the topics. Narrative research is oriented towards having the participant tell their story (Larsson & Sjöblom, 2010). My goal was to obtain information about successful interventions from social workers who counsel adult clients with CHD; I sought to accomplish this goal by enabling the participant to feel comfortable talking about his or her experience through storytelling (see Hill & Burrows, 2017). I analyzed the information provided by the social worker participants to find common themes that can be shared with the adult CHD community regarding interventions used for treating psychosocial issues for this population.

The sources of data were six social workers recruited from the 40 CHD clinics that each have a dedicated social worker. The goal was to have a geographically balanced representation of participants throughout the United States. This was accomplished by initially recruiting social workers in clinics based in the Western, Northern, Southern, and Eastern parts of the United States. These social workers have an MSW and experience working with adult clients who have CHD. The ACHA (2019) provides a list of CHD clinics across the United States, showing the number of patient visits per year, the medical director, the nursing staff, clinical resources, surgical and intervention resources, clinical services, and the care setting, as well as training and research.

ACHA provides a directory, available to the general public, of all the CHD clinics worldwide on its website. The list contains which CHD clinics have dedicated social workers. Using phone and e-mail, I invited seven social workers from seven different clinics in the ACHA directory to participate in the study. I interviewed social worker participants via video conferencing with telephone meetings and e-mail utilized to gather data or confirm findings.

The methodology was a basic qualitative design using narrative interviews with social workers, along with telephone and e-mail exchanges with each participant for clarification. Kahlke (2014) stated that a basic qualitative design is not regulated by a set of methods predetermined by the most common qualitative methodologies such as phenomenology, grounded theory, and ethnography, suggesting it does have design flexibility. Kahlke discussed interpretive description, which can be part of a basic qualitative design. The approach orients towards clinical practice with experiences and evidence adapted to the practice setting (Kahlke, 2014).

I completed verbatim transcriptions of the interviews I had with participants using the NVivo qualitative data software. I used open coding to look for themes among the individual narratives. To analyze the data, I used ethnography and talk in interaction. Syed and Nelson (2015) argue that a single analyst can use ethnographic methods or examine talk in interaction in a rigorous manner to analyze data. Talk in interaction involves analyzing not only what the participant says, but also intonations, pauses, hedges, and discourse markers (Syed & Nelson, 2015). Both ethnography and talk in interaction were applicable for this study because I have CHD and directly interacted with the social worker participants.

Significance of Study

I sought to understand and distribute phenomenon related to social workers' experiences with interventions while counseling clients who have CHD and experience psychosocial problems. A goal was to provide further knowledge on interventions for the psychosocial needs of this population. The findings may help social workers better comprehend, relate to, and learn from their colleagues' experiences with interventions while counseling clients who have psychosocial issues related to CHD from a social work context. These results may enable agencies to implement interventions they currently do not use that have been found to be successful in other clinics.

This doctoral study is needed to provide further research and information on interventions for the psychosocial issues of adult clients with CHD in a social work context. Contributions to advance social work practice include compiling vital information from social workers experienced in working with the issues facing this population to disseminate to others who could use the information to help their clients. This study will contribute to providing further knowledge on the topic of interventions for the psychosocial needs of clients with CHD, which has been identified as a need amongst therapists for this population.

The study may contribute to overall social work knowledge as it examines interventions used by social workers for these CHD clients. Several studies discuss the need for more information regarding interventions with this population (Goossens et al, 2012; Pagé et al., 2012; Wilson et al., 2015). Conducting a qualitative study with narrative inquiry among social workers who are actively working with this population will enable them to share their stories on successful and unsuccessful interventions with clients with CHD who experience psychosocial problems.

Theoretical Framework

Bronfenbrenner's ecological theory is the framework used for this study. Bronfenbrenner (1979) states the ecological environment is comprised of structures embedded in one another. The structure embedded in the middle is considered the developing person which can be anywhere and anytime during his or her life (Bronfenbrenner, 1979). As the developing person has experiences which move outside of each embedded structure it affects the core of the human development (Bronfenbrenner, 1979). Additionally, events can occur in the outside structures that are outliers which still impact the core development (Bronfenbrenner, 1979).

Gauvain and Cole (2005) state Bronfenbrenner’s framework takes the ecological systems approach, which describes social and cultural facets of the human environment, focusing on the subsystems which influence one another. Bronfenbrenner’s subsystems range from micro (immediate, or proximal process of development such as family, school) to macro (patterns of culture, economy, customs) and chrono for historical development (Gauvain & Cole, 2005).

Bronfenbrenner’s framework has two purposes one is to provide thought about environmental influences that impact human development, and second is to contribute to research questions, hypotheses, and design (Gauvain & Cole, 2005). The ecological theory informs this study by utilization of the micro, mezzo, and macro systems; these systems can be successfully mapped into the research process for this narrative inquiry and be successful in using for a qualitative study (Onwuegbuzie, Collins, & Frels, 2013).

Bronfenbrenner (1975) stated evaluating not only how the experimenter and subject react, but looking at how they affect one another with reciprocity is important. After looking at the interchange between the two, one must take into consideration a third dimension which can be also be causing an effect (Bronfenbrenner, 1975). This is pertinent when understanding a social worker's experience with the client who has CHD. The relationship between the social worker and client has an effect on how each one reacts, but the system (micro, mezzo or macro) also contributes to impacting the outcome of reaching established goals.

An example is a client and social worker have a collaborative therapeutic relationship with a high level of trust. One problem the client faces is having difficulty finding employment. The social worker assists the client in securing interviews by role playing, however the macro system which encompasses potential employers does not yield a job for the client. This demonstrates how the client and social worker have a strong relationship to impact a positive outcome, but the macro system which involves employment does not lead to a job causing the outcome and ultimate goal of employment to not be reached.

Lastly, Bronfenbrenner's ecological theory is relevant for evaluating chronic disease, specifically his bioecological theory for client's transition into adulthood and constant care (Joly, 2015; Tacon, 2008). Bronfenbrenner evolved his theory into the bioecological model taking genetic potentials, genotypes and phenotypes, actualizing them through proximal processes (Bronfenbrenner & Ceci, 1994). Proximal processes are the continued interaction between person and environment over some time. This mutual interaction includes persons, objects, and symbols which may vary in degree, complexity, and sequence (Bronfenbrenner & Ceci, 1994). Bronfenbrenner and Ceci (1994) discussed levels of proximal process could impact genotypes and phenotypes, specifying a good environment coupled with a most competent genetic inheritance produces the optimal bioecological outcome.

Bronfenbrenner's theory provides an appropriate framework for this doctoral study established by the research questions. Taking a look at the genotype of the client which is already affected by a chronic heart issue, the proximal processes experienced at the micro, mezzo, and macro levels will affect the phenotype and potentially the genotype. Understanding social workers experiences with interventions used at these levels adhere to the framework Bronfenbrenner describes in his theory.

An example of integrating Bronfenbrenner's theory with the following study is, an individual born with CHD has a compromised genotype for specific bioecological successes. This study defines the mezzo level as interventions from medical professionals, caregivers, and family. The intervention from the mezzo level is correctional surgery which a medical professional performs, and the family provides the financial means. These proximal processes enable the phenotype to be affected where the client can function at a higher physical capacity, experience extended life expectancy, and become self-sufficient.

Values and Ethics

The social work practice problem which is the focal point of this doctoral study is the absence of information regarding the experiences with interventions social workers use for adult clients who have CHD and experience psychosocial problems. These clients are marginalized by the effects of CHD, and further marginalized because of a lack information available regarding interventions to meet their psychosocial needs. (Kovacs et al. (2015) state many of these client's experience anxiety and depression due to issues CHD causes from birth. Kovacs et al. (2015) also state "within CHD we are unaware of any psychosocial interventions that have undergone empirical evaluation" (p.387). Another area in which members of this population may experience marginalization is healthcare. The current health insurance laws cause specialized care to be complicated for both healthcare professionals and patients in need, emphasizing the utilization of primary care providers (Atlas, 2014).

The NASW Code of Ethics (2017) guides social work practice in this area because it provides standards for the CHD population to receive psychosocial care specified to their needs. Empirically based interventions must be developed to address the common psychosocial issues of anxiety, depression, health insurance difficulties, and employment challenges this population experiences. Empirically based interventions will help to prevent these clients from being marginalized on appropriate techniques to treat their problems. Additionally more social workers will have empirically based research for treating the psychosocial issues of clients with CHD.

The NASW Code of Ethics declares social workers are ethically responsible to the breadth of society, in particular to social and political action (NASW, 2017). The Code of Ethics asserts social workers need to broaden alternatives and favorable circumstances for all people with particular regard for defenseless, underprivileged, maligned people and communities (NASW, 2017). This research study aligns with this Code of Ethics declaration by systematically collecting information from social workers who currently work with the CHD population to understand their experiences with interventions.

The data compiled in this study attempts to help fill the void of knowledge available regarding interventions for helping this population with psychosocial needs. The research results may broaden alternatives and favorable circumstances for adults with CHD receiving psychosocial care since more information will become available regarding successful interventions. Therefore, the research project will help contribute to minimizing some marginalization due to limited information on techniques for treating the psychosocial issues this population encounters. The research could be used as a starting point to expand choice and opportunity for improved care.

Regarding the values of the NASW Code of Ethics, the intent is to understand the experiences these social workers have with interventions for adults with CHD. Understanding which interventions have been unsuccessful or successful based upon mutually set goals tested by measurable tools may contribute to spreading knowledge and advancing clinical practice. This may provide opportunity for this population with CHD to be less marginalized on interventions for their specific psychosocial care needs.

Review of Professional and Academic Literature

Process and Steps

Initially, I searched in PsychInfo and SocIndex databases using the keywords *congenital heart disease, psychosocial issues,* and *chronic disease*. However, the information found was limited, with articles focusing mostly on parents and children with CHD. Some materials were available. However, the volume needed to conduct a thorough literature review was lacking.

Since CHD is clinically oriented, branching out to the following databases yielded better results: Medline with full text, Science Direct, Expanded Academic ASAP, Ovid Nursing Journals, and Directory of Open Access Journals. The literature searched was academic journals with full version emphasizing the years of 2012-2018. Lastly, I examined Cochrane Review to find information on interventions for psychosocial issues regarding CHD.

Prevalence of Congenital Heart Disease

Generally, 40,000 births each year nationally are affected by CHD, with the predominance of minor types of CHD increasing while other types remain stable (Centers for Disease Control and Prevention [CDC], n.d.). Babies born with a critical CHD, comprising 25% of the total, require surgery or invasive procedures during their first year of life (CDC, n.d.). Several states track CHD births among newborns and young children. However, there are no tracking programs following adolescents and adults with heart defects (CDC, n.d.). Tracking adolescents and adults with CHD in the United States is performed by applying data from administrative healthcare databases in Canada to demographics in the United States. Census data in 2010 was used to estimate over 2 million infants, children, adolescents, and adults, specifying 1 million children and 1.4 million adults have a CHD in the United States (CDC, n.d.).

CHD is the foremost cause of birth-defect-associated infant disease and death (CDC, n.d.). These deaths often happen when the baby is less than 28 days old, with survival depending on the severity of the defect, point in time diagnosed, and treatment plan (CDC, n.d.). If a baby survives CHD, 20-30% of the time he or she will have other physical, developmental, or mental issues and be 50% more prone for special education needs compared to children without CHD (CDC, n.d.). As a child matures, he or she may experience developmental delays, struggle with exercise, problems with irregular heartbeat, heart failure, cardiac arrest, stroke and premature death from cardiovascular issues (ACHA, 2018). Lastly, these CHD clients cope with a greater risk of death and disability (ACHA, 2018). While treating CHD clients, quality of life (QoL) is an essential consideration since the World Health Organization's definition of health discusses QoL as a pivotal goal for treating chronically ill patients (Vigl et al., 2011).

Psychosocial Issues Related to Congenital Heart Disease

CHD clients experience psychosocial issues, the most common being anxiety and depression. Adults are at risk for anxiety, depression, language impairment (knowing what to say and when), and additionally delayed progression to becoming an independent functioning adult (Wilson et al., 2015) Although Wilson et al. research compiles several sources and does not provide the exact methodology of the studies, it reinforces the conclusions of other published research. Wilson et al. focused on the effects CHD has on children, adolescents, and adults, from a neurological and psychosocial perspective.

CHD clients are prospects for mental disorders is the conclusion of a retrospective study analyzing information from 100 adults with CHD who participated in extensive psychological assessment (Ferguson and Kovacs, 2016). The psychological assessment included case conceptualization, assessment of mood and anxiety disorders, discussion of psychiatric diagnoses, treatment recommendations when appropriate, and a course of psychotherapy of 12 one-hour sessions. Ferguson and Kovacs state 82% had general anxiety, 71% had health/heart anxiety, 60% had depressed mood, 49% had trouble handling a medical condition, and 65% met the criterion for a mental disorder. Although the limitation of Ferguson and Kovacs research is selection bias and cannot represent the entire adult CHD population, it does reveal these clients do experience depression, anxiety, and heart health concerns. Another limitation is the study does not serve those patients with CHD who do not pursue psychotherapy, which can mean they are experiencing these symptoms and not getting help, or they are not experiencing issues related to CHD. This study is essential to consider as Dr. Kovacs has participated in several studies regarding psychological issues and CHD.

Psychiatric disorders in CHD is undoubtedly larger than a control sample from the Composite International Diagnostic Interview (CIDI) which is a national sampling of adults in Germany (Westhoff-Bleck et al.,2016). The results from Westhoff-Bleck et al. show (48% vs 35.7%), specifically mood disorders (30.7% vs 10.7%), anxiety (28% vs

16.8%), major depressive disorder (24.7% vs 7.4%) and dysthymia which is persistent mild depression (10.7% vs 4.3%). Westhoff-Bleck et al. performed their research at the Hannover Medical School in Germany where one hundred fifty patients participated, and a control sample from the (CIDI). Participants completed a Beck Depression Inventory (BDI), Hospital Anxiety and Depression Scale, and the World Health Organization Quality of Life Short Form. Additionally, Westhoff-Bleck et al. are one of the most extensive studies using CHD clients in trained interviews. These studies, although may have some limitations all conclude clients with CHD experience anxiety, depression, and mood disorders.

When treating psychosocial issues identifying personality types and relating them to psychosocial functioning for CHD helps clinicians better identify clients at risk (Rassart et al., 2016). Overcontrollers tend to internalize depression, loneliness, poor self-esteem, difficulties with peers (Rassart et al., 2016). Undercontrollers have difficulties with academics, conveying issues such as peer hostility, substance abuse and delinquent behavior (Rassart et al., 2016).

Incorporated into Rassart et al.'s (2016) study is Luyckx et al.'s (2014) research in that both studies use the same sample: 498 eligible participants from the Leuven Hospital in Belgium with a confirmed diagnosis of CHD, ages 14-18, and who were evaluated every 9 months four times. Therefore, the studies have some overlap in results, however looking at the methodology both of them are important to consider. The shared sample of Rassart et al. (2016) and Luyckx et al. (2014) is longitudinal analysis in four waves. Luyckx et al. (2014) utilize the first three waves for their results, and Rassart et al. (2016) uses the results from the third and fourth wave.

Psychosocial needs and variables influence one another; for example, loneliness contributes to depression, additionally girls with CHD show a greater propensity than boys for depressive symptoms (Luyckx et al., 2014)

Luyckx et al.(2014) evaluated every nine months for the first three waves doing the following measures, Quality of Life and Perceived Health Status using a Linear Analogue Scales (LAS). The Center for Epidemiologic Studies Depression Scale evaluated depressive symptoms, loneliness was assessed using the UCLA Loneliness Scale, and parental support was measured with the Child Report of Parent Behavior (Luyckx et al., 2014).

Rassart et al. (2016) evaluated every nine months for the third and fourth waves assessing personality types, with the effect on disease coping measuring by participants rating themselves on a Likert scale with 30 adjectives describing themselves. Six items assessed personality traits, coded in the following manners: withdrawn inversely coded as extraversion, careful coded as conscientious, sympathetic coded as agreeableness, nervous inversely coded as emotional stability, and creative coded as openness (Rassart et al., 2016). Both these studies justify CHD clients experience psychosocial issues, utilizing different measurements amongst a large sample size in Belgium.

Patient perception has an impact on their anxiety and depression. Eslami et al. (2013) conducted the study in Tehran from two referral heart hospitals using a sample of 347 patients with CHD, and 353 non-heart disease patients matched by sex and age. The assessments used were the Hospital Depression Scale, short version of the Giessen Complaint List, and Multidimensional Scale of Perceived Social Support. Eslami et al. (2013) state somatic symptoms are related to CHD. Eslami et al. continue to report the somatic symptoms are linked with the anxiety and depression with a back and forth effect in addition to lower income. Lastly, anxiety, depressive and somatic issues are linked to clients perceived financial strain and lower recognized social support (Eslami et al., 2013).

Mood and anxiety disorders in CHD patients are not attributed to the severity of the defect, but social adjustment and patient interpreted health status (Kovacs et al., 2009). Kovacs et al. culled their sample from CHD clinics at the University of Florida and University of Toronto with 90 and 190 participants respectively. Randomization of participants was done to select for a semistructured clinical interview, with the remainder completing the assessments of Beck Anxiety and Depression Inventory, State-Trait Anxiety Inventory-Trait Version, Brief Fear of Negative Evaluation, UCLA Loneliness Scale and Short Form Health Survey.

CHD clients are showing a deficit in Theory of Mind (TOM), can attribute to interpersonal issues (Chiavarino et al.,2015). TOM is the capability to judge mental states. TOM is crucial because it plays a role in social relationships, and children with CHD have a higher propensity for social difficulties. The social difficulties are not from the physiological characteristics of CHD, but from unpleasant experiences of surgeries, hospital stays as an infant, feelings of seclusion and social uncomfortableness in peer exchanges, restricted social and physical activities, overprotective parents limiting development of interpersonal and emotional skills, body image problems due to surgical scars (Chiavariono et al., 2015). Chiavario et al. conducted theory of mind tasks, as well as a semi-structured interview administering a multidimensional evaluation of TOM. Conducted in Italy, this study has a sample size of 32, half CHD patients recruited from two hospitals, and the other half a healthy control group, the age ranges were between 18 and 60 years of age. Chiavariono et al. discovered CHD patients performed equally to the TOM tasks. However, the CHD clients performed worse than the controls on the semi-structured interview assessing several aspects of TOM, which were open-ended questions the participants answered focusing on knowledge of their own and others mental states. Specifically, CHD patients performed worse than the controls on questions investigating beliefs and positive emotions, but for the mental state of desire, the results were the same. CHD clients performed worse than the control for understanding another person's mental state (Chiavariono et al., 2015).

These studies utilized different but similar methodologies to determine the psychosocial issues for clients with CHD. The differences are the places, the sample sizes recruited, and assessment scales chosen to measure depression, anxiety, quality of life, somatic symptoms, and social support were not all the same scales. However, although different samples and scales are used the findings show to be consistent concerning anxiety and depression for clients with CHD. A consistent challenge for all the studies are low sample sizes, and limitation to a specific country making the generalization to the entire CHD population difficult.

Anxiety, depression, social isolation, and body image issues are some of the psychosocial problems CHD survivors encounter due to their disease (Luyckx et al., 2014; Rassart et al., 2016; Wilson et al., 2015). These psychosocial issues CHD survivors experience are due to challenges dealing with their medical situation, health and heart related distress, and perceived health status (Eslami et al., 2013; Ferguson & Kovacs, 2016; Kovacs et al., 2009; Westhoff-Bleck et al., 2016; Wilson et al., 2015).

As these individuals become adults, the issues that manifest as stressors in life increase since concerns about mortality, decisions regarding treatment, preparing for surgery, adjusting to embedded cardiac devices, problematic pediatric to adult transitions, concerns maintaining plan of care, educational issues, loneliness, fear of negative evaluations, and compromised employability leading to financial problems become prevalent (Eslami et al., 2013; Ferguson & Kovacs, 2016; Westhoff- Bleck et al., 2016; Wilson et al., 2015).

Social isolation can happen because of low energy levels, the time needed for surgical interventions thus causing difficulties with interpersonal relationships, and an inability to participate in activities similar to one's peers (Chiavarino et al., 2015; Kovacs et al., 2009; Wilson et al., 2015). Body image issues occur because of surgical scars, symmetry on the chest due to implanted devices, as well as concerns about the ability for the body to physically perform (Chiavarino et al., 2015; Kovacs et al., 2009; Westhoff-Bleck et al., 2016). Hence, the actual CHD is not the primary reason for the anxiety and depression, but the experiences these clients encounter because of the heart defect

Ancillary Issues

Parental knowledge. Parents’ knowledge about their child’s issues contributes to a better quality of life for the child. However, Azhar et al. (2018) conclude caregivers of CHD patients need education about the disease; parents state they did not receive adequate information about the disease and caring for their child. Azar et al. (2018) conducted a cross-sectional study over February to March 2014 in Saudi Arabia at the King Abdulaziz University Hospital including 120 parents of children with CHD visiting the Pediatric Cardiology Clinic. A questionnaire developed in English, then translated to Arabic looked at demographic information, diagnosis, and care, assessment of caregivers’ knowledge of the disease, effects of the disease as well as education regarding the condition (Azar et al., 2018). The limitations of this study are the translation of English to Arabic was not detailed to show its accuracy, information about the validity and reliability of the questionnaire, and it is relegated to this specific institution in Saudi Arabia making the generalization to the population not entirely accurate. However, the study is relevant since it does provide information about parental knowledge, education and experience in CHD from an international perspective which can highlight any differences or similarities on a global landscape.

Educating parents about recognition and response to health decline, medications, as well as prediction and plan are ranked the highest in importance (Daily et al., 2016). Also, parents knowing about their child’s CHD diagnosis contributes to less parental anxiety, and increases compliance (Dailey et al., 2016) Daily et al. conducted a qualitative study at the Cincinnati Children's Hospital utilizing focus groups encompassing parents and guardians of CHD children who had at least one heart procedure between January 2010 to 2013. Also, participating in the focus groups were physicians and nurses with a minimum of three years experience caring for this population: eleven focus groups comprised of 34 parents, 26 nurses, and 21 physicians. There are a few limitations to this study(a) it was conducted at one medical center, therefore generalizing for the entire population may not be in proportion at a single medical center, (b) the study separated parents of children CHD diagnosis into the focus groups hence possibly skewing some information, and (c) the participants were self-selected (Daily, et al., 2016). Nonetheless, with the limited research available about the population it does provide some indicators of issues which need to be addressed in future research and are currently occurring for this population.

Parental education on a child’s CHD is not an issue specific the United States. Ndile and Kohi (2011) state in Tanzania 43% of parents were not able to state a sufficient description of their child’s cardiac deformity, 76% were not able to specify the symptoms, and knowledge about the impact of drugs, food, plus other factors regarding their child’s CHD was low. Ndile and Kohi (2011) conducted a quantitative study at Muhimbili University in Tanzania interviewing 84 parents who take their children to the cardiac center and hospital. The authors measured parent’s understanding regarding CHD such as medication and dosing, and explanation and symptoms of child's defect utilizing an adjusted form of Leuven's questionnaire which assesses parent's knowledge. Limitations of the study are the appropriate sample size is 106, the parents are from a specific clinic making generalizing the population difficult, and no mention regarding accurate translation efforts (Ndile & Kohi, 2011).

The Leuven questionnaire shows validity for measuring parental knowledge for CHD regarding diagnosis, physical activity, reproductive issues, medication, disease and treatment, prevention of complications but lacks measuring knowledge of psychosocial issues (Yang et al., 2012). Yang et al. conducted an extensive analysis to convert the questionnaire into Chinese and assess its validity for use with CHD patients and parents. The sample Yang et al. used was comprised of CHD Chinese speaking adolescents between the ages of 12-18 years, and their parents from the National Taiwan University Hospital. The study was conducted between June to December 2010 and consisted of 89 adolescents and their parents. The aspects measured were medication, disease, and treatment, knowledge of diagnosis, physical activity, reproductive issues, prevention of complications, however not measured is knowledge about psychosocial issues regarding CHD (Yang et al., 2012). Yang et al. found some limitations to the Chinese questionnaire regarding reliability due to it being a self-report questionnaire by parents, and knowledge is always evolving making test and retest difficult. Overall the conclusion is the Chinese form of the Leuven questionnaire is valid to test understanding in both patients with CHD as well as their parents. Leuven questionnaire psychometrics from the Yang et al. study are important because they further illustrate the validity of the results Ndile and Kohi (2011) achieved in their study, and the utilization of the Leuven questionnaire for measuring parents and patient’s knowledge regarding CHD in the future.

There is a paucity of articles pertaining to social workers education parents about their child’s CHD. Daily et al. (2016) has nurses and physicians in their focus groups for medical professionals educating parents about their child’s CHD, there were not any social workers involved in the sample. Regarding social workers helping these parents understanding the impact of CHD, Leon et al. (2013) was the single article focusing on social work practice and working with CHD parents. Leon et al. state parents face challenges making sense of the diagnosis, chronic sorrow which is different than time-limited grief, the process of normalization regarding parenting and routines with a CHD child, parental mental health concerns, as well as marital satisfaction. The focus is more on parents with CHD children under the age of 5 and a review of specific social work theories and their applications to this population. The theories consisted of attachment, stress and coping, family system, and strategic interventions such as education, stressor identification, skill development, and utilizing support systems. Lastly, Leon et al. make recommendations on what a social worker must consider when working with this population such as during assessment evaluate both internal and external factors affecting the parent due to the child's CHD, make sure parents are receiving enough education regarding CHD.

Educating the parent is about CHD is beneficial to the future well-being of the child (Azar et al., 2017; Daily et al., 2016). An abundance of information is available on educating parents about their child's CHD disease, coping strategies for parents, understanding parent's knowledge of the disease, and where they are deficient (Ndile, & Kohi, 2011; Yang et al., 2012). Specific social work interventions for parents of CHD clients are minimal with Leon et al. (2013) publishing the only article found in the search. Hence, the better prepared the parent is to cope with the disease can impact the ability of the child to handle the issues associated with CHD in the future.

Health Insurance. Health insurance coverage is an issue for this population since CHD patients need to see a specialist who has training for this specific population (achaheart.org, 2018). ACHA is a national organization providing resources for medical professionals and families regarding CHD. Families receive support finding clinics specializing in CHD, information about the disease, peer support, and the ability to attend conferences throughout the country (achaheart.org, 2018). Medical professionals obtain research information, grants, training, as well as participation in the meetings. Also, ACHA has an accrediting program which works to advance and standardize the quality of care for adults with CHD (achaheart.org, 2018). Lastly, ACHA is active in advocating for government policies to help those with CHD, often lobbying in Washington D.C. specifically on topics such as health insurance (achaheart.org, 2018).

Newly implemented health insurance policies affect payments to primary care and specialists, encouraging the use of primary care and discouraging specialists (Atlas, 2014). Atlas states healthcare is moving more towards being financed by the government through the Affordable Care Act (ACA) putting a priority on general care, negatively affecting specialist care. Atlas is a Medical Doctor and a member of Hoover's Working Group on Health Care Policy. Although the limitation of this article is its reliance on one viewpoint, it provides credible information on the multiple factors happening with ACA policies, which can affect CHD patients from being able to see specialists.

Concurring with the perspective of Atlas (2014) and providing a thorough analysis of U.S. healthcare five years after the passage of the ACA, Hellander (2015) states many individuals are underinsured, and a higher percent of the population is no longer insured by private insurance between 2003 and 2013. Private insurance coverage is not adequate, causing these individuals to frequent community centers for their healthcare needs. Doctors listed by insurance companies are not accepting insurance or offering appointments to enrollees. Insurers are implementing tiered drug reimbursement plans to reduce benefits on more costly drugs. Hellander collected data from various sources such as medical insurance companies, U.S. Census Bureau, Commonwealth Fund, News and Health Media Outlets, Congressional Budget Office, Consumer Financial Protection Bureau on the effects of ACA. Hellander limitations are slanting from a perspective about ACA having an overall negative impact, no mention of the elimination of pre-existing conditions, or individuals losing their jobs can find less expensive health insurance than COBRA.

Relating the findings of Atlas (2014) and Hellander (2015) to the CHD client’s health needs presents a dismal perspective for quality care for this population. However Lin, Novak, Rich, and Billadello (2018) have a different view. Lin et al. reviewed cardiology outpatient visits to a sizable referral institution in the United States between July 2016 and February 2017, categorizing the primary payer insurances of health maintenance organization (HMO), preferred provider organization (PPO), Medicare, Medicaid, and self-pay. The sample size contained 871 CHD adults, and 17,154 non-CHD adults, when the sample was not age matched the mean age for CHD was 38.5, and non-CHD was 63.8 (Lin et al., 2018). The results were age-matched creating a sample of 805 for each group and a mean age of 39.5, finding CHD patients utilize more often PPO and Medicare plans compared to non-CHD patients, and in the states with Medicaid expansion CHD patients had greater use of Medicaid (Lin et al., 2018). In conclusion, the study stated CHD patients insured with the ACA have adequate coverage. This study shows CHD patients utilize more PPO coverage which gives an ability to choose a doctor and facility, necessitated by the need to use a CHD specialist due to the nature of the disease and recommendation by ACHA organization (achaheart.org, 2018).

Another perspective is some CHD clients could have issues with insurance depending on what state they reside and if they are a minority. Torres et al.(2017) wanted to understand if ACA had an effect on insurance coverage for those with chronic illness, finding it did increase coverage for some, however those in the states without Medicaid expansion, as well as for minorities, there still is a void. This study has limitations since it is not directly CHD oriented. However, there is a likelihood some of the 606, 277 individuals in the sample had CHD due to the large size. Torres et al. utilized research from the Behavioral Risk Factor Surveillance System (BRFSS) derived from a self-report telephone survey to U.S. civilian, non-institutionalized people administered annually by state health departments and the CDC. The sample is adults ages 18-64 who report having a chronic disease. However, it does not include institutionalized adults and does not verify the reports or severity of chronic diseases.

The onset of the Affordable Care Act (ACA) assisted CHD patients since it eliminated pre-existing condition limitations to secure adequate health insurance (achaheart.org, 2018). Traditionally this has been perceived as an underinsured population. However, the onset of ACA and the Medicaid extension in several states has helped some of this population obtain insurance (Lin et al., 2018; Torres et al., 2017). Part of the challenge for CHD patients is healthcare moving towards being financed by the government, and ACA is putting a priority on general care negatively affecting specialist care (Atlas, 2014). Therefore, doctors may be listed on ACA policies but are not accepting the insurance or offering appointments to the enrollees (Hellander, 2015). When the specialist care physician does participate with ACA there can be such a massive influx of patients due to the policy changes enabling more people covered under insurance coupled with the reduction in specialists; appointments are difficult to obtain due to patient demand on physicians (Atlas, 2014; Hellander, 2015). Chronic conditions such as CHD, impose duress on patients causing them to have higher baseline coverage, utilization of insurance, deductibles as well as prescription and out of pocket costs (Torres et al., 2017).

Lifestyle. CHD patients encounter several lifestyle challenges they are financial, divorce, depression linked to the level of education and income level, additionally women showed higher rates of depression (Cook, Hindes, Pater, and Maul, 2016). Before their study, Cook et al. state little was known about the daily stressors amongst the CHD population. Cook et al. conducted a cross-sectional study consisting of patients from the Adult Congenital Heart Disease Center, Heart Institute Children's Hospital Pittsburgh and Heart Vascular Institute, University of Pittsburgh Medical Center. The sample consisted of 128 patients who were 18 and older, diagnosed with CHD and were having outpatient adult clinic evaluations. Cook et al. used several established scales for measurements, daily stressors based upon the Combined Hassles and Uplifts scale, and coping strategies measured by the Brief Cope self-report questionnaire. The Patient Health Questionnaire measured psychological distress, and health quality of life was measured by the short form-12 which is an established survey assessing a patient’s health (Cook et al., 2016). The limitations of this study were the results for the measurements were only reported at baseline. Therefore establishing a relationship between factors is not possible. Also, some of the hassle responses were left blank, and it is not understood if it was related to survey fatigue or question sensitivity (Cook et al. 2016). However, the advantage of the study is it provides measurable information based upon established scales regarding lifestyle issues encountered by CHD patients.

Although Cook et al. (2016) state little was known Ladouceur et al. (2013) and Waskowsky et al. (2015) conducted studies finding CHD clients experienced difficulties in daily life with employment, mortgages, insurances, sports, travel or driving, along with the essentialness of having a healthy lifestyle to prevent cardiovascular complications. Ladouceur et al. administered a research analysis regarding daily issues CHD clients encounter, and how the quality of life can be improved. Ladouceur et al. state CHD patients report difficulty with sports, only one-third of patients practice regular physical exercise due to exercise capacity. Regarding employment, 33% were unemployed compared to 16% in the matched control, and patients under the age of 40 compared to the reference group had poorer outcomes in educational attainment (Ladouceur et al., 2013). Insurability results show CHD patients have more difficulty obtaining life insurance and a mortgage compared to the control (Ladouceur et al., 2013). Airline travel is a challenge because of deep vein thrombosis on long flights, and CHD clients experience difficulty in altitude so traveling to places a certain distance above sea level can cause problems (Ladouceur et al., 2013). Patients who suffer from arrhythmias which can affect consciousness can have difficulties operating a motor vehicle (Ladouceur et al., 2013). The study conducted in Paris, France used academic journal references dating between 1986-2012. The limitation is the review contains older sources. However, it does provide a detailed overview from information back to 1986 showing the issues these clients have encountered over a long period, further disputing Cook et al. (2016) commenting meager is known about daily stressors of life with CHD.

Waskowsky et al. (2015) conducted research in the Netherlands sending a questionnaire to a randomly selected patients with CHD from five different hospitals. The study took place June 2013 to September 2014, with 406 randomly selected patients which 237 responded. The questions encompassed demographics, experiences with health, disability or life insurance as well as mortgages. They compared the results to a control group consisting of personnel from hospitals as well as random companies and people. Waskowsky et al. state employment rates were not as high in clients with CHD in comparison to the control (65% versus 88%), insurance and mortgage application rates for those with CHD were lower than the reference group. Waskowsky et al. discuss lower disability insurance rates for CHD clients associate with lower employment rates. Overall 38% of CHD participants experienced insurance limitations across all insurances compared to 9% for the control group (Waskowsky, et al., 2015).

Since employment is a major concern and affects lifestyle Geyer, Norozi, Buchhorn, and Wessel (2009) looked at men and women with CHD to understand their chances of employment and how it compares to the general population. The results show that the severity of CHD increased the possibility of full- time employment diminished, and these patients show a higher propensity for part- time or minor employment (Geyer et al., 2009). Geyer et al. states when looking at the results by gender CHD men show a larger difference in employment in comparison to the control than women. Geyer et al. attributes this to men suffering more of the aftermath of their heart defect than women, and men expected to be employed full time in comparison to women . Geyer et al. conducted their study at the University Hospital of Gottingen in Germany with a sample size of 314 patients a minimum of 17 years old and were operated on as well as receiving continuous care for CHD. A control group culled from the German Socio-Economic Panel (SOEP) which is a longitudinal study providing data on socio-economic change and social development at a national level (Geyer et al., 2009). Since the SOEP exceeded the patient population, they used a 10% random sample. The study utilized person to person interviews with a majority of close-ended questions. The only limitation to this study is it was conducted in Germany and does not consider the demands of the job market specific to other countries on the CHD patient, however it still provides some relevant information about fundamental concerns and issues this population faces when it comes to employment.

Loss of employment for those with CHD can have a greater impact on lifestyle and health than someone who does not suffer from a chronic disease. Schaller and

Stevens (2015) state employees who have chronic health conditions before losing a job, going through periods without health insurance can disrupt necessary and timely care for these workers causing health consequences. Chronic conditions cause workers to have greater baseline insurance needs, and more usage compared to an entire sample of displaced workers. This group also has higher expenditures on prescription drugs, doctor’s visits, poor general and mental health as well as higher activity limitations prior to displacement (Schaller & Stevens, 2015) Schaller and Stevens utilized a sample size of 10,000 individuals by combining 16 Medical Expenditure Panel Surveys (MEPS) through the years of 1996-2012 managed by Agency for Healthcare Research and Quality. This sample is more substantial than other non-administrative datasets used in prior literature (Schaller & Stevens, 2015). Limitations of this research are the primary focus of the study was on job loss with the effects on health conditions, insurance, coverage, and care utilization for the general public, the research is pertinent because part of the study addressed the effects specifically on those with chronic diseases. Next, the study focused on the general public, and chronic diseases in general, however many attributes of their findings are relatable to those with CHD since it is a chronic disease. The use of this research is relevant as it takes a close look at the issues surrounding chronic conditions with job loss, disruption of health insurance, higher expenditures on health insurance, doctor visits, and prescriptions.

CHD creates other implications for these client’s lifestyles such as having difficulty obtaining life insurance due to the nature of the disease, insurance companies do not want to insure these individuals or assign high premiums (Ladouceur, et al., 2013;

Waskowsky et al., 2015). Multiple surgeries required to correct issues about CHD, combined with the onset of limitations over the patient's lifetime contributes to missed schooling (Ladouceur et al., 2013). These factors attribute to lack of achieving higher level education, affecting income level which leads to financial distress resulting in depression (Geyer et al., 2009; Waskowsky et al., 2015) Employment becomes challenging to maintain, with women often opting for part-time work, and men due to the societal norms placed upon them for full time work, becoming depressed, and angry because the body is considered unreliable and insufficient (Cook et al., 2016; Geyer et al., 2009; Ladouceur et al., 2013; Waskowsky et al., 2015). Lastly, these issues cascade into difficulty obtaining mortgages, thus affecting the ability to achieve homeownership, which causes long term material disadvantage (Geyer et al., 2009; Waskowsky et al., 2015).

Quality of Life for Individuals With Congenital Heart Disease

Definition. The first step researching quality of life (QoL) for CHD is understanding the definition. A challenge Fteropoulli, Stygall, Cullen, Deanfield, and Newman (2013) found is a universal measurable definition for QoL does not exist, which needs to be determined. Fteropoulli et al. examined seven electronic databases, as well as the bibliographies of the articles, selecting 31 studies published between November 2001to 2011. These studies met their criterion of the adult population, quantitative assessment of QoL and impact of disease severity on QoL using validated measures with the majority being cross-sectional and four including a control group (Fteropoulli et al., 2013). The studies used a variety of instruments, mostly scales but the measurements were not uniform making it difficult to compare findings. The categories measured were consistent of physical, psychological, and environmental QoL; hence the comparability can be the findings in the groups. The limitations of this study were the inconsistencies in the measurements between studies, however eliminating research due to this limitation would not have yielded enough information to conduct an appropriate analysis (Fteropoulli et al., 2013).

Although Fterpoulli et al. (2013) analyzes studies back to 2001, the research illustrates the change in perception and focus regarding QoL plus how it is more closely evaluated with regards to clients with CHD as we appraise future interventions. Schoormans et al. (2014) follow up by defining QoL as "representing the functional effects of an illness and its consequent therapy upon a patient, as perceived by the patient" for their specific study (p.88). Schoormans et al. conducted their research in the Netherlands looking to identify characteristics in CHD clients which can be modified to improve QoL, focusing on illness perception.

Defining QoL, is a challenge because it has evolved over the years from quantitative measures oriented towards economic to more subjective components such as personal assessment of one's life (Theofilu, 2013) The dilemma addressed by researchers utilizing several different instruments available to measure QoL tested for their psychometric properties accurately. Theofilu wrote a theoretical paper focusing on the definition and measurement of QoL, discussing different aspects of measuring QoL depending on multiple dimensions such as health, happiness, satisfaction, work, family and subjective well-being. Theofilu also expounds on the most frequently used questionnaires for measuring QoL, stating there are more than 1000 instruments.

Illness Perception and Sense of Coherence. As the care of CHD has progressed, so has the perspective of the literature regarding QoL for this population, with a focus on what particular aspects can be addressed to improve QoL. Schoormans et al. (2014) study of modifiable characteristics which can improve QoL for a CHD client addresses illness perception improving QoL. Schoormans et al. state illness perception can regulate behavior and emotional reactions. Schoormans et al. conclude illness perceptions can independently forecast QoL, therefore modifying a client’s perception of his or her illness can improve QoL. Schoormans et al. conducted this study in the Netherlands selecting patients from five tertiary referral and three regional centers. The participants were enrolled in the nationwide CONCOR database for CHD patients. CONCOR is part of a larger longitudinal study measuring patient stated results of adults with CHD; these patients filled out questionnaires at a baseline, and two years later. The sample size was 845, and a median age of 39. The complexity of the CHD was established using simple, moderate, and complex. Functional classification of the CHD utilized the New York Heart Association (NYHA) which measures functional class. No limitations are Class I to not being able to conduct any physical activities without discomfort is Class IV (heartonline.org.au, 2018). Illness perception questionnaire (IPQ-R) was adapted for CHD, replacing illness with CHD, and areas not applicable were eliminated. The six areas evaluated were: consequences (effects on physical, psychological and social functioning), personal-treatment-control (illness or its effects modifiable with personal or treatment interventions), illness coherence (patients understanding of their disease), timeline cycle (perception on ability to change illness and its effects), and emotional representation (negative emotions experienced due to the CHD). IPQ-R has proven to have excellent psychometric properties (Schoormans et al., 2014) Schoormans et al. used the SF-36 to measure QoL at a two year follow up utilizing the 8 domains: Vitality, Social Functioning, Role Emotional, Mental Health, Physical Functioning, Role Physical, Bodily Pain and General Health. A limitation of this study is it is specific to the Netherlands; therefore generalizing to the entire CHD population may not be accurate. Schoormans et al. (2014) have several advantages; it is longitudinal and has a large sample size in comparison to other CHD studies.

Following up two years later O'Donovan, Painter, Lowe, Robinson, and Broadbent (2016) conclude the same outcome as Schoormans et al. (2014) that illness perceptions do affect psychological outcomes, especially with the CHD population. O’Donovan et al. state greater concern, emotional responses, and more symptoms regularly forecasted worse psychological results over time. O'Donovan et al. conducted a cross-sectional longitudinal study in New Zealand at the Auckland District Health Board Congenital Heart Disease Outpatients Clinic between May and September 2010. Adults with CHD 16 years and older who attend the clinic were recruited to participate in the study. After consecutive sampling amongst the patients who attended the clinic 110 completed the initial questionnaire. The questionnaire measured patients cognitive and emotional depiction of their condition by using the Brief Illness Perception Questionnaire established as being reliable and valid (O'Donovan et al., 2016). Trait anxiety was measured with the Strait Trait Anxiety Inventory which has been used in the medical context, proving dependable psychometric properties (O'Donovan et al., 2016). A heart focused anxiety was assessed with the 18 items cardiac anxiety questionnaire showing test-retest reliability being high with sensitivity to changes over time (O'Donovan et al., 2016). The Centre for Epidemiologic Studies Depression Scale- 10 measured depression symptoms which also has validity and reliability (O'Donovan et al., 2016). Lastly, two measurements were used to assess quality of life, a Linear Analogue Scale and the CHD-TNOP/AZL Adult Quality of Life Instrument (TAAQOL), no information presented about the reliability of this scale, however the Linear Analogue Scale has been used in the past by Moons, et al. (2006) showing it to be valid, reliable and responsive (O'Donovan, et al., 2016). At follow up a total of 71 patients completed the entire study. The limitation of this research is those who had a more severe illness, and first surgery at a younger age had a higher likelihood to return the follow- up questionnaire, which can skew the results making it difficult to generalize all patients with CHD (O'Donovan et al., 2016). The benefits of this study provide evidence illness perceptions do affect the CHD population; unease, emotional responses, and more symptoms usually had worse psychosocial outcomes over time (O'Donovan et al., 2016).

Sense of coherence (SOC), closely linked to illness perception, defined as a psychological resource of health and well- being with three main components: comprehensibility, manageability, and meaningfulness (Muller, Hess, & Hager, 2014). A strong SOC helps individuals identify coping mechanisms to use as resources to alleviate feelings of tension and stress to stay healthy (Muller et al., 2014). Muller et al. wanted to understand if there is a strong correlation between SOC and QoL and if SOC had a higher effect on QoL than exercise capacity. Muller et al. conclude CHD patients have a higher SOC, and it moderately corresponds to QoL, demonstrating a better predictor than exercise capacity. Although CHD patients have reduced exercise capacity, SOC can explain the favorable QoL (Muller et al., 2014). Higher SOC was related to family and friend well-being, and the fact patients with CHD have been coping with the disease since birth, therefore, cannot relate to the substantial restrictions since they have not experienced them (Muller et al., 2014). Muller et al. conducted the study in Germany using a sample size of 546 CHD patients who were referred for exercise testing. The participant's filled out a short form SOC-13 and Medical Outcomes study short form (SF-36), as well as performed a cardiopulmonary exercise test (CPET). The SOC-13 measures comprehensibility, manageability, and meaningfulness in the participant's life which has shown to be reliable with high internal consistency and re-test stability (Muller et al., 2014). SF-36 measures physical functioning, physical role, bodily pain, general health, vitality, social functioning, emotional function, and mental health. This instrument has also been shown to have internal consistency, as well as useful for various specialties in medicine without being an issue for any other diseases (Muller et al., 2014). The CPET used a bicycle ergometer as an exercise test to determine capacity. The limitation of this study is it evaluated patients in Germany, therefore applying the results to CHD clients universally may not be entirely accurate.

Physical Exercise. Another modifiable characteristic which can improve QoL is physical exercise. Dulfer et al. (2017) state children and adolescents who had CHD surgery experience reduced exercise capacity, resulting in less physical activity and lower QoL. Participating in exercise programs had positive effects on QoL and leisure time, however there is no resolute proof from the research specifying the most helpful program (Dulfer et al., 2017) Young people with CHD should participate in 60 minutes of physical exercise a day, specifically promote children and adolescents with a low QoL as they can benefit psychologically (Dulfer et al., 2017). Dulfer et al. systematic review is critical to show how exercise can positively impact the psychosocial functioning, QoL, anxiety and depressive symptoms for children and adolescents with CHD. Dulfer et al. implemented a systematic review to understand the results exercise has on the positive QoL for young people with CHD. Eight studies were chosen for the analysis from years 2000-2016, out of the studies two were randomized controlled trials, two were non-randomized prospective studies, two were prospective studies, and two were prospective pilot studies (Dulfer et al., 2017). Limitations to these studies are specific exercise programs are not able to be specified, we need to conduct further research for particular exercise programs (Dulfer et al., 2017) However, they are dependent upon the physical capabilities of each person. Dulfer et al. does establish the importance of physical exercise for CHD patients through the review of studies.

Physical exercise provides health benefits, specifically for those with CHD, the challenge is many CHD patients do not have the confidence for exercise, known as exercise self-efficacy (ESE) (Bay, Sandberg, Thilen, Wadell, and Johnson ,2018). Following up Dulfer et al. (2017), Bay et al. conducted a systematic review understanding the concepts but wanting to explore the assurance these clients have in exercise. Bay et al. wanted to obtain factors for low ESE in CHD adults and strategies for becoming physically active. Bay et al. conclude several adults with CHD have a low ESE, and age is a predictor which needs to be taken into consideration while counseling clients. Muscle endurance training can improve ESE, enhancing the possibilities for this population to be physically active (Bay et al., 2018). Bay et al. conducted this study in Sweden with a sample size of 79 adults having a mean age of 36.7 with CHD. The sample contains participants from University Hospital Centers in Umea and Lund, Sweden with 42 appropriate matched controls recruited from the Swedish national population registry in Umea. A validated version of the Swedish ESE scale showing high internal consistency and scale integrity evaluates ESE (Bay et al., 2018). The EuroQoL-5 Dimension questionnaire measured QoL, developed by the EuroQol group assessing health in five areas: mobility, self-care, usual activities, pain and discomfort, anxiety and depression. The study used the Swedish version which is a self-reported questionnaire. Muscle endurance tests were used by determining shoulder flexion and heel lift, which have good re-test reliability (Bay et al., 2018). These tests were instructed and monitored by the same researchers. Another measurement for physical endurance was Actiheart monitor which combines measuring heart rate with ambulatory use; patients wore it day and night for four days. Limitations of the study are the small sample size; however, due to the population size of those with CHD and comparison sample sizes with other CHD studies the sample size is in line. ESE does not have an established limit on high or low. Therefore, the researchers based it upon a comparison within the controls. Also, none of the patients had any recommendations for exercise. The study does have significant data showing the benefits of physical activity for CHD and QoL, as well as understanding why some CHD clients do not have ESE and how to reverse poor ESE.

Physical exercise is important in complex CHD cases because it increases the QoL, however having a specialist in cardiac rehabilitation should be involved (Karsenty et al., 2015). Karsenty et al. research was conducted in France using a sample size of 135 adults with CHD older than 18 followed at the University Hospital of Toulouse during 2013. These patients were recruited during their regular CHD follow up or hospitalization. Their physical activity was measured by the validated questionnaire WHO-MONICA Optional Study of Physical Activity Questionnaire. The responses were categorized by four levels, no physical activity, mild physical activity (20 minutes once a week) moderate (20 minutes once or twice a week) and intense (20 minutes three times weekly or more). Karsenty et al. noticed the more complex the CHD the less physical activity, and some patients with no physical activity had been recommended by practitioners. Karsenty et al. state a decrease in functional status can be attributed to cardiovascular deconditioning, due to prior beliefs these patients need to refrain from participating in sport. Karsenty et al. discuss physical activity is now deemed safe and leads to an improvement in Qof L. The limitations of the study include QoL assessment, which can be strongly associated with socio-economic level, and less severely with heart disease.

Parental and Familial Support. Parental knowledge is important to the health and well-being of a CHD patient; however, also parental and familial support contributes to QoL. Luyckx et al. (2014) researched to understand how internalizing symptoms such as depression and loneliness, parental support, and QoL predicted one another over time. Luyckx et al. concludes parental support and quality of life impact one another; parental support assists change in depressive symptoms over time which contributes to QoL. Luyckx et al. research incorporated in the Rassart et al. (2016) study, comprised longitudinal research in four waves. Luyckx et al. utilized the first three waves for their results, and Rassart et al. uses the results from the third and fourth wave. The sample for the two studies consisted of 498 eligible participants from the Leuven Hospital in Belgium with a confirmed diagnosis of CHD, ages 14-18, and was evaluated every nine months four times. Luyckx et al. assessed every nine months for the first three waves doing the following measures, Quality of Life and Perceived Health Status using a Linear Analogue Scales (LAS). The Center for Epidemiologic Studies Depression Scale was used to measure depressive symptoms, loneliness assessed with the UCLA Loneliness Scale, and parental support was measured with the Child Report of Parent Behavior (Luyckx et al., 2014).

Emotionally supportive parenting and emotionally supportive siblings were positive factors affecting QoL for adolescents with CHD (Im et al.,2018) Following Luyckx, et al., 2014 Im et al. conducted a study to understand the impact of familial factors on adolescents with CHD QoL. Im et al. (2018) recruited CHD adolescents attending follow up at a pediatric cardiology clinic in Seoul, South Korea to participate in the study during July 22- August 23, 2013. Im et al. (2018) used a sample size of 98 participants, ages 13-17 included in which they filled out a questionnaire measuring their perceptions of their parent's rearing behaviors, QoL, and sociodemographic characteristics. Also, their medical records reviewed for factors such as diagnosis. Parental rearing behaviors used the Fragebogen zum erinnerten elterlichen Erziehungverhalten (FEE) which assessed parental emotional warmth, rejection, punishment, control, and overprotection. QoL was measured using the pediatric cardiac quality of life inventory (PCQLI), which is a disease-specific QoL measure for children and adolescents. A socio-economic characteristic assigned to each child based upon gender, age, school, presence of siblings, religion, perceived economic status, and parent education levels. FEE and PCQLI were both translated into Korean, and reverse translated. Also, FEE was pilot tested by non-CHD adolescents to test for validity and PCQLI modified by healthcare personnel specifically for CHD (Im et al., 2018). The limitations of this study are the participants come from a single medical center in Korea, therefore, generalizing Korean parent's manners of bringing up their children cannot be compared with others due to differences in customs (Im et al., 2018). Other limitations are only collecting data during the summer, a small number of patients did not have siblings, and a longitudinal study is needed for describing factors of QoL for adolescents better (Im et al., 2018). The benefits of the research are significantly large sample size for CHD standards illustrating the importance of parental and familial support on QoL for adolescents with CHD.

Socio-economic Level. Socio-economic level is more difficult to modify for a CHD client, but a social worker can make an impact by helping a CHD client receive social services to improve socio-economic standing. Specific socio-economic factors contributed to better QoL such as education and age. Noted is the subjective well-being decreases due to advancing age with CHD clients more than the controls. Vigl, et al. (2011) concludes there is a significance between socio-economic level and the subjective well-being of adults with CHD, and this needs to be paid attention to when caring for this population. The severity of the heart defect was associated with the physical scale of QoL, however for the mental scale of the QoL, and satisfaction scales socio-demographic showed stronger results. Also, the patient group showed a stronger correlation to socio-economic factors and well-being than the control group (Vigl et al., 2011). Vigl, et al. wanted to comprehend the relationship between socio-economic level and quality of life among CHD adults. Vigl et al. conducted their study in Germany using the national registry which patients with CHD voluntarily self-enroll. Vigl et al. (2011) use a sample size of 709 for their study. Also, a control group was used from a national population health survey, this represents the sample of the German population and was matched up to the study by age, sex, and education (Vigl et al., 2011). Parameters measured were health-related quality of life (HRQoL), health satisfaction (HS) and life satisfaction (LS). HRQoL measured by using the SF-36 which translated into German and has shown good psychometric characteristics. Vigl et al. state SF-36 measures the following multi-component items: physical functioning (health limiting self-care, walking, climbing stairs), role functioning (health limiting work or other daily activities), bodily pain (effect of pain on normal activities), general health (perceptions of one's health), vitality (feeling energetic or tired), social functioning (health affecting social activities) role functioning emotional (measures the interference of emotional issues with daily life and work), and mental health (problems such as depression and anxiety). HS and LS were measured using two ordinal scales measuring least satisfaction, and the highest possible satisfaction, these single item, health self-assessment surveys have shown external validity (Vigl et al., 2011). Vigil et al. state socio-demographic assessment was done by the German National Health Interview and Examination Survey then operationalized in the following ways: living in a partnership was equivalent to being married, living together, living in a stable sexual relationship; higher education was secondary school diploma qualifying for university admission. Working full time equaled working at least 35 hours per week in comparison to not working 35 hours a week, not working at all, or being in school. Unemployment was measured by registered at the Federal Unemployment office. Limitations of this study include it being eight years old. However, it addresses an important aspect from a social work perspective being socio-economic level affects the well-being of the CHD client. Hence when conducting interventions with CHD clients understanding current socio-economic conditions is essential, as well as implementing interventions which positively affect socio-economic status. The sample consisted of a group who self-enrolled causing the selection to be an issue, and it is limited to the German population. An advantage is the sample did comprise of clients who may not usually follow up in a specific clinic providing access to a more elusive community to find for research.

QoL is lower in physical aspects of life, however, for psychosocial, environmental and occupational areas there was not a difference in QoL compared to healthy controls for CHD clients (Fteropoulli et al., 2013). One reason CHD clients may not experience a poorer QoL can be attributed to them adjusting their standards in comparison to a healthy individual (Fteropoulli et al., 2013). Fteropoulli et al. conducted a systematic review but did not review depression and anxiety already which Westhoff-Bleck et al., 2016 established are common amongst CHD clients impacting QoL.

Illness perception has shown to affect the CHD population; a poor attitude can impact functioning, response to treatments, and psychological outcomes (O'Donovan et al., 2016; Schoormans et al. 2014). Research shows evaluating CHD patients at a baseline, if they have poor illness perception, two years later their QoL is negatively impacted (O'Donovan, et al., 2016; Schoormans et al. 2014). Hence, illness perceptions viewed as a predictor for QoL, specifically perceptions regarding future operations, health concerns, life expectancy, and family-related issues either starting a family or being around for present family (O'Donovan et al., 2016). Interventions which change illness perception improve QoL, health behavior, medication adherence, and healthcare utilization (Schoormans et al. 2014). Psychological counseling utilizing CBT, educating patients about their disease, and discussing treatment options are interventions which may help illness perception (Schoormans et al., 2014).

The CHD client's SOC defined as the psychological ability to self-regulate health and wellbeing using the three factors of comprehensibility, manageability, and meaningfulness can have an impact of QoL (Muller et al., 2014). These attributes enable them to view the world as one they can maneuver through to identify coping mechanisms that can manage their tension and stress with the ability to stay healthy (Muller et al., 2014). A strong sense of SOC can have a more significant impact on QoL than exercise capacity (Muller et al., 2014). The CHD client coping with the disease since birth can attribute to the higher SOC since their baseline for physical restrictions has been set at an early age (Muller et al., 2014). Lastly, family and friend support contribute to a higher SOC for CHD clients (Muller et al., 2014).

Physical activity has a beneficial effect on QoL, however in the past CHD patients were discouraged from exerting themselves physically, hence cardiovascular and muscle endurance would be low (Bay et al., 2018; Dulfer et al., 2017; Karsenty et al., 2015). The results are patients not having the confidence to exercise, known as exercise self-efficacy (ESE), occurring commonly amongst aging patients. Bay et al. and Karsenty et al. state this could be due to these patients being advised to limit the exercise by family and healthcare professionals before research showing the benefits of exercise. ESE can be obtained by increasing muscle endurance with interventions which increase activity (Bay et al., 2018).

Parental and familial support affect QoL for CHD clients, the emotional support the client receives can help with depressive symptoms and the demands of CHD (Luyckx et al., 2014; Im, Yun, & Lee, 2018). Lastly, socio-economic level has been shown to affect QoL, the better the socio-economic position the client is in, the higher QoL (Vigl et al., 2011). Socio-economic level shows stronger results for mental and satisfaction scales on QoL, and severity of the heart deformity affects the physical scale of QoL for this population (Vigl et al., 2011). Lastly, when looking at the correlation between socio-economic factors and well-being, the CHD group had stronger results than the healthy control group (Vigl et al., 2011). Therefore, when working with this population, the socio-economic level needs to be addressed during care (Vigl et al., 2011).

Social Work Interventions

CHD Interventions. CBT and physical exercise are interventions used for CHD clients. Although CBT has been used and is showing promise Lane, Millane, and Lip (2013) conducted a systematic review concluding trials proving the efficacy of psychosocial interventions, including CBT, have not been completed and a properly designed random controlled trial (RCT) is needed for future research specifically for CHD clients. Lane et al. conducted a meta-analysis with the criteria being, randomized control trials (RCT) that compare psychological interventions for CHD patients over 15 years of age who have depression to a control group who received no intervention. Lane et al. (2013) determined no studies were matching their criterion. Hence the availability of RCT studies regarding psychological interventions for adults with CHD is limited.

Therefore, the study Ferguson and Kovacs (2016) conducted shows promise for CBT since they conclude most patients who engage in CBT do experience a benefit, specifically reduced psychological distress. As mentioned prior, Ferguson and Kovacs conducted a retrospective study analyzing research of 100 adults with CHD who had participated in extensive psychological evaluation which included a case conceptualization, assessment of mood and anxiety disorders, discussion of psychiatric diagnoses, treatment recommendations when appropriate, and a course of psychotherapy of 12 one hour sessions. These sessions varied according to the needs of the client. However, the scope of the clinic focuses on CBT. Although the limitation of this study is selection bias and cannot represent the entire adult CHD population, it does reveal these clients do experience depression, anxiety, and heart health concerns. Another limitation is the study does not represent those patients with CHD who do not pursue psychotherapy which can mean they are experiencing these symptoms and not getting help, or they are not experiencing issues related to CHD. This study is essential to consider as Dr. Kovacs has participated in many studies regarding psychological issues and CHD.

Physical exercise improves QoL for CHD clients. Dulfer et al. (2017) conclude athletic participation, even competitive sports can lead to improved psychosocial QoL in children and young adults with CHD. Dulfer et al. administered a systematic review to understand the results exercise has on the positive QoL for young people with CHD. Eight studies were chosen for the analysis from years 2000-2016, out of the studies two were randomized controlled trials, two were non-randomized prospective studies, two were prospective studies, and two were prospective pilot studies. Dulfer et al. systematic review show how exercise can positively impact the psychosocial functioning, QoL, anxiety and depressive symptoms for children and adolescents with CHD. However, a limitation is specific exercise programs are not able to be specified. Although Karsenty et al. (2015) and McKillop, McCrindle, Dimitropoulos, Grace, & Kovacs (2016) do not detail specific psychosocial improvements from exercise both studies herald the importance of exercise for CHD clients. Karsenty et al. concluding it improves QoL and McKillop et al. stating future interventions need to be developed to help CHD adults increase their athletic participation. Karsenty et al. conducted the study using a sample size of 135 adults with CHD older than 18 recruited during their regular check-up or hospitalization at the University Hospital in Toulouse, France. Karsenty et al. used the validated questionnaire WHO-MONICA, Optional Study of Physical Activity

Questionnaire measured physical activity. Responses were categorized by four levels, no physical activity, mild physical activity defined as 20 minutes once a week, moderate physical activity defined as 20 minutes once or twice a week, and intense physical activity defined as 20 minutes three times weekly or more. Karsenty et al. noticed the more complex the CHD, the less physical activity. However, some patients with no activity were due to recommendations by practitioners. Karsenty et al. state cardiovascular deconditioning attributes to a decrease in functional status, due to prior beliefs these patients need to refrain from participating in sport. Lastly, physical activity is now considered safe and leads to an improvement in Q of L. One of the limitations to this study is the assessment of Q of L which can be impacted by parental social status and socio-economic factors, not necessarily entirely from CHD (Karsenty et al., 2015). McKillop et al. recruited outside an adult CHD clinic and had a sample size of 15 patients, 67% which were male. The mixed methods study used an accelerometer (a device for measuring speed changes in the body) for quantitative data, and interviews for qualitative data. McKillop et al. stated patients accrued a mean of 26 minutes of vigorous exercise a day, and the interviews revealed the propensity to exercise based upon encouragement by family, parental support without being overprotective, physical activity promoted as being healthy, and some patients reported physical activity at work was sufficient. This study is limited as it does not show the effects over time exercise can have on a CHD client, it shows the comparison of CHD clients who exercise versus a control group of healthy adults without CHD 20-39 years old.

Chronic Disease Interventions. Interventions utilized for chronic diseases were reviewed for potential applicability to CHD since a relationship among depression and continuing conditions of asthma, angina, and diabetes is prevalent (Martínez, Castro, Alonso, Vöhringer, & Rojas, 2017). Martinez et al. discuss a relationship between depression and chronic physical diseases, in detailed is discussed the effects on society when depression and a co-morbid disease occur. Martinez et al. did not discuss a study; this is a proposal for a study. However, the methodology planned is a systematic review and meta-analysis of randomized clinical trials with participants 18 or older diagnosed with depression and have a chronic physical disease. Martinez et al. (2017) discuss the reason for conducting the study is a link exists among depression and continuing diseases such as asthma, angina, and diabetes. Also, treating depression has been shown to help in the control of chronic diseases (Martinez et al., 2017).

I selected asthma and diabetes to evaluate since both diseases are often at birth. Effective interventions for asthma are CBT, suggestive methods such as hypnotherapy, expressive methods such as journaling, mindfulness- based stress reduction (Ritz, Meuret, Trueba, Fritzsche, & von Leupoldt, 2013). Physical activity has shown to be a conundrum, as the objective is to reduce the amount of medicine, however partaking in physical exercise as a whole can help asthma patients. Those who have used their medicine prior to exercise has shown to benefit overall function of asthma patients. Ritz et al. completed a meta-analysis focusing on the psychosocial influences and behavioral interventions for asthma over the last ten years. However, a limitation to the research is the specifics regarding sample sizes and types of research methodology used in the studies included in the study. A benefit to the study is a chart which showed in detail the clinical applicability of behavioral treatments for asthma delineated by the further need for study, the potential for clinical intervention, and current usefulness for clinical intervention. The meta-analysis clearly showed the reader which treatments need more study, which show promise for impact on asthma, and which intervention protocols have data for implementation. Hence on the chart, CBT was shown as impactful for treating asthma. However, the evidence is mixed requiring more work regarding processes for interventions, resulting in the need for more research (Ritz et al., 2013).

Group therapy, exercise, and CBT are effective interventions for diabetics (Kok, Williams, and Zhao, 2015; Lie et al., 2017) Li et al. state a significant improvement with clients after CBT compared to a control group. However Kok et al. found group therapy and exercise being more effective than CBT. Kok et al. did a systematic review using studies published between 1998-2013, with participants 18 and older with Type 1 and 2 diabetes along with comorbid depression, with therapies used being CBT, interpersonal therapy, problem solving, and behavioral therapy. Kok et al. found group therapy to stand out in results for effectiveness in treating depression in diabetics. The interventions were mixed when it came to delivery, intensity and duration thus eliminating the ability to do a meta-analysis (Kok et al., 2015). A limitation to Kok et al. is participants ended up being 50-60 years old with a significant number having Type 2 diabetes making it difficult to reach a broad conclusion since Type 1 diabetics living with the disease since birth show to have a higher rate of depression and may have different psychological needs (Kok et al., 2015). Also, Kok et al. (2015) had ten studies in the analysis which can be considered small. Looking at the review and analysis Li, et al. (2017) conducted for CBT is pertinent since it is recent and used a range of studies from the inception of the databases up to 2016. The criteria for inclusion are patients with diabetes and depression, Type 1 and 2 diabetics, an intervention of CBT, randomized controlled trial study, and specific study results. Again, the limitations to Li et al. is the fact it is Type 1 and two diabetes patients, which makes it difficult to generalize the entire diabetic population or specify the Type 1 diabetic population plus the number of studies utilized was ten which is considered small.

Interventions specifically for CHD are exercise programs and cognitive behavioral therapy (Ferguson & Kovacs, 2016; Karsenty et al., 2015; McKillop et al., 2016; Dulfer et al., 2017). Limited information about CHD interventions necessitates evaluating interventions for other chronic diseases specifically, asthma and diabetes since they are chronic conditions occurring at birth. CBT has shown to be useful for panic disorders, reducing anxiety for asthma sufferers, and those with diabetes improving depression in addition to QoL, but not anxiety. (Li et al., 2017; Ritz et al., 2013). Additional interventions showing success for asthma patients are mindfulness-based stress reduction, suggestive methods for those who are obliging to hypnotherapy, and for children, however not so for adults, journaling was found to be beneficial (Ritz et al., 2013). Group therapy proved to be an effective intervention for diabetics, as well as exercise. (Kok et al., 2015).

The social work practice problem for this study is the inadequate information regarding the experiences with interventions of social workers with adult clients who have CHD. The literature review illustrates this population needs interventions on several levels in concert with Bronfenbrenner's ecological theory. The ecological systems used in the study are the micro system which includes psychosocial issues with depression and anxiety. The mezzo system which includes parental support, and the macro system which includes health insurance and employment.

Interventions such as CBT and physical exercise are shown to help these issues, but more information is needed. Current social work interventions empirically tested are limited with relatively small sample sizes in comparison to the norm (Lane et al. 2013; Ferguson & Kovacs, 2016; Karsenty et al., 2015; McKillop et al. 2016; Dulfer et al., 2017). Evaluating interventions for asthma and diabetes which are similar since they are chronic conditions from birth have shown mindfulness-based stress reduction, CBT, hypnotherapy, group therapy, and exercise have been useful (Li et al., 2017; Ritz et al., 2013; Kok et al., 2015). Understanding the interventions social workers are currently using at the micro, mezzo and macro levels for CHD clients may contribute to providing more information to reduce the gap in knowledge.

Summary

Today approximately 2-3 million people are living with a CHD, which is the most common birth defect (ACHAheart.org, 2018). As medical advances have improved and survival rates are rising, the psychosocial issues these patients are experiencing need addressing since depression and anxiety are common issues amongst this population (Goossens et al., 2012; Kovacs et al., 2015). More information is needed regarding the psychosocial needs for this population, particularly for adults since the research is approximately ten years behind when comparing the current studies for children (Wilson et al., 2015).

The purpose of the study is to use basic qualitative research to understand the experiences with interventions of social workers who counsel adult clients with CHD and experience psychosocial problems. The practice problem is a lack of social work knowledge regarding treatment related to psychosocial issues for CHD clients. Following are the research questions for the study:

RQ1: What are social workers experiences with interventions when working with clients who have CHD and experience psychosocial problems?

RQ2: What successful and unsuccessful interventions have been used by social workers when working with clients who have CHD and experience psychosocial problems such as anxiety, depression, healthcare, health insurance challenges, employment issues, and difficulties obtaining mortgages at the micro, mezzo, and macro system levels of Bronfenbrenner’s (1979) ecological theory.

A qualitative design with narrative interviews understands the experiences with interventions of the social workers who counsel adult clients with CHD and contributes to narrowing the gap in the literature. The participants were six social workers recruited from the 40 CHD clinics who have a dedicated CHD social worker, listed in the ACHA database. These social workers were interviewed via video conference, telephone meetings, and email to gather data or confirm the findings. Transcribing the interviews followed by coding looked for themes amongst the individual narratives.

The significance of this study may help social workers better understand their colleague's experiences with CHD clients. Agencies may be able to implement interventions which are successful in other agencies. Bronfenbrenner's ecological theory is the framework applied in this study by understanding successful and unsuccessful interventions at the micro, mezzo, and macro level.

The literature review reveals very few social work interventions empirically tested and small sample sizes compared to the research norm. Several of the studies in the literature review have concluded more information is needed to add to their research findings. The following section will further detail the research design and data collection.

Section 2: Research Design and Data Collection

The social work practice problem and the focal point of this doctoral study was the inadequacy of information regarding the experiences of social workers with adult clients who have CHD and psychosocial issues. Psychosocial issues are defined as an individual's psychological development in his or her social environment, as well as his or her interaction within the social environment (NAMI, 2019). Deficient knowledge regarding the psychosocial issues pertaining to CHD and interventions for treating those issues are problematic due to patients experiencing continuing mental hardship from the consequences of a continuous condition since birth (Page, et al., 2012).

Preliminary research demonstrates there is a gap in information for social workers regarding care for this population (Leon, et al., 2013). I conducted this study to address this gap in the literature and provide insight on interventions that might be helpful for social workers who treat adult patients with CHD. In this section, I will describe the research design and methodology, specifying the prospective data that were collected and analyzed, the participants, the instrumentation, and the data analysis techniques. Last, I will describe the ethical procedures I used to protect the participants.

Research Design

The social work practice problem that was the focus of this doctoral study was the lack of information regarding social workers' experiences with interventions for clients who have CHD and psychosocial issues. The RQs for this study were

RQ1: What are social workers' experiences with interventions when working with clients who have CHD and experience psychosocial problems?

RQ2: What successful and unsuccessful interventions have been used by social workers when working with clients who have CHD and experience psychosocial problems such as anxiety, depression, healthcare, health insurance challenges, employment issues, and difficulties obtaining mortgages at the micro, mezzo, and macro system levels of Bronfenbrenner's (1979) ecological theory.

The research was qualitative as the goal was to understand the phenomenon of CHD and social workers' experiences with interventions for clients with the disease. Howson (2013) noted that qualitative research can be utilized to explain social developments in natural settings particular to people with a disease.

Researchers use narrative interviews to understand how people constitute what the meaning is of their perceptions, experiences, and interpretations (Hickson, 2016). Narrative inquiry is befitting to healthcare research and supports practice development in mental health (Haydon, Browne, & van der Riet, 2017). Researchers conducting a narrative inquiry explore temporality looking at the past, present, and future; sociality by evaluating personal, social, and cultural attributes; and, lastly, spatiality, which is environment and institution (Hayden et al., 2017).

According to Bronfenbrenner (1979), core human development is affected by the experiences a developing person has outside of each embedded structure. Additionally, events can occur in the outside structures that are outliers which still impact the core development (Bronfenbrenner, 1979). Both narrative inquiry and Bronfenbrenner's theory address the effect environment and experience have on an individual. This shared focus provided a rationale for using Bronfenbrenner's theory and narrative inquiry for this study. Bronfenbrenner examined the micro, mezzo, and macro systems; narrative inquiry can be used to evaluate these systems and understand a participant's experience. Following are the operational definitions used in the study:

Congenital heart disease (CHD): A heart deformity at birth that results in a person enduring lifelong care for cardiac and ancillary issues (ACHA, 2018; Eslami et al., 2013).

Experiences: Interventions social workers use for CHD client issues at the micro, mezzo, and macro level (Dulfer et al., 2017; Ferguson & Kovacs, 2016; Lane et al., 2013). The experiences are defined as interventions utilized.

Interventions: Methods, procedures, and techniques used to help clients with their symptoms and issues (Dulfer et al., 2017; Ferguson & Kovacs, 2016; Lane et al., 2013).

Micro level: Experiences with anxiety and depression, which are personal issues (Gauvain & Cole, 2005).

Mezzo level: The CHD client's family, community, friends, and caregivers, including healthcare professionals (Gauvain & Cole, 2005).

Macro level: Company of employment, mortgage or rental company, insurance companies, hospital systems, and government agencies providing services and benefits to the CHD clients (Gauvain & Cole, 2005).

Psychosocial issues: Manifestations such as depression, anxiety, loneliness, and financial difficulties that result from the client having CHD (Cook et al., 2016; Luyckx et al., 2014; Rassart et al., 2016; Wilson et al., 2016).

The operational definitions of *successful* and *unsuccessful* encompassed whether the intervention was or was not helpful for the client to reach a specific goal he or she had set with the social worker (Hartsell, n.d.).

Methodology

Data

The methods used to collect the data were narrative interviews with social workers who work in CHD clinics in the United States. The initial sample size was seven, allotting for attrition by two participants. I collected the data by audio recording the hour-long interviews, which were held via videoconference. I uploaded the audio-recorded conversation files into NVivo for transcription; then I reviewed them and started coding. After I received Walden University Institutional Review Board approval number 05-30-19-0674183, I recruited participants by calling the targeted clinics to obtain the contact information for the CHD social workers. I contacted prospective participants by telephone, e-mail, or both, using the method that enabled me to get in touch with the social worker faster. Once I communicated with a social worker, I explained over the phone the study information from the recruitment letter. Telephone and e-mail were used for follow-up questions, clarification, or discussions regarding the interviews.

Participants

I used nonprobability sampling (El-Masri, 2017) to select participants who were social workers of CHD clients. Even though selection bias can be a challenge using nonprobability sampling (Stueve, O’Donnell, Duran, San Doval, & Blome, 2001), it was the best strategy for this study since I needed social workers who specifically counseled clients with CHD..

The study sample constituted social workers who counsel CHD clients culled from ACHA CHD clinics across the country that have medical social workers. I used ACHA's directory to contact and recruit the participants for the study. ACHA lists 109 clinics in the United States; a portion of these clinics have dedicated CHD social workers (see Appendix A for list). I determined which clinics have dedicated CHD social workers and then targeted seven from different geographical areas of the United States. My goal was to have geographical representation in order to achieve a national perspective. Recruiting social work participants from ACHA aligned with the focus of the RQs on social workers' experiences with CHD clients because prospective participants were among the few working at a credible organization specializing in CHD.

There are 109 CHD clinics in the United States, 40 of which have a dedicated CHD social worker (ACHA, 2018). Haydon et al. (2017) discuss that narrative inquiry research can have 4-6 participants. However, Hickson (2016) utilized 35 participants when conducting a narrative inquiry with nurses, and Gola (2009) had a sample size of 30 social workers for narrative study. Since the population of CHD social workers is small, an initial sample size of 7 was the goal, with a minimum of 5 in case a participant did not complete the full study. The final sample size I was able to cull was six.

Instrumentation

Interviews were used to collect data. Gola (2009) discusses data collection in narrative interviews being recorded and transcribed to text files. The participants were interviewed via videoconferencing, and the audio was recorded. The audio was recorded via, voice memos on the iPhone. Converting the audio to the NVivo program was done by having it in an m4a format. An m4a format is the file extension the audio recording was saved making it adaptable to upload into NVivo so it could be transcribed.

Videoconferencing was done utilizing Skype or Facetime, whichever one the participant was comfortable using. Videoconferencing did have some disadvantages such as rapport affected by not being in person, missing non-verbal cues since the participants entire body was not be able to be seen, connection and technology issues, missing participants who are not digital literate (Lo Iacono et al., 2016). These issues were overcome by before the interview the researcher and participant conducted a preparation session for technological problems. Another disadvantage is comfort with the environment of videoconferencing, this was overcome by helping the participants with anything they needed to feel comfortable, such as sending them Skype invitations so they could just click on a link to access the meeting (Seitz, 2016). Online interviews provided many benefits such as overcoming geographical issues, financial limitations, physical boundaries as well as the security of a participant being able to leave the discussion at any given time with the touch of a button (Janghorban, Latifnejad Roudsari, & Taghipour, 2014).

Videoconferencing for this project remains the best choice for the following reasons: the participants are social workers at advanced medical institutions, therefore the likelihood of them being familiar with and have access to technology is high. The subject content was related to their experiences with CHD clients clinically, hence deeply personal topics were not explored which may be uncomfortable for videoconferencing. These participants understood the need for privacy, as well as trained to have the judgment and ability to seek out an appropriate environment which will not compromise the process. Reaching social workers in various parts of the United States contributed to the quality of the data, therefore videoconferencing offered a distinct advantage while being financially efficient to accomplish this goal.

The research questions and topics guided the interview process eliminating disorganization; having the questions begin with "what" or "how" can assist with the open design of narrative research (Abdallah, 2009). However, the narrative study needs to provide the participant with the ability to tell stories, which can enable the emergence of new themes into the research. Providing flexibility in the research process to allow new ideas to emerge is an integral part of the narrative inquiry (James, 2017).

To establish the interview protocol specified in Appendix B, I used information found in the literature review regarding interventions for CHD clients, as well as diabetic and asthmatic clients. Exploring which ecological levels, micro, mezzo, and macro, interventions are used most were based upon Bronfenbrenner's theory and the interventions discussed at each level in the literature review. Lastly, my personal experience with CHD and being a social worker helped guide any questions or obtain further information from the participants as appropriate.

Data Analysis

Interviews, email and telephone conversations were collected then analyzed by coding into themes using the computer program NVivo. NVivo has proven to be efficient for sorting data from multiple sources, as well as providing the ability for the researcher to be transparent while analyzing data from different angles, by adding depth and rigor compared to traditional methods of Excel or by hand, since the program is effective at organizing data (Hoover & Koerber, 2011). Before using NVivo, the audio recordings were transcribed. NVivo has just started a transcription service. The advantage of using NVivo transcription service was the support this researcher obtained when converting the information into the NVivo program. NVivo also converted audio files directly into the program.

The research questions provided the framework for open coding. Khandkar (2009) states open coding identifies concepts, defines and establishes categories based on their properties, and is used as a component of many qualitative research methodologies like grounded theory. Open coding is the first stage of data analysis, followed by axial coding which breaks down core categories, then selective coding which takes core concepts from the coded data categories (Khandkar, 2009; Mills, Durepos, & Wiebe, (2010). After selective coding was complete, inductive coding helped build theories which is grounded theory (Khandkar, 2009).

During the analyzation of the research, themes based on information obtained from the literature review were evaluated, such as: specific interventions used, CBT, mindfulness-based therapy, education regarding CHD, physical activity. Issues at the micro level such as depression, anxiety, and quality of life. Mezzo level issues such as social isolation from friends, support from family, friends, and healthcare professionals. Lastly macro issues such as financial constraints, problems with employment, socio-economic level, experiences with healthcare institutions, insurance companies, government agencies, and housing either mortgages or rentals. Also, this researcher looked for new themes which emerged from the participants.

Syed and Nelson (2015) discuss the concept of rigor with qualitative research. Rigor is described as the degree of the researcher's engagement during the process, the interplay between researcher and participants, triangulating data, interpretation of perceptions, and comprehensive descriptions (Syed & Nelson, 2015). The data was analyzed singularly since talk in interaction was used, as well as ethnographic methods since this researcher has CHD and is a social worker (Syed & Nelson, 2015).

Triangulation was used to eliminate subjectivity and establish validity. This was done by using email, telephone, and recording personal interviews with the 6 participants (Abdallah, 2009). After the interview were conducted via videoconferencing, telephone or email was used to follow up for clarification or further questions, this ensured triangulation in case of any discrepancies between participants, assured I was coding themes correctly if there was ambiguity, and prevented any judgment during coding. Although seven participants were initially recruited, the final sample size consisted of six. Coding and categorizing themes and patterns assisted with formulating research conclusions (Abdallah, 2009; James, 2017).

Compromising data in this project can happen in the following manners, technical difficulties with recording, transcribing, and coding for themes. Another compromise which can occur is the Hawthorne Effect wherein the behaviors of the participants are affected due to being observed or assessed, this does occur during research in the health and social sciences (Sedgwick & Greenwood, 2015). Implementing the following actions during the study helped reduce the Hawthorne Effect. These actions included me investing in interpersonal relationships and sustained contact with the participants over time, triangulation by collecting data from different sources, such as several social workers through email, in-person interviews, as well as telephone to make sure participants responses are accurate and resultant themes, were consistently represented (Paradis & Sutkin, 2017; Sedgwick & Greenwood, 2015). Making sure the technology was functioning to record the sessions was critical. Transcribing was done by a professional service to alleviate compromise. I did the coding.

Ethical Procedures

Ethical issues with narrative research encompass resignation from the study, anonymity, confidentiality, and informed consent (Ngozwana, 2018). Obtaining informed consent occurred once a participant had shown interest in the research. The informed consent explained purpose of the research, ability for withdrawal at any time if they wish, agreement to be audio-recorded, as well as use of the data.

Ngozwana (2018) discusses confidentiality and anonymity as the participants, were not identifiable in some aspects of the research. Participants were not anonymous to the researcher since in-person interviews were done via video conferencing. However, to secure confidentiality, the meetings were conducted at a self-selected place by the participant, and I used a secluded space in my home. The participants were identified through codes when transcribing and translating the data; this ensured anonymity in the research data.

The data is stored on my computer and cloud which require password access not shared with anyone. The password to the data is either a letter and number combination which needs to be input, fingerprint, or facial recognition. Following 5 years, the research will be erased from the computer and any paper notes will be eradicated by shredding.

Summary

The origin of this project began when I was born with CHD, and psychological issues were emanating from the condition. Assistance for these issues was not provided at a young age, nor even considered; the main concerns were the medical procedures. As time went on, the psychological problems became more prominent and finding a social worker or therapist with CHD experience was not feasible.

My CHD cardiologist recommended the ACHA organization, and when questioned they knew of two therapists for CHD in the United States. I was incited to pursue social work, specializing in CHD, and orient research towards this topic. Delving into the research revealed a gap in knowledge; more information was needed from a social work perspective regarding interventions for CHD.

As time progressed, this researcher discovered social workers were now in CHD clinics across the United States, and some information is available, but more research needs to be done. Specifically, RCT, however before social work specific RCT’s are designed, qualitative research regarding social workers experience with interventions with adult CHD clients is still lacking. Narrative interviews help to expand the depth and breadth of their experiences, weaving in current information from the literature review, but also providing flexibility to discover new and emerging interventions. This research study can be a stepping stone to RCT, understanding which specific interventions are candidates to be empirically tested.

ACHA organization lists 109 CHD clinics, 40 of which have dedicated CHD social workers, across the United States. Compared to the past the number is much higher, however, in comparison to the number of hospitals overall it is small. Utilizing video conferencing to conduct the narrative interviews with the CHD specialized social workers will overcome geographical barriers while being financially efficient. Gathering information in various parts of the country may prove to be enlightening with different approaches to interventions. Lastly, being able to recruit across the country will ensure the ability to find a sample size of seven social workers.

Video conferencing may have some disadvantages, such as technological issues, participants being comfortable using a computer for an interview, and privacy during the meeting. Since the social worker is a professional and the nature of the topic being clinical and not personal, overcoming these obstacles is possible. Conducting a testing session before the narrative interview assisted with technological issues and ensured the participant's self-selected areas were private for the discussion.

Triangulating the data helped ensure rigor, by following up the narrative interviews using telephone and email for additional questions or needed clarification. Establishing rigor was done since the researcher has ethnographic involvement being a social worker with CHD, as well as engaged in the course of administering the interviews and evaluating the research singularly. This researcher used NVivo for transcription service, coding, and themes. NVivo added to the rigor of the research because of its capabilities to efficiently organize and query the data, providing multiple ways to analyze the information quickly. Examining themes such as specific interventions at Bronfenbrenner's ecological system levels (micro, mezzo, macro) for CHD clients, as well as ones which emerge from the narrative interviews were done while open coding.

Ethical procedures were followed by providing participants printed instruction about the nature of the research along with informed consent. Participants were able to choose their own location and I was in a secluded room during the video conference to ensure privacy; further anonymity occurred by analyzing data without names. Data will be stored for five years on a hard drive and cloud which needs either a password, facial recognition, or a fingerprint for access. After five years the data will be disposed by being permanently deleted from the hard drive and cloud. The following section will provide the presentation of the outcomes for this research study.

Section 3: Presentation of the Findings

The purpose of this study was to use basic qualitative research to understand social workers' experiences with interventions for adult clients who have CHD and experience psychosocial problems. The research questions for the study were

RQ1: What are social workers' experiences with interventions used when working with adult clients who have CHD and experience psychosocial problems?

RQ2: What successful and unsuccessful interventions have social workers used working with clients who have CHD and experience psychosocial problems such as anxiety, depression, healthcare, health insurance challenges, employment issues, and difficulties obtaining mortgages at the micro, mezzo, and macro system levels of Bronfenbrenner's (1979) ecological theory.

I collected data by conducting narrative interviews with social workers who work in CHD clinics in the United States. The initial sample size was seven; however, one participant dropped out. The interviews were audio recorded and held via video conference using Facetime or Skype. The audio was recorded on the VoiceMemo application on iPhone, airdropped to my MacBook, then uploaded into NVivo for transcription. Afterward, I downloaded the transcripts into NVivo for review and coding.

Data Analysis Techniques

Time Frame

I was fortunate and surprised by the overwhelming support I received from the adult CHD social workers I recruited to participate in my study. They were prompt with their responses, telling me right away on the phone they would be happy to participate in my research. Participants returned their consent forms to me in less than 24 hours. The videoconferences were scheduled and completed in 24-72 business hours from the initial recruiting phone call. I contacted all 40 adult CHD social workers during the afternoon of May 30 and the morning of May 31, 2019. Six of the 40 committed to a time immediately, consented promptly, and followed through on their appointment for the interview. After the discussions and over an additional week, the prospective social worker participants answered e-mails and spoke to me on the phone regarding questions arising from coding.

Following are the details about the social workers who were contacted but did not participate. Three scheduled interviews but did not e-mail the consent form back to me. One e-mailed the consent; however, at the last minute the prospective participant rescheduled with no definite time. One asked for the consent form but did not follow up to schedule an interview as promised. Two CHD clinics had a representative ask me to send them the consent to forward to the social worker, but I received no response. Three social workers informed me they did not do enough work with adults to be able to contribute appropriately. One social worker told me she did not have time but noted that she might be able to participate if I did not recruit enough participants. The remainder of the 40 did not respond to my inquiry about participating in the study.

In conclusion, in less than a week, six social workers agreed to participate, e-mailed their consent, and followed through on a video conference call. This immediate and enthusiastic response was completely unexpected. A task which could have taken weeks to complete took less than 7 days.

Data Analysis Procedures

I recorded the audio from the videoconference on my iPhone using VoiceMemo, creating an m4a file, which I airdropped into my MacBook computer. I was able to take the m4a file and upload it into NVivo transcription service, which transcribed the audio. I was able to take the transcription, convert it to a text file, download it to my computer, and then upload it to the NVivo software program.

I began with open coding, guided by the research questions. Khandkar (2009) stated that open coding to identify concepts and define and establish categories based on their properties is a component of many qualitative research methodologies. Open coding is the first stage of narrative data analysis (Mills, Durepos, & Wiebe, 2010). Following is axial coding which breaks down core categories, then selective coding which takes core concepts from the coded data categories (Khandkar, 2009; Mills, et al., 2010)

When analyzing the data, I evaluated themes based on information obtained from the literature review, such as specific interventions used, CBT, mindfulness-based therapy, education regarding CHD, and physical activity. The macro, mezzo, and micro levels were looked at to see which ones the social worker participants believed their interventions aligned to. The following definitions established the parameters for each level. Issues at the micro level were identified as depression, anxiety, and quality of life. Mezzo level issues were identified as social isolation from friends, support from family, friends, and healthcare professionals. Last, macro issues were identified as financial constraints, problems with employment and socioeconomic level experiences with healthcare institutions, insurance companies, government agencies, and housing, either mortgages or rentals. also looked for new themes which emerged from the participants.

Once the file was in the NVivo software program, I went through the transcription line by line searching for themes. This process can be considered open coding (see Khandkar, 2009). I created 45 *nodes*, the NVivo term for categories, based upon themes which came up in each social worker participant’s transcript. Appendix C lists the categories and subcategories. The subcategories break down additional details, which is called axial coding (Khandkar, 2009; Mills et al., 2010).

I selectively coded some categories. For example, for types of interventions, I open coded and then axial coded modalities. Individual modalities such as active listening I selectively coded. Using this process enabled me to conclude that social workers for adult clients with CHD who perform an intervention for depression and anxiety used active listening as one of the modalities.

Validation Procedures

I performed member checking by recording the interviews and having the participants read their transcripts along with an outline of the findings of the study. While reviewing the transcription if I did not understand a phrase, I would listen to the audio recording for clarification. Another procedure I did to provide trustworthiness is having the interview transcribed immediately after the videoconference concluded. I coded quickly once the transcription completed and while the conversation was still fresh in my mind. Therefore, I was able to make additional notes while reading and coding the transcription.

I phoned and e-mailed each participant with a request to review the transcript and an outline of the findings to make sure the themes were expressed accurately from the participant's point of view. Also, I asked each participant if there was any additional information to add following the interview, which may have come to mind. All the participants responded they did not have additional information to add. All six respondents stated that the transcriptions were accurate from their perspective. Each participant read an outline of the final description of the findings to assure their statements were factual. R. R. had two minor adjustments she wanted to make, which I completed; the others said their thoughts are accurate.

Another contributing factor to trustworthiness was the geographic location of participants. The social workers who participated were geographically balanced and represented all areas of the United States. I am using broad categories (i.e., North, South, East, West, and in the middle of the United States) to describe them; identifying them in greater detail will expose their identities because there are so few adult CHD social workers in the United States.

Limitations

A problem encountered while conducting the study is I planned on recording audio with two methods, VoiceMemo application on my iPhone, and Quicktime on the computer. During the first interview, when Skype was running, Quicktime would not engage. Fortunately, the VoiceMemo application on the iPhone worked flawlessly.

A limitation of the study may have been doing the interviews individually. A focus group may have generated some back and forth between social workers, prodding more in-depth discussions about interventions and comments about experiencing similar situations. Also, they might have been able to learn from each other right away in the focus group, therefore having an immediate beneficial impact for the study. Lastly, a focus group may have created relationships where particpants could have five other people in their network to reach out to for questions.

Another limitation is the questions are academically oriented; for a social worker doing day to day practice, they may be overwhelming at first sight. Fortunately, all the participants were very professional and knowledgeable, so having some of the questions ahead of the interview in the consent form was a help for them to prepare. In the future, if I used the same questions, I would provide more background regarding the purpose of asking each question to assist with their preparation for the interview.

Findings

Sample Description

The participants have been social workers from one to 34 years, and working with adult CHD clients from three months to nine years. I asked all the participants what inspired them to work with adult clients who have CHD. None of the participants stated they had CHD or knew someone personally with the disease.

J. O. chose to work in CHD starting with preemie children, which evolved to working with the adults since the children get older, saying it is a natural segue. The others commented the opportunity came about through applying for a job in social work. L. W. discussed having experience with heart failure patients, and when approached about working with CHD clients had not been familiar with the disease up to that point.

R. R. was working in the mental health field with homeless and after having a horrible experience applied for a social work job. She describes the opportunity of working with CHD patients as "falling into my lap." R. R. commented it is the best job she has had and wants to do it until retirement. P. S. wanted to work at the Heart Institute at the Children's Hospital, so when she applied for a job Adult Congenital was one of the assignments. R. T. had been trying to work at the Children's Hospital for a long time. She applied for a job working part-time with HIV patients, and Adult Congenital was added to the responsibilities to make it a full-time position. C. C. said a lot of her experience is with child, family, and adults with severe mental health issues. She wanted to work directly with the patients as opposed to just the parents or family, hence started working with adults with CHD.

Findings for Research Question 1

RQ1: What are social workers' experiences with interventions used when working with adult clients who have CHD and experience psychosocial problems?

These findings answer RQ1 by detailing the experiences of the participants providing the interventions used, describing the methods, procedures, and techniques. For example, the methods for the intervention of transportation are using donated airline tickets or working with health insurance to see if they provide transportation for clients. Interventions used to secure health insurance are employer-based coverage, Medicaid, Medicare, the Affordable Care Act, or hospital charity funds. If the adult client with CHD is under 25 his or her parent's health insurance policy is an option.

Although these interventions seem straightforward, they are not. A social worker may try to implement an intervention for transportation, but she may experience angst. The reasons for angst are the client lives in a rural area, does not have insurance providing transportation, or the social worker cannot access donated funds. There is an emotional toll on the client who needs the care and wants to be compliant, but also on the social worker to help the client gain access to care. J. O. commented, "I feel like so often we're just trying to help them survive" describes the pressure these social workers experience.

The social workers experience feelings of angst and stress with other interventions, for example, finding medical coverage for a client who needs surgery right away. Trying to find financial assistance for a client who has health insurance, but lives paycheck to paycheck, needs surgery but cannot afford to be out of work for the required eight weeks for recovery can be stressful. Obtaining approval for disability coverage for a client who does not meet the guidelines; however, the client cannot be self-supporting because of limited energy to work full time could create another stress. The common theme is if the social worker cannot implement an intervention to help the client both parties feel the frustration. The client desperately needs assistance, and the social worker wants to make a positive impact.

The participants have several clients with depression and anxiety. Since depression and anxiety are the most common issues, many types of interventions are employed. The participants use several modalities for anxiety and depression, such as cognitive-behavioral therapy (CBT), solution-focused therapy (SFT), grief counseling, crisis-based, and motivational interviewing.

The social workers select from the modalities to treat depression and anxiety, depending on the underlying issue. For example, a client can be anxious and depressed because he or she is in the ICU. CBT can be used to help the patient de-escalate his or her anxiety. A client can be depressed because his or her life has not unfolded as expected because of CHD, hence experiencing loss. Grief counseling is used to help a client get through these feelings. Lastly, a client may be anxious and depressed because he or she is unable to work and go to school due to lack of energy. SFT is used to help the client understand, one thing at a time, the task can be accomplished; it may just take longer. These participants have a commonality of having to work with clients who have anxiety and depression; however, the challenge is they are in a hospital setting. Therefore they have to choose an appropriate modality, and the hospital setting does not enable them to see the client for an extended time period. Hence, the modality has to have an immediate impact on finding the client relief. The participants want to counsel clients over the long term but the scope of their job in a hospital environment does not make this possible. More disturbing to the participants, is clients request to keep seeing them, and the participants have to explain it is not an option due to the scope of their job. C. C. explained the experience best stating

> I hear from cases a lot, "Why can't you be my therapist? You know I've connected with you, and I've been talking to you." It's hard to find someone who very specifically understands their condition what their life has been like. Clients will

> say, "This is my sixth heart surgery. I've had heart surgery since I was a baby, I've been in and out of the hospital all my life." It's hard to understand that's such a unique experience.

These social workers experience distress when they are forced to turn away clients who need their counseling skills. The reason for the anguish is knowing the likelihood of the client finding another therapist with CHD experience is slim. As a social worker, this is not an easy burden to carry.

The findings systematically lay out the experiences of the social workers by discussing in detail the interventions used, providing the techniques, and illustrating some of the emotions that arise for these participants while helping this population. Following are detailed findings. See also Table 1 for a summary of findings for RQ 1.

Table 1

How Often Participants Reported Implementing Various Interventions

	Interventions								
Participant	Advance directives	Connecting to peers	Disability	Disease education	Encouraging compliance	Financial	Health insurance	Referral to mental health	Transportation
1	X							X	
2	X					X	X	X	X
3		X				X	X	X	
4	X	X				X	X		
5	X		X	X	X		X	X	X
6					X	X		X	X
Total	4	2	1	1	2	4	4	5	3

Advance directives. The social workers all need to address advance directives with these adults, especially prior to surgery. The challenge is handling the situation, so the client does not get anxious before an operation he or she is going to die. Especially distressing for the social worker is a young adult client, at age 18-20, new to these decisions because he or she has relied on a parent. The client is coming in for surgery, and the social workers have to do advanced directives. R. T. commented regarding the situation "That just sometimes is just, oh no no no no. You know that just pushes things over the edge." R. T. stated she approaches the issue, saying, "This is not because you're going to die this is because you're over the age of 18." L. W. stated, "It's sometimes scary especially if you're talking to an 18-year-old, their first visit and they are like wait . . . What?".

P. S. commented they have a hospital wide initiative to have the document in place when someone is over the age of 18. She asks about the advance directive at every appointment. P. S. experiences gratification assisting a client with such an important decision "When we're able to give information have the patient review it, answer questions, and assist him or her with the document that would be quite the successful intervention."

The participants discussed the advance directive several weeks before the surgery, giving the client time to understand the situation, so he or she is not distressed before surgery. Advance directives cause consternation for the social workers because the hospital requires one for each patient, and it is necessary when the client is unable to make his or her own decision. However, L. W. stated the client is told: "the advance directive is a standard procedure to do and every healthy adult needs an advanced directive." Also, L. W. mentions to the client they are not in crisis, "taking care of it now means one less thing to do if there is a crisis."

Advance directives are a difficult intervention for social workers to implement because of the imminent stress of the situation. They also provide satisfaction with helping honor clients wishes during a crisis. Advanced directives are a different challenge for the CHD social worker because the intervention is often for young adults coming to terms CHD while having to make decisions about care during a crisis. The nature of the CHD forces the social worker to ask young patients to make difficult decisions generally reserved for clients who are older and have thought about crisis or dying.

Each of these approaches comes together with the social work goals of putting the client first and starting where the client is. Starting where the client is, would be an 18-year-old understanding CHD, is counseled on the ramifications before being approached with an advance directive. A client scheduled for surgery is contacted several weeks before the operation making sure he or she is not approached with an advance directive at the final hours before surgery. Putting the client first, not the convenience of the social worker who can get the signature on the spot right before surgery.

Connecting to peers. The social workers are efficient at connecting the clients to outside resources; however, they find value in connecting clients with peers. Clients live the disease, so they have the best, most up to date feedback and experience on outside resources. R. R. stated, "You're not going to know all the resources. I always use my patients as a resource because they've been through it; they lived through it". J. O. said, "I feel like their peer groups can have an impact on how effectively they can cope. As well as what resources they can get access to, whether it's through friends or whether it's through different things in their community."

For an intervention that seems so valuable, it is more challenging to implement than one would think. Connecting adult clients with CHD to their peers is harder than it should be. Peer groups can be beneficial with coping, as well as being able to connect to other resources in the community through friends. However, since adults with CHD is such an emerging field, many areas need to be addressed along with support groups. R. R. said, "I talked to my leader about building a support group for adult CHD patients. However, it is on hold for the time being because we need to implement a needs assessment group".

Peer support for young adults with CHD transitioning from pediatric to adult care is helpful. During this time, these clients feel isolated because of the disease, as well as encountering new adult responsibilities and concerns. J. O. commented

> I do feel like that's a gap and I feel like sometimes that piece of them knowing they're not alone and there are other people that understand. If we could have more groups, more programs or more things like that, especially during transition, especially those young 20-year-olds. I feel it could make a big difference because they already feel isolated. They're also going into a world where they will be even more isolated in general.

Another aspect of the importance of connecting to peers is an adult who has CHD who may have cognitive limitations. For example, a client who needs to apply for disability benefits. Having his or her parent connect to another parent who has helped their adult child with CHD apply and receives disability benefits can be beneficial. Applying for disability can be a confusing and challenging process because adults with CHD is a new and growing population. Hence not many have applied for disability, therefore, navigating the requirements and the system can be tenuous. R. R. has experience with this situation and said

> This patient has Deep Jaws syndrome, and he's 21 years old. His cognitive level is not very sharp. So the mom believes her son may not be able to secure a full-time job with benefits down the road. She was inquiring about filing for disability. I know the protocol about filing for disability, but I don't know what it's like to go through it. To have a significant someone who has a disease like that and going through those loopholes. I would be able to connect her with another mom that was open to sharing her experience, so they're going to be talking back and forth. I think this is the greatest hope I could provide the connections if they can speak to someone other than me. I'm not the specialist, but I can help kind figure out who else they can talk to that can help them with their journey of filing for disability.

These social workers would like to be able to provide a peer support group for their clients. Other responsibilities for clients with CHD prevent this, such as a needs assessment group, which is seen as a higher priority for now in R. R.'s system, coupled with the volume of patients. CHD organizations or a social worker in private practice would be ideal candidates to set up support groups on a regional basis for adults with

CHD. Peer support groups would be an area which could contribute to the progress of social work practice.

Disability. Adults with CHD present a challenge when it comes to securing disability. From the outset, the client can look healthy, active, and vibrant. However, they struggle with a lack of energy because of the heart defect. The heart may work at a 60% capacity of a normal heart. Hence, an adult with CHD may be able to get 60% done in a day of what a person with a normally functioning heart can complete in terms of energy level. For example, an adult with CHD would feel the same working half a day as a person with a normal heart structure would feel after putting in a full day's work. The challenge is without supportive documentation from a doctor; it is tough to get approved since adult clients with CHD are not all the same. These clients are a different population of people, which government agencies have not addressed. Essentially, they need the services, but due to the nature of the disease, they do not fit in the established parameters set by government agencies for the benefits. L. W. described it as

> Disability without supportive documentation from a doctor is really hard to get approved because it doesn't fit like a cookie-cutter, you had this so then you're going get this. No, this is a different population of people, and it's not that it's new but it just really hasn't been addressed.

Even getting the supportive documentation from the client's doctor can be a challenge. Specific standards need to be met for the Doctor to provide the necessary documentation. However, the clients with CHD have a different set of standards; even Medicare does not recognize. Social workers need to balance the set rules and explain to the doctor why the documentation is necessary from a physiological perspective. L. W. described the experience as "We've had to go to our doctors do peer to peer and explain the differences and how the physiology is different. So that's difficult when navigating government systems, they don't understand".

These social workers struggle to help clients with CHD get disability insurance, not only with securing appropriate documentation from the doctors but also working through government agency guidelines. The task can be so tricky and time-consuming, even seeking out other clients who have been successful for advice and feedback is an alternative. Helping clients secure disability is a micro issue for these social workers; making a difference one case at a time. Disability insurance for clients with CHD is a social work macro issue. Organizations such as ACHA can use their lobbying power in Washington, D.C. The lawmakers for these government agencies need to understand the trials and tribulations of adults with CHD and adjust the parameters for disability coverage. These social workers can contact the local ACHA chapters to bring the issue to their attention, so it gets recognition within the organization to lobby in Washington, D.C.

Disease education. The social workers discussed implementing disease education for two circumstances. The first the client is not attending appointments, especially when too much time is lapsing between dates. The social worker believes educating the client about his or her disease and the importance of follow up appointments can help motivate the client in scheduling and attending a check-up. L. W. stated when it comes to clients and not attending appointments, "You feel like it's not important? Do you not understand the grasp of your medical condition?". The client may need education on his or her medical condition to encourage regular check-ups. Educating the client about the disease is used when clients get caught up with home life, or too much time lapsing between appointments

Social workers use disease education to help clients whose parents did not elaborate on the CHD issues as the client grew up. Once these clients are young adults, they do not understand the impact of CHD. These clients receive education about taking care of themselves because their parents have been doing it all along, and suddenly they are fully responsible and overwhelmed with the information. R. T. stated

> So you know parents just kind of manage all that, and I just had a lovely young lady that was in her 20s who said My mom never told me any of this stuff. I just went with it until I was about 21 years old and now I'm getting hit with all of this you know which is overwhelming.

These social workers show disease education as being more than discussing proper medicine to take and when. Disease education means letting clients know the gravity of their CHD, so they make sure to attend follow up appointments and procedures. Disease education includes educating a young adult about the intricacies with compassion and sensitivity. The clients are dealing with the reality of responsibilities of being an independent adult, but also managing a chronic disease.

Encouraging compliance. Frequently clients are not compliant with their care, missing appointments, or not scheduling appointments when they are needed. The social workers revealed this could be due to two reasons, the client is in denial about the disease and care, or there could be barriers causing non-compliance. L. W. described her experience with a client who could be considered more in denial about his disease:

> I had a patient that has been in denial for years about his condition, and he had been avoiding coming to see us. I started about two and a half years ago. Before that, they had been trying to get him to come in for two years. He was still a minor, and he refused. One of my big projects was whatever you can do to get this person in here; we're just so concerned about him. Two months of ignored phone calls with me leaving messages saying "just checking in on you" for him to be able to trust me. When the patient came in, he was so sick; he had over 20 pounds of fluid built up because no one has been able to reach him for so long.

Barriers clients encounter, which negatively impacts compliance can simply be getting to the appointment; some clients are unable to drive or do not have transportation. Even just having appropriate health insurance can affect a client's ability to be compliant with his or her care. Limited or no coverage for prescriptions or specific procedures makes it financially impossible to comply with care. C. C. stated

> A lot of the interventions are focused on compliance with care and with medications, sort of readiness for care, whether they're preparing for surgery or if it is some medical intervention. Then addressing barriers to compliance, barriers to care, barriers to making it to their appointments, on a more basic level, just concrete resources such as transportation to get people to the clinic.

The social workers discussed non-compliance is not necessarily a client ignoring his or her health issues. Non-compliance can be denial or barriers they need help overcoming to receive care. Both social workers have helped their clients overcome problems with non-compliance by following up and being tuned into the needs of the client. Either it is to help obtain concrete resources or creating a rapport with the client, so he or she feels comfortable to recognize the need to attend an appointment or procedure.

Financial. The social workers try to implement some financially oriented interventions for clients. Hotel accommodations so clients can attend appointments and procedures are complicated. For clients living a certain distance from a CHD clinic, there are accommodations such as the Ronald McDonald house and similar places. A difficulty arises when clients are closer than the distance requirement but need accommodations due to their age and driving, or the nature of the procedure. R. T. stated

> Ronald McDonald House has pretty set criteria on how far away you have to live to be able to utilize it. You need to live more than 40 miles, and there are families 20 to 30 miles away. You know that's a struggle for them. They encounter the costs of getting and eating here.

A problematic financial intervention is obtaining resources to assist clients unable to work during the eight week recovery period after surgery. These clients need financial assistance to pay rent, insurance deductibles, and other expenses. C. C. stated, "You know I've had very little success finding concrete resources to pay clients to rent while they are down, plus all the other stuff. Just paying insurance deductibles, nobody pays insurance deductibles."

Hotel accommodations and helping clients with other expenses such as rent, insurance deductibles are difficult financial interventions to accomplish. These are areas the social workers struggle with because frequently the clients do not fall into the parameters required to receive assistance.

Transportation. Transportation is a common intervention the social workers' encounter, and one they have more of an ability to influence. Although transportation may be a financial intervention, it also stands alone because a client may be able to afford transportation; however, he or she may not be able to drive. Medicaid and Medicare will provide transportation for clients, but in other areas, clients need to find their own. Transportation can be particularly difficult for clients in rural areas. R. T. stated, "Fortunately at Children's we have donated Southwest tickets we can use as well as gas cards we can provide clients." C. C. commented

> Some people don't drive. They need transportation to get to their appointments. Depending on where they live if they live two states away, that's difficult. Some Medicaid's will transport people or fly them, but not everyone has Medicaid, and not every Medicaid will do that. You know that that's just another expense.

The two prominent barriers to transportation are the client can drive but cannot afford the expense, or the client is located too far away to drive. Another obstacle is the client is unable to drive and needs to be transported either within a reasonable distance or a few states away. Often transportation barriers can be overcome. However, social workers experience the following hurdles, clients do not have family or caregivers to transport them, Medicaid does not provide the service, or the social worker does not have access to funds to provide transit.

Health insurance. Health insurance is another intervention the social workers implement often. As with transportation, health insurance can also be considered a financial intervention; however, it stands on its own because, without it, there is indeed a barrier to care. Also, the financial means of a client does not impact his or her ability to secure health insurance. A client can meet parameters set by government agencies or institutions, enabling a client to receive health insurance.

Several of the participants talked about the amount of time they spend on this intervention. L. W. remarked, "literally insurance is one of the biggest issues." J. O. stated, "I do spend quite a bit of time educating them about insurance in general and then walking through the steps of how to get insurance." R. T. said, "So I do quite a bit of insurance work with families." R. R. commented, "The number one consult I get is insurance issues."

The most significant issues with insurance are clients do not have insurance, are losing coverage, or do not know how to get insurance. Clients who reach the age of 25 and 26 suddenly start panicking because they know insurance is needed, but they do not know what to do. Sometimes they are still in school because of CHD they may not have had the energy to go full time or have had to work while going to school. Schooling is delayed or interrupted due to heart procedures and recovery. J. O. stated regarding her 25 and 26-year-old clients and her insurance interventions “I walk them through the steps of how to get insurance. Through the Affordable Care Act, their employers or how to stay on their parents' insurance if they're able, so they can continue to get financial coverage." R. T. commented she deals with many clients in this predicament as well

> A lot of folks are falling off their parents' insurance. They are not established in a full-time job often because of their congenital heart disease. They do not have health care benefits coming in at the age of 24 and 25, and saying you know I knew this was coming what are we going to do?

The social workers talked about being unable to help clients secure health insurance. The clients may fall into the parameters of not having access through a job, not being able to afford it, or not qualifying for Medicaid or Medicare. J. O. discussed her experience with this challenge "I give them resources and help educate them sometimes there literally isn't anything for them. They don't qualify. They don't. They're not employed. They're still in school. They can't stay on their parents' insurance. They don't qualify for Medicaid". R. T. stated, "Sometimes folks can plug into employer policies, but I feel like more often than not, it's not a good option, or it's not available. Just because of how they're working." R. R. feels very fortunate because her hospital has a fund which she can help her patients access to get complete coverage for six months. Therefore when she is unable to secure insurance for them, she has this alternative, R. R. stated

> A patient comes in, and they're uninsured. They get charity assistance here from our hospital; it will be good for six months. We know that's effective because they're able to get care here for at least six months. It's amazing because a lot of different hospitals from what I've heard from other social workers, only give two

> weeks of charity assistance. You're not making a significant impact on helping these patients get their health back in order. They're able to have a transition into getting their insurance.

Another aspect of insurance the social workers encounter are clients who are struggling with co-pays, deductibles, and insurance coverage for procedures. As C. C. mentioned earlier, she has been hard-pressed to find concrete resources to help clients pay for their insurance co-pays and deductibles after surgery. These clients have an eight-week recovery process; they cannot work or drive a car. R. T. stated she intervenes by asking her clients, "can we help you call the people who process insurance letters? Whatever is needed, and if I can't do it, let's find out who can do it, to help you".

All the participants experience relief and stress with helping clients secure health insurance. J. O. commented sometimes it is almost easier when someone does not have insurance, instead of having existing insurance to help them, commenting, "Frankly I can't be as successful when they actually still have insurance." However, the participants encounter a gap in the system when a client is unable to work full time because of CHD constraints, but these clients are too healthy to qualify for disability. J. O. described her experience with this problem as

> It's more of a lack of the system; there aren't resources out there for clients like this; there isn't a safety net. Clients have these congenital conditions and are employed, or they're still going to school, or they can't be employed because of their heart condition, but they don't qualify for disability. They're too healthy for disability, but they're not making enough to support themselves.

The pressure to help clients get insurance can be intense. Clients may need medication or equipment to enable them to keep living, which is unaffordable unless they have coverage. J. O. stated the following, her intonation, and facial expressions show the pressure she feels when helping some of her clients with their issues. The impact it has on her stress level when she is unable to help them obtain what is needed to solve their problem.

> I feel the emotional side of the Adult Congenital patient is very unique. I feel like so often we're just trying to help them survive. There's a great motivation to get the insurance, so they get their doctors equipment, so they can stay on their meds, so they can keep living.

R. R. feels relief because her hospital has a fund she can access when she encounters a limit securing health insurance for a patient "I'm really blessed this hospital provides six months of care."

In conclusion, health insurance is an intervention for these social workers that has many facets. It can be as simple as being able to get someone on Medicaid or Medicare because he or she did not have the proper knowledge of the benefit. However, it can be grueling because a client falls into a gap where he or she is not eligible for any options, and the client is in serious need for care. Lastly, a client many have insurance but paying the premiums, deductible, and co-pays are not affordable, and the social worker is unable to find funds to help these clients.

Referral to mental health. Several of the participants discussed they are unable to provide psychosocial services to clients for an extended time period due to the scope of their job description. They are working in hospitals and are continually having a high volume of new patients come in for services. Therefore, when a client needs extended service for mental health issues, the participants need to refer them to outside services. Referral to outside service is challenging in a few ways. First, the client has developed a relationship with the participant; hence, they do not want to see someone else. Many clients come from rural areas, or out of state, making it challenging finding an appropriate therapist.

J. O. stated, "We're not able to do short term therapy in our clinic." P. S. commented the following about having clients access outside providers for mental health purposes "Outside of the clinic for mental health purposes that's 100 percent because we don't offer that". R. T. stated, "We're dealing with you know assisting folks in finding a mental health provider. We're talking to them about what's going on. You know that you're having a difficult time coping or functioning. Where can we best connect you". L. W. stated she can refer clients to her hospital's behavioral health center. However, if the client lives a significant distance away, such as three hours her hospital is not appropriate

> Our outpatient behavioral health center will see our patients. However, our patients come from very far sometimes, three hours for an appointment. So our behavioral health center wouldn't be the most appropriate; it's not close to their home. If they are close I love using Memorial's clinic then we know what's going on, we can see if there's any concern.

C. C. is told by her clients regarding her to being their therapist, stating, "I hear from cases a lot, "Why can't you just be my therapist?" You know I've connected with you, and I've been talking to you".

Also, participants are working with clients with CHD in addition to other populations, such as other patients with cardiac issues, children with CHD, and clients with HIV. On average, each participant is allotted half time of their position to adults with CHD. Making it even more challenging to foster individual therapy over a time period.

Several participants commented they are unable to find an LCSW who specializes in CHD, L. W. stated, "finding someone that specializes in congenital that's impossible.” C. C. comments, "I have very little success finding someone who has experience." The participants rely on the client having a positive therapeutic relationship with a therapist when looking for a referral. Participants discussed having clients look for someone who specializes in cardiac or chronic disease such as cancer. Lastly, the client will find a therapist, and then the waitlist to get into seeing the person can be up to six weeks when the client needs services immediately. J. O. expressed her experience finding an appropriate outside therapist for her clients

> I tell them to look for somebody that has helped cancer patients because that's the closest I can get. Since they're not very many people who understand congenital heart disease, let alone adults with this type of condition. Cancer is a little more familiar, yet the waitlist for a therapist I know I've had patients go to can be up to six weeks to two months long.

R. T. discussed it is difficult finding a therapist for her clients, especially when they do not live nearby the clinic. R. T. stated "

> For a congenital heart disease client, sometimes there's not always someone. We're researching it online, of course, looking at profiles on Psychology Today, and seeing who their insurance providers cover. Given those choices of what they're comfortable with because often these families are going to know who is in their area what they do. You know I don't live in the places they live, so they'll usually tell me you know this is working or this is not working.

C. C. discussed since she is in a hospital, and there are several hospitals in her area if patients follow up on a referral, sometimes they can find a therapist. However, the therapist may not have to experience with chronic disease or any chronic disease experience with adults. C. C. stated

> There are a few people who at the very least have had experience working in a hospital. Not necessarily with congenital heart disease, chronic disease, and with adults or children. Whatever it is we're looking for, it's also the patient's willingness to follow through with any of those referrals.

A few participants also do an outside referral for assessments to understand clients strengths and weaknesses for future opportunities with work or school. An outside referral to vocational assessment helps understand what kind of jobs are appropriate for a client with CHD. R. T. does this stating she, "connects them to the Office of Vocational Rehabilitation which is supposed to be an entity to help folks with disabilities get established or get back to work or get into schooling." Another referral is neuropsychological testing, which helps patients get a better understanding of their deficits and strengths. P. S. uses this referral, stating, "We've been starting to make referrals to this psychologist who does the full neuropsychological assessment."

The social workers do not just rely upon referrals to mental health professionals for individual therapy work, but also for assessment to assist clients in maximizing their skills and abilities. A common theme amongst the social workers is the lack of mental health professionals in private practice who have experience or specialize in adults with CHD. Also, the lack of availability of practitioners who specialize in chronic disease. All the participants would like to provide therapy for their clients over an extended time period; however, due to the scope of their jobs, it is not a possible endeavor. Hence the availability of experienced private practice social workers specializing in this population is needed.

Depression and anxiety. All the participants stated they are implementing interventions for depression and anxiety their clients' experience. Depression and anxiety are the top psychosocial issues these clients experience, and these participants confirmed it in their interviews. J. O. said, "I would say I most of my interventions are based around anxiety and depression as well as connecting patients to services." R. T. stated, "often we're dealing with anxiety depression." C. C. said, "I think everything gets grouped into anxiety which most of the time it is, but sometimes it's other stuff. On a more basic level, it can be just concrete resources, transportation to get people to the clinic."

The participants use the following modalities to treat depression and anxiety.

Active listening. Active listening is used to help delineate issues the client is experiencing to assist them. R. T. discussed several clients are hours away in rural areas, so when they are having difficulty, the intervention is over the phone. Listening on the phone to a client can be useful in helping to assess for suicidality and understanding who the client can see that day, either another therapist, friend, or family. R. T. commented, "We've had people call us being pretty depressed or pretty upset." R. T. will say to her clients, "Let's talk about what's happening and let's talk about what can we do or what you can do. Who can you see today? What are we going to do?" R. T. stated she is "making sure to assess things depending on how sad they are, assessing for suicidality and that kind of thing."

Social workers use active listening to help clients sort through their issues, but also to assess if the client is in danger of hurting him or herself. Active listening is a modality these social workers use for clients to have someone they can share their feelings and issues who can provide support and help.

Building coping skills. CHD requires quite a bit of coping from the clients and having the necessary skills can help with the unpredictability of the disease. C. C. described a situation where a client's oxygen level went down, and several people rushed into the room. The client wants to know how to de-escalate anxiety. C. C. commented, "just building coping skills is huge in that short time frame that I have." The coping skills taught by social workers can help the client apply them to a myriad of unexpected events.

Cognitive behavioral therapy (CBT). Several participants commented they use CBT to some extent. Since the social workers are restricted with the amount of extended therapeutic time they can spend with clients CBT is conducted finitely. J. O. comment regarding using CBT "I would say yes, but very limited because I mean effective CBT happens over the course of visits." R. T. said, "some CBT kind of work is used when trying to sort what is the focus and what is going on with issues." Lastly C. C. stated, “As long as it's developmentally appropriate, I do cognitive behavioral therapy. I had clients benefit doing the worksheets, just having those to find ways to de-escalate their anxiety within the context of being on the ICU.”

The social workers find CBT to be an effective modality; however, they feel constrained in the amount of time they have to administer it thoroughly. Therefore using it in the hospital setting is helpful in some circumstances, such as doing a quick determination of issues at hand, de-escalating anxiety, or helping clients dealing with being in ICU.

Crisis-based counseling. Crisis based counseling is useful because clients need help to be successful at the moment. Since there are so many clients and one social worker, who may not even be full time, in these CHD clinics crisis based counseling is used. J.O. stated, "To help them be successful at that moment, they get a little more crisis-based. There's so many of them, and then there's just me." Crisis based counseling is an intervention used by the social workers in the hospital environment to help a client experience some immediate relief from the anxiety or depression.

Grief counseling. Clients will experience feelings of depression and anxiety because their current state of health is not what it was supposed to be in their mind. R. T. stated

> Clients will comment, I thought life was going to be A, B, and C and I was going to be able to do D E and F. Now I'm being told this. None of this is what it was supposed to be. Now what? What am I going to do? I'm very depressed. I am very anxious. I can't do the things I so much wanted to do.

Grief counseling helps clients deal with the loss they experience because of CHD. Clients are disappointed because they are unable to participate in certain activities, or their life has taken an undesired direction.

Motivational interviewing (MI). A few participants mentioned using motivational interviewing to help clients with anxiety and depression. MI has been found as a wide-ranging intervention to quickly address several symptoms the anxiety and depression may be stemming from, such as preparation for surgery or compliance. J.O. stated, "mine sometimes need a quick motivational interview with technique to help them be successful." C. C. stated

> I have a lot of success with motivational interviewing and using it. MI can really be applied to anything, but it can be broadened to whatever piece we need to address. Whether it's compliance, anxiety, or looking at how motivated the patient is to meet that established goal.

The social workers find MI to be helpful in the hospital setting as an intervention to quickly address issues stemming anxiety and depression. MI is useful to help a client tap into an immediate strength or build self-efficacy to meet a goal.

Physical exercise. Physical exercise for these clients is at the discretion of the physician. Each individual has different capacities for activity level based upon their physical capabilities and motivation for exercise. As a social worker, physical exercise is a recommended intervention; however, deferring to the parameters the physician puts on the client is necessary. R. T. stated, "Physical exercise you know is at the discretion of the physician; what those restrictions are, what they're able to do. Most definitely we're encouraging that if it's something they do. Also, there are limitations on their exercise tolerances".

Physical exercise can be an effective intervention for social workers to use. However, it comes with the challenge of limited implementation based upon physician guidelines, as well as client motivation and exercise tolerance.

Solutions-focused therapy (SFT). SFT is used to work with clients for depression and anxiety. The social workers described SFT as useful when seeing clients in the hospital environment because they will not be able to see them over an extended time period. SFT gives the social workers the ability to have an immediate impact by helping the client to focus on one issue at a time and not get overwhelmed. R. R. stated, "I do use some small approved solution therapy." L. W. stated

> I do not do in-depth therapy; they are never going to come back and talk to you. It is just in the clinic, at the moment. I explain it is one step at a time. You tackle what comes at you first.

The hospital environment provides challenges for these social workers when trying to offer some clinical therapy to their clients because of the short amount of time they have to spend with them. SFT is useful for having an immediate effect in helping decrease a client's anxiety and depression as well as providing him or her with a tool moving forward. Table 2 details how often participants reported using the different modalities for depression and anxiety.

Table 2

Modalities for Depression and Anxiety

	Modalities for depression and anxiety								
	Active listening	Building coping skills	Crisis-based	Grief counseling	Physical exercise	Strength-based	Cognitive behavioral therapy	Motivational interviewing	Solutions-focused therapy
Participant									
1						X			
2	X			X	X		X		
3			X				X	X	
4									X
5									X
6		X					X	X	
Total	1	1	1	1	1	1	3	2	2

Findings for Research Question 2

RQ2: What successful and unsuccessful interventions have been used by social workers when working with clients who have CHD and experience psychosocial problems such as anxiety, depression, healthcare, health insurance challenges, employment issues, and difficulties obtaining mortgages at the micro, mezzo, and macro system levels of Bronfenbrenner’s (1979) ecological theory.

First, none of the clinics have measuring tools established to determine successful and unsuccessful interventions. Therefore the social workers are basing successful and unsuccessful on their measurements. The first part of RQ2 is answered by detailing the successful and unsuccessful interventions, along with the participants' specific responses to their experiences with the interventions. The second part of RQ2 is answered by discussing which ecological systems the participants perform interventions most often, showing it is pretty consistent among all three systems. Further, the findings then detail the individual participants feedback about their interventions and which system each one believes the interventions align.

Financial assistance was considered both successful and unsuccessful as an intervention and consistently aligned with the macro system. Outside referrals and resources were considered both successful and unsuccessful; however, aligned with all three ecological systems. Health insurance was considered a successful intervention and aligned with the macro system. Helping clients with advanced directives was deemed a successful intervention, and aligns with the mezzo system. Encouraging compliance was also considered successful and unsuccessful aligning with the micro system. Motivational interviewing used for anxiety and depression is deemed to be successful and aligns with the micro system.

In conclusion, several interventions the participants use to help clients can be both successful and unsuccessful. The success is contingent on the client meeting guidelines for a benefit, or the social worker can access certain funds. The social workers had differing and similar perspectives on how the interventions aligned with the ecological systems, which will be detailed. Also, the social workers discussed an intervention might align with more than one ecological system.

Clinic measurement of interventions. Understanding the clinics' measurements of interventions is essential to address the second research question since measurable results are the basis of the questions. Social workers stated their clinics did not have an overall measurement for interventions used in their clinics.

The six clinics the social workers are in do not have a formal measurement of interventions. A few of the participants do their measurements based upon their success in securing resources for their patients. Others keep track through their documentation on how they have helped patients. Also, another participant circles back with the client and families to make sure they are getting what is needed. Lastly, one social worker mentioned they are meeting with clients once a year to talk about the transition to adult care. A common challenge presented by the participants was that even though patients turn 18, they do not want to transition to an adult CHD program. P. S. stated

> We meet with them once a year to talk about the transition to adulthood with the ultimate goal of them transitioning into our adult program. We are looking at the

> effectiveness of that. We measure that in terms of every year, the patients do a transition readiness assessment.

As social workers discussed interventions they use, their evaluation of being successful and unsuccessful is based upon each social worker's measurement.

Successful interventions. The participants all had interventions they found to be successful when working with their clients. They are outside referrals, health insurance, financial assistance, advanced directives, and encouraging compliance. Table 3 illustrates successful interventions and the ecological system they align to.

Outside referrals and resources. The fast pace, and high volume of clients in the hospital environment does not enable the social workers to counsel clients for an extended time period. When they can refer clients to another therapist, the social workers considers this successful. J. O. stated, "Outside help since we're not able to do short term therapy in our clinic. I count that successful when I'm able to connect them or when they're open to being connected". Referring clients to an outside neuropsychologist who can help them understand their strengths and weakness when navigating everyday life has been a successful intervention to an outside referral. P. S stated, "We've found with her recommendations some of our patients have a better understanding of their deficits and their strengths."

Successful outside referrals go beyond recommending a therapist; it can be finding someone to help the client solve an insurance issue, transportation, and home health care. R. T. described some of her successful interventions in this manner as communicating to her clients

> How can we give you appropriate referrals? Who can we help you call? What can the people who process insurance letters do? Whatever is needed if I can't do it, let's find out who can do it to help you.

R. T. can then follow up and help her clients when they answer those questions for her. L. W. stated, "There are issues with insurance, transportation, home health care, and getting all of those things resolved. Those would be smaller successful interventions that aren't necessarily clinically based".

The social workers find outside referrals and resources to be a successful intervention if a client is connected to a therapist who can work with them. A client meets with a neuropsychologist who identifies his or her strengths and deficits so he or she can be more successful in everyday life. Outside referrals do encompass assistance resolving issues of insurance, home health care, and transportation.

Health insurance and financial assistance. The social workers discussed helping a client obtain health insurance is a form of financial assistance. While discussing financial assistance being a successful intervention, participants explicitly stated it is through assisting clients in obtaining health insurance. J. O. commented, "The other major thing I feel is financial. I think a lot of my adult congenital patients don't have insurance, they're losing insurance, or they don't know how to get insurance". R. R. discussed helping someone obtain the charity assistance, which is the health insurance her hospital provides for six months "There's an immediate success because there's a hundred percent financial assistance for someone that had zero assistance and they're able to get a major heart procedure that was needed."

Health insurance interventions are successful when a client who does not have insurance obtains it or educated on how to secure it based upon input from the social worker. Health insurance interventions tend to be most successful when the client does not have coverage and is seeking it. J. O. stated

> I do spend quite a bit of time educating them about insurance in general. I also walk through the steps of getting coverage through the Affordable Care Act, their employers, or how to stay on their parents' insurance, if they're able so that they can continue to get financial coverage. Frankly, I can't be as successful when they still have insurance.

R. R. discussed helping clients obtain health insurance is a successful intervention, specifically charity assistance at her hospital, which offers health insurance for six months. R. R. commented

> It's lifesaving and amazing to see the turnaround. Also, it's less possible hospitalizations, fewer episodes coming back and forth to the hospital because they are getting that needed heart surgery. This helps them bridge the gap until they're able to figure out their next direction. What insurance they are going to get, through their employer, or the county. There are many different options, but sometimes when they need immediate assistance, they don't have time to get insurance. They need immediate medical help, and it's lifesaving and life-changing.

While R. R. spoke of this program available at her hospital, it was evident by her intonation and facial expressions her appreciation as well as relief she has this option to offer clients. The charity assistance enables her to assist clients who need insurance but have no other options.

Hence when the social workers discussed successful financial interventions, they refer specifically to when they can help their clients secure health insurance. The health insurance interventions are most successful when trying to help a client who does not have insurance secure it. Lastly, from R. R.'s comments, there is great satisfaction when assisting clients in obtaining health insurance. The social workers by helping clients obtain coverage positively impact their clients financial status. Also, clients can get procedures which have a positive effect on their day to day life and future opportunities.

Advanced directives. Advanced directives can be a complicated emotional process for some clients to complete. Some clients are fearful of the process and do not want to partake in it. The information a social worker can provide and the way they present it can make the process easier for the client. P. S. stated, "When we're able to give the information, have the patient review it, answer questions, and assist them with the document that is quite the successful intervention."

Achieving a successful intervention with Advanced Directives is helpful in a few ways to the social worker. First, he or she knows what the wishes are of the patient and can execute them if needed. Second, many hospitals are promoting every client has an advanced directive on file, so the social worker can help to achieve a goal of the hospital. P. S. stated, "It's something we're promoting here hospital-wide to have that document in place in the event they cannot make decisions for themselves." Having the Advanced Directive in place is beneficial to both the client and the social worker.

Encouraging compliance. There are several underlying reasons clients are not compliant in their care. Fear, life gets too hectic, or concrete barriers they are experiencing to get care such as transportation, financial reasons. When social workers uncover the issue, address it with the client, and help the client become compliant, that is a successful intervention. L. W. described her experience where she was successful in getting a client to become compliant

> I started about two and a half years ago. Before I started the social workers had been trying to get a client to come in for two years, he was still a minor, and he refused. It was one of my big projects, to do whatever I can do to get this person in here. We were just so concerned about him. It took two months of ignored phone calls, with me saying just checking in on you, for him to be able to trust me. When he came in, he was so sick; he had over twenty pounds of fluid built up because no one has been able to reach him for so long. Although he was really sick, that was successful because they haven't been able to get him in for years. The constant communication saying I know you're going to ignore me, but just know that I still see you, and I'm still looking out for you. Eventually, that paid off, so that was one of my more successful ones.

While L. W. told her story about this success, her facial expressions, and mannerisms exhibited her happiness; she was successful in helping this client.

L. W. was persistent in reaching out to the client so he would know he could talk to her, and let her know what the barrier is keeping him from coming in. Just knowing someone out there was concerned for him and was not giving up on him was enough to encourage compliance. L. W.'s story is one example of the extent these social workers will go to ensure a successful intervention.

Motivational interviewing (MI). MI is a successful intervention because it applies to broad issues such as anxiety, compliance, adults who are developmentally delayed, and adults needing surgery. C. C. stated, "anything, including compliance, anxiety, and other issues." C. C. provided an example of successful MI when working with an adult who was cognitively impaired and had a guardian making the decisions.

> We don't involve that adult in the decision to have surgery; we say you need to be here on June 1st, you're having surgery. The motivational interviewing I do preparing that person in terms of their mental health, and being prepared for surgery which can be very traumatic. They're not prepared for that. We see on the opposite side of surgery (without MI) their anxiety is higher, they don't totally understand their new baseline, or they're new normal. So I think there's a lot to be said, for MI, it's a broader intervention, just preparing someone from all perspectives, optimizing them medically, but optimizing their mental health, their readiness, and their understanding no matter their cognitive level.

MI is an intervention which can be applied efficiently in the hospital setting, with the social workers commenting on its effectiveness for a broad range of issues. Table 3 illustrates the successful interventions used by participants and the ecological systems they align to.

Table 3

Successful Interventions and the Ecological Systems They Align to

Successful interventions

	Ecological systems		
Intervention types	Micro	Mezzo	Macro
Outside referrals and resources	x	x	x
Financial assistance/Health insurance			x
Advanced directive		x	
Encouraging compliance	x		
Motivational interviewing	x		

Unsuccessful interventions. The participants all had interventions they found to be unsuccessful when working with their clients. They consisted of financial, outside resources, and encouraging compliance. Table 4 illustrates unsuccessful interventions and the ecological system they align to.

Financial assistance. Financial assistance is unsuccessful when the social workers are unable to find appropriate resources for clients because they do not fit into the parameters of qualification for any assistance. There are a few reasons for unsuccessful financial assistance. One, clients are not compliant by not providing necessary information to qualify for assistance. Two, the financial issues these clients are experiencing do not have any programs which provide assistance. J.O. described her experiences

> Even if I give them resources and help educate them, sometimes there literally isn't anything for them. They don't qualify, they're not employed, they're still in school, they can't stay on their parents' insurance, or they don't qualify for Medicaid, but they still need care. I don't necessarily think it's a lack of my sight; I think it's more of a lack of this system there are no resources out there for these clients. There isn't a safety net when they have these congenital conditions.

R. R. discussed financial interventions are not successful because the clients are not willing to adhere to completing the tasks involved to qualify

> Regarding charity, not everyone is going to want to do what's involved such as fill out the application, write letters for financial support, and make copies of their bank statements. There's a lot of paperwork that goes into the whole process, so you definitely have to be committed and want to file for charity assistance. There are a lot of people, some months they are not ready to go through it 100 percent. So I lose some people, and I know they do not have the motivation.

C. C. discussed her experiences with finding resources for financial issues her clients need stating "I've had very little success finding clients concrete resources to pay for rent while they are down (recovering from surgery or a procedure), then just paying insurance deductibles, nobody pays insurance deductibles."

The social workers discussed financial interventions as unsuccessful for the following reasons: They are unable to find resources which can help economic issues clients are experiencing. The clients are not compliant, providing the necessary information to receive financial assistance. The financial resources are available; however, the clients do not meet the guidelines required to qualify for the support.

Outside referrals and resources. Outside referrals and resources are unsuccessful when a resource does not provide much support to a family that is proactive, patients are resistant, or specific services are not available. R. R. shared her experience with patients who are resistant to services.

> They don't have dental insurance because they have Medicaid, and Medicaid preventative dental services drop at 21 years of age. A lot of these patients need to go to a sliding scale dental clinic. I have a lot of patients right now on my caseload not wanting to get dental care because they're scared of the dentist. They don't want to get dental work because they just hate it.

R. T. discussed her experiences with a resource not providing much support to a proactive family.

> I'd say the only thing that hasn't worked necessarily well for several of the families is trying to connect them to the Office of Vocational Rehabilitation (OVR). OVR is supposed to be an entity to help folks with disabilities get established, get back to work, or get into schooling. I have some families who don't really say "thank you that was great you referred us" instead they say "honest to god I could have done that myself", "you know this wasn't helpful", "this didn't work", "we could have done the legwork ourselves" or "we didn't find this successful". I haven't connected anybody in a while, but the last time we tried that is what the families commented.

P. S. detailed her experience of clients who have mental health issues and are not willing to receive services or services are unavailable.

> An example of an unsuccessful intervention would be working with patients dealing with mental health issues which are not interested or willing to receive services, or the resources just aren't out there for them. I think some of that is just the system, the resources aren't in place for this population, and we lack that here in our department.

Outside resources and referrals are unsuccessful interventions when clients are resistant, resources are unavailable, or the referral does not provide any benefit to the client.

Encouraging compliance. Encouraging compliance is unsuccessful when clients cannot be reached for follow up care, clients are removed from the clinic database because they have been unreachable for an extended time period, and clients do not return phone calls from the clinic. L. W.'s facial expressions and demeanor show her disappointment when this happens because she is concerned about the health of these clients. L.W. described the experience stating

> We can't get patients to follow up or even return our phone calls. We lose track of them, and it's not for lack of effort trying. People really go off the radar; we encounter disconnected phone numbers for client and family. For me, it is unsuccessful when we can't keep track of our patients. They're not coming for their follow up appointments, and there's nothing that we can do to change that or intervene.

Non-compliance is stressful for a social worker, as is evident in L. W.'s expression and demeanor. Therapeutic relationships are developed with these clients, and the social workers want to see them thrive. When clients are unreachable, do not return phone calls, and do not follow up for care, the social worker realizes nothing can be done to rectify the situation.

After listening to the social workers discuss their successful and unsuccessful interventions, noted for some social workers, a financial intervention could be successful, and for another can be considered unsuccessful. However, the social workers determined interventions as successful or unsuccessful by the outcome affecting the client. Hence, if health insurance is secured, all the social workers believe it is successful if it is not secured, it was considered unsuccessful. Although the clinics do not have set measurements for interventions, and the social workers were conducting them individually, they were in alignment with each other on measurement being the direct impact on the client. Table 4 illustrates unsuccessful interventions participants reported using and the ecological systems they align to.

Table 4

Unsuccessful Interventions and the Ecological Systems They Align to

Unsuccessful interventions			
	Ecological systems		
Intervention types	Micro	Mezzo	Macro
Financial assistance			X

Outside resources and referral	X	X
Encouraging compliance	X	

Ecological systems. A few of the social workers commented they start in one system but move to another system. For example, helping a client with anxiety is in the micro system, but understanding during the assessment, anxiety is due to lack of health insurance would cause movement to the macro system.

The social workers made it evident they seamlessly move through the different systems daily in their work. An intervention which is considered macro, such as obtaining transportation for a client, can easily transcend to mezzo by positively impacting their family, and then to micro by reducing anxiety. Following are some of the responses the social workers gave regarding where their experiences fall in the ecological system. Table 5 illustrates which ecological system participants believed their interventions aligned to.

P. S. discussed where she believes the interventions she does most fall in the ecological system. Completing the advanced directives falls within the mezzo system because it impacts the client’s family. P. S. stated, "I think that would be mezzo because when you're doing that, you involve your loved ones." The mental issues clients face falls under the macro system because the scope of P. S.'s position at the hospital she is unable to perform extended clinical therapy. Therefore, clients are given an outside referral to an agency. P. S. believed this intervention is more of a macro issue because the hospital system precludes being able to provide these clients with clinical therapy over an eight-week course. I asked P. S. if she believes therapy referrals are a macro issue because her system is unable to treat the client. P. S. stated, "Yes, that's what I'm looking at." I also asked P. S. what system she considers referring clients to the neuropsychologist. P. S. replied, "micro." P. S. considers the referral to a neuropsychologist as the micro system, since the client directly benefits by obtaining more self-efficacy. P. S. had difficulty pinning down exactly which system she operates most because she believes they integrate. P. S. commented, "They all kind of blend together; it's hard to separate. I think it would be, I know I have to choose one, but for me, it would be between mezzo and macro."

In conclusion, P. S. felt that she operates in the mezzo and macro systems the most, with advance directives falling in the mezzo system. Outside mental health referrals, she considers is the macro system since her institution does not provide the service. Lastly, the neuropsychology referral she believes falls into the micro system, since it directly impacts the client.

R. T. believes she does a lot of micro work finding out from families specifically what is going on with the client, and what they need. Also, giving clients access to services is considered micro from R. T.'s perspective because the client is positively affected individually. R. T. stated, "I would say micro work is sitting with families. Finding out where they're at, finding out what is going on with the patient, and their families, helping them with what they need." When I asked R. T. if she does a lot of macro work, she referred to helping clients with health insurance issues. R. T. stated, "I do quite a bit of insurance work with families. Some of it is Medicare, Medicaid, dealing with folks that have private commercial policies and are struggling with co-pays and deductibles".

Overall, R. T. believes she does most of her work in the micro and macro ecological systems. Listening to clients and families, then referring them to the appropriate service is she feels operates in the micro system. She does a lot of work with clients who have health insurance issues, which is part of the macro system.

J. O. spends most of her time dealing with financial issues as well as anxiety and depression for interventions. J. O. considers financial interventions are at the macro level because of hospital policies, and the way the hospital system is set up. She feels they then trickle into the mezzo and micro since they affect family and client. J. O. stated

> Financial predominantly, I would say, is macro because of how our policies are set up, how our hospital systems are set up. I do feel like it can trickle into the mezzo and then micro, but I feel like a big part of it is policy-based and is access based. So I think that's a little more macro.

Regarding the interventions for anxiety, J. O. considers those micro interventions; however, they can trickle into the mezzo because parental anxiety impacts children's anxiety. J. O. stated

> I think that's definitely more on the micro, but I also feel like it can trickle into the mezzo. We know from research parental anxiety impacts children's anxiety. If these kids have been growing up with very anxious mothers who haven't received a lot of support or help, it trickles into the babies illness, and how they cope in their adult lives. I do feel that's definitely more micro based.

Lastly, J. O. discussed peer groups in the mezzo system could impact the client's coping. J. O. stated

> I feel like their peer groups are mezzo systems, which can have an impact on how effectively they can cope. Also, the resources they can get access to whether it's through friends or whether it's through different things in their community.

J. O. felt she operates in all three ecological systems because her interventions trickle into each one. For example, financial may start in macro, but affects the family (mezzo) and then the client directly (micro). The interventions she does for depression and anxiety, she considers micro when it is for the client. However, if there is parental anxiety she is addressing, she considers it mezzo. Hence, when she counsels a parent on depression and anxiety, that is considered mezzo, but she is affecting the client in the micro system. Peer groups for adult CHD patients J. O. has mentioned are difficult to establish. However, peer groups, she believes fall into the mezzo system.

R. R. does most of her interventions in the mezzo and macro systems. She does a little work the micro system when she does some anxiety and depression interventions. She believes referring a client to the dentist is in the mezzo system since it is to a healthcare professional in the community. R. R. stated "When I'm referring someone to a dental clinic I don't assess for anxiety and depression, mezzo is more of a family, community, or caregivers; hence it might be mezzo because I'm connecting them to a health care professional." Regarding anxiety and depression, R. R. believes it is micro while assessing anxiety and depression; however, when referring them to an outside provider, it is mezzo. Lastly, when asked about helping a client obtain health insurance through the hospital or elsewhere R. R. responded, she considers that the macro level. R. R. stated

> Yes. I'm connecting them with people they need to talk to and trying to help them understand the process of getting insurance, which is not a cakewalk. It's very, very complicated. I give them my knowledge, and then I refer them to the financial counselors here at the hospital.

R. R. differentiated her referrals by ecological systems depending on the issue the referral addresses. Dental work is to a family, community, and caregivers; hence, she classifies it as mezzo. Health insurance issues are macro since her referral is to a financial counselor who is a representative of the hospital system, which falls into the macro ecological system. She does micro work; performing solutions-focused therapy, and depression assessments with the Beck Depression Inventory. However, she maintains the majority of her interventions are in the mezzo and macro systems.

L. W. believes she does most of her interventions at the micro, mezzo, and macro level. When doing biopsychosocial assessments for the client, she considers that macro level. As L. W. discovers the issues, the client is experiencing she believes she moves into the micro level by referring them to an appropriate therapist. However, she often finds herself working with the client's family, which she considers the mezzo level. L. W. stated

> Let's start with the macro system first, anxiety and depression. I do a general biopsychosocial assessment, but during that is how I open the door to see if there are any mental health issues. Once I identify there might be like signs of anxiety

> or depression, I don't just refer the client; first, I have a conversation. I find some people get offended when I say this might be going on; then it's automatic "I don't need drugs." If I can get them to agree to go to one appointment, that is all I can do. Therefore in the micro system, I will find a practitioner and refer them.

L. W. commented interventions are done at the mezzo level because almost all the clients come in with family, and at times, the family needs more intervention than the client. L. W. stated, "Mezzo are family, community, friends, caregivers including health care professionals. Almost none of my patients come in alone; they almost always have family. The interesting thing is sometimes the family needs more intervention than the actual client". Lastly, L. W. performs interventions at the macro level regarding unemployment and clients unable to work because of their condition, therefore helping to secure disability becomes the intervention. L. W. commented, "In the macro system, unemployment is the biggest thing we get. Our patients unable to work due to their condition, then disability".

L. W. divides her time between all three ecological systems. She stated her referrals to a therapist for a client is micro, and needing to counsel the family coming in with the clients is mezzo. L. W. said much of her macro work is dealing with unemployment and disability issues for her clients.

C. C. believes while working with a client she works in all three levels regularly. On the micro level C. C. is looking at personal issues, especially with adults as they can speak up and show signs of personal problems or some history. C. C. stated, "In the micro level we're looking at personal issues. We're looking at this emotional, psychological piece which isn't always necessarily in the forefront for a medical provider." Then C. C. operates in the mezzo level finding out where the client's support is coming from, friends, family, community support to help the client through surgery. C. C. stated, "On the mezzo level, we look at who are your support. Do you have a family? Do you have friends? Do you have community support? Who is going to help you through this?" C. C. then operates on the macro level with the client, dealing with the hospital since they are in a clinic, and lastly health insurance. C. C. commented

> On a macro level, we are in a hospital as a clinic; we have both inpatient and outpatient. Therefore we work with the insurance company to make sure coverage is in place before we can schedule all other appointments, tests, or surgery in the hospital.

C. C. works on all three ecological levels working with clients personal issues, including emotional on a micro level. C. C. operates at the mezzo level by gaining an understanding of the client's support from family, friends, and community. Lastly, the macro level is where C. C. works to coordinate a patients surgery with the hospital and insurance company.

The majority of these social workers operate in all ecological systems. They differ in viewpoint of how interventions align with each system. For example, P. S. believes since she does not provide therapy to her clients because her hospital does not provide the service, referring them to an outside therapist, she is operating at the macro level. R. T. perceives referring clients to an outside service is micro because it affects the client individually. L. W. also concurs referring the client to an appropriate therapist operates at the micro level. R. R. believes referring a client to an outside referral is mezzo because she refers the client to someone in the community. However, R. R. perceives when it is a financial issue, and she refers someone to a counselor at the hospital that is macro since it is an insurance or hospital issue which falls in the macro system.

P. S. and J. O. believe the interventions trickle from one system to another. P.S. believes the systems integrate. J. O. used the example of a financial intervention integrating all three systems. The client is affected on a macro level, such as getting health insurance, which affects the mezzo system their family, and micro, the client, individually. C. C. believes all three levels are regularly incorporated when working with a client. Micro by addressing personal issues, mezzo, looking at their family, and macro with understanding their financial and insurance status.

In conclusion, all the social workers operate in the macro system the most, followed by the mezzo, and then the micro. If the scope of their jobs enabled them to counsel clients for anxiety and depression over an extended time period, that would change the amount of time they spend in the micro system. Table 5 illustrates which ecological system participants believed their interventions aligned to.

Table 5

The Ecological Systems That Participants Believed Their Interventions Aligned to

	Ecological systems		
Participant	Micro	Mezzo	Macro
P.S.		X	X

R.T.	X		X
J.O.	X	X	X
R.R.		X	X
L.W.	X	X	X
C.C.	X	X	X
Total	4	5	6

Unexpected Findings

Decision-making. Decision making becomes especially pertinent when the patient is 18 and 19 years old. Parents made the decisions for these clients, and the parents continue to assist them when they are an adult; however, they do not have a health care proxy. Suddenly the patient may become incapacitated, already has a developmental delay or Down's Syndrome, but the parent does not have a healthcare proxy. Hence, emergency guardianship needs to be put in place for the patient to get assistance. Decision making can be a very intense process for the social worker because the client's life depends on the outcome. C. C. described this experience in her own words

> Some clients who have Down’s Syndrome, their parents have been taking care of them forever. Medical providers have been letting it slide, saying "Oh you know mom understands what's going on." So the patient can sign, or mom can sign, but then they come in by themselves, suddenly someone in anesthesia or somebody else says, "I can't consent this person." Then we end up having to do emergency guardianship.

C. C. elaborated on the intensity "Decision making is intense because a lot of the decisions they're making their life depends on it. Medical decision making is a huge piece; I get called often to assess whether someone can make decisions, which is tough".

In conclusion, a simple healthcare proxy for a patient who turns 18 can prevent a lot of issues in the future. The challenge for the social worker is getting the patient to complete the proxy.

Lack of outside mental health professionals. All the participants say a social worker in private practice nearby to refer clients for mental health issues is either non-existent or impossible. R. T. discussed researching online for a professional who can meet with clients who can at least relate to what these clients are experiencing being a challenge. R. T. commented, "Finding someone to meet with these clients, familiar with what they're experiencing as a congenital heart disease client, there's not always someone. We're researching it online, looking at profiles on Psychology Today." P. S. expressed the consistent consternation this challenge causes her "I can only imagine what a great benefit, and we're just not there yet. I always say that's my dream before I leave or retire we would have that, but we're just not there yet." J. O. recommends to clients to look for a mental health professional who has experience with chronic disease; therefore, at least some of the aspects of CHD the therapist will understand. J. O. stated

> I'm telling them to look for somebody who has helped cancer patients; because that is the closest I can get. Since there are not very many people who understand congenital heart disease, let alone adults with this type of disease. Cancer or another chronic disease is a little more common.

C. C. discussed the difficulty finding someone who understands a client who has had multiple heart surgeries since childhood and as an adult may be on his or her sixth surgery. C. C. stated

> It is hard to find someone who specifically understands their condition and their life experiences. When a client states, "This is my sixth heart surgery. I've had heart surgery since I was a baby, plus I've been in and out of the hospital all my life." It is difficult to understand such a unique experience and medical trauma in many ways. There are a lot of cases, and it's hard to find providers that have experience with these issues.

The stories from these social workers show it is evident there is a definite need for a therapist who specializes in adults with CHD. The myriad of issues, anxiety, depression, and all the other issues surrounding surgery these clients experience plus the effects on their family having a therapist these social workers can refer their clients to would fulfill a massive void.

Parental influence at adult level. As a 49-year-old adult who has congenital heart disease, having my 79-year-old mother attend a meeting with my CHD cardiologist when surgery is imminent feels entirely natural for me. However, I believed this would be an unusual situation, which made the finding of how often this occurs unexpected. R.T. made the following comment about this experience

> Many times we see 50-year-old patients whose 70-year-old parents are still in here saying "I'm going to be here until the end, I'm always going to be here, I've been here the whole time I'm not ever not going to be here.

An issue which can arise in these scenarios is parents wait too long to educate their child who has CHD about their disease. The child becomes an adult and is overwhelmed with information to manage the disease along with coming of age issues. R. T. discussed the following experience

> We've seen some clients where parents have waited until much later in life to explain CHD. These clients haven't found out until they were young adults, because parents managed it all. Clients have not learned their medications, why they take them, what they were born with, what's going on, and why this is important. I had a lovely young lady in her 20's who said, "My mom never told me any of this stuff. I just went with it until I was about 21 years old. Now I'm getting hit with all of this which is overwhelming.

Clients who are 20 and up to 53 are starting to make decisions about CHD because before their parent made the decisions. C. C. stated her experiences

> Maybe a client just turned 20 or even 53, and they are just now making their decisions because their parents aren't around to make those decisions for them anymore. They don't have that same support, so it's a transition for the medical team too. I'm not just working with the patient; I'm working with their provider to make sure we're all providing the same support. We're all understanding where this patient's coming from, what it is they need to have a successful outcome.

In conclusion, the social workers agree parental influence at the adult level is strong; these parents remain devoted until they are unable. The parent does a disservice to the child by not educating him or her about the disease. Once the child becomes an adult and has to make decisions, he or she is overwhelmed, trying to understand CHD.

Summary

The first RQ was designed to help understand the experiences with interventions social workers have when working with clients who have CHD. The participants shared descriptive experiences related to the following interventions: referral to outside mental health, connecting to peers, transportation, advance directives, disease education, disability, encouraging compliance, and health insurance. Additionally, these participants are consistently doing interventions for anxiety and depression; hence, these interventions have been specified by modality. The modalities are SFT, physical exercise, MI, grief counseling, crisis based therapy, CBT, building coping skills, active listening, and strengths-based therapy.

The second research question was designed to understand social workers experiences with successful and unsuccessful interventions and at which ecological levels the interventions aligned. Participant responses detailed successful, and unsuccessful interventions, aligning the interventions by micro, mezzo, or macro systems with a figure and explanation.

Unexpected findings were the unavailability of a mental health professional participants can refer their clients to for extended counseling. Participants are continually searching for a social worker with CHD experience who can provide therapy for a long term period to these clients outside of the hospital. Many commented it is impossible, non-existent, and others discuss the challenge of finding someone who can at least relate to an aspect of the disease.

Lastly, the parental involvement in the care for the client who has CHD extending far into adulthood is an unexpected finding. Parents attending appointments with their 50-year-old child is not uncommon. Twenty-year-old clients lack knowledge about the intricacies CHD. Even certain necessary medications to take is not unusual because parents have been so involved in their care.

Explored in the following section are the findings, and on how they may apply to professional practice as well as implications for social change.

Section 4: Application to Professional Practice and Implications for Social Change

The purpose of the study was to use basic qualitative research to understand social workers' experiences with interventions when counseling adult clients who have CHD and experience psychosocial problems. The key findings from the study are specific interventions the participants reported using for adult clients with CHD. The interventions predominantly include health insurance, financial assistance, and outside referrals and resources, as well as modalities for depression and anxiety. The participants found some interventions to be simultaneously successful and unsuccessful, namely outside referrals and resources, encouraging compliance, and financial assistance depending on the client's specific situation. The participants reported using interventions that aligned with all three ecological systems, showing an even balance of implementation between the micro, mezzo, and macro systems.

The findings extend knowledge in the social work discipline in a few different ways. The study may enable the 40 social workers in the United States who work with CHD clients to learn from one another, as well as not feel so isolated in their specific clinic. Social workers can learn about interventions used by their colleagues to determine which ones are successful and unsuccessful, providing information to validate their plan of care. Also, if a social worker finds an intervention unsuccessful, he or she can understand that another one had demonstrated success and may be a viable option with another client.

Findings extend knowledge in another area regarding outside referrals, and resources. Social workers can learn what other hospitals provide, such as donated airline tickets or medical care for 6 months, to suggest these strategies to their institution. The participants discussed mental health providers who specialize in CHD is “nonexistent.” The research may inspire a social worker working in a CHD clinic to pursue a job in private practice. Several solutions are recommended: (a) encourage more social workers to specialize in adults with CHD; (b) promote social workers specializing in CHD to work in private practice to address ongoing mental health needs of this population; and (c) increase social action and awareness to adjust the guidelines so this population can qualify for better financial, health, and disability benefits, which would create a positive social impact.

Application for Professional Ethics in Social Work Practice

The NASW Code of Ethics declares that social workers are ethically responsible to the breadth of society, in particular to social and political action (NASW, 2017). The Code of Ethics asserts that social workers need to broaden alternatives and favorable circumstances for all people with particular regard for defenseless, underprivileged, maligned people, and communities (NASW, 2017). This research study aligns with this code of ethics declaration because I have systematically collected information from social workers who currently work with the CHD population to understand their experiences with interventions.

The NASW Code of Ethics (2017) guides social work practice in this area because it provides standards for the CHD population to receive psychosocial care specified to their needs. Empirically based interventions must be developed to address the common psychosocial issues of anxiety, depression, health insurance difficulties, and employment challenges this population experiences. Empirically based interventions may help to prevent these clients from being marginalized in the administration of appropriate techniques to treat their problems (Lane, et al., 2013). Additionally, study findings provide social workers with empirically based research for addressing the psychosocial issues of clients with CHD.

In addition, the findings may have an impact on social work practice in the area of professional ethics from a social and political action perspective. The results demonstrate the difficulty social workers experience when implementing interventions for clients regarding financial assistance with health and disability insurance. Social and political action can be taken to influence other hospitals to create policies and funds similar to where R. R. is employed. This hospital provides health insurance for 6 months, so those in need can receive and recover from a major surgery which may positively impact their life. Further action can be taken at the government level to change parameters for disability and health insurance for this population. The policies can be altered for adults with CHD to receive health and disability insurance with requirements specific to experiences with the disease.

An additional impact the findings may have on social work practice concerning professional ethics is the broadening of alternatives and favorable circumstances. Social workers need to be encouraged to engage in clinical practice specializing in adults with CHD. Increasing the number of social workers in clinical practice for this population broadens alternatives and favorable circumstances for these clients to receive the extensive mental health therapy they need (Leon, et al., 2013). Additional CHD social workers in clinical practice implementing effective modalities for depression and anxiety creates an opportunity for more evidence-based practice. Increasing evidence-based practice for the CHD population broadens alternative and favorable circumstances for this population to receive advanced techniques from a psychosocial perspective.

Recommendations for Social Work Practice

Action Steps

The first action step clinical social work practitioners can take based upon the findings is consensus organizing to create awareness and policy change. The second action step is encouraging more private practitioners to focus on this population. The first action step of consensus organizing is to gather together stakeholders, such as the ACHA, individuals who have CHD, and their families. The organizing can begin at the grassroots level for example, advocating for local hospital systems to develop a fund that can help adults with CHD receive 6 months of health insurance, similar to the program at R. R.'s hospital. Creating awareness of the need for the fund among stakeholders should enable donors to be secured to fund the program. These consensus organizing actions can help impact the policy change of creating the program.

The second action step is for CHD clinic social workers to contact the local ACHA chapters. Together, they can encourage social workers in private practice to learn about this population and specialize in working with their mental health needs. Social workers in private practice can learn from the resources ACHA provides, in addition to information from social workers who are working in the CHD clinic at the local hospital.

Implications for My Own Social Work Practice

These findings impact my social work practice by reinforcing my initial desire to go into the field. When I was growing up with CHD myself, psychosocial services for me were nonexistent. When I started encountering issues, I was unable to find a mental health provider who had any familiarity with CHD. I was fortunate to find someone willing to learn, but this was still after a lot of searching. The results have further reinforced my desire to start a private practice specializing in this population. Last, the findings have given me a starting point on the interventions and modalities used that have been successful or unsuccessful.

On a personal note, I was born with CHD in the early 1970s when little was known clinically about the disease. For both of my parents, the experience was excruciating, taking one procedure at a time not knowing what the future held. They had this little baby sleeping in their room, having to be on constant alert some nights listening to make sure her breathing was consistent. Several procedures I endured were not empirically proven, thus I became a case study for many medical students. I am one of the few and fortunate survivors of this disease from the 1970s.

Psychological issues never even crossed our minds. We focused on moving forward breaking ground in several aspects, my activity levels, schooling, and trying to have as normal a childhood as possible. As time progressed, I began experiencing psychological issues, starting with an eating disorder, then severe depression, and anxiety after my last surgery. When searching for a psychologist who specialized in CHD, none were to be found. I was fortunate to find a social worker who specialized in eating disorders, who was willing to read and learn about CHD. As time went on, I recognized with her help I had experienced trauma from my surgeries, although I felt fortunate to have lived, my body was suffering from the invasive procedures it endured. I tried several different therapies, and to this day still, recognize my struggles when experiencing stress.

These experiences have led me to where I am today, wanting to contribute from a social work perspective on how to help individuals born with CHD now and in the future cope with the psychological issues so they can avoid some of my experiences. During my journey, I have learned a simple diagnosis of anxiety and depression does not entirely help the situation; evaluating the whole system (micro, mezzo, and macro) helps to combat the issues.

Transferability of Findings to Practice

The findings of this study can transfer to the field of social work practice in three ways. First, they reinforce some interventions can be both successful and unsuccessful, depending on the client's situation. The findings can transfer to other chronic diseases at birth, such as asthma and diabetes. Lastly, the findings can transfer regarding financial assistance programs which can be implemented or utilized for other clients who have a chronic disease.

Usefulness of Findings to the Social Work Field

The findings are useful in practice for social workers who have clients with asthma and diabetes, providing additional interventions to evaluate when looking for alternatives for the issues these clients encounter from their diseases. For policy, the findings are useful to contribute to arguments for policy change regarding health and disability parameters for the adult CHD population. Usefulness for research could include taking the interventions which are successful and creating random controlled trials on their effectiveness for the adult CHD population.

Limitations Impacting Usefulness of Findings

The limitations of the study, which can impact the usefulness are the fact the successful and unsuccessful determinants for each intervention is established by each social worker's measuring. A consistent measuring scale did not determine the measurement of an intervention being successful or unsuccessful. Hence, an intervention which has been determined successful by more than one participant may not be successful in a consistent measurement. For example, one participant may find motivational interviewing successful because it caused a client to seek outside mental health assistance. However, another could find it successful because it helped a client stop drinking alcohol before surgery. Hence, the intervention was successful, but not for the same issue making measurement inconsistent.

Recommendations for Further Research

The strengths of the study are several interventions, with some consistency among the participants, were considered successful for this population. The strengths can prompt further research into these specific interventions by developing random controlled trials. The limitations are consistent measuring tools regarding success were not used. Further research may be done to create or use a standardized measuring tool to evaluate a successful or unsuccessful intervention. A standardized tool would establish consistency for measurements.

Dissemination Plans for Findings

I will create an executive summary with the findings of the project to disseminate to ACHA to share with members or post on their website in the research section. I will distribute the summary to the 40 social workers in the CHD clinics in the United States. Lastly, I will send the summary to the Medical Director of the remaining national and international CHD clinics listed on the ACHA website.

Implications for Social Change

The findings can impact positive social change at the practice, research, and policy levels. Positive social change for practice includes sharing the information with social workers who work with this population. These social workers can gather information about different interventions, or to not feel isolated because they are one of the few social workers in the United States working with this population. Enabling social workers to have more information can positively impact the clients they help. Research is impacted positively because the results contribute to filling the gap regarding information about social workers experiences with the adult CHD population. Policy is impacted positively because the findings illustrate successful policies in institutions, which can be recreated in other hospitals.

Summary

The purpose of the study was to understand social workers experiences with adults who have congenital heart disease. The six participants who graciously gave their time to contribute to the findings were extremely responsive and thorough, addressing some of the gaps in the literature. We now know some of the interventions social workers use with this population for psychosocial issues and interventions they find successful and unsuccessful when working with adults with CHD. They spend approximately equal time with interventions in all three ecological levels, micro, mezzo, and macro. The results can further practice, policy, and research for this population that continues to grow, and experience psychosocial issues. For this, I am grateful to the six participants who have contributed so much to enable me to fulfill my research study

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Appendix A: Congenital Heart Disease Clinics in the United States

Clinics marked with an asterisk have a dedicated Social Worker (achaheart.org, 2019)

109 Centers, 47 with Social Workers

Alabama Adult Congenital Heart Program
University of Alabama, Birmingham, AL

Adult Congenital Heart Disease Program
Arkansas Children's Hospital, Little Rock, AR

Arizona Cardiology Group ACHD Program
Arizona Cardiology Group, Phoenix, AZ

Phoenix Children's Hospital
Phoenix Children's Hospital, Phoenix, AZ

Mayo Clinic Adult Congenital Heart Disease Program *
Mayo Clinic Hospital and Phoenix Children's Hospital, Scottsdale, AZ

Adult Congenital Cardiology Clinic
Banner University Medical Center -Tucson, Tucson, AZ

Loma Linda Adult Congenital Heart Disease Center

Loma Linda University Medical Center, Loma Linda, CA

Adult Congenital Heart Disease Care Program at Keck Medicine of USC
Keck Hospital of USC, Los Angeles, CA

Ahmanson/UCLA Adult Congenital Heart Disease Center*
Ronald Reagan UCLA Medical Center, Los Angeles, CA

Guerin Family Congenital Heart Program*
Cedars-Sinai Medical Center, Los Angeles, CA

Kaiser Permanente Southern California Adult Congenital Heart Disease Program
Kaiser Permanente Los Angeles Medical Center, Los Angeles, CA

St. Joseph Adult Congenital Heart Disease Program
St. Joseph Hospital, Orange, CA

Sutter Sacramento ACHD Program *
Sutter Medical Center Sacramento, Sacramento, CA

University of California, Davis Adult Congenital Heart Disease Program
University of California Davis Medical Center, Sacramento, CA

Adult Congenital Heart Disease Program at UC San Diego Health
UC San Diego Health Sulpizio Cardiovascular Center, San Diego, CA

Rady Children’s Hospital/UC San Diego
Rady Children's Hospital San Diego, San Diego, CA

Adult Congenital Cardiology Program at UC San Francisco*
UCSF Medical Center (San Francisco), San Francisco, CA

Adult Congenital Heart Program, Northern California Kaiser Permanente
Kaiser Permanente San Francisco, San Francisco, CA

Adult Congenital Heart Program at Stanford *
Stanford Health Care, Stanford, CA

Harbor-UCLA Adult Congenital Heart Disease Program
Harbor-UCLA Medical Center, Torrance, CA

Colorado's Adult & Teen Congenital Heart Program (CATCH)*
Children's Hospital Colorado, Aurora, CO

Connecticut Adult Congenital Heart (CTACH) Service *

Connecticut Children's Medical Center, Hartford, CT

Yale Adult Congenital Heart Program

Yale-New Haven Hospital, New Haven, CT

Washington Adult Congenital Heart *

Children's National Health System, Washington, D.C.

University of Florida ACHD Program

UF Health, Gainesville, FL

Memorial Regional Hospital/Joe DiMaggio Children’s Hospital- Adult Congenital Heart Disease Center*

Total Heart Center at Memorial Regional Hospital, Hollywood, FL

Adult Congenital Cardiology Clinic at the University of Florida Jacksonville Pediatric Cardiovascular Center

Wolfson Children's Hospital, Jacksonville, FL

Mayo Clinic Jacksonville

Mayo Clinic Jacksonville, Jacksonville, FL

Miami Adult Congenital Heart Program (MACH)*

Jackson Memorial Hospital, Miami, FL

Advent Health Adult Congenital Heart Disease Program

Advent Hospital Orlando, Orlando, FL

Tampa Bay Adult Congenital Heart Center *

Tampa: St. Joseph's Hospital Medical Arts Bldg, Tampa, FL

Emory Adult Congenital Heart Center*

Emory University Hospital, Atlanta, GA

ACHD Clinic of Hawaii Pacific Health* (Kapiolani Staff)

Straub Medical Center, Honolulu, HI

University of Iowa Adult Congenital Heart Disease Program*

University of Iowa Hospitals and Clinics, Iowa City, IA

Lurie Children's Adult Congenital Heart Disease Program*

Ann & Robert H. Lurie Children's Hospital, Chicago, IL

Northwestern Adult Congenital Heart Center

Northwestern Medicine, Chicago, IL

Advocate Children's Heart Institute*

Advocate Christ Medical Center, Chicago, IL

OSF/CHOI Adult Congenital Heart Program*
OSF Healthcare Children's Hospital of Illinois, Peoria, IL

Adolescent and Adult Congenital Heart Disease Program at IU Health*
IU Health Methodist Hospital, Indianapolis, IN

Adolescent & Adult Congenital Heart Disease Program
The University of Kansas Hospital, Kansas City, KS

Kentucky Adult Congenital Heart- KACH at the University of Kentucky*
University of Kentucky Gill Heart and Vascular Institute, Lexington, KY

Juan Villafane, MD
Louisville Outpatient Clinic, Louisville, KY

Norton Children's Hospital Heart Center
Norton Hospital, Louisville, KY

Congenital Heart Disease Program, Ochsner Medical Center
Ochsner Medical Center, New Orleans, LA

Boston Adult Congenital Heart (BACH) Program*
Boston Children's Hospital, Boston, MA

Massachusetts General Hospital Adult Congenital Heart Disease Program*
Massachusetts General Hospital, Boston, MA

Johns Hopkins Adult Congenital Heart Disease Program
Johns Hopkins Hospital, Baltimore, MD

University of Maryland Adult Congenital Program and Comprehensive Heart Center
University of Maryland Medical Center, Baltimore, MD

University of Michigan Adult Congenital Heart Program*
Frankel Cardiovascular Center, Ann Arbor, MI

Michigan Adult Congenital Heart Center *
Children's Hospital of Michigan, Detroit, MI

The Congenital Heart Center, Helen DeVos Children's Hospital *
Helen DeVos Children's Hospital, Grand Rapids, MI

Adult Congenital and Cardiovascular Genetics Center *
University of Minnesota Health, Minneapolis, MN

Adult Congenital Heart Disease Clinic

Mayo Clinic, Rochester, MN

Saint Luke's Adult Congenital Heart Disease Program*

Saint Luke's Hospital of Kansas City - Saint Luke's Mid America Heart Institute, Kansas City, MO

Center for Adults with Congenital Heart Disease*

Barnes Jewish Hospital, St. Louis, MO

University of Mississippi Medical Center ACHD Program

University of Mississippi Medical Center, Jackson, MS

Asheville Cardiology/Mission Health Adult Congenital Cardiology Disease Program

Mission Hospital-Mission Campus, Asheville, NC

UNC Adult Congenital Heart Disease Program

University of North Carolina Healthcare, Chapel Hill, NC

Sanger Adult Congenital Heart Disease Program

Carolinas Medical Center, Main, Charlotte, NC

Duke Adult Congenital Heart Disease Center

Duke University Health System, Durham, NC

East Carolina Heart Institute Adult Congenital Heart Disease Program

East Carolina Heart Institute at East Carolina University, Greenville, NC

Wake Forest Baptist Health Adult CHD Program

Wake Forest Baptist Hospital, Winston-Salem, NC

Midwest & Omaha Congenital Heart and Aortopathy (MOCHA)

Children's Hospital & Medical Center Omaha, Omaha, NE

Dartmouth Adult Congenital Heart Program - Manchester*

Dartmouth Hitchcock Medical Center, Manchester, Nashua, Exeter and Dover, Manchester, NH

Adult Congenital Heart Center at Jersey Shore University Medical Center

Jersey Shore University Medical Center, Neptune, NJ

University of New Mexico

University of New Mexico Hospital, Albuquerque, NM

Congenital Heart Center Nevada*

Sunrise Hospital and Medical Center, Las Vegas, NV

Montefiore Adult Congenital Heart Disease Program (MAtCH)
MAP Building, Montefiore Medical Center, Bronx, NY

Adult Congenital Heart Program*
Steven & Alexandra Cohen Children's Medical Center of New York, New Hyde Park, NY

Adult Congenital Heart Disease Program
NYU Langone Health, New York, NY

Cornell Center for Adult Congenital Heart Disease
New York Presbyterian Hospital - Weill Cornell Medicine, New York, NY

Schneeweis Adult Congenital Heart Center
Columbia University Medical Center, New York, NY

University of Rochester Adult Congenital Heart Program*
Strong Memorial Hospital, Rochester, NY

Adult Congenital Heart Service
Akron Children's Hospital, Akron, OH

Adult Congenital Heart Disease Program at Cincinnati Children’s Hospital Medical Center*

Cincinnati Children's Burnett Main and Liberty Campuses, Cincinnati, OH

Cleveland Adult Congenital Heart Clinic*

University Hospitals Rainbow Babies and Children's Hospital, Cleveland, OH

Cleveland Clinic Adult Congenital Heart Disease Center

Cleveland Clinic Medical Center, Cleveland, OH

COACH: Columbus Ohio Adult Congenital Heart Disease & Pulmonary Hypertension Program *

Nationwide Children's Hospital, Columbus, OH

University of Oklahoma Adult Congenital Heart Disease Clinic

OU Physicians Building, Oklahoma City, OK

Adult Congenital Heart Program

Oregon Health and Sciences University, Portland, OR

Program for Adult Congenital Heart Disease (PACHD)

Penn State Health Hershey Medical Center, Hershey, PA

Philadelphia Adult Congenital Heart Center
Hospital of the University of Pennsylvania, Philadelphia, PA

Adult Congenital Heart Disease Center of UPMC*
Children's Hospital of Pittsburgh of UPMC, Pittsburgh, PA

Medical University of South Carolina Adult Congenital Heart Disease Program
Medical University of South Carolina, Charleston, SC

Greenville Health System Adult Congenital Heart Disease Clinic
Greer Memorial Hospital, Greenville, SC

Mid-South Adolescent-Adult Congenital Heart (MAACH)*
Le Bonheur Children's Hospital Outpatient Center, Memphis, TN

Vanderbilt Heart Adult Congenital Program
Vanderbilt University Hospital, Medical Center East, Nashville, TN

ACHD Program of Central Texas
Children's Cardiology Associates, Austin, TX

UT Southwestern and Children's Health Adult Congenital Heart Disease Program*
William P. Clements Jr. University and Hospital, Dallas, TX

Adult Congenital Heart Disease Program at Cook Children's Medical Center*
Cook Children's Medical Center, Fort Worth, TX

Houston Methodist Adult Congenital Heart Program*
Houston Methodist Hospital, Houston, TX

Texas Adult Congenital Heart (TACH)*
Texas Children's Hospital, Houston, TX

UT Adult Congenital Heart Disease Program*
UT Outpatient Sites, Houston, TX

University of Texas Medical Branch Adult Congenital Heart Center
Jeannie Seally Hospital, League City, TX

Pediatric Cardiology Associates
Outpatient office/clinic, San Antonio, TX

South Texas Adult Congenital Heart Center
Methodist Hospital, Medical Center, San Antonio, San Antonio, TX

Utah Adult Congenital Heart Disease Program*

University of Utah, Salt Lake City, UT

University of Virginia Adult Congenital Heart Clinic*
University of Virginia Health Systems, Charlottesville, VA

INOVA Adult Congenital Heart Program
Inova Heart and Vascular Institute at Inova Fairfax Medical Campus, Falls Church, VA

Centra Stroobants Heart and Vascular Institute*
Lynchburg General Hospital, Lynchburg, VA

Virginia Adult Congenital Cardiology Clinic*
The Children's Hospital of the King's Daughters, Norfolk, VA

Virginia Teen and Adult Congenital Cardiology (VTACC) Program
Carilion Clinic / Carilion Roanoke Memorial Hospital, Roanoke, VA

Program for Adults with Congenital Heart Disease
University of Vermont Medical Center, South Burlington, VT

Seattle Adult Congenital Heart Program*
University of Washington Medical Center, Seattle, WA

Providence Adult and Teen Congenital Heart Program (PATCH)

Providence Sacred Medical Center and Children's Hospital - Spokane, Spokane, WA

UW Adult Congenital Heart Disease Program*

University of WI Hospital and Clinics, Madison, WI

Cardiovascular Specialty Center

Aurora St Luke's Medical Center, Milwaukee, WI

Wisconsin Adult Congenital Heart Disease Program (WAtCH) *

Children's Hospital of Wisconsin, Milwaukee, WI

Pediatric and Adult Congenital Heart Disease Center

WVU Medicine Children's Hospital, Morgantown, WV

Appendix B: Interview Protocol

During an hour long interview this researcher will ask each participant the following questions:

1. How long have you been a social worker?
2. How long have you been working with CHD clients?
3. What inspired you to work with CHD clients?
4. How does your clinic measure the effectiveness of interventions?
5. For clients with CHD successful means the intervention collaboratively agreed upon met one or more of the established goals tested by a measurement tool. Unsuccessful is defined as the intervention did not meet the established goal tested by a measurement tool.

Tell me about the interventions you used, which were successful and unsuccessful?

6. Consider the following definitions of the ecological systems: Micro system is anxiety and depression which are personal issues. Mezzo level is the CHD client's family, community, friends, and caregivers including healthcare professionals. Macro level is the company of employment, mortgage or rental company, insurance companies, hospital systems, government agencies providing services and benefits to CHD clients.

Analyzing your interventions, with which ecological system does each align?

Appendix C: Themes and Categories

- Assessments
  - Outside Assessments
  - Sleep
  - Suicide
- Clinic Measuring Interventions
- Ecological Systems
  - Micro
    - Encouraging Compliance
    - Motivational Interviewing
    - Outside Resources and Referrals
  - Mezzo
    - Advanced Directive
    - Outside Referrals and Resources
    - Receiving Dental Care
  - Macro
    - Financial Assistance
    - Health Insurance
    - Outside Resources and Referrals
- Interventions
  - Unsuccessful
    - Encouraging Compliance
    - Financial

        - Outside Resources
        - Receiving Dental Care
    - Successful
        - Advanced Directive
        - Encouraging Compliance
        - Financial Assistance
        - Health Insurance
        - Motivational Interviewing
        - Outside Resources and Referrals
    - Modalities
        - Active Listening
        - Building Coping Skills
        - Cognitive Behavioral Therapy
        - Crisis Based
        - Depression Assessment
        - Grief Counseling
        - Motivational Interviewing
        - Physical Exercise
        - Solutions Focused Therapy
- Types of Interventions
    - Advance Directives
    - Connecting to Peers
    - Disability

- Disease Education
- Encouraging Compliance
- Financial Assistance
- Health Insurance
- Referral to Outside Mental Health
- Transportation

Challenges with Patients

- Decisionmaking
- Education
- Lack of Resources
  - Outside LCSW specializing in Adult CHD
- Parental Influence at Adult Level

Issues Clients Struggle with

- Depression and Anxiety

Reproductive Issues

Other Illness Comparison

Social Work Experience

- Working with CHD
- What brought them to CHD