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Managing life with a broken heart: An experiential journey into role development as a young
adult with chronic congenital heart disease

by
Kristy Gonder

A dissertation
submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy in the School of Nursing
Idaho State University
Spring 2023

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Committee Approval

To the Graduate Faculty:

The members of the committee appointed to examine the thesis of KRISTY GONDER find it satisfactory and recommend that it be accepted.

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October 14, 2022

Kristy Gonder
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RE: Study Number RB-FY2023-58: Managing Life with a Broken Heart: An Experiential Journey into Role Development as a Young Adult with Chronic Congenital Heart Disease

Dear Ms. Gonder:

Thank you for your responses to a previous review of the study listed above. These responses are eligible for expedited review under OHRP (DHHS) and FDA guidelines. This is to confirm that I have approved your application.

Notify the HSC of any adverse events. Serious, unexpected adverse events must be reported in writing within 10 business days.

You may conduct your study as described in your application effective immediately. This study is not subject to renewal under current OHRP (DHHS) guidelines.

Please note that any changes to the study as approved must be promptly reported and approved. Some changes may be approved by expedited review; others require full board review. Contact Tom Bailey

(208-282-2179; email humsbj@isu.edu)

if you have any questions or require further information.

Sincerely,

Ralph Baergen, PhD, MPH, CIP
Human Subjects Chair



INITIAL2022000527

October 04, 2022

MOD2022001433

October 17, 2022

Kristy Gonder

RE: Study # 2022000527 Managing Life with a Broken Heart: An Experiential Journey into Role Development as a Young Adult with Chronic Congenital Heart Disease

Dear Kristy Gonder:

This letter serves to notify you the above referenced Per the federal regulations for research at 45 CFR 46.109(f)(1)(i), this minimal risk protocol does not require continuing review. The Principal Investigator still has the obligation to report various events to the IRB, such as unanticipated problems, deviations or non-compliance, changes to the research or study staff, or study closure. Additionally, the Principal Investigator remains responsible for monitoring study team members training and reporting conflicts of interest for study staff. You will continue to receive a notification yearly to check in with you regarding the above. This notification will not be a request for continuing review submission but only to check if any changes have occurred or if you are ready to close the study.

This minimal risk study qualifies for expedited review based on the following criteria:

Research activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the following categories, may be reviewed by the IRB through the expedited review procedure authorized by 45 CFR 46.110.

Category #7. Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Approval of this study includes:

Partial Waiver of Authorization for Screening/Recruitment Purposes pursuant to 164.512(i)(2)(ii): The IRB authorizes the Investigator to collect only information essential to the purpose of screening/recruiting participants for the research.

Kristy Gonder
Study #2022000527
October 04, 2022

Page Two

The Investigator assures the IRB that access to participant information will be limited to the greatest extent possible, and that identifiable health information will not be re-used or disclosed to any other person or entity.

Use copies of the approved consent documents. These can be found in 'Site Related Documents' under the **Final** column.

In conducting this study, you are required to follow the requirements listed in the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library within the IRB system.

Should there be any questions, please contact the PSJH IRB at irbsharedservices@providence.org.

Sincerely,
PSJH IRB

Letter of Support



Date: 9/20/2022

Carl Garabedian, MD
Pediatric Cardiology Medical Director
Interventional Pediatric Cardiology/ACHD
Providence Sacred Heart Medical center
Spokane, WA

Dear Madeline Carlos,

This letter confirms my support of the study outlined in the IRB protocol, *'Managing life with a broken heart: An experiential journey into role development as a young adult with chronic congenital heart disease.'*

I have known Kristy since she began her nursing position on the ACU (6N) 19 years ago. She works closely with our adult congenital heart patients in the hospital setting (pre-and post-intervention). As a master's prepared nurse educator, Kristy volunteered to assist with the Providence Adult and Teen Congenital Heart (P.A.T.C.H.) ACHA accreditation in 2015. We were successful in achieving that and recognize her efforts in the accreditation process.

I am familiar with Kristy's skill set to engage in research. She and I worked together on a mixed methods pilot study between 2013 and 2014. She was punctual in her role as researcher. Kristy independently pursued IRB approval from the hospital and her academic institutions. Her pilot study received positive feedback from conference attendees (providers and patients/family) on the quality of the research and her ability to present. A secondary analysis of that original data was published in a peer-reviewed nursing journal this year (June 2022).

As a research certified MD, I am happy to share my expertise and facilitate Kristy from the clinic setting, which includes participant recruitment, IRB processes, and conference space as needed for interviews or other research activities that our resources can benefit her in accomplishing these activities. I look forward to her contribution to the ACHD science.

Sincerely,

Carl Garabedian, MD

Dedication

I, Kristy Gonder, dedicate this research project to the surviving young adults with complex (severe) congenital heart disease who took time out of their day to engage with me for a candid, honest interview – to share their *story*. I am grateful for this opportunity. It is my hope that each of them finds this research as meaningful as I do in authenticating the subjective experiences of adult congenital heart disease.

Acknowledgments

Thank you, **Dr. Gina Clarkson**, Idaho State University, School of Nursing, Dissertation Chair and graduate faculty mentor. I will always be grateful for your time and investment – for fostering the spirit of inquiry.

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A special Thank you, **Dr. Philip Moons**, KU Leuven (ACHD content expert). Dr. Moons graciously accepted to serve as a member of my dissertation committee. Located in Belgium, you were always prompt with emails and encouraging in your feedback. I am honored to have you as a research mentor. As a complex ACHD survivor, and cardiac nurse, I appreciate all that you have done to advance the science and acknowledge ACHD as the unique patient population that we are.

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List of Abbreviations

CHD	Congenital Heart Disease
Class III	Class III (complex defect)
ACHD	Adult Congenital Heart Disease
ACHA	Adult Congenital Heart Association
ACHD-AP	Adult Congenital Heart Disease – Anatomic and Physiologic Classification
NYHA	New York Heart Association (functional classification)
AHA/ACC	American Heart Association/American College of Cardiology
NCCDPHP	National Center for Chronic Disease Prevention and Health Promotion
CDC	Centers for Disease Control
QOL	Quality of Life
HrQOL	Health-related Quality of Life
PROs	Patient Reported Outcomes
EA	Emerging Adulthood
IPA	Interpretative Phenomenological Analysis

Managing life with a broken heart: An experiential journey into role development as a young
adult with chronic congenital heart disease

Dissertation Abstract -Idaho State University 2023

Purpose: The purpose of this study was to qualitatively explore how individuals with chronic complex congenital heart disease (CHD) make sense of developmentally anticipated life tasks during Emerging Adulthood (EA). **Background:** The life expectancy for complex CHD has improved. However, CHD survivors face multiple adverse outcomes as they age. It is not well understood how adults with CHD *make sense* of their life beyond existing QOL and PRO measures, and how they do at a time when transition to independent living sets the foundation for the rest of their life. **Methods:** 13 young adults (age 22-25) with complex CHD were recruited from a cardiac clinic in Washington State to participate in a semi-structured interview. Data were analyzed using Interpretative Phenomenological Analysis (IPA). **Results:** Findings reveal five experiential themes, and corresponding subthemes within the five (5) EA developmental dimensions: (a) *'Disease is part of self,'* (b) *'Unknown directives because of CHD,'* (c) *'Can do, but within limits,'* (d) *'Internalize the transition,'* and (e) *'There is hope, but it provisional.'* **Conclusion:** The personal experiences of young adults elucidate the unique; yet converging nature of their chronic pediatric heart disease, as adults. The findings can be used to inform patient-centered, age-appropriate care throughout the lifespan. Future research from other CHD centers is needed to add to the existing literature.

Key words: Congenital Heart Disease (CHD), Interpretative Phenomenological Analysis (IPA), Quality of Life (QOL), Patient Reported Outcomes (PROs)

Chapter I: Introduction

Between 1999 and 2006 there were 41,494 reported deaths attributed to Congenital Heart Disease (CHD) in the U.S. (Centers for Disease Control and Prevention). CHD is one of the most common birth defects, which is defined as an abnormal structure of the heart that is present at birth, that is actually or potentially of ‘functional significance’ (Mitchell et al., 1971, p. 324). Naturally, medical care focuses on the surviving infant, and due to medical advancements in the treatment and management of congenital heart disease, today there are more adults than children living with CHD (Bratt & Moons, 2015; Kronwitter et al., 2019; Marelli et al., 2007, 2014; Warnes et al., 2001). In fact, two thirds of the CHD population is comprised of adults (Marelli et al., 2014). U.S. prevalence estimates for adults 18 years of age or older with congenital heart disease (CHD) is 1.4 million (cdc.gov, 2010). With these many individuals reaching adulthood with this disease, it is therefore important to learn the challenges they may face.

Statement of the problem

Among the growing number, 69% of the 2.3 million CHD survivors are those with severe, or complex defects (Diallo et al., 2018, p. 1635), which has created a circumstance whereby the ‘pediatric’ heart condition is now a chronic condition in adulthood (Bolduc et al., 2019; Lu et al., 2022; Mutluer, & Celiker, 2018; Rometsch et al., 2019; Triedman & Newburger, 2016). Operative repairs predispose the CHD patient to adverse physical and psychological outcomes. This results in categorizing the complex/severe defects as a chronic medical condition. Research shows that many of the difficulties that individuals with CHD face manifest with age (Bolduc et al., 2019; Cateight et al., 2021; Codari et al., 2018; Steele et al., 2019). The prevalence of those with complex CHD is growing, since it was not that long ago that most infants with complex CHD died, and now people are living into adulthood. Survival brings about

unique concerns and challenges. These challenges are multifaceted – physical, psychological, and psychosocial (Cateight et al., 2021; Claessens et al., 2005; Moons et al., 2002, 2002, 2020, 2021a; Thomet et al., 2018; Van Bulck et al., 2021b). Regardless of one's specific circumstance, morbidity for adults living with CHD include dysrhythmias (Brida & Gatzoulis, 2019; Cateight et al., 2021; Mutluer, & Celiker, 2018), infective endocarditis (Goossens et al., 2013; Webb et al., 2002), and sudden cardiac death (Ombelet et al., 2020; Stout et al., 2019; Triedman & Newburger, 2016) even years after the initial repair, and throughout their life. Post-operative sequelae may also predispose one to chronic pain (Olsen et al., 2017).

A recent study found that 3.9% of adults with CHD age 18 to 29 report living with pain (Leibold et al., 2021, p. 4). In fact, adults with CHD overall (32.5%), report pain compared to 20.4% of the general population (p.5). Other cardiac-related conditions manifest, such as the risk for myocardial infarction (heart attack), coronary artery disease (Fedchenko et al., 2017; Olsen et al., 2017; Saha et al., 2019), heart failure (Norozi et al., 2006) and ischemic stroke (Pedersen et al., 2019). Additional age-related conditions emerge in ACHD. Studies show an increased prevalence of Type II Diabetes Mellitus (Gurvitz et al., 2013; Moon et al., 2015), elevated blood glucose levels (Apers et al., 2015), metabolic syndrome (Deen et al., 2016), obesity (Tamayo et al., 2015), increased inflammatory processes (Wienecke et al., 2021) and cancer (Diller et al., 2015). It is surmised that an elevated inflammatory response may be attributed to the radiographic exposures (Verstraete et al., 2018) faced throughout childhood (e.g., x-rays, contrast dyes). Accelerated or premature aging and frailty are also a concern in ACHD. Vecoli et al. (2016) found biological aging via White Cell (Leukocyte) Telomere shortening as early as young adulthood, while Sandberg et al. (2019) and Shiina et al. (2019) found a marked increased prevalence of secondary sarcopenia (loss of skeletal muscle) in those with complex CHD

primarily in response to the defect and other age-related conditions. Frailty refers to the substantial decline in functional reserves and resilience of body organ systems (Won, 2020). Uchikado et al. (2020) found frailty to be present in non-elderly cardiac patients, particularly following a stressful event (Lui et al., 2017). Such complications are lifelong (Engelfriet et al., 2005; Moons & Marelli, 2022) and manifest further with age (Moons et al., 2022).

Poor outcomes are evidenced in this patient population via impaired cognition (Bagge et al., 2018; Bolduc et al., 2019) and physical functioning (Cateight et al., 2021; Rometsch et al., 2019). Approximately 50% of 20-year olds will develop atrial dysrhythmias (Brida & Gatzoulis, 2019). Moreover, mixed-age adults with CHD report interpersonal challenges (Chiang et al., 2014; Pagé et al., 2012), and struggles with illness identity (Andonian et al., 2018; Chiang et al., 2014; Claessens et al., 2005; Journiac et al., 2020; Van Bulck, et al., 2018). The evidence further shows that adults with CHD face adverse psychosocial outcomes (Areias et al., 2014; Gleason et al., 2019; Moons & Marelli, 2022), such as difficulty with employment (Enomoto et al., 2020; Karsenty et al., 2015; Na et al., 2021) and living independently. Long-term adaptability, psychosocial well-being, and healthy transitions throughout the lifespan are all uncertain.

Emerging data further show an upward trend in affective and mental disorders (i.e., depression, anxiety) (Abda et al., 2019; Andonian et al., 2020; Claessens et al., 2005; Jackson et al., 2016; Kovacs et al., 2015; Meentken et al., 2017; Moons et al., 2021a), including medically related post-traumatic stress disorder (PTSD)/post-traumatic stress symptoms (PTSS). PTSS and PTSD are on the rise, which is another reflection of improved survivability since the individual is exposed to frequent medical procedures throughout their childhood (Deng et al., 2016; Lane et al., 2002; Meentken et al., 2017). Gleason et al (2019) found over half of their CHD sample had at least one elevated subscale for psychological distress; yet individuals denied receiving mental

health treatment. These findings are in line with Levine et al (2021) who found that physicians are often uncomfortable asking patients about their mental health.

Additionally, there is a large gap in the state of the science in this population of adults with congenital heart disease (ACHD). The above findings are commonly derived via the examination of QOL domains such as: (a) perceived health status, (b) illness perception, and (c) psychological well-being in all age groups. Scholars Dr. Philip Moons and Dr. Adrienne Kovacs are at the forefront of CHD research from a holistic perspective. Throughout the literature, there are common authors among quality of life (QOL) and patient reported outcomes (PROs) research, which has advanced the science tremendously. Most of these studies involve mixed defects (e.g., severity classifications) and QOL variables across different severities or as comparison studies with a healthy/control group. The current age-related CHD literature typically places young adults with (or compared to) adolescent cohorts or the studies include young adults, but not studied as a group in their own right. Despite the development of formal pediatric to adult CHD transitional programs (Adult Congenital Heart Association), most of the currently accredited ACHD centers in the U.S., for example, are ‘housed’ in pediatric cardiac clinics, or ‘Teen’ is in their program title. Addressing patient needs as an adult must be ongoing.

Much of the published literature comes from Europe (e.g., Belgium, the U.K, and the Netherlands) but there are valuable U.S. studies (i.e., Farr et al., 2016; Gleason et al., 2019; Jackson et al., 2016) to inform this research. More U.S. based research is necessary to advance clinical knowledge relevant to Western (U.S.) society due to differences in its cultural shifts, economic changes, and health care structure. Several scholars propose recommendations for future ACHD research, including longitudinal works (Brida & Gatzoulis, 2019; Cateight et al., 2021; Moons et al., 2021a; Moons & Luyckx, 2019; Vaikunth, et al., 2017) and studies that

investigate self-care and medical management into adulthood (Diller et al., 2021) with a life course or lifespan emphasis (Diller et al., 2021; Marelli, 2020). Further, studies that include subjective measures of health status (Kovacs & Bellinger, 2021).

Guided by the current findings that demonstrate the presence of co-morbidities in ACHD (Brida & Gatzoulis, 2019; Karsenty et al., 2015; Vaikunth, et al., 2017), more studies are needed in this area as well. The ACHD science may lack in theory and methodology (Andonian et al., 2020), and variations in conceptual frameworks (Moons & Luyckx, 2019), but what does exist highlights the multiplicity of the adverse outcomes faced and the need for a “personalized medicine approach” (Diller et al., 2021, p. 2226). Outcomes that are important enough, if overlooked, Brida and Gazpoulis claim will create a “tsunami” (2019, p. 1757) in adult CHD prevalence, heterogeneity of the disease, and greater complexity of the interventions needed. An unintended consequence of neglecting this population is that society will also suffer (Hendry & Kloep, 2007) due to a lack of productivity and potential increased health needs. Adverse outcomes create an unintended burden on society.

Not only do gaps in the literature exist in adult outcomes research, but also in the Emerging Adult population. If the transition from adolescence to adulthood is unsuccessful, individuals face isolation and maladaptive outcomes, which has negative effects on the rest of their lives. Therefore, it is further crucial to explore ACHD within the context of emerging adulthood because it is precisely within this transitional period that the individual is striving to gain autonomy. Autonomy involves learning to function independently, recognizing that they are different *because* of their heart condition (Callus et al., 2013; Claessens et al., 2005; Pagé et al., 2012) and no longer ‘kids.’ Moreover, since so many studies focus on QOL and PROs, and it is important to tackle complex psychosocial research from different directions, the concept of

sense-making was chosen as a focus for this research study. The concept, and rationale for choosing to focus on this concept, is described in more detail.

Purpose of the Study

The purpose of this research study is to investigate the experiences of young adults with chronic complex congenital heart disease in relation to their *sense making* and disease representation in formulating their role within the context of emerging adulthood. *Sense making* refers to how individuals perceive their *being* and what that means (Aho & Aho, 2008). This qualitative concept moves beyond disease processes (Körper) to the description of *being* (Leib) or sensing of self. There is a distinction between the Körper and Leib; Körper as the physical, objective knowledge, or outward appearance (focus is disease pathology), and Leib as the quality of the lived experience of that disease process. It refers to the subjective – what “completes us as living beings” (Aho & Aho, 2008, p. 5).

Health is a holistic phenomenon. Aho and Aho (2008) posit health is differentiated via its perception or ‘deviance’ (p.60). Society views disrupted or altered health as ‘sickness’ while physicians view as ‘disease,’ and the patient views as ‘illness.’ Therefore, *sense making* is about the patient. It taps into the experience of embodiment, which must include the lived suffering (p.2) and health and illness (Pinquart, 2014) as a personal phenomenon that recognizes that variations in sense-making opportunities exist. Physical manifestations and clinical metrics can be an ontological examination, but *sense making* taps into the quality of those metrics; one’s life and what it means to ‘be’ and to be ‘with CHD.’ Heidegger (1962) described sense making as *Dasein* – ‘being there;’ meaning, individuals are in ‘compartment’ with their environment and all of the past and future possibilities that make up who they are. Hence, *sense making* is the recognition of self within the social and cultural context by which one lives. This premise is

integral to understanding life within the context of the Emerging Adult (EA) developmental dimensions and CHD. One cannot overlook the lifelong impact (Diller et al., 2021) of CHD. It is through that lens *sense making* is described.

This study examined gaps in the ACHD science, guided by the Emerging Adult developmental theory and associated dimensions for development. The study aimed to qualitatively: (a) explore the individual's *sense making* as a personal experience in managing life to achieve anticipated life tasks, and (b) interpret the individual's illness representation and how the uncertainties of their cardiac condition fit into this crucial developmental stage.

Research Question

This study explored ACHD as a personal experience during the early adult (EA) developmental stage, recognizing CHD as a chronic pediatric condition as an *adult*. This research was guided by the current published research. The following research question; therefore, was addressed: *How do individuals with chronic congenital heart disease make sense of developmentally anticipated life tasks during emerging adulthood?*

Significance

This section of the research study begins by describing normal human development and then Emerging Adulthood as the developmental theory to address congenital heart disease (CHD). Before introducing CHD, chronic illness must be defined, including the incidence and its outcomes relevant to adulthood. CHD is then defined, including its incidence and classifications (minor, moderate, complex); with a rationale for categorizing complex CHD as a chronic disease and the ways it impacts individuals' QOL and life management. These concepts comprise the majority of research in the area. Therefore, this study presents this information; however, the focus is on *sense making* in young emerging adult individuals with CHD. Last, the primary gaps

in the state of the ACHD science and what is known about *sense-making* are discussed for their relevancy to this research study.

Developmental Needs in Early Adulthood

Based on the normal development/transition literature, there are primary determinants known to facilitate successful adaptation in achieving course of life tasks and subjective well-being. Developmental psychology gives us insight into the challenges that young adults face and how they master such challenges (Keil, 2013). Healthy developmental transitions include several variables, such as personality, relationships, and structure (Arnett, 2015; Erikson, 1980; Nikitin et al., 2012).

Personality

Personality traits are nonmodifiable characteristics that may influence one's adjustment and adaptive coping skills (Apers et al., 2016; Claessens et al., 2005), and health outcomes (Levine et al., 2021). Personality traits are constant but influenced by modifiable factors such as social structure (Keil, 2013) and life events. These factors further inform our identity construction (Mills et al., 2010). Personality traits and the social environment interact to stabilize each other (Nikitin et al., 2012). Individuals tend to seek and create social circles that align with their traits – a term known as homophily (Glanz et al., 2015), which affect how we view the world and 'make sense' of our position in the world.

Relationships

Essential relationships during this stage include intimate partners and friendships. Industrialized Western countries experience a vast range of opportunities (Wrosch & Freund, 2001) for personal development in achieving life goals, which occur through self-regulation. Thus, individuals embody free agency in determining their life's pathway. Face time

(*observational* behavior), sharing of values (normative beliefs), and social support are central to developing one's personal role (Bandura, 1989, 2003). Although there are few cultural guidelines, there are still expected norms within a socio-economic structure that define, or even perhaps redefine, the individual and how he or she establishes an adult identity and fits into the larger unit – into society (Arnett, 2000). The chain of evidence shows there is a positive correlation between social support and health status (Claessens et al., 2005; Glanz et al., 2015; Journiac et al., 2020; Levine et al., 2021). Likewise, social assumptions shape our capacity and attitudes to change (Kelder et al., 2015). Humans need relationships to feel they have a purpose in life. Relationships serve as a guide for social routines and structure formations. Crocetti et al (2012) found that identity stability during early adulthood did not reveal significant gender differences; therefore, identity stability is a *human* need.

Structure

When young adults between the age of 18 and 25 face major life decisions, they need structure (Erikson, 1980). Structured tasks include: (a) work/employment, (b) education/careers, (c) relationships and gender roles, and (f) engaging in activities that promote QOL and independence (Arnett, 1998, 2000, 2015; Nikitin et al., 2012). Career theorists contribute a great deal of empirical knowledge to social tasks; notably, the value of work and employment. Research shows that working is directly related to one's emotional and psychological well-being (Arnett, 2015; Erikson, 1980; Godinic et al., 2020). Moreover, work fosters economic efficiency (Henderson, 2018) and improves one's self-worth, self-esteem, and identity (Arnett, 1998, 2000, 2010). In fact, the ability to obtain work in and of itself has a direct influence on QOL and social status (Messersmith & Schulenberg, 2010; Nikitin et al., 2012). Hendry and Koep (2007) posit, individuals fail to reach their full potential if they have yet to become an active participant in the

labor market by age 30, which subsequently has implications to economic efficiency (Henderson, 2018). Working for a wage is more than a job; it serves as the conduit to develop personally and professionally through a process of interactive experiences, improving one's cognition and mental health (Nikitin et al., 2012); and his or her sense of identity (Crocetti et al., 2012; Godinic et al., 2020). Financial stability permits the purchase of goods and services (Henderson, 2018), which is essential to pursuing one's happiness and survival (Godinic et al., 2020; Mukhtar, 2020).

Employment and career planning are a function of adulthood. This may explain why unemployment and any factors that impede optimizing output create negative consequences, particularly the person's affective and cognitive domains (Barreda, et al., 2020; Cook et al., 2016; Gleason et al., 2019). Generational differences in career and occupational patterns have emerged. For example, trajectory patterns differ between the traditional Baby Boomer (birth year 1946 to 1964) generation and the Generation Z (1997-2012). Achieving anticipated milestones serves as marker of adulthood (Arnett, 2000; Arnett & Mitra, 2020; Reifman et al., 2007). It is well known education equips individuals to comprehend information and discern its relevancy to every aspect of their life (Glanz et al., 2015; Messersmith & Schulenberg, 2010). Other adult decisions, such as relationships, parenting and fulfilling gender roles are positively correlated with well-being (Arnett, 2010; Arnett & Mitra, 2020; Nikitin et al., 2012) and may be innate goals. Typically, childbearing/rearing occurs within the context of marriage, although modern society accepts reproduction in the absence of matrimony. Different paths may also be assumed guided by racial and/or ethnic norms. Society has seen a steady trend in young adults achieving parenthood, for example, prior to completing a college degree or deciding to marry (Arnett, 2015). Nevertheless, despite existing differences, the evidence demonstrates individuals are

motivated to achieve course of life milestones. Messersmith et al. (2010) found that healthy young adults who marry and become a parent by age 27 demonstrated a greater satisfaction with life. Psychological health is positively associated with mental health, including feelings of happiness and satisfaction with life (Godinic et al., 2020; Levine et al., 2021) and the relational domains for identity configuration (Crocetti et al., 2012). Individuals who disengage from their life tasks (for any reason), experience a lower perceived quality of life and efficacious beliefs (Bandura, 1989, 2003; Keil, 2013).

These concepts are crucial to examining human development contextually. If the young adult fails to develop close bonds, it potentiates the risk for social isolation. Moreover, when barriers are faced for goal attainment or there is a change in norms, the young adult may disengage and redirect his/her efforts. These circumstances could adversely impact the anticipated predictability of life course trajectories and impede personal role development. Therefore, it is important to investigate one's personal experience in managing life to achieve course of life milestones within a defined developmental period.

Emerging Adulthood (age 18-25)

While scholarly contributions to the study of human development span over several decades, in recent years a distinction has risen to place a transitional period between adolescence and adulthood. The Emerging Adult developmental theory (Arnett, 2000, 2015; Reifman et al., 2007) guided this study. EA is a U.S. or Western transitional stage (Arnett, 2015) that is unique to industrialized cultures because they foster individualism while permitting a socially accepted delay in full adult roles and responsibilities (Arnett, 2000, 2015). EA describes adulthood similar to Erikson's (1980) psychosocial developmental phases, which coins 'young adulthood' between the ages of 18 and 30. The psychosocial conflict is, '*intimacy vs. isolation.*' (Erikson, 1980; Keil,

2013); whereas Arnett (1998, 2000, 2015) does not position individuals into conflicting decisions. Rather, narrows the early adult age to 18 to 25 years while emphasizing its *transition* into full adulthood. Therefore, Emerging adulthood is a contemporary age-based theory (Arnett, 1998, 2000, 2015) characterized by the following five dimensions:

- Identity exploration (who they are and what they want out of life. Primarily love and work).
- Instability (make plans but expect revisions due to explorations of options. With each decision comes clarification for their future).
- Self-focus (few obligations to others. Little commitment. Time to learn and gain skills for daily living). Adulthood goals: 1. accept responsibility for self, 2. make independent decisions, 3. become financially independent (Arnett, 2015, p. 15).
- Feeling in-between (not an adolescent, not an adult. Progression is gradual)
- Possibilities/Optimism: Different ‘futures’ are possible. A time of hope and expectations while nothing is certain or fully tested. Envision a good job, marriage, and children.

The five dimensions of Emerging Adulthood incorporate psychological maturity into the developmental milestones, which consider historical and cross-cultural influences observed throughout the generations. To illustrate, as little as 50 years ago the traditional young American life followed a gender specific pathway; whereas today both marriage and parenthood are commonly delayed until the mid to late 20s. A young adult may move back home as they explore career options and test intimate relationships (Hendry & Kloep, 2007; Reifman et al., 2007). Reifman et al. (2007) refer to this as “boomerang kids” (p.1). Employment trends are now viewed as ‘fun’ rather than an occupation one stays through retirement. If the young adult does

not enjoy their work (Arnett, 2010), they move onto the next opportunity. The average American holds eight different jobs between the ages of 18 and 29. Individuals between the ages of 26 and 29 are referred to as, an “extended range” (Arnett & Mitra, 2020, p. 3) of Emerging Adulthood. Arnett (1998) posits early adulthood nearly “always ends by the late 20s” (2020, p. 313). Despite variations in timing (early 20s versus mid to late 20s) or personal motives, individuals still begin to explore key developmental tasks that they know set them up for the rest of their life. They make sense of social values (Mills et al., 2010) while recognizing what is going to be needed when they *are an* adult.

Emerging adulthood is a life stage in terms of attitude, cognition (Arnett, 1998, 2000), a level of self-esteem, and satisfaction with life (Arnett, 2010, p. 89). In essence, the centrality of emerging adulthood is self-sufficiency (Arnett, 1998, 2015); the most salient is personal responsibility (Arnett, 1998, 2000, 2015). A key challenge during this transition is that individuals do not perceive themselves as adolescents or as *adults* (Arnett, 2010). The latter is supported by Arnett’s qualitative work used to inform the ‘Inventory of the Dimensions of Emerging adulthood (IDEA)’ Likert type questionnaire. The IDEA was tested against other adult ranges: (a) 18-23, (b) 24-29, (c) 30-39, (d) 40-49, and (e) 50+ (Reifman et al., 2007), which demonstrated that the developmental dimension scores were higher in EAs than any of the adult ages, with the exception of a few subscales, individuals in the ‘extended’ EA age scored similarly (Arnett & Mitra, 2020). Arnett and Mitra (2020) claim the five features are normative to that U.S. age group. Moreover, Arnett (2010) found the dimensions are consistent across ethnicity and social class. Consistencies in dimensional measures indicate that all citizens live up to their social imperatives (Arnett, 1998).

Recognizing the EA period is a time for exploration, the individual must engage in life management skills to facilitate his/her role development. This is particularly crucial at a time when achieving anticipated development milestones are foundational to the rest of the person's adult life (Arnett, 2000, 2015; Pinguart, 2014). Change is substantial in terms of work/career, relationships, future planning, and formulating an ideological worldview (Keil, 2013). Emerging adulthood is clearly a distinct developmental stage. Its distinction must integrate chronic disease, or for this research study, congenital heart disease because of the chronicity's influence on role development.

Chronic Disease

According to the U.S. Department of Health and Human Services, as of 2018, 51.8% of adults have at least one out of 10 diagnosed chronic conditions and 27.2% have more than two chronic conditions (Boersma et al., 2020, p. 1). Chronic health is defined as an illness or medical condition that lasts more than three months (CDC.gov). Years ago, chronic disease was viewed as a manifestation of aging. Most of these conditions, however, are no longer limited to older adults (i.e., arthritis, cardiovascular disease, and type II diabetes) (Gurvitz et al., 2013; Oris et al., 2016). The prevalence of chronic health conditions in the United States is on the rise (Agborsangaya et al., 2013); in fact, rates have risen substantially since the 1970s (Perrin et al., 2007) and this statistic is projected to continue to rise as more individuals are diagnosed each year. The differences between those with chronic illness and those without may manifest during the young adult years (Andonian et al., 2018; Pinguart, 2014). Distinctions are important since chronic disease shares an inverse relationship with quality of life (QOL) and overall well-being (Areias et al., 2014; Ferro, 2015; Karsenty et al., 2015). The more chronic perception, the worse outcomes.

Manifestations include greater negative illness representation, lower self-efficacy, and poor mood (Rivera et al., 2020). Chronic disease further creates a delay in achieving developmental milestones (Cook et al., 2016; Ko & Cedars, 2018; Rivera et al., 2020; Sligo et al., 2019) and diminishes work and productivity (Crump et al., 2013), which are important to understand considering approximately 10 to 20 million children and adolescents live with a chronic condition (NCCDPHP). Perrin et al. (2007) report that each year 500,000 U.S. adolescents with special health needs turn 18. Adverse outcomes are observed with age, evidenced by self-rated health and lower HrQOL index scores (Ge et al., 2018). Young adults with chronic illness report concerns related to impaired relationships, financial hardships, and altered lives (Pinquart, 2014; Sligo et al., 2019). These findings cannot be overlooked due to the stigma chronic disease creates in *young* adults.

Complex CHD as a Chronic Disease

Within the prevalence estimate of the 1.4 million U.S. adults with CHD, 12% have complex CHD (cdc.gov, 2010). Complex congenital heart disease requires invasive operative procedures and a lifetime of specialized medical surveillance (Adult Congenital Heart Association) classified as CHD anatomy class III, under the 2018 ACHD guidelines (Ombelet et al., 2020; Stout et al., 2019). Respectively, minor defects are class I while moderate defects are class II. Often class I (minor) are repaired during infancy, which likely do not require lifelong ‘CHD’ surveillance. Although the latter may be true as a generalization, those with minor CHD face challenges as well (Kovacs et al., 2009; Lane et al., 2002; Moons & Marelli, 2022; Saha et al., 2019). The higher the anatomic classification, the more severe the heart defect.

Complex CHD is a *pediatric* heart condition, as an *adult*. Since CHD necessitates a lifetime of specialized cardiac management (Hilderson et al., 2009; Knowles et al., 2012; van

Staa et al., 2011; Verheugt et al., 2010), its prevalence is associated with chronic illness. An illness that exists from a very young age, yet not the typical older adult chronic condition like heart failure or angina. Lu et al. (2022) describe CHD as a “physiological derangement” (p.2). Such proclamation is supported by the 2018 AHA/ACC (American Heart Association/American College of Cardiology) clinical practice guidelines for managing adults with CHD: Medical surveillance now includes the patient’s physiological stage to improve mortality risk assessment (Stout et al., 2019). As these individuals with CHD age, additional comorbidities can and do develop. Whether or not patient concerns are related to the residual defect, additional interventions that are needed to optimize cardiac functioning, and/or the impositions the heart condition creates later in life, concerns are real (Bolduc et al., 2019; Codari et al., 2018; Leibold et al., 2021; Mutluer, & Celiker, 2018; Sandberg et al., 2019) and very personal (Callus et al., 2013). It is; therefore, essential to understand the implications that managing a pediatric chronic condition *in the presence* of other adult-related co-morbidities has on achieving expected life tasks and overall well-being.

The growing body of evidence details patient reported outcomes (PROs) for various life domains in adults with CHD (ACHD) and highlights the differences and perceived concerns that exist in many of these individuals’ lives. The empirical evidence demonstrates that the presence of CHD may mediate maladaptive behaviors (Areias et al., 2014; Ferro, 2015) and potentially lead to a poor quality of health and overall well-being (Areias et al., 2014; Ferro, 2015; Oris et al., 2016; Pagé et al., 2012). Well-being and quality of life (QOL) are influenced by patient empowerment and patient reported health. In their study investigating the association between patient empowerment, PROs and CHD transition readiness, Mora et al. (2022) found patient empowerment and other PROs improved with age, except for quality of life (QOL).

Interestingly, at the final data collection point when participants were age 18.5 years, those QOL measures improved. Differences in PROs, perceived well-being, and QOL by age are worth exploring.

The findings particularly resonate among individuals with a complex form of CHD (Areias et al., 2014; Jackson et al., 2016; Karsenty et al., 2015; Ladak et al., 2019; C. Sandberg et al., 2019). Impaired functionality in the presence of congenital heart disease may predispose one to a delay in developmental milestones (Callus et al., 2013; Pagé et al., 2012), which is crucial to understand since it is during late adolescence that the emerging adult developmental period begins (age 18-25). Emerging adulthood is marked by a time of instability as individuals *transition* to the adult role, which is likely further impacted by the uncertainties that congenital heart disease creates. Addressing this developmental time-frame in the life of an ACHD emerging adult is one gap that this study examines.

Since this is the gap that is addressed, it is necessary to look at a similar population to help inform this research. Interestingly, much of this published research was conducted qualitatively. Common themes that resonate between the various disease groups include: (a) difficulty managing life with chronic kidney disease (Coyne et al., 2019); (b) challenges with gaining independence among cancer survivors (Ricadat et al., 2019), especially from parents (Pinquart, 2014; Ricadat et al., 2019) and requests for ‘carer’ (caregiver) counseling (Coyne et al., 2019; Willemse et al., 2018) for those with chronic kidney disease and cancer survivors; (c) difficulty in connecting with others (Coyne et al., 2019; Ricadat et al., 2019; Willemse et al., 2018), and (d) feeling frustrated with setting goals for the future among young adults with Diabetes Mellitus Type I (Willemse et al., 2018). The meta-analysis conducted by Pinquart et al. (2014) included Emerging Adults with varied pediatric illnesses, which include chronic kidney

disease (CKD), cancer, asthma, Diabetes Mellitus Type I, heart disease, and hearing impairments.

In another study among young adults with cancer and asthma, Sligo et al. (2019) found the chronic nature of the disease altered their life trajectory. A positive research finding occurred via Lee et al. (2020) whereby adolescents with CHD showed greater resilience compared to adolescent blood cancer survivors. The small number of CHD studies that include EA age groups show that the young adults feel ‘disadvantaged in society’ (Kronwitter et al., 2019). These are profound concerns worth investigating further. Chronic pediatric disease in adulthood creates concerns that extend beyond a medical diagnosis. Examining chronic congenital heart disease during this vulnerable developmental stage adds to the ACHD state of the science by gaining a deeper understanding of the concerns and challenges faced by this unique patient population.

The literature search strategy involved multiple searches to inform this research. The following databases were used: (a) CINAHL Complete, (b) PubMed, (c) PsycInfo, and (d) Google Scholar. Only those peer-reviewed, published in English, and custom range between 2001 and 2022 were included. Relevant up-to-date information was used from the CHD and other pediatric chronic disease literature, as well as relevant methodological and philosophical resources.

Chapter II: Theoretical Foundations and Literature Review

Emerging adulthood (EA) is the developmental stage between late adolescence and early adulthood (age 18 to 25). It is a period described by developmental psychologists as profound emotional and social change (Arnett, 2015; Ferro, 2015). Career planning begins during the EA stage of development (Arnett, 2000, 2015; Reifman et al., 2007). Further, beginning to establish financial security is the marker to adulthood (Arnett, 2015; Erikson, 1980). Critics argue that establishing career goals predisposes the emerging adult to emotional instability caused by the ambivalence they face (Arnett, 1998, 2000). However, research indicates that emerging adults who are future oriented and engaged in vocational or academic plans, position themselves to create more meaningful life decisions (Arnett, 1998; Reifman et al., 2007).

Developmental Tasks within the Theory of Emerging Adulthood

Although even just as little as 50 years ago the traditional young American followed a more precise path in achieving developmental tasks such as securing work, marriage and family planning, these variations in timing (early 20s versus mid to late 20s) and personal motives, do not preclude the individual's capacity nor willingness to begin exploring fundamental tasks. Tasks include those that individuals know will set them up for the rest of their life, and what they will need when they ARE an adult (Arnett, 2010, 2015). EAs from all generations desire relationships and socialization, which factor into their role development; and they seek employment or an education *because* financial stability is central to their survival, their future, and to the pursuit of happiness.

Generalizations drawn from the developmental psychology research is applicable to ACHD; although achieving developmental tasks in the presence of chronic congenital heart

disease may impede that development. The ACHD literature indicates difficulties exist in the individuals' ability to secure and maintain employment over time, achieve an education, procure long-term relationships, and gain independence. The concepts of self-efficacy, sense of coherence (SOC), coping, and resilience are shown to be positive predictors of QOL in CHD (Kovacs et al., 2015; Lee & Jung, 2019; Lee et al., 2020; Moons et al., 2021a; Thomet et al., 2018). Moons and Lucykx (2019) and Thomet et al. (2018) found self-efficacy in ACHD positively influences health behavior, knowledge, and quality of life. Conversely, engulfment and enrichment negatively influence illness identity dimensions and clinical outcomes (Van Bulck et al., 2021b). These same concepts are also known predictors of QOL throughout the chronic illness literature (Gheshlagh et al., 2016; Kim et al., 2019; Ricadat et al., 2019). Chiang et al. (2014) found adult participants with CHD who engaged positive coping strategies were more equipped to handle adverse situations; yet Acuna et al. (2019) found low levels of empowerment among individuals with CHD. The individual's ability to engage positive coping skills and resilient behaviors could reasonably indicate that living with congenital heart disease does *not* impede a person's life; however, the evidence is conflicting.

Sense making

A review of the literature on sense-making describes the concept as the way individuals create meaning to understand experiences (Aho & Aho, 2008; Mamykina et al., 2015; Sandberg & Tsoukas, 2015), particularly during times of unrest (Dawson & Sykes, 2019). Originally defined by Weick (1979, 1995), *sense making* is what a situation *means* versus what is *going on* – the ideas that contribute to the outcome rather than the outcome itself (J.H. Mills et al., 2010): *What I become and who I am because of.....* (Weick, 1995).

Sense making is an active process: It is social, narrative, retrospective, and based on one's identity (Sandberg & Tsoukas, 2015). Interpretation of events is retrospective because *sense making* is based on one's existing knowledge base (Mamykina et al., 2015) and prior experiences used to face situational decisions and choose a course of action. Some scholars claim *sense-making* lacks scientific clarity and although investigated as a central concept in the relevant research, *sense-making* also lacks application (Dawson & Sykes, 2019; Sandberg & Tsoukas, 2015). The literature provides insight into how *sense making* is operationalized.

The *sense making* studies that exist center on organizational and management behaviors, educational processes, and Informatics (Dawson & Sykes, 2019; Sandberg & Tsoukas, 2015). The latter focuses on person-computer interactions. Today's technological advancements make studying *sense making* worthwhile. J.H. Mills et al. (2010) operationalized Weick's (1979, 1995) *sense making* model to understand the factors that influence organizational processes, which Mamykina and Smaldon (2015, p. 1) posit are influenced by individual meaning constructions. Meanings do not occur in isolation; they are guided by perceptions based on one's prior (baseline) knowledge, past experiences, and relation to others. It is a process that is "never ending" (J.H. Mills et al., 2010, p. 183). In their systematic review, Sandberg and Tsoukas (2015) found that *sense making* is predominantly used as strategy in the context of organizational learning, change processes, and crises. Regardless of the situation, *sense making* culminates from some sort of disruption in daily activities. Disrupting events include those planned and unplanned, and may not necessitate a crisis. The antecedent event nevertheless creates an interruption or potential problem (Russell et al., 1993) for the individual who must now reconcile and negotiate (J.H. Mills et al., 2010) with self to understand his/her position in the situation.

Sense making is environmentally interactive; therefore, it shows potential to advance the qualitative perspective; notably a hermeneutic (interpretative) approach to research (Sandberg & Tsoukas, 2015). Dawson and Sykes (2019) found one of the primary means to generating meaningful, logical structures includes the Heideggerian perspective or ‘fore’ (p.101). The Heideggerian perspective refers to the ‘fore’-sight (‘before’) in creating connections and interpretations for past, present, and future knowledge relevant to the ‘things themselves’ (Heidegger, 1962) rather than perceived conceptions. To Heidegger, the interactive nature of ‘what is’ is epistemological existence. The application of *sense making* as a temporal event has been examined in chronic illness.

While existing studies that examine sense-making in organizational behaviors found interrupted events initiate *sense-making* strategies. Similar findings occurred while Mamykima et al. (2015), investigated self-care management and glucose monitoring among adults with diabetes mellitus. The authors concluded that to manage their disease effectively, patients engaged in *sense making* as a consequence to their gap in understanding. The gap included self-management skills for monitoring and managing blood glucose levels. Such acuity disrupted their activity level, dietary choices, and other daily life management decisions. In this study’s context (2015), *sense making* occurred via three preconditions: (a) *perception* (representative set of new information related to their health and well-being), (b) *inferences* (internal representations used to validate and choose a course of action, and (c) *actions* (activities carried out to manage their disease in relation to the new information). The preconditions support the social, narrative, and retrospective characteristics of *sense making* found in other studies.

Sense making in ACHD

Studying *sense making* relevant to disease management in adults with diabetes mellitus has implications for ACHD. Mamykina et al. (2015) posit that the immediate events of assessing blood glucose levels promote sense-making opportunities. It is not well understood how *sense making* occurs in adults with complex CHD beyond the existing QOL and PRO measures. The unpredictability of one's cardiac condition in the presence of daily life events (planned and unplanned), launch sense-making opportunities because life itself *is* sense-making (J. H. Mills et al., 2010). In the 2021 American Heart Association Scientific Statement, Levine et al. emphasize the need to treat the patient, not just the disease (2021, p. e763). Aho and Aho (2008) echo such sentiment when distinguishing between the *Korper* (physical, objective metrics of biomedicine) and the *Lieb* (lived body) to understanding health and illness. The centrality of *sense making* as a retrospective; yet interactive concept explores ACHD holistically as a past, present, and future-oriented phenomenon.

Exploring ACHD for its potential and actual 'interrupted' events in self-management provides rich data. The data tap into how individuals with CHD extract their social/environmental cues to create meaning in the situational factors they face. Conducting *sense making* studies generates the conceptual *shift* recommended by current scholars to advance its application beyond organizational behaviors. The findings from this study contribute to the ACHD science and are applicable to inform other health related research.

Critical Appraisal of the ACHD Literature

The Emerging Adult developmental theory (Arnett, 2000, 2015) embodies the human need for work/employment, (b) education/careers, (c) relationships and parenthood, including gender specific roles, and (f) engaging in activities that promote QOL. During this life stage,

well-being is exemplified via one's future orientation – the goals and aspirations that begin to inform one's authentic self (Ruiz, 2018); realizing who they are (role development) and why the decisions they make are so important to the rest of their lives. This is integral to *sense making*. Chronic CHD creates several challenges that may impair the young adult's ability to engage in this vital role development. Developmental achievements during EA occurs at a time when there is the least amount of social control (Hendry & Kloep, 2007); yet it is questionable whether adults with CHD (of all ages) adjust and adapt well to their circumstance. Scholarly pursuits investigating developmental tasks in adolescent and mixed-age adults with congenital heart disease demonstrate that while some individuals with CHD function well (Kronwitter et al., 2019; McKillop, et al., 2018; Moons et al., 2018), others do not (Acuña Mora et al., 2019; Areias et al., 2014; Jackson et al., 2016; Karsenty et al., 2015).

Regardless, developmental challenges are a common thread throughout the ACHD literature. Challenges arise in securing and maintaining employment, relationships and the social network; decisions related to gender tasks (including parenthood) and the ability to gain independence. HrQOL findings particularly resonate among individuals with complex defects (Goossens et al., 2013; Jackson et al., 2016; Karsenty et al., 2015; Ladak et al., 2019), such as those with cyanotic congenital heart disease and surgically routed conduits (Moons et al., 2021a); or with residual lesions (Areias et al., 2014; Brida & Gatzoulis, 2019; Mutluer, & Celiker, 2018).

The APPROACH-IS, a multinational study (Rassart et al., 2017) that culminated into additional studies (Cateight et al., 2021; Moons et al., 2020, 2021a; Thomet et al., 2018; Van Bulck, et al., 2018) found that patient reported outcomes (PROs) from five life domains are predicted by: (a) age, (b) functional status, and (c) unemployment. Data are evolving via the

APPROAH-IS II relevant to the Covid pandemic, illness perception, illness identity, and patient empowerment (Moons et al., 2021b; Van Bulck et al., 2022b). The i-DETACH 2 also shows promising evidence via the longitudinal data collected on individuals now age 24 to 28 (Na et al., 2021), as well as the STEPSTONES-CHD trial of adolescents' (age 16 to 18.5 years) level of self-empowerment and PROs (Mora et al., 2022). PROs benefit patient care choices (Diller et al., 2021). Recognizing that financial stability is a hallmark indicator of adulthood (Arnett, 2000, 2015) and working is directly related to emotional and psychological well-being (Godinic et al., 2020; Henderson, 2018), employment or career planning must be examined in the ACHD population.

Employment and Career Planning

The current evidence as it relates to employment and career planning within the context of ACHD is varied. Inconsistencies begin to materialize by age, gender, and defect complexity. A few scholars found mixed-age CHD adults experience similar rates in working and attending college relative to their healthy peers. In fact, the CHD group was *more* likely to achieve a higher education than the healthy group. Kronwitter et al. (2019) found employment and academic rates both improved in their longitudinal analyses while Sluman et al. (2019) found in their international study that two thirds of adults with CHD were employed. The increased likelihood aligns with historical data from Crossland et al. (2005), who posited there may be intentionality on the part of the individual with CHD to promote their marketability. Moreover, deliberate actions may be an adaptive strategy (McKillop, et al., 2018) to choose a career path that these young adults know will accommodate their limitations (Areias et al., 2014; Chiang et al., 2014). Individuals with severe or complex CHD showed a 43.7% active employment rate compared to 80.8% of those with mild or simple CHD (Karsenty et al., 2015, p. 594).

Limitations are multifaceted; including surgical recovery, medical procedures and/or devices, physical capabilities, and prescribed medication use (Enomoto et al., 2020; Jackson et al., 2016; McKillop, et al., 2018; Mutluer, & Celiker, 2018).

Sequelae from the initial surgical repair, additional interventional procedures (Enomoto et al., 2020; Leibold et al., 2021; Mutluer, & Celiker, 2018), and prescribed medications (Jackson et al., 2016) create limitations that may impede occupational choice and overall participation in the workforce (Areias et al., 2014; Jackson et al., 2016). For example, the adult with CHD who has a permanent cardiac pacemaker or defibrillator is prohibited from working in an environment that exposes him/her to magnetic or electrical currents because it could interfere with the cardiac device settings. Commonly prescribed cardiac medications (Jackson et al., 2016; Neiman et al., 2017), such as anticoagulants (i.e., Warfarin), diuretics (i.e., Furosemide), and Beta Blockers (i.e., Metoprolol) also prevent the individual from performing certain job requirements. Physical exertion places the individual at risk for bleeding and syncope (fainting). Subjective reports reveal physical weakness (Ladak et al., 2019; McKillop, et al., 2018) and fatigue.

Karsenty et al. (2015) found adults with complex CHD had a reduced glomerular filtration rate (GFR) and increased rates of diabetes mellitus. Diabetes prevalence is found in additional works (Gurvitz et al., 2013; Moon et al., 2015) as well as systemic or multi organ impairments (Dent et al., 2019; Marelli et al., 2014; Uchikado et al., 2020). Webb et al. (2002) found operative repairs, particularly those with artificial heart valves, showed a greater risk for developing an immune disorder. Co-morbidities may exacerbate poor psychosocial outcomes as a combined effect of acute and chronic insult. Lifelong complications exacerbate in adult years. Khairy et al. (2010), Verheugt (2010), and Van Bulck et al. (2022a) report increased mortality

rates in adult CHD and Agarwal et al. (2019) show increased heart failure related to in-hospital mortality rates.

In studies analyzing functionality in those with a specific cardiac malformation or following a particular cardiac surgery, Buldoc et al. (2019) found patients that did not regain functionality following their cardiac repair, may warrant disability benefits (Overgaard et al., 2012) and an overall worse HrQOL (Sepke et al., 2018). These findings align with Karsenty et al. (2015) who found 31.2% of adults with complex CHD reported disabled- worker status (2015, p. 594). Karsenty et al. (2015) also found adults with CHD who experienced complications and more than two surgeries had lower education pass rates. In a study conducted by Na et al. (2021), 69.2% of adults with CHD reported absences from work or school over the past year while 15.4% reported the absence was due to their CHD (p.3).

From an historical perspective, Lane et al. (2002) found that social functioning across CHD classifications as, ‘cured’ corrected’ or palliated,’ the minor or ‘cured’ group had poorer social outcomes. Differences in social functioning in the minor/simple CHD group is an unexpected finding considering other comparative studies. In this instance the authors, Lane et al (2002), posit the ‘cured’ may have distorted perceptions based on the way other people treated them. A phenomenon known as a ‘*wrapped in cotton wool*’ attitude’ (2002, p. 74). Moons et al. (2020) also found differences in defect severity in relation to lower SOC (sense of coherence) for ‘simple’ CHD and younger age. SOC was also lower in those job seeking (Moons et al., 2020). Likewise, Thomet et al. (2018) found lower SOC if unemployed. Stress scores on the ‘*Hassles in Adults with Congenital Heart Disease*’ scale show stress scores correlated with unemployment and lower income (Cook et al., 2016). Enomoto et al. (2020), concluded adults with CHD overall experienced higher unemployment rates compared to the national trend. However, gender

differences emerged in this study: Males were more likely to work full-time and females were more likely to be unemployed.

Psychosocial limitations also manifest as an expressed fear that adults with CHD risk losing their job caused by frequent use of sick time for increased clinic appointments and hospitalizations (Cateight et al., 2021; Van Bulck, et al., 2018). Moreover, it was found adults with CHD fear losing their health and life insurance policies (Webb et al., 2002). This creates a feeling of ‘job lock’ (Crossland et al., 2005). Job-lock exists when people feel trapped in their current job or limited in advancing their career. The fear associated with lost health insurance may have improved following the passage of The Patient Protection and Affordable Care Act (2010) in the United States, which prohibits health insurers from denying coverage based on pre-existing medical conditions. Ten years later, President Donald Trump (2020), enacted an Executive Order upholding this portion of the Affordable Care Act. Vaikunth et al. (2017) found health insurance was not a factor in predicting successful transition to an ACHD program.

Adults with CHD are also at risk for cognitive impairments. Poor cognition affects one’s ability to focus and impairs memory recall and knowledge retention (Bolduc et al., 2019), which could impact their ability to achieve an academic degree. Complex CHD may impair neurological development via early brain aging and cerebral microvascular damage (Bagge et al., 2018; Codari et al., 2018; Martínez-Quintana et al., 2019). Brain abnormalities overall are greater in those with CHD compared to the matched healthy group, and those changes manifest with age (Bolduc et al., 2019; Khairy et al., 2010; Kovacs & Bellinger, 2021; Verheugt et al., 2010). Such abnormalities may influence social experiences.

Working for a wage is more than a job; it serves as the conduit to develop personally and professionally through a process of interactive social experiences (Arnett, 1998, 2000; Crocetti et

al., 2012; Erikson, 1980; Godinic et al., 2020). Social experiences facilitate establishing and maintaining relationships through human connection (Glanz et al., 2015). Human connection is an integral part of role development and necessary to reduce loneliness. Moons and Lucykx (2019) found loneliness and perceived illness negatively influence QOL. Moons and Marelli (2022) posit such risk factors are present in ACHD. Perceived stress and living alone or reported loneliness are known risks (Chen et al., 2020; Mathur et al., 2016) worth monitoring.

Relationships and Gender Roles

Gender identity and associated tasks such as intimate relationships and parenting, are best accomplished when empowered and capable. Knowing that empowerment and sense of coherence (Kim et al., 2019; Moons et al., 2020) improve QOL, this area of development poses challenges for adults with CHD as evidenced by reports of interpersonal challenges (Chiang et al., 2014; Moons et al., 2020; Pagé et al., 2012; Sepke et al., 2018). Cook et al. (2016), found stress scores correlated with marital status while Moons et al. (2020) found sense of coherence (SOC) was compromised if the individual with CHD was unmarried or divorced. Sepke et al. (2018) and Pinquart et al. (2014) found that fewer adults with CHD had an intimate partner compared to their healthy peers. A central theme in a study by Callus et al. (2013) found individuals believe their CHD made them different, *as a consequence*.

CHD has consequences. The complications ‘burden’ (Karsenty et al., 2015) of ACHD resonates in such reports as sexual dysfunction (Neiman et al., 2017) and requests for reproductive counseling services (Kronwitter et al., 2019). Although some scholars did not find gender differences (Gleason et al., 2019; Janssens et al., 2016; Sepke et al., 2018; Steele et al., 2019), most of the ACHD research shows otherwise. In general, females do not do well in this area. The research shows females demonstrate poorer outcomes: Poor quality of life in physical

functioning, role functioning, and vitality when compared to males with CHD (Barreda, et al., 2020). When compared to the healthy group, similar findings arose (Rometsch et al., 2019). Females were more likely to be depressed than males with CHD (Cook et al., 2016), showed lower self-efficacy (Thomet et al., 2018) and perceived poor mental health (Neiman et al., 2017). Enomoto (2020) found females with CHD were less likely to be homemakers.

Young females with CHD are generally recommended against pregnancy (Mutluer, & Celiker, 2018) and may experience a delay in the timing of their menses as a result of CHD-related complications. Both genders have fewer children in the presence of complex CHD, compared to those with mild CHD. Interestingly, Burstrom et al. (2021) found male adolescents with CHD showed a higher interest in contraceptive information than the females. Burstrom et al. (2021) and Leroy-Melamed et al. (2020) found both genders lacked knowledge related to reproduction and contraceptives, including contraindications with prescribed teratogenic medications. Yet, individuals with CHD do express concerns related to future offspring and fertility (Nakamura et al., 2018). Karsenty et al. found only 29.4% of those with complex CHD had children as opposed to 60% of those with mild CHD (2015, p. 594). In their meta-analysis, Pinquart et al. (2014) found individuals with pediatric chronic illnesses had a 38% reduction in parenthood (p.581) compared to the general population. Whether motivated by medical recommendations or an intentional act to guard against adverse cardiac outcomes, pregnancy decisions (Brida & Gatzoulis, 2019; Kronwitter et al., 2019; Nakamura et al., 2018) are influenced by CHD.

Independent living

Adulthood is typically viewed as the point in time that individuals are living on their own; no longer dependent on their parents or family. They are fulfilling expected adult

responsibilities while taking ownership for their decisions (Arnett, 2010; Arnett & Mitra, 2020; Erikson, 1980; Hendry & Kloep, 2007) and assuming full agency. There is a positive correlation between New York Heart Association (NYHA) classification and psychological quality of life (QOL). Impaired functionality exacerbates depressive symptoms (Ko & Cedars, 2018). CHD cohorts of all ages report feelings of anxiety and depression (Abda et al., 2019; Andonian et al., 2020; Cateight et al., 2021; Deng et al., 2016; Gleason et al., 2019; Moons et al., 2021a). Emotional symptoms arise when feeling misunderstood (Cateight et al., 2021; Chiang et al., 2014; Pagé et al., 2012; While et al., 2017). Negative emotions adversely impact one's sense-making capacity (Levine et al., 2021; Sandberg & Tsoukas, 2015). Similarly, frustrations arise when these individuals feel others hover or pay special attention to them. This is particularly observed with maternal overprotection (While et al., 2017). Consequently, many CHD patients verbalize the need for mental health services (Kronwitter et al., 2019; Pagé et al., 2012). They desire individual and group sessions to connect with other CHD patients (Pagé et al., 2012). Unfortunately, cardiac physicians often do not recognize nor intervene when social and emotional problems arise (Gleason et al., 2019; Levine et al., 2021; Meentken et al., 2017).

This perceived lack of belonging or feeling misunderstood manifests as anxiety, depression, poor self-esteem, and stigmatization. Normal human development shows depression may precipitate cardiovascular (CV) disease and increase the odds of sleep disturbances (Klakk et al., 2018). CV disease is mediated by chronic illness (Ferro, 2015). To the adult with CHD, this would be adding another CV risk to an already existing risk. The uncertainties of CHD in and of itself could be a source of anxiety because it creates a fear of the unknown. Affective disorders exacerbate the adult's challenges in managing life to engage in daily living.

Adults with CHD report a loss of self- balance (Chiang et al., 2014). Further, their adjustment is impacted by social support. If social support is lacking (Rometsch et al., 2019), it creates a challenge while positive social support facilitates physical functioning and positive health behaviors (McKillop, et al., 2018; Sepke et al., 2018). Discrepancies in parental influences were found. Ladak et al. (2019) found parental reports of adolescent and young adults' HrQOL was lower, while Abda et al. (2019) found parental reports of their child's self-esteem was better than the child's perceived reports. In mixed defect comparisons, maternal overprotection negatively affected psychological wellbeing and peer dimensions (While et al., 2017). Current ACHD literature reveals SOC, self-efficacy (SE), empowerment, and personality (Lee et al., 2020; Meentken et al., 2017; Moons & Luyckx, 2019; Mora et al., 2022) are dominant predictors for QOL.

Meentken et al. (2017) also found personality as a predisposition to PTSS (post-traumatic stress symptoms). PTSS and PTSD (disorder) begin to manifest as the individual ages. These findings are likely attributed to PROs (patient-reported outcomes) that they experienced years of medical trauma throughout their childhood (Lane et al., 2002; Levine et al., 2021). During the late adolescent to early adult years, striving for independence is difficult because on the one hand individuals value family involvement; while on the other, they want to function on their own. Despite this dichotomy, individuals with CHD indicate personal relationships are important to them – most notably, their family and friends (Abda et al., 2019; McKillop, et al., 2018; Sepke et al., 2018).

Lifestyle

Social support fosters well-being. Mixed-age adults with CHD live a relatively healthy lifestyle. Health risk behaviors were not significant for cigarette smoking or binge drinking in a

study by Goossens et al. (2013); however, overall health risk increased with age. Leibold et al. (2021) found alcohol use in ACHD – of those surveyed, 20% reported drinking twice a week (p.5). Karsenty et al. (2015) found none of the adults with complex CHD in their study used cannabis or reported alcoholism. Moreover, none of the CHD sample, regardless of defect severity, used illicit drugs. Goossens et al. (2013) found dental hygiene risks decreased during adolescence. Variations in physical activity (Jackson et al., 2016; Karsenty et al., 2015; McKillop, et al., 2018) and exercise capacity (Kronwitter et al., 2019) exist, but that follows normal trends based on self-imposed or physician guided restrictions. Unexpectedly, income was not a significant factor in QOL among defect classifications (Jackson et al., 2016), nor did income influence obesity in ACHD (Steele et al., 2019). In the I-DETACH study, Goossens et al. (2013) and Janssens et al. (2016) found unhealthy behaviors were evident between adolescence and the young adult years. The prevalence of those overweight, obese, and diagnosed with metabolic syndrome has increased (Deen et al., 2016; Tamayo et al., 2015). Steele et al. (2019) found an increase between their 1996 to 2000 and 2006 to 2010 cohorts. In the younger cohort they reached overweight status by age 16, whereas those in the latter cohort reached overweight status by age 10. Similarly, Tamayo et al.(2015) found the increase to occur between childhood and adolescence. These marked differences indicate age is an important factor in monitoring poor health behaviors.

Medical Events

A cardiac medical event is an important factor that affects the young adult managing life. Complications and acute cardiac events vary in both timing and severity, which perpetuate illness uncertainty. In mixed ACHD samples, differences between the younger and older adults manifest in how they respond to and *make sense* of cardiac events. When faced with a cardiac-

related issue, the young adult typically views these occurrences as a setback (Chiang et al., 2014). Acute events exacerbate the chronicity of CHD because the setback creates an imposition (Van Bulck, et al., 2018) just at the time when the individual is beginning to live independently and assume personal, adult responsibilities: Attempting to earn an income, follow through with parental commitments and personal relationships, and manage a home. Any setback in adults with CHD potentiates their risk to disengage from expected developmental tasks.

Disengagement may exist without an acute event. Circumstances may be related to collective personality changes or collective identity (Dawson & Sykes, 2019) in the presence of an historical event – or associated with a changing world trend in economic and moral systems (Erikson, 1980). This *collective* change is known as, “cohort effects” (Keil, 2013, p. 645). Anytime individuals disengage from their life tasks, it results in a lower perceived quality of life and efficacious behaviors (Bandura, 1989; Keil, 2013), and constructed meaning to make sense of associated experiences (J. H. Mills et al., 2010). When faced with a reoccurring medical event or an external catastrophic event, it is not well known if such a circumstance would motivate the emerging adult with chronic CHD to disengage to the point that daily functioning is markedly impaired or continue to ‘press on’ and what factors may be facilitators or barriers. In this regard, their situational awareness would have a deleterious effect on their future.

The Covid-19 pandemic.

Following the global impact of the Covid-19 pandemic (2020), every age group was adversely affected. Evidence demonstrates a positive correlation between psychological maladjustment and emotional and behavioral difficulties. Additionally, when the social network or human connection renders to virtual platforms, it creates a dissonance between one’s perceived identity and the newly “emerging reality” (Godinic et al., 2020, p. 62). Negative events impact emerging adults tremendously because it is such an unstable and vulnerable stage.

One's sense of coherence (SOC) develops during early adulthood and stabilizes by age 30 (Arnett, 2000). Disruptions to self-development are concerning. In a study by Mather and Carstensen (2005) cited in Keil (2013), it was found that in the presence of a negative event, healthy older and young individuals shifted their focus and goals to emotional regulation for the present (now) instead of the future. Future planning is at the core of the EA developmental stage.

It is K.G.'s [P.I.'s] belief that the pandemic is germane to human development, particularly during the EA transitional stage and those deemed vulnerable (i.e., chronic conditions). The collective effects of social isolation, mandatory masking, and a global economic shutdown created a public health crisis. At the time of this research, current recommendations for the prevention and treatment of Covid-19 in the ACHD population are centered on the individual's (Radke, et al., 2020) risk assessment and symptomology. The *Lancet's Covid-19 Committee Mental Health Task Force* reviews data related to psychological distress in the early stages of the pandemic (Aknin et al., 2022). Recent data relevant to the social implications of the Covid-19 pandemic are included in this final project's 'Discussion' section.

ACHD and its Impact on Role Development

Managing life independently to engage in role development are influenced by a constant interplay between physical, psychological, and psychosocial health. Impaired physical functioning influences psychological functioning (Areias et al., 2014; Ferro, 2015; Karsenty et al., 2015; Ko & Cedars, 2018; Meentken et al., 2017) and vice versa. There is reciprocity among the health dimensions, and as the existing evidence shows, differences in either or all of these life domains manifest by age, gender, and disease severity. Placing chronic CHD into the life cycle creates more adversity; supporting the direct correlation between chronic disease and poor QOL outcomes (Crump et al., 2013; Ferro, 2015; Jackson et al., 2016). Achieving developmental

milestones, particularly during the vulnerable transition between adolescence and adulthood (Arnett, 2015; Reifman et al., 2007), improves cognition (Arnett, 2000; Crocetti et al., 2012), mental health (Deci & Ryan, 2000; Nikitin et al., 2012; Wrosch & Freund, 2001), identity formation (Crocetti et al., 2012; Godinic et al., 2020), and overall functionality (Bandura, 1989, 2003; Crocetti et al., 2012; Messersmith & Schulenberg, 2010; Wrosch & Freund, 2001).

Both generic and disease-specific [CHD] health-related quality of life (Hr-QOL) measures demonstrate variable outcomes. Findings have been used to inform interventions targeting CHD populations. The ‘CH-STRONG’ is a database developed out of a survey of adults between the ages of 19 and 38 (mean age 23.5 years) that addresses psychosocial and other well-being inquiries, including healthcare utilization. Similarly, the ACHD-CARE (Kovacs et al., 2015) is an interventional strategy that targets identified adaptive (and maladaptive) predictors important to role transitions in ACHD. And the KnoCoMH (the Knowledge Scale for Adults with Congenital Heart Disease) targets health status and disease knowledge among adolescents age 14 to 18 (Burström et al., 2021).

Pediatric cardiologists may now be board certified as adult congenital heart disease (ACHD) providers (While et al., 2017). Certification paves the way for accredited ACHD cardiac centers (American Congenital Heart Association, 2019). ACHD clinics are appearing throughout the country, creating easier access to specialized providers. Access fosters continuity in care for individuals requiring lifelong cardiac care (Ladak et al., 2019; Moons et al., 2002; While et al., 2017). Specialized care is necessary as patients manage their ‘childhood’ heart defect in the presence of other adult-related physical and social issues. Hence, Adult CHD certified physicians who are proficient with the pediatric chronicity are necessary to comprehensively manage these individuals.

A newly developed defect classification scheme is showing promising results in guiding the management of ACHD patients, known as the ACHD-AP (ACHD- anatomic and physiologic) classification, which emerged out of the 2018 AHA/ACC Task Force. Standards of care for adults with CHD no longer use only the NYHA or Bethesda Defect Conference classification scheme to determine a patient's functionality. The ACHD-AP combines the native anatomic defect (class I, II, III) with the patient's physiological stage (A,B,C, or D), which details a more comprehensive approach to care. The higher the letter, the greater one's symptomology both via objective measures and subjective reports. Naturally, stage A represents little to no symptoms, whereas stage D represents severe symptoms (Stout et al., 2019). The variables that comprise each stage include the (a) NYHA function, (b) defect sequelae, including arrhythmias, valvular disease and hemodynamic stability, (c) exercise limitations (i.e., hypoxia), and (f) end-organ dysfunction (Ombelet et al., 2020; Stout et al., 2019). The classification tool has yet to be fully implemented as a standardized treatment protocol; however, research is evolving.

Mortality metrics have been investigated using the ACHD-AP. Cho et al (2020) found postoperative open-heart patients' mortality scores correlated with the ACHD-AP classification, while Kartas et al. (2022) similarly found clinical correlations between death rate and atrial arrhythmias in the presence of an anticoagulation agent using the ACHD-AP classification. This research study advances the ACHD science by analyzing role development qualitatively within the context of the five (5) dimensions of Emerging Adulthood and complex CHD (class III), ACHD-AP, physiological stage A-D.

Developmental Tasks and CHD within the Five Dimensions of Emerging Adulthood

Emerging adulthood is characterized by five dimensions (Arnett, 2000, 2010, 2015) identity exploration, instability, self-focus, feeling in-between, and a time for possibilities and optimism. Each dimension poses unique challenges but also presents a time for excitement. These premises are primarily driven by its transitional premise: A time when individuals consistently report they do not view themselves as adolescents, *or* adults (Arnett, 2000). Young adult CHD groups indicate that although they are no longer adolescents, they are not fully *adult*. The gap exists in understanding early adults with CHD within the context of Arnett's five EA developmental dimensions. Using what is known from the current Adult CHD literature, as well as other studies in EA samples with pediatric chronic conditions, results can be used to inform this study. Moreover, the recent Covid-19 pandemic effects will likely be seen in the results of the study due to its impact on public health and young adults' role development during the past two years.

Identity Exploration

Sense of coherence (SOC) is positively associated with individualism, notably from countries that promote individualism (Moons et al., 2020). Young adults living with a pediatric chronic disease strive for individualism – independence from parents (Ricadat et al., 2019); yet seek to connect with others like themselves (Glanz et al., 2015; Pagé et al., 2012) and foster interpersonal peer relationships (Sepke et al., 2018). Reifman et al.(2007), found the more that adults with CHD engaged in identity exploration, the greater percentage of perceived 'self' in the work and occupational QOL domains.

Instability

Chronic illness alters one's life trajectory (Sligo et al., 2019) It creates, 'a lot of baggage' (Coyne et al., 2019). Individuals feel different, as *a result* of CHD (A. Callus et al., 2013; Pagé et al., 2012) . It [CHD] creates 'invisible defects' (Chiang et al., 2014) and hinders social competence (Abda et al., 2019). As a chronicity, the complications 'burden' (Karsenty et al., 2015) impacts future goals (Willemse et al., 2018) and adaptability (Rometsch et al., 2019). Instability could be perpetuated by a cardiac event that may necessitate the young adult to move back home – the 'boomerang kid' phenomenon.

Self-focus

Adults with CHD have learned to adapt to their circumstance (Kronwitter et al., 2019; McKillop, et al., 2018) so that they can engage in anticipated activities and relate to their peers. A unique consideration of ACHD is that individuals do not know life any other way. Therefore, their focus has to include CHD. It is worth exploring how the individuals *make sense* in managing their lives: Do they make sense of their developmental tasks in the *context* of CHD, or do they make sense of their CHD in the *context* of developmental tasks?

Feeling 'in-between'

Feeling 'in-between' resonates in the adolescent to young adult CHD age range, particularly at the time when the individual transitions to adult CHD care (Vaikunth, et al., 2017; While et al., 2017). This transition is important for several reasons; most notably continuity in care, but also care that is age appropriate. Considering the existence of co-morbidities observed at this early stage in their adult life (Leibold et al., 2021; Pedersen et al., 2019; Shiina et al., 2019; Vaikunth, et al., 2017; Verstraete et al., 2018) and that perceived well-being and self -

empowerment are influenced by successful transition (While et al., 2017) and patient readiness (Mora et al., 2022), capturing needs during the EA period cannot be overlooked.

A Time for Possibilities and Optimism

Life with CHD poses challenges. Interpersonal challenges (Chiang et al., 2014; Pagé et al., 2012), physical and psychological (Brida & Gatzoulis, 2019; Cateight et al., 2021; C.-W. Chen et al., 2018; Ladak et al., 2019; Moons et al., 2021a; Moons & Marelli, 2022; Mutluer, & Celiker, 2018) challenges. The CHD literature demonstrates resilience, empowerment, and coping (Areias et al., 2014; A. Callus et al., 2013; Kovacs et al., 2015; S. Lee et al., 2020; Moons & Luyckx, 2019) promote successful assimilation into adulthood; however, barriers exist. Barriers are often influenced by unexpected cardiac events (Cateight et al., 2021; Ladak et al., 2019; Lui et al., 2017; McKillop, et al., 2018) that impair one's functionality (Meentken et al., 2017; Mutluer, & Celiker, 2018; Van Bulck, et al., 2018) to manage life as adults (Barreda, et al., 2020; Jackson et al., 2016; Ladak et al., 2019). This uncertainty makes it difficult to see life full of possibilities, as Arnett (2010) posits.

Those who are more successful at reducing ambivalence and navigating the uncertainty likely have some personality and social environmental factors that are helping to stabilize them (Claessens et al., 2005; Nikitin et al., 2012). Homophily, in particular (Glanz et al., 2015), is evidenced by the person's interest to participate in CHD-related activities – to engage with like individuals via CHD conferences and disease-specific group counseling sessions (Pagé et al., 2012). Although life is unpredictable for any person, life with pediatric heart disease in addition to other adult-related issues brings a sense of ambivalence to the individual's life. Heidegger (1995) describes the body as a working instrument whereby organs work effectively (i.e., brain, heart, stomach) and do so in the background, or 'hide' (p.179) until they fail. In this regard, one

is unaware of the working body. However, the beating heart is at the forefront – a conscientious awareness for the individual with CHD. In addition, although the surgical chest scar may be invisible to the external world, that too serves as a daily reminder that he/she has an abnormal heart.

Early adults with CHD may demonstrate maturity that is not evident in the general early adult populations. That is, despite feeling ‘in-between’ and engaged in identity exploration (similar to other EAs), individuals with CHD realize they are different from their peers; yet they do not know life any other way. They distinctly understand what *is* from what *may be* (Ruiz, 2018) via a conscientious situational awareness. Such an awareness exemplifies sense making. Therefore, based on the state of the ACHD science and the gap in the EA population, it is this researcher’s goal to apply these known predictors for adult and pediatric well-being to explore the lives of individuals with chronic congenital heart disease within the context of Arnett’s (Arnett, 1998, 2010, 2015) five developmental dimensions of emerging adulthood. Specifically, focusing on individuals in the mid to upper-age range (age 22 to 25) to explore their experiences at a time when the developmental tasks have culminated and their level of independence (Arnett, 1998, 2015) is enough that they are prepared to be an adult. By using the (a) contemporary developmental theory of emerging adulthood among those (b) with complex CHD – to highlight its chronicity, and (c) from the contemporary qualitative philosophy of IPA (Interpretative Phenomenological Analysis), the research exploration was conducted.

Chapter III: Methodology

“To question something is to interrogate something from the ‘**heart**’ of our existence”
(van Manen, 1997, p. 43).

“To bypass the patient’s voice is to bypass the illness itself. And to bypass the illness is to overlook the **patient**” (Toombs, 1992, p. 29).

An exploratory IPA qualitative study addressing each of the five dimensions of EA advances the ACHD science. It further is used to inform age-appropriate; yet individualized clinical interventions that promote successful role development during emerging adulthood.

Study Aim

The aim of this study is to add to the current body of knowledge relevant to adult congenital heart disease by qualitatively exploring the individual’s *sense making* as a personal experience in managing life to achieve anticipated life tasks. Further, interpret the individual’s illness representation and how the uncertainties of the cardiac condition fits into their role development during the emerging, young adult stage.

Research Question

How do individuals with chronic complex congenital heart disease make sense of developmentally anticipated life tasks during emerging adulthood?

Study Design

Analyzing one’s personal experience with a phenomenon is best achieved qualitatively. Qualitative methods are centered on the lived experience (Aho & Aho, 2008; Tracy, 2020) to illuminate personal meaning (Aho & Aho, 2008; Tuffour, 2017). Such a perspective moves the reader away from prescriptive, concrete data to rich, in-depth meaning of the proposed

phenomenon. Many phenomena relevant to nursing science are worth exploring qualitatively because qualitative methods approach the individual as a “person” (van Manen, 1997, p. 6) who is unique and holistic; recognizing the complexities of one’s worldviews. Views that are not about the experience itself; rather, the *essence* of that experience (Aho & Aho, 2008; Tuffour, 2017).

Qualitative research is particularly important in a population that has not been well studied in order to tease out small, but possibly important differences that would be helpful for interventional design. Patients do not always fit neatly into a 5-point Likert-type agreement scale, or a DRG (diagnostic related group). No two patients with the same diagnosis will manifest exactly the same needs and experience. Similarly, adult congenital heart disease is not a universal condition. The differentiation between the Körper vs. Leib resonate in this instance. Hence, a description via *sense making* (the Leib approach) illuminates the phenomenon. It is more than knowing the meaning of CHD – it is “capturing its *meaningfulness*” (Aho & Aho, 2008, p. 122). Qualitative methodologies are not empirical analyses; they are a reflective human science (van Manen, 1997). Reflective analyses are directed by a phenomenological design.

Phenomenology by definition is pedagogy – story telling that is transcribed as written text. The epistemological lens highlights an explicit, universal meaning whereby we can access and attempt to understand a person’s thoughts and feelings (Noon, 2018) and this helps us to move beyond the objective data derived from Likert-type scales to a deeper contextual definition. Phenomenology makes one stop and recognize, and reflect (Aho & Aho, 2008). Think about *being*. We are the product of our everyday world – culture, history, social constructs and relations. Within the larger text, this presumes one cannot bracket or sequester presuppositions and beliefs since these too make up who we are and how we live. Essentially, *sense making* is the

sensing person: How they exist, feel, and act (Aho & Aho, 2008). It is the ‘essence’ of the experience (van Manen, 1997, p. 10). An Interpretative Phenomenological Analysis (IPA) embraces this approach to understanding ACHD.

Interpretative Phenomenological Analysis

Applying theoretical concepts and IPA to study ACHD accounts for the multiplicity of the chronic nature of the disease and accompanying individual *sense making* framework. There is a distinction in how data are achieved and analyzed in qualitative research compared to quantitative investigations. Other distinctions include the method’s philosophical underpinning and procedural traditions. Interpretative Phenomenological Analysis (IPA) is a philosophical framework that has become more prevalent in recent years, particularly in the psychological sciences (Pietkiewicz & Smith, 2014). IPA integrates three primary aims: (a) phenomenology, (b) hermeneutics, and (c) idiography (Noon, 2018; Pietkiewicz & Smith, 2014; van Manen, 1997). van Manen describes phenomenology as how one orients to the lived experience while hermeneutics refers to how one interprets the “texts” (1997, p. 2) of the lived experience. Idiography builds on the preceding by placing value (Tuffour, 2017), the *particulars* (Pietkiewicz & Smith, 2014), and uniqueness (van Manen, 1997) of each case. The latter is known as *emic*’ (Pietkiewicz & Smith, 2014, p. 9), meaning data are drawn directly from the participants.

Heidegger (1962, 1995) first introduced the interpretative qualitative method to move beyond Husserl’s descriptive phenomenology. To Heidegger, the ontological question was *existence* itself, which includes person-environment interactions (Aho & Aho, 2008; Noon, 2018) that are context oriented, not just a stand-alone circumstance. As its own type of qualitative methodology, IPA was first proposed by Jonathan Smith (1996), cited in Noon,

(2018) using features from not only philosophers Husserl and Heidegger, but also the works of Merleau-Ponty and Sarte (Tuffour, 2017). Understanding that experience, meaning, and interpretation are intertwined (Tuffour, 2017), there cannot be an “uninterrupted phenomenon” (Pietkiewicz & Smith, 2014, p. 8).

Interpretative Phenomenological Analysis and Adult Congenital Heart Disease

Studying emerging adulthood (EA) from the IPA position includes the social, cultural, and historical contexts (Aho & Aho, 2008; Noon, 2018; van Manen, 1997) by which the individual interacts. This premise is essential as qualitative data are described and interpreted through direct narratives, but also through a psychological reference point. IPA is ideal for those “voices that may go unheard” (Noon, 2018, p. 80) and to place credence in those voices as the, “experiential expert” (Smith & Nizza, 2022, p. 6). Emerging adulthood is already a vulnerable (unstable) developmental stage. This stage, coupled with a chronic pediatric heart condition, intensifies one’s vulnerability. Generating one’s story translates how individuals make sense of their experience (J.H. Mills et al., 2010; Pietkiewicz & Smith, 2014), and further equips individuals to acknowledge one ‘self’ while empowering to recognize their authenticity.

IPA includes the researcher’s personal account of the phenomenon. In this respect, IPA differs from other qualitative orientations where the researcher [brackets] personal experiences, beliefs, and presuppositions as if to set aside all these values. Neubauer et al. (2019) acknowledge hermeneutic phenomenology includes the researcher’s personal knowledge and experiences as a worldview that ‘cannot be eliminated’ (2019, p. 95). This does not preclude the value of reflexivity to address personal beliefs and values. To address these personal beliefs and values of the researcher, Smith and Nizza (2022) recommend the researcher keep a personal journal throughout the process to ensure presuppositions do not interfere with the idiographic

analysis. Journaling addresses assumptions and thoughts. Examples may be what I see, what I am I recognizing and/or not. The self-reflexivity journal is located in Appendix A.

This researcher, [P.I.], started journaling prior to the proposal submission and continued throughout the research process. It is crucial self-reflexivity occurs so that the P.I.'s addresses personal experiences with the phenomenon; personal experiences which include (a) survivorship of complex CHD (patient) and (b) a cardiac nurse - 27 years total in the nursing profession. Unexpectedly, while conducting this research, I [P.I.] faced an episode of bacterial endocarditis (Fall 2022) followed by open-heart surgery (Winter 2023). This personal experience strengthened the necessity to reflect upon oneself while honoring participants' personal accounts of ACHD. Self-reflexivity is essential to this process because qualitative studies recognize the researcher as 'the instrument' in data collection (Tracy, 2020). Although personal experience cannot be eliminated, experience is what improves researcher credibility and entrée into the setting. Investigating ACHD qualitatively elevates the phenomenon as a human science; a science that embraces the lived experience while illustrating a story (Aho & Aho, 2008; Tracy, 2020; van Manen, 1997); the *Dasein* ('being there') as an interpretative analysis.

Participants

A purposive, homogeneous sample of Emerging Adults with diagnosed complex CHD, based on the ACHD-AP classification (class III, stage A,B,C, or D) who volunteered to participate were included in the study. This sampling strategy is necessary in IPA research because it ensures the participants are more similar than they are different so that any differences are more common than they are diverse (Smith & Nizza, 2022, p. 14). Further, specific sample characteristics improve transferability (Smith & Nizza, 2022) and the emic perspectives of the participants (Pietkiewicz & Smith, 2014; Tuffour, 2017).

Recruitment

Group participation was small and very specific. Therefore, potential volunteers were recruited via gatekeeper referral (medical director) from a regional outpatient ACHD medical clinic, who conducted an electronic query for patients who met inclusion criteria.

Inclusion Criteria

Study participants possess the following characteristics: (a) diagnosed with complex CHD (Class III, physiological stage A,B,C, or D), (b) recommended to continue life-long cardiac surveillance, (c) a history of at least one open heart surgery and/or catheter-based intervention(s) three years of age or older, (d) age at the time of participation between 22 to 25 years old, (e) fluent in English, and (f) cognitively capable to engage with the researcher for an interview.

Human Subjects Protection

Guided by current IPA procedures (Noon, 2018; Smith et al., 2009; Smith & Nizza, 2022; Tuffour, 2017), the anticipated sample size is small. The initial goal was to achieve a sample size, $n = 15-20$, accounting for attrition of $\approx n = 5$ volunteers. The final sample after initiating contact and sending invitations for interviews to all of those who met inclusion criteria within the local Providence Health system was, $n = 13$. The study was approved by Providence St. Joseph Health (study 2022000527) and Idaho State University (IRB-FY2023-58) Institutional Review Boards. E-consents were obtained using the PHI protected REDCAP database, which included a short eligibility screening form (Appendix B) and baseline demographic survey (Appendix C).

Setting

Potential participants were contacted via phone or email by the P.I. [K.G] following MD contact. Once the study had been described and questions answered, for those volunteers who agreed to participate, the electronic REDCAP url/weblink was emailed to each to complete the

eligibility forms and sign the informed consent. At this stage, four potential volunteers were disqualified to proceed because they did not meet the criterion: 'Initial cardiac repair after the age of three.' It was determined that Tetralogy of Fallot (TOF) was the class III CHD most commonly eliminated from eligibility due to its early initial repair. One potential volunteer was eliminated following the interview for cognitive delays that required parental assistance and extensive prompting to answer the questions. All of those who completed the interview received an electronic gift card to Starbucks coffee or Wal Mart, per their choosing.

Data Collection Procedures

Smith and Nizza (2022) recommend piloting the interview questions before establishing multiple interviews. This strategy enabled me (K.G.) to gain a sense of the applicability of the questions, clarity, a general understanding, and the time it takes to complete the interview. Piloting commenced using ACHD trained hospital nurses from Providence Sacred Heart Medical Center. One reviewer was a middle-aged ANM (assistant nurse manager) and two others were young adult nurses (ages 25, 26). The only recommendation that ensued from the piloting strategy was to change the sequence of questions to bring clarity and minimize in-depth questioning at the outset. No interview items were considered too difficult to understand or to answer. All 11 semi-structured interview items were used in the data collection.

Guided by the procedures by Smith and Nizza (2022), the interview guide (located in Appendix D) consists of mostly open-ended questions using the evaluative, temporal structure; meaning questions were centered on the individual experience to explore their life experience; yet follow the manifestations or 'journey' of early adulthood in the presence of CHD. The guide included prompts to ensure the dialogue took a meaningful direction and facilitated fluidity in participant responses. It is preferred to engage in a face-to-face interaction when conducting IPA

research; however, it is most important the participant is comfortable to ‘speak freely’ (Smith & Nizza, 2022, p. 17). Social distance preferences were of particular consideration following the Covid pandemic. Therefore, all interviews occurred virtually via Zoom software between November 2022 and February 2023. Participants agreed to keep the video on and verbally consented to audio transcription. Interviews ranged from 45 minutes to one hour.

Collecting data case-by-case via semi-structured questions permitted flexibility in the interview, which is integral to IPA analyses since each person’s experience is a personal experience, and some items may prompt a response or briefly take a different direction that may or may not be included in the final analysis. In this initial stage, every word was treated as potentially meaningful data. Although some participants were more conversational than others, I found all of them engaged well to candidly share their personal experience. Due to the personal nature of the questioning, close attention to each interviewee’s affect and disposition occurred. Such awareness helped to ascertain when and if to stop the interview, or even perhaps reschedule if the interview was taking too much time or showed to be exhaustive. Moreover, support resources were available via the CHD medical team for those who may have indicated emotional and/or psychological distress. No participants requested support resources, nor did they seek to stop the interview. All participants agreed ($N=13$) to permit use of their statements in the research manuscript to illustrate the authenticity of their *sense making*.

The P.I. (K.G.) conducted all the interviews. IPA is interpretative via the one immersed in the data (van Manen, 1997). Therefore, since no two investigators will present the same interpretation (Smith & Nizza, 2022), the proposed study was conducted by the primary investigator. Members of the research team were available as resources for intellectual involvement; collectively ensuring ethical conduct of the PI and that the qualitative procedural

steps were followed. Each interview was treated as an individual, in-depth interview, which is foundational to IPA research (Smith & Nizza, 2022). Each Zoom session was saved as a video ‘closed captioned’ transcript. Clarification of responses or missing data were clarified at the time of the interview. Audio recordings were typed verbatim by the PI, comparing the video to the Zoom transcript to generate a final Word document of the original interview. Italics and/or bold font were used to show changes in the participant’s tone of voice, emphatic proclamations, etc. Color coding was also used to show nonverbal communications, such as pauses, emotions, and to set apart the interview questions. The PI (K.G.) cross-checked each transcript against the recordings to ensure a verbatim transcription. Each case was given a pseudonym instead of an ID number to demonstrate the personal touch of their story (using a gender appropriate name; i.e., ‘Nicole’) without using the real name or any of those verbalized by the participant. Original transcripts were uploaded to a password protected Google Drive folder for data analysis.

Data Analysis

A thorough cross check of each transcript upholds the idiographic and inductive approach central to IPA research. This infers each interview stands as its own data, free of preconceived interpretations, or ‘theoretical constraint’ (Smith & Nizza, 2022, p. 31). K.G.; therefore, took extensive time with each interview immersing in each of their ‘world’ (Smith & Nizza, 2022, p. 24) to make sense of how they (participants) understand themselves. Tuffour (2017) refers to this as “double hermeneutic” (p. 4) whereby the researcher’s interpretation illustrates the participants’ *sense making*. This beginning stage entailed looking for similarities and differences without formulating conclusions. Otherwise, we would be moving away from the fundamentals of iterative research. Initial thoughts to the text were documented, paying close attention to each word, phrase, or sentence hand-written on a hard copy of the original transcript. Once the initial

thoughts were documented, the hard copy was discarded in a secure shredder and further analyses occurred electronically via a coding table in Google Drive. Analyses were extensive, which included reading each transcript, initial coding, and reflecting upon the emerging themes. The Emerging Adult developmental stage served as a way to organize the themes, not guide the themes.

Original texts were integrated verbatim for data authentication, followed by self-reflexivity. Self-reflexivity was an ongoing process; intentionally taking time away from each case to return hours to days later for additional review. Each review included PI self -reflectivity to address any biases or personal perspectives that could misconstrue the interpretation of the data. For the latter, it is recognized that personal intimacy with the phenomenon may not be a limitation. Rather, such intimacy is embraced since those experiences authenticate the *sense making*. IPA research is committed to the ‘double hermeneutic;’ meaning I [the P.I.] assumes the central role (Heidegger, 1962; Smith et al., 2009; Smith & Nizza, 2022) in making sense (interpreting) the participants’ *sense making*.

Exploratory Notetaking

Smith and Nizza (2022) and Smith et al. (2009) provide examples of coding templates that integrate exploratory notes with the original texts to generate experiential statements and emerging themes. Exploratory notes consist of three approaches: (a) descriptive, (b) linguistic, and (c) conceptual. Each transcript was reviewed in this manner, line-by-line as a single case analysis. *Descriptive* entailed a basic summary note, describing what the participant said. *Linguistic* notes included the meaning of the words used. This is where italics and bold font could represent connotations or changes in tone. For instance, a participant often moved between using the first-person and third-person account, which Smith and Nizza describe as a ‘distancing

strategy' (2022, p. 36) that indicates the topic/line of questioning may be particularly important or critical to the participant. *Conceptual* notetaking involved documenting researcher questions and comments that arose before the data had fully emerged. It was crucial to avoid attempting to understand or judge at this point. This step enabled K.G. [P.I.] to explore one's meaning, which is unique to *me* as the research *instrument*. At no point is the process prescriptive. Guidelines exist to do just that: guide. IPA permits flexibility to adapt to the participants while drawing upon researcher experiences.

Experiential Themes

Notetaking evolved from initial exploratory reactions to participant accounts that were grouped into a logical structure to generate a column of each participant's 'experiential' themes for the case' (Smith & Nizza, 2022, p. 32). This detailed step was repeated until each case had a table of exploratory notes with experiential themes. It was during this second stage that K.G. [P.I.] extracted the essence of the texts. Participants quotes were used to demonstrate evidence integrity, while preparing for the cross analysis. A sample of the PI's participant coding table is presented in Appendix E.

To achieve trustworthiness, the second member of the dissertation committee (G.C. faculty Chair), cross analyzed to ensure adequate triangulation of the data. Our initial meeting involved exploring general thoughts for coding and an overall impression of the data. The collaborations were intentionally scheduled at different dates to promote reflection and a thorough review of the texts. We started to generate what would be our 'emerging' themes into a secure, shared document. We then moved beyond the general 'feeling' of the data to review theory – the EA developmental dimensions to address the themes and organize accordingly. Grounding the themes included touching the data to organize (and define) each theme with

corresponding subthemes. We found that codes did not fit neatly into one of the five dimensions. Rather, the dimensions fit into the codes. This highlighted the multidimensionality of the human experience.

Following the independent analyses by each investigator, a final ‘group’ analysis was developed. The resulting collective analysis improved the trustworthiness of the interpreted data. Although the PI has prior experience in qualitative coding and analysis, G.C. (Chair), G.H., and S.T., members of the research team, have extensive qualitative research analysis experience, while P.M. serves as a content (ACHD) expert.

Reporting

The cross analysis capitalized on the connectivity of the participants’ meaning of their experiences as emerging adults with complex chronic CHD, which illustrates IPA’s convergence and divergence (Smith & Nizza, 2022, p. 56) of the data. This is crucial to highlight how the individuals were similar; yet different; while providing a detailed, holistic account of the phenomenon. Committed to the intimacy of each case, analyses were focused on the depth of data rather than breadth (Pietkiewicz & Smith, 2014). Smith and Nizza (2022) claim this step in the analysis brings the “process to life”(p. 56). *Sense making* taps into the quality of those metrics; one’s life and what it means to ‘be’ and to be ‘with CHD without compartmentalizing into one of the five dimensions of Emerging adulthood. This IPA project provides rich data to add (and compare) to the existing Adult Congenital Heart Disease (ACHD) literature. In addition, the findings inform health management outcomes from a developmental life stage (Emerging Adulthood) that have the potential to be used in other developmental stages through the lifespan.

Chapter IV: Results

Characteristics of Participants

A purposive sample of 13 young adults (age 22-25) with complex CHD participated in this study (see Table 1 for more detail). Although the Emerging Adult (EA) stage includes age 18 to 25, potential volunteers age 21 and younger were excluded to ensure the middle to upper end of the developmental stage was captured. Gender was represented as follows: 53.8% males, 46.1% female. The majority of the sample indicated 'other' for Race (76.9%) and lived in Washington State (76.9%). One participant moved to the East Coast with her husband who was transferred as an active member of the U.S. military. All defects are classified as complex (III). In this study, the most prevalent congenital defect was Double Outlet Right Ventricle (DORV) (30.7%) followed by Tricuspid Atresia (23%). Physiological stage was determined by patient reports at the time of data collection. This decision is supported by the existing literature that guides the staging portion of ACHD-AP classification via objective AND subjective reports (Stout et al., 2019). 61.5% of the participants were classified as stage B, while the other five (38.4%), classified as stage C. No participant was classified as stage A.

Although all the participants were medically stable at the time of the interview, they reported valvular sequelae and other cardiac dysfunctions, dysrhythmias, and impaired physical functioning to some variation (i.e., shortness of breath with exertion, exercise intolerance, fatigue, and/or decreased stamina and low energy). One participant inquired about the possibility to qualify for disability benefits not because she needs that assistance currently; rather, she fears at some point in the future she will lack the capacity to work at the level she does now ('Lena'). Such an inquiry demonstrates participants' consideration to provide for 'self.' At this early adult stage, five of the 13 participants already have implanted permanent pacemakers. Four of the 13

participants reported they will need a heart transplant or be placed on the transplant list at some point in the future. One specified the need for a double organ (heart/liver) transplant. These reported symptoms illustrate both the chronicity and complexities associated with CHD.

Current medical status includes recent hospitalization(s) and medications. The majority of the participants (69.25%) faced a hospitalization within the past three years: 1-2 hospitalizations ($n = 8$), greater than 2 hospitalizations ($n = 1$), while the number of months since the most recent hospitalization, less than 6 months ($n = 3$), and greater than 24 months ($n = 5$). This study did not inquire about the reason for one's hospital admission(s); therefore, there is no inference made that the admissions were due to the individual's congenital heart condition. Most of the participants (76.9%) were currently taking medications on a daily basis, including over-the-counter: 1-2 medications ($n = 5$), 3-5 medications ($n = 5$). Three participants (23%) reported they were not taking any medications on a daily basis. None of the participants took more than 6 medications per day. All but one participant ($n = 12$) reported living with other medical conditions, most commonly reported include anxiety and depression.

Two ($n = 2$) of the seven males are married with children. One male is choosing not to have children. Five ($n = 5$) still live at home. Three are single, two report they have a girlfriend. Four ($n = 4$) are employed, two of which already achieved a college degree. Three ($n = 3$) are currently enrolled in college. Three ($n = 3$) of the six females are married, one ($n = 1$) has children. Two are choosing not to have children, while one is currently undecided. Three still live at home. Two are single, one reports she has a boyfriend. Three are employed, one of the two achieved a college degree. Two ($n = 2$) are currently enrolled in college.

Qualitative Results

This study's aim was to qualitatively explore the individual's *sense making* as a personal experience in managing life to achieve anticipated life tasks. Further, to interpret the individual's illness representation and how the uncertainties of the cardiac condition fit into their role development as an Emerging adult. The IPA methodology is committed to exploring the *particulars* of one's lived experience. Hence, the semi-structured interview questions were crafted in a way that extrapolated the individuals' experience as a 'journey' through early adulthood in the presence of their chronic pediatric heart disease. Table 2 presents the final experiential themes and subthemes organized within the five dimensions of Emerging Adulthood.

Identity Exploration

Identity exploration emerged as the predominant *essence* of what it means to be a young adult with chronic complex CHD. Guided by Arnett (1998, 2000, 2015), this is the time for individuals to determine who they are and what they want out of life, primarily in the areas of love and work. Thought provoking statements generated a clear distinction between the concepts, 'normal' and 'different.' The participants *want* to be normal but know that they are not. Despite this difference, they guard themselves to minimize barriers while looking to those close to them to help overcome their barriers. Subsequently, it is clear from this study that our group of individuals demonstrates an enormous sense of gratitude in their pursuit to normalize. Four subthemes emerged within the primary theme, '*Disease is part of self.*'

Theme: 'Disease' is Part of Self '

Congenital heart disease is part of oneself. Avoiding the existence of CHD is implausible since it is a lifelong condition; and because CHD is present at birth, the individuals do not know

life any other way. When asked to answer, ‘*Who am I?*’ answers varied in perspective; yet were consistent in their desire to be normal. They wish to be like others so that they too can be ‘normal,’ and do ‘normal things.’ The following narratives exemplify the subtheme:

‘Different but want to be Normal.’

“My heart isn’t a part of me. It IS me” (line 1341)...“My heart disease has kind of a huge effect on who I am as a person” (James, line 1331,1332). Isiah (line 336,365) stated, “I’m just a 23-year-old guy with a heart defect (line 338)....”I am a son, a heart patient, a friend” (line 365)..“I’m just wired differently” (line 213)..Paul: “Growing up as a person that has defects, you forcibly grow that voice telling you that you’re not like the rest” (line 776). Nicole described life as, “this is a very different life, an abnormal life” (line 753). Sarah offered a humorous perspective: “I can’t be perfect because my heart ain’t perfect!” (line 46)..“I’m a whole different kind of high maintenance!” (line 27).

Four of the participants used the term, ‘weird,’ to describe their circumstance, which was a unique finding. This is particularly interesting in light of the participants’ strategizing to be viewed as ‘normal.’

Isiah: *It’s been a weird, rocky road” (line 493).* Similarly, **Lena** shared, *“Yeah I got a weird heart thing I gotta take care of” (line 57)* while **Steve** echoed such sentiment: *“I have a weird heart defect” (line 380). They [siblings] know that I’m a little weird” (line 286).* **Nicole** described feeling different as, *“It’s a weird middle where I can’t do too much but I need to do something” (line 211,212).*

As with any developmental stage, identity is influenced by one’s environment, which includes the areas of love and work.

Paul: *“My wife has figured out ways to love me in the way that I need to be loved”* (line 379). *“I have a really strong [family] support system”* (line 370).

Likewise, **Evan** shared, *“My girlfriend’s very supportive”* (line 194) and **Lena** said, *“I’ve been using my husband as support”* (line 225).

Steve credits employment to his sense of normalcy: *“It’s fun to talk to people I work with. That’s a Godsend”* (line 511). Subsequently he claimed, *“I don’t feel held back by the slightest. I wouldn’t factor into my personal identity”* (line 765).

Nicole shared, *“I have work friends. They’ll come over and they care, ‘how’s your health?’”* (line 532,534).

The participants must face the physical limitations that complex CHD presents, which many of them conveyed as differences in their daily functioning and capacity to engage in occupational demands. For example, although Steve denied CHD has factored into his identity, he demonstrated a conflicting perspective that underscores he is in fact, ‘different:’

Steve: *“I would like to experience what it’s like to have a fully oxygenated bloodstream”* (line 659). *“I don’t care that I have a half a heart, but I don’t think people should really care either”* (line 765,777,778)., **Chris** recognizes difficulty with memory recall: *“I had a couple of strokes when I was a baby from the surgeries”* (line 404).... *“I had to relearn everything”* (line 405)..... *“It’s an important part to consider”* (line 924).

Other participants discussed their limitations, and in some instances, the steps taken to help overcome those limitations.

Jodi: *“I do get out of breath a lot more than I used to”* (line 533). **Sarah:** *“Right now I do have a lot of limitations”* (line 239), while **Mary** shared, *“My heart*

*condition actually does hinder me a little bit in the form of energy” (line 410) and **Isiah** has to “be accommodated in most positions” (line 418) due to “low stamina” (line 69,101,103,153) but believes he “can still do the job” (line 139). Likewise, **Nicole** admitted, “I take a lot of breaks, no matter what I’m doing” (line 284)..but “I can pace myself” (line 224).*

Variations in activity level are often self-imposed. Such actions serve to help participants normalize in the presence of others, but also to minimize the potential for adverse outcomes that could set them back in this exploratory phase of their life. The following narratives exemplify the following subtheme:

‘Self-guard to Minimize Barriers and Poor Outcomes.’

Steve illustrated an unequivocal level of maturity in his actions, *“I don’t take a lot of risks. I don’t think I should, there’s no reason to” (line 426).. “I don’t drink very often (line 832).. “I know the liver’s already working overtime” (line 847). And, “I wouldn’t smoke in a million years. That’s just asking for it, you know?!” (line 858). Likewise, **Jack** (line 433) proclaimed, “All that they have put in to keep me alive to get me to where I am at 23, I kinda owe it to myself to maintain a certain level of discipline” (line 509). **James** was quite transparent in his approach as well: “It is self-imposed – when I was older I learned a breathing technique so that I wouldn’t pass out” (line 772). **Sarah** also engages in protective measures: “I have this congenital heart disease and it’s really hard, and it changes my body and I have to be careful” (line 43).. “I’m fine. I know what I’m doing” (line 49)..“I know my limits” (line 306,308). ‘**Paul**’ exclaimed, , “I knew NOT to risk myself” (line 115).*

Self-guarding is also a strategy used to keep CHD personal. The presence of a heart condition, especially as a young adult, is often something they do not *want* to share or let it be known by others, such as can be seen in the examples of the following subtheme:

‘Choose to Share or not (it is a Personal Matter).’

‘Paul’ distinguished between his home and school/work life: “*They [kids] made me feel like I was damaged*” (line 700).. “*You’re broken*” (line 706)...”*It [CHD] created 2 types of personalities. Consequently, “When I talk about myself, I talk about what I have to offer, not in terms of my past, but what I can give you today* (line 951). Jack and Sarah explicitly stated, “*I don’t let a lot of people at work know about my heart condition because I don’t want them treating me any kind of different*” (**Jack**, line 136); and, “*I don’t like to talk about it [CHD]. I don’t want that to be the only thing people think about*” (**Sarah**, line 77).

CHD lacks an outward physical disability, which Evan acknowledged when comparing himself to a friend who has a neurological condition.

Maria (line 394) affirmed, “*It’s not something people see. Like if people look at me, I look normal. But in reality they don’t know.* Similarly, **Jodi** (line 70) stated, “*A lot of people are surprised to hear that I have something so rare and interesting*”.. “*I mean, on the outside I LOOK normal*” (line 77). **Evan** (line 188), claimed, “*you would never really know unless I said anything.*”

Although CHD lacks as an outward assertion, it cannot be ignored. When asked, ‘*What are the limits of your body?*’ the most recognized limitation came in the form of a reminder: The presence of one’s surgical scar(s). Prior surgical procedures to treat their heart condition serve a daily reminder that they have congenital heart disease.

Maria stated, CHD is “*going to be with me for the rest of my life*” (line 399) while **Jack** described his chest scar as, “*Running down my chest, yea as an 11-year-old, that’s plain to see. Still is today*” (line 450). **Jodi** echoed as a matter of fact: “*I literally can’t fake it because you know, I have the scars on my body*” (line 131). **Steve** shared similar experiences but was quite adamant in, “*I don’t need sympathy, that’s ridiculous! It feels patronizing*” (line 783)!

An important observation I [P.I] made while engaging with each participant is that despite reports of stoicism and a collective desire to uphold CHD as a private matter, they all demonstrated a great deal of gratitude for their lives. The following quotes exemplify subtheme,

‘Gratitude.’

Isiah stated, “*If I was born a couple years earlier, I probably wouldn’t have made it because technology is advancing all the time*” (line 540,541)...”*I’m just really grateful that I’m still here*” (line 492), *It’s definitely been worth it*” (line 493). **Jack** (line 499,500) proclaimed, “*If I were to go out and do something stupid and then die because of it, would be a pretty waste of resources*” (line 506,509)...”*Take the opportunity and push it forward into my community and helping others*” (line 514). They celebrate proud proclamations such as, “*I am the doctor’s ‘poster child’ of CHD and my family’s ‘miracle child’*” (**Chris**, line 559,914). “*I’m grateful I’m still here*” (**Isiah**, line 492). Both James and Steve humbly posed: “*I don’t take things for granted. I thank God, thank you for the extra years!*” (**James**, line 951,996); Yes, “*I don’t take things for granted*” (**Steve**, line 951).. **Maria**: “*It [CHD] kind of is like what keeps me alive*” (line 28). Similarly, **Paul** proclaimed, “*You’re not supposed to be born. God gave you*

that gift so there's a reason you're born, a reason you're here" (line 580,581)... "so have faith in my own self and my own worth in all aspects, whether that was school or my physical ability, or anything!" (line 128,129).

Gratitude also resides in the trust that the individuals' place in their cardiologist. They acknowledged their doctor's efforts and commitment to improve (and save) their lives.

Sarah (line 164) prefers to see the adult CHD doctor because he is "*more aware of older hearts.*" **Nicole** (line 78) shared such sentiment: *I had to go to an adult doctor, and the difference is that I got an amazing doctor!*" **Mary** had a similar experience with the transition from pediatric to adult care: *"I did meet my new doctor. He's pretty cool!"* (line 107). **Evan** exclaimed, *"We've come a long way as far as congenital heart disease is concerned"* (line 409).

The individuals from our study recognize that there is a lot to be grateful for, despite their challenges and the instability that CHD potentially creates.

Instability

Instability is a time free of constraints (Arnett, 1998, 2000, 2015). This dimension permits frequent revisions because of the various options available to the young adult. However, options are easily distracted by CHD because with each decision, CHD must be a part of their clarification for the future. The formative years had a great impact on these participants. Therefore, decisions are guided by what they have already gone through as children. In fact, many of their prior experiences created psychological outcomes that they attribute to CHD. Three subthemes emerged within the primary theme, 'Unknown directives *because of CHD.*'

Theme: ‘Unknown directives because of CHD’

CHD dictates life’s options because of its unpredictable outcomes coupled with existing knowledge of prior experiences. Hence, decisions are often guided by the individual’s childhood experiences, which makes CHD a primary factor in one’s frequent revisions for the future, such as can be seen in the examples for the following subtheme:

‘Childhood Memories Shape Adulthood.’

Mary described her formative years as, *“How my life has gone, what I was given as a child growing up, I’m at a good spot. But I think I would have preferred to be somewhere else”* (line 325,326). **Lena** shared, *“because I have had those complex surgeries, I feel like it did kind of make it more real”* (line 44) while **Maria** claimed, *“I’m a strong person for having to go through all that, yeah”* (line 522). **Sarah** believes, *“It affected me growing up and having surgeries”* (line 105). **Isiah** recalled, *“I was a very sickly kid”* (line 146).. *“Wasn’t sure how to fit in”* (line 180).

Other childhood memories surfaced during the interviews specifically detailing their experiences in PE (Physical Education) or with the obligatory ‘mile run:’

Evan described, *“There was this time in 1st or 2nd grade we had to do the mile run and I got pretty far into it and then passed out”* (line 99), while **Jodi** shared, *“I had a gym teacher who wouldn’t read my doctor’s note. She made me run the mile”* (line 91). Based on his experiences, **Isiah** shared, *“I abstained from a lot of field trips”* (line 188). **Chris** candidly admitted, *“It wasn’t that I was out of shape in PE, it’s just my heart couldn’t keep up with everyone else’s”* (line 69).

Further, **Paul** shared, *“I was coddled growing up”* (line 631), *“smothered”* (line 640). *“It was in elementary school where I knew I wasn’t normal but for some reason my family treated me as I was”* (line 113,114).

Childhood experiences were similar among our group of adults. Unfortunately, many of the shared experiences made them feel ridiculed and even tormented – resulting in harmful, irrevocable memories. A distinction arose, however, between the genders in how they viewed the negative experiences.

Paul shared, *“they [kids] would use it [CHD] to hurt me and taunt me, like, ‘I’m gonna hit you in the heart! It’s gonna stop!’”* (line 189,190). **James:** *“I was consistently reminded, ‘Hey, this is a heart condition! Hey, don’t do this, don’t play like that”* (line 1298).

The males shared experiences as an opportunity to gain power so that they could avoid appearing weak or fragile.

James: *“It [CHD] drives me to push myself harder”* (line 48).. *“Absolutely not show any sort of weakness”* (line 1287), while **Paul** intentionally pushed himself to the point that, *“I couldn’t breathe and I had to sit down”* (line 218).. *“I really held my own”* (line 618) while **Steve** shared, *“people that have long term conditions that make them physically weaker go for things like----- cause that’s where you have the most control”* (line 355).. *“You feel powerful, like you’ve got something to offer people”* (line 358)...because I *“saw myself as excessively frail and weak in comparison to my peers”* (line 145,146). Despite engaging such active efforts, memories generate an emotional description. **Chris** expressed, *“I think of how much trauma my little body went through”* (line 945).

Although power was not a term used by the females, their descriptions illuminated the sadness they felt.

Nicole: *“I was kind of going through the motions because I had to as a young girl”* (line 147).. *“You know, girls are girls”* (line 516). **Jodi** recalled, *“I wanted to try to fit in, wanted to share with people, and they would laugh at me and say, ‘Oh you’re lying!’”* (line 44,45)... *“I remember telling some kid in my class and he threw rocks at me”* (line 84).. *“I ended up hiding on the bleachers because I didn’t want to get pushed in the chest”* (line 96). Following open-heart surgery as a child, **Lena** sadly recalled, *“friends abandoned me”* (line 428).. *“I had friends who ditched me because I couldn’t do the things they wanted me to”* (line 420).. *“CHD has been a lot”* (line 534).

The formative years left quite an impression on our participants. Childhood serves as a pivotal reference for the decisions they are now making as adults. Therefore, the experiences detailed are foundational to the individuals’ adult years.

Nicole described feeling different NOW as a young adult: *“I’m just a lot different than my friends...”* *“I think about my health all the time, well that’s good for me. Well that’s probably not good for me”* (line 719,720). In line with others, ‘**Mary**’ shared, *“It has definitely changed from when I was a kid”* (line 65). Conversely, ‘**Evan**’ excitedly shared that he believes he is functioning well: *“I can do quite a bit”* (line 46).. *“Now in college I play baseball and can do pretty much everything else my teammates do”* (line 122,133), while **Lena** captured the essence of this subtheme: *“What’s set in childhood is hard to get out of adults”* (line 646). Opportunities for revisions prompt her to take proactive steps in learning more

about her condition: “*Now I’m kind of curious*” (line 770)..”*doing more research about it [CHD]*” (line 631).

With greater knowledge comes more concerns; concerns that generate emotional difficulties.

This is particularly demonstrated at a time when the individuals are striving to gain independence. Recognizing that CHD creates consequences, the following statements exemplify subtheme,

‘There are Emotional Consequences.’

Steve encapsulates the essence of emotional consequences:

“*We’re all (other CHD patients) off in the personality department in one way or another*” (line 64,65)..”*It comes mostly from psychologically being heart patients*” (line 70).

This statement is profound and captures the high prevalence of anxiety and depression reported by our participants. Nearly half reported anxiety and/or a history of panic attacks ($n = 6$). Two individuals reported depression. Sadly, all the participants who reported emotional or psychological difficulties believe their disturbances are the result of growing up with CHD.

“*As a heart defect person, I have a lot of anxiety so like I overthink stuff and let it get to me*” (**Maria**, line 107,108). **Lena**: “*I’m socially awkward. Like a part of my anxiety is the social part*” (line 312)..”*I would say depression is because of my heart because once you have depression it kind of relapses*” (line 94,95)..and it “*Followed me, dealing with depression & anxiety due to it*” (line 74). In **Maria’s** case, symptoms are worsening. “*I’ve noticed in this past year that it’s [anxiety] getting worse*” (line 456).

Although no one reported PTSD (post-traumatic stress disorder) by its medical term, examples of medical trauma emerged.

Sarah proclaimed, *“There are certain things that are associated with heart surgeries that will trigger”* (line 208).. *‘Oh I can’t do that – it makes me think of hospitals”* (line 217).. *“brings back that memory”* (line 200). **Chris**: *“I got diagnosed with OCD and anxiety a couple of years ago”* (line 245).. *“maybe the trauma that I was holding onto for some reason”* (line 370). Likewise, **Nicole** shared, *“I have a lot of anxiety, anxiety about everything”* (line 373)...*anything that has to do with my health, has to do with my doctors”* (line 376).

Emotional issues influence how the individuals interact with others. Normalizing can still make them feel at odds with others. Personal experiences, therefore, factor into their socialization and relationships.

Nicole stated, *“I can’t talk to my friends about my personal stuff because they don’t understand”* (line 531). Likewise, **Mary**, *“It’s [CHD] just something that I have to live with”* (line 26).. *“I’m quiet, definitely the person you would find in the background”* (line 242).. *“It’s the being able to have a simple conversation and keep it”* (line 251).

The uncertainty of chronic complex CHD guides many decisions. Uncertainty is more prominent in some situations than others. Nevertheless, there are uncertain outcomes associated with congenital heart disease that carries over from childhood. The following narratives exemplify subtheme:

‘CHD Creates Uncertainties.’

Chris: *“I’ve grown up my whole life knowing that my doctor knows, and when I go to another one (Dr). it’s like, ‘Oh I forgot that you probably don’t study this!’”* (line 771). **Maria** shared, *“Everything can be OK right now. But I don’t know what it’s gonna look like in 5 years or 10 years”* (line 556). **Jodi** shared her fear: *“If I have to go to the hospital, are they even going to know how to take care of me?”* (line 359,360)...*“It’s [life] a little different because with my heart and my different anatomy and such”* (line 539). **Nicole** also recognizes, *“I live my life with a lot of unknown answers,”* (line 65). **‘Isiah’** described the uncertainties of his CHD as, *“it affects my day to day life”* (line 336).

Each of the participants realize how important specialized care is because of the uncertainty of their congenital heart disease. Furthermore, there exists an appreciation for the CHD survivors born several years before.

“The fact that I’m 25 is really cool, like compared to the kids before me. That makes me question what my life expectancy will be. Like I wonder, will my heart affect that?” (**Lena**, line 633). When told by his cardiologist that other patients with his same defect are living well into their 40s, **Steve** explained, *“When you have doctors say things like that, it’s kind of hard not to develop a little morbidity in your sense of humor”* (line 294,295).

Self-Focus

Self-focus is the time to find ‘self.’ Arnett (2000, 2015) posits this is the time to learn, grow, and gain skills for daily living with few obligations. This dimension melds with identity exploration through self-regulating processes that individuals engage to normalize and

demonstrate a conscientious awareness in preparation for the skills they need for daily living. Two subthemes emerged within the primary theme, *‘Can do, but within limits.’*

Theme: ‘Can do, but Within Limits’

A ‘Can do’ disposition emerged from the interviews that demonstrates both our individuals’ willingness and motivation to learn so that they are equipped with the skills they need in their lives, while not overlooking the limitations CHD creates. The following statements exemplify subtheme:

‘I Know Myself Better than Anyone Else.’

Jack presented a positive affect: *“Be smart. I make sure I am well within the boundaries”* (line 253,384)... *”Right?.. Who’s trying to make his life NOT surrounded by a heart condition?!”* (line 246), while simultaneously sharing, *“when I’m going to sleep I can hear my own heartbeat”* (line 11). **Paul** candidly responded, *“I was really raw when I understood that my condition was serious and I wouldn’t play around with it”* (line 377,378). **Evan** knows, *“If I’m hiking in high elevations sometimes it can affect my heart function”* (line 39)....but, *“my parents and my girlfriend get more worried about things happening to me than I do”* (line 200). **Chris** simply said, *“I can always limit myself when I get tired”* (line 263).

Each participant demonstrates a heightened awareness that can be used to implement strategies that help them manage their lives, as can be seen in the examples for the following subtheme:

‘Managing, not Exploring - Self-aware of the Limitations they Cannot Change.’

Jack described managing his life with CHD as, *“Remember you have a heart condition. Like, you can do it. Just keep it in mind”* (line 251). **Maria**

understands, *“He [Dr.] told me my risks were likely my valve worsening and getting extra fluid in my heart, so technically heart failure”* (line 106)...*“It’s just scary”* (line 109)...*“It’s only fixable with like scary surgeries like open heart or other stuff”* (line 416). **Evan:** *“When I was looking at schools I have to be close to areas with big hospitals. I don’t think I’d move very far”* (line 335,336).

James described managing as, *“I would first start by describing the limitations it [CHD] provides toward my everyday life”* (line 32)...*“There are so many symptoms that come from congenital heart disease”* (line 57)..*“You have to make that 50% do what a 150% because you’re pushing yourself so hard”* (line 55).

Paul credits his family for helping him manage: *“I should have so much drama growing up but I don’t. I really thank my family for that”* (line 160,161).

Feeling ‘in-between’

Feeling ‘in-between’ is the time between adolescence and adulthood. Individuals claim they are no longer teenagers; yet are not adults. The progression is gradual and typically met by late emerging adulthood (Arnett, 1998, 2015; Arnett & Mitra, 2020; Reifman et al., 2007). Here we observed the dichotomy between growing up faster than their peers while still proclaiming that ‘in-between’ feeling, as if an older teenager or just a ‘big kid.’ One subtheme emerged within the primary theme, *‘Internalize the transition.’*

Theme: ‘Internalize the Transition’

There is intentionality in the transition from adolescence to adulthood for individuals with chronic complex CHD. Such intentional efforts occur on a continuum. Understanding the transition to adulthood as progressive includes the premise that CHD exists on a continuum because it is a condition they cannot outgrow The following statements exemplify subtheme:

'It is a Conscientious Continuum.'

Isiah captured this subtheme perfectly: *"I'll be a patient, I'll be your friend, I'll sit in my room and be a loner"* (line 376).. *"I don't know the average awkwardness of my age group but I feel like I'm there"* (line 517).. *"I'm still coming into my own kind of, new to all this"* (line 433,434).. *"I'll be whatever I need to be at the time"* (line 375).. **Paul** claimed, *"I don't feel out of the ordinary. I feel like a regular dude"* (line 614) while **Mary** addressed independence as, *"Can be. Still have some learning to do"* (line 290)... *"I had to grow up earlier than most"* (line 304)... *others' don't understand"* (line 314). **Maria** described young adulthood as, *"It's something that's hard. Yeah now more, now that I'm 24, it's something that's hard, you know?!"* (line 90).

Now as young (Emerging) adults, there are additional factors to consider. The cardiac repair(s) that worked through childhood may no longer work as they (and their heart) age.

Steve honestly questions, *"I would appreciate a transplant becoming available. That'd be cool!"* (line 658)... *"When you go through the employer medical exam, I have to get a note from my doctor"* (line 139)...[CHD] *"It's limiting the kind of career I want to go into"* (line 126). **Paul** fears he may not know how to age with his limitations. *"Every Dr. says something different"* (line 201).. *"You think you're perfect but then a year ago my Dr. was saying I couldn't jump on trampolines"* (line 203).. *"Growing up with a heart defect, it never dawned on me that it could actually affect or be some sort of impact to me"* (line 212,213). **Nicole** conveyed, *"The older I'm getting the more my body is developing, so is my heart. There seems to be more problems now"* (line 192,193). Although not a

concern for her presently, **Lena** inquired, *“I was wondering if my condition would qualify for any sort of disability benefits”* (line 720). **James** described CHD as a constant: *“I was always reminded of that fact”* (line 584).

Now nearing the status of adult (age 22 to 25 years old), it generates common; yet conflicting narratives. This is where we observed the dichotomy between feeling mature for their age primarily because they had to grow up with the responsibility of tending to a heart condition. However, also feeling like they still resemble an adolescent or older kid.

Chris claimed, *“I’m a 22-year-old adult but a kid at heart”* (line 238) **Lena**: *“I still feel like a teenager, see myself as a teenager”* (line 494,498).. *“I don’t quite see myself there”* (line 510). *“When I was graduating college I kind of was feeling like the imposter child. I still feel that way”* (line 493). **Jodi**: *“Maybe get my own place in the future. Just not right now”* (line 606)... *“To me [adulthood], means a bigger kid”* (line 296). *“I think more responsibilities. It’s a good word!”* (line 306). *“I don’t really know how to do a lot of things on my own yet. I guess I’m still trying to learn”* (line 439,440). **Steve** shared a similar feeling: *“While in college, I was “poorly socialized”* (line 377). **Nicole** believes, *“I kind of like to say I make my own decisions”* (line 316)... *“Sometimes I feel like I don’t fit in, really. All my friends have kids and I don’t”* (line 349). In fact, she described herself as old before her time: *“My back hurts all the time. My head hurts. I’m like an old lady”* (line 359)... *“I feel like a 40-year old”* (line 353). **Jack** enthusiastically claimed, *“I’ve been able to make my own decisions my entire life, and so where I’m at now at age 23 doesn’t really necessarily feel like a whole lot different from when I was 12”* (line 591,596-597)... *“It’s when I found out what I*

wanted to do and why I wanted to do it, that's when I made that transition" (line 746). Likewise, **Paul** shared: *"When I moved out that's when life really kicked in as far as mental growth"* (line 811).."*because I no longer had to wake up and take my parents' opinion on what to do"* (line 812)...But, *"I didn't know who would win: My heart or my ego, and where that may take me"* (line 815).

The presence of a positive support system also arose in this dimension. For most of the participants, support is integral to their role development.

Steve acknowledged that even while on his own, he was never 'alone:' *"I was living on my own for a while in college, but even then I really had to lean on support"* (line 462).."*I think plenty of people have support structures and not know how to lean on that support"* (line 415). **Evan** admitted, *"Now about to graduate school, everybody's like 'well now what?'"* (line 434)..."*Living on my own is so expensive so living with my parents is nice"* (line 216)...though, *I think my mom's expectations of what I should be doing, and my expectations are probably very different"* (line 303).

Regardless of one's perspective on developmental expectations, emerging adulthood is a time characterized by a gradual developmental progression.

Possibilities and Optimism

Possibilities and Optimism is the transitional time for hope where 'future' possibilities can be imagined before settling on a single plan (Arnett, 2015). The young adult can envision a good job, marriage, and children. 'Hope' resonates, but within the context of the disease since CHD may (and likely will) impact those different 'future' possibilities. Illness also includes living with other adult-related medical conditions that are typically not faced until later in life.

For this dimension, three subthemes emerged within the primary theme, *‘There is hope, but it is provisional.’*

Theme: ‘There is Hope, but it is Provisional’

Life with chronic complex CHD creates a unique circumstance. The young adult may optimistically view a future full of possibilities, but a future life course that is led by CHD. Despite their circumstance, most of our participants demonstrate a profound sense of hope, as seen in the following narratives for subtheme,

‘What ifs’ (Want to/Must be Healthy).’

Jack refuses to think pessimistically: *“I don’t feel like I want to start doing it now given how hard I’ve worked for the past 3 to 4 years to get where I am now”* (line 168). Although **Jack** chooses to think positively, he also acknowledges that he sometimes feels *“heart arrhythmias and short of breath”* (line 298). **Paul** shared, *“My heart’s very healthy at this current point (line 462), but I have to keep on this heart as long as I hope I can”* (line 480). **Nicole** follows her doctor’s advice: *“They want me to keep my heart to where I’m not pushing myself too hard because it’s a matter of, they’re not sure what’s gonna happen”* (line 204,205). Likewise, **Maria** said, *“I think it’s a fear of the unknown. Just like yeah, what my future is with this, where is it gonna take me?”* (line 550).

Living with a pediatric heart defect, in addition to other medical conditions, creates more challenges. When asked, *‘Do you have other medical conditions?’* 12 of the 13 participants reported living with other illnesses. For some, the diagnoses occurred just within the past few years. Medical conditions include: (a) pre-diabetes, (b) plastic bronchitis, (c) hypothyroidism, (d) eczema, (e) and scoliosis. Although not given a diagnostic label:

Steve shared, “*If we’re talking about brain stuff, I mean because I’m literally a little bit oxygen deprived*” (line 62,63)..”*that happens to basically everyone with a condition like ours*” (line 79). Further, “*I think I’m a little Autistic but never gotten diagnosed*” (line 63). One participant reported a dual diagnosis: Asperger’s and Autism (on the Autistic Spectrum).

There were no reports of chronic pain or daily medication use that impaired their daily living. However, three ($n = 3$) participants reported a history of migraines. Whether it is CHD or another chronic illness, an important goal involves taking steps to promote good health. The participants *want* to be healthy and assume an active role in their health promotion.

Mary candidly reported, “*Stay healthy, not have to go to the hospital, like keep with where I’m at*” (line 447). **Maria** also stated, “I want to be as healthy as I can” (line 566). **Steve** was more direct: “*It’s just about maintaining health. My priority is my own personal health like a normal human being should be doing*” (line 687,688)...”*Caffeine long-term, is it going to be bad? Is it like significantly worse for a guy with hypoplastic than like a regular guy?*” (line 806,807).

Caffeine consumption is an interesting finding since caffeine is a common staple in the American culture. Most of these young adults choose *not* to drink caffeine, and when they do, they keep it to a minimum.

Only **Isiah** ($n = 1$) shared that his decision is guided by his cardiologist’s recommendation. “*I was given a leash so I’ve been able to drink some caffeine*” (line 548).

James approached the ‘*what ifs*’ with such deliberate effort that it has profound implications to his future ‘possibility:’

“I had to distance myself and break that relationship” (line 591).. “I’m not gonna put them through that pain at some point” (line 697)..... “To have a heart attack, that family is left without someone” (line 666)... “I stopped thinking about me being in the future and focused on, what can you get done today?” (line 819,820).

Our participants are not fatalistic. Rather, they understand the risks that come with having a heart condition and the realization that there is no cure, nor guarantee in the number of years they may live.

Maria: *“I start thinking, ‘Oh I don’t want to die because of my heart condition” (line 49) while **Chris** claimed, “It’s [CHD] what limits me on what I can and can’t do in life” (line 10).. “I always worry about the worst thing that could happen” (line 381). **Paul** also questions, “Maybe my health is not going to be long lasting” (line 514).*

Such personal reflections segue into the individuals’ desire for structure. The following quotes exemplify subtheme:

‘Change is Good, but not too Much as Once.’

*“I got a nice thing going. There’s no reason to give a nice thing up for the chance that something’s betterI like structure. I understand myself to be a cog in the machine and that’s OK. Just holding it down at this point in life is fine because that’s kind of what you have to be to live” (**Steve**, line 433,495,500). **Maria:** “I want my future to be simple and easy” (line 354)... “Um, because it’s complicated” (line 344).*

Structure is important to minimize facing too much, too fast. It helps our participants face these challenges at their pace, at least to some degree. Change involves taking initiative to achieve life tasks. The following quotes exemplify subtheme:

‘Where to go from Here.’ Engage in Developmental Milestones Within Limitations’

Jack claimed, *“I’m making more adult decisions like buying a truck, living on my own, how am I going to keep myself alive”* (line 597-598) with consideration to his doctor’s advice: *“I’ve been told I’ll need a 3rd open heart surgery and from what I’ve been told, that’s right around this time”* (line 898).. *“Right now that’s kind of my biggest question mark, then seeing what happens after that”* (line 906,910). **Maria** shared a similar position: *“There’s still one more [open heart surgery] and I’m gonna have to reface it”* (line 517). **Lena** claimed, *“Now I get to do what I want. I’m sure most young people my age feel that way, especially since I turned 25”* (line 492,494).

Decisions faced by all young people, as ‘Lena’ detailed, are part of achieving developmental tasks. But for these individuals, developmental milestones must integrate the pediatric heart disease. When asked, ‘What does your future look like,’ and ‘What is to be determined,’ the following responses were posed:

Steve was transparent in his response, *“So really, my priority has to be ME.....”* *“How many friends am I gonna have down the road, never gonna get serious with a girl? But I think that’s a normal young man proposition”* (line 687,485,653-655)... *“I don’t think anyone knows what the future’s gonna look like as a 23-year-old”* (line 615). Further, *“They talk like it’s something that is going to severely affect everything you do for the rest of your life”* (line 763)!

Chris detailed a difficult conversation he had with his doctor in regards to his future: *“Just so you can prepare. You might need to have a transplant”* (line 620).. *‘Oh in 10 years I might need to do this!’* (line 635).... *“It was a lot to take in”* (line 628). **Nicole** shared a similar feeling: *“I’m worried about my heart and taking care of myself in the past 5 years”* (line 67).

Adult decisions that promote independence involve securing employment, marriage, and starting a family. These decisions are handled with great effort, however, because of the preparations that CHD creates. Goals vary between the creative and the scientific; and between using one’s mind and intellect versus physical abilities.

Lena posed the question, *“It’s a lot to happen to my body. And like working high stress jobs. I’m like, ‘is this good for me?’”* (line 771). Early on, **Sarah** *“found arts and crafts and creative things help me feel productive”* (line 417), while **Jodi** enjoys studying animation, but admitted, *“I don’t think about career stuff very often”* (line 427). *“It [CHD] does affect my decisions in the career field”* (line 520). **Evan** enjoys data analytics while **James** has managed *“three businesses at one point”* (line 517). In fact, he proudly proclaimed, *“I’ve been promoted more times than I can count in the last year”* (line 960).

Other relevant decisions to occupational choice involve security in knowing they have access to specialized medical care.

Steve candidly shared that a motivating factor to stay with his current employer is, *“for their fancy insurance because I felt like I was probably going to need it for my heart”* (line 440). **Maria** admitted, *“I want to be closer to my doctors. If something were to happen to me I would not feel comfortable going to like, what’s*

my option? Where can I actually get help?!” (line 572,579,581). Similarly, **Chris** (line 751,752) acknowledged, *“If I move somewhere, I always need to be at a good place that has a good hospital or a good surgeon or a good cardiologist.”*

Nonetheless, there exists a level of excitement about attending college and planning for the future as they each strive for independence:

“The next step is getting a full-time job, starting a career” (**Evan**, line 466).

While **Chris** proclaimed, *“This kid’s getting married, having a baby. You can be the same, it’s not impossible”* (line 561), and *“I’m super excited to be a teacher”* (line 75)!

While Chris is excited to pursue a career in education, he wishes to also satisfy his domestic role.

Other questions stem from parenthood: Can they? *Should* they?

Chris: *“I want to live in a house, have a couple of kids”* (line 496,497). **Jack** would like that as well: *“I’d like to have my own wife and a kid or two, in our own house”* (line 827). Alternatively, **Nicole** made the decision, *“I would rather live a nice healthy life with my husband and have a chance to live”* (line 576)..”*So having a baby is going to be off the table”* (line 574). **Maria** shared a similar emotion when discussing her future: *Starting a family, I don’t know if I want to because of the risks and everything”* (line 95). The message was clear to **Sarah:** *“You may not be able to have kids because of your heart”* (line 397). **Lena** doesn’t eliminate the option but also acknowledged, *“being able to become pregnant, it is depending on how my heart looked”* (line 185). ..”*I have a cat, he’s my fur baby!”* (line 682,687). **Jodi** also has pets but is unsure about children (line 461).

Reproductive concerns involve more than existing health risks. Concerns prompt these young adults with a congenital heart condition to think about the risks associated with transferring CHD to their children.

Sarah shared such a concern: *"There was that fear that the babies were going to be born with the heart condition"* (line 99).....and if *"my baby was gonna have to go through what I, I've been through"* (line 104). Likewise, **Evan**: *"I don't know what kind of conditions I could transfer to my children"* (line 367). **James** teared up while discussing marriage and children because he too faces this fear: Not only the fear of passing CHD onto his offspring, but the potential that he may face an early demise, which would create a void in the family. *"I would love to have a daughter, be able to have a son of mine"* (line 1358,1349)... *"I know that I couldn't have that"* (line 1353).

What better way to approach possibilities and optimism than rhetorically.

James' asked, *"How can you maximize today so that people you leave behind have the most"* (line 822)? **Paul** stoically posed, *"It's not like 'Oh poor me, this happened to me.' It was more, these things happened"* (line 565). *"OK, what's the formula for it?"* (line 567).

Developmental transitions provide the formula, as described by **Paul**, for individuals to change. All transitional stages occur within the historical, socio-cultural, and personal context by which individuals exist. Therefore, when asked to finish the statement, *'I understand myself to be,'* it challenged them to think about the *essence* of their life experiences. They illustrated how they attach meaning to their life; including how their disease representation fits within the context of role development.

Jack: *“Whatever amount of years that I live, I will move forward and I will die and the world is going to continue moving”* (line 534). ...*“I enjoy enjoying life”* (line 496). Likewise, **Isiah** views himself in the context of something much bigger than himself: *“I’ll never be up there with someone who has a regular heart”* (line 212)...*“I’m just like one piece of the puzzle”* (line 776). **Chris:** *“I’m the person that’s actually living with it [CHD]”* (line 899)...*“I feel like it’s a part of me so I kind of embrace it instead of push it away”* (line 706). **Sarah** strives to, *“put something good into the world* (line 544)...and leave, *“at least leave one person smiling”* (line 563). Likewise, **Mary** stated, *“I help as many people as I possibly can, when I can”* (line 305), while **Lena** wants to be, *“like a light or enthusiastic energy in the world* (line 442). *I just want to be some sort of help to the world”* (line 651).

These individuals are motivated to live life to the fullest, despite their CHD. Their place in this world entails appreciating a life that most were told they should not have. The realization that they could have easily died as an infant or anytime during their childhood motivates them to embrace their heart defect.

“It [CHD] kind of made me prove to the world that I could do stuff even though I have had heart surgery” (line 63,64). **Nicole:** *“I try to sometimes picture it. How would it be, like going through that I went through and then I always think to myself, that’s who made me, was having my heart defect”* (line 627,628). **James** proclaimed, *“I am contributing to society* (line 516)... *“I’m so happy to be in the position that I’m in”* (line 416).. *“You’re not determined by what people say you’ll achieve. You’re only limited to yourself”* (line 1450,1451). Likewise, **Paul**

candidly stated, “*It means that you’re not the center*” (line 437) “*Create and restructure reality to the best of my ability*” (line 451), to be “*the best, the most positive version of myself*” (line 475).

Chapter V: Discussion

Adults with CHD are survivors. Adults with complex (Class III) CHD experience a longer lifespan, which is remarkable considering it was not that long ago there was little hope for the infant born with a severe cardiac malformation. Improved health outcomes are worth celebrating, granting credit to the talents that underlie today's medical advancements to make research like this possible. Successful disease management; however, encompasses more than just physical functioning – it includes the social, cultural, and personal *lived* experiences surrounding disease processes. This IPA study highlights the *essence* of the lived experience. Life is an experience of embodiment (Aho & Aho, 2008) that assumes one is in compartment with their environment and all of its 'pieces' – the past, present, and future possibilities (Heidegger, 1962) that make each of us who we are. This precept is in line with the Emerging Adult developmental stage that young adults (Arnett, 1998, 2000, 2015) integrate their environmental influences to achieve anticipated developmental milestones.

From an historical context, our participants only know life *with* CHD. Moreover, they attribute much of their knowledge of CHD based on their formative (childhood) years. Although everyone in the study was medically stable at the time of the interview, each of them shared concerns that could easily be overlooked if focused on the objective data &/or existing clinical guidelines. When asked about CHD as an illness or disease, all the participants described the anatomy of their defect to the best of their understanding. They recognize that their heart disease is something they were born with, and although they had surgeries to 'repair' the defect, there is no cure. Furthermore, they are well aware that future surgical procedures are likely and that lifelong cardiac surveillance is necessary. In some cases, a cardiac intervention may be planned (i.e., plan pregnancy around a valve replacement), while other events may occur unexpectedly.

This medical uncertainty they face influences our young adults' decisions, particularly in relation to future planning. They desire to be like others; to be 'normal', or as a few described, 'regular.' But they know that they are *different*. And they are different *because* of their CHD. Such perceptions are consistent with Callus et al. (2013) and Claessens et al. (2005) who also found CHD creates perceived differences. Moreover, individuals with CHD of mixed complexity face challenges (Claessens et al., 2005; Journiac et al., 2020; Kovacs et al., 2009; Lane et al., 2002; Moons & Marelli, 2022; Saha et al., 2019) that are multifaceted (Cateight et al., 2021; Moons et al., 2002, 2018, 2021a; Thomet et al., 2018; Van Bulck et al., 2021b). Hence, this research investigates one's *sense making* – taps into the quality of what it means to '*be*' and to be '*with* CHD.' The philosopher, Heidegger (1962), described this as, *Dasein* – meaning, 'being there.' To 'be there' brings the subjectivity, or patient-centered experience to the forefront of everyday life.

Complex CHD and Co-morbidities

Many of our participants experience cardiac symptoms and other co-morbidities demonstrated in prior ACHD studies. Similar to Brida and Gatzoulis (2019); Cateight et al. (2021); and Mutluer and Celiker (2018), many reported palpitations (dysrhythmias), even if it had been several years since their most recent cardiac surgery &/or catheter-based intervention. Cardiac dysrhythmias are not uncommon recognizing that Brida and Gatzoulis (2019) revealed that nearly 50% of young adults will develop an atrial dysrhythmia. Although the participants were medically stable at the time of the interview, they indicated that they face limitations relevant to their daily functioning: (a) reduced exercise capacity, (b) shortness of breath on exertion, (c) lack of stamina, (d) fatigue, and (e) less energy. These findings are similar to Cateight et al. (2021) and Rometsch et al. (2019) who found an increased prevalence of impaired

physical functioning and other post- surgical sequelae in ACHD (Enomoto et al., 2020; Jackson et al., 2016; McKillop, et al., 2018; Mutluer, & Celiker, 2018).

There are additional co-morbidities present in our participants that are consistent with previous works investigating CHD. Elevated blood glucose levels and diabetes type II (Apers et al., 2015; Gurvitz et al., 2013; Moon et al., 2015). Moreover, frailty emerged in this young adult sample, which aligns with other studies in this area (Dent et al., 2019; Moons & Marelli, 2022; Uchikado et al., 2020). In line with research trending toward increased rates of frailty, so too is secondary sarcopenia observed (Sandberg et al., 2019; Shiina et al., 2019) and early biological aging (Vecoli et al., 2016). Other commonalities include impaired cognition (Bagge et al., 2018; Bolduc et al., 2019), primarily in the reports of delayed memory and poor information recall. Most concerning is the recent data showing increased mortality rates among those with ACHD (Khairy et al., 2010; Van Bulck et al., 2022a; Verheugt et al., 2010). The existing data, in conjunction with this study, highlight the long-term effects of complex CHD.

Much of the research demonstrates consequences of CHD are more resounding among those with complex malformations, such as defects with surgical conduits (Moons et al., 2021a), residual lesions (Areias et al., 2014; Brida & Gatzoulis, 2019; Mutluer, & Celiker, 2018), and/or artificial heart valves (Webb et al., 2002). Such complex cardiac anatomy represents our participants. The prevalence of co-morbidities at this young age is profound and generates great interest considering most of the medical conditions reported are typically faced later in life. Complications of complex CHD develop with age (Bolduc et al., 2019; Kovacs & Bellinger, 2021).

Due to the defect itself and other age-related conditions, life with a pediatric (congenital) heart defect in adulthood creates a complications ‘burden’ (Karsenty et al., 2015) that our

findings support. Furthermore, our participant accounts concur with Pinquart (2014) and Sligo et al. (2019) who discovered in their qualitative work that chronic CHD ‘alters’ lives. Alterations to one’s life include feeling smothered or overprotected by those close to them. The research is conflicting regarding perceptions of parental influence beyond adolescence. For our participants, social support (e.g., parents, family, and close friends) are viewed as positive, and very important. This is consistent with Abda et al.(2019); McKillop et al. (2018); and Sepke et al. (2018) who found that adults with CHD report personal relationships are an important factor to their well-being.

Social Support Structures

Similarly, for those studies showing parental overprotection, most of our participants indicate parents and significant others tend to be more cautious about their condition than they are. This was not viewed as negative, however. Parental presence and CHD are ubiquitous, which is not surprising acknowledging that CHD is not a condition that evolves during childhood or develops suddenly. Even among those with less severe or mild CHD are likely to experience greater parental presence or hovering. Lane et al. (2002) referred to this as a, “wrapped in cotton wool attitude” (p.74).

Interestingly, when initiating the interviews for this study, K.G. [P.I] was asked by three of the participants if I wanted to interview their mom instead, or to include their mother in our interview. The individuals anticipated the research would be about the heart defect itself (i.e., anatomical structure, details of the surgery/eis); rather than their personal experiences with CHD. Therefore, they were dubious in their ability to explain the defect in detail; or they simply felt that the parent (specifically mother) was in a better position to answer the questions. Nevertheless, parental presence is central to their disease representation as the individuals

assimilate into their adult role. They appreciate their support system and even acknowledge the value in helping their loved ones work *with* them. Such reports among those living with CHD; therefore, are not uncommon. Adulthood brings about its own set of changes that may predispose individuals with chronic complex CHD to experience more psychological disturbances. The participants recognize psychological disturbances exist despite reporting, as a generalization, that they have a strong support system.

Psychological and Emotional Concerns

The existing science shows an increase in affective and mental disorders in CHD. The most notable disturbances in our study include anxiety and depression. Although not described explicitly as PTSD (post-traumatic stress disorder), many referenced the fear of hospitals and the thought of facing a doctor's appointment. Such triggers were described in detail. In fact, the prospect of facing another open-heart surgery presented the greatest fear. Chiang et al. (2014); Van Bulck et al. (2018); Pagè et al. 2012; Levine et al. (2021); and Claessens et al. (2005) published similar findings in relation to psychological impairment and struggles with illness identity among individuals with CHD. Only one of the participants in our study viewed their medical experience as 'fun' because they welcome the 'kid-like' environment when they come in for a cardiac appointment. This may demonstrate one of the values in transitional care from pediatric to adult cardiology establishing comprehensive services (Adult Congenital Heart Association) that remain housed within the same clinic the patients grew up. This claim is worth examining further.

In their work with CHD patients, Gleason et al. (2019) found greater than 50% had elevated scores for psychological distress, while Kronwitter et al. (2019), similarly found young adults with CHD feel disadvantaged in society. In this study, previous findings are consistent

with our subjective reports. However, what stood out was individuals' reports that their anxiety was increasing more recently, and that worries were manifesting now as young adults. These findings support the claim that adjustment difficulties exist in young adult cardiac patients (Andonian et al., 2018) and that personal experiences with the disease are important to formulate care management strategies (Claessens et al., 2005). The personal accounts are in line with the current literature that demonstrates various symptoms increase with age. These findings may explain why our participants embrace change, but not too quickly.

There exists an innate need for human connection. Hence, evidence shows human interactions reduce loneliness and are an integral part of role development. Adults living with congenital heart disease are no exception. It is clear from this study that individuals realize the detriment if they did not have social support. Understanding that psychological health and mental health are positively associated (Godinic et al., 2020; Levine et al., 2021) and that relationships are essential to personal development to achieve life goals (Arnett, 2015; Erikson, 1980; Wrosch & Freund, 2001), these findings cannot be overlooked. Empirical evidence further shows there is a direct correlation between loneliness and well-being. Scholars have shown that loneliness, perceived stress, and living alone inversely influence PROs and QOL in ACHD (Chen et al., 2020; Mathur et al., 2016; Moons & Luyckx, 2019). One of the female participants in this study verbalized she could not imagine going through everything that she has in life *without* family – to be alone would be frightening. Another acknowledged that if her boyfriend was not supportive about her health situation, it would create more stress.

Self-Regulating Strategies

A particular strategy that emerged from the interviews involves the participants' conscious decision to engage their loved ones to trust their intuition when it comes to their heart:

They know their body, their limits, and how best to guard against adverse outcomes. This illustrates the distinction between what *is* from what *may be*, described by Ruiz (2018) to gain a sense of situational awareness. This conscientious approach to self-management supports the presumption that the ‘beating heart’ is not an organ working in the background as a body part (the Körper) that is taken for granted until something goes wrong (Smith & Osborn, 2015). Rather, one’s heart functioning is tangible – how the heart feels and contracts (beats) is at the forefront (the Leib) of these individuals’ everyday life. They know when something is *not* right, which demonstrates a self-awareness unlike those experienced by their healthy peers. Hence, CHD serves as the lens by which the participants see their lives.

Self-regulating guides the participants to assimilate into the adult role. Strategies are implemented to help one reconcile the modifiable risks that they *can* control. This does not preclude addressing risks and adverse outcomes that are out of their control. CHD-related risks and poor health outcomes are described by Lu et al. (2022), as a, “physiological derangement” (p.2). Such a proclamation is important enough that in their 2018 statement, the American Heart Association/American College of Cardiology (AHA/ACC), included physiological stage in the clinical practice guidelines. Perceived health and objective health metrics together are important when analyzing developmental transitions.

Developmental Transition Variables

Healthy development transitions are determined by personality, relationships, and structure. In line with the developmental psychology literature, our study participants did not deviate from this ontological truth. However, chronic CHD is essential to these variables, including how they internalize their disease guided via (a) personality traits; (b) social interactions to form relationships; and (c) structure as a means to managing their lives.

Interpersonal challenges are a common concern derived from the existing CHD literature (Chiang et al., 2014; Pagé et al., 2012). Although personality traits are constant, there are modifiable characteristics that influence health outcomes (Claessens et al., 2005; Levine et al., 2021) and identity formation (J.H. Mills et al., 2010) since there is an interactive process between personality traits and the social environment (Nikitin et al., 2012).

This synergistic interaction also involves life events (Keil, 2013). In this study, an integral life event is the presence of CHD. Our participants demonstrated varying traits and discussed those traits relative to their development. The individuals who described themselves as an introvert, quiet personality and/or feeling awkward, tended to detail interpersonal challenges within the negative aspects of CHD. Compared to those who described themselves as extroverts and friendly, they touched briefly on existing interpersonal struggles, but within the context of their formative years. Now their relations are centered more so on the positive aspects of CHD and how they can use their social network to persevere. Perceptions of belonging are expectedly influenced by relationships.

Social tasks, notably career planning and employment, improve one's self worth, self-esteem, and identity (Arnett, 1998, 2000, 2010). Crocetti et al. (2012) and Godinic et al. (2020) found work promotes personal development through interactive experiences that foster relationship-building opportunities. We found this to be true in our study. The participants who indicate they were unemployed but recently started to work, or started a new job, recognized the improvement in their socialization and sense of belonging. Structure is further impacted by the degree in which individuals believe they have control to modify (and accommodate) their environment. In which way do they demonstrate efficacious beliefs to achieve developmental milestones, in the presence of chronic pediatric heart disease? To most, they are hopeful and

approach their circumstance with a positive attitude. Although this group of individuals are Generation Z, they demonstrate a motivation and desire to achieve expected developmental milestones within the Emerging Adult time frame. There still exists an underlying fear; however, of the unknown.

Fear of the uncertainty CHD poses to their future and whether or not the heart defect will create an early demise or long-lasting complications is a concern. One male participant described structure metaphorically as a ‘cog in the machine,’ while another described the transition to adulthood as a wake-up call that motivated him to, ‘break out’ of his shell. Transitions are also influenced by times of unrest, as posited by Dawson and Skyes (2019), and by negative events (Mather & Carstensen, 2005, cited in Keil (2013), such as the Covid 19-pandemic that emerged just a few years prior to beginning this research.

Covid-19 pandemic.

Guided by current evidence, in the research proposal I [P.I.], posited that Covid-19 is germane to this study because it was believed the pandemic would adversely impact the participants’ structure to the point that they remove themselves from achieving developmental tasks and procuring social relationships that are integral to role development. Bandura (1989, 2003) and Keil (2013), postulate when there is a deterioration of the normative structure (i.e., the Covid-19 pandemic), it potentiates the risk for the young adult to disengage from his/her life tasks and redirect efforts that result in a lower perceived lower quality of life (QOL) and efficacious beliefs. Further, there is a risk of impeding one’s identity construction (J. Mills et al., 2010) and identity stability. Perceptions relevant to the Covid-19 pandemic arose in the semi-structured interviews. Although no reports of financial insecurities materialized, narratives relevant to the challenges faced with mandatory masking, the risks of illness and transmission,

and work/school restrictions were discussed. These findings are in line with Moons et al. (2021b) in their longitudinal work measuring outcomes from the various waves of the Covid-19 outbreak in the U.K. Their findings revealed that overall, 91.2% reported Covid had a negative effect on their lives (p.4). Included in the findings was that there were no differences in PROs (patient reported outcomes) between those who had and had not contracted the Covid-19 virus. Such outcomes were not quantitatively measured in this study, nor were comparison data between the U.S. and U.K analyzed.

When Covid-19 became a public health crisis in the U.S., many of the participants from this study shared that the crisis motivated them to be more conscientious about their health, primarily in response to their doctor's advice. One participant shared a high statistic his cardiologist conveyed placing individuals with CHD at a higher risk for complications of the disease, even higher fatality rates. Conversely, one participant indicated her doctor did not think she would face complications because of her *type* of heart defect. Another felt optimistic about his health; prompting him to take a proactive role in strengthening his immune system. Subsequently, he declined to take the emergency-authorized mRNA vaccine. A few others believe vaccinating and receiving a booster lowered their risk for a catastrophic outcome. In terms of a lapse in medical care (perceived or actual), only one shared that she chose not to go in for a recommended test because she didn't want to 'deal with Covid stuff.' There were no references made about transmission of the virus, only their risk and personal decisions associated with the risks.

Sense making is the recognition of 'self' within the social and cultural context by which one lives. Therefore, it can be assumed that the dissonance between perceived reality and the newly "emerging reality," postulated by Godinc et al. (2020, p. 62), would commence following

the loss of the social network. Our study findings suggest that the Covid-19 pandemic did not have a deleterious effect on the participants. The economic and social ramifications; however, have yet to fully materialize. The deleterious effects of such coercive policy will likely be observed for years to come. Longitudinal data will provide the evidence necessary to substantiate such a claim. Perhaps much of the economic ills Americans are facing - even our young adults, are an unintended consequence of the Pandemic response. According to the Bureau of Labor Statistics, the U.S. inflation rate was reported to be 6.4% in January 2023. That rate was 1.5% in January 2021. Although total wages have increased, they are not enough to match the inflationary rate. Therefore, Americans face a higher cost of living. Young adults, with or without chronic disease, are no exception.

The Economic Landscape Influencing Adult Tasks

The effects of the U.S. economy did surface from the semi-structured interviews. These individuals discovered the barriers that a high cost of living creates: The costs to live on their own and an inability to relocate depending on the state and township/city. However, most acknowledged they didn't feel alone in these decisions because they could depend on their parents as a source of support, financially or otherwise. These findings align with the tenets of Western society's accepted developmental perspective that Reifman (2007) coined as the 'boomerang kid' (p.1). A term used to describe when young adults move back home while progressively working toward self-sufficiency. There is an oscillating period that does not quite permit them to be fully independent, as posited by Arnett (1998, 2000, 2010).

Emerging Adulthood Dimensions

Emerging adulthood illustrates a multidimensional approach to understanding the lived experience within the developmental context individuals' face at this time. When examining

chronic complex CHD as an illness representation to organize into the five Emerging adult (EA) developmental dimensions, K.G. [P.I] rationalized exploring those within the 22 to 25-year age range. Defining the ages permitted gaining a greater understanding of one's life management at a time when the level of independence is enough that they are ready for adulthood. The findings (study themes) were organized into the EA theory, which demonstrate that most of the adult decisions faced during this developmental transition are common and central to the lived experience. In many regards, our participants believe their sense of ambiguity in feeling self-sufficient is a normal occurrence for people their age. They too question whether they will get married, have children, and a house of their own someday; and they want these things.

However, this group of adults with complex CHD shared concerns related to reproduction and parenthood. Reproductive questions are an important factor in future planning. Both genders report concerns related to their genetic predisposition to transfer CHD onto their offspring. The females, naturally, questioned whether their heart could handle pregnancy, which is in line with the findings from Nakamura et al. (2018) and B rstrom et al. (2021). Other variables important to the participants' role development include the need for adequate health insurance. Additionally, their conscientious effort to reside in a region that ensures they maintain access to the level of specialized cardiac care they have come to trust and depend on through the years. These decisions are centered on *oneself* to facilitate gaining independence, but within the limitations of their cardiac disease.

This research demonstrates the temporality (past, present, and future) of role development – *sense making* as a process of: (a) identity exploration, (b) instability, (c) self-focus, (d) feeling 'in-between', and (e) possibilities and optimism in the presence of a chronic heart defect/condition. The data were analyzed not to generate theory, but to confirm and

organize according to the developmental dimensions of Emerging Adulthood. As anticipated, common themes arose from the semi-structured interviews, which illustrate the convergence of meanings they attach to the everyday lived experience. This is important since IPA requires that participants are more similar than they are different (Smith et al., 2009; Smith & Nizza, 2022). However, not all experienced the same health path. This highlights the divergent and unique characteristics of the personal experience – the idiographic (*particulars*), and emic that underlie IPA research. While some described adverse emotions, others described contentment. Likewise, some focused on the implications of CHD to daily life, whereas others reflected on an isolated event and/or potential events. Nevertheless, CHD cannot be excluded from daily life because of its chronicity. It is central to their identity, which is how they view their position in the world manifested in how they exist, act, and feel (Aho & Aho, 2008) – it is a reflection of what it means to ‘*be*’.

‘To be’ elucidates the multidimensionality of the human condition. A prevailing way the participants attach meaning to their life as a young adult with complex CHD is through empathy and gratitude. All of them, in one way or another, described how growing up with CHD made them more conscientious of others. They are conscientious about the lack of outward appearance of their own heart disease and subsequently, refrain from judging others. One participant discussed never judging someone with a handicap sticker because ‘no one knows their personal circumstance or daily struggles.’ The participants recognize that CHD may not necessarily be a known condition since it lacks an outward disability, which gears them with some control in choosing when to share, and with whom. These findings converge with Chiang et al. (2014) who also suggest from their qualitative work that a heart defect is often viewed as invisible. However, the presence of a chest scar, implanted cardiac device, scheduled clinic appointments, impaired

functioning, and/or the adjustments made to accommodate life's demands, all serve as a daily reminder to this group of individuals that they have a heart condition. Moreover, a heart condition that coexists with other adult related co-morbidities.

Chronic CHD predisposes one to a daily regimen of prescribed medications. Medication regimens were only discussed by one of the 13 participants, which was an unexpected finding considering 76.9% ($n = 10$) report taking medications (including over-the-counter) on a daily basis. Other results diverged from the existing CHD science. No one in our study reported a diagnosed disability. This diverges from the findings of Karsenty et al. (2015) who reported a 31.2% rate of disabled-worker status in adults with complex CHD. One of the participants sought information about disability benefits in her forward thinking that someday she may no longer have the capacity to work *because* of her heart. However, this was not a concern currently. Other differences arose that diverge from the current epistemology.

Previous research shows a high incidence of pain in adults with CHD compared to the general population (Leibold et al., 2021), even among those between the ages of 18 and 29. Our study indicates young adults with complex CHD do not live in pain. With the exception of intermittent pain experienced with their migraines, pain was not an issue. In other CHD relevant research, Callus et al. (2013) and Pagè et al. (2012) found CHD may predispose one to a delay in developmental milestones in the presence of impaired functioning. Alterations in functioning were reported by our study participants, as were the steps taken to overcome their impairments; however, not to the extent that they could not reach anticipated milestones similar to their peers.

Enomoto et al. (2020); Karsenty et al. (2015); and Na et al. (2018) found adults with CHD face difficulties with employment. This was not a concern in our small sample of adults – at least not in terms of difficulties *because* of their heart condition. Possibly, this may be in

response to the actions they take to normalize. The evidence is conflicting; however, regarding employment and educational achievements among adults with CHD. Differences also arose in comparative studies involving those with other chronic conditions. In their work, Willemse et al. (2018) found participants with Type I diabetes mellitus report frustrations with setting goals for the future. While we found our participants shared concerns with setting goals for the future (e.g., a fear of the unknown and uncertainty), frustration was not one of them. The majority of the participants reported a good relationship with their parents, which is an integral factor in goal setting because they could lean on family for any reason. Such narratives may serve to refute the findings from Pinquart et al. (2014) and Sligo et al. (2019) that young adults with chronic illnesses report financial hardship. Despite the participants' limitations, hope and appreciation resonated.

Sharing their story in a candid, honest dialogue illustrated *sense making*. Each of the participants verbalized that it is they who know best what it is like to be their age living with complex CHD. K.G. [P.I], the central interpreter of this study, also knows what it is like to live with CHD, but as a *middle-aged* adult. Retrospectively, I (K.G.) reflected on life as a young adult with complex CHD. Self-reflexive journaling details my journey through each step of the research process, and each interview, as I reconciled with the intimate familiarity with CHD. The potential existed to inaccurately interpret the participants' personal; yet converging journeys. The final interpretation; however, embraces the fundamental characteristic of Hermeneutic phenomenology: The researcher's experiences with the phenomenon.

Life is just a piece of the experience; it is the essence of survival that encapsulates our participants' lived experience. In a recent publication, Ross (2022), an elderly complex CHD survivor, described the 'silver lining' (p.1) that older CHD patients internalize *because* of their

unexpected lifespan. This patient perspective was in response to research conducted by Moons et al. (2022), who found from the international APPROACH II study that older age CHD patients report poorer physical functioning, but less anxiety and better mental health than the younger age cohorts. One could posit that today's surviving young adults with CHD may take for granted the medical advancements that are available to them, or that they may not appreciate what it's like to be told they will not live long. This study repudiates such a notion.

Similar to those born generations earlier, the individuals from this study believe they should not have survived because of the severity of their heart defect. Ross (2022) questioned whether today's CHD adults will also see the silver lining of their survival, or instead exhibit a profound sadness. The overarching impression of this group is that CHD is *not* their 'lot in life; rather, it can be a source of hope. This is not to infer there are no real concerns or uncertainties that exist, but collectively the participants described CHD as part of their life, and...it IS their life. Ironically, they are living *because* of their CHD. A question posed following the appraisal of the relevant literature included: 'Do the individuals make sense of their developmental tasks in the *context* of CHD, or do they make sense of their CHD in the *context* of developmental tasks? We found CHD creates an opportunity to *make sense* of their situation; thereby CHD plays an active role in their daily decisions, which includes achieving young adult developmental tasks.

This study elucidates the beliefs that young adults with chronic CHD have while navigating the developmental tasks of young adulthood. These include the experiential themes that evolved from the in-depth interviews to organize into theory – into the five dimensions of Emerging Adulthood. In their identity exploration, our participants show 'disease is part of self.' In other words, identity does not exist *without* a heart defect. They know that they are different, but *want* to be normal. Such findings align with Claessens et al. (2005). Some of our participants

used the term, ‘weird’ to describe: (a) themselves, (b) how others view them, or (c) life itself in the presence of CHD. They self-guard/protect to minimize barriers and poor outcomes.

Moreover, they choose with whom and when to share they have a heart condition (CHD is a personal matter). Despite knowing they are different, they are grateful. Gratitude particularly resonated among those who attributed their faith to appreciating the life they have. Each differed in the church denomination they attend or in the religious affiliation they were raised.

Nevertheless, gratitude does not overlook the consequences that CHD creates.

There are consequences to CHD, which was also found in the qualitative work by Claessens et al.(2005). In this study context, the findings highlight the Instability domain of Emerging Adulthood. Our participants recognize there are a lot of unknowns – ‘unknown directives *because* of their CHD.’ This infers there are uncertainties, which most are out of their control (occur unexpectedly). Coupled with the difficulties they faced through their childhood, there are emotional consequences. Fear and anxiety prevail. A few of these individuals verbalized that their anxiety is worsening as they age. A common rationale eluded to the unknown – whether CHD would cause long term health problems or even death. Emotional and psychological distress accompany other existing physical conditions. Adverse health is not typical in young adults.

Impaired functioning (mental or physical) impacts how the individuals view and plan for their future. Hence, this could explain why these individuals are conscientious of the transition from adolescence to adulthood – the feeling ‘in-between’ dimension of development is internalized, or more pronounced. Their self-focus manifests as an elevated awareness that guides them to manage (as opposed to explore). They manage within the limitations they cannot change. These limitations may explain why the participants welcome change, but not too much at

once. Structure helps them to navigate transitions at their pace, and to their ability. This illuminates the ‘what ifs’ associated with the dimension of Possibilities and Optimism.

Despite the consequences, uncertainties, and the ‘what-ifs’ of CHD, our participants are hopeful. They want what other young adults want: A spouse, children, and a house of their own – to live the American dream. In this regard, despite how the Media portrays Gen Zs, these young adults want to fulfill life’s tasks at this time to achieve self-sufficiency and gain the confidence to claim they are ‘an adult.’ They fear being alone or not having the social support that is central to their quality of life. A few developmental milestones do pose a problem: Both genders shared concerns about passing CHD onto their offspring, and the females reported concerns with pregnancy. A few of the females already made the decision to avoid pregnancy due to the risks, while others have (or will) plan pregnancy in collaboration with their doctor to make sure their heart can handle the increased demand of carrying a child, and to safely give birth.

Another milestone that raises questions include occupational choice. Decisions relevant to work involve location and physical demands. These individuals recognize that they need access to an ACHD center, which limits where they can live. In addition, although they may be satisfied with their employment choices now, that may not work later on. Moreover, their physical functioning may be acceptable now, but may not be later on – years later. Whether or not the participants accept the decisions they make at this time, those decisions have implications to future life stages and therefore, are foundational to the rest of their life.

Strengths and Limitations

This study presents many strengths. I [P.I.] presented an in-depth, rich account of life with chronic complex CHD within the context of the Emerging Adult developmental stage. Guided by the IPA philosophical lens, how one makes sense of their circumstance was described.

Conducting this study in the Northwest region of the United States, using a U.S age-based theory, generates knowledge relevant to Western society. IPA is predominantly found in the psychological sciences research, but this research applied the phenomenological framework to nursing and the lived experience of pediatric heart disease as *adults*. This is the first study that addresses complex-only CHD outcomes during the EA stage. Moreover, the findings strengthen the ACHD evidence that complex CHD has lifelong implications. Another strength of this research project involves tackling the proclamation posed by Brida and Gazoulis (2019), that if we (medical and scientific community) do not address the concerns of those living with ACHD, it will create a “tsunami” (p.1757). These strengths are worthy and important to advancing the CHD science. However, all research comes with its share of limitations.

A primary limitation of this study is that although IPA celebrates the uniqueness of individual accounts, findings are interpretative and subjective. Researcher as ‘instrument’ (Tracy, 2020) poses the risk for biases, while themes emerge as a manifestation for “different people” (Smith & Nizza, 2022, p. 76). The latter minimizes generalizability of the findings. Inferences are limited by the small sample (*N*) and cross-sectional design from a single outpatient clinic. Moreover, the research includes only those with complex only (class III) congenital heart disease. More research is needed for all types of CHD, or to qualitatively investigate differences in those with CHD and those without. Steps were taken to minimize the risk for biases and improve the authenticity of the findings.

Authenticity of the Final Interpretation

Validity and reliability are substantiated via the triangulation of the interpretative data. Guided by Smith et al. (2009), determining recurrent subordinate themes improves validity, while supporting emerging themes with the aggregated data improves reliability, or internal

consistency. Evidence integrity was further supported by extracting participant accounts to inform each emerging theme; that is, grounding the themes; and organizing into the dimensions of Emerging Adulthood. Moreover, the hermeneutic piece of the analysis was guided by two contemporary theories. K.G. [PI] engaged in self-reflexivity throughout the research process to address presuppositions, potential biases, and the personal experiences associated with CHD. Honoring the precepts of IPA, purposive sampling improves transferability while advancing the emic perspective. The final, detailed description occurred collaboratively to ensure the themes accurately fit the data, not that data fit the EA theory. Although the study findings support existing evidence, differences emerged. The findings elucidated how individuals make sense of their life and course of life tasks during the defined age-stage period. Within the context of *sense making* and Emerging adulthood, these are novel findings. The resulting analysis is an accurate and authentic interpretation of the phenomenon: What it *means* to have complex CHD as a young adult, and how to *make sense* of that experience.

Implications for Practice

This research project builds on the existing CHD work in many ways. Nursing is centered on promoting the physical, psychological, and social aspects of health unique to individual patients. This is where the distinction between the Leib and Körper emerges, while maximizing the synergy between the two approaches to improve health outcomes. Guided by contemporary methodological frameworks, the IPA study can be used to: (a) inform individualized, age-appropriate patient care; (c) complement clinical guidelines that are currently used in many of the ACHD centers by combining clinical metrics with the experiential; and (d) gain a deeper understanding of how patients perceive their ability to manage disease as a multidimensional construct through the life cycle.

Understanding complex CHD as a chronic medical condition, and the complexities individuals face because the effects of CHD are more apparent as patients age, makes research like ours that more meaningful. Furthermore, the findings from this research project could inform studies with other adult patients living with pediatric chronic conditions. Guided by the empirical claim that individuals who do not work by age 30 will fail to reach their full potential (Hendry & Kloep, 2007) and those who remain unmarried and do not become a parent by age 27, will experience a lower quality of life (Messersmith & Schulenberg, 2010); and the social stigma that chronic disease creates in young adults, makes studying CHD within the context of Emerging Adulthood worthwhile.

Future Research Possibilities

Many recommendations arise from this study. 1. Follow this group of patients at later stages in life to examine their outcomes longitudinally. 2. Replicate research in different regions of the U.S. and from multiple ACHD medical centers. 3. Conduct qualitative-guided studies among young adults with complex CHD from other countries. International studies similar to those published by renowned CHD scholars (e.g., Philip Moons, Adrienne Kovacs, and Liesbet Van Bulck) would highlight any diverging characteristics that may exist among the various countries. 4. Additional research that uses larger sample sizes and methodological designs would also complement the ACHD scholarship. Based on our findings, the role of faith is also worth examining. It is well known that spirituality positively influences mental well-being and resiliency, but I [PI], found for those participants who reported faith is important to them, shared differences in their theological beliefs. In this instance, faith appeared to play a greater role in the individuals' well-being than did their doctrinal allegiance.

In line with the current evidence, these concerns are real, personal, and consequential; and may potentiate an alteration in role development if neglected. A finding that particularly stood out is the prevalence of psychological distress. Nearly 50% of our participants reported anxiety and for some, the anxiety has worsened during these early adult years. Additionally, depression and other impaired social impediments were found. Psychological concerns that manifest as the individual with chronic complex CHD ages is worth exploring further as well.

Conclusion

The purpose of this research study was to investigate the experiences of young adults with chronic complex congenital heart disease in relation to their *sense making* and disease representation in formulating their role during Emerging Adulthood. Concerns manifesting during this vulnerable transitional stage highlight the implications to healthy development since the decisions that individuals make at this time are foundational to the rest of their life. Therefore, this study among a small sample of participants between the ages of 22 and 25 with chronic complex CHD advances knowledge relevant to (a) life course outcomes, (b) independent functioning, (c) perceived well-being, and (d) overall health status. Guided by two contemporary perspectives, the research elucidates what *it means* to have CHD as a young adult and *how* it affects their life. Chronic pediatric heart disease is not a childhood condition relegated to the past. It is in the present, and very much integrated into their future orientation. Therefore, CHD is not just a part of life – it IS their life, and is foundational to how they *make sense* of their personal experience.

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Table 1*Participant Characteristics and Clinical Metrics (N =13)*

Characteristic	Variable	n
Age	22	3
	23	4
	24	2
	25	4
Gender	Male	7
	Female	6
Ethnicity	Hispanic/Latino	3
	Other	10
State	Idaho	2
	Montana	-
	Washington	10
	Other (North Carolina)	1
Name of Defect	L-TGA ^a	1
	Single Ventricle/HLHS ^b	2
	DORV ^c	4
	Truncus Arteriosus	1
	Pulmonary Atresia w/HRHS ^d	1
	Tricuspid Atresia	3
	Dextrocardia (d-TGA) ^e	1
Physiological Stage	B	8
	C	5
Recommended to follow-up With ACHGD provider	Yes	12
	No	1
Clinical Metrics		n
Number of hospitalizations Past 3 yrs. (36 mo.)	None	4
	1-2	8
	>2	1
Number of months since most recent hospitalization	<6	3
	6-12	2
	13-24	3
	>24	5
Number of daily medications (includes over the counter)	None	3
	1-2	5
	3-5	5
	>6	-

Note. ^aL-TGA (Levo-Transposition of the Great Arteries), ^bHLHS (Hypoplastic Left Heart Syndrome), ^cDORV (Double Outlet Right Ventricle), ^dHRHS (Hypoplastic Right Heart Syndrome), ^ed-TGA (dextro-Transposition of the Great Arteries)

Physiological Stage. **B.** Mild hemodynamic sequelae, mild valvular disease, arrhythmia not requiring treatment, &/or abnormal cardiac limitation to exercise.

C. Significant valvular disease; moderate or greater ventricular dysfunction, arrhythmias controlled with treatment. AHA/ACC guideline. Stout et al. (2019)

Table 2*Final group Experiential Themes and Subthemes*

Early Adult Dimension	Themes	Subthemes	Examples
Identity Exploration	Disease is a part of self	‘different but want to be normal’	”Growing up as a person that has defects, you forcibly grow that voice telling you that you’re not like the rest”
		‘self-guard/protect to minimize barriers and poor outcomes’	”I don’t take a lot of risks. I don’t think I should, there’s no reason to”
		‘choose to share or not’ (it is a personal matter)	”I don’t like to talk about it [CHD]. I don’t want that to be the only thing people think about.”
		‘gratitude’	“If I was born a couple years earlier, I probably wouldn’t have made it because technology is advancing all the time”
Instability	Unknown directives <i>because</i> of CHD	‘childhood memories shape adulthood’	“What’s set in childhood is hard to get out of adults”
		‘there are emotional consequences’	“As a heart defect person, I have a lot of anxiety so like I overthink stuff and let it get to me”
		‘CHD creates uncertainties’	“I live my life with a lot of unknown answers,”
Self-Focus	Can do, but within limits	‘I know myself better than anyone else’	“Be smart. I make sure I am well within the boundaries”
		‘managing, not exploring (self-aware of the limitations they cannot change)’	“When I was looking at schools I have to be close to areas with big hospitals. I don’t think I’d move very far.”
Feeling In-Between	Internalize the transition	‘it is a conscientious continuum’	”I’ve been able to make my own decisions my entire life, and so where I’m at now at age 23 doesn’t really necessarily feel like a whole lot different from when I was 12”
Possibilities and Optimism	there is hope, but it is provisional	‘what ifs’ (want to/must be healthy)	“If I move somewhere I always need to be at a good place that has a good hospital or a good surgeon or a good cardiologist”...”I want to be as healthy as I can”
		‘change is good, but not too much at once’	”I want my future to be simple and easy”
		‘where to go from here’ (engage in developmental milestones within limitations)	“Starting a family, I don’t know if I want to because of the risks and everything.””

Appendix A

Self-Reflexivity Journal

January 2022

Reflexivity is an integral part of the IPA process to gain a deeper understanding of our personal position to the phenomenon. Qualitative research infers the investigator is the research instrument (Tracy, 2020). Therefore, I must be more aware of my own opinions, beliefs, and the value I place on the phenomenon. As an ‘insider’ (Smith & Nizza, 2022), I have first-hand experience as an adult living with CHD. Although now middle-aged, I can reflect on my EA years. Naturally, hindsight is 20/20 but I can look back and think about how I felt at that time about future planning and then sit here today and recognize how all those plans evolved.

Because of my complex CHD (Truncus Arteriosus), I knew from a young age having been in the hospital so often that I wanted to do something ‘cardiac’ as a career. I certainly toyed with just being a nurse. And that is exactly what I did. I graduated from a community college ADN program and worked as a Med-Surg nurse before entering a cardiac unit. In the 1990s when I graduated nursing school, new grads couldn’t get work in specialty areas, let alone the hospital D/T ‘lack of experience.’ After working at the local hospital for 6 years I got into cardiac by reading a newspaper article about a pediatric cardiologist expanding to include adults on a unit here at a nearby hospital. I interviewed and was hired! I have not looked back. Cardiac patients are usually rewarding. But I gotta say, experience as a nurse, and then specifically as a cardiac nurse, has taught me to approach the individual patient – it is about them (not me). As I reflect, I can honestly say in the 18 – 19 years I have worked in a cardiac unit, I only discussed my personal experience with heart surgery &/or CHD on one hand. But....it has equipped me to understand; to empathize.

I uniquely can approach the phenomenon from both a personal and professional perspective. That provides me the entre and credibility. However, these 2 ‘hats’ make it that much more important to address opinions because they have definitely emerged through the years. I see patients who are a ‘failure to thrive,’ or who have been surrounded by family and friends who enable them to assume the victim role. They may often become a ‘frequent flyer’ to the hospital/clinic, and use their defect as a reason NOT to work, live alone, or worse, to engage in unhealthy behaviors as a way to normalize (i.e., smoking, drinking ETOH).

Fortunately, I was raised to be like my older brother. Meaning, I was disciplined and held accountable, just like he was. There was never this mentality, ‘*I have a heart defect*’ so..... No! My parents would not allow me to be a victim. I just learned to accommodate my limitations. For example, I played Little League, but I didn’t play basketball because it was too strenuous. I would play outside, build forts, and wrestle with my brother. If I was out of breath, I simply took a break. Then resumed.....It was OK.

One of the decisions (addressing a young adult milestone) I made early on (a lot of it was based on what we knew at the time - medical recommendations), I had my tubes tied to avoid pregnancy. The risk was too great for not only my own health and survival, but we just did not know if the risk to pass on CHD existed. I was only 21 and planning to be married a few months later. Luckily my then soon-to-be husband was OK with not having children. Looking back, that was a decision I never realized would have such implications later in life (in my 40s). Another decision I made was getting married so young. This is not to say I would not have fallen in love and be married (a lot of girls dream of this) but I yearned to move out because I had a very controlling mother - I think mostly *because of my hx* in and out of the

hospital. I yearned to be independent and getting married was my ticket out. I also wanted independence; not feel like I had a parent hovering over me. My dad, not so much. He treated me more like an adult. Although my dad is now deceased, my mother still tries to dictate what I need to do in terms of where and how I live; my health, and who I date (I divorced 6 years after marrying). I was a divorced career gal for wow, 12 years after that! It was always just me and my dog through my late 20s-30s.

Commonalities with the experiences I hear (as an ACU nurse and webinars I attend) and read (research articles)

I never had children; yet this topic was never really discussed or understood (pre-ACHD dedicated centers)

I felt fine until an event changed things: Age 37 got endocarditis while working away for my known MD. That event created a situation where I wanted to get 'back to that region to be near good care.'

I can relate to medical trauma. I recall crying one time to my mom in preparation for yet another heart cath probably around age 8 or 9. I had >18 by the time I was age 18.. This was pre-MRI. Caths = diagnostic, not intervention. I cried because I hated the dark, cold room, the long time on the hard table, and listening to loud machines, smelling betadine. I recall telling her, 'I would rather have heart surgery than a cath!' Furthermore, the pain associated post cath: my groin would be so bruised and tender and I am scrawny 😊 .

February 2022

As I work through my literature review and categorizing findings into sections to build my case (defense), I reflect on the outcome variable, 'adaptation.' Specifically, psychosocial adaptation. I reflect my own circumstance, at age 48...(almost 49), I have such an appreciation for life. I do feel blessed to be a survivor and have the means to address my needs – that hierarchy of human needs. For example, I have great Drs and contacts, as a nurse, to ensure I access and receive quality care as needed. But.... I am alone. I don't have adult children or a husband. I have not found a boyfriend even who wants to commit and see me as long-term. Finding companionship only gets harder with age because health by natural projection begins to decline (but have my heart problem AND deformed joints that started to erode in my early 40s). Recently (prior to getting a much-needed hysterectomy) I was experiencing quite a few heart palpitations. They have simmered down but.. I don't know if my role has fully developed on where I should be at this stage in my human development. As I near my 50s, what do I have to look forward to? I tend to work most holidays so that I'm not alone. The relationship with my mom is OK as long as it is superficial.

So....where I'd like to take the IPA (keeping it open and unique to EACH participant) questions relevant to their age stage in the context of the heart defect as an illness representation and how they perceive their **role**. My role as nurse, educator, and doctoral student (professional) or my role as sister, aunt, daughter, or friend (personal) does not = adaptation.....just my thoughts.....I may have achieved 'ROLES' but they may not be *where I should be* based on my developmental stage. For example, nearing my 50s, I am not a mother, or a wife. Subsequently, I do not have adult-age children and grandchildren in my life, nor a husband with whom I may plan my retirement years.

Reviewing the current literature makes me pause when young adults are advised against pregnancy or genetic counseling that may motivate them to choose not to have children. Although such decisions come from a good place – guided by responsible thinking, little do we realize how these kinds of decisions truly

do impact the rest of our life. No children mean.....no one in my life in later years. It is my goal such distinct 'roles' during EA will show in this ACHD sample via a fluid, flexible interview.

It all came together. I sat down and literally by hand began to write out sections of my proposal – build my defense via author(s) study findings. I felt like the big puzzle was coming together – each of the findings started to create a beautiful 'bouquet.' Each section representing a flower 😊. I sent an initial draft of my dissertation proposal to Dr. Clarkson for review/feedback. I got so excited to have this come together!

March/April 2022

I received feedback and made changes to my proposal - Draft #2 sent to Dr. Clarkson (Mar 7th) for another review.

March 15th – scheduled the dissertation proposal with my committee members.

My qualifying exam opened March 27th. .

April 20th – sent the proposal to the committee in preparation for the defense next week (May 2nd). *This was tough – it made me reflect on what this is all about – what meaning does this research have if I cannot move forward with conducting the project?!

I had 15 days to complete – submitted Sunday Apr. 10th. It was tough – I had a lot of ectopy during this time– spent a lot of time on it, very little sleep. I lived with a sticky pad near me to jot down ideas or 'fixes' I need to do on the write up (no more than 25 pages). I applied philosophy (using pragmatism and constructivism to the phenomenon of ACHD). And applied research designs – of course phenomenology, and then compared to other designs (grounded theory and quasi-experimental) to study ACHD. I also discussed psychometric properties, and applied to two existing ACHD instruments/tools, and discussed statistical analyses (ones posed in the exam, i.e., ANOVA, *t*-test). I shared my 'program of research' in the exam, as well as my attempt to operationalize key concepts found in the literature (Appendices). It's coming together!

This was a tough month – I didn't hear back until Monday April 25th via email – Dr. Clarkson notified me that I passed! I was so nervous. I would have felt so disgruntled and a failure to tell my committee – especially Dr. Moons that I would have to reschedule because I did not pass the QE. But, here I go – here I launch! May 2nd here I come! That hopefully will be a good birthday/nurses' week. 😊

May 2022

May 2nd – I had the Zoom session with my committee – dissertation proposal. I thought it went well but all were very thorough and asked me to detail some areas. A valid question came up: 'what do you mean by *'making sense'?*' I really didn't have a clear answer. It's a difficult construct to describe. Not sure.....good question! It was recommended also (per Dr. Moons) to move away from QOL and build from what we know in the adolescent studies to apply to the EA group. and 'making SENSE'. He agreed that this is a piece worth exploring. It was also recommended to delve a bit deeper into phenomenology. I want to know how they make sense, such as, for 'identity exploration' (*how did you get there? Who are you? How did CHD impact – or not?*)? How do the 5 dimensions of EA go with CHD? - ** things to think about**.

Dr. Hearn recommended a book, which I ordered immediately afterward that not only describes a phenomenological approach to research but to chronic illness! I want to ask questions that tie in the EA

theory but doesn't "box" it in. Don't make this compartmentalized. For example, DC my question about Covid. It is assumed that it's an issue. It may (or may not be) and that's what IPA is all about. We simply do not know the outcome, nor should one presume. In fact, presumptions and assumptions need to be addressed via journaling. It was further recommended to journal AFTER each interview to address thoughts, not just as a 'research process.'

I also need to show my search strategy rather than simply writing that I 'conducted a comprehensively lit review.' Dr. moons noted I used him in a few of my citations where he was NOT the primary source – I need to update my statistics/epidemiology areas (i.e., ___% have complex CHD...). Certainly, my error – not sure how I missed using the primary resources. Of course, he would know – he is the 'rock star' of the ACHD science! I humbly seek such feedback, especially at this point. I did 'pass' my proposal with the changes needed. Once updated, I send back again for the committee to review.

Will pick it back up to begin IRB in the fall once Dr. Clarkson is on contract (off summer session).

June/July 2022

I have enjoyed the book Dr. Hearn recommend (Aho & Aho, 2008), just finished it (early June)! And sent the proposal back to Dr. Clarkson with the changes/edits, per my committee members.

June 7th: I worked at the hospital this evening (15:00-23:30) and was quite frustrated with a post OH ACHDer. He is only 20 years old and although he has autism and so his daily needs are higher than most, between he and his mother who never leaves the bedside, he was nearly a 1:1 care. But the care was NOT medical-needs related. He has been here >90 days and at this point all we are doing is giving him meds literally Q hour for pain/comfort and nausea. And the mother is upset if we don't stagger each as she believes he "needs." Hmm, and no one wonders why he's nauseous and vomiting?! His midline incision is healed and he has been here so long that he's off sternal precautions!

I journal this situation because the adult congenital patients on my unit have the reputation as needy and 'demanding.' We see it all the time. This is why – right here! Even as adults these patients have their mother or significant other dote on them. And then expect nursing to do the same. This patient was getting 30mg of Oxy Q HS between the PRN and scheduled XR dosing. This young male is only 140lbs. Why does the medical team (PATCH and the hospitalist) permit this? There is no reason for this. Just *because* he has a heart defect?! Times like these make me put my professional experience and personal experience (and beliefs) into perspective. As researcher, as *instrument*, I recognize these must be reconciled.....

June 23-25th: Attended the 9th National ACHA conference. I enjoyed the prior conferences attended because you really do learn a lot and can choose from patient/family and HC provider breakout sessions. I started right off the bat frustrated because the organization decided a few months ago to go virtual D/T 'Covid.' Good grief! Really?! We are dealing with the ill effects of social isolation and DC this in-person, live opportunity?! The initial breakout sessions on day 1 discussed topics such as (a) accommodations for learning deficits, (b) CHD and LGBTQ+, (c) encouraging ACHDerS to call their own CHD provider if ever in the ED – I piped up and said it is important that the specialist's # is shared with the ED doc so that he/she can call. We don't need to be disturbing our docs like this. – This goes back to when ACHDerS are admitted into the hospital and are often demanding and needy. One group of providers discussed how they keep some patients in the pediatric side all the way to age 30! Why? Because the patient &/or doc don't want to 'let go.' OK.....this is problematic in my opinion. This is why CHDerS are not growing up, or fail to thrive. Other topics include (d) health disparities and a (e) lack of interest by Med students to go into CHD so there are not enough specialized providers, and sadly, very few in "the pipeline." The

whole health disparity and inclusion bother me because those circumstances, such as living rurally are NOT unique to CHD/conditions that affect many. And I don't care that my Dr may be a White male. Likewise, he shouldn't be treating anyone differently based on status &/or genetic makeup.

But.. on a personal side, one of the conversations included a fellow ACHDer (and health professional) and her husband. He discussed how he has her ACHD doc's info in his phone too so that he can call and advocate for her in those times that she may not be able. I don't have that 'advocate.' I wish I did. That was cool to hear. And another's fear and pain R/T endocarditis was in one of the sessions. I too have been alone through my 3 occurrences of IE. I'm pretty independent likely because I'm a cardiac nurse but it's also who I am. I can do it – I don't want to draw attention to myself, nor do I want to have to be in the hospital, especially post Covid – not the place to be. I also question my care (sadly). To receive honest, individualized care is lacking. Now that the bureaucracy has officially penetrated HC and the patient/Dr. relationship.

August 2022

Met with PATCH providers about recruitment process, roles and expectations. A few changes recommended to the inclusion criteria: include catheter-based interventions since not all patients now (even those with complex) get open heart surgery. And place an age (age 3 and above) so we get patients who have a hx. from childhood and thus, a recollection of the experience(s). mid-August I enrolled in dissertation credits and started the IRB application process.

September 2022

eIRB submitted for PSJH – I got to serve as PI as a Providence employee. Very good experience but the process took some time. Met with Dr. Carl to discuss recruitment. I was going to cancel this initial visit since recruitment could not occur until final IRB approval received. But kept the meeting and he was so helpful with just basic questions re: IRB and contacts that would be helpful. I noticed too that one of the research scientists for Prov emailed me via my Providence email and cc'd my nurse manager since she was alerted for RN guided primary research. She initiated this is valuable as Prov SHMC is going to try for Magnet status here soon. Nursing research is very much supported. She was helpful; juts as was everyone in the eIRB process.

I brought up the criteria again with Dr. Carl and rationalized why I want to keep physiologic stage A despite Dr. Moon's belief there are too few. Based on his large international study, there weren't any 'As.' I want to include because I told Dr. Carl, he stages me as a Class III, Pys A; yet I should not be excluded. I too have needs and just because I may be stable in a snapshot clinical visit that doesn't mean things change a day later and certainly before I F/U again in 2 years. I have had endocarditis not once but 3xs as an adult, I have frequent dysrhythmias but not captured when placed on a monitor. I also have physical limitations. Although I do function well, overall. Still..... Dr. Carl pulled out a laminated binder with the guidelines and said, "this is how I classify my patients." Very helpful, I thought. But.....it hit me.....this is why we need qualitative research. Patients do not fit nicely into a clinical guideline.

Received 'bilateral' IRB approvals October 17th. Wow!

Oct 31st – Happy Halloween! Guess what I have? Endocarditis, again! 4th time now since 2010. 3rd time with the Melody valve. Luckily I catch my symptoms pretty quick but here we go. Everything is moving along fine and Pow! – An unexpected acute event. And....I'm a class III phys A!! see....things/status can change fast!

No hospitalization but I had to go in for a PICC and now 6 weeks of home IV antibiotics. Not only is this an inconvenience with timed meds and blood draws, but it affects my livelihood because I can't work on the unit. I planned to pull shifts through Thanksgiving break while off from teaching. At least I can focus on the research. But, a conversation will ensue on how to proceed cardiac-wise. I know the valve has to come out. I can't keep getting endocarditis Q 3- 5 years and I've been tired a lot lately anyway. I just don't want to think about the possibility of OH, especially as I try to finish my research and plan to graduate hopefully next May. Plus, facing major surgery is tough when you live alone.

The EPIC query to capture applicable patients ended up being more challenging than expected. Dr. Carl had a great attitude and powered through. Initial local (P.A.T.C.H) query elicited 17 patients who meet criteria.

November 2022

Finally, by Thanksgiving I had 7 names provided by Dr. Carl to contact. I got 5 who agreed and so I sent the REDCAP link. 1 ended up marking 'no' to consent D/T "no time," while another never did return my call – that patient I was to go through his mother (per MD). She replied from my voice message and indicated she would have the patient (her son) call me later that evening. I waited a few days after not hearing back to follow-up, but no reply this time so I let that be. I never want to be intrusive. As of the last week of the month I had 3 pts who completed REDCAP and scheduled an interview with me! This is exciting!

Nov. 28th:

I got my first interview done and everything went well. Using Zoom both the video and written transcript saved. And when done I sent the e-gift card to the participant's email. He confirmed it was received. One thought I want to reflect on is prior to the scheduled time, probably about 2 hours before, the participant text asking if he could have his mom there because "she knows more about his heart condition" than him. Immediately that hit me. How typical do we see that – There is so much 'cardiac hx.' that the young adult feels they can't explain it. Now, that can be driven by an overprotective parent or.... the innocence of knowing one's limitation, whether that be based on complexity or lack of desire *to know*. Nonetheless, I replied that it's OK if he doesn't recall details about the heart defect itself. I will respect his choice because I want him comfortable to talk with me but engaging with him 1:1 is precisely what this is all about. I want to know about HIM, from HIS perspective as a young adult– things like what HE knows, how he feels, etc. He text back that he was comfortable to talk with me without his mother. Everything moved forward, as planned and I think the interview went well. He appeared comfortable – gave thoughtful responses.

November 30th:

I had my 2nd interview, another male. Interesting point stood out: although he did not bring up or request his mother's presence, he did mention in the conversation that his mom would be the one to talk more about his childhood and to answer questions about his heart.

*later that evening he text to let me know his mom would be happy to talk with me if I did want to take that route. Again, interesting.....*Moms so far appear to be central.**

This individual was amazing – provided deep, rich data. Even a bit emotional – He was so honest, open, and showed his vulnerability; yet such a strong resilient young man. He had a difficult upbringing – aside from having a 'heart defect' so he felt he had to put his needs aside, so-to-speak, to persevere – to be there for others. He had to grow up fast. My take away was he wanted to talk. He took this opportunity and ran with it! It was as if, 'hey someone is listening and is interested, and d so here I go! I want to express all that I have done and all that I have gone through!'

December, 2022

Next day, December 1st: He text again “let me know if you are interested in talking to my mom.” I replied that I do not need to at this time, but may be interested in the future – I did not want to convey rudeness or a lack of gratitude for offering that opportunity. He sent the thumbs up. ☺ He received his e-gift card today too. Later in the evening is interview #3, this will be the first female I talk with. :

start to view ‘exploratory notes’ documented for each participant following their individual interview

Today Dr. Clarkson and I spoke re: the interviews and overall process. I transcribed the 1st interview from Monday and the 1 hr. interview took about 4 hrs. to transcribe. No way around this. Even if I submitted a modification to the ‘bilateral’ IRBs, I would need to make sure the person is CITI trained and, as Dr. Clarkson noted, sometimes it creates more work anyway because you have to make corrections. I agree, especially when dealing with cardiac-related terminology that Word and laypeople could miss or misconstrue.

I’m just frustrated because I definitely want this skill set but it is the formatting and time to type out that I feel takes away from the analysis part (the doing), which is the ‘gold, the *essence*. She reminded me NOT to get caught up in terms of time. Immerse myself in the interviews. Focus of that. Understand them, reflect, engage with my notes. Today we started the Google Drive too. Initially, the hiccup of converting the text from Notepad to Word was figured out after downloading this evening’s Zoom interview. .

I just feel like I frustrated Dr. Clarkson. Her affect and some statements are as if I am under remediation. Like with Qual coding via the shared drive: “I’ll start, but you’ll have to know how to do this.” As if I should know. I do...but this is my first research study – completing each step. As I type..... I am pushing my IV Rocephin through the PICC. Yep, I too am a CHDer.....I feel well and am grateful that I have this resource – avoid hospitalization. Can still move about my day. It feels weird going through the interviews too because I can relate in many ways. The 49-year-old ‘me’ kind of wishes I could go back & share insight with the 23-year-old me. I realize that is human nature. I mean in terms of relationship decisions. It’s tough going through what I go alone, especially since I am aging. And I have no one to talk to about my feelings. My mom claims she’s interested but the conversations and her needs always circle back to her. Even prior ‘heart’ experiences go back to how ‘a sick kid’ affected HER. I guess she’s allowed. But sometimes, just sometimes I wish it COULD be ABOUT me. She hasn’t asked how I’m feeling in quite a while; yet she knows I have endocarditis. My brother has called or text me either. Or knowing I’m divorced and last year my then-boyfriend walked out and never looked back – and just before all the holidays. His reason was he found out his daughter is addicted to Oxys and well, his time needs to be dedicated to her. He didn’t look back. Those circumstances are hard on any girl, but then when faced with health/cardiac issues, ‘aloneness’ is palpable. Heart sick – pun intended. I recall last month when I had to go in to get my PICC and echo D/T the ‘+’ blood cultures, I wish I had a husband/boyfriend who could drive me and be there with me.

Dec. 2nd: The above thought aligns with one of the statements made by today’s participant. Although this conversation tended to be a bit more, ‘I ask, she answers...and with ‘one liners’ – this kind of back and forth...I think our glitch was her weak internet in her house. It’s OK, we got through it and I think she offered great insight. But what I want to reflect on is at the end of our Zoom conversation, she said thank you. She feels she never had anyone care or ask about her heart except her “heart Dr.” Not until she “met me.” She went on to say, “Thank you for asking, and for caring.” That made me smile – knowing that I (and my research) has a ‘+’ impact. .

I wanted to tear up because I often feel that way about ACHD. But more so, more importantly, I know this research is important. Young adults facing life with CHD can feel alone. All of its ‘mandates,’ manifestations (seen and unseen), and the uncertainties it brings, are worth caring about – worth a ‘voice.’

Dec. 3rd: Today one of the patients whom I had tried to schedule, which occurred via his mom, she sent me a text asking if he could do the interview today. I sent the REDCAP link, all was completed, and the Zoom session set. Although he met criteria and consented, I decided NOT to use this interview in the data for my study. Primarily due to the cognitive delays and overall disability. His heart defect falls under the umbrella, ‘DiGeorge syndrome’ so he has multiple conditions (affects his gut, immune system, and mobility). He is delayed in his development. He is NOT able to live independently, does not drive, and currently not working or attending school/classes. He could engage in a conversation, but would frequently refer to his mom, who sat next to him for prompts and assistance, to answer most of the questions. I enjoyed talking with them both and will send a gift card for their time. However, this exchange is not a representative case, considering too my RQ and study objectives.

Walking away & thinking more about this, I realize this may happen. Someone could very well meet criteria; yet not really be a good representation of the phenomenon - have quite the complex hx. because of the heart defect itself; by default. I mean, I have rationalized using those with Class III ‘complex’ CHD. Shall see..... So far though, besides today’s interview, the participants are A/O, fully functioning young adults.

Dec. 5th: Dr. Clarkson replied to my email (I wanted to share with her my feelings of inadequacy and even lack of competence she may have perceived when we spoke. She responded with encouragement – clarified that her affect was out of sympathy, not frustration. That helped me move forward. I guess we need these moments ourselves. Just today I was helping my mom with an outpatient surgery (Lap Nissen) she had. I took her, waited, and got her home. While sitting in the waiting area (took stuff to grade), my brother & sister-in-law were texting to get updates on her. It hit me, why is there never concern for me, and the things I have faced in the past few years of my life, which have been kind of major. I mean, ‘heart’ infections, and earlier this year, abdominal surgery/Hyster. I have not once heard from my brother at any point of my life events. It’s like, does my family even know I am here? Do they care about me, I mean to the point of actually taking a genuine interest in my well-being? Particularly knowing I live alone. Of course, it could be very different if I was here with a husband and maybe even a little family of my own.....a source of support and ‘looking out for me’/after me.’ I don’t want to seem self-focused, but it does make me sad. I feel melancholy.

Dec. 9th: I had the F/U echo and clinic appt with Dr. Carl. As I suspected, he wants to replace my valve, but surgically, not percutaneous. Which means, OH. I am not opposed. I want to feel better. It’s just a matter of when. Nothing urgent but does recommend I do before I contract Endo again. Of course! He made me laugh because his analogy of how my Melody looks is, ‘ugly’ – it’s working but.....it’s not pretty. There is a lady bug and a beetle. They both serve their purpose but the lady bug is pretty, not the beetle. My valve is the beetle. So.... my analogy was a female who is a double bagger. She may have a nice body, serves her purpose (can have babies), but is unattractive (hence, the ‘double bagger’). We want a pretty woman (aka ‘pretty’ valve). His is a pediatric analogy, mine is an adult’s – and kind of funny.

☺ OK, now the plan. In some ways I want to schedule next summer so that I can get through my research and have those couple of months off from teaching. But then there’s a part of me that wants to get it done. It’s winter, I’ll have a few weeks off from teaching (and my spring classes are already set), and hopefully I recover well and feel well to move forward with the research, teaching, etc. Then I have the summer to enjoy life. If I graduate by May or not, I should be on the tail end and have the stamina needed. I guess it’ll depend on the next available date. I’ll be on 6N, which is kind of weird, but OK.

I have to deal with my mother wanting to be in the middle of things, but I will make sure she has my sweet Boomer and maybe have Jane be my ‘person’ while in the hospital. Following Covid, only getting 1 person in the same 24-hr period while in the hospital, and the realities of nursing care (we are so stretched), why not have a close friend by my side who is also a nurse?! Interesting timing to deal with this. I guess it makes this research that much more authentic.....

Dec. 14th: funny....today is the 10-year anniversary of my Melody valve. 😊 The plan is to get the PICC out Thurs. Yea, today is the last day of my Rocephin! Then next week I have a chest CT, followed by a TEE the first week in Jan. Then.....OH is scheduled for Jan. 17th, 2023.

I think this is good since I anticipate feeling much better! I’ll get a PVR and aortic valve repair. Today I text my brother & sister-in-law about surgery indicating that I want a nurse buddy to be my 1-person (D/T Covid) while in the hospital and that my mom can take care of my dog. My brother replied separately ripping me about excluding my mom saying I need to plan for the worse, and that includes leaning on friends to make sure funeral and burial plans are completed since I “isolate family.” I don’t isolate, I just don’t feel accepted and everyone is so critical! No one wants my rationale but as I think and reflect on my own situation as a middle-aged ACHDer, I can’t have family turmoil on top of a major surgery. I will include my mom to the extent she wants, luckily she agrees that Boomer needs to be taken care of too. My brother, as do many adults, do NOT understand my dog is my kid. He is important to me, he IS like family. Plus, with my mom’s recent Lap Nissen, she too has her own health to contend with. I want her to genuinely want to be there for me and care for me, in whichever capacity I need &/or ask – not use for attention seeking or to compromise her own health.

Dec. 21st: I read my echo report in ‘MyChart’ and see what Dr. Carl meant about my Melody valve not looking pretty. Functioning, yes, but doesn’t look great. And the ‘remnants’ of multiple endocarditis episodes. There is still vegetation on the stent, no infection but it’s there. OK, I gotta get this out! Now I feel even more sure to get the surgery. EF is good, 60%, it was only down to 52% during this episode of endo but yeah, this thing is officially worn out. Plus, I don’t want to risk a piece of that dislodging. I have never feared dying, per se. But I do fear of stroking. I had reached out to my ex (a lawyer), and he punted me to one of his law friends who can do a legal, ‘real’ Will and POA forms. He charged \$800 but it’s good to get this done and updated, and done right. I suppose especially considering my brother was one of the decision makers to DC life saving measures, which apparently he forgot. He text that friends would have to make arrangements since I “isolated family.” I guess I couldn’t count on him either. All things happen for a reason. I believe in Providence. So yes, friends will. I did put in there that my mom can arrange my funeral but Jane is my executor – she holds the ‘purse strings.’ 😊 Unfortunate, but it is what it is. Family dysfunction + CHD do not make a good mix. Plus, I am holding off telling my Division Chair because I think she would take my classes away, and I need my livelihood. I need my work, career. That would be such a stressor for me! I know I can work from home since I teach in an online program so unless an adverse event occurs, she doesn’t need to know.. She never knew about the endocarditis or my hysterectomy earlier this year. She doesn’t really talk much with us off-campus faculty. She’s kind of adversarial with me, actually. She doesn’t like me and I don’t know why. Truly. She sends emails as if I am her child. I have tried, I have. She certainly does not facilitate or even show interest for my dissertation. I do this on my own time. This accomplishment will be for Prov SHMC and ISU.

Dec. 29th: I interviewed a couple more this past couple of weeks and just received 2 more to reach out to, per Dr. Carl. I have to make note here as I reflect, I had another interviewee indicate that if I would like to talk with his mom, she would be happy to do so. He had been talking with her about this interview coming up and they both thought she could provide some more detail. I showed the gratitude for both their willingness but emphasized how I really value their (the participant) how they are doing and how life is at this AGE without (likely) their parent(s). Never has it been a disappointment from their end, it’s

more like a way to add to my research, give me more insight. I just think it's interesting that it is specifically 'moms' and has been offered by more than 1.

Another interesting finding as I move along is that I have faced now 2 participants, who either do not know their heart defect or refer to it incorrectly. I had one who put VSD on the baseline questions (via RedCap) and so it prompted me to reach out to Dr. Carl since VSD is not a Class III defect. But sure enough, she had quite a bit more going on clinically. But from her perspective it was a 'hole' in her heart. Then another said he never learned the actual name of his defect, he would have to look it up.

I really haven't faced anyone who declines. I did in the beginning when he/she went into Redcap to complete the consent, declined D/T 'time.' but when Dr. Carl (site MD) was initiating contact there has so far only been 2-3 who either said 'no' or did not call/email him back. One I spoke with just today to discuss the study asked if I could send the questions before we talk so she could prepare. I have yet to run into that! I told her I couldn't mostly because I hadn't offered that to others and I think it would have to go back to the hospital IRB for permission. But it prompted me to inquire why she asked. She simply said that she wanted to know to prepare in case they are personal and wants to make sure she keeps her answers private. I re-emphasized her anonymity and assured her that is exactly why I have to get permission before I can talk with her – both the hospital and University make sure I protect her anonymity. Plus, none of the Drs at the clinic know whether she participates or not and it does not affect her care. She felt better once I explained it and agreed to have the forms sent. I will F/U if I don't see her consent come through in the next few days.

I always share my cell # with the participants so they can reach me anytime (text or call). I have found some reach out for whatever reason, and I like that they are comfortable to do so.

January 2023

Jan 2nd: Interviewed another male today. As I go along applying pseudonym, I typically choose a name who the interviewee reminds me of. At this time, I already had to change one pseudonym because I met a person to interview with that same name (& spelling). It wasn't too bad to change but had to put that into consideration. Today I interviewed a male who reminded me of the TV character, 'Jack Bauer' from the action series, '24.' Funny, but works 😊

Jan. 6th: Had my first TEE. Amazingly through all these years I have yet to go through a TEE. It was fine. Dr. N-----performed the procedure and he is really good. He explained everything, prepared me well and was obviously competent. Even had that 'time out' with everyone in the room to verify me (ID), procedure, etc. It's all good! I can also appreciate his candid affect: He asked me to think about the possibility of a mechanical valve (for the truncal/aortic) considering it would last a life time and now at age, nearly 50. I see Dr. Worrall next week for my surgical consult. Shall see.....

Jan. 8th: Today I am going through one of the female interviews to code and I realized, this is the 1st one that mentions Covid! Yea, this is a surprising finding. Maybe not so much since it has been 3 years but still, would have suspected this would be a more common thread. I definitely understand why my committee directed me to DC the Covid interview question. It's better, more, 'rich' to see if it comes up or not. Now, I have yet to do any cross analyses, but in each of these case by case codings, she ('Lena') is the 1st, and it really was just relevant to scheduling an outpatient stress test, and then she also addressed it out of concern since she has this *heart defect*. She asked her cardiologist for a note to be excused from working the front (food industry) to minimize her exposure to others. She never got Covid but wanted to be careful. Good she was proactive. She is also vaccinated with booster X1.

Jan. 11th: Today's interviewee was the first one where I felt like it took quite a bit or 'prodding', 'nudging' to get her to talk – very simple yes/no answers. I asked point blank if my questions were making her feel uncomfortable and she adamantly said, 'no!' I believed her since she did show an emotional side (teared up), verbalizing that she finds this topic difficult.....so I tapped into something despite her short & sweet responses!

Jan. 12th: Today I had both my presurgical screening and surgical consult. I walk away feeling like I irritated him, which is not a good feeling considering he will have my life in his hands. Literally! I was a bit discouraged too because my size goes against me in terms of surgical risk and post-op complications. And the fact that this will be my 4th OH. Yep, age 49, and although it has been 30 years since my last OH, yes it will be my 4th. Talk about immersing myself into the phenomenon of '*managing life with ACHD!!!!*'. It did kind of hit me as I sat there with my mom (I took her because I wanted to get her to donate blood, which that did not work out), but I wish I could have been sitting there with a husband. Facing these decisions (mechanical vs. tissue valve for the truncal/aortic valve replacement). I could think about that *with him* as my support system. Isn't that where people are middle aged?! I'm alone. And because of my heart I didn't have kids so that too rears its ugly head because if I had, I may be sitting there today with an adult age child with me. But, God has a purpose, and that too guided life outcomes.

Jan. 16th: I oscillated all weekend between tissue vs mechanical. I talked with Dr. Carl yesterday and he advises mechanical. He said something that really resonated with me, not only as a patient, but what it means for my research participants. When it comes to AVR (aortic valve replacement), it is "individualized;" meaning the choice between tissue and mechanical has so much to do with that person's lifestyle, future goals, and activity level. Although mechanical is permanent (no OH), there is so much baggage with it! Weekly INRs, higher risk for bleeding, daily Coumadin, the audible click, holy cow! And.....I'm not eliminating tissue entirely because the PVR is a tissue valve. And I no longer will have the stent (Melody), so hopefully the risk for Endo is minimal. My lifestyle is simple: I enjoy the 'run of the mill' cardio (walking my dog, treadmill/stationary bike). And this will not change. In fact, I must integrate other disease processes as I age: My arthritis for sure! This is systemic, degenerative, and progressive. There is no cure and although Dr Carl reassured I could still take Naproxen PRN, it gives me pause that lifetime Coumadin would impede other conditions/medical treatments. I pray Q day for guidance on the right decision. Tomorrow is the big day. I am to tell Dr. Worrall pre-op which valve I decided on for the truncal/aortic. Not the time to still question.....

February 2023

Feb. 4th It has been a few weeks. In 2 days, I am 3-weeks post-op. I went with the tissue valves for both. I just decided it isn't worth the hassle to live with a mechanical valve. Dr. Worrall was able to place a large enough truncal (a 'juicy cow valve') that the next replacement or repair can be done via a TAVR. The goal: no more open hearts in this life! Age 49 (almost 50) and a 4th OH, my body! Surgery went well but was more extensive than he anticipated. 0 hours with 4 hours on the heart/lung machine. I recall waking up with such a raspy voice from having both the ET tube and TEE probe. That has since resolved. Surprisingly I was assigned travel nurses or newer nurses while on the units. Care was OK. Not bad, not exceptional. I know the realities though. The biggest issue I've had post-op is dysthymias, elevated HR & BP. My poor little heart just won't simmer down. I had a rub too immediate post-op, but that is improving. One day I think I was in rapid A-fib for about 6 hrs.! I know the realities of sitting in an ER so I just toughed it out. Took the PRN Cardizem as often as I could and then I have scheduled Lopressor.

While going through OH Dr. Carl got an additional 3 patients so this is exciting! I just completed the last interview. The study now has a sample size of N=13.

Kinda funny, my interviews were more brief this time. I talked with 2 girls and another 2 guys. The last guy I spoke with was a bit more talkative than the others ; the others were more just ‘to the point.’ They are all indicating they are ‘OK.’ May have some dyspnea but the limitations are not as great as some of my other participants. A few of the questions are very open-ended and can be abstract. Still, I think I got rich data to extrapolate. *Sense making* truly is an interesting construct. It’s going to be very busy as I move forward. I want to use this month to finalize data analysis and begin the ‘discussion’ portion of the project. I have 3 more recently published articles also from Dr. Moons website to include in the lit review (keep that current).

Feb. 12th: I continue to move forward with coding the transcripts. Final N=13. A couple of potential participants did not follow up with Dr. Carl so we can assume there is no interest. I anticipate enough data. Dr. Moons (as did the committee) reinforced the value of the data and reaching saturation more so than ‘numbers.’ I think it’s good – I really believe I tapped into something can and illustrate rich data. Today as I update the demographic table, I realized I could rationalize assigning a physiological stage to each of my participants since staging is intended to be current and based on symptomology. Dr. Carl preemptively let me know that updating the e-charts with patients’ physiological stage (reflect the ACHD guidelines) is still in progress. Therefore, I rationalize assigning based on patient reports and the stage criteria. Interestingly, although all are stable and functioning whether on their own or living at home, none would be classified as Stage A. Likewise, none are so impaired that they are classified as stage D. All of my study participants reported some degree of physical limitations, arrhythmias (3 have perm pacers), and valve disease. Even the need to someday have a transplant or be placed on the transplant list. Basically, sequelae exist. It’s valuable to include one’s stage with the complexity, and supports assigning at the time of data collection recognizing this can change. I look at myself. I was functioning fine and boom! Another episode of endocarditis and subsequently, open heart for valve replacement (X2) and additional defect repair. In a manner of a few months I went from an ‘A,B’ to a ‘C’. I’m improving, of course, post-op but one of the issues I’ve experienced is dysrhythmias and rapid HR. I know I was in rapid A-fib a couple of times after discharge. A little frightening and concerning. That hits me – am I going to be like a lot ACHDers with a device? I see it too on the unit. These arrhythmias are common, necessitating the need for a PPM or AICD. I get it – our hearts have been rerouted, full of scar tissue, and in my *immediate* case, irritable!

Feb. 16th: Today I finished coding the interviews. Dr. Clarkson started her coding as well. Intentionally I am holding off to review her codes until she and I come together to cross analyze. Again, I am diligent to uphold the precepts of IPA – idiographic; to treat each case as an individual analysis. To capture that personal ‘*sense making*.’

Feb. 18th: Today I am reflecting on my interviews as a whole and something that stand out to me is the unpredictability and uncertainty of CHD as an adult. As I listen to each of my participants I think, ‘Oh man, you just never know what that future looks like!’ I mean, when I was in my early 20s I was stable and doing well. Started working full time as a nurse, married, and bought a house! But what little did I know or truly realize what my future looked like: several episodes of infective endocarditis, the joy of getting a pulmonary valve in the cath lab! (good ole advancements), and then at age 49, my 4th OH. This supports existing evidence recommending longitudinal work and studies involving older aged CHDers. Thank you, Dr. Moons for sharing that ‘perspective article’ of a 70-year-old Tet. Yes, pt. perspective is so important!!! I’d be interested in following these participants say 10 years from now and capturing middle-age topics/their overall status at *that time*.

Feb 25-27th: I took these few days to review the transcripts, going back and forth, documenting my thoughts and generating my initial themes. It was upon the multiple reviews that I took the opportunity to intentionally ‘self-reflect’ on the verbatim data. A few statements by the participants that stood out to me were those R/T choosing NOT to have kids out of a conscientious action rather than emanating from MD

advice. And how for the few of those who did, are OK with this decision. One (Jodi) talked about how she's not good with kids and doesn't want them, but loves animals. I can relate to that too. I've always said God didn't put the 'mom gene' in me because having children was never an essential. For many, motherhood is the reason for being. But, having a dog, yes! The few times in my life I was without a pet (dog) were a little empty. I'd take a puppy any day over a toddler. Another statement was by Evan who shared he didn't do well living in Colorado D/T the high elevation (SOB). He could recall immediately feeling better when his parents relocated during childhood. I can relate to him with my experience at age 37 moving to Texas. I too didn't do well in that particular state but not because of elevation, but because of the hot, humid climate.

What comes to mind when these experiences jump out at me is how I feel like I could be the 'ghost of the future' for some of my participants. What little do we know. What little did I know in my mid 20s! They each recognize that their future status is unknown, but in do not necessarily dwell on this fact. Likely perhaps because they are stable in the present. They are OK. I too experienced that. I can extrapolate their *sense making* from these conversations, however. Integrating the past, present, and future to illuminate meaning within their socio-cultural environment. This has been rich!

Feb. 28th: Today was the initial collaboration between Dr. Clarkson and me to begin the group analysis - coding. We simply discussed the overarching 'feel' or impression of the data. We generated a draft of themes with corresponding subthemes. Then as we reviewed together, reflected, and began to place these emerging themes into the context of Arnett's 5 developmental dimensions. That was it for today. We are scheduled to meet again Thurs (3/2) after reflecting on these keeping the 5 dimensions in mind.

March 2023

March 2nd: Today we met again to collaborate on our thoughts of the data and codes created from this initial reflection. As we discussed, we began to group/condense, creating sub-themes within the larger context or theme. But what also occurred at this time was how the emerging themes related to the EA developmental stage. The 'take away' to reflect upon over the weekend is whether our codes fit into one of the five dimensions, or if the dimensions can be placed into each code. What fits best?

March 5th: As I sit here today – as I have all weekend, reviewing and reflecting on the interview transcripts to 'tease' out how the narratives fit into the EA dimensions of development, I came up with a metaphor: Each piece of the data is like a flower. I have a rose, a carnation, a tulip... But now, as things are coming together, I see each of these flowers create a beautiful bouquet, a floral arrangement. This makes me smile.

March 11th: I continue to reflect on the evidence trail – the patient accounts and direct quotes as they come together into the five dimensions of Emerging Adulthood. All preliminary docs are located in the shared Drive for second member (and collaborative) analyses. As I work on the dissertation, I question in which way (how) do I tie in my personal accounts of the phenomenon. What comes to mind is I want to say to all of them: 'I am like a ghost of your future' – instead of the, 'ghost of the past.' As a middle-aged complex CHDer I want to sit down and say to every one of them, 'Hey, this is what could happen; look at what happened to me!'

March 16th: Today I finalized my findings – the data analysis piece. Now it goes back to Dr. Clarkson, as 2nd member. This is one of those areas of IPA that is unique: I am central to the final interpretation; yet analyses must be supported (collaborated) to ensure accuracy of the analysis. I also created a Table to illustrate our group themes and subthemes, which will be placed in the final defense.

March 17th: Together, Dr Clarkson and I reflected back on the subtheme created from the ‘feeling -in between’ dimension of the EA stage. It changed from, ‘*handle limitations on a continuum*’ to, ‘*it is a conscientious continuum*’. This write up was quite extensive – I felt like I was putting every single quote in to substantiate the themes and subthemes (including the baby and the bathtub)! Dr. Clarkson reminded me that this needs to be more narrative, using **exemplar** quotes to support the thematic descriptions. This is where the chosen quotes are my evidence ‘trail.’ I will work on this.....

March 19th: The ‘Discussion’ section (Ch.5) was finalized & sent to Dr. Clarkson. This week involves putting it all together and fixing any recommended edits. Then send the final written defense to my committee members in preparation for the oral defense scheduled April 11th.

References

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Appendix B

Young Adult CHD Eligibility Screen

Thank you for your interest in my research study, ""Managing Life with a Broken Heart: An Experiential Journey into Role Development as a Young Adult with Chronic Congenital Heart Disease." Please answer the following set of questions which will help determine if you are eligible for participation.

Are you between the ages of 22-25 years old?

Yes

No

Please enter your age

Do you have a complex or severe congenital heart defect?

Yes

No

Name of your heart defect

Have you had open heart surgery and/or procedures for your defect in the cath lab after age 3?

Yes

No

Have you been told that you will need to follow up with a congenital heart specialist for the rest of your life?

Yes

No

Do you have access to a computer or smartphone with teleconference capability?

Yes

No

Do you think you can sit through 1 to 1 1/2 hours for an interview, using Zoom?

Yes

No

Appendix C

Young Adult CHD Study Baseline Questions

What was your gender assigned at birth?

Male

Female

Race

Black

White

Asian

Native American/Alaska Native

Native Hawaiian/Pacific Islander

Select the ethnicity you most closely identify with:

Hispanic or Latino

Other

State residence

Washington

Idaho

Montana

Oregon

Other

Please indicate your other state of residence_____

The number of hospitalizations over the past 36 months (3 years):

None

1-2

More than 2

The number of months or years since your most recent hospitalization

Less than 6 months

6 - 12 months

13 - 24 months

Greater than 24 months (2 years)

How many medications do you take on a DAILY basis (include over the counter)?

0

1-2

3-5

Greater than 6

Appendix D

Semi-structured Interview Guide

The following inclusion criteria include: 1. Diagnosed with complex CHD (Class III, physiological stage A,B,C, or D). 2. Recommended to continue life-long cardiac surveillance. 3. Have a history of at least one open heart surgery and catheter-based (cath lab) intervention(s) after age three. 4. Age 22 to 25, 5. Fluent in English, and 6. Cognitively capable to verbally engage for an interview.

Western society permits a delay in full adult roles and responsibilities. It is during the transitional period (EA) that individuals engage in explorative activities with little social constraints to gain the skills they will need as *adults* (Arnett, 2010; Reifman et al., 2007) precisely between the ages of 18 and 25. For the purpose of this study, the upper end of the emerging adult age range (22-25) is used to explore the unique challenges at a time when the individual is closer to adulthood than adolescence - when most of these transitional experiences are nearly complete (Arnett, 1998). Guided by the five (5) dimensions of Emerging Adulthood (Arnett, 2015) and the qualitative philosophy of Interpretative Phenomenological Analysis (Smith & Nizza, 2022), the semi-structured interview questions are organized in a way that addresses the developmental variables of personality, relationships, and structure to extrapolate one's *sense making*:

- Identity exploration (who they are and what they want out of life. Primarily love and work).
 - ***Who am I?***
Prompt: Describe your sense of self. Your personality.
 - ***I understand myself to be.....***
Prompts: What is your place, how do you fit in?
What is your own extension in the world?

- Instability (make plans but expect revisions due to explorations of options. With each decision comes clarification for their future).
 - ***What are the limits of your body?***
 - Prompt: Do you believe any of these are because of your heart defect?
 - ***Do you have other chronic medical conditions? If so, describe.***
 - Prompt: How does affect your life?
- Self-focus (few obligations to others. Little commitment. Time to learn and gain skills for daily living). Adulthood goals: 1. accept responsibility for self, 2. make independent decisions, 3. become financially independent (Arnett, 2015, p.15)
 - ***Talk about your social circle/support network***
 - Prompts: How are you different from others?
How is your life similar to others?
 - ***Describe your CHD as it relates to an ‘illness.’***
 - Prompt: How is the ‘beating heart’ part of you?
- Feeling in-between (not an adolescent, not an adult. Progression is gradual)
 - ***Talk about your childhood experiences with CHD to now***
 - Prompt: Discuss your parents and their role(s)/influence memories that stand out (good or bad)
 - ***What does the term ‘adult’ mean to you?***
 - Prompts: Do you feel independent in your choices and decisions?
How did you get here?
 - ***What age did you transfer to an adult CHD doctor? If you haven’t yet, discuss why.***
- Possibilities/Optimism: Different ‘futures’ are possible. A time of hopes and expectation while nothing is certain or fully tested. Envision a good job, marriage, and children.
 - ***What does your future look like?***
 - Prompts: What do you want/envision your life to be?
 - ***What is to be determined?***

Appendix E

PI Coding Participant # 7 ('Isiah')

Exploratory notes/comments	Original text/transcript	Experiential statements/emerging themes
<p>Not a disease BUT <i>messes</i> with his ability to “perform.” Contradictory statement.</p> <p><i>Steep effect</i>, not sure if this is an important meaning, but it is an interesting term used.</p> <p>Regulated, pace, self-imposed – key terms here!</p>	<p><u>Line 51,52</u>: “I’ve never really viewed it like kinda as a disease. It definitely does mess with my fiscal like ability to perform.” -clarified he meant, ‘physically.’ “but that too!” “I think about that because of all the bills I am starting to pay” (<u>line 404</u>) and “I have to be able to provide for myself and take care of myself” (<u>line 411</u>) <u>Line 70</u>: “affects my day to day life.” Line 336: “I’m just some 23-year old guy with a heart defect”. [CHD] “definitely a huge part of who I am” (<u>line 338</u>). I am “a son, a heart patient, a friend.” (line 365).</p> <p><u>Line 105, 107</u>: “I have to limit myself. It’s a “steep effect.” “I have to be careful.” Can exercise “at his pace” (<u>line 129</u>) and again, <u>line 139</u>: “pace myself and rest.” And “regulated” (<u>line 133</u>). “Umm, that was self-imposed” (line 318). “Used to doing what it takes to keep this in check”(line 339).</p>	<p>Disease [CHD] is central</p> <p>Self-regulates Paces as a protective mechanism. He self imposes.</p>
<p>Interesting term used to describe the surgical intervention(s)/status.</p> <p>May not be important, but he changes often between past tense and present tense when describing his body limits. My thought: IS....or...WAS a limitation?</p> <p>Effort put forward to be healthy.</p> <p>Some conflicting statements though.</p>	<p><u>Line 68</u>: Rewired. “so it would pump the blood so it could get to my body.” <u>Line 213</u>: “I’m just wired differently.”</p> <p>“I could never do anything physical” (<u>line 102</u>) “we want to keep my heart as calm...and as healthy as possible” (<u>line 107</u>)</p> <p><u>Line 596</u>: “I was told I was pre-diabetic.” “and it was fairly recent” (<u>line 741</u>). <u>Line 611</u>: “I have to stay healthy.” <u>Line 619</u>: “keep on top of all that.” “It kind of sucks at times” (<u>line 547</u>). “So this has been. Not that bad” (<u>line 619</u>).</p>	<p>I’m wired differently</p> <p>A conscientious effort/actions</p>

<p>1st time he mentioned depression – not until he discussed his meds. Hmm?</p> <p>does he talk about depression anywhere else?</p> <p>What is 'normal'? stamina' is an important term (I suspect)</p> <p>May not be important, but he says "your" friend, not 'a' friend. Perhaps that infers those he chooses/is comfortable with?</p>	<p>"The only other medication that I take is actually for depression" (line 699).</p> <p>Line 69, 101,103,153: low "stamina" "I just can't run that far" (line 522).....Line 104: "I can't run like a normal person." Line 157: "I can on the surface. I'm the same as anyone else."</p> <p>Line 420: "I can't stand for as long as the average person"</p> <p>Line 158: "I have a heart defect. Please don't push me."</p> <p>Line 375,376: "I'll be whatever I need to be at the time. I'll go be a student. I'll be a patient. I'll be your friend." I'll just sit in my room and be a loner"</p>	<p>Low stamina</p> <p>Life emerging</p>
<p>His CHD seems to stand out. At least at this point.</p> <p>Acceptance? In which way, how?</p>	<p>Re: the presence of other chronic conditions, Isiah responds, "Not really...the heart defect is the biggest thing" (line 120).</p> <p>Line 184: "I've definitely come to terms with it." [CHD]</p>	
<p>Shows perseverance, despite his limitations.</p>	<p>Line 139: "I can still do the job"</p> <p>Line 487: "I'm optimistic about keeping on this heart for a good long while." Line 522: "I'm not that different from other people".</p>	<p>I can do it!</p>
<p>'sick' years. Describes symptoms R/T his 'defect'. A CHD manifestation, or perhaps psychosomatic?</p> <p>The dizziness & vertigo were not included in his original list of symptoms until later in the interview (R/T to his inability to drive <i>until</i> recently).</p> <p>Childhood [dev. stage]/time in his life seems to really stand out. Not noted as present TODAY. When prompted to describe NOW, he went back to his school days.</p>	<p>Line 146: "I was a very sickly kid."</p> <p>Line 147,148: "I would suffer from anxiety." Horrible episodes of nausea or stomach aches."</p> <p>"Dizzy spells" (line 302). "eventually started having vertigo but then they kinda started tapering off" (line 303).</p> <p>Line 153,180: "I couldn't fit in. "wasn't sure how to fit in." Line 164: "I had a rough time at public school." Line 170: "it affected pretty much everything." Line 172: "my heart defect contributed to my shyness and</p>	<p>CHD affects life.</p> <p>Self is CHD</p>

<p>Mesh/mash?? As in... doctors.... or could it infer his health? What is he using this term to describe?</p> <p>‘Weird’ is used a few times too.</p>	<p>apprehension to talk to others.”<u>Line 188:</u>”I abstained from a lot of field trips.</p> <p>Terms used to describe his CHD are, “didn’t really mash well.” and “It’s like a mesh“ (<u>line 229</u>) and “like this mesh” (<u>line 247</u>). “Get all rubbed up” (<u>line 189,190</u>).</p> <p>“felt weird” (<u>line 179</u>). “It’s been a rocky, weird road” (<u>line 493</u>).</p>	
<p>Present-tense used to describe playing in the band.</p>	<p>“can’t do a wind instrument. Even now.” (<u>line 196</u>)</p> <p>“I’ll never be up there with someone who has a regular heart” (<u>line 212</u>)</p> <p>‘I’d have to be accommodated in most positions”(line 418). “I need a little more accommodations”(line 426).</p>	<p>But now....</p>
<p>Use of metaphors &/or analogies to compare himself to others or his defect.</p>	<p><u>Line 204:</u> “blowing a balloon to me is harder than it would be for a normal person.”</p> <p><u>Line 503:</u> “used to keeping in my lane.”</p> <p><u>Line 548:</u> “gave me a little leash so I’ve been able to drink some caffeine” (referring to his Dr.).</p> <p><u>Line 776:</u> “I’m just like one piece of the puzzle.”</p>	
<p>Chooses to describe now vs. ‘growing up’ with CHD when prompted about his social network.</p>	<p>“she has been there the entire time. She’s my biggest advocate” [mom] (<u>line 278</u>). “even to this day she’s just on it” (<u>line 282</u>). “Got me to my appointments; make sure I have meds” [family, friends] – <u>line 287,288</u></p>	<p>People look out for me</p>
<p>When describing some of his symptoms he refers to them as kind of not well understood. Interesting.</p> <p>Despite these experiences is he content?</p>	<p>“I don’t think it’s as much of a heart thing as it is some unknown medical mystery” (<u>line 300</u>). Really, “that was less of a heart and more of a ‘we really don’t know” (<u>line 312</u>).</p> <p>“I’m just really grateful that I’m still here” (<u>line 492</u>)</p> <p><u>Line 493:</u> “it’s definitely been worth it.” <u>Line 504:</u> “it doesn’t feel new or hard to cope with any of this anymore.” <u>Line 517:</u> “I don’t know</p>	<p>Grateful Power through Self as <u>not</u> normal, but <i>will normalize</i></p>

	<p>the average awkwardness of my age group but I feel like I'm there."</p> <p>"If I was born a couple of years earlier I probably wouldn't have made it because technology is advancing all the time" (line 540,541)</p>	
<p>The term 'adult'</p> <p>On his own, yet has support. He's not 'alone'.</p> <p>'current' (present) vs. future and what that may or may not look like.</p> <p>Hope is a key concept, I think.</p>	<p>Initial response, "pain" (line 396). "I have to get myself to these places. "I pick up the meds" (line 442). "It's definitely all on me" (line 405, 446); yet "doesn't have to be"</p> <p><u>Line 433,434</u>: "still coming into my own kind of, new to all this" "at some point. My heart's very healthy at this current point" (line 462). "keep on this heart for as long as I hope I can" (line 480).</p>	<p>Ambivalence The unknown (process)</p>