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Psychological Factors Related to Physical Activity in Adult Congenital Heart Disease

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Abstract

Adults with congenital heart disease (ACHD) are a new and growing medical population. While medical interventions previously focused on reducing rates of infant mortality, current research suggests increased risk of premature mortality in adults with CHD may be partially due to acquired cardiovascular disease. One lifestyle intervention to reduce acquired cardiovascular risk is physical activity. Physical activity has been supported in the research as a safe, efficacious, and tolerable intervention for many ACHD; however, most patients do not engage in recommended levels of physical activity. The purpose of this study was to investigate psychological factors related to physical activity in ACHD. Participants were recruited from social media websites and research groups for ACHD. Results indicate approximately three-quarters of the total sample achieved or exceeded physical activity guidelines. A majority of participants reported prior conversations with their treating medical providers about risk for acquired cardiovascular disease and physical activity. Each psychological factor, including cognitive and emotional factors, was significantly related to physical activity except perceived susceptibility to cardiovascular disease and heart-focused attention. A hierarchical linear regression suggests Protection Motivation Theory is an appropriate theoretical framework to conceptualize physical activity in ACHD. These findings can inform patient self-management of disease and acquired disease prevention as part of comprehensive ACHD healthcare.

Keywords: adult congenital heart disease, physical activity

Psychological Factors related to Physical Activity in Adults with Congenital Heart Disease

Congenital heart disease (CHD) is a group of defects that affect the structure or function of the heart or major blood vessels (American Heart Association, 2020). CHD is the most common medical defect at birth (Centers for Disease Control and Prevention, 2019), occurring in approximately 1% of live births in the United States (Benjamin et al., 2018) and worldwide (Zhao et al., 2019). From 1999-2006, approximately 48% of pediatric CHD patients died in infancy (age < 1 year; Gilboa et al., 2010). Today, the widespread implementation of advanced surgical procedures has enabled an estimated 90-95% of CHD patients to live into adulthood (Mandalenakis et al., 2017) and 84.1% of CHD patients across the spectrum of disease complexity to live to age 40 years (Moons et al., 2010). As a direct result of the decreasing mortality rate in pediatric care, adults with congenital heart disease (ACHD) currently outnumber pediatric CHD patients (Gilboa et al., 2016) and constitute a significant portion of the general population (i.e., 0.3-0.8% of adults worldwide; Bouma & Mulder, 2017). ACHD constitute a new and growing medical population.

The novelty of ACHD is due to their recent emergence as a medical population as well as their unique medical profile. CHD is classified into eleven defect types and four levels of functional severity (Stout et al., 2019). Although congenital heart disease originates in utero, congenital heart disease in adulthood is a chronic medical condition. Current guidelines from the European Society of Cardiology (Baumgartner et al., 2010; Miltner et al., 2014), American College of Cardiology and American Heart Association (Stout et al., 2019), and International Society for Adult Congenital Heart Disease (Webb et al., 2015) stipulate most ACHD engage in lifelong management of their congenital defect to reduce the potential for health complications. Disease self-management may include routine medical appointments at specialized centers, mental health and lifestyle counseling, regular cardiac assessment, or additional surgeries throughout adulthood (Stout et al., 2019). In addition to management of CHD as a chronic disease, research has recently identified an increased risk for acquired cardiovascular disease in this patient population.

Epidemiological studies indicate approximately 70-80% of ACHD have at least one cardiovascular risk factor, such as systemic or pulmonary hypertension, hyperlipidemia, hyperglycemia, and obesity (Lui et al., 2017; Bouma & Mulder, 2017). ACHD patients also present with similar rates of Type II diabetes (4-8%; Dellborg et al., 2015; Deen et al., 2016) and metabolic syndrome (15%; Niwa, 2019) compared to the general population. In conjunction with structural and functional cardiac anomalies present at birth, these acquired cardiovascular risk factors contribute to the development of additional cardiovascular disorders, a family of diseases that constitute a full two-thirds of patient deaths in ACHD (Verheugt et al., 2010; Koyak et al., 2012; Engelings et al., 2016; Yu et al., 2018; Vehmeijer et al., 2018).

Cardiovascular risk factors can increase the potential for ACHD to acquire additional cardiac conditions later in life (e.g., arrhythmia, heart failure, sudden cardiac death) due to complications or interactions with their congenital defect (Ryan et al., 2015; Cuypers et al., 2016; Frogoudaki & Gatzoulis, 2018; Moore et al., 2018; Lui & Bhatt, 2019). Arrhythmias, which encompass a range of heart rhythm abnormalities, is one of the most prevalent type of medical comorbidity and cause of mortality among ACHD

(Khairy, 2016; McLeod, 2017). Likewise, heart failure accounts for 17-30% of mortality (Guccione et al., 2018; Yu et al., 2018) while sudden cardiac death accounts for approximately 20% of deaths in adulthood (Avila et al., 2017). Research has shifted to examine the pathophysiology of acquired cardiovascular disease in this population as a result of the increased prevalence of cardiovascular risk factors (Tutarel, 2014; Giannakoulas & Ntiloudi, 2017; Roberts & Gatzoulis, 2017; Awerbach et al., 2018; Steiner & Kovacs, 2018). Following predominantly successful management of congenital defects at birth, many ACHD and their providers must manage the risk of acquired heart disease and premature mortality throughout adulthood.

Acquired cardiovascular disease risk factors (e.g., hypertension) and adverse cardiac events (e.g., sudden cardiac death) are determined by a combination of modifiable and non-modifiable factors. One modifiable lifestyle risk factor for acquired cardiovascular disease is physical activity. Previous research estimates approximately one-half of acquired cardiovascular disease in the general population results from physical inactivity (Mok et al., 2019). Recent data indicates engagement in moderate physical activity for 150 minutes per week reduces all-cause mortality by 22% (Lear et al., 2017) and delays mortality by approximately four years among healthy adults in the United States (Borrell, 2014). Further, a dose-response relation indicates every additional fifty minutes of physical activity per week results in an additional 15-19% reduction in cardiovascular disease mortality (Piercy & Troiano, 2018). For these reasons, physical activity is recommended by the American Heart Association (2020) as both a primary and secondary intervention to reduce potential for cardiovascular disease acquisition and adverse cardiac event occurrence or reoccurrence, respectively.

Physical Activity

The World Health Organization defines physical activity as “any bodily movement produced by skeletal muscles that require energy expenditure” (2020, para. 1). Physical activity is an umbrella term that includes both physical exercise and non-exercise physical movement (e.g., leisure activity, work, walking) and consists of all behavior apart from sitting or lying down. Physical activity can be further categorized by type, including aerobic activity (e.g., running, bicycling), muscle-strengthening activity (e.g., lifting weights), and stretching (e.g., yoga; American Heart Association, 2020). Exercise, as a subtype of physical activity, is defined as activity that is planned, structured, and intended to “maintain or improve a physical health outcome” (National Heart, Lung, and Blood Institute, 2020). It is important to identify the similarities and differences between exercise and non-exercise physical activity in research and healthcare.

Caspersen, Powell, and Christenson (1985) were the first health researchers to delineate between exercise and non-exercise physical activity. The constructs are similar in that both may be comprised of “mild” to “vigorous” intensities of activity that require a range of energy expenditure. In terms of differences, the authors argued exercise is structured, repetitive, and intended to maintain or improve physical fitness outcomes. While recent research reinstituted the distinction between exercise and physical activity in epidemiological measurement (Ozemek et al., 2018; Fletcher et al., 2018), the preponderance of earlier literature has focused on cardiovascular fitness as the outcome of each activity.

Any type of physical activity results in a degree of energy expenditure that could benefit cardiovascular health. Intensity, duration, and type of physical activity, rather than the intentionality underlying engagement, are essential components of cardiovascular outcomes (Myers et al., 2015; Harber et al., 2017; Ozemek et al., 2018). Cardiovascular benefit may be achieved without intention to do so, such as during the performance of labor-intensive household activities (e.g., heavy gardening) or work (e.g., manual labor). The inverse relation also supports general physical activity as a benefit to cardiovascular health. For example, the absence of physical activity, or sedentary behavior, has been identified as a risk factor for cardiovascular disease and mortality (Warburton & Bredin, 2017; Winzer et al., 2018; Lavie et al., 2019). Evidence indicates increased rates of non-exercise physical activity are associated with reduced frequency of cardiovascular events (e.g., sudden cardiac death; Arem et al., 2015; O'Donovan et al., 2017; Hagnas et al., 2018). Examination of all types of physical activity, as opposed to physical exercise, allows for the exploration of both intentional and incidental activity to promote cardiovascular health.

Physical activity in this study is defined according to the World Health Organization: "any bodily movement produced by skeletal muscles that require energy expenditure" (2020, para. 1). Physical activity refers to aerobic activity (e.g., walking, jogging, swimming, bicycling) rather than muscle-strengthening activity (e.g., weightlifting), as aerobic activity has a stronger association with cardiovascular health (American Heart Association, 2020). In addition, aerobic activity is classified according to intensity and duration of activity, where intensity is estimated by metabolic equivalents or METS of an activity. The current recommendation of the American Heart Association is 10 MET hours/week of aerobic physical activity (2020). This weekly guideline can be achieved through approximately 3.3 hours of walking (3 METS), 2.5 hours of moderate intensity activities (4 METS), 1.25 hours of vigorous intensity activities (7-8 METS), or any combination of these activities for at least 10 minutes at a time. Although the relation between physical activity and cardiovascular health is complex in adults with congenital heart disease, the guidelines listed above for the general population are considered appropriate for the majority of ACHD (Chaix et al., 2016; Mantegazza et al., 2017; Kovacs et al., 2018). For this reason, the current physical activity recommendation from the American Heart Association (2020) will be used as the standard by which to evaluate prior physical activity research in ACHD.

Physical Activity in ACHD

Epidemiological Rates of Physical Activity

Medical providers previously restricted physical activity among CHD children and adolescents due to perceptions of dangerousness (Van Hare et al., 2015). As a result, a generation of adult CHD may receive conflicting messages about the appropriate of physical activity for their cardiac defect. Previous research yields inconsistent findings about epidemiological rates of physical activity in adult CHD patients. Several studies found approximately one-quarter of ACHD met physical activity guidelines (24%-31%; Dua et al., 2007; Tikkanen et al., 2013; Bay et al., 2017; Lyle & Hartman, 2018; Larsson et al., 2019; Connor et al., 2019). One study observed a negative relation between NYHA functional class and physical activity, as 77% of Class I patients, 84% of Class II patients, and 100% of Class III patients did not meet physical activity guidelines (Dua et al., 2007).

By contrast, other studies conclude ACHD are physically active. A German group of researchers reported 50% of ACHD engaged in “health-enhancing” levels of physical activity in the past week (Muller et al., 2017). A second study observed a non-significant difference in weekly energy expenditure between ACHD and a control group of healthy adults (Prapavessis et al., 2005). In the only study that observed participants exceeding physical activity guidelines, fifteen young ACHD recorded an average 26 minutes/day of moderate-to-vigorous physical activity (McKillop et al., 2018).

Medical factors, such as functional status, appear inherently relevant to physical activity in ACHD. However, previous research pertaining to epidemiological rates of physical activity remains inconclusive. One potential reason for these equivocal findings may be inconsistent implementation of current physical activity guidelines. For example, Bay and colleagues (2017) classified rates of physical activity into “low” and “high” physical activity groups based on 3 METS/week cut-off while a 5 METS/week standard proposed by the Compendium of Physical Activities has been implemented in another study (van der Bom et al., 2015). These physical activity guidelines are significantly below the 10 METS/week presently recommended by the American Heart Association (2020). A second potential reason is related to cultural differences among participants. Specifically, samples of German ACHD (Muller et al., 2012; Muller et al., 2017) appeared more active compared to their counterparts in the United States (Dua et al., 2007; Tikkanen et al., 2013). Differences in physical activity have also been observed in international samples of ACHD (Ko et al., 2019). Assessment of epidemiological rates of physical activity can be improved through consistent application of current guidelines and contextualization of the guidelines in relation to cultural norms.

Safety, Efficacy, and Tolerability of Physical Activity in ACHD

Guidelines from the European Society of Cardiology and American Heart Association state regular physical activity or exercise at appropriate levels should be recommended by all ACHD providers (Longmuir et al., 2013; Budts et al., 2013; Stout et al., 2019). Research into the safety, efficacy, and tolerability of physical activity in ACHD support this dictum and underscore its implementation as a primary intervention for acquired cardiovascular disease.

First, physical activity is safe for the majority of ACHD. Although cases of sudden cardiac death among cardiac patients during physical activity are well-documented in the media (Campbell, 2016; Mayo Clinic, 2017), such examples are rare outcomes in ACHD. Duppen et al. (2013) reviewed 31 studies of exercise programs involving 621 children, adolescents, and adults with CHD. Results indicated less than 1% of participants experienced an adverse cardiovascular event, at least one of which occurred during non-exercise activity (Cordina et al., 2013). In a separate study, Koyak and colleagues (2012) found less than 2% of instances of sudden cardiac death occurred during exercise. Evidence from an epidemiological study of sports participation (Dean et al., 2015) and a feasibility study of a physical activity program (Lyle & Hartman, 2018) indicated no association with physical activity and adverse cardiac events. Accordingly, a recent review of sudden cardiac death studies concluded, “sudden cardiac death occurs more commonly at rest than with exercise in patients with CHD” (de Ferranti & Krieger, 2019; p. 3). The association between exercise and adverse cardiac outcomes in ACHD appears relatively weak.

Second, physical activity is efficacious to improve cardiovascular health outcomes. Exercise capacity, defined as “the maximum amount of physical exertion that a patient can sustain” (Goldstein, 1990), is a common measure of cardiovascular fitness that can also be utilized to monitor the effects of physical activity (Korpelainen et al., 2016). Exercise capacity has a strong negative relation with hospitalization and mortality both in the general population (Mandsanger et al., 2018) and ACHD (Stout et al., 2019). Measures of exercise capacity include maximal oxygen intake (peak VO2), Oxygen Uptake Efficiency Slope (OUES), and activity-associated energy expenditure (AAEE). Importantly, exercise capacity can often be improved through targeted exercise interventions (Anderson et al., 2017). For this reason, interventions designed to improve exercise capacity in ACHD may reduce cardiovascular risk.

Research on the efficacy of physical activity in ACHD has primarily consisted of exercise training and cardiac rehabilitation programs designed to increase exercise capacity. Eight studies demonstrated improvements in exercise capacity among ACHD in exercise programs (Therrien et al., 2003; Lichtman et al., 2008; Cordina et al., 2013; Winter et al., 2011; Dua et al., 2010; Gierat-Haponiuk et al., 2015; van Dissel et al., 2019). A twelve-month rehabilitation program resulted in improved exercise capacity and subsequent step-downs in NYHA functional class among participants (i.e., Class III to Class II; Martinez-Quintana et al., 2010). One study recorded null findings related to pre-post exercise capacity three years after the conclusion of a ten-week exercise training program (van der Bom et al., 2015).

Exercise programs appear predominantly efficacious to increase exercise capacity in ACHD. Evidence suggests individualized exercise programs are efficacious for patients with complex defects or severe functional impairment (Dua et al., 2010; de Ferranti & Krieger, 2019).

Further, gains in exercise capacity can be achieved through exercise programs that vary in time, intensity, and type of aerobic exercise. For example, programs ranged from daily 5-minute exercise periods over ten weeks (Dua et al., 2010) to 60-minute exercise intervals within a twenty-week training program (Cordina et al., 2013). The study that measured null findings compared pre-program exercise capacity to exercise capacity three years post-program (van der Bom et al., 2015). This finding suggests that while exercise programs may be efficacious, maintaining cardiovascular fitness outside of exercise programs represents a separate yet essential treatment target in comprehensive ACHD healthcare.

Third, exercise programs appear tolerable for ACHD. Participant drop-out rates range between 0-31%, while four studies reported program completion among all participants (Therrien et al., 2003; Lichtman et al., 2008; Martinez-Quintana et al., 2010; Gierat-Haponiuk et al., 2015). Reasons for discontinuation of the exercise protocol included too much perceived commitment, personal circumstances, lack of time or interest, and engagement in other activities, among other unknown reasons. Rates of participation in ACHD exercise programs are higher than rates in general cardiac rehabilitation programs, in which approximately one-third of patients complete the protocol (Ruano-Ravina et al., 2016). In combination with safe outcomes, high rates of completion and low drop-out rates suggest structured exercise programs are tolerable for most ACHD.

Research on exercise programs provides evidence for the safety, efficacy, and tolerability of physical activity in ACHD. Physical activity, as a larger construct that includes exercise, encompasses repetitive and intentional activity as well any daily activity in leisure or work that may produce energy expenditure. The gains in cardiovascular health that may be achieved through participation in exercise programs legitimize the need for further study of all types of physical activity in ACHD. Epidemiological evidence suggests ACHD present with an increased risk for acquired cardiovascular disease compared to the general population (Deen et al., 2016; Lui et al., 2017; Niwa, 2019). Although physical activity is generally safe and efficacious to increase cardiovascular fitness in a majority of ACHD (de Ferranti & Krieger, 2019), many patients do not engage in recommended levels of physical activity (Larsson et al., 2019). It is likely, therefore, that psychological factors contribute to low physical activity beyond what variance can be explained by medical symptomology.

Barriers to Physical Activity in ACHD

Medical Factors

Evidence indicates physical activity is a safe and efficacious intervention to reduce cardiovascular risk for most ACHD. Nonetheless, medical factors likely affect rates of physical activity in select patients. For example, cyanosis at birth or corrective surgery in childhood is correlated with reduced exercise capacity (Gierat-Haponiuk et al., 2015) Patients with specific cardiac abnormalities (e.g., hemodynamically significant arrhythmia, aortic dilation), cardiac devices (e.g., pacemakers, defibrillators), or who take certain medications (e.g., anticoagulants, beta-blockers) may require less rigorous physical activity (Stout et al., 2019; de Ferranti & Krieger, 2019). Structural or functional cardiac defects may cause subsequent physical limitations in ACHD. Impaired skeletal muscle function (e.g., heel lift, shoulder flexion, knee extension; Kroonstrom et al., 2014), reduced respiratory muscle function (Sandberg et al., 2015), or general muscle deconditioning can inhibit physical activity (Mantegazza et al., 2017), especially among patients with complex lesions (Sandberg et al., 2015). The evidence is unclear about the precise physiological mechanisms that contribute to reduced exercise capacity in ACHD given the overlap between congenital and acquired cardiac factors. A study by Warnes et al. (2008) estimating approximately 30% of physical activity can be explained by current cardiac symptomology suggests non-medical explanations may underlie low rates of physical activity in ACHD.

Health Care System and Environmental Factors

Beyond medical factors, ACHD may encounter a variety of healthcare-related barriers to physical activity. First, a preliminary barrier is inadequate patient knowledge about cardiovascular risk or physical activity. Previous research estimated 40% of ACHD may not possess sufficient knowledge about their defect (Moons et al., 2001). Similarly, only a minority understand their risk for cardiac complications (e.g., endocarditis; Janssens et al., 2014; Jackson et al., 2015; Hays, 2016) or that lifelong cardiac care may be necessary to manage their condition (Fernandes et al., 2019). In terms of physical activity, less recent research suggests 30% of patients may not be aware of appropriate physical activities for their cardiac defect (Moons et al., 2001). The same proportion of ACHD have been previously advised against physical activity by providers (Swan & Hillis, 2000). Researchers have speculated providers may hesitate to prescribe physical activity due to the perceived potential for adverse cardiac outcomes (Budts et al., 2013), although this explanation has not been examined in the literature. Inadequate patient knowledge could result in poor self-management of ACHD and increase subsequent risk for acquired cardiovascular disease. Basic research is required to assess the prevalence and content of physical activity prescription among ACHD providers.

Second, barriers in the physical environment are likely to impede physical activity. There is a negative correlation between physical activity and environmental barriers (Salvo et al., 2018), possibly owing to differences in socioeconomic status. Individuals of middle or high socioeconomic status typically have greater access to spaces conducive to physical activity (e.g., gym, sidewalks, parks; Hobbs et al., 2018) as well as higher levels of educational attainment (Schüz et al., 2017). A study of English ACHD indicated a negative correlation between distance to the nearest fitness center and exercise capacity (Diller et al., 2013). Similarly, low household income has been associated with decreased perceptions of physical functioning among ACHD patients (Jackson et al., 2017). For these reasons, ACHD providers should assess and prescribe physical activity with respect to the physical environments and demographic backgrounds of their patients.

Previous research has focused on medical factors to explain reduced physical activity in ACHD. However, cardiac symptomology and complexity should only be considered a partial explanation. In addition to medical factors, patient knowledge, environmental barriers, and demographic factors likely contribute to physical activity in ACHD. Although not previously investigated, physical activity may also be inhibited by cognitive and emotional factors.

Cognitive Factors

Cognitive factors may influence physical activity in ACHD. The first cognitive factor addressed in this paper is self-perceived health. Patients may cite a variety of medical and psychological components within their overall perception of health, such as medical status, functional capacity, distress and well-being (Ware et al., 2007), and vulnerability to acquired disease (Visscher et al., 2017). For example, ACHD may view themselves as “fixed” or having “overcome” their disease due to corrective surgery at birth, especially in patients who do not experience cardiac symptoms (Saidi et al., 2007; Harrison et al., 2011). In this model, attenuation of medical symptoms associated with the congenital defect may increase self-perceptions of health.

Alternatively, there is ACHD have reported higher self-perceptions of physical health than other chronically ill patients (Berghammer et al., 2013) and equal to self-perceived health of healthy controls (Moons et al., 2006). Several studies have demonstrated a positive relation between physical activity (Dua et al., 2010) or sports participation (Ko et al., 2019) and perceived health status in ACHD. Patients with high self-perceived health may experience the “disability paradox” in which individuals with chronic illness adapt to functional limitations and focus on their capabilities in the context of their disease (Albrecht & Devlieger, 1999). While self-perceptions of health may vary among ACHD, inaccurately low or high perceptions may result in inappropriate acquired cardiovascular disease risk management through under-engagement in physical activity.

In the context of self-perceived health, patients may not hold accurate beliefs about their exercise capacity. Previous studies have measured significant discrepancies between self-reported physical functioning and expected exercise capacity in ACHD

(Gratz et al., 2009; Buber & Rhodes, 2014). Patients who overestimate physical functioning may engage in activities that are potentially dangerous to cardiac functioning (e.g., contact sports; Dean et al., 2015), while patients who underestimate physical functioning may unnecessarily restrict engagement in physical activity (Van Hare et al., 2015). Exercise capacity can be approximated through NYHA functional classification (Bredy et al., 2018; Das et al., 2019), and should therefore be communicated to patients in order to enhance accuracy of self-perceived health and applicability of subsequent physical activity.

A second cognitive factor, outcome expectations, may be important to understand epidemiological rates of physical activity in ACHD. Outcome expectations are defined as "beliefs about the likelihood of various outcomes that might result from the behaviors that a person might choose to perform, and the perceived value of those outcomes" (Bandura, 1977). Expectations about the psychological (e.g., improvements in mood), social (e.g., increased social interaction), and physical outcomes (e.g., reduced cardiovascular risk) of physical activity may underlie exercise engagement in ACHD.

Previous research indicates ACHD endorse positive outcome expectations of physical activity both in terms of enjoyability and importance for health (Prapavessis et al., 2005). In addition, a study by Dua and colleagues (2007) indicated most patients across all NYHA functional classes desired formalized exercise prescriptions from their providers. Interviews with children and adolescents with CHD recorded conflicting perceptions of physical activity. Participation in physical activity was perceived as essential to health yet also associated with negative outcomes, such as fatigue and social exclusion (Moola et al., 2008). Due to a dearth of research on the topic in adults, physical activity outcome expectations among ACHD remain unknown.

A third patient factor is physical activity self-efficacy. Self-efficacy is broadly defined as “the conviction that one can successfully execute the behavior required to produce the outcomes” (Bandura, 1998), and is assessed in the context of specific health behaviors. Self-efficacy is different from outcome expectations in that the former is an evaluation of the competency to perform a health behavior while the latter focuses on anticipated outcomes of a behavior. An individual may perceive low physical activity self-efficacy due to psychological symptoms (e.g., anxiety, depression; Stults-Kolehmainen & Sinha, 2014), general exercise milieu (e.g., low skill, motivation, time), low social support, or inadequate access to physical activity resources (e.g., gym, parks; Centers for Disease Control and Prevention, 2020).

There is little research about physical activity self-efficacy in ACHD. Two studies indicated moderate-to-strong physical activity self-efficacy among ACHD patients (Dua et al., 2007; McKillop et al., 2018). In a separate study, Bay and colleagues (2017) examined predictors of physical activity self-efficacy among ACHD with various defects. Approximately 43% of patients endorsed low physical activity self-efficacy, and lower ratings were associated with older age, NYHA Class III status, and reduced physical performance (i.e., shoulder flexions). The same research group conducted a study examining the overall relation between ACHD and physical activity. Based on qualitative interviews with complex patients, ACHD were categorized into four categories of patients: those who enjoy the challenges of physical activity, those who adapt to physical ability, those who lack prerequisites for physical activity, and those who feel excluded from physical activity based on their physical ability (Bay et al., 2018). The few studies that have been conducted on these constructs have not related their results to rates of physical activity. For this reason, outcome expectations and physical activity self-efficacy warrant further investigation as cognitive factors relevant to physical activity in ACHD.

Emotional Factors

Emotional factors connected to their congenital defect could impact physical activity in ACHD. Specifically, patients may experience anxiety about potential medical consequences of physical activity. Fear avoidance, defined as any avoidant behavior that reduces exposure to a fear-eliciting stimulus or situation (Gidron, 2013), provides an explanation for reduced physical activity within a cognitive-behavioral framework. The fear avoidance model has been previously investigated among patients who have experienced myocardial infarction (Ahlund et al., 2013), chronic pain (Boselie & Vlaeyen, 2017), and chronic illness (Kim et al., 2016). Increased cardiac sensations produced by physical activity (e.g., palpitations, increased heart rate, shortness of breath) often mimic symptoms of adverse cardiac events (e.g., myocardial infarction). An individual may misinterpret the cause of cardiac sensations and discontinue physical activity because the otherwise benign sensations are unpleasant or unfamiliar (Eifert, 1992). Further, decreased exercise capacity may lower the threshold for cardiac sensations during physical activity. It is therefore likely that individuals who are most avoidant of physical activity, and therefore pose the greatest cardiovascular risk, also most frequently experience cardiac sensations.

Research on cardiac anxiety in ACHD may be important to understand emotional responses to physical activity. Cardiac anxiety is defined as “the fear of cardiac-related stimuli and sensations based upon their perceived negative consequences" (Eifert, 1992). Individuals with elevated cardiac anxiety may over-attend to physical sensations in their chest or avoid activities that are likely to cause such sensations (Eifert, 1992). Cardiac anxiety is present in psychiatric populations, including non-cardiac chest pain (White et al., 2010) and panic disorder (Stevens et al., 2018). Medical populations, such as heart failure patients (Sager et al., 2020) or individuals with significant cardiovascular risk (Hohls et al., 2020) also experience increased cardiac anxiety compared to the general population.

Three studies have previously investigated cardiac anxiety in ACHD. Previous research has identified positive relations between parental overprotection, defect complexity, and cardiac anxiety (Ong et al., 2011). O'Donovan and colleagues (2016) observed a negative relation between illness perceptions and cardiac anxiety among ACHD of various disease severity. A more recent study reported low cardiac anxiety within a sample of young ACHD with mild functional impairment (i.e., NYHA class I-II; McKillop et al., 2018). However, overall cardiac anxiety appears to be relatively low in these studies (i.e., approximately "rare" frequency of cardiac anxiety symptoms). Similar to cognitive factors, the relation between cardiac anxiety and physical activity has not yet been explored in ACHD. Assessment of cardiac anxiety can illustrate the spectrum of emotional and behavioral responses to physical activity.

Apart from medical and environmental factors, cognitive and emotional factors are likely to contribute to decreased physical activity in ACHD. However, there is some evidence to suggest the effects of these psychological factors do not appear consistent for all patients. Research is needed both to more fully explore psychological factors across demographically and functionally diverse patients and to assess their relative effect on physical activity. Health behavior theory may provide a foundation on which to build understanding of the role of psychological factors in physical activity among these patients.

ACHD Physical Activity within Health Behavior Theories

Theory of Planned Behavior

Only one study has investigated physical activity in ACHD within health behavior theory. Prapavessis et al. (2005) applied the Theory of Planned Behavior (Ajzen, 1985) in a sample of young adults with CHD. Results indicated attitude toward exercise, subjective norms about exercise, and perceived ability to exercise accounted for significant variance in exercise intention. However, exercise intention did not predict exercise. The disconnect between intent and behavior limits the predictive value of Theory of Planned Behavior, as a theory that is incongruent with empirical evidence may only be minimally applicable in the conceptualization of a health behavior (Prochaska et al., 2008). For this reason, alternative health behavior theories are required to analyze the role of psychological factors in physical activity.

Protection Motivation Theory

Protection Motivation Theory (Rogers, 1975) may provide an explanatory framework for physical activity in ACHD. Protective Motivation Theory proposes protective intention against a disease threat determines the likelihood of a corresponding health behavior. Intention is determined by two main cognitive factors – threat appraisal and coping appraisal – each of which are composed of two subfactors. Threat appraisal consists of perceived severity of the disease and perceived susceptibility to disease acquisition. Coping appraisal consists of perceived efficacy of the health behavior and perceived self-efficacy to perform the health behavior. According to this model, an individual who perceives heightened levels of disease threat and sufficient coping skills to respond to the threat is more likely to engage in preventive health behavior.

Meta-analytic results support Protection Motivation Theory as a framework for physical activity (Ferrer et al., 2018). One example is cardiac rehabilitation programs, in which individuals who perceive susceptibility to acquired heart disease or adverse cardiac events are more likely to engage in physical activity to reduce susceptibility (Anderson et al., 2017). An essential component of health behavior change is communication of moderately fear-inducing messages or a “fear appeal” about potential threats to health. These messages are most effective when linked with education about outcome expectations and self-efficacy (Peters et al., 2018). Thus, Protection Motivation Theory incorporates communication of both threat of disease acquisition and patient efficacy to engage in disease prevention. Assessment of ACHD ability and willingness to protect against acquired cardiovascular is likely to elucidate psychological factors that underlie physical activity.

Health behavior theory that explains the role of psychological factors related to physical activity has not yet been applied in the ACHD literature. Protection Motivation Theory may explain the relative effects of psychological factors on physical activity to reduce cardiovascular risk. It is important to note communication of threat and information about relevant health behaviors are prerequisites for Protection Motivation Theory. Therefore, patient-provider conversations about the potential for acquired cardiovascular disease and physical activity should be assessed before examination of psychological factors.

Statement of the Problem

Adults with congenital heart disease (ACHD) are a new and growing medical population. Epidemiological research suggests ACHD pose an increased risk for acquired cardiovascular disease. One lifestyle intervention to reduce cardiovascular risk is physical activity. There is evidence to support physical activity as a safe, efficacious, and tolerable intervention for ACHD. Nonetheless, epidemiological studies suggest most patients do not engage in recommended levels of physical activity. Beyond medical factors and environmental barriers, patient knowledge, cognitive factors, and emotional factors may inhibit physical activity. Therefore, this study assessed the relation between psychological factors and physical activity in ACHD. Further, these factors were analyzed in relation to physical activity within Protection Motivation Theory.

Current Study

Aims and Hypotheses

The purpose of this study was to investigate the effect of patient knowledge, cognitive factors, and emotional factors on physical activity in ACHD. In this study, physical activity was defined according to the definition from the World Health Organization (2020, para. 1): “any bodily movement produced by skeletal muscles that requires energy expenditure.”

Aim 1. A series of descriptive analyses were conducted prior to hypothesis testing. In accord with Protection Motivation Theory (Rogers, 1975), threat of disease acquisition and associated health behavior to protect against the threat must be communicated to the patient for health behavior to occur. However, it is presently unknown if ACHD are aware of their risk for acquired cardiovascular disease. Relatedly, there is sparse research about the prevalence or content of patient-provider conversations related to physical activity (Swan & Hillis, 2000). The first aim of this study was to assess the prevalence of patient-provider conversations about acquired cardiovascular disease risk and physical activity (e.g., physical activity prescription, benefits, risks or safety concerns, safe activities). No a priori hypotheses were generated related to the prevalence of patient-provider conversations about risk for acquired cardiovascular disease or physical activity.

Aim 1a: Patient-provider conversations about acquired cardiovascular disease risk. Aim 1a of this study was to assess the prevalence of patient-provider conversations about acquired cardiovascular disease risk (e.g., heart failure, heart attack, arrhythmia).

Aim 1b: Patient-provider conversations about physical activity. Aim 1b was to assess the prevalence of patient-provider conversations about physical activity, including conversations about the benefits of physical activity, risks or safety concerns related to physical activity, safe physical activity, and when to discontinue physical activity.

Hypothesis 1c: Perception of risk for acquired cardiovascular disease. Hypothesis 1c was related to perceived risk for acquired cardiovascular disease. Perceived risk was comprised of two components – perceived susceptibility to and perceived severity of acquired cardiovascular disease.

Hypothesis 1c-i*: *Perceived susceptibility to acquired cardiovascular disease. Perceived susceptibility to acquired cardiovascular disease will be positively correlated with physical activity.

Hypothesis 1c-ii: ***Perceived severity of acquired cardiovascular disease.*** Perceived severity of cardiovascular disease will be positively correlated with physical activity.

Aim 2. The second aim of this study was to examine the relation between patient cognitive variables and physical activity. Protection Motivation Theory (Rogers, 1975) asserts perceptions of a health behavior as effective to reduce risk of disease acquisition, also termed outcome expectations, contribute to engagement in the health behavior. Nonetheless, physical activity outcome expectations remain largely unexplored in this population. Self-efficacy is another component of coping appraisal that is associated with physical activity in other patient populations.

Hypothesis 2a: Physical activity outcome expectations. Physical activity outcome expectations will be positively correlated with physical activity.

Hypothesis 2a-i: Perceived benefits to physical activity. Positive physical activity outcome expectations will be positively correlated with physical activity.

Hypothesis 2a-ii: Perceived barriers to physical activity. Negative physical activity outcome expectations will be negatively correlated with physical activity.

Hypothesis 2b: Physical activity self-efficacy. Physical activity self-efficacy will be positively correlated with physical activity.

Aim 3. The third aim of this study was to examine the relation between cardiac anxiety and physical activity. While previous research has indicated low cardiac anxiety among ACHD with mild functional impairment, the relation between cardiac anxiety and physical activity has not been examined across the spectrum of NYHA functional classes.

Hypothesis 3: Cardiac anxiety. Cardiac anxiety will be negatively correlated with physical activity.

Hypothesis 3a: Heart-related fear. Heart-related fear will be negatively correlated with physical activity.

Hypothesis 3b: Avoidance of cardiac sensations. Avoidance of cardiac sensations will be negatively correlated with physical activity.

Hypothesis 3c: Heart-focused attention. Heart-focused attention will be negatively correlated with physical activity.

Aim 4. The fourth aim of this study was to evaluate Protection Motivation Theory in physical activity in ACHD. Protection Motivation Theory (Rogers, 1975) is comprised of threat appraisal (perceived susceptibility to disease, perceived severity of disease acquisition) and coping appraisal (outcome expectations, self-efficacy) to predict the likelihood of engaging in a preventative health behavior. The present study examined Protection Motivation Theory in physical activity in ACHD.

Hypothesis 4: Evaluation of Protection Motivation Theory in physical activity in ACHD. Protection Motivation Theory will predict significant variance in physical activity in ACHD.

Methods

Participants

A total of 212 ACHD patients accessed the questionnaire through several online sources (i.e., Adult Congenital Heart Association website, ResearchMatch, Craigslist, ACHD Facebook pages and groups). Inclusion criteria for participation included age 18 years or older, a reported medical diagnosis of congenital heart defect, and the ability to speak fluent English. The exclusion criterion for this study was inability to independently complete the informed consent form. A complete list of participant recruitment sources can be located in Appendix A.

Measures

A compendium of study measures can be located in Appendix B.

Demographics. A demographic questionnaire listed questions about participant age, sex, marital status, race/ethnicity, education level, employment status, and annual household income.

Medical History. Medical history relevant to this study was gathered via self-report using a standardized form utilized in international ACHD studies (Apers et al., 2015). Medical information included the type(s) of congenital heart defect, NYHA functional classification, past cardiac interventions (e.g., cardiac surgeries, catheterizations, implantable cardiac device), frequency of medical follow-up appointments, number of emergency inpatient admissions, comorbid medical conditions (e.g., heart failure, arrhythmia), and previous or current psychiatric disorders (e.g., mood disorder, anxiety disorder).

Patient-provider conversations. A series of questions assessed the occurrence and content of conversations between participants and their ACHD medical provider. Patients who were not connected with a specialized ACHD cardiologist were prompted to recall conversations with the medical provider treating their CHD. Questions were based on the Health Knowledge, Attitudes, and Practices Questionnaire (Dunstan, 2002) and were formatted: “Has your cardiologist ever talked with you about…?” Participants were instructed to choose one of three response options: “Yes”, “No”, and “I Don’t Know”/

"I'm Not Sure." The first question asked participants about previous conversations with their provider about risk for acquired cardiovascular disease (e.g., heart failure, heart attack, arrhythmia). A second set of questions asked participants about previous conversations with their medical provider about physical activity, including the benefits, risks or safety concerns, and safe physical activities (e.g., approved activities, when the patient should stop exercising).

Physical activity. Physical activity was measured using the International Physical Activity Questionnaire-Short Form (IPAQ-S; IPAQ Group, 2012). The IPAQ-S is a seven-item measure that assesses the total minutes of physical activity at different intensities (e.g., vigorous, moderate, walking, and sitting) within the past seven days. Minutes of physical activity in each intensity category is multiplied by its approximate metabolic equivalent (Walking = 3.3; Moderate = 4; Vigorous = 7; World Health Organization, 2020) and then summed to calculate weekly metabolic equivalent hours (METS). There is evidence of over-estimation of physical activity in self-report data (Steene-Johannessen et al., 2016). Nonetheless, IPAQ-S data correlates moderately with objective measurements of physical activity (r = .39; Mader et al., 2006) and shares the strongest correlation with vigorous activity (r = .44-.47; Dinger et al., 2006) and walking (r = .56; Kolbe-Alexander et al., 2006). The IPAQ-S has demonstrated good test-retest reliability ($\alpha < .80$) and has been previously implemented in patients with chronic obstructive pulmonary disease (Todt et al., 2015), patients with a previous transient ischemic attack (Brouwer-Goossensen et al., 2016), and adult congenital heart disease (Muller et al., 2017).

Perception of cardiovascular risk. Perceived risk for acquired cardiovascular disease is comprised of two components – perceived susceptibility to and perceived severity of acquired cardiovascular disease.

Perceived susceptibility to acquired cardiovascular disease. Perceived susceptibility to acquired cardiovascular disease was assessed using the Health Beliefs related to Cardiovascular Disease Scale-Susceptibility subscale (HBCVD-Susceptibility; Tovar et al., 2010). The HBCVD-Susceptibility subscale consists of five questions about perceived risk for heart attack or stroke (e.g., "It is likely that I will suffer from a heart attack or stroke in the future") with response options on a Likert scale from 1 ("Strongly Disagree") to 4 ("Strongly Agree"). Higher scores are indicative of greater perceived risk for acquired cardiovascular disease. The subscale demonstrated excellent internal reliability in the original study (Cronbach's $\alpha = .93$). The scale has been validated in individuals with Type II diabetes (Tovar & Clark, 2015) and college students (Tran et al., 2016). In addition to the validated five-item subscale, this study added five modified items specific to acquired cardiac disease associated with mortality in ACHD (e.g., heart failure, arrhythmia; Lui & Bhatt, 2019). The language from the original scale was retained to maximize resemblance to the validated items. The singular modification of the items was the substitution of "heart attack or stroke" with "heart failure or arrhythmia" (e.g., "It is likely that I will acquire another cardiac disease (e.g., arrhythmia, heart failure) in the future). Necessary grammatical changes were made to improve readability. A separate "Not Applicable (N/A)" option was presented for individuals who may have previously been diagnosed with these conditions. Cronbach's alpha is reported to demonstrate internal reliability of the additional items.

Perceived severity of acquired cardiovascular disease. Perceived severity of acquired cardiovascular disease was assessed using Champion's Health Belief Model Scale-Seriousness subscale (CHBMS-S; Champion, 1984). The CHBMS-Seriousness scale is a twelve-item subscale that was developed in the context of breast self-examination. Four items related to fear responses were not included in this study due to overlap with other study measures (i.e., cardiac anxiety). Respondents rate their agreement to statements about consequences of disease acquisition on a Likert scale from 1 ("Strongly Disagree") to 4 ("Strongly Agree"; e.g., "My feelings about myself would change if I acquired cardiovascular disease (e.g., heart attack, heart failure, arrhythmia)." A fifth "Not Applicable (N/A)" option was presented for individuals who may have been previously diagnosed with these conditions. The CHMBS-Seriousness subscale has been recently validated in testicular cancer screening (Cronbach's $\alpha = .86$; Avci & Altinel, 2018).

Physical activity outcome expectations. Physical activity outcome expectations were measured using the Exercise Benefits/Barriers Scale (EBBS; Sechrist, 1987). The 43-item EBBS assesses perceived benefits and barriers to physical activity. Benefits of physical activity include physical performance, psychological outlook, life enhancement, and preventative health, while barriers to physical activity include time expenditure, family discouragement, and general exercise milieu. Participants provide responses on a Likert scale from 1 ("Strongly Disagree") to 4 ("Strongly Agree"). Internal reliability was acceptable for the full EBBS scale (Cronbach's $\alpha = .89$), and strong for each of the Benefits ($\alpha = .95$) and Barriers ($\alpha = .95$) subscales. The EBBS has been previously validated in healthy adult populations (Farahani et al., 2017).

Physical activity self-efficacy. Physical activity self-efficacy was assessed using the Exercise Self-Efficacy Scale (ESES; Neupert et al., 2009). Based on the Exercise Self-Efficacy Scale by Bandura (1997), the nine-item ESES measures perceived ability to regularly engage in physical activity (i.e., “5 times a week for 30 minutes”) and in various conditions (e.g., “feeling tired”, “when there is too much to do at home”). Participants provide responses on a Likert scale from 0 (“I cannot do this activity at all”) to 10 (“I am certain that I can do this activity successfully”), where higher scores indicate higher levels of physical activity self-efficacy. The ESES demonstrated good internal reliability for the full scale ($\alpha = .88$) and has been previously validated in spinal cord injury patients (Pisconti et al., 2017) and hemodialysis patients (Hatef et al., 2018).

Cardiac anxiety. Cardiac anxiety was assessed using the Cardiac Anxiety Questionnaire (CAQ; Eifert et al., 2000). The CAQ is an eighteen-item self-report measure that consists of three underlying factors related to cardiac anxiety: heart-related fear (e.g., “If tests come out normal, I still worry about my heart”), avoidance of cardiac sensations (e.g., “I avoid physical exertion”), and heart-focused attention (e.g., “I pay attention to my heartbeat”). Participants rate the frequency of anxious symptoms on a Likert scale ranging from 0 (“Never”) to 4 (“Always”). Higher total scores represent higher levels of cardiac anxiety. The CAQ has demonstrated good internal consistency for the full scale ($\alpha = .83$) as well as the fear ($\alpha = .83$), avoidance ($\alpha = .82$), and attention subscales ($\alpha = .69$). The CAQ has been previously implemented in ACHD (Cronbach’s $\alpha = .87$; Ong et al., 2011).

Procedures

The study questionnaire was presented in an online format using Qualtrics Survey Software. Participants were directed to the online questionnaire that included an informed consent form in which the participant must review the form and select “I Agree” to proceed to the study questionnaire.

Participants were recruited through several online sources (i.e., Adult Congenital Heart Association website, ResearchMatch, Craigslist, ACHD Facebook pages and groups). Postings about the study included a brief description of the study and study participation (e.g., nature and purpose of the study, eligibility requirements, risks and benefits of participation). As a requirement of the Adult Congenital Heart Association website, participants were directed to email the principal investigator to access the study link. Postings on other online sources included a direct link to the online questionnaire.

At the end of the questionnaire, participants were presented with the option of entering a raffle for one of three $100 Amazon gift cards as compensation for their time and effort. Contact information for each participant was collected in order to contact the winners of the prize raffle after the completion of data collection. Participant contact information and participant responses were collected and stored separately to ensure anonymity of participant responses.

Results

Preliminary analyses. All proposed analyses were conducted using SPSS v26.0 (Statistics, 2019). The data was screened for missing values and outliers. In addition, statistical assumptions related to the proposed analyses were examined prior to hypothesis testing.

Missing data. A total of 212 participants accessed the survey and 156 participants (73.6%) completed the survey. A missing value analysis was conducted to determine the prevalence and type of missing data. Questions with an optional response (e.g., "Other" congenital defect), questions with responses that were contingent upon endorsement of a previous item (e.g., "What year was your most recent cardiac surgery?"), and questions about a specific medical disorder (e.g., congenital, medical or psychiatric comorbidities) were excluded from the missing value analysis due to their single-response format. Results of the missing value analysis indicated data was not missing completely at random (χ^2 (14527) = 13741.4, p = 1). There was a high prevalence of missing values (> 5%) on questions about age (7.2%), patient-provider conversations (61.5%; e.g., benefits, risks or safety concerns about physical activity; safe physical activities; when to stop physical activity), and weekly physical activity (8.6%-93.7%; e.g., hours and minutes per week at different intensities of physical activity). A subsequent missing value analysis without these items suggested missing values among the remaining items were missing completely at random (χ^2 (1679) = 1776.02, p = .04).

Seventeen participants (8% of total sample) completed between 1-6% of the survey, which signified discontinuation of the survey before completion of ACHD-specific questions. Listwise deletion of these participants was implemented to remove their data from descriptive analyses and hypotheses testing. Twenty participants (9% of total sample) discontinued the survey before completion of the International Physical Activity Questionnaire-Short Form (IPAQ-S). However, these participants completed questions about their medical background (e.g., NYHA functional classification, medical comorbidities) and patient-provider conversations. Data from these participants was included in descriptive analyses and hypothesis testing of Aim 1a and Aim 1b (i.e., patient-provider conversations about risk for acquired cardiovascular disease and physical activity, respectively). To minimize the effect of missing data on hypothesis testing, within-case mean imputation was implemented for cases with 30% or less missing values on a measure (i.e., 17 cases on the HBCVD-Susceptibility subscale, 4 cases on the CHBMS-Seriousness subscale, 10 cases on the EBBS, and 1 case on the CAQ).

Univariate outliers. Questionnaire items were combined into scales and subscales for analysis. Each of the continuous study variables were standardized using z-scores (i.e., HBCVD-Susceptibility, CHBMS-Seriousness, EBBS-Total, EBBS-Benefits, EBBS-Barriers, ESES, CAQ-Fear, CAQ-Avoidance, CAQ-Attention, CAQ-Total, IPAQ-S). Z-scores of ± 2.5 were considered outliers and further examined to determine eligibility for analysis (Meyers, Gamst, & Guarino, 2013). Although twenty univariate outliers were identified, several univariate outliers were present on both total scale and subscales for a particular measure. In total, there were two outliers detected on the HBCVD-Susceptibility subscale, one outlier on the CHBMS-Seriousness subscale, one outlier on the EBBS-Total scale, one outlier on the EBBS-Benefits subscale, three outliers for the EBBS-Barriers subscale, two outliers for the CAQ-Total scale, one outlier for the CAQ-Fear subscale, one outlier for the CAQ-Avoidance subscale, four outliers for the CAQ-Attention subscale, and five outliers for the IPAQ-S scale. Overall, there was a low frequency of outliers on any study variable in the overall sample (0.5%-2%).

Outliers were further examined for clinical significance. Examination of the outliers suggests their scores were associated with their medical condition. For example, one individual with increased cardiac anxiety reported an anxiety disorder, impaired physical functioning, and a history of medical procedures. Outliers were retained for analyses and considered representative of the spectrum of ACHD functioning. However, univariate outliers on physical activity (IPAQ-S) reported unlikely responses (i.e., 6 hours per day of vigorous physical activity). These five cases were removed from study analyses involving the IPAQ-S due to the extreme nature of their responses. However, these cases were retained for descriptive analyses of study variables that did not involve the IPAQ-S.

Multivariate outliers. The total sample was examined for multivariate outliers from the centroid of the five independent study variables (HBCVD-Susceptibility, CHBMS-Seriousness, EBBS-Total, ESES, CAQ-Fear; χ^2 (5) < 20.52). Mahalanobis distance tests were examined, and multivariate outliers were not present in the remaining sample.

Normality. Study variables were examined for normal distribution of values. The skewness and kurtosis values for all study variables fell between -1.0 to +1.0 with the exception of IPAQ-S scores, which demonstrated a significant positive skewness (1.46) and kurtosis (1.67). A square root transformation of the IPAQ-S scores increased the normality of the distribution according to skewness (.205) and kurtosis (-.386) values. Therefore, the transformed IPAQ-S data was utilized for hypothesis testing.

Linearity. Bivariate scatterplots were generated and suggested pairwise linearity of the study variables.

Homoscedasticity. The statistical assumption of homoscedasticity, or equal variance among the residual values, was visually examined using scatter plots of the standardized predicted values against standardized actual values. Visual inspection of the scatter plots indicated the assumption of homoscedasticity was satisfied. Further, Levene's tests statistics were not significant for study variables ($p > .05$).

Multicollinearity. Multicollinearity was investigated using Variance Inflation Factor and Tolerance statistics. Per the recommended cut-off values of these statistics of below 2.5 and above 0.4, respectively (Miles, 2014), the independent variables did not evidence issues with multicollinearity.

A priori power analyses. Power analyses were conducted using G*Power (Faul et al., 2009) and analyses used an alpha of $p < .05$ and power of 80% ($1 – \beta$). Hypothesis 1c, Hypothesis 2, and Hypothesis 3 utilize bivariate correlations, and analyses indicate that 84 participants are required to detect a medium effect size ($r = .3$). Evaluation of Protection Motivation Theory (Rogers, 1975) required a hierarchical linear regression equation with six independent predictors. Analyses indicate 146 participants were required to detect a medium effect size ($f^2 = .15$). Therefore, the proposed total N was 150 for the hierarchical linear regression and moderation analysis to account for potential missing data.

Descriptive Analyses

Demographics. Participants reported a mean age of 40 years, 9 months (*SD* = 13 years, 2 months) and ages ranged from 18 to 79 years. The sample was predominantly female (76.6%) and no individuals identified as a sex other than male or female. Most participants identified as White/Caucasian (92%), with smaller subsets of individuals who identified as members of minority racial or ethnic backgrounds (i.e., Hispanic/Latino - 3%; Asian - 3%; Black/African-American - 0.5%; Biracial - 0.5%; "Prefer not to say" -

0.5%). Marital status was more evenly split among individuals who were currently married or partnered (61.7%) and individuals reported being single (25.4%), separate or divorced (11.4%), or widowed (1.5%).

Two-thirds of the sample reported earning a college degree (66.7%; i.e., professional or graduate degree - 29.9%; four-year degree - 21.9%; two-year degree - 14.9%) and most remaining individuals indicated receiving at least “some” college education (25.4%). 8% of participants reported receiving a high school education or less. Approximately half of the sample reported full-time employment (49.8%). Individuals also indicated their employment status as part-time (17.4%), living with disability/government financial status (8.5%), unpaid position (e.g., student, homemaker, retired, volunteer), or currently “job-seeking” (1.5%). Data on annual household income indicated many participants earned more than $75,000 per year (45%), 8.5% earned $60,001-$75,000, 13.5% earned $45,001-$60,000, 12% earned $30,001-$45,000, and 21% of the sample earned less than $30,000.

Medical History. In terms of functional classification, 44.6% of the sample identified as NYHA Class I, 33.2% as NYHA Class II, 15.5% as NYHA Class III, and 6.7% as NYHA Class IV. The most common cardiac defects among participants were Tetralogy of Fallot (18.9%), Transposition of the Great Arteries (14.2%), and Atrial Septal Defect (12.7%), while the least common cardiac defects were Complete Atrioventricular Canal (0.9%) and Ebstein’s Anomaly (0.5%; see Table 1). The mode number of cardiac defects was one (72%) and the average number of defects was approximately 1.5 (*SD* = .92).

Information was collected from participants about prior ACHD medical treatment. Frequency of ACHD-specific medical appointments was variable among participants. 17.6% of participants attended appointments more than twice a year, 24.4% twice per year, 46.6% once per year, 4.7% every two years, and the remaining 6.7% of participants attended medical appointments for their congenital defect between every three years to less often than every five years. Approximately three-quarters (77.7%) of participants previously underwent surgery for their cardiac defect and a majority (64.8%) had undergone at least one catheterization. 83.9% of respondents did not report an emergency hospital admission in the past year and only 26.9% reported currently living with an implantable cardiac device (e.g., pacemaker).

Medical history data concluded with questions about medical and psychiatric comorbidities. Specifically, participants reported current or past cardiovascular and pulmonary comorbidities, listed in descending order according to prevalence: arrhythmia (30.2%), hypertension (18.4%), congestive heart failure (17%), hyperlipidemia (11.8%), stroke or TIAs (9.9%), Type II diabetes (6.1%), myocardial infarction (5.7%), chronic lung disease (3.3%), and coronary artery disease (2.4%). Approximately one-third (29.2%) of participants wrote in additional medical comorbidities (e.g., diastolic heart failure, pulmonary hypertension, asthma). Overall, 89.8% of participants reported at least one medical comorbidity. NYHA Class IV participants (M = 3.18, SD = 2.18) reported significantly more comorbidities than participants from other NYHA classes (F (3,153) = 7.04, p = .00, η_p^2 = .12). The most common psychiatric comorbidities were anxiety disorders (42%) and mood disorders (18.4%). A minority of participants reported other psychiatric conditions (22.6%), such as PTSD (2.8%) and ADHD (2.8%).

Physical Activity. Total weekly physical activity was computed by multiplying weekly minutes at each intensity (e.g., walking, moderate, vigorous) by the respective metabolic equivalent (Walking = 3.3 METS; Moderate = 4 METS; Vigorous = 7 METS; World Health Organization, 2020). In the total sample, participants reported engaging in an average of 37.10 weekly METS hours (*SD* = 37.55). Results of a one-way ANOVA indicated no significant differences in weekly physical activity among NYHA functional classes (F (3,162) = 2.67, p = .05; η_p^2 = .05): Class I (M = 46.32, SD = 43.06), Class II (M = 31.05, SD = 33.19), Class III (M = 28.47, SD = 28.88), and Class IV (M = 28.25, SD = 26.66). 76.5% of the total sample met or exceeded 10 weekly METS hours recommended by the American Heart Association (2020; Class I - 79.2%, Class II - 77.6%, Class III - 69.2%, and Class IV - 70%).

Hypothesis Testing. A series of descriptive aims was conducted prior to testing study hypotheses. Cronbach's alpha was reported on study scales and subscales. Descriptive statistics (e.g., mean, standard deviation) for study variables in Hypotheses 1c, 2, and 3 were reported for the total sample as well as NYHA functional classes. One-way ANOVAs and Tukey's HSD post-hoc tests were conducted to detect differences in relevant study variables among NYHA functional classes. T-tests were conducted to detect differences between the sexes.

Aim 1a: Patient-provider conversations about acquired cardiovascular disease risk. Patient-provider conversations about acquired cardiovascular disease risk was analyzed using frequency distributions of participant responses to a multiple-choice question (e.g., "Yes", "No", "I Don't Know"/ "I'm Not Sure"). Frequency distributions were reported for each response option in the total sample, NYHA functional classes, and participant sex. The relation between patient-provider conversation about acquired cardiovascular disease risk and participant age was examined in a separate point-biserial correlation (i.e., participants who responded “Yes” versus participants who responded “No” or “I Don’t Know/ I’m Not Sure”).

In the total sample, approximately two-thirds of participants (65.3%) indicated a prior conversation with their medical provider about their risk for “other cardiac diseases,” while 26.9% denied such a conversation and 7.8% responded “I Don’t Know/I’m Not Sure.” The frequency of patient-provider conversations differed among NYHA functional classes: Class I (55.8%), Class II (68.8%), Class III (76.7%), and Class IV (84.6%). However, similar rates of this conversation were present among male (65.9%) and female (65.1%) participants. Results from a point-biserial correlation indicated a non-significant correlation between conversation about acquired cardiovascular disease risk and participant age (r (179) = -.12, p = .10, r^2 = .01).

Aim 1b: Patient-provider conversations about physical activity. Patient-provider conversations about physical activity were analyzed using frequency distributions of participant responses to multiple-choice questions (e.g., “Yes”, “No”, “I Don’t Know/I’m Not Sure”). Frequency distributions were reported for each response option in the total sample, NYHA functional classes, and participant sex. The relation between patient-provider conversation about acquired cardiovascular disease risk and participant age was examined in a separate point-biserial correlation.

85% of the total sample (NYHA Class I - 80.2%, Class II - 89.1%, Class III - 86.7%, Class IV - 92.3%) endorsed a previous conversation with their medical provider about “physical activity or exercise.” The prevalence of this conversation was similar between the sexes (Male - 86.4%, Female - 84.6%) and did not differ according to participant age (*r* (179) = .09, *p* = .24, r^2 = .01). By contrast, only 38.9% of participants from the total sample reported receiving an "exercise plan" from their medical provider (Class I - 33.7%, Class II - 40.6%, Class III - 46.7%, Class IV - 46.2%). Prevalence of physical activity plan recommendations from a medical provider was similar between the sexes (Male - 36.4%, Female - 39.6%) and there was no significant correlation with participant age (*r* (179) = .01, *p* = .95, r^2 < .00).

If participants endorsed a previous conversation with their medical provider about physical activity, he or she was subsequently prompted to recall the content of the conversation. A vast majority of participants reported discussing benefits of physical activity with their provider (96% total; Class I - 96.6%, Class II - 100%, Class III - 92.9%, Class IV - 83.3%) and rates of conversation did not differ by NYHA class (*F* (3, 71) = 1.32, *p* = .27, η_p^2 = .05). Prevalence of conversation about the benefits of physical activity were comparable between the sexes (Male - 93.8%, Female - 96.6%) and there was no significant correlation with participant age (*r* (68) = -.09, *p* = .49, r^2 = .01). Most participants recalled discussion of the "risks or safety concerns" about physical activity (82.7% total; Class I - 72.4%, Class II - 88.5%, Class III - 92.9%, Class IV - 83.3%). Male participants reported a higher prevalence of conversation about risks or safety concerns (93.8%) than female participants (79.7%), though this difference was not significant (*t* (2, 73) = -1.72, *p* = .09, 95% CI [-.31, .03], Cohen's *d* = .55). Conversations of the "risks or safety concerns" of physical activity was not significantly correlated with participant age (*r* (68) = -.03, *p* = .78, r^2 < .00).

Similar to conversations about risks, 81.3% of the total sample reported receiving information from their provider about "when to stop" physical activity (NYHA Class I - 75.9%, Class II - 84.6%, Class III - 85.7, Class IV - 83.3%). Prevalence of conversation about when to discontinue physical activity was similar between the sexes (Male - 81.3%, Female - 81.4%) and did not significantly correlate with participant age (r (68) = -.05, p = .70, $r^2 < .00$). Finally, most participants reported prior conversations with their medical provider about activities that are safe people with their heart condition (81.3% total; Class I - 75.9%; Class II - 80.8%, Class III - 92.9%, Class IV - 83.3%). Prevalence of conversations about activities that are safe were similar between the sexes (Male - 87.5%, Female - 79.7%) and did not significantly correlate with participant age (r (68) = .11, p = .39, $r^2 = .01$).

Hypothesis 1c-i: **Perceived susceptibility to acquired cardiovascular disease**. Hypothesis 1c-i regarding perceived susceptibility to acquired cardiovascular disease was analyzed using the Health Beliefs related to Cardiovascular Disease Scale-Susceptibility subscale (HBCVD-Susceptibility; Tovar et al., 2010), which included an additional five items associated with mortality risks specific to ACHD (e.g., heart failure, arrhythmia). Cronbach's alpha was reported on the full subscale, the original five items, and the separate additional five items to validate internal reliability. Analysis of perceived susceptibility to acquired cardiovascular disease included descriptive statistics on the HBCVD-Susceptibility subscale. The relation between perceived susceptibility to cardiovascular disease (HBCVD-Susceptibility) and physical activity (IPAQ-S) was examined using Pearson's r correlation coefficient at $p < .05$.

The HBCVD-Susceptibility subscale demonstrated strong internal consistency (Cronbach's α = .91). The original five items about susceptibility to heart attack and stroke (Cronbach's α = .87) and the additional five items about arrhythmia and heart failure (Cronbach's α = .92) also demonstrated strong internal consistency. In the total sample, participants responded with approximately neutral ratings to statements about their susceptibility to cardiovascular disease (i.e., mean rating between "Disagree" and "Agree" response options). However, results of a one-way ANOVA indicated significant differences in perceived susceptibility among NYHA classes (F (3,163) = 9.86, p = .00, η_p^2 = .15). Post-hoc comparisons indicated Class I participants (M = 2.18, SD = .51) perceived lower susceptibility than Class III (M = 2.71, SD = .61, p = .00, 95% CI [-.87, -.19]) and Class IV participants (M = 3.04, SD = .48, p = .00, 95% CI [-1.39, -.33]). Similarly, Class II participants (M = 2.39, SD = .65) perceived lower susceptibility than Class IV participants (p = .01, 95% CI [-1.19, -.12]; see Table 2).

There was no significant relation between perceived susceptibility to acquired cardiovascular disease (HBCVD-Susceptibility) and physical activity (IPAQ-S) in the total sample. However, there was a significant negative correlation among NYHA Class III participants (r (24) = -.41, p = .04, r^2 = .17), which suggests higher perceived susceptibility to acquired cardiovascular disease was associated with lower rates of physical activity. A negative correlation between perceived susceptibility to acquired cardiovascular disease and physical activity signifies Hypothesis 1c-i was not supported by the data.

Hypothesis 1c-ii: **Perceived severity of acquired cardiovascular disease.** Hypothesis 1c-ii regarding perceived severity of acquired cardiovascular disease was analyzed using the Champion's Health Belief Model Scale-Seriousness subscale (CHBMS-Seriousness; Champion, 1984). Cronbach's alpha was reported on the full subscale. Analysis of perceived severity of acquired cardiovascular disease included descriptive statistics on the CHBMS-Seriousness subscale. The relation between perceived severity of acquired cardiovascular disease (CHMBS-Seriousness) and physical activity (IPAQ-S) was examined using Pearson's *r* correlation coefficient at $p < .05$.

The CHBMS-Seriousness subscale demonstrated acceptable internal consistency (Cronbach's $\alpha = .83$). In the total sample, participants reported approximately "neutral" perceptions of acquired cardiovascular disease severity (i.e., mean rating between "Disagree" and "Agree" response options). Results of a one-way ANOVA indicated no significant differences in perceived severity of acquired cardiovascular disease among NYHA classifications (F (3, 165) = 1.78, p =.15, $\eta_p^2 = .03$; see Table 3). There was a significant negative correlation between perceived severity of acquired cardiovascular disease (CHBMS-Seriousness) and physical activity (IPAQ-S) in the total sample (r (160) = -.19, p = .01, $r^2 = .04$), which suggests higher ratings of disease severity were associated with lower rates of physical activity. This relation was also significant in NYHA Class I participants (r (68) = -.31, p = .01, $r^2 = .10$). A negative correlation between perceived severity of acquired cardiovascular disease and physical activity signifies Hypothesis 1c-ii was not supported by the data.

Hypothesis 2a: Physical activity outcome expectations. Hypothesis 2a regarding physical activity outcome expectations was analyzed using the Exercise Benefits/Barriers Scale (Sechrist, 1987). Analyses included descriptive statistics on the total scale (EBBS-Total) and each of the two subscales (i.e., EBBS-Benefits and EBBS-Barriers). EBBS-Total was calculated by reverse-scoring the EBBS-Barriers values and adding them to the EBBS-Benefits values to create a total scale score for each participant. Cronbach's alpha was reported on the total scale and each of the two subscales. Hypothesis 2a, the relation between outcome expectations (EBBS-Total) and physical activity (IPAQ-S), was examined using Pearson's *r* correlation coefficient at $p < .05$, Hypothesis 2a-i, the relation between positive outcome expectations (EBBS-Benefits) and physical activity (IPAQ-S), was examined using Pearson's *r* correlation coefficient at $p < .05$. Hypothesis 2a-ii, the relation between negative outcome expectations (EBBS-Barriers) and physical activity (IPAQ-S), was examined using Pearson's *r* correlation coefficient at $p < .05$.

The Exercise Beliefs/Barriers Scale (EBBS-Total) demonstrated strong internal consistency (Cronbach's $\alpha = .95$). In the total sample, participants rated approximate agreement with outcome expectations of physical activity ($M = 2.93$, $SD = .44$). Results of a one-way ANOVA indicated significant differences in physical activity outcome expectations among NYHA classes (F (3,161) = 8.19, $p = .00$, $\eta_p^2 = .13$). Class I participants ($M = 3.08$, $SD = .47$) endorsed higher total physical activity outcome expectations than Class II ($M = 2.88$, $SD = .39$, $p = .04$, 95% CI [.01, .39]), Class III ($M = 2.73$, $SD = .34$; $p = .00$, 95% CI [.11, .60]) and Class IV participants ($M = 2.56$, $SD = .30$; $p = .00$, 95% CI [.16, .89]; see Table 4). There was a significant positive correlation between total physical activity outcome expectations (EBBS-Total) and physical activity (IPAQ-S) in the total sample (r (156) = .29, $p = .00$, $r^2 = .08$), which suggests greater total physical activity outcome expectations were associated with higher rates of physical activity. This relation was also significant among Class I participants (*r* (66) = .36, *p* = .00. r^2 = .13). Therefore, Hypothesis 2a was supported by the data.

Hypothesis 2a-i: Perceived benefits of physical activity. The Benefits subscale of the Exercise Benefits/Barriers Scale (EBBS-Benefits) demonstrated strong internal consistency (Cronbach's α = .96). In the total sample, participants rated approximate agreement with perceived benefits of physical activity (*M* = 2.94, *SD* = .51). Results of a one-way ANOVA indicated significant differences in perceived benefits of physical activity among NYHA classes (*F* (3, 161) = 7.36, *p* = .00, η_p^2 = .12). Class I participants (*M* = 3.11, *SD* = .53) perceived greater benefits of physical activity than Class III (*M* = 2.71, *SD* = .43; *p* = .00, 95% CI [.11, .68]) and Class IV participants (*M* = 2.53; *SD* = .42; *p* = .00, 95% CI [.15, 1.00]; see Table 4). There was a significant positive correlation between perceived benefits of physical activity (EBBS-Benefits) and physical activity (IPAQ-S) in the total sample (*r* (156) = .25, *p* = .00, r^2 = .06), which suggests greater perceived benefits to physical activity was associated with higher rates of physical activity. This relation was also significant among NYHA Class I participants (*r* (63) = .34, *p* = .01, r^2 = .12). Therefore, Hypothesis 2a-i was supported by the data.

Hypothesis 2a-ii: Perceived barriers to physical activity. The Barriers subscale of the Exercise Benefits/Barriers Scale (EBBS-Barriers) demonstrated acceptable internal consistency (Cronbach's α = .87). In the total sample, participants rated approximate disagreement with barriers to physical activity (*M* = 2.11, *SD* = .48). Results of a one-way ANOVA indicated significant differences in perceived barriers to physical activity among NYHA classes (*F* (3, 161) = 4.13, *p* = .01, η_p^2 = .07). Class I participants (*M* = 1.98, *SD* = .47) perceived fewer barriers to physical activity than Class

IV participants (*M* = 2.41, *SD* = .30; p =.04, 95% CI [-.83, -.02]; see Table 4). There was a significant negative correlation between perceived barriers to physical activity (EBBS-Barriers) and physical activity (IPAQ-S) in the total sample (r (156) = -.28, p = .00, r^2 = .08), which suggests greater perceived barriers to physical activity was associated with lower rates of physical activity. This relation was also significant among Class I participants (r (66) = -.32, p = .01, r^2 = .10) and Class IV participants (r (8) = -.72, p = .02, r^2 = .52). Therefore, Hypothesis 2a-ii was supported by the data.

Hypothesis 2b: Physical activity self-efficacy. Hypothesis 2b regarding physical activity self-efficacy was analyzed using the Exercise Self-Efficacy Scale (ESES; Neupert, Lachman, & Whitbourne, 2009). Analysis included descriptive statistics and Cronbach's alpha on the total scale. The relation between physical activity self-efficacy (ESES) and physical activity (IPAQ-S) was examined using a Pearson's r correlation coefficient at $p < .05$.

The ESES demonstrated strong internal consistency (Cronbach's α = .95). In the total sample, the average rating from participants reflects adequate physical activity self-efficacy (*M* = 5.66, *SD* = 2.39). Results of a one-way ANOVA indicated significant differences in physical activity self-efficacy among NYHA classes (F (3, 152) = 8.29, p = .00, η_p^2 = .14). Class I participants (*M* = 6.50, *SD* = 2.30) perceived higher physical activity self-efficacy than Class III (*M* = 4.51, *SD* = 2.26; p = .00, 95% CI [.64, 3.35]) or Class IV participants (*M* = 3.44, *SD* = 2.66; p = .00, 95% CI [.89, 5.24]); see Table 5). There was a significant positive correlation between physical activity self-efficacy (ESES) and physical activity (IPAQ-S) in the total sample (r (148) = .25, p = .00, r^2 = .06), which suggests higher physical activity self-efficacy was associated with higher rates of physical activity. This relation was also significant among Class I participants (r (64) = .24, p = .04, r^2 = .06). Therefore, Hypothesis 2b was supported by the data.

Hypothesis 3: Cardiac anxiety. Hypothesis 3 regarding cardiac anxiety was analyzed using the Cardiac Anxiety Questionnaire (CAQ; Eifert et al., 2000). Analyses included descriptive statistics on the total scale (CAQ-Total) and each of three subscales (i.e., CAQ-Fear, CAQ-Avoidance, CAQ-Attention). The relation between total cardiac anxiety (CAQ-Total) and physical activity (IPAQ-S) was examined using Pearson's r correlation coefficient at $p < .05$. The relation between subfactors of cardiac anxiety, including heart-related fear (i.e., Hypothesis 3a; CAQ-Fear), avoidance of cardiac sensations (i.e., Hypothesis 3b; CAQ-Avoidance), and heart-focused attention (i.e., Hypothesis 3c; CAQ-Attention) and physical activity (IPAQ-S) was examined using a Pearson's r correlation coefficient at $p < .05$.

The CAQ demonstrated acceptable internal consistency (Cronbach's α = .87). In the total sample, participants reported frequency of total cardiac anxiety between "rarely" and "sometimes" (M = 1.80, SD = .61). Results of a one-way ANOVA indicated significant differences in total cardiac anxiety among NYHA classes (F (3, 150) = 13.31, p = .00, η_p^2 = .21). Class I participants (M = 1.53, SD = .54) reported less frequent total cardiac anxiety than Class II (M = 1.90, SD = .58; p = .00, 95% CI [-.63, -.11]), Class III (M = 2.13, SD = .47; p = .00, 95% CI [-.93, -.27]), and Class IV participants (M = 2.49, SD = .61; p = .00; 95% CI [-1.49, -.43]). Similarly, Class II participants reported less frequent total cardiac anxiety than Class IV participants (p = .03, 95% CI [-1.13, -.05]; see Table 6).

There was a significant negative correlation between total cardiac anxiety (CAQ-Total) and physical activity (IPAQ-S) in the total sample (*r* (146) = -.23, *p* = .01, r^2 = .05), which suggests greater frequency of cardiac anxiety was associated with lower rates of physical activity. Therefore, Hypothesis 3 was supported by the data. However, there was no significant relation between total cardiac anxiety and physical activity within any NYHA functional class.

Hypothesis 3a: Heart-related fear. The heart-related fear subscale (CAQ-Fear) demonstrated marginal internal consistency (Cronbach's α = .73). In the total sample, participants reported "sometimes" experiencing fear about cardiac symptoms (*M* = 1.89, *SD* = .66). Results of a one-way ANOVA indicated significant differences in heart-related fear among NYHA classes (*F* (3, 150) = 3.74, *p* = .01, η_p^2 = .07). Class I participants (*M* = 1.73, *SD* = .64) reported less frequent heart-related fear than Class III participants (*M* = 2.13, *SD* = .54; *p* = .04, 95% CI [-.79, -.01]; see Table 6).

There was a significant negative correlation between heart-related fear (CAQ-Fear) and physical activity (IPAQ-S) in the total sample (*r* (146) = -.18, *p* = .03, r^2 = .03), which suggests increased frequency of heart-related fear was associated with lower rates of physical activity. Therefore, Hypothesis 3a was supported by the data. However, there was no significant relation between heart-related fear and physical activity within any NYHA class.

Hypothesis 3b: Avoidance of cardiac sensations. The avoidance of cardiac sensations subscale (CAQ-Avoidance) demonstrated strong internal consistency (Cronbach's α = .90). In the total sample, participants reported avoiding cardiac sensations with a frequency between "rarely" and "sometimes" (*M* = 1.60, *SD* = .94).

Results of a one-way ANOVA indicated significant differences in avoidance of cardiac sensations among NYHA classes (*F* (3, 151) = 13.53, *p* = .00, η_p^2 = .21). Class I participants (*M* = 1.17, *SD* = .84) reported lower avoidance of cardiac sensations than Class II (*M* = 1.77, *SD* = .78; *p* = .00, 95% CI [-1.00, -.20]), Class III (*M* = 2.19, *SD* = .78; *p* = .00, 95% CI [-1.53, -.51]), and Class IV participants (*M* = 2.43, *SD* = .82; *p* = .00, 95% CI [-2.07, -.44]; see Table 6).

There was a significant negative correlation between avoidance of cardiac sensations (CAQ-Avoidance) and physical activity (IPAQ-S) in the total sample (*r* (147) = -.34, *p* = .00, r^2 = .12), which suggests increased avoidance of cardiac sensations was associated with lower rates of physical activity. This relation was also significant among Class I (*r* (64) = -.31, *p* = .01, r^2 = .10) and Class III participants (*r* (23) = -.44, *p* = .03, r^2 = .19). Therefore, Hypothesis 3b was supported by the data.

Hypothesis 3c: Heart-focused attention. The heart-focused attention subscale (CAQ-Attention) demonstrated marginal internal consistency (Cronbach's α = .76). In the total sample, participants reported experiencing heart-focused attention with a frequency between "rarely" and "sometimes" (*M* = 1.85, *SD* = .77). Results of a one-way ANOVA indicated significant differences in heart-focused attention among NYHA classes (*F* (3, 151) = 11.17, *p* = .00; η_p^2 = .18). Class I participants (*M* = 1.56, *SD* = .68) reported less frequent heart-focused attention than Class II (*M* = 1.96, *SD* = .71; *p* = .02, 95% CI [-.73, -.06]) and Class III participants (*M* = 2.07, *SD* = .73; *p* = .01, 95% CI [-.94, -.09]; see Table 6). Class IV participants (*M* = 2.90, *SD* = .74) reported significantly more frequent heart-focused attention than Class I (*p* = .00, 95% CI [-2.02, -.66]), Class II (*p* = .00, 95% CI [.25, 1.64]), and Class III participants (*p* = .02, 95% CI [.09, 1.57]). There was no significant correlation between heart-focused attention and physical activity in the overall sample nor within any NYHA class. Therefore, Hypothesis 3c was not supported by the data.

Hypothesis 4: Evaluation of Protection Motivation Theory. Evaluation of Protection Motivation Theory in physical activity in ACHD was tested using a hierarchical linear regression. Protection Motivation Theory assumes previous communication of disease threat (i.e., risk acquired cardiovascular disease) and a specific health behavior to reduce threat (i.e., physical activity). Therefore, participants who responded “Yes” to both multiple-choice questions about patient-provider conversations about acquired cardiovascular disease and physical activity were included in the analysis. Correlations between all independent variables and physical activity were examined, relevant assumptions for multiple regression were assessed (e.g., multicollinearity, homoscedasticity), and significance of the model was assessed at $p < .05$. The effect size (f^2) of the model and each predictor was also reported and interpreted.

Participant age and NYHA functional classification were entered into Step 1 as independent variables. Components of threat appraisal, perceived severity (CHMBS-Seriousness) and perceived susceptibility to cardiovascular disease acquisition (HBCVD-Susceptibility) were entered into Step 2 as independent variables. Finally, components of coping appraisal, physical activity outcome expectations (EBBS-Total) and physical activity self-efficacy (ESES), were entered into Step 3 as independent variables. Physical activity (IPAQ-S) was entered as the dependent variable. The model of Protective Motivation Theory in this study is represented in Appendix D.

Approximately 60% of participants (N=94) who completed the survey endorsed previous conversations with their medical provider about both acquired cardiovascular disease risk and physical activity. According to the results from G*Power, the participant total is 52 less than the necessary minimum to detect a medium effect size (f^2 = .15). Effect sizes are reported to account for the underpowered analysis. A hierarchical linear regression was conducted on this subsample of participants to evaluate Protection Motivation Theory in the context of physical activity in ACHD.

Participant age and NYHA functional status did not account for significant variance in physical activity in Step 1 (F (2, 91) = 2.82, p = .07). Similarly, components of threat appraisal (CHMBS-Seriousness, HBCVD-Susceptibility) did not account for significant variance in physical activity when added to the model in Step 2 (F (4, 89) = 2.00, p = .102). The addition of components of coping appraisal (EBBS-Total, ESES) into Step 3 resulted in significance of the full model to predict physical activity (F (6, 87) = 3.28, p = .01). Participant age (t = -2.47, p = .02, 95% CI [-.77, -.08]) and physical activity outcome expectations (t = 3.30, p = .00, 95% CI [7.47, 30.15]) were significant predictors in the full model and predicted of 24% and 32% of the variance in the model, respectively. In sum, the regression equation predicted approximately 18.5% of the variance in physical activity and had a medium effect size (f^2 = .23; see Table 7).

Discussion

The purpose of this study was to investigate psychological factors, including patient knowledge, cognitive factors, and emotional factors, related to physical activity in adults with congenital heart disease. Patient factors were selected for inclusion in this study based on a review of gaps in the literature related to ACHD healthcare and self-management of disease. Protection Motivation Theory was implemented to conceptualize physical activity as a behavioral response to reduce risk for acquired cardiovascular disease.

Medical History & Acquired Cardiovascular Disease Risk

Rates of cardiovascular risk factors and medical comorbidities of participants in this study were variable compared to epidemiological rates in ACHD. For example, participants endorsed rates of arrhythmia (Drakopoulou et al., 2018; Moore et al., 2018), stroke or TIAs, congestive heart failure, and Type II diabetes similar to population estimates (Diller et al., 2015; Giang et al., 2018; Toyoda et al., 2020). However, participants also self-reported lower rates of several cardiovascular risk factors and cardiac diseases compared to previous ACHD studies. Hypertension (18.4% vs. 28-80%; Lui et al., 2017; Toyoda et al., 2020), hyperlipidemia (11.8% vs. 19%; Toyoda et al., 2020), myocardial infarction (5.7% vs. 10%; Olsen et al., 2017), and coronary artery disease (2.7% vs. 14%; Flannery, 2018) were less prevalent in this sample than in population norms. Further, the prevalence of hypertension and coronary artery disease were significantly lower than in the general adult population in the United States (45% and 6.7%, respectively; Center for Disease Control, 2020).

The variability in cardiovascular risk factors and medical comorbidities within this sample may be attributable to the general heterogeneity in the medical profile of ACHD. It must also be established that cardiovascular risk is a dynamic and individualized metric of patient health, especially among ACHD (Koyak et al., 2017). Medical status at a single time-point should not negate assessment of future cardiovascular risk nor interventions that may mitigate the potential for poor medical outcomes in this patient population.

Physical Activity

Approximately three-quarters of participants met or exceeded American Heart Association physical activity guidelines (2020). This percentage is approximately 20% higher than the national average among healthy American adults (54.2%; Center for Disease Control, 2020). In addition to greater prevalence, the average quantity of physical activity reported by participants was almost four times the minimum recommended amount and there were no significant differences in physical activity among NYHA classes. The rate of physical activity in this study is higher than most epidemiological studies in ACHD. To date, a study of fifteen young ACHD with minimal functional impairment is the only other study that reported a similar prevalence of sufficient physical activity (i.e., 75%; McKillop et al., 2018). It is clear the average physical activity reported in this study falls near the upper threshold among published research.

There are several potential explanations for unexpectedly high rates of physical activity in this sample. First, the self-report nature of the International Physical Activity Questionnaire-Short Form (IPAQ-S) may have resulted in overestimation of physical activity. Overestimation is well-documented on self-report measures of socially desirable behaviors in general (Van de Mortel, 2008). Estimates suggest participants self-report between 62%-84% greater physical activity on the IPAQ-S than objective measures of physical activity (Dyrstad et al., 2014; Steene-Johannessen et al., 2016). Second, participants may have experienced difficulty classifying physical activity. Many daily non-exercise physical activities occur at a “moderate” intensity level (e.g., walking fast, chores) and are included by participants in retrospective estimations of weekly totals. This explanation, known as the “cutpoint bias hypothesis,” may result in overestimation of physical activity because many daily activities exist at the threshold of measurable metabolic expenditure (Olds et al., 2019). Third, exercise capacity likely influenced perceived exertion at each physical activity intensity. For example, a “moderate” activity for an NYHA Class I participant may require comparable metabolic expenditure to a “vigorous” activity for a NYHA Class III participant due to differences in exercise capacity. For these reasons, it is possible participants in this study overestimated weekly physical activity. However, with the assumption of uniform overestimation of physical activity across NYHA functional classes, examination of the relations between physical activity and patient factors can provide insight into patient self-management of ACHD.

Patient-Provider Conversations about Acquired Cardiovascular Disease Risk & Physical Activity

Approximately two-thirds of participants reported a prior conversation with their medical provider about their risk for acquired cardiovascular diseases. such as heart failure, heart attack, or arrhythmia. Current guidelines from the American Heart Association and American College of Cardiology state, “evaluation for acquired cardiac conditions is warranted in patients with [cardiopulmonary] risk factors” (Stout et al., 2019, p. e718). Accordingly, 90% of participants in this sample endorsed at least one medical risk factor associated with premature mortality in ACHD (e.g., prior surgical intervention, coronary artery disease, hypertension, hyperlipidemia). This incongruity between the prevalence of medically at-risk patients and the prevalence of patient-provider conversations about future medical risk represents a profound shortcoming in ACHD healthcare.

A greater proportion of participants endorsed prior conversations with their medical provider about physical activity and relevant aspects of physical activity (e.g., benefits, risks, activities; 81-96%) than conversations about acquired cardiovascular risk. The discrepancy between prevalence of these conversation topics may suggest the topics are not linked in patient-provider interactions. For example, physical activity may be conceptualized as preventive medicine while acquired cardiovascular risk may represent a “problem-focused” discussion. Protection Motivation Theory dictates conversations about acquired disease risk and preventive behaviors to reduce risk should occur in sequence to increase engagement in health behaviors.

Although many participants reported conversations with their medical provider about physical activity, it is concerning only a minority (38.9%) reported receiving a physical activity prescription. Education about benefits, risks, and activities that are safe may have limited effect if a patient has not obtained an individualized physical activity plan. Indeed, the difference between efficacy and effectiveness of an intervention is its translation to an ecological setting (Singal et al., 2014). One potential obstacle to physical activity prescription is that cardiopulmonary exercise testing, which is widely considered the first step in individualized physical activity prescription (Tran et al., 2020), is recommended but not mandated as part of standard ACHD care (Stout et al., 2019). Individualized physical activity prescription informed by objective assessments of exercise capacity is a necessary component of effective acquired disease prevention in ACHD.

Perceived Susceptibility to and Severity of Acquired Cardiovascular Disease

Patient cognitive factors were examined following analysis of patient-provider conversations. The differences in perceived susceptibility to acquired cardiovascular disease among NYHA classes were expected. Specifically, Class I participants "disagreed" with statements about their susceptibility to acquired cardiovascular disease while Class III and Class IV participants "agreed" with such statements. Class IV participants reported significantly more medical comorbidities than participants from other classes. It may be understandable that patients with several pre-existing medical conditions perceive a heightened possibility of acquiring another cardiac disease.

Participants perceived the severity of acquired cardiovascular disease as approximately "neutral" (i.e., neither agree or disagree). Further, there were no differences in participant ratings among NYHA classes. These results suggest ACHD do not anticipate severe psychosocial consequences (e.g., impairment in relationships, work, finances) of acquired cardiovascular disease. Perceived severity of acquired cardiovascular disease may be related to current self-perceived health status. ACHD may view the effects of acquired cardiovascular disease as negligible or "neutral" in the context of current functional impairment caused by their congenital defect, regardless of degree of current impairment. Previous research has demonstrated ACHD perceive a heightened ability to "overcome" consequences of disease (Saidi et al., 2007; Harrison et al., 2011), which may represent adaptive adjustment to current or future disease.

Perceived susceptibility to and perceived severity of acquired cardiovascular disease evidenced negative correlations with physical activity. This finding contradicts Protection Motivation Theory, which hypothesizes individuals who perceive greater susceptibility to and severity of acquired disease should more frequently engage in a preventive health behavior.

It may be that many participants do not have an accurate understanding of their risk for acquired cardiovascular disease, perhaps due to poor communication or misunderstanding during conversations with their medical providers. Beyond patient knowledge, distorted illness beliefs about disease acquisition (i.e., locus of control; Mercer et al., 2018; Strudler-Wallston & Wallston, 1978) or significant emotional symptoms (e.g., anxiety, depression; Larkin & Chantler, 2020) may underlie decreased physical activity in the presence of acquired cardiovascular disease risk. It is clear additional research is necessary to examine what patient factors may underlie perceptions of acquired cardiovascular disease risk in ACHD.

Physical Activity Outcome Expectations and Physical Activity Self-Efficacy

This study also examined physical activity outcome expectations and physical activity self-efficacy as cognitive factors related to physical activity. NYHA Class I participants perceived significantly more benefits and fewer barriers to physical activity than participants from other NYHA classes. These differences may be due to the negative relation between cardiac defect complexity and functional capacity, owing primarily to the structural or functional cardiopulmonary abnormalities of the defect (Bredy et al., 2018). To this end, functional impairment may underlie the perceived “upper threshold” of physical activity benefits and increased barriers to physical activity in NYHA Class III and Class IV patients.

The hypothesized relations between perceived benefits of physical activity, perceived barriers to physical activity, and physical activity were supported with the data.

One notable finding is the strong negative correlation between barriers to physical activity and physical activity in Class IV participants. Additional analyses indicated the strength of this relation was supported by elevations on the Physical Exertion subscale (e.g., “Exercise tires me”), which suggests anticipated bodily responses to physical activity inhibit physical activity in severely impaired patients. Functional capacity, however, should not be considered a comprehensive explanation for physical activity in ACHD. It remains unclear what proportion of variance in outcome expectations is directly attributable to the congenital defect and its disease sequalae versus acquired impairment through physical inactivity.

Participant perceptions of physical activity self-efficacy followed a pattern similar to physical activity outcome expectations. Namely, NYHA Class I participants reported greater physical activity self-efficacy than Class III or Class IV participants. In addition, there was a positive correlation between physical activity self-efficacy and physical activity in the total sample and a stronger positive correlation in Class I participants.

While differences in physical activity self-efficacy and its relation to physical activity among NYHA classes may be expected based on differences in functional capacity (Bredy et al., 2018), the same relation could be expected from a behavioral explanation of the data. Successful engagement in physical activity may function as the precipitant rather than the product of self-efficacy. Evidence that individuals gain self-efficacy as the result of successful experiences suggests the relation may be bidirectional (Maddux & Kleiman, 2018). As a result, physical activity outcome expectations and self-efficacy may be the result of functional capacity and previous physical activity. A comprehensive medical and health behavior assessment is required to understand components of coping appraisal and determine points of intervention in order to maximize potential for sufficient physical activity in ACHD.

Emotional Factors

The final patient factor assessed in this study was cardiac anxiety and its components of heart-related fear, avoidance of cardiac sensations, and heart-focused attention (Eifert et al., 2000). NYHA Class I individuals reported less frequent experiences of cardiac anxiety than all other classes in each of these domains. However, similar to previous research (O'Donovan et al., 2016; McKillop et al., 2018), the overall frequency of cardiac anxious symptoms in this sample was "rare." Less frequent experiences of cardiac anxiety among NYHA Class I individuals may be explained by less frequent cardiac symptoms or greater perceived health status. Previous studies have classified many Class I individuals as "asymptomatic" due to the low frequency or absence of cardiac symptoms (e.g., arrhythmia; Berghammer et al., 2013; Bredy et al., 2018). Alternatively, NYHA Class I individuals may have attenuated their response to cardiac symptoms through reduced avoidance of physical activities. Evidence for the explanation is Class I individuals reported "rarely" avoiding physical sensations, which was significantly less frequent than participants of NYHA Classes II, III, and IV who reported "sometimes" avoiding physical sensations. Additional research is necessary to test the medical and behavioral models of cardiac anxiety in ACHD.

As hypothesized, there was a negative correlation between cardiac anxiety and physical activity, owing to negative correlations between heart-related fear, avoidance of cardiac sensations, and physical activity. The non-significant correlation between heart-focused attention and physical activity was not expected. In accord with the "cutpoint bias hypothesis" (Olds et al., 2019), one potential explanation is that ACHD are less aware of cardiac sensations during routine daily activities. Active monitoring of cardiac functioning, such as checking a pulse or "feeling my heart in my chest," may be associated with high-intensity exercise rather than daily physical activity. A second potential explanation is the lower internal consistency of the heart-focused attention subscale in this study and the original scale development. Two items on the subscale query whether cardiac sensations wake an individual from sleep. Cardiac sensations of this magnitude may be indicative of severely impaired cardiac functioning (e.g., arrhythmia), clinical anxiety disorders (e.g., Panic Disorder), or another medical condition (e.g., obstructive sleep apnea) rather than an anxious response to normal cardiac sensations. For these reasons, it is possible heart-related fear may be less useful to understand cardiac anxiety or its relation to physical activity.

It is important to recognize cardiac anxiety does not exist in isolation of other patient factors. Approximately 42% of ACHD in this sample endorsed lifetime prevalence of an anxiety disorder (e.g., Generalized Anxiety Disorder). Previous studies have reported lifetime prevalence of anxiety symptoms between 26%-42% in ACHD (Jackson et al., 2018; Benderly et al., 2019) compared to approximately 33% lifetime prevalence in the general adult population (Bandelow & Michaelis, 2015). This finding is significant for two reasons. First, anxiety can cause physical symptoms that are frequently reported in episodes of panic (e.g., palpitations; American Psychological Association, 2013). Individuals may misinterpret cardiac palpitations as indicators of medical illness rather than psychological distress, which may result in subsequent anxiety about and avoidance of future cardiac sensations. In ACHD, baseline anxiety may influence interpretation of cardiac sensations in the context of physical activity. Second, evidence from longitudinal studies indicates higher rates of cardiovascular and respiratory conditions in individuals with anxiety disorders, possibly due to repeated activation of the sympathetic nervous system (Meuret et al., 2020). Further, rates of psychiatric disorders are higher among individuals with chronic medical conditions (Walker & Druss, 2017). Anxiety, independent of its relation to physical activity, may function as a partial explanation for high rates of acquired cardiovascular disease in ACHD.

Evaluation of Protection Motivation Theory

This study examined Protection Motivation Theory as a framework to conceptualize physical activity in ACHD. Analysis of frequency distributions of participant responses indicated 60% of individuals who completed the study endorsed conversations with their medical provider about both acquired cardiovascular disease risk and physical activity. That only three-fifths of patients received fundamental health-related information represents a significant need for intervention in ACHD healthcare.

It is perhaps unsurprising that the full regression equation was significant given the significant correlations between many patient factors and physical activity. Nevertheless, participant age was a significant predictor of physical activity in the final regression equation despite the non-significant relation to physical activity in a separate point-biserial correlation. Older age is typically associated with increased risk for acquired cardiovascular disease, decreased functional capacity, and decreased physical activity in ACHD (Tutarel et al., 2014; Rosa et al., 2018). Patient age should represent an additional patient factor in physical activity assessment and intervention. Overall, the finding that Protection Motivation Theory explained significant variance in physical activity is a significant contribution to ACHD research.

Study Limitations & Directions for Future Research

One limitation of this study was the lack of corroboration of participant self-report medical data with medical records. Verification of participant medical history (e.g., medical comorbidities, cardiac interventions) and current NYHA functional status through a medical record review would enhance validity of participant data. An alternative method would be to assess participant functional status through cardiopulmonary exercise testing (e.g., six-minute walk test). Future studies should seek to implement objective assessment of medical data within the epidemiological study of physical activity in ACHD.

A second potential limitation is low generalizability of these findings due to selection bias associated with online participant recruitment. Participants in this study were recruited through social media websites and research groups for ACHD and may therefore represent a select sample of patients who are resource rich and highly engaged with their healthcare. Further, only a small minority of participants identified as a member of a minority racial or ethnic background. Individuals with more education (Zajacova & Lawrence, 2018) and higher socioeconomic status (Williams, Priest, & Anderson, 2016) achieve better health outcomes than individuals who rate low on these variables, and this relation has been previously supported in ACHD (Kempny et al., 2016; Connor et al., 2019). Future studies should selectively recruit participants from demographic backgrounds associated with poor health outcomes (e.g., low education, low socioeconomic status, minority racial and ethnic backgrounds) to assess disease self-management in the context of socioeconomic barriers.

Recommendations for Clinical Practice

Findings from this study inform clinical recommendations for ACHD healthcare. First, it is well understood that ACHD of different functional classes pose various levels of risk for acquired cardiovascular disease and mortality. However, it is also understood that disease risk is dynamic and disease course can be incalculable in these patients. The prevalence of patient-provider conversations about acquired cardiovascular disease risk and physical activity was significantly below prevalence estimates of at-risk ACHD. Healthcare providers must discuss risk for acquired cardiovascular disease and preventive strategies with every patient as part of standard clinical care.

Second, ACHD providers should prescribe a physical activity plan to their patients. Physical activity plans should be informed by a comprehensive medical record review, physical activity history, and initial cardiopulmonary exercise test to establish baseline functional capacity and inform prognosis for disease course (Mantegazza et al., 2017; Birkey et al., 2018; Burstein et al., 2019). The Physical Activity Recommendation Form is a single-page template that has been piloted in ACHD to individualize physical activity recommendations for patients. The form includes recommendations for type and duration of activity, activities to avoid, and target metabolic expenditure (Lyle & Hartman, 2018). Results of the pilot program indicated increased physical activity among participants as well as increased confidence of ACHD providers during conversations with patients about physical activity. The Physical Activity Recommendation Form and similar physical activity prescriptions should be utilized in clinical encounters.

Third, ACHD providers should attend to patient psychological factors in their discussions of acquired cardiovascular disease risk and physical activity. Providers may identify general physical activity milieu (e.g., time, money) or ACHD-specific barriers (e.g., cardiac anxiety, increased physical fatigue) as potential barriers to physical activity adherence. Likewise, ACHD should develop problem-solving strategies to overcome barriers and improve self-efficacy in order to increase physical activity. Psychological intervention, as part of comprehensive patient care, will likely assist long-term adherence to physical activity in ACHD.

Conclusions

This study provides evidence for the relevance of psychological factors, including patient knowledge, cognitive factors, and emotional factors, to physical activity in ACHD. Further, results indicate Protection Motivation Theory can be a useful theoretical framework to conceptualize physical activity in this population. Each cognitive and emotional factor examined in this study correlated with physical activity except heart-focused attention. NYHA Class I participants reported higher functioning or less frequent impairment than participants of other functional classes on most patient factors. Results of this study should propel future epidemiological research on physical activity and inform patient-provider interactions with the overall goal to improve acquired disease prevention in ACHD.

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Appendix A

Participant Recruitment Sources

Adult Congenital Heart Association website
ResearchMatch
Craigslist
Facebook (*listed in order of contact)*

- Congenital Heart Defects (page)
- Adults with Congenital Heart Defects (group)
- Living with Adult Congenital Heart Disease (group)
- Adult Congenital Heart Defects (ACHD) (page)
- Aortic Stenosis Research (page)
- Aortic Stenosis (page)
- Bicuspid Aortic Valve Heart Condition (group)
- Atrial Septal Defect Survivors Network (ASDSurvivors.org) (page)
- Adults Atrial Septal Defect (Hole in the Heart) (group)
- Coarctation of the Aorta (group)
- Transposition of the Great Arteries (group)
- Ebstein's Anomaly (groups)
- Ebstein's Anomaly Congenital Heart Disease (group)
- PDA (patent ductus arteriosus (group)
- Pulmonary Valve Stenosis support group (group)
- Pumlonary Valve Stenosis (page)
- Hypoplastic Left Heart Syndrome ! (group)
- Tetralogy of Fallot (groups)
- Tetralogy of Fallot Support (group)
- Tetralogy of Fallot Community & Support (page)
- Tetralogy of Fallot Foundation Inc. (page)
- Truncus Arteriosus Kids And Adults (group)
- Adult CHD patients answering CHD Parents ?'s (group)
- CHD Athletes (group)
- American Heart Association (page)
- C.H.D. Awareness – Congenital Heart Disease (page)
- CHD Awareness Quilt Project (page)
- Pediatric Congenital Heart Association (page)
- CHD Community (page)
- CHD Awareness! (group)
- Hope for CHD (page)
- Hope for Hearts-CHD Awareness (page)
- Adult Congenital Heart Disease at Nationwide Children's Hospital (page)
- Adult Congenital Heart Page (page)
- The CHD Life (pages)
- British Heart Foundation (page)
- Congenital Heart Defects (page)
- Congenital Heart Defects Families Association – Chdfamilies (page)

Appendix B

Compendium of Study Measures

Demographics

Date: _____ / _____ / 20____

Age: ________ years

Sex:
❑ Male
❑ Female
❑ Another (please specify): __________________
❑ Prefer not to say

What is your marital status?
❑ Single, never married
❑ Married
❑ Living with partner
❑ Separated or divorced
❑ Widowed
❑ Another (please specify): ____________________

With what racial background do you most identify?
❑ Middle-Eastern/Arabic
❑ Asian
❑ Black/African-American
❑ Hispanic/Latino
❑ White/Caucasian
❑ Biracial
❑ Another (please specify): ____________________

What is your highest level of education?
❑ Less than high school
❑ High school graduate
❑ Some college
❑ 2-year degree (e.g., Associate's)
❑ 4-year degree (e.g., Bachelor's)
❑ Professional or graduate degree (e.g., Master's, Doctorate)

What is your current work situation?
❑ Full-time paid work
❑ Part-time paid work
❑ Volunteer
❑ Homemaker
❑ Job-seeking
❑ Unemployed
❑ Disability/Government financial assistance (disability rate: ____ %)
❑ Retired
❑ Another (please specify): ____________________________

What is your annual household income?
❑ Less than $15,000
❑ $15,001-$30,000
❑ $30,001-$45,000
❑ $45,001-$60,000
❑ $60,001-$75,000
❑ More than $75,000

Medical History

Please select your congenital heart defect:
❑ Aortic Valve Stenosis (AVS)
❑ Atrial Septal Defect (ASD)
❑ Coarctation of the Aorta (CoA)
❑ Complete Atrioventricular Canal defect (CAVC)
❑ Transposition of the Great Arteries
❑ Ebstein's Anomaly
❑ Patent Ductus Arteriosis (PDA)
❑ Pulmonary Valve Stenosis
❑ Single Ventricle Defect (Hypoplastic Left Heart Syndrome; Pulmonary Atresia/Intact Ventricular Septum; Tricuspid Atresia)
❑ Tetralogy of Fallot
❑ Total Anomalous Pulmonary Venous Connection (TAPVC)
❑ Truncus Arteriosus
❑ Ventricular Septal Defect (VSD)
❑ Other defect (please specify): ___________________________________
❑ I don't know/I cannot remember

How frequently do you have medical appointments for your congenital heart defect?
❑ More than twice a year
❑ Twice a year
❑ Once a year
❑ Every 2 years
❑ Every 3 years
❑ Every 4 years
❑ Every 5 years
❑ Less often than every 5 years

Have you had any cardiac surgeries related to your congenital heart defect?
❑ Yes
❑ No

If "Yes", what year was your most recent cardiac surgery? ____________

Have you had any emergency hospital admissions related to your congenital heart defect within the past year?
❑ Yes
❑ No

If "Yes", how many emergency hospital admissions within the past year? _______________

Do you have an implantable cardiac device (e.g., pacemaker, defibrillator)?
❑ Yes
❑ No

Have you undergone a cardiac catheterization?
❑ Yes
❑ No
If "Yes", how many times? _______________
If "Yes", what year was your most recent cardiac catheterization? ___________

Please indicate whether you *have experienced* or *are currently diagnosed* with any of the following medical conditions (check all that apply):
❑ Myocardial infarction (heart attack)
❑ Congestive heart failure
❑ Coronary artery disease (e.g., atherosclerosis, unstable angina)
❑ Stroke or TIAs
❑ Type 2 Diabetes
❑ Hypertension (high blood pressure)
❑ Hyperlipidemia (high cholesterol)
❑ Arrhythmia
❑ Chronic lung disease (e.g., COPD)
❑ Other (please specify): ____

Please indicate whether you *have experienced* or *are currently diagnosed with* any of the following psychiatric conditions (check all that apply):
❑ Mood disorder (e.g., Major Depressive Disorder)
❑ Anxiety disorder (e.g., Generalized Anxiety Disorder)
❑ Other psychiatric diagnosis (please specify): __________________________

Below are descriptions of how individuals may be limited in their physical functioning. Which description is most applicable to you? Please only consider the limitations that you believe are caused by your congenital cardiac defect.
❑ I am not limited during physical activities. Ordinary physical activities do not cause extraordinary fatigue, palpitations, or shortness of breath.
❑ I am slightly limited during physical activities. I do not experience any symptoms at rest, but ordinary physical activities cause extraordinary fatigue, palpitations or shortness of breath.
❑ I am considerably limited during physical activities. I do not experience any symptoms at rest, but less than ordinary physical activities cause extraordinary fatigue, palpitations, or shortness of breath

❑ I am unable to be physically active without experiencing discomfort. I experience one or more of the following complaints at rest: fatigue, palpitations, or shortness of breath. When I am physically active, the discomfort increases.

Patient-Provider Conversations

Health Knowledge, Attitudes, and Practices Questionnaire (Dunstan, 2002)

For the following questions, please focus on conversations you have had with the cardiologist who treats your congenital heart defect.

Has your cardiologist ever talked with you about…
…your risk for other cardiac diseases (e.g., heart failure, heart attack, arrhythmia)?
☐ Yes
☐ No
☐ I Don't Know/I'm Not Sure

…physical activity or exercise?
☐ Yes
☐ No
☐ I Don't Know/I'm Not Sure

Has your cardiologist ever recommended or prescribed an exercise plan to you?
☐ Yes
☐ No
☐ I Don't Know/I'm Not Sure

If you answered "yes" to this question, proceed to questions "a" through "d." If you answered "no", please continue to next questionnaire.

Has your cardiologist ever talked with you about…
a. …the *benefits* of physical activity or exercise?
☐ Yes
☐ No
☐ I Don't Know/I'm Not Sure
b. …*risks or safety concerns* of physical activity or exercise?
☐ Yes
☐ No
☐ I Don't Know/I'm Not Sure
c. …*when you should stop* physical activity or exercise (e.g., physical symptoms)?
☐ Yes
☐ No
☐ I Don't Know/I'm Not Sure
d. …activities that are safe for people with your heart condition?
☐ Yes
☐ No
☐ I Don't Know/I'm Not Sure

Physical Activity

International Physical Activity Questionnaire-Short Form (IPAQ Group, 2012)

We are interested in finding out about the kinds of physical activities that people do as part of their everyday lives. The questions will ask you about the time you spent being physically active in the last 7 days. Please answer each question even if you do not consider yourself to be an active person. Please think about the activities you do at work, as part of your house and yard work, to get from place to place, and in your spare time for recreation, exercise or sport.

Think about all the vigorous activities that you did in the last 7 days. Vigorous physical activities refer to activities that take hard physical effort and make you breathe much harder than normal. Think only about those physical activities that you did for at least 10 minutes at a time.

1. During the last 7 days, on how many days did you do vigorous physical activities like heavy lifting, digging, aerobics, or fast bicycling?
_____ days per week
No vigorous physical activities: Skip to question 3

2. How much time did you usually spend doing vigorous physical activities on one of those days?
_____ hours per day
_____ minutes per day
_____ Don't Know/Not Sure

Think about all the moderate activities that you did in the last 7 days. Moderate activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal. Think only about those physical activities that you did for at least 10 minutes at a time.

3. During the last 7 days, on how many days did you do moderate physical activities like carrying light loads, bicycling at a regular pace, or doubles tennis? Do not include walking.
_____ days per week
No moderate physical activities Skip to question 5

4. How much time did you usually spend doing moderate physical activities on one of those days?
_____ hours per day
_____ minutes per day
_____ Don't Know/Not Sure

Think about the time you spent walking in the last 7 days. This includes at work and at home, walking to travel from place to place, and any other walking that you have done solely for recreation, sport, exercise, or leisure.

5. During the last 7 days, on how many days did you walk for at least 10 minutes at a time?
_____days per week
No walking Skip to question 7

6. How much time did you usually spend walking on one of those days?
_____ hours per day
_____ minutes per day
_____ Don’t Know/Not Sure

The last question is about the time you spent sitting on weekdays during the last 7 days. Include time spent at work, at home, while doing course work and during leisure time. This may include time spent sitting at a desk, visiting friends, reading, or sitting or lying down to watch television.

7. During the last 7 days, how much time did you spend sitting on a weekday?
_____ hours per day
_____ minutes per day
_____ Don’t Know/Not Sure

Perceived Susceptibility to Acquired Cardiovascular Disease

Health Beliefs related to Cardiovascular Disease-Susceptibility subscale (Tovar et al., 2010)

For the following questions, please imagine the possibility of experiencing another cardiac disease (e.g., heart attack, arrhythmia, heart failure) other than your congenital heart defect. If you have already experienced another cardiac disease (e.g., heart attack), please answer as if you could acquire another disease (e.g., stroke).

DIRECTIONS: Please indicate how much you agree or disagree with the following items. Please choose from one of the following options:

1- Strongly Disagree 2- Disagree 3- Agree 4- Strongly Agree 5-N/A

1. It is likely that I will have a heart attack or stroke in the future
2. My chances of having a heart attack or stroke in the next few years are great
3. I feel I will have a heart attack or stroke some time during my life
4. Having a heart attack or stroke is currently a possibility for me
5. I am concerned about the likelihood of having a heart attack or stroke in the near future
6. It is likely that I will acquire another cardiac disease (e.g., arrhythmia, heart failure) in the future
7. My chances of acquiring another cardiac disease (e.g., arrhythmia, heart failure) in the next few years are great
8. I feel I will acquire another cardiac disease (e.g., arrhythmia, heart failure) sometime during my life
9. Acquiring another cardiac disease (e.g., arrhythmia, heart failure) is currently a possibility for me
10. I am concerned about the likelihood of acquiring another cardiac disease (e.g., arrhythmia, heart failure) in the near future.

Perceived Severity of Cardiovascular Disease

Champion's Health Belief Model Scale-Seriousness subscale (Champion, 1984)

DIRECTIONS: Please indicate how much you agree or disagree with the following items. Please choose from one of the following options:

1- Strongly Disagree 2 3 4 5- Strongly Agree

1. If I acquire another cardiac disease (e.g., heart attack, arrhythmia, heart failure), my career would be endangered
2. Another cardiac disease (e.g., heart attack, arrhythmia, heart failure) would endanger my marriage (or significant relationship)
3. Another cardiac disease (e.g., heart attack, arrhythmia, heart failure) would be a hopeless disease
4. My feelings about myself would change if I acquire another cardiac disease (e.g., heart attack, arrhythmia, heart failure)
5. My financial security would be endangered if I acquire another cardiac disease (e.g., heart attack, arrhythmia, heart failure)
6. Problems I would experience from another cardiac disease (e.g., heart attack, arrhythmia, heart failure) would last a long time
7. If I acquire another cardiac disease (e.g., heart attack, arrhythmia, heart failure), it would be more serious than other diseases
8. If I acquire another cardiac disease (e.g., heart attack, arrhythmia, heart failure), my whole life would change

Outcome Expectations of Physical Activity

Exercise Benefits/Barriers Scale (Sechrist, 1987)

DIRECTIONS: Please indicate how much you agree or disagree with the following items. Please choose from one of the following options:

1- Strongly Disagree *2- Disagree* *3- Agree* *4- Strongly Agree*

1. I enjoy exercise
2. Exercise decreases feelings of stress and tension for me
3. Exercise improves my mental health
4. Exercising takes too much of my time
5. I will prevent heart attacks by exercising
6. Exercise tires me
7. Exercising increases my muscle strength
8. Exercise gives me a sense of personal accomplishment
9. Places for me to exercise are too far away
10. Exercising makes me feel relaxed
11. Exercising lets me have contact with friends and persons I enjoy
12. I am too embarrassed to exercise
13. Exercising will keep me from having high blood pressure
14. It costs too much money to exercise
15. Exercising increases my level of physical fitness
16. Exercise facilities do not have convenient schedules for me
17. My muscle tone is improved with exercise
18. Exercising improves functioning of my cardiovascular system
19. I am fatigued by exercise
20. I have improved feelings of wellbeing from exercise
21. My spouse (or significant other) does not encourage exercising
22. Exercise increases my stamina
23. Exercise improves my flexibility
24. Exercise takes too much time from family relationships
25. My disposition is improved by exercise
26. Exercising helps me sleep better at night
27. I will live longer if I exercise
28. I think people in exercise clothes look funny
29. Exercise helps me to decrease fatigue
30. Exercising is a good way for me to meet new people
31. My physical endurance is improved by exercising
32. Exercising improves my self-concept
33. My family members do not encourage me to exercise
34. Exercising increases my mental alertness

35. Exercise allows me to carry out normal activities without becoming tired
36. Exercise improves the quality of my work
37. Exercise takes too much time from my family responsibilities
38. Exercise is good entertainment for me
39. Exercising increases my acceptance by others
40. Exercise is hard work for me
41. Exercise improves overall body functioning for me
42. There are too few places for me to exercise
43. Exercise improves the way my body looks

Physical Activity Self-Efficacy

Exercise Self-Efficacy Scale (Neupert et al., 2009)

DIRECTIONS: How certain are you that you can do each of the following? Please choose from one of the following options:

0	1	2	3	4	5	6	7	8	9	10

I cannot do this activity at all (1)

I am certain that I can do this activity successfully (10)

1. Exercise regularly (5 days/week for 30 minutes/day)
1. Exercise when you are feeling tired
3. Exercise when you are feeling under pressure to get things done
4. Exercise when you are feeling down or depressed
5. Exercise when you have too much work to do at home
6. Exercise when there are other more interesting things to do
7. Exercise when your family or friends do not provide any kind of support
8. Exercise when you really don’t feel like it
9. Exercise when you are away from home (e.g., traveling, visiting, on vacation)

Cardiac Anxiety

Cardiac Anxiety Questionnaire (Eifert, 2000)

DIRECTIONS: Please indicate the extent to which the following items occur. Please choose from one of the following options:

0- Never 1- Rarely 2- Sometimes 3- Often 4- Always

1. I pay attention to my heart beat
2. I avoid physical exertion
3. My racing heart wakes me up at night
4. Chest pain/discomfort wakes me up at night
5. I take it easy as much as possible
6. I check my pulse
7. I avoid exercise or other physical work
8. I can feel my heart in my chest
9. I avoid activities that make my heart beat faster
10. If tests come out normal, I still worry about my heart
11. I feel safe being around a hospital, physician, or other medical facility
12. I avoid activities that make me sweat
13. I worry that doctors do not believe my chest pain/discomfort is real
14. When I have chest discomfort or when my heart is beating fast…
    a....I worry that I may have a heart attack
    b....I have difficulty concentrating on anything else
    c....I get frightened
    d....I like to be checked out by a doctor
    e....I tell my family or friends

Appendix C

Tables

Table 1

Participant Congenital Defects by Type

Type of Congenital Defect	Percentage of Sample (%)
Tetralogy of Fallot	18.9
Transposition of the Great Arteries	14.2
Atrial Septal Defect	12.7
Ventricular Septal Defect	12.7
Aortic Valve Stenosis	11.8
Single Ventricle Defect	7.1
Coarctation of the Aorta	6.1
Pulmonary Valve Stenosis	5.7
Patent Ductus Arteriosus	2.4
Truncus Arteriosus	2.4
Complete Atrioventricular Canal defect	0.9
Ebstein's Anomaly	0.5
Total Anomalous Pulmonary Venous Connection	0
Other Defect	40.1
Bicuspid Aortic Valve	9
Pulmonary Atresia	2
Multiple defects	4.2
PAPVC	1.4
All other write-ins	0.5

Table 2

Perceived Susceptibility to Acquired CVD (HBCVD-Susceptibility)

NYHA Class	Descriptive Statistics			Correlation with IPAQ-S	
	n	*M*	*SD*	*r*	*p*
Total sample	167	2.38	0.62	-0.12	0.13
Class I	75	2.18	0.51	-0.08	0.52
Class II	57	2.39	0.65	0.07	0.62
Class III	26	2.71	0.61	-0.41	0.04*
Class IV	9	3.04	0.48	0.41	0.28

*$p < .05$.

Table 3

Perceived Severity of Acquired CVD (CHMBS-Seriousness)

NYHA Class	Descriptive Statistics			Correlation with IPAQ-S	
	n	*M*	*SD*	*r*	*p*
Total sample	169	2.84	0.84	-0.19	0.01*
Class I	75	2.78	0.79	-0.31	0.01*
Class II	59	2.76	0.84	0.03	0.82
Class III	26	3.03	0.86	-0.3	0.14
Class IV	9	3.32	1.05	-0.06	0.87

*$p < .05$.

Table 4

Physical Activity Outcome Expectations (EBBS)

NYHA Class	Descriptive Statistics			Correlation with IPAQ-S	
	n	*M*	*SD*	*r*	*p*
Outcome expectations (Total)					
Total sample	165	3.86	2.93	0.29	0.00**
Class I	73	3.08	0.47	0.36	0.00**
Class II	56	2.88	0.39	0.11	0.42
Class III	26	2.73	0.34	0.20	0.32
Class IV	10	2.55	0.30	0.17	0.65
Perceived benefits (Benefits)					
Total sample	165	2.94	0.51	0.25	0.00**
Class I	73	3.11	0.53	0.34	0.01*
Class II	56	2.89	0.45	0.10	0.46
Class III	26	2.71	0.43	0.08	0.69
Class IV	10	2.53	0.42	-0.09	0.80
Perceived barriers (Barriers)					
Total sample	165	2.11	0.48	-0.28	0.00**
Class I	73	1.98	0.47	-0.32	0.01*
Class II	56	2.15	0.47	-0.08	0.59
Class III	26	2.25	0.48	-0.27	0.19
Class IV	10	2.41	0.30	-0.72	0.02*

*$p < .05$. ** $p < .01$.

Table 5

Physical Activity Self-Efficacy (ESES)

NYHA Class	Descriptive Statistics			Correlation with IPAQ-S	
	n	*M*	*SD*	*r*	*p*
Total sample	156	5.67	2.39	0.26	0.00**
Class I	70	6.50	2.30	0.31	0.01*
Class II	53	5.44	2.09	-0.04	0.78
Class III	25	4.51	2.26	0.28	0.17
Class IV	8	3.44	2.66	0.55	0.16

*$p < .05$. ** $p < .01$.

Table 6

Cardiac Anxiety (CAQ)

NYHA Class	Descriptive Statistics			Correlation with IPAQ-S	
	n	*M*	*SD*	*r*	*p*
Cardiac anxiety (Total)					
Total sample	154	1.80	0.61	-0.25	0.00**
Class I	69	1.53	0.54	-0.14	0.25
Class II	52	1.90	0.58	-0.15	0.27
Class III	25	2.13	0.47	-0.32	0.07
Class IV	8	2.49	0.66	-0.47	0.24
Heart-related fear (CAQ-Fear)					
Total sample	154	1.89	0.66	-0.20	0.02**
Class I	69	1.73	0.64	-0.10	0.43
Class II	52	1.94	0.69	-0.17	0.24
Class III	25	2.13	0.53	-0.30	0.15
Class IV	8	2.28	0.72	-0.47	0.24
Avoidance (CAQ-Avoidance)					
Total sample	155	1.60	0.94	-0.33	0.00**
Class I	70	1.17	0.84	-0.26	0.03*
Class II	52	1.77	0.78	-0.22	0.11
Class III	25	2.19	0.94	-0.44	0.03*
Class IV	8	2.43	0.82	-0.52	0.19
Attention (CAQ-Attention)					
Total sample	155	1.85	0.77	-0.02	0.83
Class I	70	1.56	0.68	0.10	0.44
Class II	52	1.96	0.71	0.05	0.73
Class III	25	2.07	0.73	0.05	0.80
Class IV	8	2.90	0.74	-0.19	0.65

*$p < .05$. ** $p < .01$.

Table 7

Hierarchical Regression of Protection Motivation Theory

Variable	*B*	95% CI for *B* LL	95% CI for *B* UL	*SE B*	β	R^2	ΔR^2
Step 1						0.06	
Constant	59.93	41.90	77.95	9.08			
Age	-0.32	-0.67	0.02	0.17	-0.19		
NYHA Classification	-3.58	-8.63	1.47	2.54	-0.14		
Step 2						0.08	0.02
Constant	72.37	44.14	100.60	14.21			
Age	-0.39**	-0.75	-0.03	0.19	-0.23**		
NYHA Classification	-2.73	-0.83	2.88	2.82	-0.11		
HBCVD-Susceptibility	-0.28	-8.33	9.19	4.49	0.01		
CHBMS-Seriousness	-4.30	-8.64	1.49	2.91	-0.17		
Step 3						0.19	0.13**
Constant	7.06	-40.58	54.70	23.97			
Age	-0.43**	-0.77	-0.08	0.17	-0.25**		
NYHA Classification	0.27	-5.39	5.93	2.85	0.01		
HBCVD-Susceptibility	2.33	-6.26	10.92	4.32	0.06		
CHBMS-Seriousness	-4.71	-10.23	0.81	2.78	-0.18		
EBBS-Total	18.81**	7.46	30.15	5.71	0.35**		
ESES	0.04	-0.15	0.23	0.10	0.04		

*$p < .05$. ** $p < .01$.

Appendix D

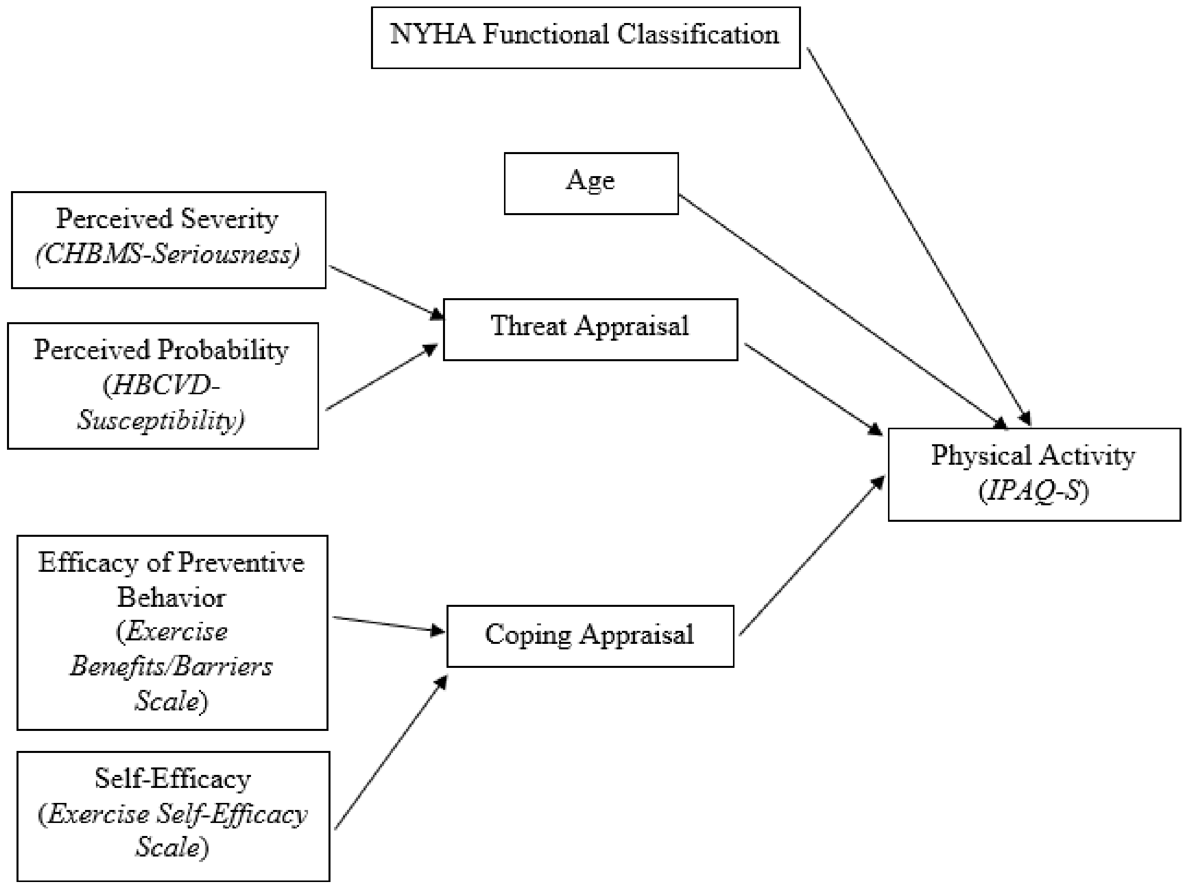

Figure 1. Evaluation of Protection Motivation Theory (Rogers, 1975) in ACHD