

**Initiation and Maintenance of Physical Activity Behaviour
in Adults with Congenital Heart Disease**

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Abstract

The purpose of this study is to qualitatively explore how physical activity engagement is initiated and maintained in adult patients with congenital heart disease (ACHD). The rising number of aging ACHD patients means they could need more healthcare resources for lifelong treatments to maintain their health. One cost-efficient and natural way to maintain the health of ACHD patients is through physical activity participation. Unfortunately, though, ACHD patients tend to be sedentary, and research has yet to adequately explore the factors influencing physical activity behaviour within this population. To gain a better understanding on this topic, this study combines the transtheoretical model and social ecological model to uncover factors influencing physical activity behaviour in ACHD patients who are at different levels of motivation. This study utilizes a qualitative research design: over six months, 27 participants took part in three individual semi-structured interviews for a total of 78 interviews (three participants did not complete all three interviews). The study revealed that several factors influenced physical activity behaviour in ACHD patients at different stages of motivation. In addition, findings on the characteristics of participants in each stage, meanings of physical activity and strategies for promoting physical activity for ACHD patients are also presented, as well as practical findings (i.e., physical activity program for ACHD patients). This thesis is important for healthcare professionals as it could facilitate the development of stage-specific interventions designed to increase physical activity behaviour in ACHD patients.

Keywords: ACHD, stages of behavioural change, social ecological model, physical activity, qualitativ

Chapter 1: Introduction

Initiation and Maintenance of Physical Activity Behaviour in Adults with Congenital Heart Disease

Congenital heart disease (CHD) is the most common birth defect in the world and affects 1% of live births (Avila et al., 2014; Reller et al., 2008). Among all children born with CHD, half will have mild defects that do not require immediate treatment, while the other half will require treatment early on in life. Prior to the possibility of cardiac surgery in the 1960's, many children suffering from CHD did not survive childhood, and less than 20% survived until adult age (Healio, 2014). However, with medical advancements in cardiac surgery and perioperative care, the life expectancy of youth CHD patients has increased significantly, as 90% now reach adulthood (Healio, 2014; Marelli et al., 2007; Moons et al., 2010).

The increased life expectancy in children living with CHD brings with it a much higher prevalence of adults with congenital heart disease, or ACHD patients as they are commonly referred to in the literature. Thus, the number of ACHD patients has risen substantially in recent years (Avila et al., 2014; van der Bom et al., 2011), and for a long time now, ACHD patients have outnumbered pediatric CHD patients (Marelli et al., 2007). Specifically, reports suggest that the number of ACHD patients has increased six-fold since the year 2000 (Tutarel et al., 2013). The median age of ACHD patients has also increased throughout the years, as it is now common for ACHD patients to reach middle age and live well past 60 (Tutarel et al., 2013).

Moreover, while modern surgical practices have allowed children born with CHD, once considered untreatable, to live full lives, cardiac function is never completely restored and many patients experience complications upon adulthood (Cuypers et al., 2013, 2014a, 2014b; Menting et al., 2015). Thus, ACHD patients are resource-intensive and have a significant impact on

healthcare systems, as many require lifelong monitoring, and more hospitalizations and interventions than young CHD patients (Tutarel et al., 2013). While healthcare professionals who take care of ACHD patients spend the majority of clinical visits discussing risk factors such as arrhythmias, heart failure and pregnancy, disease prevention (e.g., physical activity) is often neglected (Rosenthal et al., 2016).

Prior to the development of CHD-specific physical activity guidelines, ACHD patients were discouraged from engaging in physical activity during their youth, which has resulted in many living a sedentary lifestyle today (Cuypers et al., 2016; Longmuir et al., 2013; Reybrouck & Mertens, 2005; Roche & Silversides, 2013). Sedentary ACHD patients are at higher risk of mortality from the acquisition of coronary heart disease than the general population (Cuypers et al., 2016; Roche & Silversides, 2013; Rosenthal et al., 2016), and as ACHD patients continue to age, they are subject to diseases that aging healthy individuals commonly acquire, such as obesity, type-2 diabetes, and myocardial infarction which is a leading cause of death in noncyanotic ACHD patients (Pemberton et al., 2010; Pillutla et al., 2009). In addition, ACHD patients are at higher risk of experiencing psychosocial challenges such as negative thoughts, heart-focused anxiety, difficulty transitioning from childhood into adulthood, treatment-related worries (e.g., decision making, lifestyle adjustments) (Kovacs, et al., 2009; Ong et al., 2011; Rietveld et al., 2002), and high levels of depression (Carazo et al., 2020), anxiety and somatic symptoms due to life-long medical follow-ups adding stress to their daily lives (Eslami et al., 2013).

It is well understood that physical activity is a critical component of health promotion and disease prevention (WHO, 2021). Regular physical activity is linked to the prevention of major chronic physiological and psychological diseases such as cardiovascular disease, diabetes, cancer, obesity, depression, hypertension and osteoporosis (Warburton et al., 2006; WHO, 2021) and to

benefits such as increased energy, self-confidence, self-efficacy, well-being and quality of life (USDHHS, 2000), each of which address important health concerns in the ACHD population. In contrast, physical inactivity is a major contributor to noncommunicable diseases worldwide, regardless of socioeconomic status, and contributes to millions of deaths every year (Lee et al., 2012). Given that ACHD patients have higher incidences of health-related issues in different dimensions of life compared to the general population, encouraging these patients to increase resiliency when it comes to maintaining a physically active lifestyle is critical (Longmuir et al., 2013). This thesis will therefore seek to understand how various components influence ACHD patients' desire to maintain a physically active lifestyle.

Significance of the Research

An estimated 257,000 individuals are living with CHD in Canada (CCHA, 2017b). The number of Canadians living with CHD exceeds the number of patients suffering from Parkinson's disease ($n = 100000$), multiple sclerosis ($n = 100000$), HIV/AIDS ($n = 71300$), cerebral palsy ($n = 50000$) and cystic fibrosis ($n = 4000$) (CCHA, 2017b). Despite the prevalence of CHD, awareness, research, and funding dedicated to developing and increasing our knowledge of CHD remain scarce (CCHA, 2017b). Research in all aspects pertaining to ACHD patients has yet to reach the level of sophistication found in other areas of heart disease research, despite the possibility for research on CHD to have important implications for the ACHD population (CCHA, 2017b). Peer review committees rarely release research funds to ACHD specialists and frequently associate the lack of sophisticated research to quality and relevance (CCHA, 2017b). There are far fewer resources allocated to the care and treatment of ACHD patients than to other cardiac patients (e.g., heart attack patients) (CCHA, 2017b). Consequently, wait times for clinical visits and surgical

interventions far exceed those for other cardiac patients, which has the effect of increasing anxiety, risk and death in ACHD patients (CCHA, 2017b).

While funds dedicated to improving the health of ACHD patients are minimal, it is imperative to work towards optimizing their health during times of adversity. Emphasis on physical activity should continue, as it is an alternative and cost-efficient method for maintaining good health, increasing quality of life and psychological well-being, increasing longevity and reducing symptoms (Fox, 1999; Kujala et al., 1998; Wannamethee & Sharper, 2001). While some healthcare professionals are still reluctant to prescribe and promote physical activity for ACHD patients, they are expected to discuss and provide appropriate guidance on participation to all ACHD patients during routine clinical visits (Longmuir et al., 2013). Healthcare professionals are expected to discuss the benefits of physical activity for their patients (CDC, 2021), including ACHD patients, and tailor recommendations to their clinical status (Longmuir et al., 2013). For many ACHD patients, physical activity participation can be unlimited, yet literature suggests that many are sedentary and neglect engaging in active behaviour. The issue with prescribing physical activity for ACHD patients based solely on their clinical status and physical abilities is that it ignores the psychosocial factors that these patients experience when engaging in physical activity behaviour. It cannot be assumed that individuals are at the same level of readiness to take on a physically active lifestyle (Sallis & Owens, 2015) even if they have the abilities to engage in regular physical activity.

While an individualized approach is often associated with better outcomes for sustained involvement in physical activity (Latimer et al., 2010), healthcare professionals need to progress beyond regular physical activity prescription by taking a holistic approach. Understanding factors that influence physical activity behaviour in ACHD patients in all dimensions of life, including

psychological, social, physical and spiritual, can help us understand what prevents and promotes engagement in physical activity behaviour and enjoyment. This change in approach to physical activity prescription could potentially have a significant impact on long-term engagement and enjoyment in physical activity behaviour, because when individuals enjoy physical activity, the frequency and length of participation increases (Williams et al., 2006). Thus, an in-depth understanding of why ACHD patients engage in physically active, or sedentary, behaviour can help with the development and implementation of multilevel interventions (Bauman et al., 2012). This study is important for healthcare professionals as it could eventually facilitate the development of effective and individualized interventions designed to increase physical activity behaviour in ACHD patients.

Purpose of the Research

To date, there has been very little research on experiences and perceptions towards physical activity in the context of ACHD patients. ACHD patients experience a wide range of challenges which may significantly impact their ability and desire to engage in physical activity. Yet, physical activity has the potential to be an effective, low-cost strategy to alleviate the difficulties ACHD patients face on a daily basis. It can be assumed that ACHD patients vary in their level of motivation to engage in physical activity and are influenced by a variety of factors, just like any other population group. This study will therefore situate its findings within both the transtheoretical model (TTM) on stages of behavioural change and the social ecological model (SEM). The integration of these two frameworks will allow the researcher to identify what factors impact physical activity outcomes in ACHD patients at different levels of motivation to engage in physical activity behaviour.

The purpose of this study is to qualitatively explore how physical activity behaviour is initiated and maintained in ACHD patients. Several ACHD patients at varying levels of motivation were questioned on their experiences when engaging in physical activity. Specifically, ACHD patients were asked about the factors they perceived as influencing their desire or ability to engage in physical activity behaviour, the meaning of physical activity in their life, the strategies they employed to initiate or maintain physical activity behaviour, as well as the short- and long-term benefits and risks they perceived were associated with physical activity behaviour.

Research Questions

The overarching research question this thesis seeks to address is how engagement in physical activity is initiated and maintained in ACHD patients. The following sub-questions will be used to answer the overarching question. The sub-questions relate to each stage of behavioural change in physical activity in ACHD patients:

- 1) What is the process for initiating and maintaining physical activity behaviour in ACHD patients?
- 2) What is the meaning of physical activity in the lives of ACHD patients?
- 3) What are the experiences and perceptions of physical activity throughout different stages of physical activity engagement in ACHD patients?
- 4) What are the perceived constraints and facilitators that influence physical activity engagement in each stage of behavioural change in ACHD patients?
- 5) What are the short- and long-term benefits and risks of physical activity behaviour as perceived by ACHD patients?
- 6) What strategies do ACHD patients employ to maintain their engagement in physical activity?

7) What types of activities promote maintenance and prolonged engagement in physical activity as perceived by ACHD patients?

Definitions

The following section provides definitions of key concepts mentioned throughout the study.

Congenital Heart Disease

CHD is a heart condition, or defect, that an individual is born with (Heart & Stroke, 2020). CHDs affect the structure of a baby's heart and the way it works (CDC, 2020a). For example, CHD can affect the way blood flows through the heart and circulates to the rest of the body by slowing it down, sending it in the wrong direction or area, or completely blocking it (CCHA, 2017a; CDC, 2020a). More specifically, CHDs are apparent when the chambers, walls, valves and blood vessels of the heart do not develop normally before birth (Heart & Stroke, 2020). Several types of CHDs exist, such as abnormal routes in the heart or between blood vessels, problems with the heart valves, problems with the placement or development of blood vessels near the heart, and problems with the development of the heart itself (CCHA, 2017a).

CHD has been associated with risk factors that tend to revolve around the mother's experiences during pregnancy (AboutKidsHealth, 2010). For instance, the use of prescription or over-the-counter-drugs (e.g., Accutane to treat acne, lithium to treat mental health issues) and anti-seizure medications during pregnancy are often cited as risk factors leading to CHD (AboutKidsHealth, 2010). Other factors such as the use of alcohol, tobacco or cocaine, viral infections such as rubella during the first trimester, pre-existing conditions such as diabetes (AboutKidsHealth, 2010; Heart & Stroke, 2020; Jenkins et al., 2007; Patel & Burns, 2013), fevers in early pregnancy stages, living near hazardous waste sites and obesity are considered risks for

bringing on CHD (AboutKidsHealth, 2010; Heart & Stroke, 2020; Jenkins et al., 2007; Patel & Burns, 2013). In general, though, healthcare professionals believe that genetics play a more important role than environmental factors in causing CHD (AboutKidsHealth, 2010; CDC, 2020a; Heart & Stroke, 2020).

CHDs are typically grouped based on their severity and are considered to be simple, moderate, or complex (Cove Point Foundation, 2020). Patients with simple CHDs can often be cared for in the general community, while patients with moderate or complex CHD should be seen regularly at CHD-specific clinics (Cove Point Foundation, 2020). Signs and symptoms associated with CHD are dependent on the severity of the defect (CDC, 2020a). Certain individuals will have limited experiences with signs or symptoms, while others will have heart murmurs, abnormal heart rhythms (i.e., arrhythmia), blue-tinted nails or lips (i.e., cyanosis), heart palpitations (e.g., pounding, fluttering), rapid breathing, shortness of breath, tiredness when feeding, as well as fainting, poor weight gain, and clubbed fingers (CDC, 2020a; Heart & Stroke, 2020). Appendix A provides descriptions of the CHDs that the participants in this study had been diagnosed with.

Physical Activity

A central concept for this study, physical activity can be understood as a broad notion encompassing all types of physical movement (Longmuir et al., 2013), and may consist of unstructured (e.g., spontaneous activity, walking, jogging) or structured (e.g., programs offered at a designated time at an institution such as sports or aerobics classes) activities (Playground Centre, 2021). Physical activity distinguishes itself from exercise, which refers to a structured regimen of repetitive physical activity designed to increase fitness (Longmuir et al., 2013). While this thesis mainly refers to physical activity, participants often used the concepts of physical activity and exercise interchangeably. In addition, sport was also commonly mentioned by participants when

discussing physical activity, so we included it in this study. Sport refers to organized team or individual sport consisting of regular competitions against others with the intention of achieving a certain goal (e.g., winning) (Graham et al., 2005). Thus, when questioned on their engagement in physical activity, participants described their perceptions and experiences in physical activity as a whole, which at times included exercise and sport contexts. The researcher therefore encouraged discussions on physical activity, exercise and sport, as these are all within the realm of physical activity.

Behavioural Change

Behavioural change is often described as a process that depends on the individual's readiness to modify current, or adopt new, behaviour (Prochaska et al., 2015) and will experience behavioural change in their own unique way (Oreg et al., 2007). For certain individuals, behavioural change can be a source of joy and benefits, while for others it may be a source of suffering and stress (Oreg et al., 2007). These differing perceptions with regards to behavioural change is reflected in literature conceptualizing individuals' reactions towards change (Oreg et al., 2007). While some scholars use terms such as readiness or commitment to change, over others who use terms such as resistance to change, many scholars tend to use the all-encompassing term attitude toward change (Lines, 2005; Vakola et al., 2004). Growing interest in individual attitudes toward change means that concepts such as meanings and concepts referring to attitudes toward change (i.e., readiness/resistance for change, commitment to change) are often used interchangeably (Bouckennooghe, 2010).

Elizur and Guttman (1976) described attitudes as a tridimensional concept consisting of cognitive, affective, and intentional/behavioural aspects. Cognitive aspects of attitudes speak to the opinions individuals have regarding the advantages, disadvantages, usefulness, necessity, and

knowledge required to make a behavioural change (Elizur & Guttman, 1976). Affective aspects of attitudes refer to the feelings about making a behavioural change (Elizur & Guttman, 1976). Lastly, the intentional/behavioural aspect of attitudes refers to the actions that will be taken in the future, or have already been taken, to make a behavioural change or not (Elizur & Guttman, 1976).

There is a considerable overlap between the concepts of readiness for change and attitudes. Readiness for change has been described in literature as an individual's beliefs, attitudes, and intentions with regards to successfully making behavioural changes (Armenakis et al., 1993). This description covers the three basic concepts of attitudes, however, emphasizes on the cognitive aspect when referring to the need for making a behavioural change (Bouckennooghe, 2010). Thus, by assessing one's readiness for change, it is possible to identify the gap between the individual's current situation and where they stand in terms of their desire to change (Bouckennooghe, 2010). Given that behavioural change is deeply rooted within one's attitude and readiness for change, behavioural change in this study will be defined as a cognitive precursor to behaviours that either resist or support efforts towards making a behavioural change, which is inspired by Armenakis et al.'s (1993) description of readiness for change.

Readiness for change can be further understood as psychological process consisting of a series of stages (Cunningham et al., 2002) and the Transtheoretical Model (TTM) on stages of behavioural change (Prochaska et al., 2015). For instance, in the first stage (i.e., pre-contemplation) of readiness for change, individuals do not desire to change, while in the second stage (i.e., contemplation), individuals will compare the risks and benefits to making a change, and assess the demands and resources required to change. Thus, prior to making behavioural changes, individuals will consider the advantages and disadvantages of making a behavioural change (Prochaska et al., 2015).

Perceived Benefits and Risks

The final key concepts to be defined for this study are perceived benefits and risks. Perceived benefits, in this study, can be understood as beliefs pertaining to the positive outcomes associated with a behaviour (NCI, 2020). Perceived benefits are a concept that is typically associated with health behaviours and is determined by the individual's perception of benefits that will come from participating in a specific health action (NIC, 2020). For example, benefits such as increasing muscle mass and strength may be perceived by an individual who engages in regular physical activity. The concept of perceived benefits has been linked to health behaviour models, including the Transtheoretical Model (Prochaska et al., 2015), when referring to decisional balance which includes considerations of the benefits and constraints of participating in a specific health behaviour (NIC, 2020).

Moreover, objective risk is commonly described in literature as the probability of negative outcomes weighted by their severity (ISO 31000, 2018). The same description applies to subjective, or perceived risk, in that individuals can subjectively assess the severity and probability of possible outcomes and estimate a perception of risk based on the information they have (Loewenstein et al., 2001; Slovic, 2016). This description of perceived risk will therefore be retained for this study. In addition, the concept of worry is also closely associated with perceived risk but are not necessarily synonymous (Rundmo, 2002; Wolff & Larsen, 2014). For instance, perceived risk consists of a cognitive evaluation that may be influenced by affect and is not necessarily considered to be a feeling (Loewenstein et al., 2001). However, worry is generally a key determinant of anxiety, and therefore characterized as a tendency to view certain situations as threatening (Craske et al., 2017). Fear and anxiety are feelings that often trigger somatic responses to a threat (Crasket et al., 2017), yet it must be understood that while things that are perceived as

risky may cause worry or anxiety, this may not always be the case. For example, skydivers and white-water rafters may experience fear, but they also understand that there is no real risk or danger when participating in the activity (Wolff et al., 2019).

Chapter 2: Literature Review

The content presented in the literature review will cover topics as they relate to this study's research questions. Topics to be covered are physical activity behaviour and ACHD patients, meanings of physical activity, and the SEM and TTM as these are the theoretical frameworks that will guide this study. The literature review begins with a presentation of research on physical activity in ACHD patients, including recommended guidelines, as well as the benefits and risks of physical activity. Afterwards, the meaning of physical activity and the significance it holds in individuals' lives are presented. The literature on the SEM emphasizes conceptualizing and categorizing factors influencing individuals' physical activity behaviour. The TTM is then presented to highlight how individuals can be at different levels of motivation to engage in physical activity behaviour. Lastly, the theoretical framework used to situate the study's findings is discussed.

Physical Activity and ACHD Patients

While physical activity was once considered high-risk behaviour for ACHD patients, there is a consensus today on encouraging ACHD patients to maintain an active lifestyle to experience long-term health benefits (Longmuir et al., 2013; Thaulow & Fredriksen, 2003). Indeed, it must be recognized that ACHD patients vary in disease severity, which can have implications for their ability to engage in physical activity. Differences in abilities for ACHD patients are often illustrated through the New York Heart Association's (NYHA) functional four-level classification system (Stout et al., 2019). Class I patients generally have no symptoms of fatigue, palpitations or chest pain when active, and thus have no physical activity limitations (Stout et al., 2019). Class II patients have minor limitations to physical activity participation, as they may experience fatigue, palpitations and chest pain during moderate exertion (e.g., commuting two

blocks or going up two flights of stairs) (Stout et al., 2019). Class III patients have considerable physical activity restrictions, as they could experience symptoms of fatigue, palpitations and chest pain through minimal exertion (e.g., commuting one block or going up one flight of stairs), but are unlikely to experience symptoms at rest (Stout et al., 2019). Lastly, Class IV patients are unable to participate in physical activity without experiencing discomfort and could experience symptoms even at rest (Stout et al., 2019). However, regardless of the symptoms experienced or not when active, it is possible for ACHD patients to engage in physical activity if appropriate guidelines are recommended (Chaix et al., 2016; Hirth et al., 2006; Zipes et al., 2005).

Physical Activity Recommendations for ACHD Patients

Current physical activity guidelines for the general population sit at two days of muscle strengthening activities and 75 minutes of vigorous physical activity per week, or 150 minutes of moderate physical activity per week (Canadian Society for Exercise Physiology, 2021; CDC, 2020b). While these guidelines were developed for the general population, they are also applicable to ACHD patients as very few have a type of CHD that would prevent physical activity engagement (Longmuir et al., 2013). For ACHD patients who do have clinical considerations impacting how much they could exert themselves (e.g., situation in the NYHA classification system), researchers have created recommendations tailored to the complexity of their diagnosis and physical capacity (Chaix et al., 2016; Hirth et al., 2006; Zipes et al., 2005).

Historically, the Bethesda guidelines were among the first recommendations tailored to ACHD patients with clinical considerations (Zipes et al., 2005), some of which are specific to the types of CHDs that participants in this study live with. For instance, ACHD patients with coarctation of the aorta could return to sports as early as three months post-corrective surgery, while ACHD patients with Marfan syndrome (i.e., often characterized by long arms and legs,

flexible joints, vision impairment) could engage in moderate static or low dynamic competitive sports (The Marfan Foundation, 2014; Zipes et al., 2005). For Marfan patients who do not have a family history of sudden cardiac death, weight training could be recommended, while dynamic exercises should be avoided (Zipes et al., 2005). In addition, ACHD patients who have received corrective surgery for transposition of the great arteries and who do not experience arrhythmias, syncope or chamber enlargement, who have abnormal exercise tests or who engage in low-to-moderate static activity or low dynamic competitive sports could be recommended (Zipes et al., 2005).

Furthermore, recent guidelines developed by Chaix et al. (2016) are more lenient as they suggested that most ACHD patients, including those with atrial septal defect, ventricular septal defect, pulmonary stenosis with no right ventricular dysfunction, surgically corrected coarctation of the aorta, and surgically corrected transposition of the great arteries, have no limitations when it comes to physical activity or sport participation (Chaix et al., 2016). Only those who experience significant ventricular arrhythmias or hypertension, or live with symptomatic atrial septal defect, Tetralogy of Fallot with significant pulmonary regurgitation, and Eisenmenger syndrome have limitations and should engage only in low intensity activities such as golf, bowling, cricket, billiards, riflery, walking, etc. (Chaix et al., 2016). Taken together, physical activity at appropriate recommended levels should be strongly promoted for all ACHD patients by healthcare professionals (Longmuir et al., 2013; Takken et al., 2012).

Benefits of Physical Activity for ACHD Patients

Research on the benefits of physical activity for ACHD patients has been primarily from a quantitative perspective, which does not allow for a well-rounded understanding of the benefits experienced by ACHD patients when active. Most research has emphasized the physical benefits

of physical activity for ACHD patients, specifically through exercise prescription (Dean et al., 2015; Dua et al., 2010; Martinez-Quintana et al., 2010; Therrien et al., 2003; Winter et al., 2012). For instance, it has been shown that prescribing exercise regimens in either lab-based, home-based or hospital-based contexts could increase cardiac performance, exercise ability, VO₂ max and walking distance in ACHD patients (Dean et al., 2015; Dua et al., 2010; Martinez-Quintana et al., 2010; Therrien et al., 2003; Winter et al., 2012).

Little research has adequately explored the psychosocial benefits of physical activity for ACHD patients, apart from a few studies (Dean et al., 2015; Dua et al., 2010) that have determined that physical activity could improve quality of life in ACHD patients. Aside from those studies, the psychosocial implications of physical activity for ACHD patients have been neglected. Thus far, literature has mostly implied that ACHD patients could potentially experience similar psychosocial benefits through physical activity as do individuals from the general population, rather than support such claims with evidence. For example, evidence suggests that physical activity and sports participation enhance self-esteem and social inclusion in healthy populations (Babiss & Gangwisch, 2009). Thus, ACHD patients should be free to engage in recreational physical activity and sports so they can experience similar benefits, as avoiding these could have important repercussions (Horner et al., 2000; Longmuir et al., 2013). Restrictions on such activities could also falsely reassure healthcare professionals, patients and families about the risks associated with physical activity for ACHD patients (Dean et al., 2015).

Risks of Physical Activity for ACHD Patients

With the exception of excessive endurance sport, which could lead to dilation and arrhythmias (La Gerche et al., 2012; Stuart, 2014; Warnes, 2009), it is fairly uncommon for ACHD patients to experience risks related to physical activity (Koyak et al., 2012; Lim et al., 2010; Zomer

et al., 2012). It is understood that ACHD patients, even those who are asymptomatic, have a lower exercise capacity, and that exercise intolerance could potentially lead to hospitalization and death (Diller et al., 2005). Although infrequent, the risk of death, specifically sudden cardiac death, is therefore an understandable concern for healthcare professionals prescribing exercise to ACHD patients (Koyak et al., 2012).

Evidence suggests that sudden cardiac death from physical activity is quite uncommon. For example, research on circumstances of death in 231 ACHD patients revealed that deaths typically occurred at rest, with only eight percent occurring during exercise (Zomer et al., 2012). Other findings by Koyak et al. (2012) using a multinational registry consisting of 25,790 ACHD patients also emphasized the low probability of sudden cardiac death caused by exercise. Findings revealed that of the 1,189 ACHD patient deaths, only 19% were sudden cardiac deaths, and of that 19% only ten percent occurred during exercise in ACHD patients known to have a history of arrhythmias during exercise testing (Koyak et al., 2012). Thus, the data suggests that the benefits of regular exercise outweigh the small risk of sudden cardiac death that may occur when active (Zomer et al., 2012).

Meanings of Physical Activity

The extent to which individuals associate meaningfulness to an activity through positive emotions (e.g., enjoyment) reinforces continued participation in that activity (Porter et al., 2010). Associating meanings to activities is a natural process, as the human mind is constantly putting ideas together to form connections and develop meanings within, and from, life experiences (Baumeister & Vohs, 2005). The essence of meaning is connection, as meaning creates a relationship between two entities even if they are physically separate (Baumeister & Vohs, 2005). The connection between these two entities, however, is not part of their physical makeup and can

only be appreciated by the human mind (Baumeister & Vohs, 2005).

The process in which individuals attach meaningfulness to an activity through experience is called meaning-making (Porter et al., 2010). When individuals try to find meaning within a specific situation or context, they are engaging in meaning-making (Baumeister & Vohs, 2005). Meaning-making is experienced personally, but the process of meaning-making is influenced by social and contextual factors (Baggini, 2005; Baumeister & Vohs, 2005; Park & Folkman, 1997). Thus, meaning can be defined as ‘a socially and contextually grounded psychological/emotional experience that holds inner significance for an individual’ (Porter et al., 2010, p. 169). Meaning directs behaviours when it comes to making choices, effort, persistence, and performance (Lewthwaite, 1990). Thus, meaning is a precursor to motivation, which is described as a consequence of meaning and a process where internal and external factors direct and energize thoughts, feelings and actions (Lewthwaite, 1990).

Research has investigated the meaning of physical activity for individuals living with chronic diseases. In Bedini’s and Anderson’s (2005) study on adolescent girls with various disabilities (e.g., osteogenesis imperfecta, spina bifida, cerebral palsy and brain injury), results suggested that participants associated physical activity with freedom, providing a sense of empowerment, and perceptions of normalcy. In studies on individuals with multiple sclerosis, findings revealed that participants associated exercise with maintaining function and health, enhanced exercise self-efficacy, feelings of hope and optimism (Kasser, 2009), being normal and savoring current health/level of functioning (Dlugonski et al., 2012).

In more recent research by Erikssen et al. (2013) on individuals with Parkinson’s disease, findings revealed six meanings associated with physical activity, that is, having explicit life goals (e.g., being able to live independently), having confidence in one’s abilities, taking rational

positions (e.g., taking responsibility for one's health), exercising to slow progression of the disease, exercising to achieve well-being and using exercise as a coping strategy. Similar findings were uncovered in Maley et al.'s (2013) study exploring meanings of physical activity among women cancer survivors, and Gaskin et al.'s (2009) study on a woman living with cerebral palsy. Findings from these studies suggested that participants perceived physical activity as a way to take control over their health, diminish feelings of vulnerability, increase self-esteem, increase competence, avoid isolation, enhance body image and cope with stress (Gaskin et al., 2009; Maley et al., 2013). In the context of ACHD patients, there remains a need to explore the significance of physical activity as a motivational basis for sustained participation. By doing this, we can gain a better understanding of the motives behind their current level of engagement in physical activity, as well as the factors influencing physical activity behaviour in ACHD patients.

Social Ecological Model (SEM)

The SEM is highly regarded by the Institute of Medicine, Public Health Foundation, and Centers for Disease Control as one of the most important frameworks for understanding and conceptualizing multilevel factors influencing physical activity behaviour (Carlson et al., 2012; IOM, 2000; Saelens et al., 2012; Sallis et al., 2006; Sallis & Owens, 2015; USDHHS, 2020a; Warner, 2006). The SEM allows us to identify factors influencing health behaviour, including physical activity, within the environmental, social and personal domain of individuals (Sallis & Owens, 2015). The SEM distinguishes itself from other behavioural models and theories, as it incorporates environmental and policy levels of influence on behaviour (Sallis & Owen, 2015). Other models and theories tend to focus on individual characteristics, skills, and proximal social influences including family members and friends, while neglecting broader community, organizational and policy influences (Sallis & Owen, 2015). The SEM therefore acts as a meta-

model used to examine psychological, social, organizational, environmental and policy factors influencing health behaviours (Sallis & Owen, 2015). The SEM also combines individual, social, environmental and policy level factors in order to determine what factors and conditions are more likely to facilitate healthy behaviours and develop interventions aimed at promoting behavioural changes that can be maintained (Glanz & Bishop, 2010; McLeroy et al., 1988; Sallis & Owen, 2015). Considering all factors of the SEM can therefore help health practitioners develop comprehensive approaches to studying and intervening on health behaviours (Sallis & Owen, 2015).

Social Ecological Factors

Many versions of the SEM have existed and continuously evolved in the fields of behavioural sciences and health promotion since its inception over two decades ago (Sallis & Owen, 2015). Several ecological models have been put forth to explain and categorize factors promoting physical activity behaviour. Early versions of the SEM included internal and external, intrapersonal and interpersonal, intervening and antecedent, blocking and inhibiting, as well as permanent and temporary factors (Brawley et al., 1998). However, the SEM was eventually refined by McLeroy et al. (1988), and now the most commonly cited factor classifications are intrapersonal, interpersonal, community, institutional, and policy and system factors (McLeroy et al., 1988). These five categories are hierarchically ordered because intrapersonal factors, along with interactions immediately surrounding the individual, have a greater influence on behaviour, while environmental factors (i.e., institutional, community, policy and systems) are less influential (McLeroy et al., 1988).

The individual and their social relationships are at the core of the SEM in the intrapersonal and interpersonal levels (McLeroy et al., 1988). Intrapersonal factors refer to individual

characteristics influencing behavioural action such as knowledge, attitudes, behaviour, beliefs, abilities, self-efficacy and previous life experiences (McLeroy et al., 1988). Factors at the interpersonal level refer to the individuals formal and informal social networks and support systems (McLeroy et al., 1988). Individuals are connected to family members, friends and other social contacts acting as sources of behavioural cues, resources and reinforcements (McLeroy et al., 1988). Interpersonal relationships provide individuals with opportunities for emotional support, physical and financial resources, information and opportunities to connect with others (McLeroy et al., 1988). Social norms can also influence the individual's perception of acceptable behaviours (McLeroy et al., 1988).

Individual behaviour is also influenced by environmental factors (McLeroy et al., 1988). Place-based influences on individual behaviour revolve around the places and networks they move through in their lives (McLeroy et al., 1988). Examples of places and networks include schools, work, health care settings, community groups, as well as resources in those environments such as transportation (McLeroy et al., 1988). In the environment, institutional factors such as the physical structures, products, services, rules and practices, as well as community factors such as cultural messages, accessibility, quality of the environment (e.g., safety, green space, aesthetics), available resources and transportation influence individual behaviour (McLeroy et al., 1988).

Public policy and systems-level factors are recognized as distal factors in determining individual behaviour (McLeroy et al., 1988). Public policy and systems factors help develop broad contexts of services, funding, physical environments, information, laws and regulations influencing individual practices (McLeroy et al., 1988). Service systems such as education and transportation comprise several elements operating in an interconnected manner to fulfill a purpose or function (IOM, 2013). Although control over public policy and systems factors is distant to the

individual, these factors influence their behaviour daily (McLeroy et al., 1988). For example, in the context of individuals accessing healthy foods from grocery stores in their neighbourhood, access to those foods is likely regulated by federal policies for retail incentives (McLeroy et al., 1988). Thus, factors distant to the individual with regard to policies, structures and services influence the operation of institutions, communities and networks (McLeroy et al., 1988).

Empirical Research on the SEM

Social ecological factors have been investigated in vulnerable populations such as the elderly, colorectal cancer survivors, individuals living with multiple sclerosis, individuals living with Parkinson's disease and children with autism spectrum disorders (Carlson et al., 2012; Lynch et al., 2010; MacCosham et al., 2021; Obruiskina & Cavalier, 2011; Silveira & Motl, 2019). Findings in such populations have revealed that intrapersonal factors typically preceded environmental factors in terms of influencing physical activity participation (Carlson et al., 2012; Lynch et al., 2010; MacCosham et al., 2021; Obruiskina & Cavalier, 2011; Silveira & Motl, 2019), which is supportive of the SEM framework. Specifically, factors such as self-efficacy, disease-specific issues, believing one is active enough, motor challenges, lack of time and being interested in sedentary activities (e.g., board/video games) over physical activity were listed as among the most influential in determining physical activity within these populations (Carlson et al., 2012; Lynch et al., 2010; MacCosham et al., 2021; Obruiskina & Cavalier, 2011; Silveira & Motl, 2019). Conversely, facilitating intrapersonal, along with interpersonal, factors including self-efficacy and receiving social support were more likely to lead to physical activity participation in these populations (Carlson et al., 2012; MacCosham et al., 2021; Obruiskina & Cavalier, 2011; Silveira & Motl, 2019).

The influence of environmental factors on physical activity behaviour were also acknowledged within these populations. Several institutional and community-based factors such as perceptions of the environment/aesthetics, perceived safety, access to suitable recreation facilities, and community environments rich in resources such as sidewalks, swimming pools, parks, playgrounds, physical activity programs and transportation played an important role in either constraining or facilitating physical activity participation (Carlson et al., 2012; Lynch et al., 2010; MacCosham et al., 2021; Obruškinova & Cavalier, 2011; Silveira & Motl, 2019).

Furthermore, findings in recent studies have suggested that relationships exist between multilevel factors (MacCosham et al., 2021; Hanlon et al., 2019). For example, for individuals living with Parkinson's disease, lacking social support (i.e., interpersonal) triggered fear (i.e., intrapersonal) associated with compromised safety and the possibility of injuring oneself if active alone (MacCosham et al., 2021). In another study on Malaysian women, friends (i.e., interpersonal) encouraged participants to join programs to experience enjoyment (i.e., intrapersonal), programs (i.e., institutional) provided relief from other life obligations such as work and family (i.e., interpersonal) and increased psychological well-being (i.e., intrapersonal), while programs (i.e., institutional) playing music increased enjoyment and reduced stress (i.e., intrapersonal) (Hanlon et al., 2019). While relationships between multilevel factors were pointed out in this study, it was established that physical activity outcomes were determined more by intrapersonal factors than other interacting factors (Hanlon et al., 2019). Findings from that study therefore support the SEM as well, by unveiling intrapersonal factors as the most dominant in determining physical activity behaviour (Hanlon et al., 2019).

Social Ecological Factors and ACHD Patients

Research on factors influencing physical activity behaviour in ACHD patients, specifically from an SEM approach, is limited. Much of the research in this area has focused primarily on factors constraining physical activity behaviour in ACHD patients. For instance, research has suggested that physical activity behaviour in ACHD patients tends to be constrained by patient fears (e.g., causing harm), overprotection as a child, poor lifestyle advice and choices, severe anxiety, misconceptions on what constitutes physical activity, physical limitations (e.g., lower physical capacity, diminished lung capacity, arrhythmias when active and underlying arrhythmias, having surgery, risk of acute cardiac deterioration), developmental challenges, finding it easier to take medications than modify lifestyle, healthcare professionals' reluctance to provide adequate physical activity guidelines to ACHD patients, obesity and personal preferences (Buys et al., 2011; Chaix et al., 2016; Giannakoulas & Dimopoulos, 2010; Reybrouck et al., 2005; Stuart, 2014; Ubeda Tikkanen et al., 2013; Warnes et al., 2008). While these factors may certainly influence physical activity behaviour in ACHD patients, it is important to consider the many factors that could facilitate physical activity behaviour in this population. Just as individuals vary in their level of motivation to be active (Prochaska et al., 2015), the way in which physical activity participation is influenced by constraining factors may also vary between highly motivated and unmotivated ACHD patients. This study will therefore consider all factors, both constraining and facilitating, to provide an in-depth and well-rounded understanding of the factors influencing physical activity behaviour in ACHD patients.

Principles of the SEM

The SEM guides research and the development of interventions designed to increase physical activity behaviour through a series of general principles (Sallis et al., 2015). Principle 1

explains that there are multiple levels of influence on health behaviours (Sallis et al., 2015). The SEM specifies that multilevel factors will influence health behaviours, and the degree to which those factors influence health behaviour varies from one context to the next (Sallis et al., 2015). Principle 2 claims environmental contexts as significant determinants of health (Sallis et al., 2015), as behaviour can be predicted by circumstances as well as by individual characteristics (Wicker, 1979). Principle 3 suggests that influences on behaviours interact across levels (Sallis et al., 2015). Thus, it is possible for factors from different levels to interact with one another to influence behaviour (Sallis et al., 2015). The fourth principle implies that the SEM should be behaviour-specific in that it is most useful for guiding research and the development of interventions when tailored to specific health behaviours (Sallis et al., 2015). Lastly, the fifth principle suggests that multilevel interventions are most effective in changing behaviours (Sallis et al., 2015).

Transtheoretical Model (TTM) - Stages of Behavioural Change

The TTM provides an understanding of behavioural change processes and distinguishes individuals who vary in their motivation to be active (Prochaska & DiClemente, 1983). The TTM is an intrapersonal theory, which uses stages of behavioural change to integrate processes and principles from leading intervention theories (Prochaska et al., 2015). The TTM was developed through a comparative analysis of 25 leading theories in psychotherapy in an attempt to integrate a field that had been divided into more than 300 theories (Prochaska, 1979). When comparing theories, it was discovered that most revolved around why individuals changed their behaviour rather than how (Prochaska et al., 2015). Theories were therefore described as theories of behaviour, personality or psychopathology rather than theories of behavioural change (Prochaska et al., 2015).

The TTM describes behavioural change as a dynamic process and considers how it could require continuous effort and several attempts before individuals successfully change their behaviour (Prochaska et al., 2015; Velicer et al., 1998). Thus, the TTM implies that intending to adopt, modify and maintain health behaviour is a process that takes place over time (Prochaska & DiClemente, 1983; Prochaska et al., 2015; Velicer et al., 1998). Other behavioural change theories, such as the Health Belief Model (Rosenstock, 1974) and Theory of Reasoned Action/Planned Behaviour (Fishbein & Ajzen, 1975), tend to view behavioural change as single event actions (Prochaska et al., 2015). Those theories are better suited for understanding single event actions such as getting a flu shot or participating in cancer screening. The TTM therefore distinguishes itself from other behavioural change theories by incorporating time as a critical dimension of behavioural change (Prochaska & DiClemente, 1983; Velicer et al., 1998). The specific context in which the TTM was first applied was smoking cessation programs (Prochaska & DiClemente, 1983). Through extensive observations of individuals attempting to quit smoking, it became apparent that they moved through distinct stages during the quitting process, which researchers referred to as stages of change (Prochaska & DiClemente, 1983).

Stages of Behavioural Change

Stages of change have been used to examine several behaviours including smoking, alcohol, and drug cessation, dieting, sunscreen use, condom use, as well as adherence to physical activity regimens (Prochaska et al., 2015, Zimmerman et al., 2000). According to Prochaska et al. (2015) who developed the TTM framework, individuals making a behavioural change progress through different stages over time. Individuals who adopt or modify a behaviour move through phases pertaining to thinking about behavioural change, experimenting with behaviours, actively changing behaviour and working to maintain behavioural change (Prochaska et al., 2015).

The process of behavioural change is represented by five stages: pre-contemplation, contemplation, preparation, action, and maintenance (Prochaska et al., 2015). Although stages of change are presented in a straight-line progression, individuals may not progress through stages in a linearly fashion (Prochaska et al., 2015). In the pre-contemplation stage, individuals have no intention of changing their current behaviour (Prochaska et al., 2015). Individuals, here, are not considering a behavioural change nor do they have the desire to change their behaviour within the next six months (Prochaska et al., 2015). Individuals in the pre-contemplation stage have no awareness of the consequences and risks of their current behaviour (Prochaska et al., 2015). It is also likely that pre-contemplators have previously attempted and failed to change their behaviour, possibly several times, which has discouraged them from trying again (Prochaska et al., 2015; Prochaska & Velicer, 1997). Pre-contemplators avoid reading, talking and thinking about their current behaviour and are considered to be resistant and unmotivated to engage in health promotion programs (Prochaska et al., 2015). Consequently, many health promotion programs are not designed for individuals in pre-contemplation, as they are not ready nor do these programs match their needs (Prochaska et al., 2015).

In the contemplation stage, individuals intend to make a positive behavioural change within the next six months (Prochaska et al., 2015). Individuals in the contemplation stage weigh the pros and cons of making a behavioural change, as they understand the benefits of changing their behaviour but are also aware that there may be negative aspects to behavioural change (Prochaska & Velicer, 1997). Thus, if the balance between pros and cons does not favour the benefits of changing, contemplators may be indifferent and remain in this stage for an extended period of time (Prochaska et al., 2015). During that time, contemplators will continue to weigh the pros and cons of adopting or modifying their behaviour (Prochaska et al., 2015). Contemplators are also not

prepared for action-oriented programs where participants are expected to take immediate steps to change their behaviour, and pushing them to engage in such programs is unlikely to successfully induce behavioural change (Prochaska et al., 2015). Instead, building contemplators' self-efficacy is the more suitable stage-matched approach to inspire behavioural change (Prochaska et al., 2015).

After contemplating behavioural change, individuals reach the preparation stage (Prochaska et al., 2015). Individuals in the preparation stage intend to actively change their behaviour within the next month (Prochaska et al., 2015), and take steps and spend time developing an action plan to change their behaviour (Prochaska et al., 2015). Action plans may consist of signing up for a class, talking to a healthcare professional or counselor, and buying resources (e.g., self-help books) (Prochaska et al., 2015). Thus, individuals in the preparation stage are ready to be recruited to participate in action-oriented programs (Prochaska et al., 2015). The preparation stage consists of making small actions of change where individuals experiment with the behaviour they want to adopt or modify (Prochaska et al., 2015). Experimenting with the behaviour consists of trying different versions of it as a means to build self-efficacy and develop action strategies (Prochaska et al., 2015). For example, individuals may register for different types of physical activity classes at a recreation centre or take a walk during their lunch breaks at work. Through trial and error with different physical activity contexts, the individual can develop an action plan to further pursue preferred physical activities (Prochaska et al., 2015). Together, the contemplation and preparation stages are characterized as cognitive and affective stages of change, as individuals are more likely to experience intrapersonal factors (Prochaska et al., 2015).

Individuals are considered to be in the action stage when they have made significant changes to their behaviour in the past six months (Prochaska et al., 2015). Thus, individuals who have made minor changes to their behaviour are not considered to be in the action stage (Prochaska

et al., 2015). To be in the action stage, individuals need to meet established criteria for reducing the risk of disease that were developed and agreed upon by scientists or professionals (Prochaska et al., 2015). For example, in the context of physical activity, one would have to meet the recommended 150 minutes of moderate to vigorous physical activity per week guideline on a consistent basis. If the individual does not consistently reach 150 minutes of moderate to vigorous physical activity per week, they are not committed nor have they made significant changes to their lifestyle. Individuals in the action stage are also prone to relapsing and regressing to an earlier stage (Prochaska et al., 2015). It is therefore crucial for individuals in this stage to receive support and encouragement (Prochaska et al., 2015).

The maintenance stage encompasses individuals who have made significant behavioural changes by continuing the behaviour they adopted in the action stage or maintaining already established behaviours over an extended period of time (Prochaska et al., 2015). Individuals in the maintenance stage are less likely to relapse to previous unhealthy behaviours and are confident that they can continue their behaviour on a long-term basis (Prochaska et al., 2015). Yet, the possibility of relapse and regression always exists, even for those in maintenance (Prochaska et al., 2015). Those in the maintenance stage rely less on processes of change, as the behaviour is second nature to them (Prochaska et al., 2015). Thus, individuals who reach the maintenance stage tend to stay there permanently or for several years (Prochaska et al., 2015; USDHHS, 2020b).

In recent years, researchers have suggested that there is a sixth stage of change, called the termination stage (Prochaska et al., 2015). Individuals who reach the termination stage experience no temptation and their self-efficacy is said to be 100% (Prochaska et al., 2015). However, there has been little research or practical attention on the termination stage due to the length of time it takes for individuals to reach it (Prochaska et al., 2015). The criteria for the termination stage are

also too limited and instead represent an ideal goal for people in the maintenance stage (Prochaska et al., 2015). Thus, there is no consensus on this stage, and researchers and practitioners use the five-stage model (Prochaska et al., 2015).

Temptations

Individuals going through behavioural change may experience regressions and relapses (Prochaska et al., 2015). Regression is defined as any backward movements through stages, and relapse refers to moving from a higher stage (e.g., action) to a lower stage (e.g., preparation) (Prochaska et al., 2015). Regression and relapse are common in individuals making a behavioural change and should not be considered a failure (Zimmerman et al., 2000).

Individuals are likely to regress or relapse when encountering temptations (Zimmerman et al., 2000). Temptations are one of the main challenges experienced by individuals when making a behavioural change (Prochaska et al., 2015). Temptations are described as impulses to engage in or return to previous unhealthy behaviours in challenging or stressful situations (Prochaska et al., 2015). There are three types of temptations, namely emotional distress (e.g., death of a family member), positive social situations (e.g., being with others who engage in unhealthy behaviour), and cravings (e.g., strong desire to engage in unhealthy behaviour) (Prochaska et al., 2015).

The concept of temptations implies that there is a distinction between factors that promote progression into higher stages of change and factors that lead to regression or relapse into lower stages of change. A distinction can thus be made between facilitating and constraining factors to physical activity behaviour. This is consistent with literature by Raymore (2002), who contested that constraint theory tends to emphasize factors that impede participation, while ignoring factors that may encourage participation. Therefore, research focusing solely on constraints covers only half of what influences participation (Raymore, 2002). Thus, it is suggested that facilitating factors

will interact with constraints to either promote, or limit, participation in desired activities, including active recreational pursuits (MacCosham et al., 2021; Raymore, 2002). Together, then, constraints and facilitators provide an understanding as to how engagement in preferred activities is influenced and maintained (Raymore, 2002). The present study will therefore document the facilitating and constraining social ecological factors experienced by ACHD patients in each stage of behavioural change.

Processes of Change

Processes of change are the strategies utilized by individuals to move through stages of change or maintain their current behaviour (Prochaska & DiClemente, 1983, Prochaska et al., 2015; Velicer et al., 1998). Processes of change were developed from leading theories in psychotherapy and counselling (Prochaska, 1979). For instance, consciousness raising stems from Freudian theories (Freud, 1959), contingency management from Skinnerian theories (Skinner, 1971), and helping relationships from the Rogerian theories (Rogers, 1951).

In addition to the theories listed above, other important concepts that helped shape the development of processes of change are decisional balance (i.e., weighing pros and cons), self-efficacy and temptation (Prochaska et al., 2015). In its infancy, the TTM drew inspiration from Janis and Mann's (1977) model of decision making. Janis and Mann's (1977) decision making model emphasized the importance of perceived positive (pros) and negative outcomes (cons) of behavioural change. It is understood that an individual will not make a behavioural change unless they perceive the pros as outweighing the cons (Prochaska et al., 2015). Thus, the concept of decisional balance can help us understand why individuals are in different stages of behavioural change (Prochaska et al., 2015). For example, individuals in the pre-contemplation stage perceive the cons as heavily outweighing the pros of changing or adopting a new behaviour (Prochaska et

al., 1994). In the contemplation stage, the perceived balance between pros and cons of making a behavioural change is fairly equal (Prochaska et al., 1994). However, individuals in the preparation, action and maintenance stages perceive the pros of behaviour change as outweighing the cons (Prochaska et al., 1994).

Self-efficacy stemmed from Bandura's (1982) Social Cognitive Theory and refers to an individual's situation-specific confidence to cope in high-risk situations (i.e., temptations) without relapsing to former behaviours (Glanz & Bishop, 2010). For example, individuals maintaining a low-fat diet by consuming a lot of fruits and vegetables may be confident in their ability to eat healthily at home (Orlowski, 2016). Self-efficacy in this context would be represented by the individual's confidence in maintaining their diet when surrounded on vacation by unhealthy foods (Orlowski, 2016). Similar to the perception of pros in each stage of behavioural change, individuals' self-efficacy will typically increase from one stage to the next (Prochaska et al., 2015). Lastly, temptation, as described above, was integrated into the TTM to contrast the concept of self-efficacy (Prochaska et al., 2015).

Ten processes of behavioural change have been identified, namely, consciousness raising, dramatic relief, environmental reevaluation, self-liberation, self-reevaluation, stimulus control, helping relationships, counterconditioning, reinforcement management and social liberation (Prochaska & DiClemente., 1983, Prochaska et al., 2015; Velicer et al., 1998). Processes of change are categorized as either cognitive or behavioural. Cognitive processes (i.e., consciousness raising, dramatic relief, environmental reevaluation, social liberation, self-reevaluation) influence individuals' knowledge and emotional readiness, while behavioural processes (i.e., reinforcement management, helping relationships, counterconditioning, stimulus control, self-liberation) emphasize behavioural skills and actions (Prochaska & DiClemente, 1983).

Relationships between stages of behavioural change and processes were uncovered in the past by suggesting that in early stages of behavioural change individuals relied mostly on cognitive, affective and evaluative processes, while in action-oriented stages individuals relied mainly on commitments, conditioning, contingencies, environmental controls and social support (Marcus et al., 1994; Nigg & Courneya, 1998; Prochaska & DiClemente., 1983). More specifically, individuals in early stages of behavioural change, such as the pre-contemplation stage, tend to rely on consciousness raising, dramatic relief, and environmental reevaluation, while individuals in the contemplation and preparation stages rely mostly on self-reevaluation (Prochaska & DiClemente., 1983). Conversely, individuals in later stages of behavioural change such as the action stage rely on behavioural processes such as self-liberation, while individuals in the maintenance stage rely on counterconditioning, helping relationships, reinforcement management and stimulus control (Prochaska & DiClemente., 1983). Each process of change is optimal in specific stages except for social liberation, which has not been associated with any particular stage (Prochaska et al., 2015).

The TTM is an integrative model and thus reflects how individuals change behaviour on their own and when receiving professional guidance (DiClemente & Prochaska, 1982). To better understand how processes of change were employed, DiClemente and Prochaska (1982) compared smokers and former smokers who were self-changers and who received professional treatment. The study sought to assess how frequently each group utilized each of the ten processes of change (DiClemente & Prochaska, 1982). Findings suggested that participants utilized different processes of change in different stages during their journey of smoking cessation (DiClemente & Prochaska, 1982). Findings revealed that cognitive strategies were typically utilized by individuals in the pre-

contemplation, contemplation and preparation stages while behavioural strategies were employed in the action and maintenance stages (Prochaska & DiClemente, 1983, Prochaska et al., 2015).

Consciousness raising refers to individuals increasing their knowledge of underlying causes, side effects, and cures or treatments of a problematic behaviour (Prochaska et al., 2015; Velicer et al., 1998). Individuals gather this knowledge through attending or joining classes, media campaigns and other educational programs (Prochaska et al., 2015; Velicer et al., 1998). Dramatic relief is typically used to elicit negative or positive emotional responses (e.g., fear or inspiration) to motivate individuals into action (Prochaska et al., 2015; Velicer et al., 1998). Effective ways to elicit emotional responses are to have individuals listen to testimonials of those suffering from illness, pay attention to media campaigns and participate in health screenings (Prochaska et al., 2015; Velicer et al., 1998). Environmental reevaluation is an individual's assessment of how their behaviour affects their social circle (Prochaska et al., 2008; Velicer et al., 1998). This process of change helps the individual understand if they are a positive or negative role model to others (Prochaska et al., 2015; Velicer et al., 1998). Social liberation impacts the health of a population at large (e.g., access to walk paths or parks for members of a community) (Prochaska et al., 2015; Velicer et al., 1998). Interventions for social liberation generally emphasize advocacy, empowerment and policy formation (Prochaska et al., 2015; Velicer et al., 1998). Self-reevaluation refers to the individual imagining their self-image with and without the unhealthy behaviour they aspire to change (e.g., picturing themselves as a smoker and non-smoker) (Prochaska et al., 2015; Velicer et al., 1998).

Reinforcement management refers to rewarding oneself for engaging in positive behaviours and eliminating rewards for engaging in unhealthy behaviours (Prochaska et al., 2015; Velicer et al., 1998). Examples of reinforcements can be public such as certificates of achievement

for reaching a milestone as a group, or private such as positive statements or affirmations (Prochaska et al., 2015; Velicer et al., 1998). Helping relationships refer to surrounding oneself with positive interpersonal relationships built on trust, caring, honesty and acceptance (Prochaska et al., 2015; Velicer et al., 1998). Examples of helping relationships include workout buddies, counsellors and support groups (Prochaska et al., 2015; Velicer et al., 1998). Counterconditioning is when individuals substitute healthy behaviours for unhealthy behaviours (Prochaska et al., 2015; Velicer et al., 1998). An example of counterconditioning can be replacing soda with bottled water in their refrigerator (Prochaska et al., 2015; Velicer et al., 1998). Individuals utilize stimulus control to remove cues that trigger unhealthy behaviours and by adding cues that prompt healthy behaviours (e.g., removing all ashtrays from one's home and car) (Prochaska et al., 2015; Velicer et al., 1998). Self-liberation is when individuals believe that they can make a behavioural change and continue to commit to changing (Prochaska et al., 2015; Velicer et al., 1998). Individuals who share their commitment to behavioural change publicly with friends and family members are typically the most successful (Prochaska et al., 2015; Velicer et al., 1998). Individuals who have multiple alternatives in how to change their behaviour are very successful as well (Prochaska et al., 2015; Velicer et al., 1998). In the context of smoking cessation, a smoker should be provided with the choice of nicotine replacement patches, gum or going cold turkey to make the best-informed decision on how to proceed (Prochaska et al., 2015; Velicer et al., 1998).

Empirical Research on TTM

Processes of change and its associated concepts have been researched extensively in the past (Dishman et al., 2010; Gourlan et al., 2016; Kim, 2020; Kirk et al., 2004; Levy et al., 2009; Lowther et al., 2007; Marcus et al., 2000; Plotnikoff et al., 2001; 2010; Skaal & Pengpid, 2012). Research using various populations, such as healthy adults, multiethnic groups, overweight

women, individuals living with Type-2 diabetes and individuals living with multiple sclerosis, have determined that self-efficacy, decisional balance and the use of cognitive and behavioural strategies are predictors of behavioural change (Dishman et al., 2010; Kim, 2020; Levy et al., 2009; Plotnikoff et al., 2001; 2010; Romain et al., 2014). Specifically, the transition from the pre-contemplation stage to the contemplation stage, or higher, was predicted by higher self-efficacy, higher perception of pros and higher use of cognitive strategies (Kim, 2020; Levy et al., 2009; Lowther et al., 2007; Plotnikoff et al., 2001; 2010; Romain et al., 2014). Comparatively, adherence to exercise in the action and maintenance stages was associated with higher levels of perceived pros and the use of both cognitive and behavioural processes of change (Dishman et al., 2010; Kim, 2020; Levy et al., 2009; Lowther et al., 2007; Plotnikoff et al., 2001; 2010; Romain et al., 2014).

An important aspect of the TTM is that it helps the development of stage-matched interventions designed to facilitate behavioural change (Kirk et al., 2004; Rhodes & Quinlan, 2015). For instance, Skaal and Pengpid (2012) looked at physical activity behaviour in 200 healthcare workers in South Africa exposed to four different interventions over six months. Interventions in this study were stage matched. Pre-contemplation to contemplation interventions consisted of exposing participants to posters, pamphlets and radio stations designed to increase knowledge and change perceptions for three months. To transition participants into the preparation stage, they were presented after three months with new pamphlets emphasizing the need to develop a physical activity regimen. To facilitate the transition into action stage, an employee wellness awareness day was organized for participants, consisting of health checkups, a fun run and aerobic dancing to expose participants to programs and encourage participants to take action. Lastly, to promote maintenance, weekly radio health talks were organized for three months to support

participants and further encourage physical activity behaviour (Skaal & Pengpid, 2012). Post-intervention results indicated that using these stage-matched interventions increased physical activity by 66.9% (Skaal & Pengpid, 2012).

Critical Assumptions of the TTM

Similar to the SEM principles, the nature of behavioural change, as well as the development of stage-matched interventions, is guided by the TTM's critical assumptions (Prochaska et al., 2015). The first assumption states that theories of behavioural change in health-related contexts distinguish themselves from theories of health behaviour (Prochaska et al., 2015). Theories of health behaviour are concerned with factors predicting future behaviours by relying on past behaviours, while theories of behavioural change are mainly concerned with factors influencing future behavioural change (Prochaska et al., 2015). The second assumption of the TTM is that since no single theory accounts for all complexities of behavioural change, more comprehensive models will emerge from the integration of multiple theories (Prochaska et al., 2015). The third assumption is that behavioural change is a process that takes place over time and is characterized by undergoing a series of stages (Prochaska et al., 2015). The fourth assumption is that while stages of behavioural change are stable, they are open to change (Prochaska et al., 2015). The fifth assumption claims the majority of at-risk populations are not prepared for action and will not see the benefits of action-oriented behavioural change programs (Prochaska et al., 2015). The final assumption states that specific processes and principles of change must be emphasized in specific stages of behavioural change (Prochaska et al., 2015).

Theoretical Framework

Perceived factors influencing behavioural change differ for individuals in lower and higher stages (Prochaska et al., 2015). Thus, understanding how behaviour is initiated and maintained

implies that we must consider how different factors influence the behavioural change process in each stage (Prochaska et al., 2015). The theoretical framework for this study constitutes a combination of the SEM and the TTM frameworks. The development of this framework is rooted in the second assumption of the TTM that no single theory accounts for all complexities of behavioural change and that new integrative models involving multiple theories are likely to arise (Prochaska et al., 2015). By integrating the SEM and the TTM into a single framework, the researcher is aiming to identify how different types of factors influence physical activity behaviour in each stage of behavioural change in the context of ACHD patients.

In recent years, research has combined the SEM and the TTM frameworks to better understand factors influencing physical activity behaviour in vulnerable populations (MacCosham et al., 2018; Verschuren et al., 2013). For instance, findings from MacCosham et al. (2018) determined that individuals with Parkinson's disease tended to experience intrapersonal constraints more frequently in the pre-contemplation stage compared to those in the maintenance stage. The nature of factors also differed in early stages compared to later stages. For example, participants in early stages experienced factors such as lacking knowledge of the benefits of physical activity, interest in available physical activity programs, experience in physical activity prior to diagnosis, guidance from healthcare professionals, as well as feelings of social isolation and perceived stigma, while in the maintenance stage factors such as poor weather and injuries were experienced more frequently (MacCosham et al., 2018). Constraining factors of each type also saw a decrease from one stage to the next (MacCosham et al., 2018). In contrast, the number of facilitating factors saw a drastic increase in later stages compared to early stages (MacCosham et al., 2018). Conversely, in a similar study by Verschuren et al. (2013) on children and adolescents with cerebral palsy, findings suggested that barriers to physical activity were mostly experienced

in the intention stage, which is comparable to the contemplation and preparation stages. Participants also experienced a higher number of facilitating factors, specifically intrapersonal factors, as stages progressed (Verschuren et al., 2013). Thus, the ability to identify commonly experienced factors influencing physical activity behaviour in each stage could be a valuable contribution to our knowledge of ACHD patients and allow for the development of stage-matched interventions in this population (MacCosham et al., 2019).

Chapter 3: Methodology

The purpose of this study is to qualitatively explore how physical activity behaviour is initiated and maintained in ACHD patients. The methodology chapter discusses the researcher's process for gathering relevant information from participants to then answer the study's research questions. The chapter begins with a presentation of the philosophical paradigm to better understand the researcher's lens when approaching the data. The research design is then presented to gain a better understanding of the approach used for collecting relevant data. The methods for recruiting suitable participants are then explained. Next, data collection strategies are described to illustrate how information was collected from participants. A description follows of how the interview guide was constructed to assure appropriate data is collected. Finally, the data analysis strategies utilized by the researcher are discussed.

Philosophical Paradigm

The philosophical approach used in this study is the constructivist paradigm. Constructivism seeks to understand how individuals make sense of their experiences and how social behaviours influence population groups' perspectives (Adom et al., 2016). According to constructivism, individuals construct knowledge of the world through lived experiences by experimenting and doing, and then reflecting on those experiences (Crotty, 1998; Dogru & Kalender, 2007; Honebein, 1996;). Constructivism has also been described as a way for individuals to develop an understanding of the natural world in which they live and to develop subjective meanings based on their experiences (Creswell, 2017).

Constructivist ontology is relativist, as meanings of realities are considered to be socially constructed and ungoverned by universal laws (Creswell, 2017; Lincoln & Guba, 1985). Truth is therefore not an absolute; rather, it is the best informed and most sophisticated construction that is

perceived at any given moment (Guba & Lincoln, 1998). In order to gain the best understanding on the experiences of ACHD patients when engaging in physical activity, the researcher relied on the perceptions and constructs of those individuals. Yet, their perceptions may not have necessarily represented an absolute truth on the experiences of ACHD patients in physical activity.

Constructivism has been criticized as radically relativist, as it rejects the idea of a specific reality and states that what is real is simply someone's constructions (Labonte & Robertson, 1996). Despite this criticism, it must be acknowledged that whether an absolute and singular reality exists, individuals' understandings of reality are a socially constructed account of what has been lived (Labonte & Robertson, 1996). Accordingly, constructivists view reality as subjective, and the meanings they associate to their experiences can be multiple or varied (Adom et al., 2016; Creswell, 2017). Subjectivity was maintained in this study, as the findings from this research were generated mostly through participants' narratives of their experiences in physical activity.

Epistemologically, the researcher worked towards reducing the distance between the participants and himself (Creswell, 2017). The researcher attempted to build a relationship with participants by spending time with them in the field and becoming an insider (Creswell, 2017). The relationship between participants and researcher was relatively close, as the researcher participated in various events held by ACHD organizations outside of the study. For instance, the researcher spent time attending a bowling fundraiser held by the Canadian Congenital Heart Alliance (CCHA) (CCHA, 2017b), a non-profit CHD organization in which several participants were members. The researcher also volunteered and actively participated in Fearless Physical Activity events for CHD patients, where some of the participants were recruited. Thus, meeting with participants in informal settings during the inquiry process facilitated discussions on daily life between the participants and researcher.

Methodologically, constructivism is hermeneutic, and uses interpretive and dialectic methods of inquiry (Lincoln & Guba, 1998). The researcher employed a flexible research methodology for this study by having participants respond to pre-determined open-ended and semi-structured questions (Adom et al., 2016). This format of questioning encouraged participants to discuss their unique perceptions and thoughts more freely (Adom et al., 2016; Dogru & Kalender, 2007). In addition to pre-determined questions, the researcher asked spontaneous questions during the interviews to further probe participants' narratives (Adom et al., 2016). Once data was collected from the interviewees, the researcher produced a narrative (rather than technical) report by making comparisons between different interpretations and using a continuous process of going over the data, analyzing, critiquing, going over the data again, re-analyzing and synthesizing (Lincoln & Guba, 1985; Schwandt, 1990).

While this study utilized a theoretical framework consisting of a combination of the SEM and TTM to situate its findings, suggesting that the interpretation of findings could have potentially occurred through a post-positivist lens, the researcher did not actively seek out themes that could fit within the different components of either framework. For instance, while the SEM framework identifies five different types of factors that could influence physical activity behaviour, the researcher did not attempt to uncover specific factors that could be categorized within each of these categories. In addition, while the benefits presented in this study were either physical, psychological or social, the researcher did not specifically ask participants for examples of benefits within each of these domains. Rather, the researcher sought to have the voices of participants heard and let their narratives speak for themselves by having themes and subthemes emerge naturally for each component of the study. Themes and sub-themes for this study were therefore uncovered

through the data collection and analyses processes, and then situated within the theoretical framework of the study.

Research Design

Qualitative, and more specifically, phenomenological, research designs are typically associated with constructivist philosophy (Adom et al., 2016), since constructivism attempts to gain a better understanding of participant experiences (Adom et al., 2016). The researcher can then construct meanings derived from the participants' experiences with the phenomena being investigated and evaluate what participants are saying (Adom et al., 2016). Phenomenology is described as a person's perception of events that take place in their life, as opposed to the event existing externally to that person (Leedy & Ormrod, 2013). The phenomenological approach is commonly used when exploring the essence of individuals' experiences with a particular phenomenon (Grbich, 2013). The emphasis of this study was deeply rooted in the reality of ACHD patients and the factors influencing their lived experiences with regard to physical activity. Thus, qualitative phenomenology was seen as better suited for this study than other research designs that do not focus specifically on the participants' reality as filtered through their perceptions of experiences with particular phenomena.

In this study, the phenomenon was ACHD patients' experiences while engaging in physical activity behaviour. This particular lens allowed the researcher to gain a better understanding of how meanings, experiences and behaviours were shaped by their unique circumstances, which could not be done using experimental or survey instruments (Maxwell, 2004a; 2004b). Qualitative phenomenology is also an approach concerned with the documentation of changes in participants' feelings, perceptions and experiences, and behaviours over time (Grbich, 2013), which was relevant to this study. The use of qualitative phenomenology was therefore well-suited for this

study, as a temporal factor was incorporated into the methodology and data being sought. Specifically, the researcher interviewed ACHD patients over a span of six months to better understand their experiences while engaging in physical activity behaviour over time.

Participants

The purpose of this study was to qualitatively explore how engagement in physical activity is initiated and maintained in ACHD patients. Accordingly, individuals were expressly chosen for their ability to provide the most relevant information on the phenomenon in question (Creswell, 2017; Maxwell, 2013; Palys, 2008). This deliberate choice of individuals also increased the confidence that the conclusions drawn would reflect the participants' experiences with the phenomenon as they perceived it (Maxwell, 2013). Individuals were eligible to participate in this study if they had been diagnosed with a simple to complex CHD by a physician, were 18 years of age or older, lived in Ottawa or the surrounding region, had the ability to engage in physical activity behaviour on a regular basis, and had the cognitive capacity to understand and respond to the interview questions.

Participants were recruited primarily from the University of Ottawa Heart Institute (UOHI) (n=23) and directly from Fearless Physical Activity (n=4) events held in Ottawa, Ontario, Canada. When recruiting from the UOHI, the researcher was present at the ACHD patient clinic twice per week and recruited most participants in person. The researcher would enter the clinic rooms during ACHD patients' routine appointments before they met with their cardiologist in that same room. Once in the clinic room, the researcher briefly described the overall purpose of the thesis and handed patients a recruitment letter (Appendix B). If patients expressed an immediate interest in participating, the researcher would take note of their contact information (i.e., email, phone number) in a password-protected excel spread sheet. If the researcher was unable to attend clinic

hours, the nurse practitioner of the ACHD patient clinic would hand the recruitment letter to eligible participants to take home instead. From there, participants had the opportunity to contact the researcher directly via email or telephone if they were interested in participating.

The researcher also volunteered at three adult Fearless Physical Activity events held in the Ottawa region. The researcher participated in event activities alongside other volunteers and ACHD patients. By engaging with the participants, the researcher was able to build a rapport with potential candidates for the study. The researcher would provide a brief explanation of the thesis research and distribute the recruitment letter at the end of the event (to all participants) or during the event (just to those with whom the researcher engaged in activities). Directly engaging with participants while they were experiencing the phenomena of the study was beneficial, as it gave the researcher an inside look at how participants were feeling in real time (Adom et al., 2016).

Qualitative research allows the research design to be reconsidered or modified in-study thanks to new developments or changes in its various components (Maxwell, 2013). Qualitative research designs are therefore characterized as flexible (Maxwell, 2013; Robson, 2011). Qualitative research designs also consist of a reflexive process operating throughout each stage of the study (Hammersley & Atkinson, 1995). Consequently, the processes whereby the data were collected and analyzed, the theory was developed and modified, and the research questions were prepared and re-focused occurred simultaneously, as each component influenced the other (Maxwell, 2013).

Participant recruitment coincided with data collection and analyses. For instance, ten participants were recruited and took part in their first semi-structured interviews as soon as they were available, with recruitment ceasing temporarily during that time. This allowed the researcher to assess the recruited participants' level of motivation, abilities, and perceptions and experiences

with regard to physical activity. Subsequently, the researcher was able to narrow down his selection when recruiting more participants. By doing this, the researcher was able to gather information from ACHD patients at different levels of motivation, abilities, and perceptions and experiences with regard to physical activity. For example, most ACHD patients recruited in the first group of participants were highly motivated and active individuals who did not perceive their CHD as having any major effect on them. Following interviews with the first group of participants, the researcher talked to the nurse practitioner of the UOHI ACHD clinic about recruiting ACHD patients who varied in their level of motivation to obtain a wider range of narratives. The researcher would then recruit specific individuals fitting the criteria to participate and assess their level of motivation, abilities, and perceptions and experiences towards physical activity, and the process began anew.

The number of participants recruited for this study (27) exceeded the recommended number (i.e., five to 25) for qualitative research (Leedy & Ormrod, 2013). The demographics of each participant are presented in Table 1. Participants consisted of eight ACHD patients who identified as male and 19 as female, ranging between 19 and 71 years of age and representing a wide variety of CHD diagnoses. The number of participants recruited for this study was determined by the point in which data reached saturation, and no new themes emerged during the collection and analysis of the data (Trotter, 2012). Prior to participant recruitment and data collection, ethics approval was granted by both the Ottawa Health Science Network Research Ethics Board of the UOHI and the Office of Research Ethics and Integrity for Health Sciences of the University of Ottawa.

Table 1***Participant demographics***

ID Number	Gender	Age	Diagnosis
ACHD1	F	34	Pulmonary atresia with ventricular septal defect
ACHD2	M	30	Coarctation of the aorta
ACHD3	F	32	Marfan syndrome
ACHD4	F	71	Gerbode type ventricular septal defect
ACHD5	F	53	Mitral valve prolapse
ACHD6	F	54	Tetralogy of Fallot
ACHD7	M	42	Tetralogy of Fallot
ACHD8	F	54	Pulmonary valve stenosis and bicuspid aortic valve
ACHD9	F	37	Pulmonary atresia
ACHD10	M	32	Transposition of the great arteries D-Type
ACHD11	F	33	Tetralogy of Fallot with atrial septal defect and left pulmonary artery stenosis
ACHD12	F	61	Severe mitral valve regurgitation
ACHD13	M	25	Transposition of the great arteries D-Type
ACHD14	F	52	Ventricular septal defect
ACHD15	F	60	Marfan syndrome with mitral valve prolapse and mild aortic root dilation
ACHD16	F	57	Tetralogy of Fallot with moderate aortic regurgitation
ACHD17	F	67	Anomalous left coronary artery
ACHD18	M	41	Bicuspid aortic valve with moderate aortic regurgitation
ACHD19	F	62	Eisenmenger syndrome with severe pulmonary hypertension
ACHD20	F	35	Marfan syndrome with bileaflet mitral valve prolapse and aortic root dilation
ACHD21	M	41	Dysplastic tricuspid valve with moderate regurgitation
ACHD22	F	19	Total anomalous pulmonary ventricle defect
ACHD23	F	59	Marfan syndrome and associated aortopathy
ACHD24	F	66	Sinus venosus atrial septal defect and partial pulmonary vein drainage
ACHD25	F	19	Tetralogy of Fallot
ACHD26	M	68	Transposition of the great arteries
ACHD27	M	68	Tetralogy of Fallot and congestive heart failure

Fearless Physical Activity

Fearless Physical Activity consisted of seasonal one-day events put on by the CCHA. Participants included patients with CHD, their friends, family and medical professionals, as well as members of the Children Hospital of Eastern Ontario's Healthy Active Living and Obesity

Research Institute (Fearless Physical Activity, 2017). The overall goal of the CCHA is to raise awareness and improve the quality of care for CHD patients (CCHA, 2017c). Fearless Physical Activity events were therefore designed to offer high-quality, meaningful physical literacy-enhancing experiences to children, youth and adults with CHD throughout Ontario (i.e., Ottawa, London, Thunder Bay, Toronto, Sudbury). The intention behind the events, which took place between 2016 and 2018, was to create a permanent program for CHD patients throughout Canada. The purpose of Fearless Physical Activity was to connect CHD individuals with one another, help them and their families discover community resources that could enable them to pursue an active lifestyle, and teach them a variety of pleasurable physical activities within their abilities to motivate them to be physically active without being fearful (Fearless Physical Activity, 2017).

The Ottawa adult Fearless Physical Activity events were held on Saturday mornings from 9:00am to 12:00pm at different YMCA recreational facilities throughout the region. The events began with a 15-minute introductory game so participants and volunteers could become acquainted with one another. After the introduction activity, participants and volunteers typically engaged in 45 minutes of Tai Chi with the volunteer coordinators guiding the session. After Tai Chi, participants engaged in an exercise debriefing session where they would discuss their experiences, challenges and motivators to physical activity in general. Events would then continue with participants and volunteers taking part in either a 45-minute physically active team game (e.g., frisbee golf, relay race, outdoor scavenger hunts) or crafting (e.g., kite building). The events would conclude with another debriefing session on the event's activities and solutions and goals on how to better incorporate physical activity into their daily lives.

Data Collection

Participants in this study took part in three individual face-to-face semi-structured interviews over the span of six months. This allowed the researcher to understand and document changes in perceptions and behaviours pertaining to physical activity over time. Given that changes in behaviour can occur between one and six months according to the stages of behavioural change framework (Prochaska et al., 2015), it was deemed appropriate to have one baseline interview, a second interview three months after the baseline interview and a third interview six months after the baseline interview. All but three participants took part in all three interviews and those who did not took part in two. A total of 78 interviews were conducted. The shortest interview lasted 17 minutes while the longest lasted 86 minutes. The average length of the interviews was 45 minutes. Interviews were recorded using a digital audio recording device and occurred at a time and place that was most convenient for the participants. The physical settings for the interviews varied: 48 were held in coffee shops, 22 in participants' homes and eight in the researcher's Graduate Students office on the University of Ottawa main campus. The length of time from the first interview to the last was ten months.

To ensure the proper flow of the interviews, the researcher employed a series of steps (Rubin & Rubin, 2005). First, the researcher created a natural environment and expressed an interest in the participants' life by discussing general daily topics at the start of each interview before turning on the audio recording device. By doing this, the researcher was able to establish a rapport with participants and gain their trust. Once that conversation came to an end, the researcher handed the participant a consent form (Appendix C) to read over and ask any study-related questions before signing it. The researcher then wrote the participant's password on their copy of the consent form and explained that they would use that password to unlock all three of their

transcript documents. Once participants were satisfied and signed the consent form, the researcher asked if they were ready to begin the interview and turned on the recording device. To encourage conversational competence, the researcher began by asking non-threatening and easily-answerable questions on the study topic. Participants were then asked open-ended questions slightly more specific to the research questions and had the opportunity to discuss topics at large. Meanwhile, the researcher made mental notes of descriptions during the interview. Subsequent questions were geared to collecting information on the participants' experiences, motives and challenges while engaging in physical activity. The use of probing and follow-up questions at this point of the interview demonstrated that the researcher was engaged and empathetic towards participants. Once the researcher was satisfied with the information obtained during the interview, he toned down the emotional level by giving participants the chance to ask the researcher any questions. The interview concluded with the researcher pausing the recording device and resuming casual conversation with the participant. At this point, the researcher sometimes turned the recording device back on so that participants could provide final thoughts or additional information on some of the topics discussed during the interview.

Construction of the Interview Guide

Qualitative research probing ACHD patients' experiences when engaging in physical activity behaviour is uncommon. Thus, there were no standard qualitative instruments or lists of open-ended questions that could serve as a source for this study's interview guide. To develop the interview guide for this study, the researcher drafted questions that seemed to address the research questions and topics under investigation. The draft version of the interview guide was divided into six sections: 1-participant, 2-physical activity, 3-meaning of physical activity, 4-constraints,

facilitators, and strategies, 5-Fearless Physical Activity program, and 6-Fearless Physical Activity events. Each section contained its own set of core questions and probes.

The first section of the interview guide consisted of general questions about the participants' life as an ACHD patient (e.g., What is it like to live with CHD? Can you talk to me about your daily living habits?). This allowed the researcher to gain an initial understanding of the participants' background. The second section contained retrospective questions about the participants' history and perceptions of physical activity in general (e.g., Can you talk to me about your experiences/history in physical activity? What are physical activities that you have enjoyed in the past? What do you think are the benefits of physical activity?). The third section focused on the significance and meaning of physical activity for participants. Such questions as, 'What does physical activity mean to you?', 'Can you describe a significant experience when engaged in physical activity?' and 'Can you describe a non-significant experience when engaged in physical activity?' were asked. The fourth section explored factors that constrained and facilitated physical activity behaviour for participants, as well as the strategies they employed to sustain physical activity participation. Questions included: 'What stops you from participating in physical activity?', 'What strategies do you use to overcome barriers that prevent you from engaging in physical activity?', and 'What facilitates or allows you to participate in physical activity?' The fifth and sixth sections of the interview guide focused on Fearless Physical Activity specifically. Fearless Physical Activity data collection was added to this study, as the program was created to initiate and hopefully maintain physical activity behaviour in CHD patients and was therefore relevant and in line with the purpose of this study. The data collected on Fearless Physical Activity became relevant for understanding how physical activity behaviour in the ACHD population could be promoted and initiated within a practical context. Questions pertaining to Fearless Physical

Activity included: ‘Can you discuss your perception (or knowledge) of the Fearless Physical Activity program?’ ‘How would you advertise the Fearless Physical Activity program?’ (this question was put to all participants regardless of whether or not they attended events), and ‘Can you tell me about your experience at the Fearless Physical Activity event?’ (this question was put to those who attended the event(s)).

Once questions were developed, the researcher piloted the interview guide on individuals who were not involved in the study but were similar in that they lived with a long-term disease. This helped the researcher refine any questions in the interview guide and determine whether participants would understand the questions so as to provide relevant information. Pilot testing of the interview guide took place with 12 individuals diagnosed with Parkinson’s disease (seven females, five males) recruited from the Boxing 4 Health program and the NeuroLogic Clinic in Ottawa, Ontario.

The pilot interviews revealed that the interview guide was appropriate for gathering the information the researcher needed to address the study’s research questions. However, a few questions, mainly in the meaning of physical activity section, were eliminated and refined as they were confusing and redundant for respondents. For instance, the meaning of physical activity section contained several probing questions such as, ‘What do you see?’, ‘How do you feel?’, ‘What are others doing?’, and ‘What were the events leading up?’, but respondents had already provided this information when asked ‘Can you discuss what is going on when you are having a significant experience in physical activity?’. As a result, those questions were eliminated. Another confusing question for participants was ‘How does the meaning you give to physical activity influence your desire to participate in physical activity?’, The researcher therefore eliminated the question and kept the probe, ‘What factors make physical activity personally meaningful to you

(e.g., motivation, attitude, challenge)?’ as the core question so participants could naturally talk about the significance of physical activity in their life.

The final interview guides for this study consisted of several open-ended questions so that participants were not limited in their responses and the researcher could ask probing questions. The use of open-ended questions allowed participants the opportunity to elaborate more naturally and provide in-depth information on topics that were being discussed (Fontana & Frey, 2005; Rubin & Rubin, 2005). Upon entering the data collection phase, the researcher had only one interview guide (Appendix D), described above. This guide was used for each of the participants’ first interview. However, given the nature of qualitative research and its flexible structure, the researcher used a modified interview guide for participants’ second and third interviews. The second and third interview guide (Appendix E) consisted of core questions, most of which were from the first interview guide. However, unique probing questions (e.g., Last interview you mentioned pursuing a Tai Chi program, did you pursue the activity?) were added to gather more information specific to the participants’ physical activity pursuits. This meant that the researcher had a set of tailored follow-up questions for each individual participant at their second and third interviews to document and follow up on changes in certain perceptions or behaviours. This helped the researcher collect more information on specific themes that had emerged in prior interviews and that warranted further inquiry.

Data Analysis

Acknowledging researcher bias is important for the trustworthiness of qualitative research (Merriam, 2009). The researcher employed steps proposed by Grbich (2013) and Creswell (2017) to reduce bias prior to thematically analyzing the data. The first step consisted of bracketing the self when it came to personal experiences and assumptions. However, it must be understood that

the researcher's background was responsible for shaping interpretations, as these came from personal, cultural, and historical experiences (Moustakas, 1994). Thus, the complete bracketing of personal experiences was not fully achieved. The second step consisted of reflecting on what was gained through reading, re-reading the transcripts and journaling thoughts, including any questions on how participants responded. Journaling thoughts by utilizing an audit trail and reflecting on what was discussed during interviews helped the researcher maintain the integrity of the participants' narratives and helped reduce bias in interpretations that may have emerged through the researcher's pre-conceived notions on physical activity behaviour from his past experiences. The third step consisted of identifying the major themes from narratives and text through a preliminary analysis of the data. The fourth step consisted of questioning the data and any emerging assumptions to ensure that new descriptions and conceptualizations were more likely to arise.

Data for this study was both inductively and deductively analyzed using thematic analysis. For instance, deductive analysis of overarching categories of themes was guided by the different types of factors within the SEM framework (i.e., intrapersonal, interpersonal, institutional, community, public policy and systems), the TTM's stages of behavioural change, as well as the processes of change described in the TTM (e.g., social liberation, helping relationships). Other broad categories of themes containing their own subthemes were then inductively analyzed and classified within each category of SEM factors. Participant narratives were also classified within different stages of behavioural change based on how they aligned with characteristics of individuals in each stage. Inductive analysis was also important in revealing new processes of change, meanings of physical activity and identifying patterns of physical activity. Themes were presented in the final report if they were mentioned by several participants or if they were described

in-depth by a single participant. For example, few of the participants' narratives were classified within the pre-contemplation stage, but discussions with the same participant across multiple interviews allowed the researcher to collect a significant amount of detailed data on certain topics.

Specific steps for thematic analysis proposed by Grbich (2013) and Creswell (2017) were utilized. The first step consisted of becoming familiar with the data by reading and re-reading it, and by comparing different aspects until the researcher was sure of what it contained. The second step consisted of underlining key information segments by developing a list of significant statements and writing descriptive comments beside them while letting the data speak and reveal ideas, behaviour patterns, actions and events. The third step consisted of matching and grouping segments of data with other relevant, or similar, segments. The fourth step consisted of attaching overarching labels and identifying sub-groups within the previously highlighted segments. The fifth step consisted of conceptualizing the groupings and linking them with the literature when starting to write the final report. This step involved writing a description of the participants' experiences with the phenomenon and describing how the experience happened. Thus, participant quotes were utilized to support the themes and researcher interpretations presented in the results. Some themes contained more participant quotes as they were discussed more frequently and sometimes offered a different perspective on the same theme.

Data analysis revealed several broad themes, each containing their own set of subthemes and concepts that evolved in nature from one stage to the next. Themes that were intrapersonal in nature consisted of meanings (i.e., addressing the significance of physical activity in the lives of ACHD patients), readiness for change (i.e., addressing perceptions towards physical activity, factors that have a direct impact on preventing or promoting behavioural change), CHD-specific (i.e., addressing CHD-specific ailments such as requiring surgical intervention) and non-CHD-

specific (i.e., addressing non-CHD related ailments such as general illnesses), perceived benefits (i.e., addressing benefits specifically within the physical and psychological domains) and perceived risk (i.e., addressing perceptions of risk ranging from having an impact on participants' CHD or risk of injury), limitations (i.e., addressing physical or psychological impairments or challenges constraining physical activity behaviour), lifestyle (i.e., addressing factors pertaining to one's organizational skills or everyday factors such as lack of time), knowledge (i.e., addressing factors that have to do with participants' knowledge ranging from the way they conceptualize physical activity, knowledge of benefits, knowledge of diagnosis, knowledge of their abilities), and experience (i.e., addressing participants' history of physical activity and exposure/experiences during childhood, past experiences when participating in certain activities or programs). The following interpersonal themes were identified: professional guidance (i.e., addressing recommendations and guidance received from healthcare professionals), encouragement (i.e., addressing how others motivate participants to be active) and discouragement (i.e., addressing how others do not support participants for being active), and inclusion (i.e., addressing feelings of being part of a group or developing interpersonal relationships) and exclusion (i.e., addressing feelings pertaining to not being part of a group within a social context).

The following institutional themes were identified: program environment (i.e., addressing programs providing a comfortable setting), adaptability (i.e., addressing programs having equipment and staff that can meet the needs of participants to feel comfortable and safe), logistics (i.e., addressing the structure of programs and how they are delivered), and cost (i.e., addressing the fees for joining certain physical activity programs or other physical activity contexts provided by facilities). Community themes consisted of convenience (i.e., addressing abilities to frequent facilities or physical activity opportunities based on location and amount of time needed to prepare

for participation), and weather (i.e., addressing how poor and fair weather conditions influence one's ability to be active). Themes pertaining to public policy and systems were not uncovered in this study. No themes pertaining to public policy and systems were found.

Lastly, while the themes presented above were also consistent in findings on the Fearless Physical Activity program events, two additional themes were identified. The first was intrapersonal and related to identity (i.e., addressing how individuals perceive their self-concept and its influence on pursuing physical activity opportunities), while the second was institutional in nature and related to program purpose (i.e., addressing how participants perceived the intention of the program and the activities they would be offering).

In addition, since this study included participants' physical activity histories, their narratives were at times placed in stages that did not correspond with the stage they currently find themselves in. For example, some participants were at one point unwilling to modify their physical activity behaviour and therefore had quotes placed in the pre-contemplation stage when discussing that time of their life, even though they may currently be in the preparation stage.

Steps were also taken to ensure trustworthiness and establish credibility during the analysis of data and the themes that were developed by the researcher. For instance, after interviews were conducted, recordings were transcribed verbatim and sent to participants via email in a password protected document. A member-checking process was established by sending participants their transcript with a unique password allowing them to unlock all three of their transcripts. Participants were asked to go through each of their transcripts to determine if the transcribed conversations represented the information that was shared during their interviews. Giving participants the opportunity to review their transcripts allowed them to make corrections in the text and add information where needed to elaborate on certain topics. Participants were asked to make any

corrections to their transcripts in red so that the researcher could easily identify those changes. This member-checking process was important, as it allowed the participants to verify the accuracy of the information collected during their interviews. It is important to note that not all participants took the time to review each of their transcripts. In total, 56 of the 78 transcripts were verified and confirmed as being accurate.

While some participants did not review the accuracy of each of their transcripts, the researcher assured accuracy of his interpretations with participants who took part in all three interviews. After the third interview, the researcher had a debriefing discussion with participants and shared preliminary themes that had emerged throughout the data analysis process. This strategy added validity to the researcher's member-checking efforts. In addition, the researcher presented a description of each stage of behavioural change for participants to read after the third interview. He then asked participants what stage they would have classified their narratives in for each interview and why. Afterwards, he explained what stage he had classified the participant in for each interview and why. Comparisons revealed that the participants' and researcher's classifications of narratives for each interview were the same. There were only two instances where the researcher had to clarify why the participant believed their narratives belonged to a different stage than that chosen by the researcher, whereupon each participant agreed that the researcher's choice was justified after all. After this process, the researcher discussed some of the themes most commonly experienced in each stage by the participants involved in the study, and asked for feedback on these themes. This also ensured that the themes were appropriate and reflected the experiences of ACHD patients when engaging in physical activity. Confirming the accuracy of the researcher's preliminary themes during the debriefing discussion may have also been a reason why some participants did not review their third transcript afterwards. The use of multiple interviews

for collecting data was also considered to increase the trustworthiness of the findings, as the researcher was able to compare the content of each interview for consistency. Finally, the researcher acquired feedback through peer debriefing, by letting colleagues in the field review findings and themes to see if they agreed or disagreed with the researcher's interpretations.

Chapter 4: Results

The purpose of this study was to qualitatively explore how physical activity behaviour is initiated and maintained in ACHD patients. In this chapter, each stage of behavioural change is presented along with its associated themes and subthemes. Themes are not necessarily presented in order of importance. A summary of the participants' physical activity behaviour over the three interviews spanning six months is presented in table 2. One participant had interviews classified in the pre-contemplation stage, six had interviews classified in the contemplation stage, fourteen had interviews classified in the preparation stage, eight had interviews classified in the action stage, and twelve had interviews classified in the maintenance stage.

Table 2

Summary of participants' physical activity behaviour spanning six months

ID Number	Stage	Physical activities and exercises
ACHD1	Preparation	Dog walking twice per week
	Action	Gym 3-4 times per week for 30mins
	Preparation	Daily dog walking for 20mins
ACHD2	Maintenance	Daily running, cycling, swimming treadmill, or weightlifting
	Maintenance	Daily running, cycling, swimming treadmill, or weightlifting
	Maintenance	Daily running, cycling, swimming treadmill, or weightlifting
ACHD3	Maintenance	Pilates and walking 3-5 times per week for 60mins
	Maintenance	Pilates and gym exercising 4 times per week
	Maintenance	Gym exercising 4 times per week for 60-90mins
ACHD4	Maintenance	Home yoga and walking 5 times per week for 60mins
	Maintenance	Home yoga and walking 5 times per week for 60mins
	Maintenance	Home yoga and walking 3 times per week for 60mins
ACHD5	Maintenance	Daily running, yoga, cardio gym exercises, or weightlifting
	Maintenance	Daily running, yoga, cardio gym exercises, or weightlifting
	Maintenance	Daily running, yoga, cardio gym exercises, or weightlifting
ACHD6	Pre-contemplation	Daily 60mins dog walking (for work), household activities
	Pre-contemplation	Daily 60mins dog walking (for work), household activities
	Pre-contemplation	Daily 60mins dog walking (for work), household activities
ACHD7	Maintenance	Running 4-5 times per week for 60mins
	-	-
	-	-
ACHD8	Maintenance	Daily walking, yoga, Zumba, cycling, gym exercises, or outdoor activities

	Maintenance	Daily walking, yoga, Zumba, cycling, gym exercises, or outdoor activities
	Maintenance	Daily walking, yoga, Zumba, cycling, gym exercises, or outdoor activities
ACHD9	Preparation	Home exercise program 1-2 times per week
	Preparation	Tai Chi class once a week for 60mins
	Preparation	Tai Chi class once a week for 60mins
ACHD10	Contemplation	Neighbourhood walks 2-3 times per week
	Preparation	Daily home yoga program
	Preparation	Neighbourhood walks, household activities
ACHD11	Contemplation	Walking once per week for 60mins
	Preparation	Daily home yoga program
	Preparation	Daily home exercises for 20mins
ACHD12	Preparation	Weekly personal trainer for 60mins
	Action	Personal trainer 50mins twice per week, pickleball 60mins twice per week, walking 30mins per week
	Action	Personal trainer 50mins twice per week, pickleball 60mins twice per week, walking 30mins per week
ACHD13	Maintenance	Physical labour (as part of job), weightlifting in gym 2-4 times per week for 60mins
	Preparation	Physical labour (for work)
	Preparation	Physical labour (for work)
ACHD14	Preparation	Walking 3 times per week for 30mins
	Contemplation	Household activities
	Action	Gym 3 times per week for 90mins
		Cycling twice per week for 20mins
ACHD15	Maintenance	Walking 3 days per week for 30mins
	Maintenance	Yoga or walking 3 times per week for 20-60mins, outdoor activities
	Maintenance	Yoga or walking 3 times per week for 20-60mins, outdoor activities
ACHD16	Maintenance	Yoga or walking 3 times per week for 20-60mins, outdoor activities
	Maintenance	Daily walking, aqua fitness, cardio gym exercises, or weightlifting
	Maintenance	Daily walking, aqua fitness, cardio gym exercises, or weightlifting
ACHD17	Maintenance	Daily walking, aqua fitness, cardio gym exercises, or weightlifting
	Contemplation	Neighbourhood walk 3 times per week for 30mins
	Preparation	Occasional neighbourhood walks
ACHD18	Action	Walking 3-5 times per week for 60mins
	Maintenance	Physical labour (for work), weekly broomball
	Maintenance	Physical labour (for work), weekly broomball
	Maintenance	Physical labour (for work), baseball 4 times per week

ACHD19	Maintenance	Daily 20mins walks, household activities
	Maintenance	Daily 20mins walks, household activities
	Maintenance	Daily 20mins walks, household activities
ACHD20	Preparation	Weekly ballet class for 60mins, occasional yoga
	Preparation	Weekly ballet class for 60mins, occasional yoga
	Preparation	Weekly ballet class for 60mins, occasional yoga, walking 3 times per week for 60mins
ACHD21	Maintenance	Weekly swimming, cycling, and hockey
	Maintenance	Weekly swimming, cycling, gym exercises, and hockey
	Maintenance	Weekly cycling, gym exercises, and hockey
ACHD22	Contemplation	Walking 3-4 times per week for unspecified amount of time
	Preparation	Gym exercises 2 times per week
	Action	Walking 60mins per day Physical labour (for work) 6 times per week
ACHD23	Contemplation	Neighbourhood walk 3-4 times per week for 20mins
	Preparation	Walking 4 times per week for 60mins, gardening
	Action	Daily walking for 20mins
ACHD24	Preparation	Weekly Tai Chi program, daily walking
	Action	Home exercise program 2 times per day for 30mins
	Preparation	Daily walking for 60mins, occasional gym exercises
ACHD25	Preparation	Physical labour (as part of job), occasional walking
	Action	Walking/jogging 60mins 4-5 times per week
	Action	Walking 45mins per day
ACHD26	Preparation	Household activities, minimal walking
	Preparation	Household activities, minimal walking
	-	-
ACHD27	Preparation	Household activities
	Preparation	Household activities, home video program
	Preparation	Household activities

Pre-Contemplation Stage

According to the TTM framework, individuals in the pre-contemplation stage are not looking to make a behavioural change within the next six months and are unmotivated to engage in health promotion programs. Consequently, health promotion programs are not designed for pre-contemplators because they do not match their needs. The themes presented below were associated with participants in the pre-contemplation stage. The themes associated with pre-contemplative participants appeared to be in line with the description of pre-contemplators, as they engaged in minimal physical activity and had little to no desire to modify their physical activity behaviour. A summary of the themes associated with pre-contemplative participants is provided in Table 3.

Table 3

Factors influencing physical activity behaviour in the pre-contemplation stage

Themes	Constraints	Facilitators
	Intrapersonal factors	
Meanings		• Physical activity is meaningful • Achieve well-being • Maintain health and function
Readiness for change	• No desire to modify behaviour • Procrastination • Anticipating death • Survivor mentality	
Knowledge	• Misconceptions on what constitutes physical activity • Misconceptions of level of participation • Lack understanding on cardiovascular benefits • Lack understanding on diagnosis	
Non-CHD specific	• Non-cardiac related illness	

Limitations	Physical: Lack of energy, age-related fatigue, stiffness, pain, lack of endurance	
Perceived risk	- Fear: Towards activities, damaging surgical repair site, unknown - High perception of risk	Low perception of risk
Experience	- Lack exposure during childhood - Lack of competence	
Interpersonal factors		
Discouragement	- Overprotective parents - Encouraged to be inactive during childhood by healthcare professionals - Lack of encouragement from significant others - Dramatizing disease to others - Inactive social circle	
Exclusion	- Perceived stigma: Body perceptions - Exclusion by others - Isolation	
Institutional factors		
Logistics	Lack of variety	
Cost	Cost	
Community factors		
Convenience	Convenience	
Strategies		
Cognitive	- Dramatic relief: Fear and intimidation from healthcare professionals - Consciousness raising: Increase knowledge of diagnosis	
Behavioural	Reinforcement management: Receiving unhealthy rewards	

Meanings

During her interview, participant ACHD6 explained that she did “[physical activity] out of necessity. It’s not meaningful to me at all. [...] Physical activity to me is just because I should [do it].” (ACHD6-1). Thus, physical activity was perceived as having no meaning or significance for this participant. However, she contradicted her perceptions towards physical activity again by

mentioning how she had pleasurable experiences when walking in nature, “Some days I still go for a walk. [...] I think everybody loves [walking and] being close to nature.” (ACHD6-1). While the participant previously suggested that physical activity had no significance for her, she found occasional walks in nature to be enjoyable as they enhanced her well-being.

Additionally, when the participant was asked why she engaged in occasional walking she stated, “To be healthy. To be ready for when you do get sick [that] you’re not too sick. When you do fall you don’t hurt yourself as bad that’s all.” (ACHD6-2). Thus, the participant was speaking to maintaining health and function in that she was preparing to reduce her risk of experiencing ailments or of increasing the severity of the ailments she would experience in the future.

Readiness for Change

When discussing current involvement in physical activity, the same participant mentioned that she engaged in no physical activity other than what was required for her profession as a dog walker. The participant expressed that her interests were primarily in sedentary activities such as playing cards:

[I don’t do] enough [physical activity]. I walk dogs that’s it. I should be stretching and toning. [...] I used to walk [the dogs] twice a day but now I only walk them once because I’m not getting more [money] for it. Aside from handling the dogs I play cards a lot, bridge, poker, [and] euchre. (ACHD6-1)

While the participant mentioned that she engaged in physical activity, most of which revolved around walking dogs as part of her profession, she also included navigating her home and performing daily living and household tasks as physical activity. She explained that she was “handling the dogs and playing bridge. To say I’m going over to the pool to swim or something, nope. [I do] natural activity like getting up and getting a coffee.” (ACHD6-3). Here is another

statement that stood out with regard to the participant's desire to modify her physical activity behaviour; "To be honest I'm not anticipating [taking up any physical activity in the future]." (ACHD6-3). Not only did her physical activity behaviour stay the same over the course of six months, but she had no desire to increase physical activity behaviour in the future.

The participant also recognized being a procrastinator when it came to engaging in physical activity. She described the relationship between procrastination and the belief that she would pass away because of her CHD by explaining how she had surpassed her life expectancy and that engaging in physical activity would not have a role in extending her life. She claimed that she had convinced herself that because she was anticipating death at any given moment, there was no need to modify her physical activity behaviour:

I just put it off. I just don't care pure and simple and maybe I'll tick off before I need to [be active]. I'm being honest because your mind will tell you all sorts of lies so you don't have to do something. I say to myself, "What's the use of getting all fit you're just going to die of a heart attack?" I don't know [my life expectancy] because I'm a statistic standing. I'm one of the few that was repaired that did survive. [...] I play those games in my head [and say], "What's the bother you're going to be dead when you're 60." (ACHD6-1)

Furthermore, the participant described having a survivor mentality, which leveraged the theme of anticipating death. This theme refers to the participant's belief that they have surpassed their life expectancy as an ACHD patient with their current physical activity regimen. Thus, the participant explained how she continued to survive without experiencing any severe health issues or repercussions from engaging in the physical activity she was doing, "I think subconsciously I'm a known survivor. [I] say to myself, "I survived another day." So, what I did yesterday doesn't

matter and I keep going on with life.” (ACHD6-3). The participant implied that she did not experience any consequences to her health and explained how she continued to survive with her current regimen. Thus, she felt no need to modify her physical activity participation, as she got “away with something for so long you don’t really feel you need to do it.” (ACHD6-3).

Intrapersonal

Knowledge. While participant ACHD6 engaged in physical activity because of work, she mentioned that she was not active enough. The participant stated that she reduced her amount of work-related physical activity (i.e., walking dogs once per day instead of twice) since she was not being compensated for doing extra work. In her second interview, however, she contrasted her previous statement with the belief that she was active enough, “I think I’m active enough to be honest.” (ACHD6-2). Yet, later in the same interview the participant contradicted herself again by claiming that she was in fact not active enough, “I know what I’m doing is not enough. [...] [I’m active] just [for] maintenance of the body. [...] There’s no excuse because you can [use] cans in your house. It’s pure laziness.” (ACHD6-2).

The participant appeared to have misconceptions on whether she participated in enough physical activity or not. When asked about what constituted physical activity, she explained that it was “full of effort obviously. I don’t want to exude. [...] Who wants to do a sit up and all that even though it makes you a nice tummy?” (ACHD6-2). The participant therefore perceived physical activity as something that was very exerting, as opposed to activities of moderate exertion such as walking. She appeared to have a poor understanding of what constituted physical activity, as she only associated it with exerting exercises.

Moreover, the participant indicated that she lacked understanding of the cardiovascular benefits of physical activity. This theme refers to participants having minimal or no knowledge on

how physical activity benefits the heart specifically. The participant briefly explained how physical activity participation provided a variety of physical benefits (e.g., flexibility, oxygen flow to muscles) as well as psychological benefits (e.g., clearing the mind). However, she lacked knowledge of how physical activity related to cardiovascular health, which was particularly relevant for her as an ACHD patient. She described not understanding the translation of cardiovascular benefits from physical activity and how they related to her personally:

I don't really understand how physical activity helps the heart, like cardio. [...] I don't really understand about the heart pump why it's any good to be pushed to a degree of safe pushing. [...] What I've learned is it gets oxygen into your muscles. It clears your head. It keeps you limber and flexible. But the heart rate thing I really don't understand. (ACHD6-1)

Another factor influencing physical activity participation for the participant was lacking understanding of one's diagnosis. This theme refers to participants lacking knowledge of their type of CHD, including the structural abnormalities of their CHD. The participant had little knowledge of the limitations and risk factors associated with her CHD, which could have repercussions on her physical activity behaviour. She mentioned, "I went through my teenage years not even knowing I was left with a leaking valve. I was eight [years old and] I never heard nothing until I was 20 about [my diagnosis]." (ACHD6-1). When asked how her lack of understanding of her CHD impacted her involvement in physical activity, the participant stated, "I would've done a lot of other things having known all that." (ACHD6-1).

Limitations. One of the first topics discussed during interviews with the pre-contemplative participant was physical limitations. The first physical limitation discussed by the participant was lacking energy related to living with a chronic disease. This theme was associated with suffering

from a chronic disease (e.g., thyroid disease) that was not related to CHD. When asked what prevented her from being active, she described having a lack of energy caused by thyroid disease:

I got thyroid disease back when I was [in my] late 20's. I think that knocked me down a few pegs. I even got close to dying. [...] Ever since then I was trying to fight for any bit of energy. (ACHD6-3)

The participant also described experiencing general age-related fatigue as a constraining physical limitation to physical activity participation. She explained that this type of fatigue was not associated with CHD, "I'm getting older. I'm getting more tired. I don't know. But I do what I want." (ACHD6-2). In addition to fatigue as a physical limitation, the participant mentioned how she experienced stiffness and pains from not doing enough stretching and loosening muscles, thus constraining physical activity participation, "I get up now [and have] severe pain in my feet [from] lack of stretching. [...] But then tomorrow will come [for me to be active and stretch]. That's what I always say, tomorrow." (ACHD6-1).

Perceived Risk. A series of themes related to risks and fears were uncovered. The fear of engaging in certain physical activities was a theme closely associated with a high perception of risk. For instance, a participant described that if she were to experience heart failure or run out of stamina when swimming, the consequences could be fatal. Swimming was therefore perceived as a high-risk physical activity compared to hiking, where she could rest at any given moment:

One fear I have in water with my heart is if I have to fight to get up because I went under for some reason in the deep end. I was always afraid, and I still am today that I will have heart failure [and] something will happen that I can't finish fighting to get up. In other words, endurance failing. When you're under water you can't just sit down and rest like you could [when] hiking. (ACHD6-1)

In addition, the participant expressed a fear of damaging surgical repair sites by participating in certain physical activities. She described being fearful of partaking in physical activities that strained the chest or sternum where incisions had been made during past open-heart surgeries. She reported having sold her bicycle post-surgery because she had experienced discomfort squeezing her chest when holding the handlebars, and she avoided bowling due to the perceived risk of tearing her surgical wounds:

I used to bicycle, and I sold it a while ago shortly after I had surgery because [squeezing my chest when holding the] handlebars bothered my sternum. [The same thing applies to] bowling. I like bowling but I haven't bowled since I had the surgery because I was afraid to [tear my surgical wound]. (ACHD6-1)

The last type of fear discussed by the participant was fear of the unknown. This theme refers to a lack of desire to engage in physical activities with which the participant has no prior experience. This lack of familiarity dissuaded the participant from taking up any such physical activities in the future. The participant mentioned, "The unknown I didn't bother with. It's the unknown I can't be bothered with." (ACHD6-1).

Interestingly, while the participant perceived certain physical activities as highly risky, she also perceived physical activity as low risk in general. When asked about the risks of engaging in physical activity, she mainly emphasized the general musculoskeletal risks and overexertion: "I doubt there are any [risks] if you're not stupid about it. Don't go twisting your ankles because the terrain is bumpy. [...] Know your limits and your body." (ACHD6-1). However, the primary physical activity that the participant engaged in was walking, which was low risk and required little exertion. She stated, "[Walking is] a [low] injury [risk activity] and it's the most primal to do with your body." (ACHD6-1).

Non-CHD-Specific. The participant mentioned how she suffered from a non-cardiac related illness which prevented her from engaging in physical activity on a regular basis. During the second interview, she explained that she did “nothing more. [I’m] still walking dogs. [...] When I was sick with the cold I just [worked and rested]. I didn’t jump into anything. I still play bridge [but] no physical activity.” (ACHD6-2).

Interpersonal

Discouragement and Experience. When describing their history of physical activity, participants explained that they had been sedentary for most of their childhood due to overprotective parents. Instead, participants entertained themselves by playing sedentary games. A participant described how one of her parents prevented her from being involved in sports or any form of organized physical activity during childhood, “When I was really little my mom was maybe a little overprotective to a point where maybe that’s why I wasn’t overly involved in sports or like organized activity.” (ACHD11-1). Another participant described not having any interest in pursuing physical activity even though she had one parent who encouraged physical activity and one who was overprotective, “I was carried a lot [by my mom]. My dad would tell [her] “put her down she can do it.” [But] I didn’t have any drive to [be active].” (ACHD6-1).

Participants explained how their lack of exposure to physical activity during childhood led them to opt for sedentary over physical activity. For example, one participant stated, “I sat until I was four. I had to play games [...] I think my issue with exercising is because it’s not hardwired pure and simple. There’s not much to care about [when it comes to physical activity after that].” (ACHD6-1). Another participant related similar experiences during childhood: “I didn’t do [any physical activity when I was young]. I’m a gamer; cards, monopoly. [...] I became interested in different things.” (ACHD20-1).

Another factor contributing to lacking exposure during childhood was healthcare professionals discouraging participants from being active. A participant described how she was told to avoid synchronized swimming by her cardiologist despite never having any issues when participating in that activity. And so she gave up synchronized swimming on her cardiologist's advice:

I remember I was doing synchronized swimming and [we] had to swim for two-three hours. I remember my cardiologist at that time after I did it was like, "You should not have done that." That was kind of the end of synchro because at that point I was like, "If I can't do it, I'm not going to do it." (ACHD20-1)

The participant explained that when she was presented with opportunities to partake in physical activity, she often dismissed them. She developed a negative perception towards physical activity and did not reconsider being active for a long time after receiving that advice from her cardiologist, "[When] I was about ten [years old] it was at that point when I started to say, "Well if I can't do it then too bad." [I developed] that kind of attitude." (ACHD20-1).

Another factor preventing physical activity participation was lacking encouragement from significant others. A participant explained how lacking encouragement during adolescence left her with little interest in structured physical activities (e.g., sports) or unstructured physical activities (e.g., outdoor recreational physical activities). Additionally, the participant described lacking competence due to her limited exposure to physical activity during these years. Accordingly, her physical literacy development was hindered, and she began to perceive physical activity as work. Lacking encouragement from significant others decreased her motivation to participate in physical activity, which incidentally led to her lacking exposure and competence. Thus, a relationship was identified between these factors:

I wasn't encouraged [by my family] so I [didn't] engage. I know I'm not good at any sports. In high school I was on the basketball team [and] I got the ball in the face and that was the end of me. I don't like the outdoors. I'm not a skier or anything like that. Nobody pushed me. Nobody said, "You should walk more, you should do this, you should do that." It's like, "Do you feel like it?," "No I don't feel like it."

Physical activity to me is not fun, it's work. (ACHD14-1)

With little exposure to or interest in participating in physical activity during childhood, participants sometimes began to dramatize their disease to others to avoid engaging in physical activity. For example, participants were able to sit out gym class at school after telling teachers that they were unable to take part in activities due to their CHD, "When I was younger, I never took part in physical education [in school]. [...] I would ask for notes to get out of everything." (ACHD27-1). Teachers would therefore feel sympathetic towards them and due to their lack of knowledge of CHD, would let participants sit out gym class:

I remember some [activities] in gym class [where I'd say], "I can't do this" and there were other things that I could've probably done but I was like, "Sorry I can't do this because, I have Marfan." [...] [The teachers] knew that there were some activities that I couldn't do. Whether they knew that I was choosing not to do other activities is debatable. (ACHD20-1)

Another participant claimed:

In school I played on the fact that I had this and skipped a lot like going to a school with a swimming pool. [...] They were scared too because it was new to them, and they didn't want anything happening on their watch. (ACHD6-1)

A participant mentioned that her lack of desire to engage in physical activity stemmed from having an inactive social circle. This theme can be explained as the participant's friends, family members, spouses or partners being sedentary, which translates to the participant also being sedentary. The participant suggested that her lifestyle was affected by her friends, as activities they did together were geared towards dining rather than being active. She claimed, "The problem with [our] social [circle] is sometimes it's around eating and drinking and not about doing [physical activity]. I'd say we fell into that lifestyle that it was more about eating and drinking." (ACHD12-1). While having an inactive social circle may have influenced pre-contemplative participants when pursuing physical activity, it is worth noting that those who had an active social circle were not interested in being active either. For instance, a participant explained that she had active friends, yet her procrastination was such that she did not pursue those opportunities with friends:

[I should be doing] the things that you should do when you're this age. All my friends do it. The city has programs, so it doesn't have to cost you money. I should be joining walking groups. [...] I feel I lack that commitment. I'm a procrastinator.
(ACHD6-1)

Exclusion. A participant expressed perceiving stigma towards her when active during childhood. She described the relationship between her lack of endurance when taking part in team sports and perceptions of stigma. Since she was unable to keep up with others when playing, she believed that others would not want her on the team. She suggested, "I didn't join sports groups [in high school]. I thought, "What would they want me for?" You want teammates that are an asset to the team." (ACHD6-1). Thus, the participant felt that she would be a liability to her team due to her limited endurance and felt that others would not want her on the team. Similarly, she mentioned being excluded by others when it came to team sports that she enjoyed, adding that she

eventually developed a disdain of team sports during adolescence since she was never chosen to play with others, “In school when the team picks I didn’t [get picked]. [...] [So] to go in high school and play [team sports], why? [...] You don’t want to be huffing and puffing and saying, “I got to sit down.”” (ACHD6-1).

A participant spoke about how she perceived stigma brought on by body perceptions. The participant discussed how she did not want to be judged by others when seen with thin women:

I was starting to feel like I was pulling myself away from [my friends] and I couldn’t figure out why. But it was because [I] didn’t want to be seen as, “Look at all these pretty thin girls” and then there’s me [trying to keep up]. (ACHD25-2)

What must also be understood from this quote is that while perceived stigma was triggered by body perceptions, this also led to social isolation. In the quote above, the participant explained that she began to avoid her friends because she did not want to be judged by them. A relationship was therefore identified between perceptions of stigma related to body perceptions, and social isolation.

Institutional

Cost. Only one theme emerged with regard to institutional factors, namely the cost of participating in certain physical activities or programs of interest offered by recreational facilities. A participant expressed, “I like horseback riding. It’s just expensive.” (ACHD6-1). Yet, the participant also stated that cost should not have dictated physical activity participation and acknowledged that there were cost-efficient ways to participate in physical activity. Unfortunately, however, the participant described cost-efficient physical activities as lacking variety and leading to lethargy, “I’m not rich [...] but that’s no excuse. I can go in my house and pick up cans [to lift] but that’s boring.” (ACHD6-2).

Community

Convenience. A constraining factor associated with the community domain was convenience. A participant explained how she would be interested in mountain walking if she were to consider modifying her physical activity behaviour, but there were no mountains where she lived: “I don’t get into [mountains] because of where we [live]. If I lived [somewhere else where] there’s hills everywhere [I’d enjoy that].” (ACHD6-1).

Strategies

Cognitive. Given that pre-contemplative participants were unwilling to modify their physical activity behaviour, the strategies discussed by participants in this stage were propositions on what would make them want to modify their behaviour. The first cognitive strategy discussed was dramatic relief. For one participant, an emotional response (fear and intimidation) was elicited by a healthcare professional in the past when she smoked cigarettes. When asked how physical activity participation could be modified for her, she talked about having gone through smoking cessation and how that context could apply to modifying her physical activity participation. She described being shamed by her cardiologist who described the severity of smoking for someone with CHD. The participant therefore valued the conversation with her cardiologist, who had bluntly explained the risks of her smoking habit:

[My cardiologist] said, “Somebody has to have their head examined that smokes with this condition.” [...] That’s when my whole condition was explained. He said, “Your heart won’t tolerate your lung getting anything infectious.” So, I had to commit to quitting smoking that year because I had to see him again next year. So, I had one year to figure out how to quit. (ACHD6-1)

The participant then described the fear of having to see her cardiologist the next year for her annual follow up appointment. She explained how she feared perceptions of stigma from her cardiologist had she not quit smoking. She also contrasted the approaches between her current and previous cardiologists: she perceived her previous cardiologist's recommendations as less valuable because he did not emphasize the severity of smoking for someone with CHD:

The threat of having to see [my previous cardiologist] again scared me to quit smoking. Otherwise, I wouldn't have bothered. I was scared into it. [...] I'm happy that I've quit. Sometimes when you're scared into doing something it makes you. It's not a good way to learn but sometimes it's necessary. [My previous cardiologist would ask me], "Do you still smoke? It's not good." and that was it. He was too nice to me. (ACHD6-1)

While the participant acknowledged that intimidation may not have been the best way to inspire behavioural change, she understood that it was necessary, explaining that recommendations had to be delivered in a specific way to provoke a long-lasting behavioural change for her:

It has to come from the right person at the right time with the right tone. [...] I'm afraid of [my cardiologist] because he was harsh. He said it like he meant it. It becomes very real and then I had to quit smoking. (ACHD6-2)

Another cognitive strategy that emerged was consciousness raising, which refers to increasing the participant's knowledge of their disease and its risk factors in this stage. More specifically, having others (e.g., teachers, healthcare professionals) educate the participant during childhood on their ability to engage in physical activity. A participant suggested that from a young age, healthcare professionals should inform them about their disease so that they understand their diagnosis rather than giving that responsibility to parents. That way, the participant would have

had a better understanding of her diagnosis and could have explored various physical activity opportunities from a young age:

[Healthcare professionals], without the mom and dad, should really make sure that the child knows what they have. [...] A child breaking out of childhood into adulthood should make sure they know their whole health problems. My parents didn't sit me down and say, "[Healthcare professionals are] not done [repairing your heart]. You still have a leaking valve. You got to make sure you see a cardiologist every year." (ACHD6-2)

The participant added that accurate information on the limitations of a child with CHD should be provided to physical education teachers at school. She explained that if physical education teachers had better knowledge of a child's limitations instead of relying on the child for that information, the child would be forced to take part in physical activities, because they would not have the opportunity to dramatize their disease and have teachers let them sit out gym class:

It should have started when I was younger when I didn't have a choice. [In school] the teachers should inquire with the heart doctors directly and say, "What are the limitations of this person?" Kids are quick to play up on things and manipulate. They catch you feeling sorry or fearful that you might collapse. [...] The doctor knows and won't lie. He's not going to say, "Feel sorry for them." [...] That person that has [CHD] will learn that they can do [physical activity] instead of going on until their teenage years [thinking] that they can't do it so why bother. (ACHD6-1)

The participant acknowledged a personal responsibility to inform herself about her CHD, stating that it is up to the individual to ask healthcare professionals about what physical activities they could engage in:

To be informed about your health and all that is your choice. It was my choice as a child to pamper it but as an adult you don't have to pamper. Doctors will tell you, "You can do that and if you get tired stop or if you get that palpitation [stop]." It's your choice as an adult. It's your problem. (ACHD6-2)

Behavioural. When asked about strategies that could be used to help modify her physical activity behaviour, a participant emphasized the need to be rewarded. Note: reinforcement management in this stage consists of rewarding a negative-behaviour participant for participating in a positive behaviour, rather than eliminating negative behaviours. When asked what would encourage the participant to be active, she stated, "Smarties. There has to be an incentive for me. Just going and doing [physical activity] there's nothing that will lure me to it." (ACHD6-1). Thus, the participant needed reinforcements in the form of unhealthy behaviours (e.g., treats) to encourage physical activity participation.

Contemplation Stage

Individuals in the contemplation stage intend to make a positive change to their behaviour within the next six months and tend to weigh the pros and cons of making a behavioural change. In this stage, individuals are not ready to pursue action-oriented programs, so forcing them to engage in such programs is unlikely to be successful in changing their behaviour. The themes and subthemes discussed below were associated with participants in the contemplation stage. The themes associated with contemplative participants were in line with the description of contemplators, as they understood the importance of engaging in physical activity but did not necessarily have a desire to modify their physical activity because of indifference. A summary of the themes and subthemes associated with the contemplation stage is provided in Table 4.

Table 4

Factors influencing physical activity behaviour in the contemplation stage

Themes	Constraints	Facilitators
	Intrapersonal factors	
Meanings		• Maintain health and function
Readiness for change	• Indifference towards modifying behaviour • Physical activity is not prioritized • Easier to take medications	• Feelings of guilt • Desire to pursue unstructured physical activities • Understand importance of being active • Initiative on educating on benefits • Initiate conversations with healthcare professionals
Knowledge	• Lack understanding on benefits • Lack reliable resources • Lack awareness on appropriate activities • Lack awareness on personal abilities	

CHD-specific	• Diagnosis • Cardiac surgery • Feeling better	• Cardiac surgery • Recovery from surgery
Lifestyle	• Imbalanced lifestyle • Lack of time • Lack of structure in daily life	
Limitations	• Physical: Shortness of breath, chest pain, lack of endurance • Psychological: Self-doubt, anxiety	
Perceived benefits	• Not experiencing benefits	• Experiencing benefits • Physical: Increased energy, weight loss, increased strength • Physical benefits translating to other aspects of life • Psychological: Sense of accomplishment, escapism, increased well-being, rejuvenation
Perceived risk	• Fear • High perception of risk	
Interpersonal factors		
Discouragement	• Lack of social support • Overprotective significant others	
Exclusion	• Perceived stigma: Body perceptions	
Professional guidance	• Receiving vague guidance • Receiving vague information	• Receiving specific recommendations
Institutional factors		
Logistics	• Timing of programs • Overcrowding	
Cost	• Cost	• Cost
Adaptability		• Activities within abilities • Perceived safety • Segregated facilities
Community factors		
Convenience	• Convenience • Weather	

Strategies	
Cognitive	• Goal setting: Setting small or short-term goals
Behavioural	• Stimulus control: Scheduling time for physical activity in calendar on short-term or long-term basis. Register for a structured physical activity program. Keeping a journal. Use electronic devices (e.g., Fitbit) • Helping relationships: Have a workout buddy to motivate participation to provide a sense of support, comfort and safety. Healthcare professionals having an active role in encouraging physical activity participation since they are a reliable source of information • Reinforcement management: Receiving unhealthy rewards

Meanings

The only meaning of physical activity identified in this stage was maintaining health and function, specifically with regard to achieving cardiovascular health. A participant emphasized how cardiovascular health was more important to him than enhancing his self-image. Yet, he also indicated that cardiovascular health was not enough to motivate him to modify his physical activity behaviour:

It's not about being in shape because there are some people that want to look great and that's their thing. That's what motivates them, looking at themselves in the mirror and going, "You look great." That's not something I can achieve ever to a certain degree so that doesn't motivate me. It's just cardiovascular health [that] motivates me. But it's not pushing me enough to get out there and do it as often as I should. (ACHD10-1)

The participant added that his current lifestyle and behaviours did not always promote cardiovascular health. He believed that engaging in occasional physical activity counteracted the effects of his lifestyle:

I know that I'm doing something cardiovascular related [when I'm active] so that helps me say, "This is good for my heart." and I'm not always good to my heart.

I've got to do this, "Look at me, I'm making it better." [I have] those, "I'm drinking green tea so I'm healthy." kind of moments. (ACHD10-1)

Similar sentiments were expressed by another participant who did not prioritize physical activity but understood its importance in maintaining health and function. This participant indicated that engaging in physical activity helped her maintain her independence and decrease her risk of falls. She recognized, as an elderly individual, that she needed to be active to maintain her muscle mass and ability to walk. She said she did not want to spend the end of her life confined to a chair or relying on assistive walking devices, adding that seeing her father be sedentary for several years before passing away helped her recognize the importance of being active:

It's not a high priority but I realize that it's necessary and as I'm aging it's good to keep [the] body moving. [...] I just learned that from watching my father sit for five years in a lazy boy. [...] My father died [and] he sat in a chair for the last five years and he wasn't motivated to do anything. He lost muscle mass. He was having difficulty walking. As we age, we need it to keep our strength up to not have to use walkers and canes and falling. So, I realize the importance of that. (ACHD17-1)

Another participant expressed similar thoughts on physical activity benefitting them at the end of their life by preventing age-related symptoms, or ailments. The participant described how physical activity promoted longevity and extending one's life expectancy and mentioned that if life expectancy was not increased, physical activity helped with managing pain and overcoming ailments during old age:

It will probably extend your life. If not extend your life longevity wise, maybe to the day that you die there's less pain. You might endure things better. I think an active person might live not a longer life but a healthier life than a person who is

sedentary. Like now I have a bad back and they can just avoid more ailments.

(ACHD10-1)

Readiness for Change

A defining characteristic of contemplators is weighing the pros and cons of making a behavioural change. In line with this characteristic, participants explained that they often thought of modifying their physical activity behaviour but failed to follow through with it due to indifference. However, participants in this stage distinguished themselves from pre-contemplators in that they experienced feelings of guilt when putting off physical activity engagement, even though guilt was not enough to provoke change:

[Physical activity is] always churning in the back of my mind. Does it mean I'm actually going to do it? I can't say. I can say that, "I should do that." and then I might even feel guilty for not doing it. Those two things are not motivating me enough to do it. There is a constant, "You should go out and do it." I do go out and get my walk in so for me the guilt is not enough, or the guilt needs to be more serious like, "If you don't do it, it's bad." or "If you do it the benefits are just so great." like that's going to do it. Those things will motivate me. I mean there should be like a little reward.

(ACHD10-1)

When discussing physical activity participation, several participants indicated that their physical activity consisted mainly of unstructured physical activities, such as neighbourhood walks. A participant explained that he went for neighbourhood walks with his mother and on his own as well, "Every week I go for a walk with my mother [and] with the dog. I try to at least get out once or twice on top of that around the neighbourhood and I do three or four miles." (ACHD10-1).

Another participant described her desire to pursue unstructured outdoor physical activities rather than structured physical activities. For instance, participants indicated an interest in activities like paddle boarding, canoeing, snowshoeing and biking, activities that required little preparation or commitment and could be done as one pleased:

I like to do activities that are a little bit more like doing something. Like when [I] went paddle boarding or canoeing and stuff on the lake. I'm more intrigued by activities where I'm doing something and not necessarily being a sport. [I] go snowshoeing a bit [too]. (ACHD11-1)

Other participants explained that they preferred outdoor physical activities to functional activities such as weight training. This was confirmed by a participant who stated, "Not weights. I wouldn't be interested in anything like that." (ACHD23-1). Another participant elaborated on the distinction between pursuing outdoor activities and exercise, or programs bound by rules and contexts of an institution, such as spinning classes:

Biking is a very pleasurable and nice thing to do. Snowshoeing is just fun and interesting. Getting on a spin class machine in the [gym] in the middle of [someone] who's reading a book is not that exciting. It's only so fun. [...] You just look at a bunch of miserable people doing the same thing and that doesn't reward you. (ACHD10-1)

Similar to those in pre-contemplation, participants in this stage felt as though they were not active enough. A participant stated that despite going for neighbourhood walks three to four times per week, she felt that she was not as active as she should be since that constituted all her physical activity participation. She stated that she went "walking and probably not as much as I should be doing for sure and that's it. [...] [I go] three or four times a week for about 20 minutes."

(ACHD23-1). However, some participants included walking for work in their total amount of weekly physical activity participation, which also bears similarities with pre-contemplative participants. A participant appeared to have a misconception on what to include as physical activity behaviour when asked what she did in terms of physical activity. The participant did not seem to think that physical activity in the workplace counted toward her total physical activity, “If I count work [I walk] three to four times. I’ll go for walks to the marina but that’s like once a week or every two weeks. It’s not very active.” (ACHD22-1).

Another defining characteristic of contemplators is that they understand the benefits of making a behavioural change. This sentiment was expressed by participants who understood that it was important to be physically active despite not actively looking to modify their level of physical activity. A participant explained that she perceived physical activity as important and something that she was interested in, which suggested that she was not against modifying her physical activity behaviour:

[Physical activity] sounds like it’s not important. When I think about it, I know it is, definitely. I don’t ever think being active isn’t important and not something I’m interested in. I think it’s just more something I don’t actively pursue. (ACHD11-1)

An elderly participant expressed similar sentiments: she understood the importance of physical activity but was hesitant to modify her physical activity behaviour in the near future, “At this stage of my life it’s not that important but I know it should be let’s put it that way.” (ACHD23-1). Another participant added, “I know it’s important. I just don’t want to do it.” (ACHD10-1). Building on this theme, another participant explained that physical activity was not a priority compared to other aspects of her life. She mentioned how she could find time during the day to increase her physical activity, but other aspects of her life, such as work and school, took

precedence over physical activity. She indicated that physical activity “is not a priority. I’m putting my work and my school before that. I could possibly find 30 minutes, but I’d usually just rather take a nap because I’m tired from waking up and standing at work.” (ACHD22-1).

Participants in this stage also spoke about initiating conversations with healthcare professionals to increase their knowledge of the benefits of physical activity. A participant mentioned, “I don’t know if I was more active would my heart actually be stronger? I don’t know. Maybe these are conversations I should be having with the cardiologist.” (ACHD11-1). Another participant initiated conversations with healthcare professionals to receive feedback on his level of activity and if he had to modify his physical activity regimen. He added that hearing a healthcare professional explain how the benefits of physical activity outweighed the harm of being sedentary could influence his desire to modify his physical activity regimen:

I understand [physical activity is] beneficial but to what degree is it beneficial? I don’t know. I assume that there is a value to it and I’m sure at some point a cardiologist might be like, “You’re at the point where you don’t do cardio, you’re now in sedentary stage.” [The cardiologist] did say, “Where you are currently, in fact, the benefits outweigh the costs.” [...] So that helps. (ACHD10-1)

Intrapersonal

Perceived Benefits and Knowledge. A participant attributed his indifference to participating in physical activity to not experiencing any benefits of physical activity. He explained that he had not experienced benefits from physical activity and that benefits such as endurance may be experienced only over a prolonged period of time, “Endurance is never something that’s going to be like, “You’re going to get endurance.” In fact, [after] doing it for ten years you actually will not be able to [notice the change].” (ACHD10-1). To overcome his indifference, the

participant reiterated his need to be made aware of the specific benefits of physical activity participation. He also cited a lack of reliable resources for educating himself on the benefits of physical activity as a factor contributing to his lack of understanding of those benefits :

If I go [to a physical activity program] and [I'm asked], "How do you feel?"

"Indifferent." "Do you want to do it again?" "No." It's just a bunch of indifference.

I need that, "If you do this for a year you'll live longer." or "If you were to have a heart attack because this is on point, you'd have a better chance of living." I'll even look that stuff up maybe not specific to heart conditions like what are the benefits of skating. There's always a write up but you never know what you're reading.

You're just reading stuff, same with biking. (ACHD10-1)

While lacking an understanding of and resources on the benefits of physical activity bore similarities with those in pre-contemplation, a distinction could be made when comparing them to contemplative participants. Participants in contemplation had taken an initiative on educating themselves about the benefits of physical activity but remained skeptical of the validity of their resources.

Facilitating factors were identified that led participants to consider modifying their physical activity behaviour or sustaining their current physical activity regimen. Some participants cited benefits from engaging in physical activity, which contrasted other participants' experiences. When asked how she felt when physically active, a participant identified both physical and psychological benefits, "It felt like I was doing something good physically and mentally." (ACHD23-1). More specifically, the participant described physical benefits such as increased energy, as she felt less fatigued during the day. She said that physical activity made her "not [feel] tired. [Having] a little more energy" (ACHD23-1). She also experienced the physical benefit of

weight loss and linked it to increased energy, as well as the psychological benefit of sense of accomplishment. Losing weight made her feel more energized and prouder about her achievement, which implied relationships between the intrapersonal factors of weight loss, increased energy and a sense of accomplishment. She stated, “Keeping weight down and giving you more energy. Feeling good about yourself and not being so tired all the time.” (ACHD23-1).

Participants also described how physical benefits translated to other aspects of life. For instance, a participant described how yoga exercised her shoulder and back muscles, which ultimately reduced the strain in those areas when sitting at her work desk, “One thing that does motivate me to do yoga is working at a desk because it feels so much better on your back and shoulders.” (ACHD11-1). Another participant described how increasing upper body strength through physical activity participation allowed her to perform activities of daily living such as reaching in cupboards, washing windows, gardening, and hanging laundry:

I can still reach things in the cupboards and get up on small step ladders and do some window washing. It lets me do household things. [...] I can still do things like gardening, [...] take the laundry out to the line and hang it up. (ACHD17-1)

Other psychological benefits were also discussed by participants. One explained that although she was hesitant to go to the gym, when she did go, she experienced escapism by losing track of time and enjoyed being there, “Before going to the gym I think, “I don’t really need to do this.” but when I arrive there, I don’t even see the time pass because I enjoy it.” (ACHD22-1). Forgetting daily stresses was also associated with increasing well-being. The participant described how physical activity participation “makes people happier in general. When they’re feeling down and go for a walk, they feel better. You go to the gym and even if you don’t like being there you walk out and feel better in life.” (ACHD22-1). Lastly, another participant spoke about

rejuvenation, mentioning how physical activity was “good for your emotional well-being. When I do go for a walk, I feel rejuvenated.” (ACHD17-1).

Limitations and Readiness for Change. Participants expressed being skeptical about the benefits of physical activity, as they tended to experience physical limitations such as shortness of breath and chest pain when active. A participant explained, “Sometimes I’ll just have to take a deep breath and I can’t take full deep breaths if my sternum is too tight. If I [can’t] do that I don’t enjoy going doing physical activity.” (ACHD22-1). Another participant discussed experiencing shortness of breath and chest pain during physical activity participation and thus, failing to understand how physical activity benefitted her. She explained how she was taking medications that had cardiovascular effects similar to those of physical activity participation, suggesting that it was easier to take medications than to be active:

I’m probably not fully aware. I find it makes me short of breath and gives me angina so it’s hard to see that as helping. I know it’s good to get your heart rate up but I’m on metoprolol which keeps my heart rate at a certain level and it’s probably as effective [as physical activity]. (ACHD17-1)

Participants experienced a lack of endurance as another physical limitation, specifically during childhood and adolescence when they were unable to keep up with others while playing team sports. Having less endurance to keep up with others eventually deterred one participant from engaging in team sports today:

I [started] playing basketball and really took notice that I wasn’t able to keep up as much with others. Then in high school I didn’t play at all and I think it was because I was noticing more and more. That was kind of the point where if you were really good you were on the [competitive] team and I knew I could never keep up and get

to that point. So, I think that's partly why I stopped [playing]. I think still today I don't like doing physical activities [like] a team sport. (ACHD11-1)

The participant recounted neglecting group physical activities that required a higher level of endurance in the present day, explaining that she felt embarrassed at not being able to keep up with others. Thus, a relationship was identified between lack of endurance and perceived stigma:

If our friends ask to go for bike rides, I'll say, "No." and I won't go just because I know I can't keep up and it's somewhat embarrassing [...]. It just kind of became a deterrent after a while for me to do a group activity. (ACHD11-1)

Knowledge and Limitations. Another subtheme that emerged was lacking knowledge of appropriate physical activities suited to participants' abilities. A participant spoke about receiving little guidance from trainers on appropriate physical activities she could engage in other than walking at the gym. The participant tried various exercise stations such as weight training and stationary cycling to test her abilities, as she felt she could take part and experiment with those activities. However, she was uncertain if they were appropriate for her and remained unsure of what activities she could try:

[I do nothing] beyond walking [...] I'm assuming that I can do some weights, but I don't know. I did the stationary bicycle so I know I can do that. But [the trainers] didn't encourage me to use some of the other equipment that they had there. I don't really know what I can do and what I can't do. (ACHD17-1)

Similarly, another participant was uncertain if engaging in biking, household tasks such as carrying heavy grocery products, or going up stairs were appropriate for him. He stated that lacking knowledge of appropriate physical activities and failing to experiment with different activities had left him unaware of his personal abilities. The participant expressed, "It's just more limitations on

my own ability that make me feel like I couldn't do something. [I ask myself], "Is that bad for me? Should I be carrying 50 pounds of cat litter up the stairs?" (ACHD10-1).

In line with the lacking awareness of personal abilities, the same participant doubted what he could engage in for physical activity and questioned his personal abilities, "Something in my head will twist and turn. [It's] that cognitive thought [of], "Is this good?" [...] It's not specific to an activity [but if] I'm going biking [for example], "Maybe I shouldn't bike." (ACHD10-1). Thus, the participant appeared to experience the psychological limitation of self-doubt from doubting his personal abilities. Self-doubt can be triggered when a participant cannot distinguish symptoms associated with participation in strenuous physical activities and symptoms associated with CHD. Consequently, the participant may become anxious and refrain from participating in physical activity. This theme was related to the participant lacking awareness of his personal abilities and therefore doubting his abilities when experimenting with physical activities:

[I ask myself], "Should I run up the stairs, I'm a little out of breath?" I ask myself, "Am I out of breath because my heart or is it [because] I just ran up three flights of stairs and anybody would be out of breath?" It's more or less second guessing. A good way to describe it is, "Is it just normal?" I have no way of gaging, "Well most people are out of breath." or is that something inward reflecting or is that more my heart struggling and then it's hard. I don't have a gage. [I ask myself], "Is this going to be the right thing to do?" (ACHD10-1)

Perceived Risk and Limitations. In addition to the previous interrelated themes, a participant spoke about her fear of being physically active. Fear was closely associated with the psychological limitation of self-doubt in addition to the anxieties triggered by thoughts of being endangered if pushing beyond one's abilities. A participant stated that her lifestyle changed

significantly after being diagnosed with Marfan syndrome later in life. She was active on a regular basis and enjoyed engaging in physical activity prior to her diagnosis. However, after being diagnosed she no longer pursued the same physical activity regimen, as she became fearful of endangering herself and did not know if the activities she had previously engaged in were appropriate for her now:

I wasn't diagnosed until I was in my mid-forties. [...] I was scared. I didn't know what I could do or what I couldn't do as far as physical activity. Before I used to be at the gym all the time [...] But I was faced with this big thing and I thought, "Oh my god." [I don't know what to do anymore]. (ACHD23-1)

The participant added that it was difficult to consider recommendations from healthcare professionals regarding physical activity. The impact of being diagnosed and the severity of her cardiac surgeries made her fearful to participate in physical activity. She also recognized that neglecting resources detailing her diagnosis and appropriate activities for her was partly her responsibility. She therefore remained in a state of fear when engaging in most forms of physical activity:

Doctors would say, "You just have to take it easy. You could do light exercise like walking but don't let your blood pressure [go up] because the Marfan with the connective tissues it has a lot to do with your blood pressure." I was never certain [and] always scared to do anything. [...] I wish I had been educated more on that [but] partly I'm to blame for that because I should've looked at more places for what I could be doing and not be doing. I had two really serious surgeries and I was scared to death of what to do after. (ACHD23-1)

The same participant also felt that physical activity participation was associated with a high perception of risk. The severity of the perceived risks associated with physical activity determined her level of physical activity, as she believed death could be an outcome if she exerted herself:

I don't want my aneurysm to blow on me. I don't want to start my dissection up again. [...] I don't want that. I'm not ready to die yet. Let's just put it that way. I'm having a great life but I'm not ready to check out yet. (ACHD23-1)

The participant also described how anxieties were triggered when she experienced symptoms such as pain and discomfort when active. The symptoms served as a reminder of the time she first had to seek emergency medical intervention and cardiac surgery. She was unable to make a distinction between symptoms related to CHD and those associated with exertion in physical activity:

I get pain in my back and around my shoulder blade and that reminds me of when I first went into emergency, and I had the dissection. But that pain is not as bad as that. I just think, "Could this be starting something?" Maybe that's psychological too. I don't know it's hard to determine. (ACHD23-1)

CHD-Specific. Important factors in determining physical activity for participants included significant life events such as receiving a diagnosis or requiring cardiac surgery. Despite having occurred in the past, these events have had a lasting impact on their physical activity participation to the present day. Conversely, significant life events may have also occurred recently and forced participants to withdraw from physical activity participation, to the point where they struggled to resume their previous physical activity regimen. For instance, a participant said she lived as a healthy adult and enjoyed taking part in physical activity on a regular basis in the past. However, she was diagnosed with CHD later in life, which impacted her physical activity behaviour.

Activities the participant once participated in, such as cardiovascular exercises, walking and biking, were no longer considered appropriate for her after she was diagnosed with CHD. As a result, she fell into a state of contemplation as she was uncertain if she should engage in physical activity with CHD:

Up until the time I was diagnosed, every day I was at the gym doing mostly cardio like an hour a day and riding my bike. I walked everywhere. Now I can walk but not [a lot] and I think that's from being nervous. [I] then [started] to be inactive because once you stop working out and stuff it doesn't take long for you to go down that slope. (ACHD23-1)

Similarly, another participant related that she was unable to maintain participation in basketball during her childhood because she required cardiac surgery, explaining that she withdrew from her team prior to her surgery and did not return after recovering from the operation. Thus, surgery marked the point where she dropped out of team sports, and she has never taken part in team sports since: "I was playing basketball at that point like there was a stopping point of, "I can't play for a while." I had my surgery and then I didn't play basketball [again]." (ACHD11-1).

Another participant also made distinctions between her physical activity behaviour pre- and post-surgery. Pre-surgery, she experienced shortness of breath when going up stairs and stated that she avoided physical activity participation as a result. She described how she gained weight, felt lethargic, slept more during the day and no longer performed household tasks. As she recovered from surgery, her capacity for exertion increased. Thus, her experience with cardiac surgery contrasts with participants who withdrew from physical activity post-surgery:

Pre-surgery I was short of breath if I did things. I had to stop in the stairs to go upstairs and post-surgery all of that improved. I'd say I had weight gain before the

first surgery. I wasn't in good shape before, particularly my first surgery. But I was much improved after they rerouted things and did some bypass [...] I put on weight because I was sitting a lot. My husband was doing a lot of stuff in the house and I was lying on the couch napping in the afternoon [before the first surgery]. [After the second surgery] it was much improved after about six months. (ACHD17-1)

Although recovering from surgery increased the participant's capacity to exert herself when physically active, it did not necessarily have an impact on her physical activity behaviour. Rather, recovery allowed her to partake in the physical activity she already engaged in. She explained that she resumed her pre-surgery level of physical activity and as she continued to feel better, she no longer felt the need to participate in physical activity, "I just got feeling fairly good again [and] I thought I didn't need [physical activity] I guess. I [said], "I'm OK, hearts working, I'm still here so do I need to include [more physical activity] in my routine?" (ACHD17-1). The participant added that there had been no signs of the deterioration mentioned by healthcare professionals during follow-up appointments, which also fed into her perception of not needing to modify her physical activity behaviour, "I seem to get along and cope with my current regimen. I went back this year and everything's still stable. No big changes in the echocardiogram. So, I figure I'm doing OK with what I'm doing." (ACHD17-1).

The last CHD-specific factor identified was transportation. For instance, a participant mentioned losing her license because of CHD-related issues. The challenges of commuting to recreational facilities to go swimming therefore became a deterrent, "I've lost my license to drive so I can't get to places like the [recreational centre]. I would've gone swimming there. [...] It's not like I was drinking and driving it's not like that. It's for health." (ACHD23-1).

Lifestyle. A participant cited the challenges she faced when entering university while maintaining a job and her struggles with an imbalanced lifestyle. She found it difficult to take on physical activity in her daily routine. When asked what influenced her physical activity behaviour, she mentioned, “It’s just harder to balance first year university. I find it more stressful and then working. I’m just having trouble balancing everything.” (ACHD22-1). The participant also mentioned that the need to dedicate most of her time to studying and work prevented her from engaging in physical activities she would have considered pursuing, “I always wanted to re-get into soccer because I do miss it. [But] I’m not able to do so with work and school.” (ACHD22-1).

A closely related theme to imbalanced lifestyle was lack of time. Participants acknowledged that lacking time was an excuse, and that physical activity was simply not a priority over other aspects of their life. A participant suggested that she was fatigued after work and would rather take the time to rest over participating in physical activity, “I think that’s more of an excuse. I could find time, but I just like my down time after being at school or going to work. I just want to sleep because I’m exhausted.” (ACHD22-1). The participant continued by stating, “I don’t make the time [for physical activity] is more the answer.” (ACHD22-1). Another participant expressed similar thoughts, “Sadly I think it’s making the time for it. Making that a priority outside of work because I have a fairly sedentary job.” (ACHD11-1).

Similar to lacking time, participants also spoke about their lack of structure in daily life, i.e. not having a schedule for regular daily activities or events. A participant mentioned that not having a daily routine left her unable to make time for additional activities like physical activity, “Everybody needs structure and if I don’t have structure there’s sometimes when it’s eleven or twelve [o’clock] and I’m not dressed.” (ACHD23-1).

Interpersonal

Professional Guidance. The most commonly mentioned interpersonal factors influencing physical activity behaviour in this stage involved conversations with healthcare professionals. One subtheme identified within this area was receiving vague information from healthcare professionals on the participants' health status and physical activity participation. A participant described how conversations with his cardiologist tended to be brief and not informative, as the latter did not provide information as to whether his average health status was attributed to his current lifestyle:

[...] You hear from the cardiologist once a year, "You're doing well, average." which is great. You want to hear, "I'm average or maybe you're a little bit above average." but that has nothing to do with your physical activity level. It's just, "Your heart sounds like you're doing OK. Good job." That could be due to being quite sedentary. (ACHD10-1)

Participants spoke about receiving vague guidance from healthcare professionals when it came to encouraging physical activity participation. A participant described being told by her cardiologist to avoid using certain exercise machines that strained her chest at the gym, but was uncertain as to why those machines should be avoided. She therefore speculated that there might be a risk associated with those machines for CHD patients such as stressing the heart or damaging the surgical repair site. But she was never formally told by her cardiologist that those were risks:

I remember my cardiologist saying [not] to do heavy weights, not to do anything chest [related] like a machine that [uses] butterfly motion in and push ups. [...] I guess a risk that I took from that was that doing heavy lifting or upper body activity was obviously affecting my chest and my heart negatively. That's what I took away

from that so I guess I would say that's kind of a risk of over stressing my heart [and] maybe it was just more to do with the healing process of having surgery. I don't know. (ACHD11-1)

Another participant made comparisons between youth and adult CHD clinics when it came to healthcare professionals encouraging physical activity participation, stating that those at the adult clinic made more of a point of promoting physical activity but did not elaborate nor provide guidance on how to actually pursue it:

It's my first year at the [adult clinic]. [...] They don't really talk to you. They just do their thing and leave. [...] It was only my second time here [and] it was more, "Stay active." That's all it was, "Stay active and eat well." It was just that they didn't really expand or elaborate on anything. (ACHD22-1)

However, it was acknowledged by some participants that they should have taken responsibility for initiating conversations on physical activity with healthcare professionals. A participant mentioned how she hoped to have an average report on her health status at annual appointments and avoided any further conversation on factors influencing her health such as physical activity:

I'm not making an effort. So much time has passed, and I don't know what they would have at the [hospital] now that would be available for me. I don't go on the website all the time and half the time if I can get out of there with an OK report then I'm not turning around and looking back. I'm just getting out of there and waiting until next time I have to go. Out of sight out of mind. (ACHD23-1)

In contrast, some participants claimed they received specific recommendations on what physical activities to pursue based on their health status. A participant mentioned how her

cardiologist told her to go for short walks to avoid overexertion since she had artery issues, “My cardiologist does encourage me to exercise and to walk but you see I have blockages again. I don’t think he wants me to push too hard and that’s why he says, “Do short walks.” (ACHD17-1).

Discouragement. Participants in this stage also described lacking encouragement from others (e.g., friends) when it came to physical activity participation. For example, a participant stated that having a friend to be active with would have motivated her to be active by making her accountable:

I’m not a leader. I’m more of a follower. If there had been someone [like a friend] that had been pushing me [saying], “OK you got to come in and you got to do this, you got to do that.” it may have been different. (ACHD23-1)

Another participant explained that she enjoyed walking with a neighbour until she was no longer able to keep up with them and maintain the same speed, “I quite enjoy walking. My neighbour used to walk with me, but I go too slow for her. [...] She’s willing to slow down but she finds that very difficult. So, I don’t make her come with me.” (ACHD17-1).

Overprotective significant others also emerged as a constraining factor to physical activity participation. A participant described how her husband was fearful that she would be putting her health at risk and told her to be cautious when active. When asked how significant others influenced physical activity participation for her, she mentioned, “My husband came with me. [...] He’d start telling me, “Well you shouldn’t, you should be careful doing this or that or you’re supposed to watch.” (ACHD17-1).

Exclusion. Similar to participants in the pre-contemplation stage, those in the contemplation stage experienced perceived stigma, triggered mainly by body perceptions, specifically for female participants. For instance, a participant thought about joining an aqua

fitness program but suggested that she would be self-conscious about wearing a bathing suit, “I’ve often thought about doing [aqua fitness]. I thought about that, but I don’t like putting on a bathing suit.” (ACHD17-1). Another participant expressed similar thoughts on her interest in swimming, “I was on the fence because I didn’t want to get in there with a bathing suit on.” (ACHD23-1).

Institutional

Logistics. One common institutional factor experienced by contemplative participants was the time at which physical activity programs were offered. Timing of programs was a factor for participants when considering joining structured physical activity programs offered by recreational facilities. A participant described how she enjoyed skiing; however, ski lessons were offered early in the morning, which was a deterrent for her, “I liked skiing. I skied for a bit [...]. It was earlier mornings and I’m not an early morning person.” (ACHD22-1). Another participant described how a walking program she had once engaged in conflicted with daily living activities such as supper and having to feed her children. As a result, she withdrew from the program after six months:

The time wasn’t very good. It was at supper time. It was six o’clock or something.

It was around dinner time, and I probably did it for about six months but then my kids were still at home and stuff, and it was a pain to mess up dinner and everything.

(ACHD17-1)

Participants expressed dissatisfaction and disinterest in frequenting public gyms to exercise because they were often overcrowded. A participant described overcrowding and time spent waiting for exercise machines in public gyms as deterrents, “I don’t like big crowds and there’s just too many people I find. I feel like if you want a machine, you actually have to wait beside because there’s so many people and it looks packed all the time” (ACHD22-1).

Another institutional factor facilitating physical activity participation was segregated facilities. A participant said she occasionally enjoyed attending a gym because it had a female-only exercise section, “There’s [a] gym [near my house] [and] there’s a girl side only so that’s interesting.” (ACHD22-1).

Cost. Similar to the pre-contemplation stage, the cost of physical activity programs was identified as a constraining factor. A participant mentioned occasionally going to yoga classes because of how much money she spent to register for them but would have also been more motivated to go if yoga classes were cheaper. She stated that the program classes provided her with structure and a designated time to be physically active:

I think the structure and spending a tonne of money on yoga classes, which I also don’t go to. I would be motivated to go to a place that costs me 25 [dollars]. I think even when you do [yoga] you feel good afterwards and that bit of euphoria tends to stimulate you to go the next time. I feel in better shape and less weak. That tends to motivate me but it’s breaking through that barrier of “I’ll be fine anyway.” (ACHD10-1)

Adaptability. Participants expressed enjoyment of physical activity programs within their personal abilities. A participant said she enjoyed physical activity programs such as yoga, where she could go at her own pace and avoid overexerting herself:

I don’t have to keep up with anyone. I can completely go at my own pace and part of yoga too is focused on your breathing. I like that aspect of it. I’ve never ran out of energy doing yoga I’ve never felt like I’m behind everyone [and] moving in the wrong direction where I’m told to move in class. (ACHD11-1)

Perceptions of safety also facilitated participation in physical activity programs. This theme mostly related to the knowledge and trustworthiness of facility staff, or program facilitators. A participant who was fearful when engaging in physical activity due to the severity of her CHD said she relied heavily on the guidance of program staff. The participant described how programs she would engage in must be “safe because [the staff] know what I should be doing and what I can’t be doing. I would feel comfortable” (ACHD23-1).

Community

Convenience. Convenience emerged as a community-related factor for participants in this stage. Convenience, in this stage, refers to the amount of preparation required before participating in physical activity. A participant said he preferred to engage in walking as it was something that could be done when he desired and required no travel time, “I prefer to go for a walk because it’s like, “When are you going for a walk? Now. I can go and do the walk for 45 minutes and then I’m done. [...] It’s a convenience factor.” (ACHD10-1). He added that preparation and travel time greatly affected his desire to pursue physical activity:

If I want to do something I don’t want to spend 20 minutes prepping to go do the [gym] because in my head all of a sudden I’m measuring time and it’s going to take me 20 minutes to get there, and then I get there and that’s ten minutes, and then I do the workout for 45 minutes, and then it’s another 30 minutes back and it’s like two hours and I’ve already basically did the math and the math in my head said, “Inconvenient. Don’t do it.” (ACHD10-1)

Weather. Another community-related factor identified for those in this stage was weather. A participant described the challenges of walking during winter due to poor outdoor conditions, but added that walking was facilitated by good weather in other seasons. When asked what

motivated physical activity participation, the participant responded, “Nice weather for walking. [I’m] dreading the winter when it’s not so great to be outside.” (ACHD11-1).

Strategies

Cognitive. The only cognitive strategy identified in this stage was goal setting, which refers to participants establishing small or short-term goals to promote physical activity participation. A participant mentioned she should set smaller goals when exercising rather than engage in prolonged exercise sessions at the gym, “Maybe [I] can just set shorter goals. I go for an hour and that’s an OK workout. It’s not two to three hours.” (ACHD11-1). Another participant stated that he should set a primary goal of being active on a consistent basis before establishing further physical activity-related goals, “Goal one should be to go [to the gym] consistently. Goal two should be the next thing.” (ACHD10-1).

Behavioural. Participants in the contemplation stage proposed mainly behavioural strategies to modify their physical activity behaviour. Among the most commonly discussed behavioural strategies by participants was stimulus control. Participants speculated that scheduling time for physical activity in their calendar could prompt participation and help them establish a routine by including physical activity in their daily routine. A participant stated, “For me it’s scheduling. I try and do these walks more often [but] there’s no real routine for me. I’d need something like, “This is when you go for a walk.”” (ACHD10-1). Another participant stated that using a calendar could create a sense of accountability in that she would have to be active because it was scheduled in her calendar, “I realize I don’t have any other time during the week and say, “OK you have to go right now or you’re not going.”” (ACHD22-1). Another participant writes activities in her calendar several weeks in advance to designate times for physical activity participation on a regular basis:

I have to set a time to do it. I keep a calendar now of everything that I do ahead in the weeks. [...] I find that helps. If I said, “OK I’m going to designate next Monday morning to look into some sort of exercise or aqua fitness or walking program.” That would make me do it because I have to tick it off the calendar.

(ACHD17-1)

The participant explained that engaging in a structured physical activity program would be beneficial as well, as she would have a pre-determined schedule to follow. She stated that establishing a routine of being active would be easier since the time dedicated to being active would be scheduled for her based on the programs schedule:

[...] That’s why signing up for a program they say, “You have to be here Monday, Wednesday, Friday from ten to eleven.” then the scheduling of it or the routine of it [is done]. It becomes a habit. Now [for] other things I think, “Maybe I’ll go for a walk every morning from 8:30 until 9.” but then something else [happens]. You get distracted. So, if it’s an outside thing and if you have to pay for it that would make you go. At least it would me. (ACHD17-1)

Another participant proposed entering in a journal the amount of physical activity she engaged in, as this would allow her determine when physical activity behaviour took place and schedule time for physical activity accordingly:

For me personally [keeping a] journal, and if you do miss a certain amount of days [you] got to push yourself to get past that little breaking point because you get deterred by that, by seeing a nice chart and then you see a big lag in that and then you think, “It’s not as nice.” (ACHD11-1)

The participant also cited the importance of using electronic devices in addition to journals to determine when physical activity would take place during the day:

I think too having a Fitbit or something like that [would be good]. [...] I know our friend has one and she can track of steps and stuff she did a day. It's like similar to a journal where you have a visual of what you've done in a day. (ACHD11-1).

Another participant indicated that some of the features that come with electronic devices could be a deterrent to engaging in physical activity. He mentioned becoming fearful when he saw his heart rate increase on electronic devices when active:

I would like [a device to show how active I am]. I just don't want it to have my heart rate. I wish I could just turn that part off and be like, "You did your 10000 steps, but your heart was doing 180 and you were fine." I would be fine, but when I see it, I'm like, "It freaks me out." (ACHD10-1)

Helping relationships was identified as a strategy that could encourage physical activity participation in this stage. Participants indicated that having someone to exercise or join a physical activity program with, such as friends or family members, would motivate them to be active. A participant explained that having someone encourage them to be active could reduce procrastination and make them feel obligated to be active:

I looked into getting a pool membership because my friend has one. She goes in the morning and I thought I could start going with her [...] I'd have someone there with me that motivates me to actually go. If I don't want to go and I have no one to push me. I'll just be like, "I'll go tomorrow." but I won't actually go. Whereas if someone is counting on me, I'm more likely to go. (ACHD22-1)

Another participant described how being active with significant others made her feel comfortable and safe when active. She stated that when she was with a significant other, there was no need to explain why she was fatigued or unable to keep up. Thus, she felt less pressured to push herself beyond her comfort zone:

[With my husband] I obviously have that relationship that I don't have with other people with the comfort level. As I say to him, "I'm out of breath." that's the end of the conversation. There's no explaining more as if I was with a friend. He just gets it and I'm also really comfortable to say that to him, "I need to stop." [If] I was doing that with a friend I would feel pressured to keep up. (ACHD11-1)

Another participant expressed similar thoughts about being active with his spouse. He expressed a preference for the care and support he received from his spouse when fatigued to situations where his friends might feel guilty when he struggled to keep up:

If I'm exercising with [my wife] I feel comfortable. [...] You might struggle but there's a compassion there that's bred in [where] other people it's not that they wouldn't have compassion, but you don't want to explain it to anybody. [...] You don't want to guilt someone, and you don't want to not be able to keep up. (ACHD10-1)

Participants claimed they would have benefitted from healthcare professionals encouraging them to be physically active despite their CHD. They said this encouragement from a trusting source would have likely pushed them to be active. A participant stated, "If you have a little bit of push from the specialists [or] cardiologists that say, "Yes you do have this, but you can exercise a little more and I think that it's important." [It would push you to be active]." (ACHD24-2).

Another participant emphasized the importance of trusting physical activity program staff when encouraged to be active. He cited the need to receive reliable feedback that detailed his improvements:

I need someone to say, “This is good, you’re doing good.” and someone who knows what they’re talking about. You can’t just have a life coach or whoever helps you when you’re working out. They have no experience they just [say], “Lift more, jump, good job you did all the things I told you.” [...] Having someone who [is knowledgeable] like, “There’s actual improvement.” for me is always a benefit.

(ACHD10-1)

Like those in the pre-contemplation stage, participants cited reinforcement management as a strategy that could promote physical activity participation. Participants stated that rewards in the form of unhealthy behaviours such as candies or alcohol could promote physical activity participation. When asked what would have facilitated participation in physical activity, a participant said, “I don’t know what would give me the push, a bag of candies at the end.” (ACHD23-1). A participant who enjoyed occasional alcohol consumption stated that if he wanted to keep doing so, he needed to engage in a certain amount of physical activity to counteract alcohol’s effects on his health:

I do things that are not healthy like drink six or seven beers. I know that it’s bad, but I’ll do it. So, it’s like, “If you want to keep drinking six or seven beers you should go to skating twice a week, put some effort into it.” It’s the truth just being honest.

(ACHD10-1)

Preparation Stage

Individuals in the preparation stage have taken steps and have spent time developing action plans to change their behaviour within a month's time. They have perhaps registered for a class, spoken with healthcare professionals or purchased resources. They experiment with the behaviour they want to adopt by trying different versions of it. Through trial and error with different forms of the behaviour, individuals can develop an action plan to further pursue the behaviour. The themes and subthemes discussed below were associated with participants in the preparation stage. The themes associated with prepared participants were in line with the description for those in the preparation stage, as most participants' physical activity participation was characterized by experimenting with various forms of physical activity. A summary of the themes and subthemes uncovered through discussions with participants in the preparation stage is provided in Table 5.

Table 5

Factors influencing physical activity behaviour in the preparation stage

Themes	Constraints	Facilitators
	Intrapersonal factors	
Meanings		• Achieve well-being • Taking rational position • Maintain health and function • Having explicit life goals
Readiness for change	• Perceive physical activity as work	• Experiment with various activities • Desire to pursue structured programs • Self-awareness • Trying something new
Knowledge		• Better conceptualization of physical activity
CHD-specific	• Cardiac surgery • Feeling better	• Significant life events perceived as singular • Feeling better • Severe diagnosis

Lifestyle	• Lack of time • Imbalanced lifestyle	
Limitations	• Physical: Fatigue, lack of endurance, shortness of breath, lack of competence	
Perceived benefits	• Not experiencing benefits	• Body image • Physical: Increased endurance, weight loss, increased energy, enhanced sleep quality, better posture, increased heart health, increased flexibility • Psychological: Decreased stress, escapism, enhanced mood, increased well-being, increased confidence
Perceived risk	• Fear • High perception of risk	• Low perception of risk
Experience	• Lack exposure during childhood • Mismatch between experience and expectations	• Previous enjoyment • Exertion as secondary component
Interpersonal factors		
Discouragement	• Encouraged to be inactive during childhood by healthcare professionals • Overprotective parents	
Exclusion/Inclusion	• Nothing in common with others • Perceived stigma: Body perceptions	• Common interests with others • Coming out of isolation • Perceived stigma: Body perceptions • Being active with others • Sense of belonging, developing relationships
Professional guidance	• Healthcare professionals more likely to prescribe medication	• Seeking validation • Receiving recommendations
Institutional factors		

Logistics	• Short-term commitment programs	• Short-term commitment programs
Cost		• Cost
Adaptability	• Staff not adapting to needs • Activities not within abilities	• Activities within abilities • Staff adapting to needs
Community factors		
Convenience	• Convenience	• Convenience
Weather	• Weather	• Weather
Strategies		
Cognitive	• Consciousness raising: Experimenting to determine abilities, Raising awareness on cardiac friendly programs thanks to hospital staff and recreation facilities. Using resources to determine personal abilities and learn what programs are available • Goal setting: Setting goals that can be achieved	
Behavioural	• Stimulus control: Register for a structured physical activity program. Use electronic devices (e.g., Fitbit) and calendars. Modifying current daily regimen • Helping relationships: Have a workout buddy to motivate participation • Substitution: Substituting a physical activity behaviour for another similar behaviour • Counterconditioning: Maximizing physical activity participation by modifying daily living tasks (e.g., placing home items in places that require navigation, parking further away when shopping • Self-liberation: Sharing experiences with healthcare professionals	

Meanings

Regarding the significance of physical activity, a participant in this stage stated that physical activity allowed her to achieve well-being. She considered that physical activity would mainly enhance the quality of her life as she continued to age, “I perceive it to be a factor that contributes to quality of life as opposed to quantity.” (ACHD12-1).

Participants in this stage reported taking a rational position in that their desire to modify their physical activity behaviour was a result of consciously making the decision to take better care of themselves. For instance, a participant explained that although her children required constant

care, she wanted to care for herself more as she continued to age. She stated that her ability to overcome health issues could be more challenging as she aged compared to when she was younger:

Now that I have kids it's a little [hard]. [It's] just getting older it's [like], "I should really do more [physical activity] as opposed to when you're young and it's like, "There's something wrong with my heart, but it's fine. You're invincible. Whereas now it's like, "Something can actually happen. I should probably take more care of my body." At this stage of my life, it means taking some time to take care of myself instead of everybody else and hopefully staying alive for a lot longer. (ACHD20-1)

Another participant severely affected by her CHD suggested that through physical activity, she could increase her heart health and extend her life expectancy to have the opportunity to continue to spend time with family and friends:

I have pursued all my treatment options and the last option is a double lung and heart transplant. [I] have decided not to go ahead with it. The statistics felt a little much for me. So, [if I] want to have the best heart health, [I need to be active]. [The] better it is, the longer you're going to live. [That's a] motivator for me and the reason I want to be here is for my family and friends. I need to move so that I can be here for them. (ACHD1-1)

Another participant described physical activity as an opportune way to maintain her body function by increasing her physical conditioning, in addition to extending her life expectancy and decreasing her risk of physical ailments in the future:

If you do lots of physical activity you can probably lengthen your life span quite a bit by keeping in shape and keeping the blood flowing and not just kind of sitting

around. I've heard if you get swelling in your legs it's because you didn't move around enough. (ACHD9-1)

With a view to increasing their life expectancy, participants said they wanted to work towards increasing their health to be able to live independently in their old age. A participant mentioned in multiple interviews that he was active because he does not “want to be bedridden or be hospitalized.” (ACHD27-3). He explained that his CHD was not fatal and so he wanted to maintain his independence for as long as possible before his CHD affected his abilities, “You got this but it's not fatal. You don't have to become an invalid before it makes you.” (ACHD27-2). Another participant said she wanted to minimize her reliance on medications and assistance when older:

[I want to] grow old to be a [healthy] old lady. For me it's about longevity. [It's] all about try and live as long as possible and as active [so I am] relatively medication and assistance free. I know I'm never going to be completely normal. But, as long as I can try to control [what I can], as compared to what I can't control, [like] how I want to feel about myself, [I] can learn to stay [healthy]. [It's] taken me that long to realize I should try to work towards being a healthier version of myself. (ACHD25-1)

Participants in this stage also described explicit life goals, such as enjoying retirement, as a factor motivating physical activity participation. A participant mentioned how she sought to modify her physical activity behaviour because she was nearing retirement and did not want to spend her retired years doing nothing. Rather, she wanted to be in good physical condition to be able to walk when travelling and keep up with her significant other:

Now it's more about just realizing it's kind of good for me. [...] I am looking to retire [and] my other half he's probably going to retire in the next 8 months [and me and my partner] want to do some travelling when we retire. If we go to Italy, it's not all flat so I think, "I better keep my fitness so I can walk those hills." I want to be able to keep up. (ACHD12-1)

Readiness for Change

One of the first subthemes discussed by participants in this stage was self-awareness. For instance, one participant sought out physical activity opportunities after being inactive for a long time, "Getting to the first step is usually something that makes me feel like I haven't exercised in months [and] I have to do something. [...] I have to get to the point where I'm like, "This is ridiculous." and then I do something." (ACHD20-1). Another participant wanted to modify her physical activity behaviour because she was feeling depressed and wanted to change her physical appearance, "I was just feeling really overweight and feeling not happy with myself. I knew something needed to change so that's what I did." (ACHD1-2). Another participant described how she had relapsed for a few months and struggled to continue the physical activity regimen she had taken on prior to going on a vacation. However, she eventually realized that she wanted to return to her previous physical activity regimen after being lethargic during her relapse:

I totally fell off the wagon of physical activity that was done. I kept it up for a little while then I kind of fell off the wagon for two months. I was going on another vacation, and I got back and just was completely lazy for two months. [Then I said], "[I] really have to do something." (ACHD14-3).

Participants in the preparation stage often cited their journey towards modifying their physical activity behaviour. Specifically, they described how they had been experimenting with

various physical activities and how their perceptions towards physical activity in general had changed. A participant described the process of actively changing her physical activity behaviour and the initial steps she took to do so:

I was starting to make the changes [...] It's been a roller coaster with certain weeks and months where it was extremely hard to get out. But I was still changing the way I was acting and changing the way I was perceiving physical activity and actually starting to change my whole attitude about it. [...] I'm playing with how much I exercise. I'm kind of toying with what's going to get me the best results right now. I'm still preparing myself. (ACHD25-3)

Another participant described how experimenting with various forms of physical activity and figuring out which one she was most comfortable with could benefit her in various ways:

I think physical activity will make you feel better, whether it's emotional, spiritual, or physical. Any of those realms. I think there are times that you will do physical activity and it will not feel good and it will not feel comfortable and my answer to that is that's probably not the right one then. I don't think that people should push themselves into doing things [where] they go, "Jogging is healthy. It'll make me better." If you're not having fun doing it [and] if it's not comfortable then it's not right and you shouldn't be doing that. You should do something else. I just need to find something that does and there are things out there I just have to pursue them. (ACHD1-1)

Participants in this stage described their desire to pursue structured physical activity programs offered by recreational facilities. A participant planned to register for a yoga program because she believed it offered a variety of psychological and physical benefits, "I feel compelled

to follow up on the yoga program because I've never enjoyed any physical activity. It's always been a chore [until recently]. It really is good for your mind body and soul." (ACHD14-1). She went on to say that if the yoga program was not exactly what she was looking for, she would actively look for different programs to try, "There's some place by my house that offers [yoga programs]. If it's not exactly what I'm looking for I can go [to] city [websites]. I can certainly look for something more private [since] yoga is so popular right." (ACHD14-1).

Another participant recently began Tai Chi and walking on a regular basis but would also like to join a structured program to maintain physical activity participation on a regular basis:

I've been practicing Tai Chi more than anything else and I find it wonderful. Tai Chi and walking are what I do the most, but [I'm] very frustrated because I would like to do more. I would like to be part of a group or to participate in something more structured because it's the only way that I force myself to go and to have the discipline. (ACHD24-1)

Intrapersonal

Knowledge. Participants in this stage appeared to have a better conceptualization of physical activity. A participant mentioned how she did not perceive physical activity as engaging in activities that overexerted her to the point of harm. As she was severely impaired by her CHD, physical activity for her included doing household activities like going up and down stairs, "I don't think physical activity is running necessarily. I don't think you need to be passed out gasping for air to have physical activity. You just need to move. For me going downstairs and doing laundry is moving." (ACHD1-1).

As participants experimented with various forms of physical activity, they developed a dichotomized perception of what constituted physical activity. For instance, one participant

considered physical activity to have two categories, the first consisting of physical activities that were exerting but within her personal abilities, and the second geared toward exercising, developing muscle mass and pushing herself beyond her personal abilities:

Physical activity, I see it as two categories. There's the stuff I do which is the doing physical activity and then there's the showy physical activity where there's a bunch of [people] where they're just like, "Look at this muscle group. I'm going to have such a ripped figure after I do this ridiculous amount of exercise." Whereas for me I just do physical activity [like], "I'm going to do this today. It's not much, but I'm going to feel good after and I'm still moving and I'm still being active." I see that as slightly more attainable than the gym stuff right now. I am still learning how to be healthy. If I can eventually work my way up to the gym activity, then great.

(ACHD25-1)

Other participants cited two different forms of participation when conceptualizing physical activity. A participant viewed physical activities within her abilities, such as bike riding and yoga, as pleasurable, compared to activities like going to the gym, which was less appealing to her:

I think of physical activity like organized, going to the gym Monday, Wednesday, Friday, take Sunday off that kind of thing, or weightlifting [and] doing some for muscles that's effort. That's not my idea of fun. But going for a bike ride is fun, doing yoga is fun. (ACHD14-1)

A participant also cited the importance of engaging in moderately exerting physical activities to stay moving:

For some people, physical activity would mean you have to be doing cardio and for some people, it's going walking. I guess for me at this point in my life it's moving. I

think that there's real benefits whether it's ten minutes or 30 minutes. I think it's just trying to incorporate moving in ways of life. (ACHD12-1)

Experience. Participants explained that previous enjoyment of certain physical activities facilitated their desire to re-engage in similar activities in their search for physical activity opportunities. One participant had joined a women's gym several years ago and recently stumbled upon the same existing program. Since she knew the program was within her abilities, she wanted to re-register for it:

I actually did [go to that gym] previously, probably about seven to ten years ago. I knew then that it was something that I could do so I thought that maybe I should [re-join]. [...] I walked in to [the gym] instead of [a restaurant next door] by accident and I went, "Oh my gosh I can do this I'm going to sign up for this."
(ACHD1-2)

Many participants explained that one of the challenges of modifying their physical activity participation was their lack of exposure to physical activity during childhood and the fact that they had not developed a strong interest in physical activity. A participant attributed her current lack of interest in sports and outdoor physical activities to her not being encouraged to be active during childhood, adding that she perceived physical activity as work rather than pleasurable:

I wasn't encouraged so I don't engage [now]. I'm not good at any sports. [...] I don't like the outdoors. I'm not a skier or anything like that. [...] It's like, "Do you feel like being active? No, I don't feel like it." Physical activity to me is not fun. It's work. (ACHD14-1)

Another participant expressed how rarely engaging in sport or physical activity during her childhood led to her developing an interest in sedentary activities, which is similar to participants

in previous stages. The participant mentioned how engaging in physical activity today (e.g., running) did not get easier with more frequent participation:

I wasn't ever a really sporty kid. [...] I was like well if I can't do it then I'm not going to do it. [...] I became interested in different things. I'd do something for a couple of years than do something else. [...] [Today], I don't know if that the fact that running never gets easy is related to my heart. [I] never did a lot of it as a kid so then I don't really think of it as I can't do this because of my heart. (ACHD20-1)

However, trying something new was identified as a facilitating factor for many participants in this stage. A participant expressed excitement about starting ballet classes for the first time and taking part in something that was out of the ordinary for her, "I just wanted to try something creative. [It] was just a mom thing just feeling like all I do is work, take care of the kids, [and] [...] I was actually excited to start something new." (ACHD20-1). Other participants enjoyed engaging in new physical activities of interest such as golf and yoga, "Golf is new to me and yoga's new to me. These are two things that I never really did before and I'm like, "I actually like this. I'm enjoying it." I'm seeking it out." (ACHD14-1), and "[Yoga is] something to do. I don't know why but that's it. No other real motivation just like, "I haven't done this before it looks interesting. Give it a try"" (ACHD10-3). Another participant looked forward to engaging in martial arts and learning new skills that could translate to other aspects of her life such as improving balance, endurance and self-defence, "It's martial arts. I thought even though it's really slow movement I kind of thought, "Well with this maybe it'll have some self-defence applications and also I guess maybe it would help improve balance and stamina and stability."" (ACHD1-1).

In addition to trying something new, participants were motivated to engage in physical activities where exertion was a secondary component of the activity. This theme can be described

as participants enjoying physical activities where the primary goal is to achieve something other than physical exertion. For example, a participant recounted taking ballet classes to engage in an activity that allowed her to express herself creatively. However, with learning to dance ballet, she found that there was a physical exertion component to the activity as well:

I actually started [ballet] because I was looking for a creative thing more than a physical thing. But it is actually a pretty good workout. [...] It's because they're not things like exercise. When I feel like I should do [exercise] I also feel like I don't want to do that thing. [If it's] fun then I'm getting more out of it. (ACHD20-3)

Another participant cited jogging in the context of camping, explaining that it would be more motivating to jog when making her way to a campsite, "I think that that's a big thing, secondary. I think that's [my] thing like if you tell [me], "Let's go jogging." [I'm] like, "No." but if I said, "[I was] doing [camping] that resulted in jogging a little bit." it would be good." (ACHD10-3).

Another challenge faced by participants in this stage was a mismatch between experience and expectations when engaging in physical activities. Consequently, participants may have had a poor experience and been deterred from engaging in that particular physical activity afterwards. For instance, participants discussed joining a specialized yoga program that they believed emphasized well-being and respiration techniques, but they had misunderstood, or been misinformed, about what types of exercises were performed in that yoga program. The participants therefore had poor experiences and did not return to that type of yoga:

We wrapped ourselves in blankets and then lay there for half an hour while a drum was beat, and I was like, "This isn't yoga. I'm getting zero benefit." [...] [I was] just

in the wrong class. I think it just made [me] think, “This is stupid.” [I] just got frustrated. (ACHD10-2)

I tried hot yoga a couple times I almost died in there. [I] think that already being a heart patient you really put yourself at risk and they don’t explain this to you. It might be printed somewhere on the wall, but there should be something that you sign when you go in saying, “If you have cardiac issue this is not for you.” (ACHD14-1)

CHD-Specific. Participants cited the prospect of cardiac surgery as an obstacle to physical activity participation. One participant did not engage in her Tai Chi program because she was debating about having heart transplant surgery. Thus, participating in Tai Chi was not perceived as a priority at the time. When asked what prevented the participant from engaging in Tai Chi, she said, “I know why [I didn’t go] last time. [...] Because I was trying to decide whether or not I wanted a transplant. [So], Tai Chi was not a high priority on the list” (ACHD1-1). Another participant speculated she would likely be unable to participate in physical activity for some time after having cardiac surgery, “I suppose that it’s going to affect me for a little while. You have to recuperate. I don’t know how long that takes to heal.” (ACHD24-1).

While cardiac surgery may have been perceived as a constraining factor to physical activity participation, participants perceived significant life events as singular. One said that she did not fear or worry about being active after her surgery because she believed she was completely healed of CHD:

I knew that once I was healed, I was good. I didn’t have any fear because it’s not like I had a heart attack and I’m thinking that I’m going to have another heart attack. [...] [So], I didn’t stop walking and if I did something and got short of breath I would just stop. (ACHD12-1)

Participants in this stage also described how feeling better after participating in regular physical activity could be constraining at times. One participant would go through cycles of engaging in regular physical activity, followed by being sedentary once she started experiencing the benefits of physical activity, “I [go] through bouts of being physically active on a regular basis and then when I’m feeling better, I stop. [...] I usually go for about six months of [continued] physical activity and then it wanes off.” (ACHD14-1). Another participant described going through similar cycles between being active and struggling to maintain a physical activity regimen:

I’m an intermittent [exerciser]. When I go, I really like going and I get kind of addicted to how good it feels but as soon as I don’t go for a week or so then it’s like, “I hate the gym, I’m never going again.” That’s my issue is that I forget that it feels good. [...] I’m like healthy for a little while then totally unhealthy and then healthy and then totally unhealthy. (ACHD20-1)

Another participant, feeling the need to modify his physical activity behaviour, took up walking while going through a sedentary cycle. However, he struggled with maintaining his walking regimen over time:

I had been doing little walks. I had in my mind what am I going to do I have to do something. [...] Then I start doing them and it’s all about being able to continue with it. I did start and it went sour. [...] (ACHD10-2)

One participant, severely affected by his CHD and in end-of-life cycle, was forced to live a sedentary lifestyle despite a desire to be active. He said that while he would have enjoyed being more active, the severity of his CHD prevented him from doing so, “I try to be as active as possible but unfortunately it’s pretty rudimentary [and] extremely rare because of the disease I have. [...] Someone like me shouldn’t be alive.” (ACHD26-1). The severity of his CHD has made him

incapable of increasing his physical activity participation due to lacking endurance, “Stamina and everything is going downhill.” (ACHD26-1). At this point in his life, he is no longer capable of performing even household tasks, “I’ve offloaded everything off to my wife. She cuts the grass, shovels the snow. She goes up and down the stairs to get things to me.” (ACHD26-2).

Perceived Benefits. An important facilitating factor in motivating participants to continue their journey towards modifying their physical activity behaviour was to maintain their body image. This theme was experienced mainly by female participants, as male participants did not mention losing or maintaining weight as a motivator for being active. For instance, a participant mentioned, “I thought, “If I take this class, hopefully I’ll lose some weight and get fit. That would be nice.”” (ACHD9-2). Another participant mentioned no longer being able to fit in her clothes and said she wanted to be able to wear that size again:

I know it sort of seems a little shallow, but I wasn’t fitting into my size fourteen [clothes]. There are some stores for women who if I were to have gone up a size, I would no longer shop in them and that’s scary for me. I’ve never been unable to shop anywhere. (ACHD25-1)

Other participants wanted to keep off the pounds they had already lost from non-cardiac related illness and from exercise itself:

When I was sick in December, I literally lost 30 pounds and I was so pleased with that. Not how I got there because I was sick, but I did. [...] I weigh myself every day and [I’m] not obsessive about it, but it keeps me on track. As a couple pounds creep up you notice them, and I just want to still have that good feeling about myself. (ACHD14-1)

I started exercising and I lost a few pounds. I thought, “If I could keep this going, it would be a good thing. [I] actually managed to lose 35 pounds and I continued to lose weight. [I] didn’t really stabilize at a weight and now since then. I have put back on some of that weight, but I thought, “It would be nice to lose some of that weight again.” (ACHD12-1)

Participants stated that a lack of benefits from physical activity participation influenced their desire to pursue certain physical activities. A participant exercised to lose weight but had yet to experience any weight loss. When asked about the challenges of maintaining participation in that type of physical activity, she said, [I’m] using hand weights and resistance bands and stuff. I’ve been doing that and in terms of losing weight I have lost nothing actually.” (ACHD9-1). Another participant never felt as though she was benefitting from cardiovascular exercises such as running on a treadmill: “I don’t like running the treadmill. It never really feels good when I’m doing it. [It] never feels good. It never feels easy. It’s never enjoyable. it’s always hard. Who wants to do something hard?” (ACHD20-1).

Some participants described how their interest in physical activity stemmed from experiencing certain physical benefits. One participant felt as though she could participate in physical activity for longer periods of time and therefore remained interested in physical activity, “I feel like I can tolerate more physical activity. So right now, I’m still on that high. I’m really excited about it. Right now, I haven’t lost interest [and] it’s to keep that going.” (ACHD14-1). Another participant mentioned physical benefits, such as weight loss, as seen in her progress photos:

What I find is helping me is just the fact that I’m taking progress pictures. [It’s] more,
“Hey look at how good you’re going to look in the next photo. Imagine how good

you're going to feel the next time [...] [Or,] "Hey you know that thing you really wanted to buy and it was just a little bit smaller? Imagine how awesome it's going to be when you can rock those whether you're in the house or going out with friends."

(ACHD25-1)

Additionally, participants cited increased energy as a physical benefit. One said she was less fatigued and could take on many physical activities and household activities at a time:

I'm stronger now. [I] used to be like "Well, I'm done that I need my nap." But now that I'm stronger and I'm getting more physical activity. I can do more. I can even be gardening and then I can go for a walk a couple hours later and then I can come home and still have the energy to make supper. (ACHD14-1)

Another participant derived more energy through her engagement in a Tai Chi program, which in turn enhanced the quality of her sleep, "This [Tai Chi] class gave me more energy and I'm able to do more stuff and sleep better at night." (ACHD9-2). Another participant described being less fatigued and how physical activity participation led her to make other healthy choices when it came to nutrition and alcohol consumption. However, she also engaged in poor eating habits when going through sedentary cycles:

I probably feel less tired. When I've been exercising, I'm more motivated to eat better, to drink more water and to drink less alcohol. It's kind of like a domino and when I stop exercising it's like, "Let's eat some chips." It's not like after I work out or do an hour of yoga that after I want to go on the couch and sit and eat chips.

(ACHD20-1)

Participants mentioned physical benefits such as better posture. One said that physical activity allowed her to experience the psychological benefit of decreased stress, which in turn

helped her maintain a better posture, “I feel less stressed, and I think it’s helping with my posture.” (ACHD20-1). Another participant found ballet to be an outlet for reducing her stress, “I went to ballet and when I’m there I’m just so focused on the moves I felt much more clear headed after. [It] helped to reduce my stress.” (ACHD20-2) while another participant claimed that her posture was better after engaging in strengthening exercises using proper weightlifting techniques with a personal trainer:

When I tried having a personal trainer, there were some other exercises that she had me do where I was sitting on a bench and pulling a handle towards me. I was lifting some weights on a pulley system and then she said, “I want you to sit with your back straight and doing this exercise will give you body awareness.” [I’d] like to be more aware of my body and maybe it would give me better posture and I’d slouch less. (ACHD9-2)

The physical benefit of increased heart health was perceived by participants. One participant mentioned, “I know that it’s probably very good for my heart in some ways because the hearts a muscle [and] I need to keep it working.” (ACHD17-2). Another participant claimed that physical activity could strengthen his heart and increase its ability to circulate blood, as well as increase his chance of survival and recovery if he experienced a significant cardiac event:

With regards to your heart, you’ll have a better chance of [surviving a major cardiac event]. If you have good circulation and your heart is strong you have the cardiovascular strength because you’ve actually been working on it. (ACHD10-2)

The final physical benefit mentioned was increased flexibility, in that participants were more limber when performing certain movements like reaching for objects. A participant mentioned how yoga exercises allowed her to gradually increase her ability to reach further, “I do

yoga. [When] I don't do it and then I start I can stretch this far and then a month later it's like, "I'm so much better." It's a gradual improvement." (ACHD20-1).

Participants reported various psychological benefits. Escapism was mentioned by one participant, who described physical activity as an opportune way to withdraw from regular life and forget about stresses of daily life related to work and childcare, "[It] takes me out of regular life and from worrying about kids and work." (ACHD20-1). Participants also mentioned how physical activity participation enhanced their mood and increased well-being. For instance, a participant mentioned, "[Physical activity] does enhance your mood. [You] feel better. You look better." (ACHD12-1). Another participant mentioned that positive changes in her mood were noticed by her husband when she was performing household tasks like cleaning, "I was cleaning the fridge and I was humming and stuff and [my husband] was like it's because of the yoga. [I] do feel a bit more mentally happy." (ACHD11-2).

Perceived Risk. Among the most commonly mentioned factors during interviews was a low perception of risk associated with physical activity participation. Participants in this stage had similar experiences to those in pre-contemplation stage. While they realized that being active posed a risk of injury and overexertion, they understood that there was a greater risk of being sedentary than active, "Well, you can hurt yourself. Anything you do has risk, but there's more risk when you're not active so it's not very much risk." (ACHD12-1). Although having issues with healing a surgical scar, another participant strived to increase her physical activity engagement in golf and cycling, despite being fearful of falling off her bicycle:

There's been some problems healing [on my chest] and I'm sore. Once I know I can [swing a club] I'll be fine. [...] My idea of fun is to go to the driving range and bicycling, [but] I'm really afraid to fall off. (ACHD14-1)

Conversely, while some participants perceived physical activity as low-risk, others viewed it as high-risk. A participant mentioned being aware of the risk of falling from slipping on ice when walking outdoors during the winter, “At this point of my life, I think that I’m afraid of walking on the ice and breaking a bone. Those are the risks that I am afraid of.” (ACHD24-1). Another participant mentioned a risk of more severe injuries such as tendon and muscle tears, as well as cardiac events through overexertion in sport:

There’s obviously the risk of hurting a joint, tearing muscle, or breaking tendon. Plus, the whole extreme sports category of [faceplanting]. Then there’s the overexertion that everyone’s been warning me about where I push myself way too hard and that’ll cause my heart to hurt. (ACHD25-1)

Other participants brought up the risks of significant cardiac events associated with overexertion through physical activity. One mentioned that she would be “scared that [being active is] going to tear my aorta again.” (ACHD23-2). Thus, a relationship was identified between having a high perception of risk and the fear of being active. Another participant stated that if she experienced severe palpitations that would not go away at rest, she would most likely have to be hospitalized and take various medications:

What it could lead to is either [doctors would] put me on medication like [metoprolol] or a beta blocker. Or I guess if my palpitations really got out of control, such as they went on for hours without stopping, I would get some drug intravenously to reduce palpitations. (ACHD9-2)

Lastly, participants were aware of the risk of sudden death if they overexerted themselves when active, “There’s risks of having an increased heart rate [which could] send me into sustained

ventricular tachycardia at which point then I would have my defibrillator kick in. Without the defibrillator, the risk for sudden cardiac death is there” (ACHD1-3).

Limitations. Participants expanded on some of the limitations they experienced when engaging in physical activity. The physical limitation of fatigue was mentioned as hindering participation at times. Fatigue in this stage can be described as feeling as though one is incapable of performing physical activities with the same level of energy due to general fatigue or CHD-related fatigue. For example, a participant mentioned how she sometimes had the energy to perform exercises, while other days she did not, “Some days I have more energy than other days. I’m just like, “Why is it so much effort for me to move this up and down? It wasn’t a few days ago.”” (ACHD9-1). Another participant, due for upcoming cardiac surgery, also reported fatigue at a quicker rate than normal, which was a CHD-related symptom, “Last times I went to Tai Chi [I was] beginning to feel tired, which I was not used to. After a while it was like, “[I’m] getting tired sooner.” (ACHD24-1). Another participant severely affected by his CHD attributed his lack of energy to “losing muscle mass hand over fist. I can’t walk enough to work muscles and the troubled things like pulmonary, kidney and all this stuff are not working strong enough because they are not getting enough blood flow.” (ACHD26-2). He was thus limited to short walks and minimal household activities.

Participants also cited physical limitations such as lack of endurance and shortness of breath. One mentioned that one of the main challenges she experienced when active was keeping up with others due to her lack of endurance, “Keeping up with everybody else I think that’s mainly what I worry about.” (ACHD9-2). Another attributed his lack of endurance to his CHD and the lack of blood flow and oxygen distribution in his body. Consequently, he was not able to sustain physical effort for a long period of time, “My muscles can still work physically hard, but they give

out really quick because there's no oxygen going to them." (ACHD10-2). Another participant stated she would have liked to take up curling with her husband, but the motions involved in curling made her lose her breath very quickly, "I would love to my husband curls, [but] the sweeping is too hard. I get so out of breath so quickly." (ACHD1-1). Another participant claimed that her lung capacity was low as a result of chest surgery she experienced during childhood. She believed the surgery still impacted her lung capacity today:

When I was a kid, I had pectus excavatum, which is a pretty common Marfan thing.

The bones kind of cave in. [I] had that repaired when I was six. [...] I think it actually [does affect me today] because I feel like my lungs aren't strong enough and I think that's it's from that. (ACHD20-1).

Lifestyle. Lack of time was cited as a factor preventing physical activity participation for participants in this stage. Many claimed that hours spent at work and on childcare after work prevented them from integrating physical activity into their daily schedule. One had this to say: "I have so much [work] at this moment that I sort of haven't had the time to organize that routine." (ACHD24-1). Another said that while she was motivated to engage in physical activity, it was difficult to pursue it because of work and tending to her young children, "Nothing makes me not want to [be active], but just work and kids [get in the way]." (ACHD20-1), while another said "I think time becomes a factor right. [You] got work and kids and house and supper and homework." (ACHD14-1). A younger participant also spoke about the challenges of maintaining a balanced lifestyle between post-secondary schoolwork, work and other essential activities of daily living and how it left little time to pursue physical activity:

I'm working usually almost 20 hours in a weekend, but during the week I've got to make time to do my schoolwork. I've got to make time to prepare my food. [Every]

once in a while, it's like, "I really want a sweatpants day." Then that turns into a sweatpants week. Then it turns into a sweatpants month. (ACHD25-1)

Interpersonal

Exclusion. An interpersonal factor that emerged from discussions with participants in this stage was having nothing in common with others in group physical activity contexts. For instance, a participant expressed how she would have enjoyed the company of others her age when participating in an aqua fitness class, "Aqua fitness [often] you're with all the old [women]. The last thing you want to do is go and hang out with a bunch of old [women]." (ACHD1-1). Another participant expressed similar thoughts in that she would have preferred a running program with people similar in age, "I just find that when I'm with the run group I'm stuck with like an older woman." (ACHD9-1).

Participants discussed how they withdrew from physical activity during their childhood due to perceived stigma triggered by lack of competence in team sports, which incidentally affected their desire to pursue physical activity presently. One participant played baseball during her adolescence but eventually withdrew from her team because teammates were frustrated with her ability to perform. Consequently, the participant described being deterred from pursuing team sports to this day, "I played until I was about [thirteen]. At that point I just couldn't run the bases anymore and my teammates were getting frustrated with me. [So], I gave up baseball and since then I don't do any organized sports." (ACHD1-1). She participant also said that perceived stigma made her feel socially withdrawn, "I remember when they told me they didn't want me on the team anymore. I was devastated. [...] I felt really alone." (ACHD1-1). Another participant mentioned how she isolated herself from others to avoid being a nuisance to teams, "I just decided

it would be better to keep myself from other people just to save them, I guess, from me.” (ACHD25-1).

Presently, however, perceived stigma experienced by participants was mostly related to body perceptions. One mentioned how she did not enjoy aqua fitness because she did not want to wear a bathing suit, which has been mentioned previously, “I don’t really like [aqua fitness]. I don’t like putting a bathing suit on and going so those things hold me back.” (ACHD17-2). Describing her experience playing pickleball at a recreational facility, another participant said she felt out of her depth physically in terms of her skill and fitness compared to others, “I felt [out of place] when I went there the first time. These were people who were more advanced players, and they were fit.” (ACHD12-2). Another participant felt judged and was self-conscious about her body image when she joined a gym:

I was really self-conscious of myself. I still felt like everyone was looking at me even though they were focused on their work out. They could see me going through the door as big as I felt. I just felt like everyone was giving me dirty looks [like], “There’s the fat person at the gym. They must be there just to lose weight.” (ACHD25-1)

Inclusion. In contrast, however, participants also recounted enjoying programs they had recently joined because they had common interests with others. One mentioned that she enjoyed the social aspect of her ballet class because she was with other women similar in age, “It’s mostly women my age which is a weird phrase. [It’s] nice to have a social thing and to have my own social thing.” (ACHD20-1). Another enjoyed being able to share her experiences meeting others who had experienced health-related issues, “It’s particularly nice when you’ve suffered setbacks because of illness [and] when you can get together as a group and discuss and compare stories that’s really comforting.” (ACHD1-1).

Participants mentioned how engaging in physical activity with others helped them come out of isolation. One said: “I would like to get as active as I can [because] I would like to get socially active. I’ve been very isolated [for the past few years].” (ACHD27-3) when asked why he was searching for physical activity programs to engage in. Another participant said that engaging in physical activity with others helped her become more sociable and willing to meet others, which led her to become more outgoing. Incidentally, she mentioned how becoming more social left her more confident, which translated into other areas of her life such as work:

It's kind of helped me come out of my shell a bit. [...] I’m more outgoing than I was before and I’m willing to actually talk to people more. At work I can project my voice a lot more confidently than I did before. (ACHD25-3)

In addition, participants expressed an interest in physical activity contexts among other individuals. One found physical activity unpleasant when doing it alone compared to with others, “Exercise on its own is boring. I would much rather do something with somebody else.” (ACHD12-1). Another felt a sense of belonging after joining a Tai Chi class, “Now that I have joined a [Tai Chi] class I feel more motivated because I feel like I’m part of a group of people and I want to learn this stuff.” (ACHD9-2). She added that physical activity was an opportunity to develop new interpersonal relationships, “Through physical activity there’s also the socializing aspect like you can meet new people from doing it” (ACHD9-1). Another participant mentioned, “I gain friendships meeting people.” (ACHD1-3).

Discouragement. Similar to those in the pre-contemplation stage, participants in this stage mentioned how they were often discouraged from being active by healthcare professionals during childhood. However, in this stage, participants cited the challenges of taking on physical activity as an adult. One found it hard to make physical activity part of her daily regimen today:

After my last heart surgery at age 26, [cardiologists] were saying, “Before when you were younger, we used to say don’t exercise. We don’t want you to stress your heart out or get your heart going rapidly, but now we want you to exercise.” So, after 26 years of us saying, “No don’t exercise, we are now saying yes, exercise just forget all that stuff that’s hardwired into your brain and start exercising.” [It’s] hard to totally break that pattern. (ACHD9-1)

Another participant stated that restrictions placed on her by healthcare professionals during childhood led her to develop a negative perception of physical activity. However, she does realize that she has to seek physical activity opportunities that are appropriate to her abilities over others that are not:

As a kid there was a lot that I was told, “You can’t do that because you have Marfan.” It kind of gave me a negative association with exercise and physical activity. It’s more that you can do it you just have to find the right activities the ones that work for you and feel good. I guess just stick with those instead of trying to force [being] a runner when it’s maybe not the right type of exercise for you. (ACHD20-1)

Another childhood-related factor discouraging physical activity participation was overprotective parenting. Similar to those in pre-contemplation, participants explained that because they were diagnosed with CHD, their parents restricted them from engaging in activities considered to be risky for their health, including physical activity. One was not allowed to do certain activities in gym class at school, and her parents did not let her play extracurricular team sports like soccer, “When I was a kid it was more noticeable because I couldn’t do certain things in gym class, and I remember wanting to play soccer and my parents wouldn’t let me play soccer.”

(ACHD20-1). Another mentioned how overprotective parenting had continued into her adult life as well:

Whenever I was younger, there was a lot of worry because I was born with this condition. [So], I was kind of bubble wrapped for at least the first five to ten years of my life. Even now my parents worry about over-expending myself. [They'll say], "If you're going somewhere let us know where you're going" or "If you're walking take it easy, it's hot out or really cold out we don't want you to over work yourself."

(ACHD25-1)

Another participant claimed that since her parents did not allow her to take part in physical activity, she did not develop an interest in physical activity. She therefore found it unjust to have to force physical activity into her daily regimen and try to form an interest in physical activity as an adult:

I'm kind of thinking [my parents] were too overprotective of me and they should've let me try my hand at stuff instead of just babying me to death. [Today, it's like], "It's on you to do everything now," [which is difficult]. [...] [It] was just the thinking at the time like, "Don't do physical activity. We don't want you overexerting yourself. (ACHD9-2)

In a previous interview, she stated that leaving home and her parents to pursue post-secondary education was a liberating opportunity to try activities that she had not had the chance to pursue during childhood:

When I was younger, I wasn't allowed to do a lot of physical activities and I kind of missed out on a bunch of socializing which isn't good. But then it got better after

high school when I left for university. I was like, “Yes, I’m finally on my own, this is awesome.” and then that was great. (ACHD9-1)

Professional Guidance. Participants claimed that they did not want to be judged by healthcare professionals during routine clinical visits if they told them that they had not pursued physical activity, “I just think if I wasn’t doing enough physical activity they might think, “You’re really lazy. You should do more.” I don’t want them thinking that.” (ACHD9-2). Accordingly, participants sought to modify their physical activity behaviour to be validated by healthcare professionals. One participant sought to impress healthcare professionals at routine clinical visits by telling them that she had made significant changes to her lifestyle, “The last four years [my doctor has] been like, “Everything’s good. [You’re] stable. Nothing’s changed. Come back in a year.” So, I’m working towards being able to hear them say, “Wow things are actually improving.”” (ACHD25-1).

Participants provided mixed opinions when it came to healthcare professionals promoting physical activity. One mentioned that healthcare professionals were more likely to prescribe medication during routine clinical visits than provide adequate guidance on physical activity:

[My cardiologist is usually] like, “I’m prescribing a pill for you. This is what I want you to do.” Then following up is so easy [he’ll say], “You know what? Your blood pressure is up, you need to take two 30-minute walks a day that’ll bring it down.” (ACHD14-1)

Yet, participants in this stage said that while some healthcare professionals did not provide encouragement to be active, they understood that obtaining knowledge on suitable physical activities was perhaps up to them and not healthcare professionals. For example, a participant mentioned that behavioural change had to be motivated by herself and not healthcare professionals,

“I don’t know if there’s anything that they’re not saying exactly or anything that they could that’s better. They are doing pretty well as they’re doing now. I think that it’s more something that’s within me.” (ACHD9-1). Another participant mentioned that her cardiologist had to tell her that she would need cardiac surgery, so she recognized that promoting physical activity was not a priority to discuss during her visit:

We didn’t talk about much about [physical activity] with the cardiologist last time. I think because he had to tell me that I need an operation and I didn’t like that. So, they had to focus on just supporting that part of my need at that moment. So, we haven’t talked about that yet. (ACHD24-1)

Participants mentioned that they received recommendations from healthcare professionals and were explained the importance of being active. A participant mentioned how her cardiologist suggested, “Do physical activity just like you’re any other normal person.” (ACHD22-2). Another participant was motivated to modify his physical activity behaviour after his cardiologist described specific benefits of physical activity, “It does [motivate me] especially when they tell me things like, “[If] you do that here’s what is likely to happen.” [They] kind of give me the quick rundown. [Then] it’s like, “I want that.” (ACHD10-2). Another participant stated that her cardiologist explained that physical activity participation was determined by her level of comfort during participation and not what they prescribed:

It’s more like, “You’re able to do this. How do you feel after? It seems possible you can continue doing this, but if there is any notable changes and you’re finding it hurts your chest maybe you should stop or maybe you should try and take it a little easier. It’s more of a self-governing. It depends more on how you feel rather than I’m going to advise you to do this or I’m going to advice against this.” (ACHD25-1)

Institutional

Logistics. In seeking out physical activity programs, participants tended to pursue short-term commitment programs. One participant enjoyed short-duration programs because once they were completed, she could move on to a different type of program, “I prefer these little mini programs that go from January, February until March and then find something else that I like.” (ACHD14-1). However, short-term commitment programs were also a disadvantage for integrating physical activity into participants’ daily regimen on a long-term basis, as the likelihood of participants registering for a new short-term program or re-registering for the same program was unlikely. One participant did not pursue aqua fitness classes once the program ended, “Aqua fitness was fun. [...] I liked doing the exercises in the water and then they finished, and I just didn’t rejoin.” (ACHD23-1). Other participants struggled to sustain a physical activity regimen once short-term programs ended. One had this to say about her Tai Chi program, “I had to stop doing it because the course ended and unfortunately, I just kind of went back to my former ways of just being a lay about. I tend to do that.” (ACHD9-1) while another participant referred to how she felt after her aqua fitness program, “I’m not sure what my mindset was. Maybe because it was a six-week program and once I was finished, I thought, “I’m going to take a little break now.” and that little break turned into longer and longer.” (ACHD23-2).

Lastly, a participant claimed that one of the main motivators for joining a running program was its timing – because it was in the evening, she could burn off calories gained during dinner and get a better night’s sleep, rather than being fatigued all day had the program run during mornings:

You’ve already eaten dinner so you’re probably just running and burning off that [dinner]. I just did a lot better in the evening runs than the early morning runs

[because I wasn't as tired the rest of the day]. And, at the end of the run [I'd] just walk home from run group [and] go right to bed and have an amazing sleep because I was so tired from running. (ACHD9-1)

Cost. The cost of programs was identified as a factor influencing physical activity participation as well. A participant mentioned how spending a lot of money to register for a walking group motivated participation, "I went to these early morning runs thinking, "I paid for this course. I want to get my money's worth." (ACHD9-1). In her following interview, the participant explained how spending money on physical activity programs such as Tai Chi was her primary motivating factor to continue participation, "I should go to this Tai Chi class because it was expensive, and it will be fun. That's the extent of my motivation." (ACHD9-2). Other participants also said that they were more likely to commit to physical activities if they had invested money on equipment, "Buy a bike. Once I spend the money on the bike that would probably be [my motivation]." (ACHD20-3), and "It's a bit of an investment. It's not cheap. [We] invested in camping gear last year and so it definitely motivates us to book in a couple of camping trips." (ACHD11-3).

Adaptability. Another subtheme frequently mentioned by participants pursuing new physical activity programs was that the activities were within their personal abilities. For instance, a participant described how the series of exercises in her home exercise program could be easily done and could be adapted to make the exercises easier to do:

For the home program it seems to be just like do lots of walking and also hand weights, resistance bands and stretches as well. I remember one thing [it] told me which was rather interesting is you should go up to a counter and do push ups from

the counter. That seemed like a good idea instead of going on the ground and trying to push myself up. (ACHD9-1)

Other participants said they enjoyed programs such as Tai Chi and ballet because the programs allowed them to learn the activity at an introductory level before progressing to advanced levels. The nature of the activities and the gentle movements also enhanced participants' experiences:

It's a beginner ballet class. We're doing first positions plier and stuff that my daughter is also doing in her four-year-old ballet class. I think I like that it's precise. I know what moves we're doing now that I've been doing it for a couple of months. I like that I am feeling like I am slowly getting better. (ACHD20-1)

[Tai Chi] is fitness. You have a set is 108 movements and it depends on how fast or how slow you do the set and how many sets that you do in a row. There is a part of me that really enjoys the movements in a slow motion. [It's] something that really attracts me. (ACHD24-1)

Participants said that they did not have pleasurable experiences in certain programs where the staff members did not adapt activities to their needs. One stated that her yoga instructor was unwilling to modify exercises when she was pregnant, which eventually led her to withdraw from the program, "I really like doing yoga. [...] When I was pregnant there was three people in the class and [the instructor] would not make any accommodations for the fact that I was pregnant. [...] So, I just stopped going." (ACHD20-1). Another participant expressed disdain towards gym staff members for failing to show her how to properly use an exercise machine, "[The trainers were] very pompous and not very helpful. I don't think you should have to pay for a personal trainer to ask how to use a machine." (ACHD14-1). However, when program staff did adapt

activities to their needs, participants reported pleasurable experiences. One had this to say: “[The instructor] takes her time and she never pushes you to do anything that you don’t want to do. She says, “You have to be comfortable when you’re doing it.”” (ACHD23-2).

Another participant said it was difficult for her to commit and pay for physical activity programs if it was not within her personal abilities:

[It’s] always a big key for me knowing that I can do it. I’m very slow to start new activities especially if I haven’t done them before. [...] When you have to fork out money because you find something and you go, “Maybe I’ll try this.” and then you fork out all this money and you can’t do it that’s super frustrating. (ACHD1-1)

Community

Convenience. One of the first community factors mentioned by participants in this stage was convenience. One participant liked to take part in a Tai Chi program, but transportation to the facility was a challenge and prevented her from pursuing the program, “I have to go out and take three buses to get [to the Tai Chi center]. It stops me.” (ACHD24-1). However, other participants in this stage indicated that they lived in proximity to recreational facilities that offered programs of interest to them. One said that a ballet studio was near her home, which facilitated participation, “The ballet class is [near my house] so it’s really convenient.” (ACHD20-1). Another explained how accessible it was to do a home yoga program as it did not require travelling. Rather, he could participate at any time in his home, “I think the fact that it’s convenient [and] we have a room for it. [It’s] not like it’s a struggle. It’s like, “[I’m] doing yoga in five minutes.” [I] do it and then half an hour later were done.” (ACHD10-2).

Weather. Weather was another community-related factor influencing physical activity for participants in this stage. One related that poor weather conditions (i.e., rain) prevented her from

taking part in outdoor physical activities like cycling, compared to days where the weather is acceptable, “I was here to use my bike and [you] can’t use it in the rain. [It] has to be a nice sunny day so that sort of dictates when I can use it.” (ACHD1-1). Another participant wanted to take up outdoor pole walking, considering it an appropriate physical activity for her. Yet, winter weather and early darkness deterred her from pursuing the activity:

I wanted to do the Nordic pole walking with some little groups around [the city]. I thought, “That’s about my speed.” I’m not a runner. [It] would be great but I looked into it very briefly and then decided that I don’t like the weather or the dark at night [during wintertime]. (ACHD14-1)

Participants also explained how very hot and humid weather or very cold weather made it difficult for them to breathe and thus deterred them from being active in that weather, “Shortness of breath if you work too hard or it’s really hot and humid outside.” (ACHD14-1), and “Winter it is harder to get around and if it’s very cold out its hard breathing.” (ACHD23-2).

Strategies

Cognitive. Participants in this stage mainly employed consciousness raising as a cognitive strategy to sustain physical activity behaviour. Most participants in this stage had learned to experiment with certain physical activities to determine their abilities. One had begun to experiment with running by progressively increasing running distance and duration. Unaware of his personal abilities, he was able to use this strategy to set boundaries and determine his limits if he were to experience symptoms:

[I] would walk for a minute and then I’d jog for a minute. That’s exactly what I did, and it felt good. Then I kept changing the time for jogging to go further and then it was just a matter of practice. [I] could jog four or five minutes straight comfortably

[then] I could jog ten or 15 minutes straight comfortably. [...] It just gradually happened quicker and quicker and I had no gage on that. It was like, “Take your time. You’re safe. You’re fine.” I just do it to figure it out. (ACHD10-2)

Another participant became aware of what she could do in terms of physical activity through the hospital after undergoing cardiac surgery. Staff members had steered her toward facilities and organizations offering or promoting programs suitable for cardiac patients. Thus, she understood that if others with cardiac diseases could participate in the programs that were promoted there, she could too:

After my last heart operation, the staff at the [hospital] sent me to the track for rehab and it was there that they had a sheet that informed me about where to find all the heart healthy places where it’s OK to go and exercise. [And,] I think it may have been the CCHA that mentioned the running [program]. This made me realize, “Wait a minute. If people in CCHA like other heart patients are doing running [programs] like maybe I can do it too.” (ACHD9-1)

Lastly, another participant mentioned using resources to discover available programs in her community suited to her personal abilities. She discovered a Tai Chi program after reading newspaper ads on the various programs offered at her community recreational facility, “It was in the local newspaper. They have a little insert that tells you what kind of activities are going on in the neighbourhood regarding the community centre and physical activities.” (ACHD9-2). Another participant wanted to use resources to learn about her abilities and limitations without having to rely on the information her parents gave her, which discouraged physical activity participation:

The best thing I could have told myself at that point would be to research what I can do outside of what my parents were telling me because my parents were basically

telling me, “You’re this close to possibly needing surgery. We’re going to be even more bubble wrapping you’re not going to exert yourself nearly at all because we don’t want you to make your heart work harder than it has to.” (ACHD25-1)

Behavioural. Stimulus control was one of the most oft-cited behavioural strategies among participants in this stage, who use a variety of electronic devices (e.g., phone applications, Fitbit) to determine their degree of physical activity. A participant mentioned using a free phone application to determine her daily step count and nutritional elements such as calorie intake and burning. She claimed that knowing the number of steps and time she had been walking motivated her to surpass previous goals and increase the length of time spent walking. For her, goal setting was a strategy in that she used electronic devices to prompt participation and achieve pre-determined goals:

I have a free app on my phone. [Basically] for me it’s mostly calorie counting, but I also have a step counter. When I see that number going up it’s kind of like a cool high score and some days I’m like, “I’m about this this many minutes, but I still feel restless. I’m going to go see if I can make it to this many minutes” or “I’m almost done my goal but I really want to push it so I’m going to go for a three kilometer walk with my dog.” (ACHD25-1)

The participant also explained that the app served as a prompt to be active if data showed that she had not been active for a long period of time, “It’s more of a reminder like, “You haven’t moved in five hours. You should probably go and stretch or walk.” [It’s] really a motivator just to see that how many calories I’m burning how many calories I’m inputting” (ACHD25-1). Another participant used a Fitbit to achieve daily step count goals, “[I have a] Fitbit. I have it set at 8000 steps right now. That’s my goal. I need to meet it.” (ACHD14-1).

Another participant stated that joining structured physical activity groups, such as walking groups, helped establish a routine of regular physical activity participation, “If I have a routine of a walking group, it would be nice.” (ACHD24-1). Other participants expressed similar thoughts on the importance of joining structured programs, or classes, as having a designated time during the week for those classes facilitated the integration of physical activity into their daily schedule. One participant enjoyed having Tai Chi classes scheduled at the same time each week, “It’s every Monday evening at six o’clock and goes for an hour. [...] I went to the first Tai Chi class I thought, “I really want to go to this.” (ACHD9-2). Another participant touted the effectiveness of joining a ballet class (versus an unlimited gym membership), saying that it made her want to look for other similar classes:

I found with the ballet was having it at a scheduled time each day is helping. I was thinking of finding other activities that are like that and signing up for a specific class as opposed to just the unlimited membership. [It’s] always at the same time and now that I think about it when I did the yoga classes here at lunch it was always like Tuesday at lunch again. [That] seemed to help at least at this place in my life having the scheduled time. (ACHD20-1)

Participants also discussed the importance of using calendar prompts to assure they integrated physical activity participation into their daily regimen, “You can put a star on the calendar. [...] You really have to put it in your agenda for a daily [reminder].” (ACHD14-1). Another participant explained how using a calendar prompt helped her establish a routine and facilitated regular physical activity participation, “It kind of puts you in a routine [and] I think routine helps people make better decisions. [You’re] more likely to succeed I think in a routine-based environment.” (ACHD22-2).

Lastly, a participant described how he modified his current daily regimen to better integrate physical activity into his daily life. He modified the structure and time designated for tasks of daily living to have physical activity participation at a more convenient time:

[I've] changed some rules around the way [I] come home. [It's] a weird thing but it adds to how [I'm] doing well. [I] used to come home after work [be] kind of be brain dead and then [I'd] cook a meal, eat the meal and [then] not get a spark to do anything. [...] But, if [I] come home, [I] don't eat, [I'll] do yoga instead. [I] think that will help [me] continue. [I] just had to change [the] structure. (ACHD10-2)

Helping relationships was also identified as a strategy for participants. One stated that pairing up with a friend made her liable to be active so as not to disappoint them, "I think a buddy system works a lot it's like, "OK we're going tomorrow at nine am." and I don't want to let her down or her let me down." (ACHD22-2). Other participants echoed this sentiment, "I think buddy programs are an awesome way to do stuff. I've been trying to set up walking once a week with a girlfriend." (ACHD1-3), and "It's going to sound silly but a workout partner. [Having] someone in the same boat as you and to feed off each other. It's just so much better working out with someone." (ACHD13-3). Another participant said that being active with her spouse facilitated participation, and that engaging in friendly competition with friends helped her keep up with her physical activity participation, "[Me and my husband] started doing [yoga] every day since the new year and one of our friends is doing it as well. so were kind of keeping in check with her and she's checking with us." (ACHD11-2).

Another behavioural strategy employed by participants was substitution, which can be described as participants replacing one physical activity behaviour with another similar behaviour.

For example, a participant mentioned that although she no longer takes ballet, she now engages in Tai Chi because the movement patterns and coordination were transferrable from ballet:

I really like Tai Chi. In a way it replaces the ballet that I used to dance because all the rhythm and the movements is something that I really enjoy. [...] I wouldn't say that it has similar movements, but [the] patterns in my mind [and] movements are coordinated [similarly]. (ACHD24-1).

Another participant, who had to give up baseball due to the amount of running, decided to become an umpire to stay involved in the sport that she enjoyed, "If you're becoming a hindrance to the team than you have to think, "Is it really worth it?" [What] I did after baseball is I tried umpiring because I didn't have to run the bases." (ACHD1-1).

Counterconditioning was also mentioned as a strategy to increase physical activity participation. A participant explained how to maximize physical activity participation by substituting walking for driving to restaurants and shopping, "You might walk [to the restaurant] to get [food]. You make better choices. I need to go to [the store] and it's a 20-minute walk. I'm going to walk there instead of getting in my car." (ACHD14-1).

Another strategy used by participants was self-liberation. One participant shared her experiences in physical activity with healthcare professionals to let them know what she had been doing, while asking them about her progress and seeking guidance on physical activity:

I would try to update my doctors more. [I] would ask them about what sort of calorie intake I can try, what sort of activity I can try that's going to be more muscle oriented than cardio or what levels of cardio I can try. [I] take more charge in how I feel about exercising. (ACHD25-1)

Action Stage

Individuals reach the action stage once they have made significant changes to their behaviour in the past six months. The themes and subthemes discussed below were associated with participants in the action stage. The themes identified in this stage bore similarities with those contained in the literature on individuals in the action stage. Most participants had developed a strong interest in physical activity and effectively pursued or included participation in both structured and unstructured physical activities into their daily regimen. A summary of the themes and subthemes associated with participants in the action stage is provided in Table 6.

Table 6

Factors influencing physical activity behaviour in the action stage

Themes	Constraints	Facilitators
	Intrapersonal factors	
Meanings		• Achieve well-being • Taking rational position • Maintain health and function
Readiness for change		• Active for several months • Adopted a structured regimen • Physical activity becoming natural part of life • Do not perceive physical activity as work • Desire to pursue various physical activities
Non-CHD specific	• Non-cardiac related illness	•
CHD-specific		• Significant life events perceived as singular • Upcoming cardiac surgery
Lifestyle	• Schedule conflicts	
Limitations	• Physical: Shortness of breath, chest pain	

	• Psychological: Feelings of depression, feeling lethargic	
Perceived benefits		• Body image • Physical: Weight loss, increased heart health, increased energy, increased mobility • Psychological: Sense of accomplishment, enhanced mood, increased well-being, coping, escapism, rejuvenation
Perceived risk	• High perception of risk • Fear	
Interpersonal factors		
Discouragement/ Encouragement	• Overprotective significant others	• Receiving encouragement from healthcare professionals
Inclusion		• Developing relationships • Maintaining relationships
Professional guidance	• Receiving specific recommendations	• Receiving specific recommendations • Perceived stigma • Seeking validation
Institutional factors		
Logistics	• Timing of programs • Lack of variety	• Promoting environment • Positive staff
Adaptability		• Activities within abilities
Community factors		
Convenience		• Convenience
Weather	• Weather	• Weather
Strategies		
Cognitive	• Consciousness raising: Recognizing physical symptoms (e.g., elevated heart rate, body temperature, catching one's breath, tachycardia) and reducing the intensity of physical activity participation • Goal setting: Setting small or short-term goals as well as larger goals	
Behavioural	• Stimulus control: Using calendars. Journaling. Using electronic devices (e.g., Fitbit) • Helping relationships: Have a workout buddy to motivate participation	

-
- Counterconditioning: Maximizing physical activity participation by modifying daily living tasks (e.g., placing home items in places that require navigation, parking further away when shopping)
-

Meanings

Perceptions of physical activity and its priority among participants in the action stage differed considerably from those of participants in previous stages. However, meanings of physical activity for participants in this stage were similar to those in previous stages. For example, a participant described how she no longer had to force herself to be active and did not always have to schedule time for physical activity. Physical activity had become a priority in her life because she understood it was beneficial to her health, “Physical activity is something more spontaneous than planned. [...] It is a priority because I understand that it’s good for you.” (ACHD24-2). Similarly, participants mentioned how physical activity became a way for them to achieve well-being through physical and psychological benefits. A participant claimed being active helped her “feel stronger [which gives me] that positive reinforcement of how much better I feel. That keeps me motivated to keep going.” (ACHD14-3).

Additionally, participants mentioned wanting to maintain function and health in order to live independently in the future – a desire cited by participants in earlier stages as well. Participants stated that they engaged in physical activity to prevent deterioration in hopes of extending their life expectancy. A participant touched on these aspects while discussing her motivation to take part in activities with her significant other during retirement:

It makes you feel like you’ll be here a bit longer, be able to do things with my [boyfriend] like travel, be able to walk and climb. [...] I want to be able to do things that’s why we’re looking at retiring so we can travel. (ACHD12-2)

Similar thoughts were expressed by another participant who was motivated to maintain her health to engage in physically demanding activities with friends:

I'd like to be able to keep up with my healthier friends. [...] I need to keep up with them. That's another motivation for me, to be healthy. I'm very interested in activities that do require a bit more physical labor like full scale gardening and hiking and rock climbing. (ACHD25-2)

The same participant also spoke about family members experiencing significant deterioration caused by health issues. Consequently, she had increased her physical activity participation to decrease her risk of experiencing similar issues in the future:

My family history is not good with a lot of disease, mostly heart disease and cancer and weight related heart disease and diabetes. I know there's some things I have a higher risk of. So, I wanted to try to at least lower what risks I can. (ACHD25-2)

Taking rational positions also held meaning for participants in this stage. One participant appeared to take responsibility for her health by deciding to increase her physical activity participation and seeing it through. She spoke about fully committing to her decision to keep moving:

This is what I chose. I chose to have more physical activity, so I do it. You have to go and walk and go to the gym. I have a way of being in my life that is when I decide something my word is very important. If I decide something, I do what I say. (ACHD24-2)

Finally, another participant mentioned it was important for her to lose weight to enhance her health and extend her life expectancy, which bore similarities with themes pertaining to

maintaining health and function and taking rational positions. She had managed to modify her physical activity participation after being diagnosed with CHD later in life. Prior to being diagnosed, she felt as though she was not as active as she could be. Thus, after receiving her diagnosis, she felt the need to adopt a healthier lifestyle to lower her weight and stay healthy despite having CHD:

I think that now I was told that I have this heart problem and I realized that I am not exercising or was not exercising, and I was gaining and gaining. That made me think about it. I said, “OK it’s time for you to think about it otherwise you will continue gaining weight and continue exercising less and if you want to be a healthy person [you have to change].” (ACHD24-2)

Readiness for Change

Participants in the action stage had made significant changes to their behaviour by taking on a highly structured physical activity regimen. For instance, a participant explained, “I joined [a] female gym. I’ve been doing that now for six weeks or so. I go three to four times a week and it’s a half hour full body workout.” (ACHD1-2). Other participants claimed, “[I’m] going on walks. [I] do about four kilometers a day four or five times a week. [...] It takes about an hour.” (ACHD22-3), and “I have increased my physical activity. I’m going I’m walking for 30 mins three to five times a week. I’m trying to get up to five times. So, it’s 150 minutes a week.” (ACHD17-3).

Another participant explained how she drastically modified her physical activity behaviour over three months by adding more home workouts with her personal trainer, joining a pickleball club at a nearby recreational facility and walking more frequently to and from dinner as a part of a weekly routine:

I [increased] my trainer to two times a week versus one [and] I've carried that on. [...] I have a personal trainer I've been doing that twice a week on Tuesdays and Fridays. [The trainer] comes in for 50 minutes. [...] I started [pickleball] and I played for an hour and a half this past Monday. Also, on Wednesdays we usually walk to dinner and back. So, I get 25 minutes of walking at a good pace. That means four days out of seven I have something physical that I'm doing. (ACHD12-2)

Similarly, another participant took on home exercise programs as a part of her physical activity regimen. Her home program consisted of simple whole-body exercises such as cardiovascular fitness and exercises for her abdominal and neck muscles:

It's twice a day half an hour. [...] It's very simple straight forward things that you can do at home. For example, I have two floors in my house I just run the stairs five times up and down. I do some exercises for my stomach muscles and for my neck. (ACHD24-2)

Perceptions of physical activity among participants in this stage differed considerably from those of participants in previous stages. Most participants in the action stage no longer perceived physical activity as work. One participant used to perceive physical activity as something that meant overexerting herself to the point of physical discomfort, while now, she tended to have pleasurable experiences:

I used to compare physical activity to going in for a huge exam. Everything was on display. You had to show that you knew what you were doing. You had to leave the place completely drenched in sweat and that was your badge of honor. That was what being physically fit was. If you weren't feeling like you were dying at the end, then you didn't do a good job. Whereas now it's like I'm going to walk

to the park. [...] I'm going to walk to the store [and] it's like, "That was a good workout." But it didn't feel like a workout because now it's just what I do.

(ACHD25-3)

Participants in this stage also perceived physical activity as becoming a natural part of their daily routine, which was a characteristic generally associated with participants in maintenance. For example, a participant claimed, "Physical activity is a nice part of my life. A very natural part of my life. It is very natural. I didn't even think much about it." (ACHD24-1). Another participant indicated that physical activity was as natural to her daily routine as other tasks of daily living:

I think that it's so well integrated that it's become a normal part of my day. I feel that it's not something that I have to think about. It's just like you have to brush your teeth every day. [It's] just part of my everyday activity. (ACHD14-3)

Intrapersonal

CHD-Specific. Participants in this stage discussed perceiving significant life events, such as cardiac surgery, as singular, which was similar to participants in previous stages. Similar to those in the preparation stage, participants discussed being able to overcome significant cardiac events with ease and not being deterred from engaging in physical activity post-surgery. Participants gave themselves an appropriate recovery time to be comfortable physically and returned to their established physical activity regimen afterwards. Participants believed that unlike heart attacks, which could lead to ongoing issues, corrective surgeries repaired their issue, and they could resume normal life afterwards:

I knew I had to give myself that time to recover and I knew I would see the physiotherapist at the [hospital]. Once I had that over with, I knew that I could work my way back to what I was doing before. [...] I really felt like it was an event as

opposed to a reoccurrence. If you've had a heart attack or something that happens [to be a persisting issue], [but] I just feel like it's fixed so life goes on. (ACHD12-2)

Another participant described optimism as helpful in believing cardiac surgery was not going to prevent her from pursuing physical activity. She perceived surgery as merely a time to take a break from her current pursuits and would resume normal life post-recovery:

I think because I'm an optimistic person I didn't even think that [open heart surgery] would stop me from [being active]. I just [see it as] a little break like, "OK I do this; I rest for six months and after that I just keep on going." (ACHD24-2)

Another factor facilitating physical activity participation for those in this stage was upcoming cardiac surgery. Several participants spoke about increasing and maintaining their current physical activity regimen as they anticipated needing cardiac surgery in the future. A participant said, "If I'm going to have surgery, I want to be in my best shape in order to recover as fast and as soon as possible." (ACHD24-2). Another participant claimed:

I have to go through this difficult procedure [so] I said, "I have to face this in my best shape possible." [...] If you have surgery and you are overweight, and you don't exercise ever, and you have surgery it's going to take you a little longer to recuperate. (ACHD24-2)

Another participant explained that to qualify for the type of surgery she needed, she had to be within a certain weight range. She also required emergency surgery that was preceded by extensive therapy. Thus, she maintained her physical activity regimen to assure she would be in good physical condition in advance of any future surgery:

I didn't know [my surgery] was coming. It was an emergency so if I knew I had one coming up I would probably be keen to get myself as fit as possible. I know how much it plays a role in recovery. For example, when I was doing transplant, I had to be a certain weight and have therapy three or four times a week leading up to the surgery because they want you in peak physical condition. (ACHD1-2)

Perceived Benefits. Another theme associated with a strong desire to pursue physical activity participation was body image. A participant claimed that she wanted "to be normal weight. I want to not have to worry about the scale or health effects if I do start to slip up [on] my diet [and] my exercise." (ACHD25-3). When probed on what motivated her to be active, she cited disdain of having to purchase clothes from a plus-sized store:

The danger of the fact that I was getting close to having to go into special stores for plus sized clothing. I could no longer shop at the stores that I wanted to. I'd maybe find one thing in six months of searching [at regular stores] and even at that it didn't fit as well as I thought it would or hoped. (ACHD25-3)

She also spoke about the importance of maintaining a healthy weight because of the health risks associated with obesity, as evidenced by family members who suffered from obesity-related health issues:

[Once I lose weight it's all about] maintenance. [...] I was veering towards the size that a lot of my relatives started getting health problems at and I'm still fairly young. [...] I did feel that if I didn't change anything that my health problems were going to get worse. (ACHD25-3)

Another participant weighed herself every day to make sure she did not exceed her desired weight. While she said she was not necessarily obsessive over her weight, she felt the need to weigh herself daily and take immediate action had she gained any weight:

I weigh myself almost every day not because I'm fixated on weight but because if I start going up I go, "Obviously I'd like to be less." [...] I feel like I'm just trying to have a healthy balance like I said I'm not fixated on certain numbers. Would I like to lose 25 or 50 pounds? Absolutely. [...] I'm just going to keep working at it and try not to go up [and] maintain or go down. [...] I am obese. I don't want to be an obese person. I want to be a fit person. (ACHD12-2)

Building on the theme of body image, when participants, mainly female, were asked about the main factors responsible for their recent behavioural change, many mentioned losing weight. One stated, "I have lost 15lbs in a month." (ACHD24-2). Another felt obliged to sustain her current physical activity regimen to continue losing weight, "I've lost some weight and it makes me feel better overall. I know I have to keep doing it." (ACHD1-2). Another participant said losing weight provided her with a sense of accomplishment as a psychological benefit, explaining that pushing through a difficult workout and experiencing weight loss made her feel good about herself because she was increasing heart health. Thus, a relationship appeared to exist between the themes of weight loss and a sense of accomplishment:

Even though working out isn't my favourite physical activity, going hard 30 second [intervals] three times is tough. You know that you're doing something good for yourself. [...] You start to feel tighter. It makes you feel a little bit better about yourself because you're doing something good for yourself and improving your lifestyle and improving your cardiac health. (ACHD12-2)

Weight loss was also associated with the physical benefit of increased energy. A participant described how losing weight made her lighter and gave her more energy for other activities such as getting around faster at work:

The boost in energy I've had lately. I have lost 25 more pounds so it's like you're lighter now. You have so much more energy now. You got to find something for you to do and I'm always kind of jogging to and from places in the workplace.

(ACHD25-2)

Another participant claimed she felt stronger physically and had more energy to accomplish daily living tasks, "[I feel] stronger where you have more energy to do just your daily activities [and] things like housework. Stronger where you don't have to have a little nap every day." (ACHD14-3). Similarly, another participant mentioned, "I have the energy to be able to cook dinner and eat healthy." (ACHD1-2).

Participants also experienced physical benefits such as increased heart health. One mentioned how she often pushed herself physically within her comfort zone, which she perceived to have a positive effect on the condition of her heart and could be a reason why she required fewer hospital visits:

Having grown up doing physical activity I think that's made my heart stronger because I wasn't limiting it. I think that's also one reason why I don't have to go back for more checkups because I've always pushed it to the limit. Well, I knew the limit I would stop. [...] Whereas a child that grew up and did not do physical activity, they weren't pushing [their heart]. They weren't exercising which could cause your heart to fail. (ACHD22-3)

The last physical benefit mentioned in this stage was increased mobility. One participant related being able to get around with more speed and fewer aches. She explained that her normal walking path now took less time, and she was able to keep up with friends when active as a group:

I'm finding I can move a lot faster. [The] walk from my house to here usually takes about a half hour but this time it took less than 15 minutes. I'm finding I can do things a lot faster I can move myself around a lot faster and I can keep up with my friends a lot easier. (ACHD25-3)

In addition to physical benefits, participants experienced several psychological benefits, such as enhanced mood and well-being. One participant suggested that her attitude and outlook on life were more positive since increasing her physical activity, and that family members had noticed these changes. For her, feeling positive was more motivating to maintain an active regimen than it was to lose weight, "I just have a more positive disposition. [...] My mood is better. [...] Even my family has noticed. I'm not looking for any weight loss out of this. That would be a bonus. I'm just looking for that attitude." (ACHD14-3). This was echoed by another participant, "It feels positive. You feel more upbeat. You feel more ready to try things, ready to welcome more positivity into your life." (ACHD25-3). Another participant explained how her enhanced mood made her more sociable, "[Physical activity] impacts my relationships with people. I'm generally happier and more willing to engage with people." (ACHD1-2).

The same participant also described how being active relieved occasional feelings of depression brought on by being severely impaired by CHD. This led her to use physical activity to cope with the disease. She added that physical activity helped her cope better with challenges than she did when she was less active. Her ability to cope had therefore become more effective as the participant increased her physical activity participation, "I feel stronger mentally. [...] It helps with

my depression. Life has been very trying right now and I'm handling it much better than I would have six months ago [when I was less active]." (ACHD1-2). Another participant described coping with the disease through physical activity participation and mentioned that it relieved stress and anxiety, "I'm able to cope with [my CHD] that much easier because you can let off some steam when you're working out and power through and get rid of some of that stress." (ACHD14-3).

Another psychological benefit experienced by participants was escapism. One described how being active helped her focus on the task at hand and appreciate her surroundings while forgetting the outside world:

When I'm adventuring in my physical activity, I'm in the moment. I'm not overthinking. I'm not thinking forward like "my gosh I'm going to step on a rock five steps ahead of me." It's more like "look a rock, I'll step around it." It really helps me be in the moment and appreciate my surroundings. [...] If I'm not actively doing something I tend to overthink and over analyse things [and] internalize it. But, when I'm active everything else kind of blurs out and I'm just in the moment. (ACHD25-3)

Another participant explained how she felt rejuvenated physically after engaging in physical activity. Interestingly, she pointed out that although being active was challenging at times, she understood that she would feel better afterwards, "I feel revived especially with fresh air after a good walk. It feels good. Sometimes it's hard [to get out] but I know at the end I'll feel better." (ACHD22-3).

Perceived Risk. Like participants in previous stages, some participants had a high perception of risk when engaging in physical activity. One mentioned that she was aware that there could be severe risks associated with being active, as she was severely affected by her CHD. She

described the possibility of losing consciousness and how that triggered a fear of being active, “I do understand that something could happen. I could just collapse right there. It’s definitely a fear, but I can’t let my fears run me. If I did, I would be on my couch all day.” (ACHD1-2). Interestingly, although she mentioned being fearful, fear did not necessarily constrain physical activity behaviour. Instead, as evidenced by the abovementioned quote, she did not let fear dictate her decision to be active. Another participant had to reassure herself that physical activity was safe when she experienced CHD-related symptoms while active. Yet, she engaged in physical activity to test her personal limits:

I have to be more aware of what might be putting a lot of strain on my heart even if I know the activity is safe for me. [...] [It] usually ends in me trying the activity anyways and seeing how far I can push it until it’s too much for me so that I know for next time how far I can push. (ACHD25-2).

Other participants talked about the risk of experiencing regular non-cardiac related injuries from physical activity participation. One mentioned that sports posed a risk of musculoskeletal injuries from falling, but was not concerned about experiencing CHD-related symptoms or injuries:

[With] pickleball [it’s] falling. I am competitive but the second time I was playing I tried to get the ball and I fell forward. [...] I didn’t hit my head or anything, but you always think, “Am I going to hit my head or break my wrist?” [But] I don’t really have a real concern with my heart. (ACHD12-2)

In contrast, however, another participant mentioned being fearful of experiencing chest pain when being active soon after eating, “I was a little bit fearful before but as long as I know not to [be active] right after I eat, which can sometimes trigger the chest pain.” (ACHD17-3).

Limitations. Participants experienced a wide variety of physical and psychological limitations that constrained physical activity behaviour. Some spoke about experiencing shortness of breath and chest pain, which were also mentioned by others in previous stages. When asked about factors preventing her from being active, one participant described how increasing her walking distance with a friend made it difficult for her to maintain a normal breath, “I started going on walks with my friend. We go four kilometers and I have trouble catching my breath.” (ACHD22-3). Another participant experienced chest pains when active as a result of being overweight. However, as she modified her physical activity behaviour and lost weight, she became used to taking on that much physical activity and no longer perceived it as a risk:

My big risk I know back whenever I hadn't lost the weight was definitely sharp pain in my chest. That is still a real possibility, but it seems more farther away of a risk. It seems more distant and not as related to me than it used to be. [It] doesn't seem as big as a threat [as] it used to be. (ACHD25-3)

Participants stated that physical activity participation was hindered at times by feelings of depression. However, participants turned to physical activity to overcome depression and enhance their well-being. One participant severely affected by her CHD described her experiences of depression and the importance of integrating physical activity in her life:

Usually [when depressed] I'd feel extremely down about myself. It was just a dark period for a couple of days and the only thing that brought myself out of it was the fact that I'd say, “OK I don't like this how about we try having a shower.” Then I'd feel a bit better. Then [I'd say], “I know you feel like everything [is bad] right now but we're going to go for a walk.” Then I'd slowly do more and more and that

would bring me out of dark feeling times. Then I'd want to be more active because it kept me feeling better. (ACHD1-2)

Another factor preventing physical activity behaviour was the psychological limitation of feeling lethargic. A participant described her disdain towards swimming because it involved going back and forth without any variation in the activity, "Swimming the laps I found it long. I was like, "It's only been five minutes that I'm here, it feels like forever." [...] I prefer change of scenery." (ACHD22-3). Another participant expressed a lack of interest in exercising on elliptical machines for similar reasons compared to when she played sports, which she found more stimulating, "I'm trying to sell my elliptical because that's boring. When it's a game you don't even feel like you're exercising. You're just having fun." (ACHD12-2).

Lifestyle. Other participants mentioned schedule conflicts between work, school and physical activity participation. When a participant was asked what prevented her from being active, she mentioned, "When work gets in the way [...] I'll cancel and reschedule." (ACHD12-2). Interestingly, however, she rescheduled her physical activity instead of abandoning it, which marked a difference between how schedule conflicts impacted physical activity participation for those in this stage compared to previous ones. Another participant found her work physically demanding and in some cases was too fatigued to engage in physical activity afterwards:

Most of the time, it's just the fact that after a long day of work I'm so physically exhausted I can't move my body anymore. Then the next day I'm like, "I'm going to treat myself to a nice relaxing day. I'm not going to do anything." (ACHD25-3)

A participant cited work, school and weather as the main factors preventing her from being active at times: "A couple of weeks ago it was schoolwork. Obviously, I had to get schoolwork

done. Now, the only things keeping me from being as active as I want to are my part time work and some days the weather.” (ACHD23-3).

Non-CHD Specific. The last intrapersonal factor influencing physical activity participation for participants in this stage was non-cardiac related illnesses. One had been sick during the winter season, which prevented her from being active, “I was really sick in January, so I didn’t actually go back to play [pickleball] [because] I was a bit dehydrated because of the congestion.” (ACHD12-2).

Interpersonal

Professional Guidance. A participant mentioned that she once withdrew from a cardiac rehabilitation program because she was no longer scheduled for cardiac surgery, but that when apprised of her reason for withdrawing , her cardiologist re-registered her for the program. She added that her cardiologist’s straightforward approach made her perceive stigma from him. She had been living a sedentary lifestyle at the time, which was why the cardiologist employed a straightforward approach to promoting physical activity. Today, however, she has an active lifestyle and is motivated to be active to impress and seek validation from her cardiologist during routine clinical visits:

Last time I was there [my cardiologist] asked me if I was doing cardiac rehab and I said, “No.” and my excuse was that I wasn’t going to get the transplant so therefore I didn’t need to do the rehab. Her answer was, “Nice try.” She’s very forward with me which I like. She said, “You need to be doing physical activity and I’d like you to do cardiac rehab.” [Knowing] I have an appointment coming up and knowing what she’s going to say to me I kind of feel better saying, “Look

what I've been doing." and she won't be mad at me, which is very exciting.

(ACHD1-2)

One participant was more motivated to engage in a particular physical activity after her healthcare professionals advised her against it. She wanted to prove she could participate in any physical activity she desired. She would do so by gradually increasing the intensity of participation without putting herself in danger, believing her cardiologist would not consider the physical activity risky for her:

When you tell me I can't do something, I'm going to prove you wrong. Say there was an activity where [doctors would] say, "No you can't do that." [I] wouldn't do [the activity] right off the bat. I would stick to where I was comfortable and where the doctor was comfortable. [I] would work myself in gently to be able to get to a point where if I asked them again, I would be able to do that activity with their permission. (ACHD25-3)

Participants' discussions on physical activity guidelines with healthcare professionals brought up an interesting perception. When participants were told to reach at least 30 minutes of moderate physical activity per day by their healthcare professional, some believed it would be a nuisance for those who were less motivated to be active. Participants' perceptions of predetermined physical activity guidelines were as follows: once someone attained the minimum of 30 minutes, they could reward themselves by engaging in unhealthy behaviour. One participant described how she reacted when given that guideline earlier in her life when she was sedentary:

It's like, "All I have to do is hit 30 minutes then I can sit down and eat a bag of chips and have a pop and boy I've done so well." I think you need to incorporate more than just 30 minutes a day. (ACHD14-3)

The participant also perceived the minimum of 30 minutes to be low, but recognized that some are less motivated to be active and less efficient at dedicating time for physical activity participation in their day. She therefore devised a strategy of breaking up the 30 minutes into ten-minute intervals to help those who are less motivated from being overwhelmed:

It's a little on the low side, but to a lot of people it's kind of overwhelming. They don't know how to fit it in their day. That's why breaking it up ten minutes in the morning, ten minutes at lunch, and ten minutes in the evening [helps]. (ACHD14-3)

Discouragement and Encouragement. An interesting subtheme for those who had recently increased their physical activity regimen was overprotective significant others. A participant described how friends sometimes perceived certain physical activities to be unsafe for someone with CHD, even though she herself was not concerned. Friends' perceptions led her to re-evaluate the activity and doubt her ability to participate:

If [friends] are doubting me in that they think it's not safe for me. Sometimes say I want to go hiking, someone will say, "That's not good for someone with a congenital heart defect, you should just stick to walking." I know it's safe, but it makes me think, "OK I need to at least be more careful than I would be." I definitely second guess things that usually ends in me trying the activity anyways and seeing how far I can push until it's too much for me. (ACHD25-2)

On the other hand, a common interpersonal factor promoting physical activity participation in this stage was encouragement from healthcare professionals. Participants in this stage described being motivated to stay active after receiving positive feedback from healthcare professionals. One participant had this to say, "Since I'm slowly stepping into maintenance [and] I've lost 55lbs the

doctor is like, “Wow you're doing really, good, keep it up.” So, it’s a big pat on the back for me.” (ACHD25-3). Another participant who did not receive appropriate guidance or encouragement to increase physical activity said she was motivated by the positive reinforcement she received after sharing her physical activity regimen with healthcare professionals:

I don’t recall anything that they said, or did, that suggested I should go and be physically active other than the last time I went in [for my annual appointment]. I came in and [the nurse] said, “You're looking great.” So, from the perspective of, “Keep on doing what you're doing.” [I am motivated when I hear that]. [But] it wasn’t a specific “keep doing this or you should do this, you should do more.” (ACHD12-2)

Inclusion. Participants said that participating in physical activity programs allowed them to develop new interpersonal relationships. One participant indicated that taking up pickleball had exposed her to a new group of people and that it became an opportunity for her to “Meet new people.” (ACHD12-2). Others used physical activity to maintain existing interpersonal relationships. Now that she was able to walk longer distances, one participant said that she planned to get together with friends so she could do a physical activity they all enjoyed. The ability to take longer walks allowed her to stay integrated within her social circle:

I’m actually planning on going for a walk with my best friend who’s training for marathons. She’s helping me learn to run and walk longer. [...] I’m walking more to see my friends. Any time I go out with them we’re always moving whether it’s shopping or going on a nature walk. (ACHD25-2)

Institutional

Program Environment. Programs, or gyms, that promoted a comfortable environment through a sense of community emerged as an institutional factor. This theme can be described as recreational facilities providing a positive and welcoming environment for participants at different levels of skill or abilities. One participant related that a judgment-free sign was displayed at the entrance to a gym at a recreational facility, which she perceived as inviting :

It has this huge sign when you go in and it says, “No judgement.” You [also] see all kinds of people there from people older than me by ten-twenty years, to mentally challenged. Not everybody is this athletic fit little body. Everyone does their own thing. People say hi to you. It’s very friendly. (ACHD14-3)

Still on the topic of facilities, other participants indicated that the positive attitude displayed by program staff in promoting a comfortable environment made them feel welcomed. One said: “[The facility] is truly a no judgement zone which is important to me. The staff are very friendly and so are the other patrons. It’s really just a nice place to be it’s comfortable.” (ACHD1-2). Another participant described how the environment of the facility where she played pickleball made her comfortable and less fearful when playing, “It turned out my fears were taken away because it’s a relaxed easy environment.” (ACHD12-2).

Adaptability. One participant cited the importance of facilities offering activities that were within her physical abilities. When she took up pickleball, the facility had times designated for specific age-groups to play at, which allowed her to engage with others her age and with similar physical abilities, “[It’s] 55+. I thought, “it’s sort of designed for my age group.” [...] The ball is bigger than a tennis ball and it’s hollow. So, it doesn’t bounce as hard.” (ACHD12-2).

Logistics. Some participants said that program timing preventing them from joining. One participant stated that she would have liked to join a Tai Chi program, but it was offered in the evening, when her energy levels are at their lowest, “I was going to join a Tai Chi class but it’s at the end of the day [but] at the end of the day I’m usually pretty toast. So, I’ve decided against it, but I may go in the future.” (ACHD1-2).

With regard to exercise programs specifically, when a participant was asked why she discontinued her involvement, she explained that it was because she always did the same exercise regimen, and it became repetitive. Thus, the exercise program or circuit appeared to lack variety, “It’s the same thing. There’s no variety really. It’s eleven or twelve machines and in between it’s a 30 second rotation. [It’s] the same type of routine so I don’t really like that.” (ACHD1-2).

Community

Weather. The most common community-related factor influencing physical activity behaviour in this stage was weather. Participants spoke about engaging in outdoor activities, such as walking and biking, because of good weather conditions. One claimed, “I can walk and bike. I’m beginning to walk more that’s because of the weather.” (ACHD24-2). The participant also cite challenges related to being active and eating properly in the winter compared to the summer months, “We have to consider that is the weather. [During springtime] I normally start feeling better. Winter is tough for me. It’s not just the food and exercising, but it is the weather.” (ACHD24-2). Another said that warm weather allowed her to engage in season-specific activities that were physically demanding, such as gardening:

[Because of the] warm weather for the past couple weeks I’ve started my garden.

[I’m] moving huge bags of dirt, getting on my hands and knees to rip out old plants and put in new plants and walk around a lot. (ACHD25-3)

Convenience. Participants mentioned convenience in accessing recreational facilities as a factor influencing physical activity behaviour. Participants who had a short commute from their home to a recreational facility found it easier to stay active on a regular basis. One had this to say: “We ended up settling on [a gym] [because] it’s close to us. We love it. [...] We go three times a week.” (ACHD14-3). Her physical activity regimen consisted of going to a nearby gym and engaging in season-specific activities like walking and biking, “[We go to the gym] and on the other the times we walk. [We] just started biking. [...] We live [by the river] and my goal is to be able to go up by the bike path [to downtown].” (ACHD14-3).

Strategies

Cognitive. The main cognitive strategy employed by participants in this stage was consciousness raising. However, unlike in previous stages, this involved the use of electronic devices while active to identify CHD-related symptoms, such as elevated heart rate, body temperature, catching one’s breath, and tachycardia, and reducing the intensity of physical activity participation in response. One participant used an electronic device to track her heart rate when active. If her heart rate went above her ideal parameters, she would reduce participation, “I know what my target heart rate is. I got my Fitbit on and it’s pretty accurate when my heart rate goes really high it registers. I can feel it. So, I can just take my time.” (ACHD14-3). She mentioned that her cardiologist had advised her to include a warmup and cool-down when active so her heart rate would not increase too quickly and put her in danger:

I had a cardiologist appointment not long ago and [they] warned me about my atrial fib [and how] when I exercise, I really need to have my warmup and my cool down because with my atrial fib, my heart rate goes high very quickly. [...]

I'm very conscious of that and I do that even when we mall walk. We start off at a slower pace. (ACHD14-3)

Another participant made sure to maintain a normal body temperature and use proper breathing techniques when active. Upon recognizing that she was out of breath, she reduced the intensity of her participation:

Keeping my body temperature down is a huge thing for most of the hinderances.

If I'm having a hard time breathing, I'll try and slow down to get my breathe back then keep myself in a situation where I can get calm and then I'll try again maybe; a bit slower but still I'll keep pushing myself as much as I can. (ACHD25-2)

Another participant experienced a significant cardiac event (tachycardia) as a result of increased physical activity participation, so she now avoids gyms altogether in favour of other types of physical activities, "Last time I quit [the gym] because I was in the middle of a workout, and I had a run of the tachycardia and it scared me. I just thought I can't go back, and I didn't go back." (ACHD1-2).

Goal setting also emerged as a cognitive strategy employed by participants. While participants in this stage set small goals, which was similar to participants in previous stages, they set larger goals as well. One had set a larger goal of increasing the frequency of her physical activity participation with her significant other to every day, since she aspired to maintain her physical activity regimen, "It's a goal. [...] We're doing an activity every day so it just kind of got us into that mindset that we got to move we got to do something." (ACHD14-3). Another participant described using physical activity to reach a desired weight as a larger goal, but this larger goal would be reached through achieving smaller goals such as weight loss and weight maintenance:

It's still my goal to be 145lbs. I have added a small goal. My first small goal would be to be at 155lbs, but I guess that's the small further down goal. My first immediate goal is to stay 166lbs consistently at least for a week or two or even try to go lower than 166lbs. [...] I've been there for so long I want to get out of there first. So, then get to 155lbs and then push to 145lbs, which is my big ultimate goal and then maintenance and taking care of myself. (ACHD25-3)

Behavioural. One behavioural strategy that emerged from the interviews was stimulus control. Many of the participants used calendars to prompt physical participation in a pre-determined timeslot and could effectively reschedule physical activity participation to another time if a conflict emerged. Thus, participants were able to efficiently time manage to maintain their physical activity commitments:

I have it in my schedule. I'm going to play pickleball. I have in my schedule that Tuesdays and Fridays I'm going to work out with my trainer. [...] I can often reschedule things during the day, but I still try and keep those commitments. [...] Time planning are all very important to be the most sufficient with your time were all busy people. (ACHD12-2)

Similarly, participants spoke about journaling their physical activity participation in a calendar to set a time for physical activity participation. One claimed, "Since I've been going to the gym. I've been putting it on my calendar. I went to the gym for this long, I biked for this long." (ACHD14-3). Another participant cited the importance of using electronic devices (i.e., FitBit) to quantify her daily step count and use the data for friendly competitions with her mother to see who was more active. This motivation to compete against her mother has its genesis in the dual strategies of stimulus control and helping relationships:

I got a Fitbit, and it has made a tremendous difference. I'm in a daily showdown with my mother on who can get the most steps. So, there are times where I'm pacing my house trying to catch up to her. We just have daily step competitions, and it has an app. It follows your step patterns, your heart patterns, your exercise patterns; it lays it all out for you. (ACHD1-2)

Counterconditioning was frequently mentioned by participants as a strategy to maintain an active lifestyle. In this stage, it consists of trying to maximize physical activity participation by modifying the way they accomplish daily living tasks, which bore similarities to participants in the preparation stages. Participants used strategies such as placing objects within their home in places that required more navigation to retrieve them:

One of the things that I do, and it sounds silly, but I'll put certain stuff downstairs, so I have to go downstairs to get it. because I don't like doing stairs, stairs are not the easiest for me but they're good to do. [It] gets my heart pumping a little bit. (ACHD1-2)

She added that to include more physical activity into her day, such as increasing step count, she would park her car further away from stores when shopping, "When I go somewhere instead of using the handicap pass if I feel like I don't need it I'll park farther away so that I'm getting more exercise to get to the grocery store." (ACHD1-2). Another participant mentioned using the same strategy when shopping, to increase her daily step count, "Unless it's freezing cold, when I go shopping, I park further away so I add a few steps. I just try and add a few steps wherever I can." (ACHD12-2).

Maintenance Stage

In the maintenance stage, individuals continue behaviours they adopted in the action stage. They tend to rely less on processes of change, as the behaviour is second nature to them. Accordingly, they stay in the maintenance stage either permanently or for several years. The themes and subthemes discussed below were associated with participants in the maintenance stage, most of whom engaged in a high frequency of physical activity and maintained a structured physical activity regimen while experiencing few constraints. A summary of the themes and subthemes for participants in the maintenance stage is provided in Table 7.

Table 7

Factors influencing physical activity behaviour in the maintenance stage

Themes	Constraints	Facilitators
	Intrapersonal factors	
Meanings		• Maintain health and function • Taking rational position • Sense of normalcy • Perceived freedom
Readiness for change	• Occasionally force themselves to be active	• Physical activity completely integrated into daily regimen
Knowledge		• Broad conceptualization of physical activity
Experience		• Exposure during childhood • Previous enjoyment during childhood
Non-CHD specific	• Non-cardiac related illness and ailments	
CHD-specific		• Moderate diagnosis • Anticipating cardiac surgery • Significant life events perceived as singular
Lifestyle	• Lack of time	

Limitations	• Physical: General fatigue, aches and pain, chest pain • Psychological: Self-doubt	
Perceived benefits		• Seeing results • Body awareness • Physical: Increased strength, increased flexibility, increased coordination, increased bone health, decreased pain, enhanced sleep quality, increased energy, weight loss, quicker recovery from cardiac surgery, increased heart health • Psychological: Enhanced body image, sense of accomplishment, increased confidence, enhanced mood, increased well-being, escapism, decreased stress, perceived control
Perceived risk	• Fear: Unknown • High perception of risk	• Low perception of risk
Interpersonal factors		
Encouragement		• Active family members • Active social circle • Receiving encouragement from healthcare professionals
Inclusion		• Active with others • Active with significant others • Being part of a team • Developing relationships • Strengthening relationships
Professional guidance		• Receiving specific recommendations
Institutional factors		
Logistics	• Activity structure • Temperature regulation	
Adaptability		• Activities within abilities

		• Staff adapting to needs
Community factors		
Convenience	• Convenience	
Weather	• Weather	
Strategies		
Cognitive	• Goal setting: Maintaining or adding more physical activity to current regimen	
	• Consciousness raising: Using resources to inform oneself on health behaviour	
Behavioural	• Stimulus control: Using calendars. Using electronic devices (e.g., Fitbit)	
	• Substitution: Substituting a physical activity behaviour for another similar behaviour	
	• Helping relationships: Have a workout buddy to motivate participation. Role modelling for others	
	• Cyclical commitment: Alternating between high frequency of participation and low frequency of participation	

Meanings

Among the most commonly mentioned meanings of physical activity for participants in this stage was maintaining health and function. Similar to previous stages, participants focused on being active as a means to avoid future ailments. One participant put it this way: “The more active I am, the less problems I will have when I get older.” (ACHD15-2). Another explained that she maintained physical activity participation so that she could continue to complete tasks of daily living, “Physical activity is more than sports. It’s about maintaining a level of fitness so that you can achieve what you want, whether that’s just a matter of being able to walk to the grocery store.” (ACHD3-1).

Many participants stated that physical activity promoted longevity and would help them live independently in the future, in addition to extending their life expectancy without complications or the need for cardiac surgery. Participants stated, “[Physical activity means] long term is health.” (ACHD18-1), “[I’m] physically active to hopefully be able to lead a long and healthy life. Less stress and hopefully adding many years to my life.” (ACHD7-1), and “To me it

means longevity. Hopefully it will keep me healthy. Living longer without surgery.” (ACHD5-1). Another participant remained active to maintain her independence and avoid having to rely on others for assistance in the future, “I want to be able to do certain things without the assistance of others and so for me it’s about the independence more than anything else.” (ACHD16-3).

Additionally, a participant described physical activity as a means of developing his individual identity. Going to the gym and identifying himself as physically active impacted his life and the people he surrounded himself with. This had implications on deciding to maintain an active regimen:

It helps you become who you are. You just want to keep up with people. You also want to prove it to yourself, and it changes you. I probably wouldn’t be the type of person I am today or probably dealt with certain experiences throughout my life if I wasn’t active. [It] dictates your life. [You] attract a social group to that standard. (ACHD13-1)

Participants in this stage also expressed how physical activity provided them with a sense of normalcy. One mentioned that her parents were apprehensive about her participating in physical activity, but she did so anyway to experiment with her limitations and to be with her friends without feeling different:

My parents, I’m not going to say sheltered me, but just wanted to be cautious. [I] kind of started believing that if I wanted to go and do something I’d tell myself, “I can’t do that.” I’d believe it because what my parents tell me, but they don’t know [my abilities]. Only I can know. [My] friends were going off and I was like, “I want to go do that too. I don’t want to feel like an outsider or different.” (ACHD13-1)

Other participants also mentioned wanting to push themselves to determine their abilities in physical activity and not let their CHD be a reason to hold back and feel different. One said: “Don’t let [CHD] be an excuse. I never wanted to be an excuse unless it was something extremely [detrimental] to my health. [I] just wanted to do it like everyone else.” (ACHD13-1). Another participant mentioned that being able to return to the gym post-surgery made her feel like everyone else again:

I wanted to push the limits because I wanted to have a sense of normalcy in my life.

[...] The gym ironically was probably my life saver after my surgery because that’s when I couldn’t wait to get my exercise shorts back on and feel like that normal person again. (ACHD8-1)

Physical activity allowed participants to experience perceived freedom, serving as a context for them to explore personal abilities without perceiving any constraints imposed on them. Participants focused on being in the moment and on the activity they were engaged in, “When I was skiing, I was in that moment. When I was rushing down the hill like a crazy person I was in that moment, and it felt free. Just being free of everything.” (ACHD16-1). For another participant, physical activity was a context in which others were not there to impose limitations on him, allowing him to explore his abilities and experience personal development, “I get to work on myself and do my own thing. Nobody’s there telling me, “Don’t go do that.” I get to just be like, “I want to do this. I get to do this.” (ACHD13-1).

Readiness for Change

Many participants said that their physical activity behaviour was completely integrated into their daily regimen, along with other activities of daily living. One put it this way: “It’s kind of like [you] always wash your face or you take a shower. It’s just become part of my daily routine.”

(ACHD8-3), and “As anything does with repetition it just becomes a part of our lifestyle and I just enjoy doing it all the time.” (ACHD13-1). Another participant expressed how physical activity was second nature to her in that she did not have to think about participating as it was so integrated into her lifestyle, “I don’t even think about it it’s that meaningful. It has to happen and if it doesn’t happen then I make it happen.” (ACHD5-2). Participants also likened their devotion to physical activity behaviour to that of a drug addiction in that they experienced significant gratification when active, “It becomes an addiction. [...] It’s almost like a drug. [...] It’s just its own reward.” (ACHD13-1), and “It just makes me feel really good. [...] I just love it. it’s almost intoxicating. I guess it’s my drug of choice.” (ACHD16-1).

Yet, participants in this stage also felt as though they occasionally had to force themselves to be physically active, particularly when fatigued from having to do tasks of daily living such as work, groceries, etc. One found it difficult at times to motivate herself to be active after working all day, but wanted to maintain her active regimen regardless:

It’s hard to motivate myself to go. I do it because I know it’s good for me [...]. I love the walking and the running. The weight training: it’s good and I like the results, but you work all day and think, “I got to go do an hour of this now.” but once I’m done, I feel good. [...] I know I just have to do it. It’s just not an option. (ACHD5-1)

Another participant perceived physical activity participation as a chore and decreased his participation at times, as it was not a priority compared to other tasks. However, he did not maintain this mindset for long, as he missed and enjoyed being active:

When I switch from being active to being less active and where it becomes a chore is when I get really busy, and it really is like the tenth thing on my list. I got to get all this stuff done at work. I got to get the groceries. I’m trying to fit it in and it’s one

of those things that's less important than say getting the groceries or getting the laundry done. If I have to take a break that's one of the things that gets bumped off. [After] I've been in that low and not exercising much I get to a point where I'm like, "I got to fit this in. I got to do it." and I go and do a run, or I go to the gym and I go, "This is so good. It's fun and I enjoy it." and then it builds from there and you just do more and more. (ACHD21-1)

Intrapersonal

Knowledge. Participants in this stage had a broad conceptualization of physical activity as something that could be done in a variety of ways, be it walking, sports, gardening and so forth. Thus, they did not view it as limited to a structured activity. But they stated that it must be something that elevated their heart rate: "Getting up and move. [...] Taking a fair enough walk and jogging. Doing anything that gets your heart beating faster than it does at rest." (ACHD18-2), and "Any kind of movement is physical. It doesn't have to be playing hockey or playing basketball just as long as you're up and moving. Gardening is considered physical activity." (ACHD15-3). Another participant emphasized the importance of developing a good understanding of what constituted physical activity so that young CHD patients could learn to engage in various forms of physical activity, and not only forms that involved exertion:

I think people with Marfan syndrome need to develop a more nuanced understanding of what it means to be physically active. When I was younger it wasn't really engrained into me that there were a variety of ways to be physically active. It was basically you play sports, or you don't. [...] But that's not the way it is. There are lots of ways for me to be physically active and I don't have to be doing competitive sports and I don't have to be pushing myself beyond my limit. (ACHD3-1)

Experience. When recalling their history of physical activity, most participants in this stage reported being exposed to physical activity at a young age and having taken part in various forms of physical activity, ranging from structured, or regimented, sports, to recreational sports and physical activities: “I did sports growing up. I played soccer, hockey, basketball, recreationally.” (ACHD7-1), and “As a youth [I did] typical kid stuff like cycling, playing recreational tennis, [and] typical outdoor play stuff. [I was also on a] youth softball team, [and] jazz [dance] was a big part.” (ACHD8-1). In addition, participants explained that their previous experiences of enjoyment in physical activity during childhood made them want to pursue similar physical activities during adulthood. One participant had played broomball as a child, and it remained to this day an important part of his and his children’s life , “[Broomball] looked like fun. I still play. Now both my kids play. I coach my one kid provincially and I coached house league for both of them. [...] I just kind of got good at it and stayed there.” (ACHD18-1).

CHD-Specific and Perceived Risk. Participants described how having a moderate CHD diagnosis allowed them to engage in and pursue physical activities throughout their life. They explained that their type of CHD had very little impact on their personal abilities and that they never had any physical activity restrictions placed on them throughout their life: “I don’t have big restrictions because of my particular congenital heart defect. [...] That’s what allows me [to be active].” (ACHD8-1), “I don’t think my heart problems are as bad as some peoples. It never stopped me from [being active]. I just did it.” (ACHD15-1), and “Mine is so non impactful. It doesn’t cause me a lot of problems.” (ACHD21-2). Interestingly, however, one participant mentioned how having little to no restrictions placed on him had led him to experience some fear and self-doubt as to how far he could actually push himself in a safe manner, “The main challenges are the fear of not knowing [and] the self-doubt. There’s no actual physical parameters. I don’t

have any doctor restrictions, so your head plays games with you a lot.” (ACHD2-2). A relationship between fear of the unknown and self-doubt from having no limitations with regard to physical activity was therefore identified.

Other interrelated themes that emerged from discussions with participants were anticipating cardiac surgery and quicker recovery from cardiac surgery. Participants described how they anticipated having to undergo cardiac surgery in the future. Thus, they sought to maintain their physical activity regimen to be in the best possible physical condition in preparation for potential upcoming surgeries and to speed up their recovery post-surgery: “In my case, [I’m] going to need not another open-heart surgery again but I am going to need something. [...] So, by being physically active I’m just setting myself up for better recovery time down the line.” (ACHD7-1), “If you know down the road, you’re going for more surgery it can only be beneficial for you to go in the best possible shape you can be going into surgery.” (ACHD8-1), “If you end up having to have an operation for your heart or whatever if you’re already active then you’re stronger to begin with whereas if you’re totally sedentary it’s probably harder to get over.” (ACHD15-1), and “I exercised right before I got in the best shape, and I think positive thinking helps. I attribute that honestly my recovery to exercise.” (ACHD16-1).

Participants perceived cardiac events as singular, much like participants in previous stages had done. They spoke about experiencing cardiac issues and requiring cardiac surgery, but maintained that once they had recovered from surgery, they sought to be active:

I really started feeling the effects of my faulty valve and had a leakage. [...] I went to talk to my cardiologist [and asked], “Was this due to my heart deteriorating, having the patches deteriorate having issues there or my age?” He said, “It’s really more the

heart probably than your age at this point.” [And] then post after the surgery recovered and continued running. (ACHD7-1)

I couldn’t wait to get back. That was the hardest thing for me. [I] had some lung issues after my surgery so it took me a while to get back. I was also told after my surgery, “You’ve been fixed.” (ACHD8-2)

Participants also described experiencing cardiac issues when being active such as syncope and abnormal breathing, yet those experiences did not deter them from their desire to maintain their active lifestyle:

I ended up passing out sometimes but that didn’t even deter me. [...] A psychologist came to see me [and] provided information and I said, “Thanks a lot but I just have this little problem and once the surgery is over if I’m alive I’ll just move on.” (ACHD16-1)

I was working out with a friend and after the workout I came home, and I just felt a general strain on my heart, and I couldn’t get my breathing down. [...] I came home and even my parents were even worried about me at that time because they’re like, “Do you want to go to the hospital?” [But that didn’t stop me from going back after a little while]. (ACHD13-1)

Perceived Risk. Subthemes pertaining to the degree of risk associated with physical activity behaviour emerged from interviews with participants in the maintenance stage. Many expressed a low perception of risks from physical activity participation. When asked what they believed the risks of being active with CHD were, many said that there were very few risks if they avoided overexertion, “If you overdo it too much. If you don’t know your own limits. [If] you over push [it’s] not good for your heart [but] I guess that could apply to anybody.” (ACHD18-1), and

“I don’t think you should overdo it. I think that you need to listen to your body. If my heart starts to beat out of control, I need to slow it down. [I] do listen to my body.” (ACHD16-3). Participants also explained that while there could be some risk related to overexertion, most of the risk lay in experiencing musculoskeletal injuries such as muscle tears or breaking bones from slipping, “[It] can be risky for the heart but that’s if you push yourself to [the] limit. [...] [But I think] it has to do with my muscles. [So], connective tissue tears are a risk when I’m doing Pilates.” (ACHD3-1), “I’ve hurt myself a couple of times at hockey where I had to take long times off but other than that I don’t think so.” (ACHD21-3), and “If you do a lot of walking in the winter there’s a lot more risks because you can fall and break a hip.” (ACHD15-1).

Conversely, many participants in this stage also expressed a high perception of risk associated with physical activity participation. When asked about the risks of being active with CHD, they described some of the potential issues that could arise for them specifically and their type of CHD. One cited the possibility of atrial fibrillation, “I’d be afraid of getting a heart attack and the palpitations because they’d be like [atrial fibrillation].” (ACHD19-3). Another discussed the risk of muscle tears, dislocated joints, retinal detachment, aortic dissection and aneurysm as a Marfan patient:

For me there’s a lot of risks that I’m aware of. In terms of my body and my anatomy I know that I’m at an increased risk of muscle tears and ligament tears and dislocated joints and I’ve experienced some of these in my life. [I’m] at risk of an aortic dissection or aneurysm. I know I’m at risk of retinal detachment. (ACHD3-1)

Still another mentioned the risk of sudden cardiac death associated with being active, but perceived that the benefits of being active outweighed costs and thus was not deterred from being active despite the risk of sudden death:

If you drop dead, you drop dead. [My] understanding of sudden cardiac death is if I did have a bicuspid valve and it does fail it's kind of one of those things that you just say, "If I'm going to go, I'm going to go" and just own it. [The] pros always outweigh the cons. [...] I feel great. I'm getting faster, fitter, I'm eating extremely healthy. So, [if] something was to happen it's kind of like, "At least [I was] moving towards a better goal." (ACHD2-2)

Perceived Benefits. Participants felt that their physical activity participation was motivated and facilitated by evidence of their progress in the form of objectively measured and quantifiable results (i.e., step counts, heart rate, time spent doing exercise circuits, sport statistics). One put it this way: "Seeing the numbers on [my device] that's a motivator as well." (ACHD3-1), while another participant mentioned:

[It's] just an obsessive nature that it's a quantifiable result. In hockey, a quantifiable result would be making a team, how many goals you score. [...] You can record so much nowadays. My cycling meter on my bike. My watch for running. Everything is just extremely quantifiable that you can get better. You can improve the weight drops. (ACHD2-1)

Participants in this stage experienced a variety of physical benefits which motivated their desire to maintain an active regimen. One mentioned increased strength through physical activity, which she enjoyed since it countered the weakness she experienced from cardiac surgery, "I liked the fact that it made me stronger because I'm always really weak and it's due to the heart condition surgery." (ACHD16-1). Another participant touted the increased flexibility she got from yoga, "When I started yoga, I realized that I could [sit cross legged]. So, it does help with the flexibility. That's a big plus." (ACHD15-1). She also cited increased bone health through weightlifting, which

has had a benefit on her osteoporosis, “I have osteoporosis and when I went [to the doctors] they said that my osteoporosis had improved. So, weightlifting [is] why staying active is good.” (ACHD15-1). Coordination was also mentioned as a benefit, as a participant described having better hand eye coordination from playing broomball and baseball, “It helps out because the more stuff you do, you improve your hand eye coordination.” (ACHD18-1).

Participants with Marfan syndrome said that physical activity participation helped them reduce and manage their muscle and joint pain. A participant stated, “[...] less aches and pains just levels everything out.” (ACHD15-1). Another mentioned how pain management through physical activity allowed her to accomplish tasks of daily living:

For quality of life and pain management. [I] feel terrible if I don’t incorporate physical activity into my day. I feel tired I can’t move very well. I know that my muscles are basically disappearing and falling apart. I’m mostly physically active just so that I can keep living day to day. (ACHD3-1)

Many participants cited better sleep quality from being physically active. “I can sleep sometimes better too.” (ACHD19-1), and “I like to be physically active to wear myself out and to have a good sleep.” (ACHD3-3). In addition, participants explained that by sleeping better they tended to experience increased energy during the day, establishing a relationship between these two themes. “I sleep better if I’ve been physically active in the daytime and if I sleep better then I’m more energized the next day.” (ACHD3-1), and “Everything from sleeping better to feeling better to having more energy throughout the day.” (ACHD8-1). Participants also described how having more energy allowed them to accomplish more tasks of daily living, reduce sedentary behaviour such as watching television, and have enough energy to make it through the day, “The more active I am, the more energy I have. I stay in motion and not just sit on the couch and watch

TV.” (ACHD18-3), “You get more stuff done around the house.” (ACHD18-3), and “It gives me a good jolt and I feel very alive once I’m done. I feel a burst of energy which gives me enough energy for the night.” (ACHD5-1).

Similar to previous stages, female participants cited weight loss as a benefit of being active. “It keeps my weight where I want it to be.” (ACHD5-2), “You realize your health benefits like obviously weight loss.” (ACHD13-1), “I noticed that a heavy running week will result in weight loss.” (ACHD2-1), and “It helps me keep my weight down which is a big issue.” (ACHD15-1). Additionally, a participant mentioned that as a result of being able to lose and maintain a certain weight, she began to have an enhanced body image when dressing for the day, “I put my clothes on I think, “That looks pretty good. I feel good.” It makes me feel very healthy and very happy.” (ACHD5-3).

Participants said that regular physical activity helped improve their heart health, keep their heart strong and ward off cardiovascular diseases unrelated to CHD, “If you get lazy then your heart gets lazy, and everything goes downhill. You got to keep it in shape because it’s not in shape and then [you’re in trouble].” (ACHD18-1), “Exercise is so important for the heart and prevents cardiovascular diseases.” (ACHD4-1), and “It’s keeping our heart healthy. [Just] because you’re a CHD person doesn’t mean that you can’t be susceptible to other cardiovascular diseases too so just keeping that in mind.” (ACHD8-1).

In addition to physical benefits, participants described several psychological benefits which motivated continued physical activity engagement. As in previous stages, participants described feeling a sense of accomplishment through physical activity, “It feels like you’re doing something, like you’ve accomplished something by going and doing the exercise.” (ACHD21-3), and “When I come back from walking [it] gives me self-confidence.” (ACHD4-2).

Another participant described the increased confidence brought on by participating in physical activity, and indicated that physical activity “helps your confidence. It helps make you look better. It makes you feel better about yourself. It’s also really nice when you see people taking notice.” (ACHD13-1). Building on this increased confidence, participants noted that being active enhanced their mood and well-being, a benefit also mentioned by participants in previous stages. One participant claimed that her enhanced mood translated to other areas of her life, such as interacting with others, “I have a better mood with others because I know that I did something good for myself.” (ACHD4-2). Another participant credited physical activity with overcoming feelings of depression and stress, “It makes me in a better mood. It makes me happier. I think that sadness and depression and stress take a toll on your life and your body. [If] I was inactive I’d be in a depression.” (ACHD16-2).

Participants in this stage perceived having control over their health by maintaining an active regimen. “I can control my body more instead of being told what my limitations are.” (ACHD4-1), “I felt like I was in control. Rather than letting someone else have control I was in control, and it made me positive.” (ACHD16-1), “I’m always in control. I always know what I’m doing. I never try something new where I’m not sure what will happen.” (ACHD13-1), and “Some Zumba instructors I will not take their class because it’s just too high intensity. [...] I like to push my limits but I also kind of like to be in control of where I’m at.” (ACHD8-1).

Several participants used physical activity to experience escapism and decreased stress, “I use Pilates as a way to de-stress and I’ll either put on music or I’ll put on an audio book and just kind of get lost in it.” (ACHD3-1), “It allows me to escape for that one hour [class] where I just have myself and I don’t think about anything.” (ACHD16-2), and “There’s a spiritual aspect. [...]

When I'm gardening, I am putting soil, trees, and so on and I'm not thinking of anything else.” (ACHD4-3). Participants also touted yoga specifically, as an effective activity for reducing stress:

What I love about the yoga is that it is a very soothing type of [physical activity] which teaches you through meditation. You can actually calm down your brain, your thought, [and] your breathing. If you're feeling anxious there's different types of breathings you can do. (ACHD5-2)

If you have stress in your life, [yoga] helps with that because for that one hour you don't think of anything but what you're doing. You're in that moment and [yoga] makes you in that moment. I believe because you're feeling good you're less stressed. (ACHD16-1)

Yoga also had the ability to help raise body awareness for many participants, as participants believed they were able to manage symptoms, be it CHD-related or not, when active:

It has helped me a lot as far as keeping myself calm and just being mindful of everything that is going on in my body. Not to panic. Just think about it let it pass. Because the more I panic the more my heart races that doesn't feel good. (ACHD5-1)

[There are] many benefits with the yoga. [...] There's body awareness. Really getting to know and understand your breathing and your body especially I think for people with congenital heart disease it's really tough because we're always [questioning], “Are you short of breath? Do you have heart palpitations?” So, it's really nice to pay attention to your body. (ACHD8-1)

Limitations. While participants in this stage experienced several physical benefits, physical limitations prevented them from being active at times. General fatigue was identified as

a factor influencing physical activity participation. When asked what prevented them from being active, participants stated, “If you didn’t sleep well the night before the next day you don’t feel like doing anything. I think everybody goes through that.” (ACHD18-3), and “I have fatigue where I’m pretty tired.” (ACHD8-1). Body aches and pain were identified as another physical limitation. A participant cited the challenges of living with Marfan syndrome as a factor preventing physical activity participation, “I have a lot of chronic pain, back pain, joint pain, muscle cramps. That kind of thing that Marfan syndrome affects.” (ACHD3-1). Another participant reported chest pain as a factor constraining physical activity participation when lifting weights, “I get pains in the chest [...]. I’ve tried to do five pounds [weights] with my arms up for maybe 15-20 minutes [and] I get pains. So, I stop that.” (ACHD19-1).

Non-CHD Specific. While cardiac issues were mentioned, participants also described how non-cardiac related illnesses and ailments constrained physical activity at times. They stated that if they were feeling sick, they would avoid physical activity participation, “The only thing that would prevent me is if I got a cold.” (ACHD5-2), and “I got sick with the flu, so all my routines have been very disrupted.” (ACHD3-2). Participants also reported injuries from engaging in too much physical activity as an occasional constraining factor, “I had a bit of back problems about a month ago and that kind of slowed me down a little bit.” (ACHD18-3), “I ran five kilometers every day and on the weekends. [...] I started having issues in my joints and my lower back. They figured out that I was getting some degeneration happening in my upper and lower disks.” (ACHD5-1), and “What precluded me from further playing [volleyball] had nothing to do with my heart. It had to do with an elbow injury, so I just stopped.” (ACHD8-1).

Lifestyle. Lack of time was mentioned by many participants as a factor preventing physical activity participation. Having to deal with life priorities like work, family and childcare made it

difficult for participants to time-manage and include physical activity in their daily regimen, “Works ramped up so that’s usually what it is. I usually don’t have a lot of time to do anything else.” (ACH

D18-3), “It’s a time spent working and taking care of our children, so it sometimes feels like it’s not a necessity at times.” (ACHD4-1) and “Time management barrier. Wife and kids and trying to fit in the activity where you can.” (ACHD7-1).

Interpersonal

Encouragement. Participants in this stage reported that physical activity behaviour was encouraged by having had active family members during childhood. Participants who had been surrounded by physical activity growing up (parents and siblings engaging in regular physical activity) claimed that being active was a natural part of their lifestyle from a young age, “I grew up on [sports]. My [dad] played them growing up so I just kind of followed in his footsteps.” (ACHD18-1), and “I grew up with a pretty active family. My sister played soccer. My father played soccer all his life. My mom is a dancer. [...] It was just part of our lifestyle to be active and doing something.” (ACHD7-1). One participant mentioned that being active with family members eventually evolved into him becoming active with close friends and being confident enough to exercise alone when older, “It just grew from [exercising with] my big brother. Then it turned into close friends you work out with. You learn [from them] and then you don’t need anyone [and] it just becomes a way of life.” (ACHD13-1). Participants also claimed they enjoyed and were motivated by being active with significant others (partners and spouses). “To do doing something active with your partner is great and I really enjoy it.” (ACHD13-1), and “When me and [my husband] go together [for a walk] [it’s] just being outside is kind of nice.” (ACHD15-1).

Participants also mentioned that they maintained their desire to be physically active because they had an active social circle. Since their friends engaged in regular physical activity, which they sometimes did together, it became a focal point of discussion, “We belong to a group of very active friends. We do the once-a-month thing [where] we all talk about, “What did you do you?” [and] “Went for this hike.” Sometimes we do things together.” (ACHD5-1), and “That’s where I’m really lucky and a lot of my friends that I’m friends with is through physical activity.” (ACHD8-1).

Another factor motivating physical activity participation was receiving encouragement from healthcare professionals. Participants attributed their desire to be active in part to healthcare professionals telling them to be active during routine clinical visits and trusting their advice:

It’s funny that’s how trusting I am because of how amazing these physicians are.

[...] I totally trusted when [my cardiologist] told me, “Regular physical activity is a must.” and that always plays in my head. It stays there. Every time I go see him [he] was saying, “What level of physical activity are you doing? What are you doing?” So, I knew he was my check in. (ACHD5-1)

While one participant said her desire to be active remained the same after discussions on physical activity with her cardiologist, “I’m probably the same [level of motivation] because I already do a lot.” (ACHD15-2), others mentioned being more motivated to stay involved in physical activity after hearing positive feedback from their cardiologist, “It’s nice to hear someone say, “You’re doing a good job.” or “It’s helping your heart condition.” (ACHD21-3), and “The reinforcement keeps me going and feeling good keeps me going.” (ACHD5-2).

Inclusion. Participants suggested that being part of a team through participating in sports motivated their desire to be active. Not only did they feel obliged to attend their scheduled games,

but they also saw the skills they had learned through team sports (learning to work with others and achieving team goals with coworkers) translate into their workplace. “I’m part of a team. I know I have to be there. [...] You work as a team. You use it when you go to work. [...] It’s part of my job to know most of the people around.” (ACHD18-1), and “You [learn] to be part of a team. When you’re at work you got to be part of a team. [We do our] part to help out and each person [does] their part makes a success.” (ACHD21-2).

Participants expressed how being involved in physical activity, be it walking, exercising or playing team sports at recreational facilities, allowed them to meet new people and develop new interpersonal relationships. “[Being active is creates] opportunities to meet different people. Stay connected.” (ACHD8-1), “You talk to the neighbors and meet other people on the street.” (ACHD19-1), and “I like that I get some comradery there and go hang out with the guys.” (ACHD21-2).

Participants added that being active together with friends and family members allowed them to strengthen existing bonds and interpersonal relationships. “You get a better bond with someone when it’s just you two in a gym. Your friends [are] obviously your social circle and then when you’re done you go, “Let’s go out and do this.”” (ACHD13-1), “If I’m walking with my sister, we discuss our day and [when] we’re walking we’re laughing hysterically.” (ACHD16-2), and “I think it makes me a better friend or wife.” (ACHD8-3).

Professional Guidance. Other participants felt that specific recommendations from their cardiologists influenced their physical activity behaviour. One put it this way: “[My cardiologist] says, “If there’s something going on with you, you’ll be the first to know.” I’ve never felt anything go wrong with me.” (ACHD18-1). Other participants mentioned, “[My cardiologist] says don’t go towards your heart rate max. So, I use that as a guideline.” (ACHD2-1), “[My cardiologist] signed

a paper saying I was capable doing exercises that are moderate intensity.” (ACHD4-1), and “I had mentioned to my cardiologist, “Should I stop doing things or is it safe for me to continue what I’m doing?” He goes, “As long as you’re not feeling lightheaded, feel like you’re going to pass out just know your limitations and just continue being active.”” (ACHD7-1).

Institutional

Logistics. An institutional-related subtheme uncovered in this stage was temperature regulation within facilities. One participant mentioned that if the temperature was not regulated in a yoga class, she felt uncomfortable and could experience CHD-related issues:

If I go into a class and say the temperature is not regulated because the A/C is broken that’s definitely a barrier for me. [If] it’s a [yoga] class often I want to be near the fan in the room. [I’ve] had bouts of tachycardia in the past. (ACHD8-1)

A constraining institutional factor to physical activity participation for those in this stage was program structure, and specifically, when sports seasons or classes take place over a specified period. Participants took a break from physical activity between the end of one season and the start of the next. “In between seasons I usually get a month and a half-two months off.” (ACHD18-3), and “Right around now at the end once hockey is starting to slow down before summer stuff starts, I tend to find that I’m not as active for a month or so.” (ACHD21-3).

Adaptability. A facilitating factor motivating participants’ desire to pursue physical activity programs was that the activities were within their personal abilities. One participant thoroughly enjoyed aqua fitness, as the resistance and impact were appropriate for her personal needs, “[I enjoyed] the activity itself because you’d be dancing in water. It was low impact and the resistance on your knees, your hips, your ankles [was good]. I really enjoyed that. I actually had to kind of slow down.” (ACHD16-1). Another stated how important it was to engage in a

physical activity program that could be modified to match her needs, which is why she was drawn to Pilates:

My fitness has to be tailored to what I need and not to what an instructor wants to teach. On a day-to-day basis, I need to do fitness that meets my goals for that day. [...] I found a Pilates studio that offered these kinds of supervised classes where you were doing your own individually tailored program. [...] That's why Pilates stuck with me. (ACHD3-1)

Program staff's ability to tailor program activities to the participants' needs emerged as a motivating factor to continue pursuing physical activity programs. When participants attended a physical activity program, it was important that staff offered alternative ways to perform certain activities if they struggled. One participant noted, "Instructors need to ensure that exercise classes could be offered that "accommodate" or are flexible enough to include various levels of activity for a specific class. In other words, an instructor provides accommodations before or during the class." (ACHD8-1). Another participant cite the importance of program staff tailoring activities to her personal abilities when she first joined an exercise program:

I couldn't keep up with the class. There [were] things I couldn't do. [So], the teacher instructed us when she started the program [by saying], "Not everybody can do the same thing so I'm going to give you other things to do." [...] I'm still working on my cardio but I'm not doing exactly what the class is doing. (ACHD16-2)

Community

Convenience. Similar to previous stages, convenience was an important community-related theme for participants in this stage. The opportunity to frequent nearby recreational facilities helped motivate them to be active. Some participants attended facilities that were close

to their work, “I was looking for Pilate’s studios and there was a studio that was close to my work. So, it was really easy for me to pop out. It was a five-minute walk away from work.” (ACHD3-1), and “[Swimming] laps is something I thought of myself and that it would be a good exercise and there’s a pool close to work so I could get over there and get in and do it.” (ACHD21-1). Participants also indicated that the amount of equipment required to take part in physical activity was a consideration when taking on an activity. One participant enjoyed taking up snowshoeing, as it required little equipment and was convenient to participate in, “Snowshoeing I can pretty much bring my snowshoes anywhere. It’s easy.” (ACHD8-1). In contrast, another participant did not wish to continue to pursue rock climbing, as he would have had to purchase new equipment in addition to the facility not being conveniently located, “You got to buy new gear and you got to get to the climbing gym. Convenience is big with me. [The] rock gym is not close.” (ACHD21-1).

Weather. Another community-related theme for participants in this stage was weather. Participants in this stage, as in previous stages, felt less likely to participate in physical activity when weather conditions were poor. They did not go to recreational facilities or take part in regular outdoor physical activities like walking in icy winter conditions. “Sometimes I won’t go to Zumba if it’s an ice storm.” (ACHD8-1), and “The only time [I] didn’t go [walking] was when it was really frigid out [like] minus 34 [degrees].” (ACHD16-2). However, while participants avoided going outside during poor conditions, they would take on similar indoor activities instead. One explained that while she did not walk outside in the rain, she walked on her treadmill instead, which speaks to her level of self-efficacy, “Only time [I] don’t [walk] is when it rains and then when it does rain, I sometimes hit the treadmill.” (ACHD16-1).

Strategies

Cognitive. A cognitive strategy identified for those in the maintenance stage was goal setting. Unlike in previous stages, goal setting for those in this stage stemmed from a desire to maintain their current physical activity regimen or to add more physical activity, or structure, to their existing regimen. One participant wanted to add a personal coach to aid with his current training regimen so that he could compete in a triathlon and iron man, “I’m pretty confident that by next spring if I focus and get a coach to structure [my training]. [...] I’ll probably do just a sprint triathlon which is just super short and then maybe move to an iron man.” (ACHD2-1). Another participant did not necessarily have a strategy for maintaining her physical activity behaviour, other than having the goal of exercising five days per week, “I don’t have any strategy. I guess my goal is to exercise five days a week.” (ACHD16-1).

Another cognitive strategy employed by participants in this stage was consciousness raising (using resources to learn about health behaviours). Participants described reading magazines and information online to better inform themselves about health behaviours, “[I read] everything that talks about health like magazines. I do a lot of research on the internet about health.” (ACHD4-1), and “I’m always reading a health magazine or something online. [...] Stuff like that [and] the benefits of [whatever is health related].” (ACHD8-1). Another participant used online platforms such as YouTube to increase his knowledge on proper exercise techniques to apply when exercising:

I’d watch a certain bodybuilder [on YouTube] do workouts and they describe what they’re doing. Because they’re a bodybuilder they know the form. [...] [It’s] just someone teaching you who’s done it and knows how to feel [and] you’re like, “I can try that.” (ACHD13-1)

Behavioural. Of the behavioural strategies employed by participants in this stage, stimulus control was one of the most popular. One form of stimulus control involved participants scheduling physical activity participation in their calendar as a prompt, regardless of the number of activities planned for that day:

I have to make it fit in my daily schedule because if I don't it's easy to put it on the back burner. My strategy for this year is I get up at quarter to five, I'm at [work] by six, I get all of my work done [and] by 3:30 I'm gone, and I go to the gym. (ACHD5-2)

Another participant cited the importance of maintaining a regimented schedule to assure physical activity was included in his daily regimen, "[I'm] always on the go in my life. I always try and set myself from the time I get home which is probably around 4:30 to 6 o'clock [to be active] [...] I like to be regimented." (ACHD13-1). Another participant used her calendar to identify when she would take part in structured physical activity programs during the week, "I'll check my smartphone to see what my schedule is. I've already committed myself to classes throughout the week. [I] schedule it in." (ACHD8-2). Similarly, another participant explained that if he joined a team, then he had committed to play sports at the scheduled times, adding that he made sure to schedule other activities around the times designated for sports, "If I sign up for a sport, I plan on being there. [I] work my schedule around that kind of stuff." (ACHD18-2).

Other participants used electronic devices (e.g., Fitbit) to determine when physical activity behaviour occurred and keep track of their physical activity, which fed the desire to stay active. One used a step counter to have an accurate number of steps she took during a day, "When you sync [my device] every night you know what you've done. [...] I noticed since I have [my device] my stepping is [close] to 8000 steps every day." (ACHD15-3). Another participant also used a

Fitbit to keep track of the duration of her physical activity participation, “I started actually keeping track of what I could do like how long I could work out for and how far I could go. I have a Fitbit and I love my Fitbit.” (ACHD3-1).

Participants maintained their desire to be active through substitution, taking part in activities similar to ones they had pursued in the past. For example, a participant mentioned that she took up “Zumba [because it] reminds me of my youth in dance.” (ACHD8-1). Another participant said that as her eyesight deteriorated because of complications brought on by Marfan syndrome, she switched from downhill to cross-country skiing to stay involved in a similar activity, “My eyes [limited me in] downhill skiing. [My husband] did downhill skiing and I couldn’t join him. That’s why we started doing the cross-country skiing instead.” (ACHD15-1). Lastly, a participant stated that he stayed involved in broomball by taking on a coaching role for his child’s team, “I’m pretty heavily in to coaching my son so that’ll keep me involved in the sport.” (ACHD18-3).

Another behavioural strategy that emerged was helping relationships. A participant explained that he enjoyed exercising with friends and that he could push himself harder knowing that he was not alone if he were to experience a cardiac event:

I was always working out with the guys. [So,] I never had to push myself like crazy by myself. That could be scary [if] you get pushing weight by yourself and something happens when no one’s around. So, I did always have someone watching me but because they had to watch me, I can push myself harder. (ACHD13-1)

Another participant usually went walking with her sister to make sure they were both likely and committed to being active together, “I usually meet my sister. It’s really good to have someone

to [walk] with because if I'm a little tired and she calls me typically I feel guilty if I don't meet her." (ACHD16-2).

Participants claimed they maintained their involvement in physical activity so that they could be a role model to others. One said he was motivated to be active because he wanted to be a positive influence on his children and motivate them to be active, "I just want to keep moving [because] I want to be a decent influence on the kids." (ACHD18-3). He added that he was "proud that [my kids are] trying to follow a little bit in my footsteps." (ACHD18-2). Participants also said that they "want to empower people" (ACHD2-1) and be a source of inspiration for non-CHD individuals to be active as well:

I'm able to do more than most people even who don't have CHD. [After] the surgery [work colleagues] saw me running again. [They] looked at me and said, "I was thinking of [running] but that inspires me to get active again" and it's like, "I'm just trying to do what's best for me but I'm happy that inspires you." I have a couple people come out and join me during my lunch time run and wanting to run and they say, "If you can do it then I can do it." (ACHD7-1)

The final behavioural strategy identified in this stage was cyclical commitment, as participants sometimes alternated between a high frequency of physical activity and taking a break from physical activity and using that time for self-maintenance before the next period of high frequency physical activity. One used the time away from physical activity to heal injuries, "It's good for motivation and letting the bumps heal up." (ACHD21-3), while another participant mentioned:

I'm just very tired and my bones ache, my joints ache and it's good actually. My personal trainer said to me, "It's good to take a break to replenish. Maybe like once

a month take three days or a week and then kickstart it again and you'll feel good and rested." (ACHD5-3)

Another participant described the process of cycling back and forth between intense periods of participation and periods of rest:

I go through these cycles of being intensely physically active for maybe several weeks and then I go through a cycle of not being active at all. That's usually brought on by hectic life changes or being sick or surgery or injury. So, it dips down and gets low and then it ramps back up again. (ACHD3-3)

Synthesis

Table 8 presents a synthesis of key findings and recommended strategies for each stage, derived from the results of this study. For instance, ACHD patients in the pre-contemplation stage typically have no desire to modify their behaviour in the future, as they do not fully understand the meaning of physical activity and its benefits. Strategies for addressing these challenges could revolve around educating them on the benefits of physical activity while emphasizing the risks of sedentary behaviour, which may encourage the desire to either take on additional physical activity or maintain their current level of physical activity. Most ACHD patients in the contemplation stage are indifferent to modifying their physical activity behaviour as they may be uncertain of what activities to pursue yet feel guilty when putting off physical activity participation. As contemplative ACHD patients may wish to pursue mostly unstructured physical activities, those promoting physical activity in ACHD patients could leverage this by guiding them towards low-cost unstructured physical activity opportunities and encouraging them to set short-term goals to inspire behavioural change. Most ACHD patients in the preparation stage have begun to experiment with various physical activities as they work towards developing preferences.

Recommended strategies for prepared ACHD patients should revolve around recognizing their efforts towards lifestyle improvements and guiding them towards facilities that offer a wide variety of physical activities and programs. Action-oriented ACHD patients have adopted a structured physical activity regimen and wish to pursue various forms of physical activity in search of experiencing benefits. Accordingly, those promoting physical activity in ACHD patients are advised to provide positive feedback and support and to encourage them to set small and larger goals to achieve and maintain their desire to pursue physical activity. Lastly, ACHD patients in the maintenance stage have often fully integrated physical activity into their lifestyle and pursue a highly structured physical activity regimen. They should therefore be offered feedback and support for their lifestyle and advised that it is acceptable to alternate between intense periods of activity and periods of rest for self-maintenance to sustain their active lifestyle.

Table 8***Synthesis of key findings and recommended strategies for each stage***

Stage	Key factors	Recommended strategies
Pre-contemplation	• No desire to modify behaviour • Misconceptions on what constitutes physical activity • Lack understanding on cardiovascular benefits and diagnosis • Lack of encouragement from others • Isolation	• Educate on physical activity and its benefit • Emphasis on risks of sedentary behaviour
Contemplation	• Indifference towards modifying behaviour • Feelings of guilt • Desire to pursue unstructured physical activities • Initiate conversations with healthcare professionals • Lack awareness on appropriate activities	• Recognize minor improvements made to lifestyle • Set short-term realistic goals to establish routine • Educate on appropriate low-cost activities to pursue

	• High perception of risk	• Encourage workout buddies
Preparation	• Experiment with various activities • Desire to pursue structured programs • Trying something new • Self-awareness • Taking rational position • Coming out of isolation	• Recognize lifestyle improvements • Guide towards facilities offering various activities/structured programs • Encourage workout buddy for liability
Action	• Active for several months • Adopted structured regimen • Desire to pursue various physical activities • Emphasis on physical and psychosocial benefits	• Provide positive feedback and support • Set small and large goals • Encourage friendly competition with friends and family members • Maximize physical activity when possible
Maintenance	• Physical activity completely integrated into daily regimen • Broad conceptualization of physical activity • Emphasis on wide variety of physical and psychosocial benefits • Activity structure	• Provide feedback and support lifestyle • Educate on various health behaviours as needed • Encourage to take on various/adapted roles to stay involved in activity as needed • Alternate between intense periods of participation and rest • Encourage role-modelling

Fearless Physical Activity

The following section will present themes related to participants' experiences in the Fearless Physical Activity program, and perceptions of the program for those who did not attend program events. The purpose of Fearless Physical Activity was to connect CHD individuals with each other, help CHD patients and their families discover community resources promoting active living, and help CHD patients learn about pleasurable physical activities within their personal abilities without being fearful. The themes and subthemes discussed below were associated with participants' perceptions of the Fearless Physical Activity program events. A summary of the themes and subthemes pertaining to the Fearless Physical Activity program is provided in Table 9.

Table 9

Factors influencing participation in the Fearless Physical Activity program

Themes	Constraints	Facilitators
Intrapersonal factors		
Identity	• For severely affected ACHD patients • Not identifying with disease • Not seeking CHD-specific programs	
Limitations	• Psychological: Anxiety	
Knowledge		• Explore personal limits
Lifestyle	• Already pursue structured regimen • Lack of time	
Interpersonal factors		
Inclusion	• Meeting similar others	• Meeting similar others • Comparing abilities • Developing relationships • Maintaining relationships • Role modelling
Institutional factors		
Program purpose	• Overemphasis on CHD	• Program name

	• Program name • Lack understanding on program	
Logistics	• Events too structured • Low frequency of events • Nature of program activities	
Adaptability		• Activities adapted to needs • Exposure to new activities
Community factors		
Convenience	• Convenience	• Convenience

Intrapersonal

Identity. An important factor leading participants to skip the program events was that they did not identify with the disease. One participant avoided thinking about her CHD and did not want to be considered as sick, which is why she did not attend any events, “I don’t want to think all the time that I got heart disease. I don’t want to think about it. [...] I’m not sick.” (ACHD17-1). Another participant mentioned, “I don’t think it really defines me. [I’m] pretty much as healthy as anyone else.” (ACHD22-2). Another participant did not want to acknowledge that something was wrong with her by attending such a program, “You don’t want to feel like there’s something wrong with you.” (ACHD20-1).

Since many participants did not identify themselves as CHD patients, they did not actively seek CHD-specific programs to engage in. One participant had this to say: “I don’t think [I] actively search it. [...] [I’m] not currently seeking it out.” (ACHD10-1). Another participant said the thought of looking for ACHD-specific programs had never crossed her mind, “I just never thought of it. I never thought of going to look and saying, “I wonder if they have any group activities or programs.” (ACHD11-1).

Another factor preventing participants from attending Fearless Physical Activity events and relating to a CHD identity to a certain degree was that those with mild CHD diagnoses perceived the program to be for severely affected ACHD patients. When asked why he did not attend program events, one participant said it seemed to be for “people who are worse off or have worse problems than I do.” (ACHD18-2), while another stated, “I would say [it’s] for the people with the more severe stuff.” (ACHD21-2). Another participant felt that the program targeted newly diagnosed patients who were looking for information on the disease itself, “[It’s] good for newly diagnosed patients. [...] I think [it’s] great if you’re just finding out and you want to find out more about it, but we’ve been living with it for the last 40 years basically.” (ACHD15-1).

Lifestyle. Certain participants who experienced little in the way of CHD-related challenges skipped the events because they already pursued a structured physical activity regimen on their own time and did not feel the need to engage in additional programs, “I already have things that I am doing. [...] [I’m] happy doing my own thing.” (ACHD12-2), and “It doesn’t motivate me a whole lot. I’m happy to exercise on my own.” (ACHD10-2). Another participant explained that in addition to already having a structured physical activity regimen, she did not have the time to take part in the program on weekends, “I already do so much on my own. [...] My weeks are very busy. Weekends are time with my husband. [I] don’t like to overbook.” (ACHD5-2).

Knowledge. Participants who attended the program saw it as an opportunity to explore and learn about their personal limits when exerting themselves during program activities. One mentioned how engaging in the program’s activities allowed her to develop an understanding of her endurance and exertion levels, “[They’re] fun physical activities and [you get to] figure out your limits of endurance and stamina and exertion.” (ACHD9-1).

Interpersonal

Inclusion. The most common factors motivating participants to attend Fearless Physical Activity events were social in nature. One involved the opportunity to compare personal abilities with others in a similar situation. One participant wanted to participate in physical activities with other CHD patients to compare notes on when they began to feel exerted and out of breath. “[I want] to visualize how much they’re doing. [Say] the person says, “Run around the lap.” I can see how they’re coping. Do they pant? Do they [breathe heavily]?” (ACHD6-2). Another participant wanted to know how others with the same type of CHD compared to her when it came to abilities, “It would be nice to see what people with Tetralogy of Fallot [are] feeling because I’m always gaging myself against someone with either no health issues or similar health issue, but we clearly have differences in our physical ability” (ACHD11-1).

Some participants indicated that meeting others in a similar situation motivated them to want to attend the program. One explained that the events were an opportune way to get in touch with other ACHD patients to find and provide support to each other. In addition to social support, the participant described how she developed new and maintained existing interpersonal relationships after program events, which meant a relationship existed among these three themes:

A big part of it is knowing you’re not alone. It’s that support group. We’re all at different levels. We all have different issues. [...] We’re all there to help each other. You make that connection and keep in touch afterwards and [provide] words of encouragement too. (ACHD7-1)

According to another participant, being a CHD patient meant belonging to a group of individuals who shared common life experiences. The participant explained that the program

allowed her to share her experiences with surgeries and other challenges, and that in itself motivated her to attend the program:

When you're a CHD patient [there's] an unspoken understanding. When you're going to events like [Fearless Physical Activity] and even though all of us have more limitations than others there's kind of that like when someone says, "When I was four, I had an angio cardiac catheterization" [you] didn't know anyone else going through that. So, I think a lot of us talk at Fearless Physical Activity [about] that anxiety and going through things that come with it. [...] I found that really motivating. (ACHD8-1)

In contrast, some participants did not see meeting fellow patients as a motivating factor to attend the program. One perceived the program to be aimed at people seeking social support from other ACHD patients rather than seeking to be active, "It's for people who have CHD [and] have to be in a group. [...] I don't need to confirm it with other people. [...] My expectation is if you go to this it's going to be a little "supporty."" (ACHD10-2). He added that engaging in this type of program would have triggered his anxiety, because being with other ACHD patients at varying levels of deterioration, or severity of diagnosis, would have made him rethink his current health status, causing stress:

For me it would cause too much anxiety. [...] To see someone really deteriorating [is] shocking. Ignorance is bliss in my mind. [That] would be unfortunately my reason for not going. [My] biggest thing would be like, "I have to go home and analyze, and I don't want to, but I will do it." [...] When it's a sit down and [you're asking], "How are you going to die?" [I] don't find that very motivating even if it doesn't happen. (ACHD10-2)

Other participants felt that being with other ACHD patients and discussing their issues would be a strange concept. One participant who had been part of discussions with other cardiac patients in the past did not feel comfortable repeating the experience, “I go back and revert to thinking about how I felt at those heart talks and how it was awkward to sit there with a bunch of people and talk about it. It’s weird.” (ACHD11-2). Similar thoughts were expressed by another participant when it came to being in a group with ACHD patients, “It feels a little weird to say, “I’m going to the exercise group for people with heart problems.”” (ACHD20-1).

Echoing previously discussed subthemes, participants stated that attending the program allowed them to develop new and maintain existing interpersonal relationships with other ACHD patients. A participant mentioned how the events often had the same participants, some of whom she had known previously and did not see frequently. Thus, the program became a way for her to socialize with them, “We’re always the same people and we’re all in CCHA together. We all know each other very well but we don’t always get to socialize [and] it’s nice that [we] get to work together as a group.” (ACHD1-2). She mentioned developing stronger relationships with the people she already knew, “I’ve made deeper relationships with my co-fundraisers.” (ACHD1-1). Another participant who attended multiple events also experienced a sense of comradery with those she met at program events, “This is my third Fearless and what was nice is now I know the people there’s comradery.” (ACHD8-2).

Many participants who were already physically active were motivated to attend events to be a role model for those who were struggling with ACHD. One participant who attended an event stated, “I’ve been blessed to be quite physically active. [I thought I could] maybe be a bit of a role model for some of those people who didn’t have as good an experience in physical activity.” (ACHD8-1). Another participant made a similar comment: “If I am able to inspire someone then

that's amazing because it means that something I'm doing is helping another person reach their best potential." (ACHD25-2). Finally, another participant who was active explained that he wanted to share his experiences with others in hopes that it would make them less fearful when exploring their personal limits in physical activity, "I would love to be able to be face to face with someone [and] show them what it's like on the other side [and] to not be scared and be able to test like yourself." (ACHD13-1).

Institutional

Program Purpose. One institutional theme that was discussed with a participant who attended program events involved an overemphasis on CHD. While the participant acknowledged the importance of having discussions on CHD due to the nature of the program, she felt that those discussions consumed most of the participant interactions:

I think it's important we're recognizing CHD people, but sometimes I feel like let's talk about it and let's kind of get it out of the way and try some new fun things. Let's not be too always focused on throughout the whole day CHD, CHD, CHD. [...] But I know you have to because part of the particular program. (ACHD8-1)

Another important factor influencing participants' desire to engage in the program was the name of the program. Participants' perceptions were mixed as to whether "Fearless Physical Activity" was a suitable name to reflect the program's purpose. One participant liked the name of the program, "I like it because it's like, "Anything is possible." I like the title. [It's a] very strong message." (ACHD5-2). Another found the name confusing as to the intent of the program, "I'm kind of wondering what they mean about Fearless. Are they talking about ziplining, rock climbing, or are they talking about being able to do things that you thought you weren't able to do?" (ACHD15-2). Many participants said that they would not attend the program, as they believed the

name implied they would be engaging in extreme physical activities or sports. When asked how they perceived the meaning of the name “Fearless Physical Activity,” they responded, “Skydiving or something and then I wouldn’t want to go.” (ACHD6-2), and “For me, it gives me the impression that I’ll be doing a triathlon or something. [...] I would name it something a little calming and less intimidating.” (ACHD26-2). Upon hearing about the program and its name, another participant immediately thought of extreme activities and would not want to engage in activities associated with the word “fear:”

I had a bunch of images pop into my mind. I was thinking extreme sports. So I was like, “What is this? Are they going to have me skydiving and bungee jumping? [...] I don’t want to do any physical activity that remotely touches the word fear. (ACHD3-2)

Still others did not attend the program events as they did not understand the nature of the program. One participant did not attend the program because she believed it was meant for elderly ACHD patients who wanted to exercise, “I was picturing the elderly so sit down and raise your legs and [you’re] sitting [and doing activities to their level of fitness.” (ACHD5-2). Another did not attend because he has “no idea what goes on there.” (ACHD10-2).

Logistics. One participant felt that the program events were too structured, in that the itinerary did not allow for opportunities to explore activities of interest. She mentioned that she would have enjoyed having time dedicated to exploring interests, or available activities at event locations, rather than having a completely pre-determined itinerary:

Structure is certainly important, and you need it to get it up and running. But just within the structure maybe have an opportunity where there’s time for an hour to go

for a hike or I don't know if there's a swimming pool there go for a nice swim or if there's a lake go for a canoe ride. (ACHD8-1)

The low frequency of program events was also a constraining factor for participants. One explained that she did not attend the program events since there were very few of them, and that she was looking for a more structured physical activity program to engage in, "The fact that it's only once or twice a year didn't attract me much. I would be more attracted to a more regular type of [program]." (ACHD24-2), while another participant who did not attend program events made a similar comment, "It's not a regular thing? Who cares then." (ACHD6-2). One participant who did attend the events said she would have preferred if the program occurred on a regular basis as well, since it was difficult to experience benefits from the activities and stay motivated to pursue physical activity after the events:

It's hard to see the benefits as it's just a once-a-season event. It would be better if there was more consistency like if it was a weekly event. I did not feel terribly motivated to keep active after the event. (ACHD9-1)

Another participant who also attended the program mentioned how it would have been beneficial to offer the events on a frequent basis in one city to attract more participants and have a greater impact on them:

I'm wondering if there would be more buy in if it was offered as a series on a weekly basis over a period of time, for example. That way participants could gain some familiarity with the program, get to know other participants, and perhaps individuals would gain more confidence in trying out new activities by building on experiences from the last week. [If] they just narrowed it down to one city instead that would've been good. (ACHD8-1)

Similarly, a participant mentioned how the program would have benefitted from having several shorter events during the week rather than having one long event on weekends. The participant suggested that having more frequent and shorter events could also have facilitated the development of a community among participants :

Three hours is a big chunk of your day. Maybe if they had more frequent and shorter because part of it is you're supposed to be building the community. [...] Maybe if it was more of an ongoing every Monday for six weeks because then you would get more of a repeat. (ACHD20-2)

Finally, some participants said they did not attend the program because they did not enjoy the nature of certain program activities. One mentioned looking into the program but did not attend because he was not interested in doing crafts, "I researched all the stuff they do [and] I mean the stuff they're doing [like] crafts and what not turned me off." (ACHD13-2). Another participant mentioned that although she had pleasurable experiences once she was playing games, she believed she was wasting her time when playing those games. As for Fearless Physical Activity, she ultimately chose not to attend the program because of gamified activities:

I have never enjoyed games. I just don't so even though once I'm there I might have a good time. I think it's funny and I just laugh and I do it there is a little voice inside me that when I'm playing games it says, "You are wasting your time." So that part doesn't attract me it does attract me. (ACHD24-2)

Adaptability. Participants enjoyed the fact that activities were adapted to their needs. For example, a participant adapted her role during a team race activity that was too exerting for her by having another team member run for her while she took on an adapted role to stay engaged in the activity. "I was able to sit whereas another person would have to run back and forth. [...] I didn't

have to run back and forth so it was just adapting and picking roles that were OK for me to do.” (ACHD1-2).

Participants also enjoying being exposed to new physical activities. A participant who was severely affected by her CHD described how being exposed to new physical activities was very important to her, “They’re critical because they’ve taught me different activities.” (ACHD1-2). She enjoyed the activities she was exposed to, such as yoga and Tai Chi, and said that it could prompt her to seek those opportunities within her community after program events, “We did yoga or Tai Chi and that was great. [...] It was great to experience it and then go, “OK maybe I could actually do this.”” (ACHD1-1). Another participant enjoyed novel experiences through physical activities she would not normally do in her daily life, “You’re out in the wilderness and you have the opportunity to do stuff you wouldn’t normally in the city. [...] I just like those physical activities for the novelty aspect of it.” (ACHD9-1).

Community

Convenience. The only community-related theme identified was convenience, specifically with regard to event locations. One participant said that while she did not attend events held further away from where she lived, she did attend those held at a closer location, “I haven’t really been going is because it’s all the way out in [a town outside the city]. The one that was in [the city] I thought, “That’s pretty easy. I can just take the bus home.” (ACHD9-1). This was echoed by other participants who did not know the communities where the events were held or would not attend the events if they were too far from their home, “I don’t even know where that is.” (ACHD11-2), and “I would not go there an hour out for it.” (ACHD10-2).

Chapter 5: Discussion

The purpose of this study was to qualitatively explore how physical activity behaviour is initiated and maintained in ACHD patients. This chapter begins with a discussion on findings related to participants' readiness to change their physical activity behaviour based on the characteristics of the TTM framework. Findings on the meaning of physical activity in the lives of participants are then discussed, followed by a look at findings on the social ecological factors that emerged in each stage of behavioural change, and how they evolve from one stage to the next. Findings on processes of change are then discussed. Lastly, findings related to the Fearless Physical Activity program are presented. The theoretical and practical implications of this study, as well as the limitations and directions for future research, are also presented in this section.

TTM

Exploring physical activity behaviour from the perspective of ACHD patients had yet to be addressed in past research. As with any other population group, findings suggest that ACHD patients vary in their desire to modify or adapt their physical activity behaviour. The physical activity behaviour characteristics of participants in this study were very much in line with those from the TTM (Prochaska et al., 2015), as they were distinguished by stage-specific perceptions and behaviours. Over the course of the study, participants either evolved into later stages or stayed within the same stage depending on the length of time it takes for behavioural change to occur (e.g., one month, six months) (Prochaska et al., 2015). Results therefore reflect behavioural change as a process that requires significant effort and takes place over time, which is also consistent with features of the TTM framework (Prochaska & DiClemente, 1983; Prochaska et al., 2015; Velicer et al., 1998).

Findings in this study uncover new meanings for understanding physical activity behaviour in ACHD patients. For instance, while individuals in the pre-contemplation stage have no desire to modify their behaviour (Prochaska et al., 2015), findings suggest that it may be because these ACHD patients already participate in a considerable amount of physical activity and have no desire to modify their current lifestyle. This statement is supported by findings on a participant whose narratives were classified in the pre-contemplation stage, and while they did not pursue a structured physical activity regimen and had no intention of modifying their physical activity behaviour, they performed necessary household activities and walked daily in nature out of interest or because of work obligations.

According to findings of this study, most of the challenges faced by pre-contemplative ACHD patients revolve around their understanding of what constitutes physical activity and the benefits that it offers. The issue of understanding what constitutes physical activity has been brought up in past literature (Giannakoulas & Dimopoulos, 2010), and may have to do with the cognitive component of attitudes towards behavioural change and the usefulness of and knowledge required to making behavioural change (Elizur & Guttman, 1976). The implications of these perceptions of physical activity are that pre-contemplative individuals may not seek to adopt new physical activity behaviours or modify their current ones if they believe that physical activity refers to exuding forms of exercise and that its benefits for ACHD patients play only a small role in their overall health. Thus, educating pre-contemplative ACHD patients on opportunities to pursue unstructured activities that are of low-to-moderate intensity (e.g., walking, cycling, yoga, Tai Chi) as acceptable physical activities and on following basic guidelines on low-intensity physical activity (Canadian Society for Exercise Physiology, 2021; CDC, 2020b) may be suitable for promoting physical activity to them. Emphasizing these forms of physical activity as acceptable

pursuits, the specific benefits they offer and the risks of sedentary behaviour may also help pre-contemplative ACHD patients sustain their current physical activity behaviour, or modify their behaviour to take on additional physical activity.

Individuals in the contemplation stage weigh the pros and cons of being active, and if these are perceived to be equal, they will remain in contemplation (Prochaska et al., 2015). Characteristics of contemplative participants in this study are consistent with these, as it was found that they were indifferent to modifying their physical activity behaviour (Prochaska et al., 2015). Contributing factors towards indifference among contemplative ACHD patients, based on the findings of this study, are that they tend to prioritize other aspects of life over physical activity, have not experienced benefits, have limited knowledge on the benefits of physical activity, and lack reliable resources. These factors are likely to have a strong impact on keeping ACHD patients in contemplation over other characteristics associated with contemplators, such as considering the positive outcomes of behavioural change. For example, findings suggest that while contemplative ACHD patients understand the importance of being active (Prochaska et al., 2015), they may lack interest in pursuing physical activity. Thus, while contemplators understand the importance of making a behavioural change, they may struggle to follow through with making a change (Prochaska et al., 2015).

Yet, findings also suggest that contemplative ACHD patients recognize that they may not be active enough and feel guilty when putting off physical activity. This can be a valuable angle to explore for those promoting physical activity to ACHD patients, who should be encouraged to develop, step by step, a plan for modifying physical activity behaviour. Reinforcing the benefits of physical activity could help them shift their perceptions in favor of the benefits of being active. This idea complements findings suggesting that contemplative ACHD patients are working

towards developing a better understanding of the benefits of making a behavioural change. For instance, while participants in this stage did not pursue a structured physical activity regimen, they had taken steps on educating themselves on the benefits of physical activity and had initiated conversations with healthcare professionals to learn more about the benefits of physical activity (Prochaska et al., 2015). Informing ACHD patients in the inquiry process about and encouraging them to pursue unstructured physical activities are also likely to be effective in modifying their physical activity behaviour. This is supported by findings suggesting that participants in this stage are mostly interested in low-intensity unstructured, and often outdoor, physical activities over structured and exerting forms (e.g., weight training, aerobics classes). Those promoting physical activity to ACHD patients should also work towards informing contemplative ACHD patients on the benefits of low-intensity physical activities to help persuade them to perceive more pros than cons to behavioural change or help them understand the specific benefits brought on by their current physical activity behaviour.

The most prominent characteristic for participants in the preparation stage was experimenting with various forms of physical activity, which is consistent with the literature (Prochaska et al., 2015). ACHD patients in this stage have a different perception of physical activity, as most are willing to engage in various forms of physical activity to determine which of these they enjoy the most (Prochaska et al., 2015). Incidentally, many participants in this stage have already taken steps or have developed an interest in pursuing certain physical activity opportunities over others. Specifically, findings suggest that ACHD patients in the preparation stage are more inclined to pursue structured physical activity programs, in addition to unstructured ones that they already pursue. These findings are particularly relevant for those promoting physical activity behaviour to prepared ACHD patients. An appropriate promotion strategy for those in this

stage could therefore consist of providing resources on or raising their awareness of local recreational facilities that offer a wide range of physical activity programs or activities in general. By doing this, ACHD patients who are prepared to modify their physical activity behaviour can have the opportunity to experiment with various activities and programs with hopes that they will develop an interest in certain opportunities and continue to pursue these. Specific types of programs that ACHD patients in this stage may be interested in may involve moderate-level activities such as yoga and Tai Chi, based on findings of this study, rather than exerting forms of physical activity (e.g., weightlifting). Guiding such ACHD patients towards facilities offering various programs and activities is therefore likely to help them develop their self-efficacy and initiate the process of developing a more structured physical activity regimen (Prochaska et al., 2015).

In the context of ACHD patients, it is important to consider personal abilities and how these determine physical activity behaviour (Chaix et al., 2016; Hirth et al., 2006; Stout et al., 2019; Zipes et al., 2005). This was particularly important for understanding physical activity behaviour in an ACHD patient in his end-of-life cycle who was prepared to be active but was forced to be sedentary due to limited abilities. In this specific instance, the participant was unable to sustain any form of physical activity participation due to the severity of his CHD. This finding also points out a limitation within the TTM framework, as the physical activity behaviour of individuals in lower stages may be dictated more by their abilities than their desire to modify their behaviour.

Participants' adoption and modifications of physical activity behaviour, and their ability to sustain these behavioural changes in physical activity on a regular basis, implied that they had reached the action stage (Prochaska et al., 2015). Participants in the action stage had made drastic

changes to their physical activity behaviour by sustaining their participation in various activities including structured ones like exercising with a personal trainer and recreational sports, and unstructured activities, such as walking, cycling, or exercising at the gym. Participants in this stage also tend to emphasize the benefits they have experienced through their behavioural changes. Findings also imply that ACHD patients in this stage are on their way to maintenance, as they pursue a structured physical activity regimen that has become a natural part of their daily routine (Prochaska et al., 2015). Given that participants in this stage have established a structured physical activity regimen, continued encouragement and support of their behavioural changes while emphasizing the benefits they experience is necessary to help them avoid relapsing to a previous stage (Prochaska et al., 2015).

Participants who sustained their physical activity regimen for several years and who sought to continue to increase their knowledge on forms and types of physical activity to pursue were in the maintenance stage. These findings are consistent with characteristics of those in the maintenance stage provided by Prochaska et al. (2015). Physical activity for ACHD patients in this stage was integrated into participants' lifestyle in such a natural way that they did not have to think about being active. Similar to participants in the action stage, findings suggest that ACHD patients in maintenance engage in a variety of structured and unstructured physical activities that vary in intensity. For instance, it was found that most ACHD patients in maintenance were likely to engage in low- and high-intensity unstructured activities, such as walking, cycling, gym exercises and weightlifting, swimming and running, as well as low- and high-intensity structured activities like Pilates, yoga, Zumba and recreational sports.

While individuals in the maintenance stage are typically active on a regular basis, it is possible for them to lack motivation to be active at times (Prochaska et al., 2015). While this study

did not see any participants in the maintenance stage relapse to an earlier stage, it must be acknowledged that they occasionally had to force themselves to be active. This finding was evident in discussions with participants describing how other aspects of life sometimes consumed most of their time, leading to a lack of desire in maintaining their active regimen. Accordingly, even though some ACHD patients are in the maintenance stage, continued reinforcement and support of their lifestyle is important, as it helps with motivating them to overcome adversities, in addition to their own motivation to maintain an active lifestyle. Letting ACHD patients in the maintenance stage know that it is normal to occasionally lack motivation to be active is important as well, as it can help them understand that it is part of everyday experiences. Promoters of physical activity to ACHD patients who are in this stage should also emphasize physical activity behaviour that is not necessarily part of their regimen (e.g., caring for children, walking at work) as it can help them realize that they may in fact be participating in active behaviour unknowingly and continue to experience benefits through these pursuits.

Furthermore, a summary of the physical activities in which participants engaged during this study is summarized in Table 2. According to findings of this study, the physical activities ACHD patients pursue are somewhat in line with recommendations pertaining to certain diagnoses (Chaix et al., 2016) and recommended guidelines for the general population (Canadian Society for Exercise Physiology, 2021; CDC, 2020b). For instance, it is recommended that ACHD patients with Marfan syndrome take part in moderate static or low dynamic sports, in addition to weight training if appropriate (The Marfan Foundation, 2014). While ACHD patients with Marfan may not participate in low dynamic sports, based on this study's results, they may participate in other forms of low dynamic activities, such as yoga, Pilates and ballet, in addition to exercising at the gym and walking. Findings also suggest that ACHD patients with Tetralogy of Fallot and

Eisenmenger syndrome are inclined to participate in low-intensity activities, such as walking, yoga and aqua fitness, which is somewhat consistent with the recommendations (Chaix et al., 2016). Similarly, some participants with transposition of the great arteries participated in low-intensity activities, such as walking and yoga (Zipes et al., 2005).

In addition, findings suggest that most ACHD patients meet the recommended guidelines for the general population (Canadian Society for Exercise Physiology, 2021; CDC, 2020b). However, the need to take an individualized approach when promoting physical activity to ACHD patients remains critical, as they may vary in their abilities and have different perceptions and desires to modify their physical activity behaviour because of factors such as their knowledge of what constitutes physical activity, appropriate physical activities to pursue and their benefits.

While it has been said that ACHD patients tend to be sedentary (Cuypers et al., 2016; Moschovi et al., 2020; Reybrouck & Mertens, 2005; Roche & Silversides, 2013), the findings of this study suggest that this may not be the case for many ACHD patients. These findings contradict previous research by suggesting that many ACHD patients participate in a considerable amount of physical activity behaviour on a regular basis, and thus, it is important not to generalize the idea that ACHD patients live sedentary lifestyles. According to findings of this study, it appears as though ACHD patients participate in various forms of physical activity and at varying intensities. Findings are therefore supportive of the notion that very few ACHD patients have a CHD that would prevent physical activity participation altogether and that they can pursue physical activity with few to no restrictions (Chaix et al., 2016; Longmuir et al., 2013).

Meanings

Part of this study was dedicated to uncovering the meaning of physical activity in the lives of ACHD patients. The meaning an individual associates to an activity serves as the motivational

basis for engaging in that activity (Lewthwaite, 1990). While the meaning of physical activity was individually explored in each stage of behavioural change in this study, most of the themes overlapped between stages. In addition, the themes identified in this section resemble those found in previous research on individuals with various diseases (Bedini & Anderson, 2005; Erikssen et al., 2013 Gaskin et al., 2009; Maley et al., 2013).

Based on the findings of this study, ACHD patients understand that physical activity is a source of health benefits. Regardless of their level of, and desire to engage in, physical activity, participants in each stage reported that maintaining health and function motivated them to be active. This theme is consistent with findings from studies by Kasser (2009) and Dlugonski et al. (2012) on individuals with multiple sclerosis, and Erikssen et al.'s (2013) study on individuals with Parkinson's disease. Given that participants in this study suffer from a disease as well, it is reasonable to assume that they will also seek to maintain their health and function to sustain long-term, or future, health, as do individuals living with other diseases. Additionally, patients living with a cardiac-related disease, such as CHD, often require lifelong medical care and cardiac surgery, and experience deterioration as they continue to age (Cuypers et al., 2013, 2014a, 2014b; Menting et al., 2015). Thus, the findings from this study suggest that ACHD patients want to achieve cardiovascular health benefits to decrease their risk of experiencing ailments and illnesses in the future, which also bears similarities to findings in previous research (Dlugonski et al., 2012; Kasser, 2009). It is therefore reasonable to assume that a motive for ACHD patients to engage in physical activity would be to increase cardiac health to overcome CHD-related health issues and decrease their likelihood of requiring additional medical care in the future.

Similarly, according to findings in this study, ACHD patients engage in physical activity with the hope of extending their life expectancy and have a desire to live independently in the

future. These findings resemble themes discussed by Erikssen et al. (2013) on individuals with Parkinson's disease who seek to maintain their independence as a life goal. Interestingly, while participants in this study saw physical activity participation as a way to stay healthy in the long term and extend their life expectancy, which perhaps speaks to remnant worries of pre-modern medicine life expectancies for CHD patients (Healio, 2014), their specific desire to live independently may have less to do with issues brought on by CHD. Rather, findings suggest that ACHD patients may be active to sustain their ability to continue to perform a variety of activities, including tasks of daily living (e.g., walking, groceries, gardening), physical activities with friends, and travelling during retirement. Thus, maintaining health and function can perhaps be a point of emphasis when encouraging physical activity participation for ACHD patients, regardless of their level of motivation, as they are likely aware that being active on a regular basis can help them to achieve long-term health, by addressing CHD and non-CHD-related issues, and to live a fulfilling lifestyle as they continue to age.

Another meaning that seems common for ACHD patients in different stages of behavioural change, specifically the pre-contemplation, preparation, and action stages, is being active to achieve well-being. These findings also overlap with themes in previous research by Erikssen et al. (2013). While participants in the pre-contemplation stage are typically unmotivated to engage in physical activity (Prochaska et al. 2015), for a pre-contemplative participant, their minimal desire to take part in occasional outdoor activities, such as walking to enhance well-being, was triggered by their love of nature. While this theme was mentioned by a participant in the pre-contemplation stage, it is not likely a motive unique to that stage, as most participants enjoyed engaging in outdoor physical activities.

However, since participants in later stages are more likely to experience benefits through physical activity participation (Prochaska et al., 2015), they are more likely to be more driven to be active to experience benefits, and in turn achieve well-being. For instance, findings suggest that action oriented ACHD patients may be motivated to be active because they understand it is healthy, and the benefits they experience will motivate continued participation. These findings are similar to those reported by Erikssen et al. (2013), implying that well-being can be achieved through the satisfaction of experiencing benefits from being active. Experiencing benefits therefore serves as a reinforcement for ACHD patients by feeding their perception that they are increasing their health, which in turn helps them sustain their engagement in physical activity. Lastly, the findings of this study suggest that physical activity engagement is motivated by ACHD patients' desire to enhance quality of life over longevity, similar to their desire to maintain long-term health. These findings contradict discussions above on maintaining health and function, as a participant in the preparation stage emphasized living quality life experiences in the present, as opposed to the possibility of extending their life expectancy.

While discussions on the meanings above are associated with participants across most stages, some meanings were specific to later stages. For instance, taking rational position serves as a motivational basis for participants in the preparation, action and maintenance stages. Taking rational position is the conscious decision to engage in physical activity in a purposeful way (Erikssen et al., 2013). For example, findings suggest that ACHD patients in the preparation stage take a rational position to better care for themselves, while those in the action stage do so to commit to their decision to sustain an active lifestyle. These findings are in line with characteristics of individuals in these two stages, as participants in the preparation stage are in the process of following through on their decision to increase their physical activity behaviour to benefit

themselves, while those in the action stage are committed to sustaining their physical activity regimen (Prochaska et al., 2015).

Moreover, as physical activity is a central aspect in the lives of participants in the maintenance stage, it is not surprising that physical activity is integrated in their individual identity. This theme is also consistent with previous research by Erikssen et al. (2013) on individuals with Parkinson's disease who identified themselves as active individuals. Findings suggest that ACHD patients in the maintenance stage who engage in social physical activity contexts among others on a regular basis, such as gyms, will tend to associate with the types of individuals who frequent those same contexts, as they likely have similar interests. Findings therefore suggest that engaging in such physical activity contexts can impact the social circles ACHD patients gravitate towards and, in turn, help them develop an identity as an active individual among their active peers.

Other meanings that may be associated more with ACHD patients in the maintenance stage, according to findings in this study, are sense of normalcy and perceived freedom. For instance, some ACHD patients may be highly motivated to engage in any physical activity they desire and exert themselves as any other healthy individual would. Thus, when ACHD patients engage in physical activities to experiment with their personal abilities and exert themselves without experiencing any CHD-related symptoms, they are likely to feel as though they are normal like their healthy peers. Findings also suggest that feeling normal as a motivation for being active can be achieved by ACHD patients' ability to maintain the same physical activity regimen as healthy individuals, as they do not feel as though they are living with any limitations. These findings are consistent with the experiences of other vulnerable population groups such as women with multiple sclerosis (Dlugonski et al., 2012) and girls living with various physical disabilities including osteogenesis imperfecta, cerebral palsy, spina bifida and brain injury (Bedini & Anderson, 2005).

Similarly, perceived freedom was found to be a motive for continued physical activity participation for participants in the maintenance stage. Findings suggest that ACHD patients have a desire to liberate themselves from the limitations often imposed on them by others (e.g., parents) by engaging in physical activities of interest, regardless of the intensity they demand when participating, and showing that their CHD is not affecting them as much as others believe. Physical activity therefore serves as a context where ACHD patients can be in the moment with the activity they are participating in and feel liberated from the constraints they experience and often imposed on them. These findings perhaps speak to specific constraining factors commonly associated with physical activity participation among ACHD patients such as overprotection and healthcare professionals being hesitant when promoting physical activity (Giannakoulis & Dimopoulos, 2010). It is therefore understandable that ACHD patients would react to living under the limitations imposed on them by others and seek opportunities where they can exercise their own choices without feeling limited in what they can do.

While the themes presented in this portion of the study are not necessarily new, they help us understand some of the motivational bases for physical activity participation in ACHD patients. Findings suggest that basic motives for physical activity participation in ACHD patients are no different than in individuals who live with other types of diseases, which suggests transferability in the findings of this study. This is an important point to consider for those seeking to promote physical activity participation in various patient populations, inclusive of ACHD patients, as they may have common motives for being active.

Another important point to consider is that although motives for being active were similar across stages, the significance of physical activity in the lives of ACHD patients likely differs between those in early stages and those in later ones. For example, a theme that emerged after

conversing with a pre-contemplative participant was that physical activity was engaged in out of necessity and was not prioritized in their life. In contrast, physical activity participation for a participant in the action stage did not feel forced and became a priority because they enjoyed experiencing the benefits physical activity has to offer. Thus, a distinction can be made between basic motives for engaging in physical activity and the significance that physical activity holds in the life of ACHD patients. By using the TTM framework, it was possible to determine how ACHD patients vary in their motive to be active, which incidentally reflected how significant physical activity was in the life of those in different stages of behavioural change. Despite participants in pre-contemplation understanding the implications of physical activity on health, their lack of motive to be active implies that it is not a significant aspect of their life. Conversely, for participants in the action stage, the implications of physical activity are well-understood, and it is prioritized, which suggests that physical activity holds greater significance in their life. Findings of this study therefore imply that the significance of physical activity in the lives of ACHD patients is more likely than its meaning to determine physical activity behaviour. Research has yet to make such a distinction between the meaning and significance of physical activity in the lives of ACHD patients, as they have not considered the TTM when looking into this topic.

Social Ecological Factors

Unlike meanings of physical activity which tend to be a precursor for participation in physical activity, the exploration of social ecological factors in this study was utilized to uncover factors that influence actual participation in physical activity in ACHD patients.

Evolution of Social Ecological Factors Across Stages

To date, researchers have yet to utilize the SEM and TTM frameworks to better understand physical activity behaviour in the context of ACHD patients. Applying these frameworks made it

possible to determine what types of factors, both constraining and facilitating, influence physical activity behaviour in ACHD patients in different stages and illustrate how these evolve from one stage to another. Factors influencing physical activity in ACHD patients have been identified in the past (Buys et al., 2011; Chaix et al., 2016; Giannakoulas & Dimopoulos, 2010; Reybrouck & Mertens, 2005; Stuart, 2014; Ubeda Tikkanen et al., 2013; Warnes et al., 2008). However, as ACHD patients find themselves at different levels of desire to be active, the impact of factors influencing physical activity behaviour within each stage differs from one stage to the next.

Participants in the pre-contemplation stage mostly experienced intrapersonal constraints, followed by interpersonal constraints. Findings suggest that the main types of intrapersonal constraints experienced by pre-contemplative ACHD patients are knowledge-based. For instance, having a poor conceptualization of physical activity, lacking understanding of the cardiovascular benefits of physical activity, and lacking understanding of one's own diagnosis were cited as factors preventing the pursuit of physical activity. These findings are consistent with characteristics of individuals in pre-contemplation, as they typically avoid reading, thinking or talking about their current behaviour and the behaviours they should adopt (Prochaska et al., 2015). Participants in the pre-contemplation stage also experienced several interpersonal constraints, mostly revolving around social exclusion. Findings suggest that ACHD patients in this stage lack significantly in social support, specifically in the form of encouragement to be active by others. Participants lacked encouragement from significant others, perceived stigma, felt isolated and excluded by others when engaging in social physical activity contexts, and did not have active friends.

Similar to those in pre-contemplation, findings suggest that contemplative ACHD patients are likely to experience intrapersonal constraints more than other types of factors. Participants in

this stage also experienced knowledge-based intrapersonal constraints, which bear similarities with those in the pre-contemplation stage. However, the nature of knowledge-based constraints for contemplative ACHD patients differs from those in pre-contemplation, as they lack knowledge when it comes to personal abilities and appropriate physical activities to pursue, as well as have a tendency to doubt their personal abilities.

While intrapersonal constraints were experienced more frequently by participants in the contemplation stage, it must be acknowledged that they experienced a variety of intrapersonal facilitators as well. For instance, findings suggest that contemplative ACHD patients do not pursue a structured physical activity regimen and thus have limited experiences with benefits brought on by physical activity participation. Others, however, do experience physical and psychological benefits from being active, which motivates physical activity participation even though their regimen is unstructured. These findings likely speak to the notion of contemplative individuals weighing the pros and cons of increasing physical activity participation (Prochaska et al., 2015), as participation can at once seem rewarding when experiencing benefits and unrewarding if benefits are not experienced. Ultimately, it may be perceived by ACHD patients in this stage that the benefits experienced are too minimal to inspire behavioural change. Participants in the contemplation stage were also affected by lifestyle factors, such as living an imbalanced lifestyle, lacking structure in daily life, and lacking time to incorporate physical activity into their daily regimen. These factors appear to be in line with literature suggesting that contemplative individuals lack self-efficacy in their ability to manage activities of daily living (Prochaska et al., 2015).

Second to intrapersonal constraints, results suggest that contemplative ACHD patients experience interpersonal constraints revolving around the information they receive from healthcare

professionals. For instance, participants spoke about receiving little information and guidance from healthcare professionals on the types of physical activities they can safely pursue. These findings, in addition to the uncertainties contemplative ACHD patients already have, would make it difficult for them to obtain knowledge on what physical activities they can safely pursue based on their abilities.

Furthermore, participants in the preparation stage experienced the greatest number of factors. This stage also marks a shift in the number of constraints versus facilitators experienced by participants compared to previous stages. Unlike in previous stages, findings suggest that ACHD patients in the preparation stage experience a somewhat equal number of constraints and facilitators. The increase in factors experienced by ACHD patients in this stage is likely a result of experimenting with various physical activity contexts (e.g., unstructured physical activities and structured physical activity programs) through trial and error and being exposed to many new experiences (Prochaska et al., 2015).

Similar to those in earlier stages, findings suggest that ACHD patients in the preparation stage will also experience intrapersonal factors more commonly than other types of factors. According to findings in this study, ACHD patients will most likely experience both constraining and facilitating intrapersonal factors related to experimenting with various physical activities. These factors may include intrapersonal constraints such as mismatches between experiences and expectations, and not experiencing benefits, while intrapersonal facilitators such as self-awareness through developing an understanding of personal abilities, being excited to try new physical activities, and experiencing both psychological and physical benefits through increased participation may be experienced. Interpersonal constraints are also likely to be frequent for prepared ACHD patients engaging in various social physical activity contexts, such as having

nothing in common with others in programs, and perceived stigma. However, ACHD patients in this stage may have a greater amount of social support, have common interests with others in programs, come out of isolation, be active with others, and hold themselves liable to be active with others since they are exposed to more social physical activity environments.

Findings also suggest that ACHD patients in the preparation stage often engage in structured forms of physical activity (i.e., programs), and thus will experience institutional factors. For example, participants were less inclined to engage in programs at recreational facilities that were not conveniently located for transportation, costly, and contained staff members that were unwilling to adapt program activities to their personal needs. In contrast, participants were more likely to engage in programs at recreational facilities that were located near their home, consisted of activities that were within their personal abilities or contained staff members that were willing to adapt program activities, were cost efficient, and were offered at a convenient time. Findings also suggest that short-term commitment programs are attractive to ACHD patients in this stage, as it allows them to explore various physical activity programs and narrow down what programs they will continue to pursue based on interest. These findings are therefore in line with the idea that prepared individuals will build self-efficacy by developing an action plan on what activities, or programs, they will continue to pursue in the future (Prochaska et al., 2015).

Participants in the action stage mainly experienced facilitators, with their frequency increasing in sequential order from intrapersonal, interpersonal and institutional. The action stage also marked an important phase, as it was the first stage where the number of facilitators outnumbered constraints. Findings suggest that physical activity participation is facilitated by the desire in ACHD patients in this stage to experience physical, social, and psychological benefits. Additionally, findings suggest that interpersonal factors will revolve around ACHD patients'

relationships with healthcare professionals and how they encourage physical activity. As individuals in the action stage are prone to relapsing to previous stages, but have also developed a more established physical activity regimen (Prochaska et al., 2015), it is understandable why participants in this stage shift from asking for guidance on suitable physical activities to pursue from healthcare professionals, to emphasizing encouragement, validation and wanting to be perceived as an active individual by healthcare professionals, as they have a desire to show them how active they are now. As action-oriented ACHD patients continue to refine their physical activity regimen (Prochaska et al., 2015), the results show that programs that promote a sense of community, contain a comfortable environment, have positive program staff, are offered at convenient times, and consist of activities within their personal abilities are likely to be the most attractive for them.

Finally, findings suggest that participants in the maintenance stage experience the greatest number of facilitators over constraints compared to any other stage. These findings are perhaps an indication as to why individuals in the maintenance stage can sustain an active regimen on a long-term basis, or permanently, with minimal risk of relapsing (Prochaska et al., 2015; USDHHS, 2020b), as they rarely perceive constraints. As in previous stages, however, intrapersonal factors have the most influence on physical activity behaviour for participants in this stage. According to findings in this study, ACHD patients in maintenance are motivated by the physical and psychological benefits they experience when physically active. This finding bears similarities to the experiences of those in the action stage, yet those in maintenance experience a greater number of benefits. Participants in this stage also have a significant amount of social support compared to previous stages, as they are, or have been, surrounded by active family members, significant others, team members and active friends. Findings also suggest that physical activity is an opportune way

for ACHD patients in this stage to maintain and strengthen existing interpersonal relationships, in addition to developing new interpersonal relationships when active with others, which are similar findings to those in the action stage.

Findings of this study bear similarities with existing research on various vulnerable populations (e.g., elderly, colorectal cancer survivors, multiple sclerosis, autism spectrum disorders), suggesting that intrapersonal factors have an important role in determining physical activity behaviour (Carlson et al., 2012; Lynch et al., 2010; Obruškinova & Cavalier, 2011; Sallis & Owens, 2015; Silveira & Motl, 2019). Many of the factors identified in this study are consistent with previous studies on vulnerable populations as well, such as encouragement from friends, an active social circle, a lack of social support, increased well-being, reduced stress, disease-specific issues, lack of time, and accessibility to community physical activity opportunities (Carlson et al., 2012; Lynch et al., 2010; Obruškinova & Cavalier, 2011; Sallis & Owens, 2015; Silveira & Motl, 2019), which suggests that these themes may not be unique to ACHD patients.

While research has yet to apply the SEM and TTM in combination in the context of ACHD patients, research in this area exists among other populations. Findings from this study are consistent with previous research on individuals with Parkinson's disease and children with cerebral palsy in that participants in the pre-contemplation stage are more likely to experience intrapersonal and interpersonal constraints than participants in the maintenance stage (MacCosham et al., 2018; Verschuren et al., 2013). Findings in each study also suggest that those in early stages for these population groups tend to experience knowledge-based constraints to physical activity (MacCosham et al., 2018; Verschuren et al., 2013). Other comparable findings between this study and others (MacCosham et al., 2018; Verschuren et al., 2013) exist, in that these population groups are likely to gradually experience fewer constraining factors as stages progress, while the number

of facilitators increases. The similarity in trends with regard to ACHD patients in this study and other population groups listed above suggests that there may be transferability in findings, as they appear to have similar experiences in the factors they experience. The ability to highlight trends in the types of factors experienced in each stage adds to existing knowledge on factors influencing physical activity behaviour in ACHD patients.

CHD-Specific Social Ecological Factors

Social ecological factors influencing physical activity participation in ACHD patients have been identified in the past (Buys et al., 2011; Chaix et al., 2016; Giannakoulas & Dimopoulos, 2010; Reybrouck et al., 2005; Stuart, 2014; Ubeda Tikkanen et al., 2013; Warnes et al., 2008), and are consistent with findings in this study. However, some of the factors that have been identified are more likely to be relevant to certain stages and cannot be generalized to all ACHD patients. For instance, ACHD patients in earlier stages (i.e., pre-contemplation, contemplation, preparation) are likely to have misconceptions on what constitutes physical activity and were overprotected as children, based on findings of this study. According to the findings of this study, some ACHD patients in earlier stages may also perceive that they receive inadequate guidance from healthcare professionals, although this may be because individuals in these stages often do not seek out information on behaviours they should be adopting (Prochaska et al., 2015). Factors such as anxiety and finding it easier to take medication may be experienced by contemplative ACHD patients, based on the findings of this study. These two factors may be attributed to contemplative ACHD patients' perceptions leaning towards the disadvantages of making a behavioural change, which triggers anxiety in response, in addition to being hesitant to increase physical activity behaviour because of the effectiveness of medications.

In addition to factors that are consistent with past research, other unique CHD-related factors were also uncovered in this study. For example, findings suggest that pre-contemplative ACHD patients may not have a strong desire to modify their physical activity behaviour because they are anticipating death, and thus, do not feel the need to modify their current behaviour. This finding is supported by participants who believed they had long surpassed their life expectancy. Similarly, findings suggest that ACHD patients in pre-contemplation feel as though they do not have to be active because they have survived this long with their current physical activity behaviour despite living with CHD. Findings also suggest that contemplative ACHD patients are likely to lack knowledge of appropriate physical activities to pursue and lack awareness of their personal abilities. As these ACHD patients in the contemplation stage may be in early phases of thinking about increasing their level of physical activity (Prochaska et al., 2015), it is understandable that they would have limited knowledge of suitable activities to pursue and are uncertain about how much they can exert themselves.

Findings suggest that ACHD patients across all stages are likely to experience fears when engaging in physical activity, as well as physical limitations that may hinder physical activity participation. Cardiac surgery was also identified as a factor influencing physical activity behaviour for participants in most stages. Interestingly, however, the way in which experiences with cardiac events are perceived may differ from one stage to the next, based on this study's findings. For instance, findings suggest that ACHD patients in earlier stages (i.e., contemplation, preparation) are likely to perceive cardiac events, such as requiring cardiac surgery, as a constraining factor to physical activity participation. In contrast, the anticipation of cardiac surgery, or knowing they have an upcoming cardiac surgery, may be a motivator for physical activity for ACHD patients in later stages (i.e., action, maintenance). This finding is supported by

participants who sought to continue, or increase, their physical activity regimen to be in the best possible physical condition going into surgery. In addition, findings suggest that ACHD patients in later stages are likely to perceive cardiac events, such as cardiac surgery or symptoms, as non-reoccurring. Thus, after experiencing such events, findings imply that ACHD patients in later stages are likely to continue participating in their physical activity regimen post-surgery as they normally would, instead of being turned off by physical activity after experiencing these events.

While CHD-specific factors influencing physical activity behaviour have been uncovered in past research, as well as in the present study, the way ACHD patients perceive these factors based on their desire to be active must be considered. For example, fear appears to be experienced by ACHD patients across most stages, but how it is perceived by these patients and its impact on physical activity behaviour are critical. ACHD patients in the maintenance stage are active despite having a high perception of risk and thus, fear is not a constraint that has an influence on physical activity behaviour. Rather, ACHD patients will either avoid activities that have caused them harm or triggered perceptions of fear and instead pursue physical activities they are comfortable doing. Similarly, participants who experience CHD-related symptoms when active, such as chest pain, fatigue and shortness of breath and have a limited exercise capacity also maintained a physically active lifestyle as they will modify their physical activity behaviour according to the constraints they experienced rather than avoiding physical activity altogether.

While research in the past has uncovered such factors as primary constraints that dictate physical activity behaviour in ACHD patients, it is likely that most of these studies generated their findings through surveys and controlled lab environments. However, through the use of a qualitative research design focusing on the perceptions of ACHD patients, this study was able to show how constraints to physical activity behaviour are actually perceived and experienced by

ACHD patients and that these do not have a strong influence on physical activity participation. This finding has important implications for those promoting physical activity to ACHD patients as it emphasizes avoiding pre-conceived notions about the factors that prevent physical activity behaviour for ACHD patients. Healthcare professionals should not assume that ACHD patients are not active because they are fearful or have a diminished capacity to be active, hence the critical need to assess ACHD patients on an individual basis (Longmuir et al., 2013). Researchers cannot have a checklist of pre-determined factors when asking ACHD patients which ones influence physical activity participation, nor can healthcare professionals promote generalized physical activity recommendations as a result of these findings.

General Social Ecological Factors

While it is important to acknowledge how CHD-specific factors influence physical activity behaviour in ACHD patients, it must be understood that they experience common factors as do individuals from the general population.

Findings suggest that ACHD patients experience various constraining intrapersonal lifestyle factors such as the cost of registration fees for physical activity programs, convenience when it comes to the location of and transportation to recreation facilities, poor weather conditions and lack of time, which are typical physical activity barriers experienced by the general population (AHA, 2018; CDC, 2020c). Convenience presents challenges when it comes to pursuing physical activity participation in ACHD patients, particularly in early stages, as it makes it difficult to access desired programs. Participants in early stages tend to have lower motivation and are in infancy when it comes to developing strategies to improve self-efficacy (Prochaska et al., 2015). Thus, if ACHD patients in these stages are unable to access desired physical activity opportunities, regular physical activity participation could be difficult to achieve, as they are not motivated and do not

use effective strategies for overcoming accessibility barriers. These findings bear similarities with previous research on individuals with various diseases (i.e., multiple sclerosis, colorectal cancer survivors, autism spectrum disorders), citing self-efficacy and accessibility to recreational physical activity opportunities as factors influencing physical activity participation (Lynch et al., 2010; Obruskinova & Cavalier, 2011; Silveira et al., 2019).

In addition, given that participants in early stages struggle with time to incorporate physical activity behaviour into their daily life, they will likely be unwilling to take the time to travel to facilities that are not nearby, especially if they do not offer low-cost programs. In contrast, participants in later stages, such as action and maintenance, likely require less intervention when dealing with convenience, as they already have a structured physical activity regimen in place and are far more resilient in sustaining their physical activity regimen (Prochaska et al., 2015). It is therefore crucial to promote physical activities that can be pursued at any time, any place, and require little equipment/resources such as outdoor walking (AHA, 2018; CDC, 2020c), for ACHD patients in early stages.

Other factors that were not discussed by participants in all stages (this does not necessarily mean they are stage-specific) were dealing with non-cardiac related illnesses such as seasonal colds and flus, recreational facilities failing to accommodate for overcrowding, having experiences that do not align with expectations of the program based on the way it is advertised, and poor weather conditions. Realistically, participants who are ill can engage in mild or moderate physical activity if symptoms are not too severe (ALA, 2019) and do not bring on additional complications related to their CHD. When it comes to poor weather conditions, if ACHD patients tend to engage in outdoor physical activities, it would evidently be recommended for them to participate in indoor physical activities that are appropriate to their abilities, such as going up and down stairs in their

home, home yoga or frequenting local recreational facilities offering programs, classes or activities that align with their interests. For example, if participants tend to go for neighbourhood walks, they could frequent local recreational facilities that have walking tracks.

Interestingly, factors pertaining to body perceptions were commonly experienced by female participants in most stages. Body image is an individual's perceptions, thoughts and feelings about their body (Zarshenas et al., 2013), and body dissatisfaction occurs when there are discrepancies in perceptions between one's actual body shape and ideal body shape (Sun et al., 2018). Findings of this study are consistent with trends among the general population, as it has been said that females are often more likely to believe they are being judged by their attractiveness (Dijkstra & Barelds, 2011), particularly when active among others (Thompson et al., 1999). This was especially evident in female ACHD patients who avoided physical activity contexts such as aqua fitness, where they would have to reveal their body in swimsuits. In addition, it was expressed by female participants that perceptions of being overweight when active among others triggered perceptions of stigma, which is perhaps why weight loss and maintenance, in addition to enhancing one's body image, were important motivators. These findings are also consistent with previous research suggesting that preoccupation with weight and appearance may be associated with the desire to be physically active (Davis, 1990).

Furthermore, similar trends between participants of this study and the general population were evident when it came to long-term engagement in physical activity and exposure during childhood. Physical activity is often promoted in children because active children tend to be active adults (Pate et al., 1999; Thompson et al., 2003). Childhood is a critical time to expose children to physically active lifestyles, as it is then that they will develop attitudes and skills that will be considered important during adulthood (Pate et al., 1999; Thompson et al., 2003). Thus, positive

experiences and learning skills acquired during childhood physical activity participation facilitate similar physical activity involvement, as well as participation in new forms of physical activity and sport, in adulthood (Telama et al., 1997; Thompson et al., 2003).

Findings support past research for exposure to physical activity during childhood, as those in early stages had limited exposure during their youth, while those in later stages had been involved in physical activity from a young age. While similar physical activity trends were found between ACHD patients and individuals in general, it must be acknowledged that certain CHD-related factors limited childhood physical activity exposure. For instance, in addition to having overprotective parents, participants in early stages were encouraged to be inactive during childhood by healthcare professionals, which was typical prior to the development of modern medical treatments in ACHD patients (Cuypers et al., 2016; Longmuir et al., 2013; Reybrouck & Mertens, 2005; Roche & Silversides, 2013). However, findings suggest that ACHD patients who were discouraged from being active during childhood have not developed a strong desire to pursue physical activity during formative years, which is consistent with previous literature (Cuypers et al., 2016; Longmuir et al., 2013; Reybrouck & Mertens, 2005; Roche & Silversides, 2013). This may be one of the greatest challenges for promoting physical activity participation in ACHD patients who were given this advice in the past, as developing an interest in physical activity during adulthood is difficult according to findings of this study. It is therefore critical to inform ACHD patients of the risks of a sedentary lifestyle while emphasizing its benefits in hopes that they will want to better their health and live a fulfilling life. In addition, since the norm today is for healthcare professionals to promote physical activity for all CHD patients (Chaix et al., 2016; Longmuir et al., 2013), this may be less of an issue in the future.

Perceived Benefits and Risks

Findings suggest that ACHD patients can experience a variety of physical, psychological and social benefits through physical activity. Perceived benefits were discussed by participants in most stages and thus, are not necessarily stage specific. Rather, the number of benefits experienced by participants increased from one stage to the next. For example, participants in the pre-contemplation stage had not perceived any benefits from physical activity participation, while those in the maintenance stage mainly emphasized the benefits they experienced from prolonged engagement in physical activity.

Participants experienced several physical benefits from participating in physical activity, some of which are consistent with previous research (Dean et al., 2015; O'Byrne et al., 2013; Pemberton et al., 2010; Therrien et al., 2003). For instance, it was reported by participants in most stages that participating in physical activity helped them lose or maintain a desired weight. This finding is particularly important, as obesity is an important health concern for the ACHD population (Pemberton et al., 2010). Weight loss also has implications beyond reducing the risk of obesity, as participants in this study indicated that it can generate an increase in energy to disperse in other aspects of life. Specifically, having more energy to spend means that ACHD patients may have an easier time with the constant movements their workplace requires, and completing household tasks without becoming too fatigued. Incidentally, findings suggest that the ability to do more activities can lead to improvements in ACHD patients' sleep quality. Having more energy therefore enables a cycle where ACHD patients can have more energy to do activities during the day and be more fatigued in the evening and sleep better at night. The cycle can then begin anew in subsequent days, as better sleep means that ACHD patients can have more energy the next day.

Participants engaged in a variety of physical activities ranging from unstructured activities, such as household tasks, cycling, walking and running, to structured regimens, such as exercising at the gym or with personal trainers, Tai Chi and yoga programs, aqua fitness and team sports. The activities listed here incorporate various static and dynamic movements that exert the body in different ways. As a result, findings suggest that ACHD patients can experience a variety of functional physical benefits, such as increased endurance, strength, flexibility, mobility, coordination and better posture when participating in these types of activities, which is consistent with benefits experienced by the general population (USDHHS, 2000). Not only do these benefits motivate continued physical activity participation, but they also translate to other areas of life for ACHD patients. For instance, ACHD patients who engage in yoga are likely to become more flexible, leading them to experience less upper-body pain when working prolonged hours at a desk. In addition, increasing strength through exercising and weightlifting means that some ACHD patients are addressing concerns related to osteoporosis, which is a concern in elderly individuals (WHO, 2021). Findings also suggest that engaging in moderate physical activities, such as yoga and Pilates, is effective in helping ACHD patients with Marfan syndrome manage common challenges they face, including daily joint and body pain (The Marfan Foundation, 2014).

A distinction can be made between the physical benefits listed above, which tend to benefit participants over the short term, and other benefits like increased heart health, which can have long-term implications. Findings imply that ACHD patients understand that physical activity can improve cardiac health, or performance, by reducing the risk of acquired heart disease, which addresses a significant health concern for ACHD patients (Pemberton et al., 2010; Pillutla et al., 2009). These findings are also consistent with previous research on ACHD patients, suggesting that physical activity can increase cardiac performance (Dean et al., 2015; Dua et al., 2010;

Martinez-Quintana et al., 2010; Therrien et al., 2003; Winter et al., 2012). Increasing cardiac health is therefore an important benefit to consider when promoting physical activity to ACHD patients, as even those who are not constrained by CHD and have undergone successful corrective surgeries may experience complications later in life (Cuypers et al., 2013, 2014a, 2014b; Menting et al., 2015).

Participants also described a series of physical activity benefits that were social in nature. Findings suggest that some ACHD patients may lack endurance and competence due to insufficiencies brought on by CHD, which triggers perceptions of stigma. As a result, ACHD patients who go through these experiences may withdraw from social physical activity contexts, such as team sports, because they feel excluded, resulting in them living in isolation. However, for ACHD patients who manage to maintain their involvement in physical activity by engaging in activities with friends or structured physical activity programs, physical activity can become an opportunity to come out of isolation and sense belonging among a group of individuals sharing similar interests. These findings resemble those from research on other vulnerable population groups, including Parkinson's disease and cerebral palsy (Artigas et al., 2015; Gaskin et al., 2009; MacCosham et al., 2019; Maley et al., 2013).

Participating in social physical activity contexts, be they unstructured or structured, can enhance the social life of ACHD patients, based on findings from this study. For instance, findings suggest that physical activity is an opportune way for ACHD patients to develop new interpersonal relationships with others attending the same programs or recreational facilities and strengthen existing interpersonal relationships with friends and family members when participating in unstructured physical activities with them (e.g., walking). According to findings in this study, the social benefits experienced by ACHD patients through physical activity can also be a motive for

becoming more sociable with friends, family members and significant others. These findings have important implications for promoting inclusivity among ACHD patients, as it is common for them to feel socially isolated and experience loneliness (Kovacs et al., 2009). These findings also imply that ACHD patients can experience social inclusion through physical activity, as do individuals from the general population (Babiss & Gangwisch, 2009).

The psychological benefits of physical activity, as perceived by ACHD patients, have yet to be adequately explored. Previous research on individuals with Parkinson's disease and other neuromuscular disorders (MacCosham et al., 2019; Newitt et al., 2016) suggest that physical activity provides an outlet for these individuals to escape, or forget about, the stress that is brought on by living with their disease. Findings suggest that as some ACHD patients are severely impaired by their CHD, being active can relieve feelings of depression and anxiety, in addition to helping them cope with their disease. Thus, findings suggest that severely impaired ACHD patients use physical activity in similar ways as individuals living with severe neurological diseases (MacCosham et al., 2019; Newitt et al., 2016). These findings also stress the importance of engaging in physical activity to overcome depression and anxiety, which are common challenges for ACHD patients (Bromberg et al., 2003; Eslami et al., 2013). However, it must be acknowledged that very few participants in this study were severely impaired by their CHD and rarely considered CHD as a constraint to physical activity participation. Thus, unlike others living with severe CHD or neurological diseases, findings suggest that ACHD patients are more likely to use physical activity to escape stress brought on by everyday life, such as work and family life, rather than issues related to CHD. Being fully immersed in activities like gardening, Pilates and therapeutic activities such as yoga were among the most effective for releasing stress for ACHD patients in this study.

Furthermore, findings suggest that ACHD patients can experience positive emotions and increase their well-being by alleviating feelings of depression and anxiety through physical activity. These findings are consistent with literature on individuals from the general population, as well as ACHD patients, claiming that physical activity is an opportune way to increase well-being and quality of life (Dean et al., 2015; Dua et al., 2010; USDHHS, 2000). In addition, increasing well-being can be related to sensing accomplishment. For example, according to findings in this study, accomplishing goals like weight loss through physical activity participation can be a source of feeling accomplished and increase confidence and well-being in ACHD patients.

Moreover, despite the low risk associated with physical activity participation in ACHD patients (Chaix et al., 2016; Koyak et al., 2012; Zomer et al., 2012), some participants were fearful when active and held varying perceptions of the risks associated with physical activity. Because participants across all stages expressed fear in various ways when it came to being active, the perception of risks was not necessarily unique to certain stages.

Findings of this study are supportive of literature suggesting that fear is one of the most common physical activity constraints among ACHD patients (Reybrouck & Mertens, 2005). Specifically, participants reported fears associated with overexertion, such as heart failure, sudden cardiac death, tearing the aorta, palpitations, and aneurysms, which are common concerns among active ACHD patients (Warnes et al., 2008). Yet, in addition to CHD-related complications, findings suggest that ACHD patients are also aware of the risk of experiencing musculoskeletal injuries in joints, muscles, tendons and bones when engaging in certain activities (e.g., team sports, falling when walking in poor weather conditions). These findings add depth to perceptions of fears and risks that come with physical activity participation, as research has yet to explore how ACHD patients take into consideration non-CHD related injuries associated with physical activity.

Interestingly, findings suggest that fears and perceived risks may not necessarily prevent physical activity in ACHD patients over other factors. For instance, participants in all stages believed that physical activity could be highly risky. These findings therefore suggest that the risks alone do not necessarily deter ACHD patients from being active, as even participants with established physical activity regimens had a high perception of risk. Fear as a constraining factor was also dismissed by a participant who mentioned that if fear dictated her life choices, she would never leave her home. This finding therefore stresses the importance of considering how various factors likely play a role in determining physical activity behaviour in ACHD patients. The only context in which fears can have a strong influence on physical activity behaviour, according to findings in this study, is newly diagnosed ACHD patients. This finding is supported by the experience of a participant who was traumatized upon being diagnosed with CHD and required cardiac surgery at an adult age. This event changed the way she perceived her ability to live a normal life as she once did, and ultimately made her fearful to be as active as she was pre-diagnosis.

The perceived benefits and risks of physical activity participation unveiled in this study add to a body of literature that was lacking in the context of ACHD patients. Research in the past has suggested that ACHD patients can benefit from physical activity in several ways, as do individuals from the general population (Longmuir et al., 2013), but had yet to be adequately supported with empirical evidence. Most of the benefits identified in this study have short-term implications for ACHD patients by providing them with immediate physical and psychological relief. Yet, it must be acknowledged that most benefits (e.g., increased heart health, increased well-being, weight loss, maintaining interpersonal relationships) can also have long-term implications on the physical and psychosocial health of ACHD patients. Similarly, participants' perceived risks

revolved mostly around short-term complications (e.g., palpitations, minor injuries), while other risks (e.g., aneurysm, tearing of the aorta, severe musculoskeletal injuries) could have long-term implications depending on their severity.

Conversations With Healthcare Professionals

Healthcare professionals have an important role in motivating and supporting regular physical activity participation in ACHD patients, as it is supposed to be a topic of discussion during routine clinical visits (Longmuir et al., 2013). Indeed, it is important for healthcare professionals to clinically assess and consider disease severity when promoting physical activity to ACHD patients (Chaix et al., 2016; Longmuir et al., 2013). Motivational interviewing strategies have also been established to facilitate the promotion of physical activity to ACHD patients (Ockene et al., 2002; Rollnick et al., 2007). However, the manner in which these clinical interactions are perceived by ACHD patients has yet to be explored.

While healthcare professionals are expected to have a role in encouraging ACHD patients to be active (Chaix et al., 2016; Longmuir et al., 2013), many are not equipped to do so. Healthcare professionals often lack adequate resources, knowledge, skills or time to effectively promote or counsel patients on physical activity (Ackerman et al., 2011; Lin et al., 2010; McDonagh et al., 2004), which was acknowledged in findings of this study. Yet, such things may not be completely necessary in the case of ACHD patients, as just a few words can prove effective based on their perception of conversations with healthcare professionals.

Differences in the way ACHD patients in earlier stages perceive conversations with healthcare professionals compared to those in later stages may occur according to findings in this study. For instance, findings suggest that ACHD patients in early-to-mid stages (i.e., contemplation, preparation) typically associated with uncertainties about the benefits of physical

activity and who are experimenting with various activities (Prochaska et al., 2015) often leave conversations with healthcare professionals with the same uncertainties they walk in with. Based on findings in this study, ACHD patients in these stages perceive that they receive little information on how physical activity impacts health and fail to understand why they should avoid certain activities if they are told to do so by healthcare professionals. In addition, findings suggest that it is likely that ACHD patients in these stages perceive that healthcare professionals emphasize medication while rarely discussing current physical activity engagement, which is consistent with previous literature on this topic (Rosenthal et al., 2016). Consequently, findings imply that these ACHD patients leave conversations with healthcare professionals with minimal information on the importance of being active and have little motivation to be active afterwards, which is a common issue (Orrow et al., 2012; Swan & Hillis, 2000).

Participants in early stages also stated they were discouraged from being active during childhood by healthcare professionals. Having minimal exposure to physical activity during childhood may therefore have long-lasting effects on ACHD patients according to this study's findings, as they may have a poor attitude towards being active and lack motivation to be active today. While it is no longer common for healthcare professionals to discourage physical activity participation in ACHD patients, unless clinical assessment requires it, findings suggest that it is harder for them to take on and develop an interest in physical activity at an adult age. These findings reaffirm literature suggesting that children who develop positive attitudes towards physical activity during childhood through pleasurable experiences are more likely to pursue similar physical activities during adulthood (Pate et al., 1999; Telama et al., 1997; Thompson et al., 2003). Nonetheless, healthcare professionals must seek ways to promote physical activity in unmotivated ACHD patients. Given that these ACHD patients tend to have knowledge-based

challenges involving physical activity, educating them on the benefits of physical activity and the risks of sedentary behaviour may be a first step, in addition to emphasizing the benefits of engaging in recommended activities, and the risks associated with activities to be avoided.

Participants in mid (i.e., preparation) to later (i.e., action) stages often perceived stigma when going into conversations with healthcare professionals. Counselling strategies employed by healthcare professionals during actual conversation are typically non-judgmental (Ockene et al., 2002; Rollnick et al., 2007), but findings suggest that ACHD patients may go into these conversations with preconceived perceptions of stigma towards them. Findings suggest that as ACHD patients in these stages are on the path to establishing a structured physical activity regimen (Prochaska et al., 2015), they are likely to seek validation or recognition from healthcare professionals for their efforts in increasing their level of activity. Findings therefore suggest that ACHD patients in these stages do not want to be judged for failing to be active when going into conversations with healthcare professionals and want to be recognized for the improvements they have made to their lifestyle. In addition, findings suggest that ACHD patients in later stages (i.e., action, maintenance) who have an established physical activity regimen are likely to be motivated after leaving conversations with healthcare professionals if they are provided with support and positive feedback on their active lifestyle.

Interestingly, findings revealed that while physical activity participation was often motivated in participants who received specific recommendations from healthcare professionals, it was felt that discussing specific guidelines of 150 minutes of moderate physical activity per week (Canadian Society for Exercise Physiology, 2021; CDC, 2020b) could be a nuisance. Thus, findings regarding ACHD patients' perceptions of what is considered as a specific recommendation suggest that they may not need a specified amount of time being active per week.

For instance, results suggest that ACHD patients may consider recommendations such as being told to pursue physical activity as would any healthy individual and adjust the intensity of their participation based on comfort and symptoms experienced as specific. These recommendations, while still broad, gave ACHD patients in this study the opportunity to pursue various physical activities of interest that required different levels of exertion. Being overly specific can also limit physical activity in those who are less motivated, based on discussions with ACHD patients in this study, as they could engage in the minimum amount of 150 minutes of moderate physical activity per week and be mostly sedentary afterwards.

Findings illustrate how ACHD patients' perceptions of conversations with healthcare professionals impact their desire to pursue physical activity. These findings are particularly relevant when trying to promote physical activity behaviour in ACHD patients. While it is acknowledged that healthcare professionals may not have the resources to provide physical activity recommendations to ACHD patients, it is important for them to provide information or guidance appropriate to the stage of motivation in which the patients are situated. For example, ACHD patients in early stages need to be informed about the benefits of being active and the risks of being sedentary, as well as understanding why they should pursue certain activities over others. These recommendations would also address challenges facing individuals in early stages, as they often lack knowledge in these areas (Prochaska et al., 2015). If it is not feasible for healthcare professionals taking care of early stage ACHD patients to do so, it may be more suitable to refer them to individuals who specialize in physical activity promotion. For ACHD patients in later stages, simply telling them to continue pursuing physical activities of interest, based on their abilities, while monitoring the symptoms they experience may be suitable as a recommendation over a detailed prescription. The reassurance ACHD patients in these stages receive after sharing

their recent uptake or maintenance of physical activity behaviour may be seen as valuable and motivate continued physical activity behaviour.

Processes of Change

The processes of change highlighted in this portion of the study can be used to inform the development of stage-specific interventions designed to increase physical activity behaviour in ACHD patients. ACHD patients in this study employed both cognitive and behavioural strategies to sustain physical activity behaviour, many of which have been described in past literature (Prochaska et al., 2015; Kennelly et al., 2013; MacCosham, 2017). Findings suggest that sustaining physical activity behaviour is complex, as ACHD patients may not only experience constraints to physical activity but may be aware of them and use various strategies to overcome them (Fendt & Wilson, 2012; Kennelly et al., 2013).

The strategies employed by participants in this study diverged substantially from what literature suggests on processes of change typically used in each stage (DiClemente & Prochaska et al., 1982; Prochaska et al., 2015). While it has been said that individuals in stages such as pre-contemplation, contemplation and preparation are more likely to use cognitive strategies (Prochaska et al., 2015), findings of this study did not support this claim. Aside from the pre-contemplation stage in which only one more cognitive strategy was identified over behavioural ones, participants in the contemplation and preparation stages used mainly behavioural strategies to sustain physical activity participation. It was also found that participants in the action and maintenance stages employed mainly behavioural strategies, which is consistent with past literature (DiClemente & Prochaska et al., 1982).

With regard to specific strategies typically employed in each stage, both similarities and differences were found when comparing findings of this study to past literature. For example,

participants in the pre-contemplation stage proposed using dramatic relief and consciousness raising, which is consistent with the literature (Prochaska et al., 2015). Participants in the contemplation and preparation stages did not cite self-reevaluation as a strategy employed, which differs from the literature (Prochaska et al., 2015), while participants in the action stage did not rely on self-liberation as a strategy, which is also inconsistent with the literature (Prochaska et al., 2015). However, it was found that participants in the maintenance stage used stimulus control and helping relationships, among other strategies, which is consistent with past literature (Prochaska et al., 2015).

Cognitive Strategies

Findings suggest that ACHD patients tend to employ cognitive strategies such as dramatic relief, consciousness raising and goal setting. It has been said that healthcare professionals who use non-judgmental counselling approaches are more likely to enhance a patient's ability to sustain behavioural change (Ockene et al., 2002; Rollnick et al., 2007). However, findings from this study contrast this, as does literature suggesting that behavioural change is a process that begins intrinsically when the individual is ready to change (Prochaska et al., 2015), as participants in the pre-contemplation stage proposed using dramatic relief in the form of intimidation from healthcare professionals as an effective way to motivate physical activity participation. Specifically, findings suggest that if healthcare professionals emphasize the severity and life-threatening consequences of being sedentary, they could elicit enough fear in pre-contemplative ACHD patients to prompt immediate behavioural change. This finding is supported by an example provided by a pre-contemplative participant who discussed how her cardiologist judged her and emphasized the severity of smoking for someone living with CHD. Upon feeling judged and being informed of the severity of smoking for someone with CHD, the participant committed to ceasing smoking soon

after, in fear of being judged and reminded of the severity of smoking in subsequent clinical visits. Thus, the participant was suggesting that this strategy could also be used in the context of physical activity and inspire an uptake in physical activity participation for her. While stigmatizing ACHD patients may not be the most appropriate approach to take by healthcare professionals, it may be suitable to provide highly unmotivated ACHD patients with resources on the benefits of physical activity while emphasizing the more severe consequences of sedentary behaviour, in addition to providing guidance on appropriate and cost-friendly physical activity opportunities. Giving them this information could be enough to spark an initial desire to increase physical activity in predominantly sedentary ACHD patients, as they have limited knowledge in these areas (Prochaska et al., 2015).

Furthermore, participants across most stages used consciousness raising as an educational strategy to increase their knowledge in various ways. For participants in pre-contemplation, consciousness raising was proposed as a strategy to address a need to educate young CHD patients on the limitations of their diagnosis, as well as making sure that childhood educators are aware of these patients' limitations and thus unreceptive to their attempts to dramatize their disease and avoid physical education. While consciousness raising was associated with using resources (e.g., newspapers, websites) to gain knowledge of appropriate physical activity programs, this strategy also contained a behavioural component in some instances. For example, since ACHD patients in the preparation and action stages often experiment with various forms of physical activity and are working towards developing a structured physical activity regimen (Prochaska et al., 2015), they used this strategy to learn about their personal abilities and how much they could exert themselves before experiencing CHD-related symptoms. ACHD patients in these stages may therefore engage in physical activity behaviour to become more cognizant of their personal abilities to determine

appropriate levels of physical activity. In addition, participants in the maintenance stage used resources to further inform themselves on various topics related to health behaviour, not necessarily limited to physical activity, in addition to further educating themselves on proper exercise techniques, such as physical form and new exercises when engaging in certain forms of physical activity (e.g., weightlifting).

Goal setting emerged as a cognitive strategy among participants in most stages. This can have important implications for healthcare professionals when promoting physical activity to ACHD patients, as goal setting has been cited as one of the most effective strategies for promoting behavioural change (Ammerman et al., 2002). Research in the past has shown that collaborative goal setting between healthcare professionals and patients is most effective for developing trust and improving aspects of health in patients with diabetes (Lafata et al., 2013). Goals typically include two components, that is, goal specificity where the parameters and target behaviours are clearly defined (e.g., 150 minutes of physical activity per week), and level of difficulty, which is the probability of successfully achieving set goals (Latham et al., 2011). Behavioural change counselling strategies used by healthcare professionals on adult patients can help them identify relevant goals, which in turn helps them develop and implement meaningful action plans (Rollnick et al., 2007). Creating action plans that are in line with the patients', and their family's, values is most effective in sustaining behavioural change (Longmuir et al., 2013).

Findings of this study illustrate a gradual increase in goal specificity and level of difficulty in ACHD patients in the contemplation stage to the maintenance stage. While goal setting was employed solely by participants, including healthcare professionals in the goal setting process could be helpful to them when assessing current levels of physical activity, in addition to being actively involved in the process of helping ACHD patients achieve set goals, based on what

literature suggests (Lafata et al., 2013; Latham et al., 2011; Rollnick et al., 2007). According to findings of this study, effective goals to establish for contemplative ACHD patients are not small ones, such as developing a habit of engaging in physical activity on a regular basis, however much or little. To do this, findings suggest that it would be most effective to use various tools such as electronic devices or calendars to track the frequency and types of physical activity engaged in per week and use that information to identify times in which physical activity can or is most likely to occur. Afterwards, getting into a routine of dedicating that timeframe to physical activity on a regular basis, while maintaining broad goals (e.g., having to walk a certain amount per week), can be established.

Once these goals are achieved on a regular basis, the following step would be to establish harder and more specific goals, while still maintaining broader achievable goals, which is supported by findings in the preparation stage. For example, an achievable goal in this phase could be to walk a certain number of times per week, with a more difficult and specific goal being to walk a specified distance per day or week. Once ACHD patients have more structure in their physical activity regimen, as do those in the action stage, , helping them achieve more difficult goals (if appropriate and desired) could be set, such as increasing the intensity or exertion of physical activity participation. Similarly, a goal could be set to help ACHD patients in maintenance to achieve difficult goals or to achieve more specific goals (e.g., participate in competitions such as races or triathlons), or to add physical activity to their already established regimen if safe. As participants in the pre-contemplation stage have no intention of modifying their behaviour (Prochaska et al., 2015), it is understandable why goal setting was not identified as a strategy for ACHD patients in this stage.

Behavioural Strategies

ACHD patients in this study employed several behavioural strategies, including stimulus control, substitution, counterconditioning and cyclical commitment, in order to modify behaviour to either increase or sustain physical activity participation.

Cyclical commitment was employed by participants to maintain engagement in physical activity and sport over a prolonged period of time. This strategy was associated with participants in the maintenance stage, as they often engaged in high frequencies of and physically demanding forms of physical activity. Findings suggest that ACHD patients who engage in physical activity pursuits that are physically cumbersome and consume much of their time will alternate between intense periods of participation, followed by periods of reduced participation for self-maintenance. Once self-maintenance is achieved, ACHD patients in this stage will then be motivated to continue their pursuits afterwards, based on this study's findings. These findings are in line with research by Kennelly et al. (2013) on amateur athletes who were fully committed to the pursuit of triathlons and MacCosham's (2017) study on a fully committed epileptic amateur musician. Findings in those studies suggested that highly committed individuals go through bouts of high frequencies of intense participation followed by instances of decreased participation when realizing they need to recuperate physically and mentally. It is therefore understandable that this strategy would be associated with ACHD patients in the maintenance stage, as they are fully committed to their recreational physical activity pursuits.

Stimulus control strategies used by participants across stages revolved mainly around planning and time management and were deemed most effective in reducing time related constraints (Kennelly et al., 2013; MacCosham, 2017). Findings suggest that many ACHD patients utilize calendars or electronic devices to identify, and effectively manage, time constraints and

schedule conflicts between time dedicated to physical activity and time dedicated to other facets of life (e.g., work). In many instances, participants joined structured physical activity programs, as they took place at a designated time, and therefore reserved time during the week for physical activity. Joining structured programs to stay active bears similarities with the concept of discipline props in Kennelly et al.'s (2013) study, in that they serve as a protection to reduce constraints related to lacking time and schedule conflicts. The concept of planning and time management to reduce time and schedule conflicts is also consistent with findings in MacCosham's (2017) study, as well as Loucks-Atkinson and Mannell's (2007) study on individuals living with fibromyalgia.

Counterconditioning was utilized in a consistent way as the literature suggests by reducing unhealthy behaviours (i.e., being sedentary) and creating favorable behaviours (i.e., being active) (Prochaska et al., 2015). Findings suggest that to incorporate additional physical activity into their daily regimen, ACHD patients substituted behaviours that favour a sedentary lifestyle, such as parking close to stores when shopping to avoid walking and having objects in their home conveniently located, with behaviours favouring an active lifestyle. Parking further away from stores to get additional steps in and placing objects throughout their home in a way that required more navigation to retrieve them, maximized participants' time to be active whenever they could during the day.

Relationships were found between stimulus control and strategies such as goal setting and helping relationships. This finding adds to existing knowledge on processes of change by demonstrating that behavioural strategies can be used in collaboration with cognitive ones to sustain physical activity participation. Specifically, findings suggest that ACHD patients in later stages use calendars and electronic devices not only to schedule time for physical activity, but also to determine the frequency and intensity of participation to see if they are achieving set goals (e.g.,

reaching daily or weekly step counts). In addition, stimulus control appears closely related to goal setting and helping relationships, as ACHD patients use electronic devices to track weekly physical activity participation to compare with others during friendly competitions, which motivates continued participation to win, based on findings of this study. These findings contradict statements by Jackson and Rucks (1995) who claimed that cognitive and behavioural strategies are typically utilized separately but are supportive of more recent research claiming that cognitive and behavioural strategies can be utilized together dynamically (Kennelly et al., 2013; MacCosham, 2017).

Mentioning physical activity interests to family and friends and inviting them to be active are effective strategies for promoting physical activity participation (CDC, 2020c). Findings of this study reflect this claim, as helping relationships played an important role in sustaining physical activity participation for participants in all stages, except for pre-contemplation. According to this study's findings, being active with others can be a source of motivation for ACHD patients, in that it makes them liable to be active with others when inviting, or planning to be active with, others. In addition, findings suggest that being active with others facilitates perceptions of safety and comfort from knowing that someone else is close if ACHD patients experience a cardiac event and need assistance. Being surrounded by trustworthy and knowledgeable individuals (e.g., healthcare professionals, program staff) who ACHD patients may see as reliable sources of information on physical activity was also deemed crucial for encouraging physical activity behaviour in ACHD patients, as it could help them understand how their health and personal abilities are progressing when active.

Interesting findings emerged on the theme of reinforcement management and its utility for a participant in the pre-contemplation stage. Findings suggest that rewarding unmotivated ACHD

patients with unhealthy behaviour (e.g., treats such as a candy bar) could be a way to encourage physical activity participation. This finding contrasts our current understanding of reinforcement management (Prochaska et al., 2015), by implying that physical activity could be encouraged by providing highly unmotivated ACHD patients with additional unhealthy behaviours or treats to motivate continued participation. While it may be worth exploring this concept in future research or when promoting physical activity behaviour to primarily sedentary ACHD patients, proceeding with caution would be necessary. On one hand, it may be an effective approach for introducing such ACHD patients to physical activity with hopes that they would gradually develop an interest without needing unhealthy rewards. On the other hand, however, it may only motivate a desire to receive unhealthy behaviours through physical activity participation rather than being a step towards long-term change.

Strategies can be used to adapt to factors constraining recreational pursuits (Hubbard & Mannell, 2001; Jackson, 2000; Jackson & Rucks, 1995). A unique contribution of this study is the theme of substitution, a strategy that relied on participants' ability to modify their behaviour as they adapted to constraining factors. For instance, participants' abilities changed due to life events such as having children or experiencing challenges brought on by CHD. As a result, in some instances participants found alternative ways to stay involved in physical activity, be it by taking on adapted roles within the same physical activity context or pursuing physical activities that were similar in nature. This finding can have implications for healthcare professionals when discussing physical activity with ACHD patients who may be seeking ways to stay involved in preferred physical activity. For those experiencing CHD-related issues, proposing similar alternative physical activities that are lower intensity could prevent complete withdrawal. These findings are supported by a participant who described switching to cross-country skiing from downhill skiing

once she began to experience vision impairment as a complication of Marfan syndrome. Conversely, those who experience lifestyle challenges but already have a structured physical activity regimen may be more equipped at finding alternative ways to stay involved by taking on coaching positions for their children who are engaged in the same physical activities, which was described as an example by a participant in this study.

Fearless Physical Activity

To date, there are no known ACHD-specific community physical activity programs. Fearless Physical Activity was created to help connect individuals living with CHD, help CHD patients and their families become aware of community resources on physical activity and help CHD patients become knowledgeable of physical activities within their personal abilities to motivate continued participation without being fearful (Fearless Physical Activity, 2017). While the intention of Fearless Physical Activity was to become an ongoing program (Fearless Physical Activity, 2017), it did not continue past its original scheduled timeframe between 2016 and 2018. The adult program events in Ottawa in particular saw a low turnout, averaging roughly 4 participants per event. This portion of the study therefore presents perceptions towards and factors influencing ACHD patients' desire to attend the ACHD-specific Fearless Physical Activity program events.

The most important factors influencing participants' desire to attend Fearless Physical Activity events revolved around their identity as an ACHD patient. Findings suggest that many ACHD patients live a normal life without experiencing any CHD-related issues and thus do not perceive themselves as an individual living with a disease. Engaging in a CHD-specific program would remind these participants that they are living with a disease – an unwelcomed reminder, since in their mindset they live normal lives. Findings therefore suggest that ACHD patients living

normal lives without limitations do not feel the need to attend CHD-specific programs, as they already pursue a physical activity regimen on their own within the community. Taking on an additional program emphasizing the idea that ACHD patients are not normal and live with a disease means that they are not interested in pursuing these types of programs, based on the findings of this study. Participants who were not limited in any way by their CHD felt that these types of programs were more suitable for severely affected ACHD patients.

Interpersonal factors were cited by participants as the primary motivators for attending program events. As the program was ACHD-specific, some participants who attended were severely affected by their CHD, while others were less affected. Regardless of how affected they were by CHD, participants were aware of the challenges of living as an ACHD patient, particularly those who were severely affected. Participants who were less affected by their CHD and whose lifestyle incorporated a structured physical activity regimen attended program events to be a role model and source of inspiration for those who were severely affected. The program therefore became an opportune way for participants, be they severely affected or not by CHD, to meet and find social support in one another, as they were either aware of or had lived similar life experiences. Through sharing common life experiences, participants were able to find security in one another and developed new interpersonal relationships with other ACHD patients. Program events often consisted of the same participants as well, which facilitated the development of interpersonal relationships between newly introduced ACHD patients, as well as helping ACHD patients who already knew each other to maintain their existing relationship. These findings illustrate how Fearless Physical activity was able to accomplish their goal of connecting CHD patients (Fearless Physical Activity, 2017), in addition to addressing social challenges experienced by many ACHD

patients such as loneliness, which is a common challenge faced by this population (Kovacs et al., 2009).

Interestingly, however, some participants found that being surrounded by similar others was a source of anxiety. For participants who did not perceive themselves as having a health issue or needing social support, being with and observing ACHD patients who were severely impaired made them re-think how comfortable they were with their current health status. Having discussions with severely affected ACHD patients was also perceived as strange and uncomfortable for participants who did not feel the need to seek out social support. Ultimately, participants who perceived Fearless Physical Activity events as being a source of anxiety and discomfort chose to skip the events.

The findings described above appear to echo those in the literature on integrative recreation and leisure programs. Integrative leisure is founded on the principle of inclusion, that is, acknowledging social considerations among oppressed and marginalized population groups (Son, 2018) by creating welcoming social and physical environments where all participants can participate and gain a sense of belonging and empowerment (Sen, 1999; Shefter et al., 2017). Such programs attempt to improve the social lives of marginalized groups of individuals by placing them with similar others and by promoting social support (Mead et al., 2001; Rosenfeld & Wenzel, 1997). For instance, a study on programs designed for individuals living with psychiatric disabilities suggested that they would be less likely to experience stigmatization and discomfort when interacting with similar others over members of the general population (Mead et al., 2001; Rosenfeld & Wenzel, 1997). This concept was founded on the idea that a specialized program for individuals living with psychiatric disabilities would improve quality of life and help them find

security, acceptance and belonging among others sharing common limitations (Mead et al., 2001; Rosenfeld & Wenzel, 1997).

Yet, these programs can be problematic, in that findings on individuals with psychiatric disabilities revealed that a program designated specifically for them served as a constant reminder of their limitations, and that it did not allow them to develop relationships with others that were not based solely on sharing experiences with the same disability and hospitalization (Davidson et al., 2001; Pyke & Atcheson, 1993). Similar findings were unveiled in a study on adults residing in group homes, which found that as they were constantly surrounded by similar others, their experiences with leisure activities within the context of their group home was not perceived as a time for leisure, but as a time of loss in social contacts and reduced diversity in their daily regimen (Rossow-Kimball & Goodwin, 2009).

As regards the Fearless Physical Activity program and structure itself, several factors contributed to participants attending program events or not. One of the most discussed themes influencing participants' desire to attend program events was related to the name of the program itself, "Fearless Physical Activity." The name of the program was a source of confusion for many participants, who found the name of the program inappropriate for promoting physical activity participation to ACHD patients. While the name "Fearless Physical Activity" was intended to promote being physically active without being fearful, participants perceived that the program was trying to get them to engage in extreme sports, which are not suitable for many ACHD patients (Chaix et al., 2016; Zipes et al., 2005). Given that most participants misinterpreted the meaning of the program name, they did not pursue the program upon hearing about it. Yet, it must be acknowledged that some participants' perceptions of the program name were in line with the program's vision. This factor is important to consider for program specialists who in future may

seek to develop CHD-specific or physical activity programs for other vulnerable population groups. The name of a program alone can be an important factor determining if they will seek to learn more about an advertised program or avoid it. As fear is one of the common factors constraining physical activity participation in ACHD patients (Reybrouck & Mertens, 2005), it would perhaps be worth considering avoiding title words that could trigger fear in many ACHD patients.

In addition to the program's name, findings suggest that the low frequency of program events in Ottawa was an important factor contributing to many ACHD patients having little interest in attending events. According to findings of this study, had program events taken place on a regular basis in Ottawa, ACHD patients would have been more inclined to attend. Findings suggest that ACHD patients seeking a structured physical activity program or to adopt an active regimen had little interest in going to a program that took place once per season. Thus, when designing a program aimed at increasing interest and participation in physical activity for ACHD patients, the frequency program events may need to be considered. It was suggested that the events would have perhaps been more successful had they been held more frequently in one city as opposed to several simultaneously. That way program events could have been held on a frequent basis for those seeking ongoing participation in a structured physical activity program. Had program events been frequent, the duration of sessions could have been diminished as well. Making those changes to the program structure may have garnered a larger number of participants, as there would have been more opportunities to engage in program events, and perhaps reduce time constraints for those unable to dedicate a long period of time to engaging in the program on weekends.

Findings suggest that being able to adapt activities to the participants' needs and exposure to new physical activities were factors leading to pleasurable experiences for ACHD patients who

attended the program. Two of the Fearless Physical Activity's program objectives were to help CHD patients discover community resources to facilitate the adoption of an active lifestyle and help CHD patients learn about physical activities within their abilities (Fearless Physical Activity, 2017). The ability to have participants engage in program activities that may be outside of their personal abilities by taking on adapted roles allowed all participants to stay engaged in program activities. These findings bear similarities with those on individuals with Parkinson's disease citing the need to adapt program activities based on the abilities of participants (MacCosham et al., 2021; Sánchez-Lastra et al., 2020), which is a critical aspect for increasing pleasurable experiences and continued participation in a physical activity program (O'Brien et al., 2008). Findings from this study therefore illustrate common perceptions of physical activity programs between ACHD patients and those living with Parkinson's disease. Additionally, being exposed to new and previously unknown physical activities was cited as a factor encouraging participants to seek similar activities and opportunities in community-based programs. These factors therefore demonstrate the program's effectiveness in achieving some of their objectives.

Other participants who attended the program felt that while the program was meant to be informative for ACHD patients (Fearless Physical Activity, 2017), there was too much emphasis on CHD. Considering that most participants did not identify as CHD patients, rethinking the way in which such programs are promoted may need to be considered to gain the interest of ACHD patients. To appeal to a wider audience of ACHD patients, findings suggest that physical activities during program events could have been more thematic and dedicated to one activity while having fewer discussions on CHD and physical activity between activities. For example, had certain program events been more frequent, they could have been dedicated solely to Tai Chi, while others could have been dedicated to Yoga. ACHD patients with varying abilities and who were interested

in these types of activities could have attended, with program staff adapting activities to their needs.

Findings also suggest that had event activities varied from week to week, ACHD patients would have had the opportunity to attend events with activities that were of interest to them, instead of skipping entire events because one activity did not appeal to them. The program's emphasis would have therefore been on the activities taking place during those events with participants being ACHD patients, rather than promoting the program as a way for ACHD patients to become aware of appropriate physical activities and have CHD-centered discussions afterwards. In addition, program events took place at various recreational facilities, sometimes at opposite ends of the city. Having each program event in the same location and conveniently located for transportation could have perhaps encouraged a wider audience of ACHD patients to participate according to findings in this study.

Taken together, these findings provide insight on the motives of ACHD patients for engaging in a CHD-specific physical activity program. These findings and suggestions could perhaps be helpful for recreation program specialists when developing and implementing physical activity programs for ACHD patients, and perhaps other patient populations, in the future. Findings of this study often revolved around the way ACHD patients identify themselves. This finding is particularly important, as ACHD patients are more than just patients, and as such, it is important to acknowledge that they have other dimensions to their individual identity.

Theoretical Implications

Findings from this study have generated new knowledge and understandings around physical activity behaviour within the ACHD population. To date, research has yet to adequately address the various aspects influencing physical activity behaviour in ACHD patients. To the

researcher's knowledge, this is the first qualitative study exploring the topics covered in this study from the perspective of ACHD patients. Many of the themes presented in this study have already been identified in previous research and literature, but have yet to be unveiled in the context of ACHD patients. Findings of this study that bear similarities with themes in past research suggest that there is transferability in the findings, as similar experiences can be had between ACHD patients and individuals from other patient population groups, as well as individuals from the general population. In addition, a multitude of themes beyond those already uncovered in past research were identified in this study.

Understanding how behaviour is initiated and maintained means that we must consider the factors influencing the behavioural change process in each stage (Prochaska et al., 2015). An important contribution of this study is that it utilized both the SEM and TTM frameworks to situate its findings. To date, research has yet to determine how multilevel factors influence physical activity behaviour in ACHD patients at varying levels of motivation.

Findings of this study are also supportive of the key principles of the SEM framework. For instance, findings revealed that multilevel factors (e.g., intrapersonal, interpersonal, community, institutional, public policy and systems), played a role in determining physical activity behaviour in ACHD patients (Sallis et al., 2015). Interactions between some multilevel factors were also experienced at times for participants, which is consistent with the SEM framework (Sallis et al., 2015), which also complements existing literature suggesting that relationships exist between various types of factors (Hawkins et al., 1999; MacCosham, 2017; MacCosham et al., 2021; Samdahl, 2007). For instance, several instances were found of relationships between intrapersonal factors, such as lacking exposure being related to lack of competence, fear being related to self-doubt and anxiety, and weight loss being related to increased energy. Relationships between

interpersonal and intrapersonal factors also existed. For example, perceived stigma was related to lacking endurance when playing team sports, while coming out of isolation was related to increased confidence. Interpersonal factors also related to one another in some cases. For instance, perceptions of stigma related to body perceptions sometimes triggered a desire to isolate oneself, while being active among others was related to developing new interpersonal relationships. However, findings suggest that intrapersonal factors may need to be addressed over other factors, which bear similarities with previous research (MacCosham, 2017), as they were the most oft-experienced by participants in each stage.

The themes unveiled in this study can be valuable for healthcare professionals seeking to understand how physical activity behaviour is initiated and maintained in ACHD patients. Thanks to the knowledge generated in this study, it was possible to highlight ways in which physical activity behaviour can be motivated by professionals who care for ACHD patients at varying levels of motivation. Many of the practical suggestions provided in this study relate to themes that are associated with particular stages of behavioural change, as stage-specific interventions for promoting physical activity are most effective (Latimer et al., 2010). Findings in this study also have implications for other health promotion specialists, such as recreation programmers, when developing and implementing community-based physical activity programs that might attract individuals with various abilities such as CHD.

Findings of this study support the critical assumptions of the TTM framework as well. This study supports both theories of health behaviour and theories of behavioural change, as it looked at past behaviours from participants in order to gain knowledge for developing practical suggestions to promote physical activity in the future (Prochaska et al., 2015). The theoretical framework of this study consisted of integrating the SEM and TTM frameworks, which is

grounded within the second assumption of the TTM, in that using multiple theories can bring on a more comprehensive understanding of health behaviours (Prochaska et al., 2015). Participant narratives were classified into categories representing different stages of behavioural change that evolved over the course of the study. Findings therefore demonstrate that the process of behavioural change takes place over time (Prochaska et al., 2015). Findings also demonstrate that the characteristics and description of stages can be flexible (Prochaska et al., 2015). For example, it was found that participants in the pre-contemplation stage, while unmotivated to increase their level of physical activity, do in fact engage in some forms of physical activity, albeit minimal. In addition, findings suggest that ACHD patients in the contemplation stage may display characteristics of those in preparation, as some had taken initiatives on educating themselves on the benefits of physical activity and conversed with healthcare professionals on the topic (Prochaska et al., 2015). Participants in the action stage also described physical activity as becoming second nature to them, which is a characteristic commonly associated with those in maintenance (Prochaska et al., 2015).

Moreover, an assumption of the TTM is that at-risk populations may not be ready for action and may not experience the benefits of action-oriented programs (Prochaska et al., 2015). Findings of this study are not supportive of this assumption, as many participants across stages had positive experiences from engaging in a variety of structured physical activity programs. While certain individuals in vulnerable populations, such as ACHD patients, may not be ready for action-oriented programs, particularly in lower stages of motivation, it is important not to disregard anyone from any stage, or with any ability, from such programs. For instance, ACHD patients who are highly motivated or in early phases of establishing a structured physical activity regimen may already engage in action-oriented physical activity programs. Findings also suggest that having

healthcare professionals emphasize the severity of sedentary behaviour could promote a desire to engage in action-oriented programs in highly unmotivated ACHD patients.

The strategies identified in each stage of behavioural change, as well as the additional practical implications of this study, are indeed associated with certain stages over others. As such, the processes and principles of change identified in this study could be utilized in specific stages (Prochaska et al., 2015). In addition, findings suggest that certain processes of change may be utilized to manage specific constraints. For instance, findings suggest that consciousness raising could be effective in addressing constraints such as lacking understanding of one's diagnosis and of the cardiovascular benefits of being active. Helping relationships may be most effective in addressing a lack of social support and decreasing perceptions of risk by increasing perceived safety. Stimulus control in the form of utilizing calendar prompts, electronic devices and joining structured programs appear to play an important in addressing time constraints and schedule conflicts. Finally, cyclical commitment may be helpful for dealing with non-cardiac related ailments and injuries.

Practical Implications

The topics covered in this study have important practical implications for healthcare professionals and recreation specialists seeking to understand how physical activity behaviour is initiated and maintained in ACHD patients. The meanings, physical activity patterns, social ecological factors, and strategies identified in each stage of behavioural change can inform the development and implementation of stage-specific interventions designed to increase physical activity behaviour in ACHD patients. The use of stage-specific interventions, instead of general physical activity guidelines based solely on personal abilities or physiological differences of ACHD patients, could be effective. To see an increase in physical activity participation in ACHD

patients, it is therefore crucial for interventions to be tailored to each stage of behavioural change (Nigg, 2003) in addition to personal abilities. Doing this reduces the risk of applying interventions to stages that do not correspond with those individuals' level of motivation (Nigg, 2003), as evidence suggests that tailored and stage-specific guidance is more effective at increasing levels of physical activity behaviour (Latimer et al., 2010).

According to findings from this study, ACHD patients experience many physical and psychosocial benefits when participating in physical activity. Indeed, there are several constraints that may prevent ACHD patients from possibly experiencing those benefits, which is why facilitators and strategies should be emphasized to reduce the perception of constraints. Specifically, facilitators can be used to help participants optimize their experiences when seeking physical activity opportunities, while stage-specific strategies can be used in addition to either increase or sustain physical activity participation in ACHD patients. Emphasis on facilitators and strategies can be particularly relevant for ACHD patients in early stages, to help them develop a positive perception of physical activity and incidentally facilitate behavioural change by helping them adopt an active lifestyle.

While there are guidelines in place when it comes to the frequency, intensity and appropriateness of physical activities based on diagnosis severity for ACHD patients (Chaix et al., 2016; Zipes et al., 2005), these do not consider levels of motivation, nor factors that prevent ACHD patients from meeting those guidelines. Findings from this study suggest a need to revise how physical activity is currently promoted in clinical settings, as there are a multitude of factors to consider when trying to promote physical activity behaviour to ACHD patients. In addition, findings suggest that informing ACHD patients about basic physical activity guidelines of 150-minutes per week (Canadian Society for Exercise Physiology, 2021; CDC, 2020b) may be a

nuisance. It is acknowledged that healthcare professionals may lack the resources and time for developing effective counselling strategies and as a result, may overlook or not have meaningful discussions during clinical visits about disease prevention strategies that include physical activity (Ackerman et al., 2011; Lin et al., 2010; McDonagh et al., 2004; Rosenthal et al., 2016). This was reflected in discussions with participants who explained that at times they did not receive adequate guidance on physical activity participation. However, by interrogating ACHD patients on their current level of physical activity, perceptions of physical activity and main factors preventing physical activity participation, healthcare professionals could easily identify and employ strategies in line with their level of motivation. As with other populations, individualizing recommendations to the needs of ACHD patients should be taken into consideration (Giannakoulas & Dimopoulos, 2010).

Results from this study may also be important to consider for recreation program specialists working on developing and implementing physical activity programs in recreational facilities. Program staff's inability or ability to adapt activities to the needs of ACHD patients was documented as an important institutional factor. It is therefore crucial for facilities to have program staff who are knowledgeable, within reason, about some of the limitations associated with CHD and adapt program activities according to the needs or symptoms of these patients. Tailoring programs to the individual is typically common practice in facilities that deal with diverse groups of individuals who vary in their level of physical functioning (Sánchez-Lastra et al., 2020).

Limitations

The limitations of this study must be acknowledged. First, findings from this study may not reflect the majority of ACHD patients' experiences in physical activity. Although this study's total number of participants was large for a qualitative study, there were few participants classified

within certain stages (e.g., pre-contemplation, contemplation). In addition, this study contained participants with a wide variety of CHDs instead of a homogenous group of participants with the same type of CHDs. Thus, as with the most qualitative research, findings from this study cannot be generalized to the ACHD population. Rather, this study provides new and insightful knowledge on ACHD patients' experiences in physical activity generated from in-depth narratives and qualitative data.

In addition, this study did not consider several factors such as age, gender identity, sexual orientation, ethnicity or socio-economic status as potential factors that could influence ACHD patients' abilities and opportunities to take part in various physical activity contexts. Future research should consider such factors when looking at physical activity behaviour in ACHD patients as they could have important implications on their physical activity opportunities and choices. The sample for this study also consisted of Caucasians and did not capture the voice of ACHD patients who may have different cultural beliefs, or were part of various other population groups (e.g., Indigenous population). While the researcher recruited participants who varied in disease severity, future research in this area should consider recruiting participants from various cultural backgrounds and see how these influence their ability to pursue physical activity opportunities to capture the essence of the lived experiences of a diverse ACHD population.

Findings from this study do not allow us to understand which specific factors have the most influence on determining physical activity behaviour for ACHD patients. While it is evident that certain types of factors (e.g., intrapersonal in the pre-contemplation stage) are more likely to be experienced by ACHD patients in certain stages over others, findings do not allow us to know which factors have the greatest impact. Yet, in some instances, distinctions can be made, and factors can be seen as more important than others based on the frequency of mention by

participants and the depth of information shared on the factor. While it can be assumed that those factors may have a greater role in facilitating or constraining physical activity behaviour in ACHD patients, it remains unclear if these factors were more influential than others. Future research should strive to develop and utilize different instruments to determine the impact of the identified factors' influence on determining physical activity behaviour in ACHD patients.

Leveraging the previous limitations, this study did not consider grouping factors influencing physical activity behaviour for specific types of CHD. Consequently, findings do not always help us understand if ACHD patients with certain types of CHD are more likely to experience certain factors than others. Rather, this study grouped participants based on their levels of motivation to be active rather than their type of CHD. However, findings from this study are still useful in that participants in each stage shared similar narratives and perceptions regarding their experiences in physical activity, despite having different types of CHD.

The data generated in this study also depended on participants being truthful when sharing information during interviews. Qualitative data collection relies heavily on the memories of participants recalling past events, behaviours and perceptions. Yet, memory can be inaccurate and subject to considerable distortion (Leedy & Ormrod, 2013). For example, participants recalling experiences from their past physical activity behaviour may have required greater recollection compared to discussing their current behaviour. However, the themes presented in this study were deemed truthful and accurate, as a variety of participants within different stages provided feedback and comments on the legitimacy of what other participants stated, in addition to the researcher's interpretations.

Another limitation of this study is that the interview guide was developed and piloted with individuals living with Parkinson's disease and not ACHD patients, as the study had originally

considered including both individuals living with Parkinson's disease and ACHD patients and drawing comparisons between the two. While the questions in the interview guide were developed to be generic and did not necessarily focus on disease-specific factors, the study could have benefitted from piloting the study with ACHD patients. This could have avoided the potential for compromising some of the data collected when transitioning from one population to another with the same interview guide. It is also important to note that the interview guide was initially developed in English and then translated to French by the researcher. While the translated interview guide underwent additional review through the process of ethics approval, the French interview guide could have benefitted from being professionally translated to avoid discrepancies in the responses between English speaking and French speaking participants.

Lastly, interview bias is also important when considering the findings of this study. Some participants mentioned how they were more inclined to participate in physical activity after each interview. For instance, after discussing and reflecting on their level of physical activity at the time of the interview, some participants realized that they were in fact not active enough and believed they had to make a behavioural change. Thus, participants' perceptions of physical activity and the factors they discussed in subsequent interviews may have been different. The environment in which the interviews took place may have also biased the way participants divulged information to the researcher. For instance, some participants may have been more comfortable sharing personal or sensitive information within the confines of their home than in public areas such as coffee shops. For example, more participants may have elaborated on concepts such as anticipating death and psychological limitations of depression had they been interviewed in their home or in an office compared to public environments. The researcher may have been able to obtain more information on sensitive topics like these, or potentially uncover other themes addressing sensitive

issues, which in turn could have led the researcher to place more emphasis and importance on them had more information been gathered. Future research should consider recruiting ACHD patients in different stages for one-time interviews and hold each interview in a similar environment to obtain the most consistent results. Alternatively, longitudinal studies spanning several years with the same participants taking part in multiple interviews could help determine the impact of interview bias.

Future Directions / Implications for Future Research

Based on the outcomes of this study, there are multiple avenues for future research, such as considering implications with regard to sampling by including a larger number of participants classified within each stage of behavioural change. Having a larger sample of participants within each stage could potentially uncover new themes that were not discussed in this study and help determine the importance of certain themes based on frequency mention and depth of information provided. Future research on this topic may also benefit from comparing findings and themes based on the participants' type of CHD and draw comparisons between themes from those living with various types of CHD. By doing this, researchers could identify similar themes experienced by ACHD patients living with different types of CHDs and create a more generalized representation of ACHD patients' experiences in physical activity. Doing this may also highlight the discrepancies that exist in experiences in physical activity in ACHD patients living with various types of CHD.

The final recommendation for future research in this area with regard to sampling is to assure that the sample consists of a diverse group of ACHD patients regarding such things as gender identity, ethnicity, socioeconomic status, sexual orientation and cultural background to capture the essence of the everyday lived experiences of ACHD patients in physical activity. In

addition, future research on this topic should consider how these types of factors influence physical activity behaviour in the ACHD population, as these were neglected in the current study. It is imperative that these factors be included in future research to determine their influence on physical activity behaviour in ACHD patients. The importance of these factors can complement other themes that have been identified to see which have greater influence on physical activity behaviour in the ACHD population.

Building on the previous recommendation, future research should use the findings generated from this study to generate instruments such as questionnaires and surveys to determine the significance of the identified factors in determining physical activity behaviour in ACHD patients. Such instruments will allow researchers to develop a better understanding on the most prominent factors influencing physical activity behaviour in this population and focus on these to develop and apply interventions aimed at addressing specific factors. Given that this study did not have a significant number of participants within each stage, it is possible that some of the themes presented in this study are not relevant to many ACHD patients. Survey questionnaires will therefore help researchers narrow down the scope of factors to consider and emphasize factors that are most influential on physical activity behaviour in ACHD patients. Research in this area should also consider distributing such instruments to ACHD patients in different stages to determine the most influential factors within each stage. Questionnaires and surveys used for research purposes must also consider how the perceptions of ACHD patients towards certain factors influences physical activity behaviour rather than simply providing a checklist of pre-determined factors.

Future researchers and healthcare professionals responsible for promoting physical activity to ACHD patients should also consider using the strategies presented in this study to determine their applicability and effectiveness. Results revealed several stage-specific strategies mentioned

by participants that could potentially be used for increasing a desire to change in ACHD patients. Researchers and healthcare professionals should perhaps consider using these strategies, particularly for ACHD patients in lower stages, and monitor participants to determine if the strategies were effective in motivating behavioural change. In addition to the strategies listed in this study, facilitating factors could also be an avenue for developing stage-specific interventions designed to promote behavioural change in ACHD patients. Similar to identifying the most prominent factors influencing physical activity behaviour, looking into the effectiveness of the strategies and facilitating factors could help narrow the strategies that are most effective in promoting long-lasting behavioural change. This research could also help us understand what strategies are most effective in helping ACHD patients overcome specific factors that may prevent behavioural change in physical activity.

Reflections

Throughout the study, I took the opportunity to reflect on some of the concepts and ideas that emerged from conversations with participants and the analyses of the data. Early parts of data collection and analyses were influenced by my personal experiences as a previous competitive amateur athlete who has maintained a physically active lifestyle. For instance, most participants who were recruited at the beginning of the study were highly motivated to be active and pursued a structured physical activity regimen. Thus, most of the themes that emerged were related to the physical and psychosocial benefits of being active, along with being exposed to physical activity during childhood and being surrounded by an active social circle. Such findings were very much in line with the researcher's personal interests in pursuing and maintaining his own involvement in sports throughout his life.

However, as the collection of data continued, I recognized that highly motivated ACHD patients experienced certain CHD-specific factors that sometimes influenced physical activity behaviour such as perceived risk, fears and self-doubt, and diminished exercise capacity due to impairment, each of which were unfamiliar to me as factors preventing physical activity behaviour. This led me to believe that several other factors had been neglected during the initial analyses, and as these factors did not significantly deter highly motivated ACHD patients from being active, I felt I needed to broaden this selection of participants to obtain information from a wider range of ACHD patients with varying abilities and desire to be active. The recruitment of participants therefore shifted to ACHD patients who were more severely affected by their CHD and who struggled to maintain a desire to be active. During this portion of data collection and analyses, I held a stronger emphasis on trying to uncover factors that were CHD-specific (e.g., physical limitations, the need for cardiac surgery, pre- and post-surgery behaviour, conversations with healthcare professionals), while neglecting the importance of non-CHD-specific factors that also emerged within transcripts.

While I modified the recruitment to obtain information from both severely affected and moderately ACHD patients who vary in their desire to be active, I recognized that in many cases, participants' desire to be active was not often deterred by their CHD. Rather, lifestyle factors such as lack of time, convenience, weather, schedule conflicts, cost, timing of programs and imbalanced lifestyle played an important role in determining ACHD patients' physical activity participation in addition to other factors. The regular emergence of these themes through conversations with participants therefore opened a new realm of factors that influenced physical activity participation in ACHD patients. Thus, in my journey to obtain information on ACHD patients' physical activity behaviour, I went from emphasizing themes in line with the factors that influenced my desire to

pursue sports, to overcompensating to a certain degree in trying to uncover CHD-specific themes that I believed would prevent physical activity participation in severely affected ACHD patients, to recognizing the importance of lifestyle factors influencing physical activity behaviour for most individuals. My ability to reflect during this process helped me become aware that participants experienced factors influencing their physical activity behaviour in various realms of life that could not necessarily be targeted during interviews with various ACHD patients. Through this realization, I approached the subsequent interviews with newly recruited participants with an open mind, by remembering that the findings should capture the voices of participants and that the themes should emerge naturally from the narratives rather than emphasizing certain themes that fit my projections regarding the experiences of ACHD patients in physical activity.

Through conversations with participants and the analyses of the data, I further reflected on the meaning of the key concept of this study, that is, physical activity, and its representation in everyday life. Physical activity is described as a broad concept that includes all types of physical movement, including both structured and unstructured activities (Longmuir et al., 2013). While the concept of physical activity is certainly broad, I struggled at many points in the study with its definition and what participants considered as physical activity. In many instances, I felt torn about whether or not to include participants' experiences that came from physical activity in the workplace, caring for children and family members, and basic navigation within their household. In some instances, most of the participants' activity consisted of working labour intensive jobs or caring for young children. However, some of these participants also pursued recreational sports and other activities that they considered more as physical activity than the activity they did at work or as part of child caring. I should have therefore considered the definition in its broadest sense to avoid such tensions when determining what narratives to include in the study. That way all types

of physical activity, be it recreational sports or walking at work, could have been considered as physical activity. I could have then explored the factors influencing physical activity behaviour within these various contexts.

Reflecting on the ongoing tensions throughout the study also helped me realize that it is imperative to consider the circumstances in which individuals live and what it truly means to be physically active. It must be understood that many individuals lack the means to be active outside of work and family obligations because of the commitments they have towards these aspects of their life. Many individuals work jobs or care for young children, each of which requires significant mobility and strain on the body, and that should be considered physical activity. Many individuals are also incapable of joining structured physical activity programs because of cost and convenience and may consider household activities such as cleaning, walking up and down stairs and doing laundry as physical activity. Finally, individuals who live in disadvantaged communities or who are part of marginalized groups may have similar constraints imposed on them, as they have limited resources to pursue certain physical activity opportunities. Thus, a discussion on the meaning of physical activity and how it is captured in scholarly work should be considered. The lived experiences of individuals vary significantly, and what researchers perceive to be physical activity may vary significantly from what participants perceive, creating unwanted tensions. If physical activity is to be considered in its broadest sense, all forms should be included to capture and reflect the actual lived experiences of individuals within our society.

Conclusion

The purpose of this study is to qualitatively explore how physical activity behaviour is initiated and maintained in ACHD patients. Findings presented in this study were uncovered through a thematic analysis of interviews with ACHD patients in different stages of motivation to

be active. The framework of this study consisted of a combination of the SEM and TTM models to situate the findings. Results revealed both differences and similarities in the meanings, physical activity patterns, factors influencing physical activity behaviour, and strategies used to sustain physical activity behaviour for participants in each stage of behavioural change. Results from a practical context (i.e., Fearless Physical Activity) were also generated. Taken together, the themes uncovered in this study could be useful for healthcare professionals and recreation practitioners when providing guidance on appropriate physical activities, designing interventions aimed to increase physical activity behaviour, and creating recreation programs for ACHD patients.

To date, research has yet to thoroughly investigate factors influencing physical activity behaviour within the ACHD population. Healthcare professionals and recreational practitioners should continue to stay current on new literature on this topic to gain new and insightful understandings of factors influencing physical activity behaviour in ACHD patients. This study offers a unique look into the different factors influencing physical activity behaviour for ACHD patients by not only presenting factors, but also illustrating how factors influence ACHD patients differently based on their level of motivation.

As ACHD patients continue to age and require more healthcare resources, physical activity is a cost-efficient way for them to alleviate such needs and maintain their health, as do individuals from the general population (Fox, 1999; Kujala et al., 1998; Wannamethee & Sharper, 2001). Considering the applicability of these findings, it is imperative for healthcare professionals and recreation practitioners to utilize these findings in practice. One way to achieve this would be to present findings of this study at practice-oriented and academic conferences to increase other researchers' knowledge on this topic. Pamphlets encouraging ACHD patients to be active or join structured physical activity programs could also be created and distributed in healthcare settings

(i.e., hospitals, clinics) and recreational centres. Lastly, publishing findings in peer reviewed scientific journals could be a way to keep highlighting issues related to this topic and move forward in providing strategies to address the issues uncovered in this study. To conclude, increasing awareness and continuing to investigate factors influencing physical activity behaviour could lead to the development and application of new and innovative strategies to promote physical activity behaviour in ACHD patients.

References

- AboutKidsHealth (2010, January 15). *About heart conditions*. Retrieved from <https://www.aboutkidshealth.ca/Article?contentid=1576&language=English>
- Ackerman, E., Falsetti, S. A., Lewis, P., Hawkins, A. O., & Heinschel, J. A. (2011). Motivational interviewing: A behavioral counseling intervention for the family medicine provider. *Family Medicine*, 43(8), 582–585.
- Adom, D., Yeboah, A., & Ankrah, A. K. (2016). Constructivism philosophical paradigm: Implications for research, teaching and learning. *Global Journal of Arts, Humanities and Social Sciences*, 4(10), 1-9.
- Ammerman, A. S., Lindquist, C. H., Lohr, K. N., & Hersey, J. (2002). The efficacy of behavioral interventions to modify dietary fat and fruit and vegetable intake: A review of the evidence. *Preventive Medicine*, 35(1), 25–41. <https://doi.org/10.1006/pmed.2002.1028>
- American Heart Association (AHA) (2018, April 18). Breaking down barriers to fitness. Retrieved from <https://www.heart.org/en/healthy-living/fitness/getting-active/breaking-down-barriers-to-fitness>
- American Lung Association (ALA) (2019, February 19). Can you exercise with a cold? Retrieved from <https://www.lung.org/blog/can-you-exercise-with-a-cold>
- Armenakis, A. A., Harris, S. G., & Mossholder, K. (1993). Creating readiness for organizational change. *Human Relations*, 46(6), 681-703. <https://doi.org/10.1177%2F001872679304600601>
- Artigas, N. R., Striebel, V. L. W., Hilbig, A., & Rieder, C. R. D. (2015). Evaluation of quality of life and psychological aspects of Parkinson's disease patients who participate in a support

- group. *Dementia & Neuropsychologia*, 9(3), 295-300.
<https://dx.doi.org/10.1590%2F1980-57642015DN93000013>
- Avila, P., Mercier, L. A., Dore, A., Marcotte, F., Mongeon, F. P., Ibrahim, R., Asgar, A., Miro, J., Mondésert, B., de Guise, P., Poirier, N., & Khairy, P. (2014). Adult congenital heart disease: A growing epidemic. *Canadian Journal of Cardiology*, 30(12), S410-419.
<https://doi.org/10.1016/j.cjca.2014.07.749>
- Babiss, L. A., & Gangwisch, J. E. (2009). Sports participation as a protective factor against depression and suicidal ideation in adolescents as mediated by self-esteem and social support. *Journal of Developmental & Behavioral Pediatrics*, 30(5), 376–384.
<https://doi.org/10.1097/dbp.0b013e3181b33659>
- Baggini, J. (2005). *What's it all about?: Philosophy and the meaning of life*. Oxford University Press.
- Bandura, A. (1982). Self-efficacy mechanism in human agency. *American Psychologist*, 37(2), 122-147. <https://psycnet.apa.org/doi/10.1037/0003-066X.37.2.122>
- Brawley, L.R., Martin, K.A., Gyurcsik, N.C. (1998). Problems in assessing perceived barriers in exercise: Confusing obstacles with attributions and excuses. In J. L. Duda (Ed.), *Advancements in sport and exercise psychology measurement* (pp. 337-350). Fitness Information Technology, Inc.
- Bauman, A. E., Reis, R. S., Sallis, J. F., Wells, J. C., Loos, R. J., & Martin, B. W. (2012). Correlates of physical activity: Why are some people physically active and others not? *Lancet*, 380(9838), 258-271. [https://doi.org/10.1016/s0140-6736\(12\)60735-1](https://doi.org/10.1016/s0140-6736(12)60735-1)

- Baumeister, R. F., & Vohs, K. D (2005). The pursuit of meaningfulness in life. In C. R. Snyder, and S. J. Lopez, (Eds.), *Handbook of positive psychology* (pp. 608-618). Oxford University Press.
- Bedini, L. A., & Anderson, D. M. (2005). I'm nice, I'm smart, I like karate: Girls with physical disabilities' perceptions of physical recreation. *Therapeutic Recreation Journal*, 39(2), 114-130.
- Bouckennooghe, D. (2010). Positioning change recipients' attitudes toward change in the organizational change literature. *The Journal of Applied Behavioral Science*, 46(4), 500-531. <https://doi.org/10.1177%2F0021886310367944>
- Bromberg, J. I., Beasley, P. J., D'Angelo, E. J., Landzberg, M., & DeMaso, D. R. (2003). Depression and anxiety in adults with congenital heart disease: A pilot study. *Heart & Lung*, 32(2), 105-110. <https://doi.org/10.1067/mhl.2003.26>
- Buyts, R., Cornelissen, V., Van De Bruaene, A., Stevens, A., Coeckelberghs, E., Onkelinx, S., Thomaes, T., Delecluse, C., Budts, W., & Vanhees, L. (2011). Measures of exercise capacity in adults with congenital heart disease. *International Journal of Cardiology*, 153(1), 26-30. <https://doi.org/10.1016/j.ijcard.2010.08.030>
- Canadian Congenital Heart Alliance (CCHA) (2017a). *What are congenital heart defects?* About congenital heart defects. Retrieved from <https://www.cchaforlife.org/about-congenital-heart-defects>
- Canadian Congenital Heart Alliance (CCHA) (2017b). *CHD facts and issues*. Facts and issues. Retrieved from <https://www.cchaforlife.org/facts-issues>
- Canadian Congenital Heart Alliance (CCHA) (2017c). About us. Retrieved from <https://www.cchaforlife.org/about-us>

Canadian Society for Exercise Physiology (2021). Canadian 24-hour movement guidelines: An integration of physical activity, sedentary behavior, and sleep. Retrieved from <https://csepguidelines.ca>

Carazo, M., Kolodziej, M. S., DeWitt, E. S., Kasparian, N. A., Newburger, J. W., Duarte, V. E., Singh, M. N., & Opatowsky, A. R. (2020). Prevalence and prognostic association of a clinical diagnosis of depression in adult congenital heart disease: Results of the Boston adult congenital heart disease biobank. *Journal of the American Heart Association*, 9(9), e014820. <https://doi.org/10.1161/jaha.119.014820>

Carlson, J. A., Sallis, J. F., Conway, T. L., Saelens, B. E., Frank, L. D., Kerr, J., Cain, K. L., & King, A. C. (2012). Interactions between psychosocial and the built environment factors explaining older adults' physical activity. *Preventive Medicine*, 54(1), 68-73. <https://doi.org/10.1016/j.ypmed.2011.10.004>

Centers for Disease Control and Prevention (CDC) (2020a, November 17). *What are Congenital Heart Defects?* Retrieved from <https://www.cdc.gov/ncbddd/heartdefects/facts.html>

Centers for Disease Control and Prevention (CDC) (2020b, October 7). *How much physical activity do adults need?* Retrieved from <https://www.cdc.gov/physicalactivity/basics/adults/index.htm>

Centers for Disease Control and Prevention (CDC) (2020c, December 6). *Overcoming barriers to physical activity*. Retrieved from <https://www.cdc.gov/physicalactivity/basics/adding-pa/barriers.html>

Center for Disease Control and Prevention (CDC) (2020d, November 17). *Facts about tricuspid atresia*. Retrieved from <https://www.cdc.gov/ncbddd/heartdefects/tricuspid->

[atresia.html#:~:text=Tricuspid%20atresia%20occurs%20when%20this,a%20critical%20congenital%20heart%20defect](#)

Centers for Disease Control and Prevention (CDC) (2021, April 5). *Benefits of physical activity*.

Retrieved from: https://www.cdc.gov/physicalactivity/basics/physical-activity/index.htm?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fphysicalactivity%2Feveryone%2Fhealth%2Findex.html

Cedars Sinai (2021). Mitral valve regurgitation. Retrieved from <https://www.cedars-sinai.org/health-library/diseases-and-conditions/m/mitral-valve-regurgitation.html>

Chaix, M. A., Marcotte, F., Dore, A., Mongeon, F. P. Mondésert, B., Mercier, L. A., & Khairy, P. (2016). Risks and benefits of exercise training in adults with congenital heart disease. *Canadian Journal of Cardiology*, 32(4), 459-466. <https://doi.org/10.1016/j.cjca.2015.12.007>

Cove Point Foundation (2020, December 7). *Overview of Adult CHD*. Retrieved from <http://pted.org/?id=overview1>

Craske, M. G., Stein, M. B., Eley, T. C., Milad, M. R., Holmes, A., Rapee, R. M., & Wittchen, H. U. (2017). *Anxiety disorders*. *Nature Reviews Disease Primers*, 3, 17024. <https://doi.org/10.1038/nrdp.2017.24>

Creswell, J. W. (2017). *Qualitative inquiry & research design: Choosing among five approaches* (4th ed.). Sage Publications.

Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. Sage Publications.

CTSNet (2012, April 11). The gerbode defect: A ventriculo-atrial defect. Retrieved from <https://www.ctsnet.org/article/gerbode-defect-ventriculo-atrial-defect>

- Cunningham, C. E., Woodward, C. A., Shannon, H. S., MacIntosh, J., Lendrum, B., Rosenbloom, D., & Brown, J. (2002). Readiness for organizational change: A longitudinal study of workplace, psychological and behavioral correlates. *Journal of Occupational and Organizational Psychology*, 75(4), 377-392. <https://psycnet.apa.org/doi/10.1348/096317902321119637>
- Cuypers, J. A. A. E., Eindhoven, J. A., Slager, M. A., Opic, P., Utens, M. W., Helbing, W. A., Witsenburg, M., van den Bosch, A. E., Ouhlous, M., van Domburg, R. T., Rizopoulos, D., Meijboom, F. J., Bogers, J. J. C., & Roos-Hesselink, J. W. (2014b). The natural and unnatural history of the Mustard procedure: Long-term outcome up to 40 years, *European Heart Journal*, 35(25), 1666–1674. <https://doi.org/10.1093/eurheartj/ehu102>
- Cuypers, J. A. A. E., Menting, M. E. Konings, E. E. M., Opic, P., Utens, E. M. J. W., Helbing, W. A., Witsenburg, M., van den Bosch, A. E., Ouhlous, M., van Domburg, R. T., Rizopoulos, D., Meijboom, F. J., Boersma, E., Bogers, A. J. J. C., & Roos-Hesselink, J. W. (2014b). Unnatural history of tetralogy of Fallot: Prospective follow-up of 40 years after surgical correction. *Circulation*, 130(22), 1944–1953. <https://doi.org/10.1161/CIRCULATIONAHA.114.009454>
- Cuypers, J. A. A. E., Opic, P., Menting, M. E., Utens, E. M., Witsenburg, M., Helbing, W. A., van den Bosch, A. E., Ouhlous, M., van Domburg, R. T., Meijboom, F. J., Bogers, A. J. J. C., & Roos-Hesselink, J. W. (2013). The unnatural history of an atrial septal defect (ASD): Longitudinal follow-up of 35 years after surgical ASD closure at young age. *Heart*, 99(18), 1346–1352. <http://dx.doi.org/10.1136/heartjnl-2013-304225>
- Cuypers, J., Utens, E., & Roos-Hesselink, J. (2016). Health in adults with congenital heart disease. *Maturitas*, 91, 69-73. <https://doi.org/10.1016/j.maturitas.2016.06.005>

Davidson, L., Haglund, K. E., Stayner, D. A., Rakfeldt, J., Chinman, M. J., & Tebes, J. K. (2001).

“It was just realizing...that life isn’t one big horror”: A qualitative study of supported socialization. *Psychiatric Rehabilitation Journal*, 24(3), 275–292.
<https://psycnet.apa.org/doi/10.1037/h0095084>

Davis, C. (1990). Body image and weight preoccupation: A comparison between exercising and non-exercising women. *Appetite*, 15(1), 13–21. [https://doi.org/10.1016/0195-6663\(90\)90096-q](https://doi.org/10.1016/0195-6663(90)90096-q)

Dean, P. N., Gillespie, C. W., Greene, E. A., Pearson, G. D., Robb, A. S., Berul, C. I., & Kaltman, J. R. (2015). Sports participation and quality of life in adolescents and young adults with congenital heart disease. *Congenital Heart Disease*, 10(2), 169–179.
<https://doi.org/10.1111/chd.12221>

DiClemente, C. C., & Prochaska, J. O. (1982). Self-change and therapy change of smoking behavior: A comparison of processes of change in cessation and maintenance. *Addictive Behavior*, 7(2), 133-142. [https://doi.org/10.1016/0306-4603\(82\)90038-7](https://doi.org/10.1016/0306-4603(82)90038-7)

Dishman, R. K., Vandenberg, R. J., Motl, R. W., & Nigg, C. R. (2010). Using constructs of the transtheoretical model to predict classes of change in regular physical activity: A multi-ethnic longitudinal cohort study. *Annals of Behavioral Medicine*, 40(2), 150–163.
<https://dx.doi.org/10.1007%2Fs12160-010-9196-2>

Diller, G. P., Dimopoulos, K., Okonko, D., Li, W., Babu-Narayan, S. V., Broberg, C. S., Johansson, B., Bouzas, B., Mullen, M. J., Poole-Wilson, P. A., Francis, D. P., & Gatzoulis, M. A. (2005). Exercise intolerance in adult congenital heart disease: comparative severity, correlates, and prognostic implication. *Circulation*, 112(6), 828–35.
<https://doi.org/10.1161/circulationaha.104.529800>

- Dlugonski, D., Japp, J., & Motl, R. W. (2012). Meanings, motivations, and strategies for engaging in physical activity among women with multiple sclerosis. *Disability & Rehabilitation*, 34(25), 2148-2157. <https://doi.org/10.3109/09638288.2012.677935>
- Dijkstra, P., & Barelds, D. P. H. (2011). Women's meta-perceptions of attractiveness and their relations to body image. *Body Image*, 8(1), 74–77. <https://psycnet.apa.org/doi/10.1016/j.bodyim.2010.09.007>
- Dogru, M., & Kalender, S. (2007). Applying the subject “cell” through constructivist approach during science lessons and the teacher's view. *International Journal of Environmental & Science Education*, 2(1): 3–13.
- Dua, J. S., Cooper, A. R., Fox, K. R., & Stuart, A. G. (2010). Exercise training in adults with congenital heart disease: feasibility and benefits. *International Journal of Cardiology*, 138(2), 196–205. <https://doi.org/10.1016/j.ijcard.2009.01.038>
- Elizur, D., & Guttman, L. (1976). The structure of attitudes toward work and technological change within an organization. *Administrative Science Quarterly*, 21(4), 611-622. <https://doi.org/10.2307/2391719>
- Eriksson, B. M., Arne, M., & Ahlgren, C. (2013). Keep moving to retain the healthy self: The meaning of physical exercise in individuals with Parkinson's disease. *Disability and Rehabilitation*, 35(26), 2237-2244. <https://doi.org/10.3109/09638288.2013.775357>
- Eslami, B., Sundin, O., Macassa, G., Khankeh, H. R., & Soares, J. (2013). Anxiety, depressive and somatic symptoms in adults with congenital heart disease. *Journal of Psychosomatic Research*, 74(1):49-56. <https://doi.org/10.1016/j.jpsychores.2012.10.006>
- Fearless Physical Activity (2017). *Canadian Congenital Heart Alliance*. Fearless Physical Activity. Retrieved from <https://www.cchaforlife.org/fearless-physical-activity>

- Fendt, L. S., & Wilson, E. (2012). "I just push through the barriers because I live for surfing": How women negotiate their constraints to surf tourism. *Annals of Leisure Research*, 15(1), 4-18. <http://dx.doi.org/10.1080/11745398.2012.670960>
- Fishbein, M., & Ajzen, A. (1975). *Beliefs, attitudes, intentions, and behavior: An introduction to theory and research*. Addison-Wesley.
- Fontana, A., & Frey, J. H. (2005). The interview: From neutral stance to political involvement. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (pp. 695-727). Sage Publications.
- Fox, K. R. (1999). The influence of physical activity on mental well-being. *Public Health Nutrition*, 2(3a), 411-418. <https://doi.org/10.1017/S1368980099000567>
- Freud, S. (1959). The question of lay analysis. In J. Strachey (Ed. & Trans.), *The standard edition of the complete psychological works of Sigmund Freud* (Vol. 20, pp. 183-250). Hogarth Press.
- Gaskin, C., Andersen, M. & Morris, T. (2009). Physical activity in the life of a woman with severe cerebral palsy: Showing competence and being socially connected. *International Journal of Disability, Development, and Education*, 56(3), 285-299. <https://doi.org/10.1080/10349120903102312>
- Giannakoulas, G., & Dimopoulos, K. (2010). Exercise training in congenital heart disease: Should we follow the heart failure paradigm? *International Journal of Cardiology*, 138(2), 109-111. <https://doi.org/10.1016/j.ijcard.2009.06.024>
- Glanz, K., & Bishop, D. B. (2010). The role of behavioral science theory in development and implementation of public health interventions. *Annual Reviews in Public Health*, 31, 399-418. <https://doi.org/10.1146/annurev.publhealth.012809.103604>

- Gourlan, M., Bernard, P., Bortolon, C., Romain, A. J., Lareyre, O., Carayol, M., Ninot, G., & Boiché, J. (2016). Efficacy of theory-based interventions to promote physical activity. A meta-analysis of randomised controlled trials. *Health Psychology Review*, 10(1), 50 – 66. <https://doi.org/10.1080/17437199.2014.981777>
- Graham, T. P., Driscoll, D. J., Gersony, W. M., Newburger, J. W., Rocchini, A., & Towbin, J. A. (2005). Task Force 2: Congenital heart disease. *Journal of the American College of Cardiology*, 45(8), 1326–1333. <https://doi.org/10.1016/j.jacc.2005.02.009>
- Grbich, C. (2013). *Qualitative data analysis: An introduction* (2nd ed.). Sage Publications.
- Guba, E., & Lincoln, Y. S. (1998). Competing paradigms in qualitative research. In N. Denzin & Y. Lincoln (Eds.), *The Landscape of qualitative research* (pp. 195-220). Sage Publications.
- Hanlon, C., Khoo, S., Morris, T., & Eime, R. (2019). Factors influencing women in physical activity programs in Malaysia. *Health Promotion International*, 34(3), 389-399. <https://doi.org/10.1093/heapro/dax093>
- Hawkins, B. A., Peng, J., Hsieh, C., & Eklund, S. J. (1999). Leisure constraints: A replication and extension of construct development. *Leisure Sciences*, 21(3), 179–192. <https://doi.org/10.1080/014904099273066>
- Healio (2014, October 1). *Adults with congenital heart disease present challenges, rewards for cardiologists*. Cardiology Today. Retrieved from https://www.healio.com/news/cardiology/20150821/j050_1710_01_news_print_1
- Heart and Stroke (2020). Congenital heart disease. Retrieved from <https://www.heartandstroke.ca/heart/conditions/congenital-heart-disease>
- Hirth, A., Reybrouck, T., Bjarnason-Wehrens, B., Lawrenz, W., & Hoffmann, A. (2006). Recommendations for participation in competitive and leisure sports in patients with

- congenital heart disease: A consensus document. *European Journal of Cardiovascular Prevention and Rehabilitation*, 13(3), 293-299.
<https://doi.org/10.1097/01.hjr.0000220574.22195.d6>
- Honebein, P. C. (1996). Seven goals for the design of constructivist learning environments. In B. G. Wilson (Ed.), *Constructivist learning environments: Case studies in instructional design* (pp. 11-23). Educational Technology Publications.
- Horner, T., Liberthson, R., & Jellinek, M. (2000). Psychosocial profile of adults with complex congenital heart disease. *Mayo Clinic Proceedings*, 75(1), 31-36.
<https://doi.org/10.4065/75.1.31>
- Hubbard, J., & Mannell, R. C. (2001). Testing competing models of the leisure constraint negotiation process in a corporate employee recreation setting. *Leisure Sciences*, 23(3), 145-163. <https://doi.org/10.1080/014904001316896846>
- Institute of Medicine (IOM) (2013). *Evaluating obesity prevention efforts*. National Academies Press.
- ISO 31000 (2018). A risk practitioners guide to ISO 31000 – 2018. Retrieved from <https://www.theirm.org/media/3513119/IRM-Report-ISO-31000-2018-v3.pdf>.
- Jackson, E. L. (2000). Will research on leisure constraints still be relevant in the twenty-first century? *Journal of Leisure Research*, 32(1), 62-68.
<https://doi.org/10.1080/00222216.2000.11949887>
- Jackson, E. L., & Rucks, V. C. (1995). Negotiation of leisure constraints by junior-high and high-school students: An exploratory study. *Journal of Leisure Research*, 27(1), 85–105.
<https://doi.org/10.1080/00222216.1995.11969978>

- Janis, I. I., & Mann, L. (1977). *Decision making: A psychological analysis of conflict, choice and commitment*. Free Press.
- Jenkins, K. J., Correa, A., Feinstein, J. A., Botto, L., Britt, A. E., Daniels, S. R., Elixson, M., Warnes, C. A., & Webb, C. L. (2007). Noninherited risk factors and congenital cardiovascular defects: Current knowledge: A scientific statement from the American Heart Association Council on Cardiovascular Disease in the Young: Endorsed by the American Academy of Pediatrics. *Circulation*, 115(23), 2995-3014. <https://doi.org/10.1161/circulationaha.106.183216>
- Kasser, S. (2009). Exercising with multiple sclerosis: Insights into meaning and motivation. *Adapted Physical Activity Quarterly*, 26(3), 274–89. <http://dx.doi.org/10.1123/apaq.26.3.274>
- Kim, Y. (2020). Relationships of physical activity with the transtheoretical model constructs among Korean adults. *International Journal of Health Promotion and Education*, 1-10. <https://doi.org/10.1080/14635240.2020.1740608>
- Kirk, A. F., Mutrie, N., MacIntyre, P. D., & Fisher, M. B. (2004). Promoting and maintaining physical activity in people with type 2 diabetes. *American Journal of Preventive Medicine*, 27(4), 289–296. <https://doi.org/10.1016/j.amepre.2004.07.009>
- Kennelly, M., Moyle, B., & Lamont, M. (2013). Constraint negotiation in serious leisure: A study of amateur triathletes. *Journal of Leisure Research*, 45(4), 466-484. <https://doi.org/10.18666/jlr-2013-v45-i4-3895>
- Kovacs, A. H., Saidi, A. S., Kuhl, E. A., Sears, S. F., Silversides, C., Harrison, J. L., Ong, L., Colman, J., Oechslin, E., & Nolan, R. P. (2009). Depression and anxiety in adult congenital heart disease: Predictors and prevalence. *International Journal of Cardiology*, 137(2), 158-

164. <https://doi.org/10.1016/j.ijcard.2008.06.042>

Koyak, Z., Harris, L., de Groot, J. R., Silversides, C. K., Oechslin, E. N., Bouma, B. J., Budts, W., Zwinderman, A. H., Van Gelder, I. C., & Mulder, B. J. M. (2012). Sudden cardiac death in adult congenital heart disease. *Circulation*, 126(16), 1944–1954. <https://doi.org/10.1161/circulationaha.112.104786>

Kujala, U. M., Kaprio, J., Sarna, S., & Koskenvuo, M. (1998). Relationship of leisure-time physical activity and mortality. *JAMA*, 279(6), 440–444. <https://doi.org/10.1001/jama.279.6.440>

Labonte, R., & Robertson, A. (1996). Delivering the goods, showing our stuff: The case for a constructivist paradigm for health promotion research and practice. *Health Education & Behavior*, 23(4), 431–447. <https://doi.org/10.1177%2F109019819602300404>

Lafata, J. E., Morris, H. L., Dobie, E., Heisler, M., Werner, R. M., & Dumenci, L. (2013). Patient-reported use of collaborative goal setting and glycemic control among patients with diabetes. *Patient Education and Counseling*, 92(1), 94–99. <https://doi.org/10.1016/j.pec.2013.01.016>

La Gerche, A., Burns, A. T., Mooney, D. J., Inder, W. J., Taylor, A. J., Bogaert, J., Macisaac, A., Heidbüchel, H., & Prior, D. L. (2012). Exercise-induced right ventricular dysfunction and structural remodelling in endurance athletes. *European Heart Journal*, 33(8), 998–1006. <https://doi.org/10.1093/eurheartj/ehr397>

Latham, G. P., Ganegoda, D. B., & Locke, E. A. (2011). Goal setting: A state theory, but related to traits. In T. Chamorro-Premuzic, S. von Stumm, & A. Furnham (Eds.), *The Wiley-Blackwell handbook of individual differences* (1st ed., pp. 579–587). John Wiley & Sons, Inc.

- Latimer, A. E., Brawley, L. R., & Bassett, R. L. (2010). A systematic review of three approaches for constructing physical activity messages: What messages work and what improvements are needed? *International Journal of Behavioral Nutrition and Physical Activity*, 7(36), 1-17. <https://doi.org/10.1186/1479-5868-7-36>
- Lee, I. M., Shiroma, E. J., Lobelo, F., Puska, P., Blair, S. N., & Katzmarzyk, P. T. (2012). Effect of physical activity on major non-communicable diseases worldwide: An analysis of burden of disease and life expectancy. *Lancet*, 380(9838), 219-229. [https://doi.org/10.1016/s0140-6736\(12\)61031-9](https://doi.org/10.1016/s0140-6736(12)61031-9)
- Leedy, P. D., & Ormrod, J. E. (2013). *Practical research: Planning and design* (10th ed.). Pearson Education Inc.
- Levy, S. S., Li, K.-K., Cardinal, B. J., & Maddalozzo, G. F. (2009). Transitional shifts in exercise behavior among women with multiple sclerosis. *Disability and Health Journal*, 2(4), 216–223. <https://psycnet.apa.org/doi/10.1016/j.dhjo.2009.04.001>
- Lewthwaite, R. (1990). Motivational considerations in physical activity involvement. *Physical Therapy*, 70(12), 808–19. <https://doi.org/10.1093/ptj/70.12.808>
- Lim, Z., Gibbs, K., Potts, J. E., & Sanatani, S. (2010) A review of sudden unexpected death in the young in British Columbia. *Canadian Journal of Cardiology*, 26(1), 22–26. [https://dx.doi.org/10.1016%2Fs0828-282x\(10\)70329-9](https://dx.doi.org/10.1016%2Fs0828-282x(10)70329-9)
- Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Sage Publications.
- Lines, R. (2005). The structure and function of attitudes toward change. *Human Resource Development*, 4(1), 8-32. <https://doi.org/10.1177%2F1534484304273818>
- Lin, J. S., O'Connor, E., Whitlock, E. P., & Beil, T. L. (2010). Behavioral counseling to promote physical activity and a healthful diet to prevent cardiovascular disease in adults: A

- systematic review for the U.S. Preventive Services Task Force. *Annals of Internal Medicine*, 153(11), 736–750. <https://doi.org/10.7326/0003-4819-153-11-201012070-00007>
- Loewenstein, G. (2005). Hot-cold empathy gaps and medical decision making. *Health Psychology*, 24(4S), 49–56. <https://doi.org/10.1037/0278-6133.24.4.S49>
- Longmuir, P. E., Brothers, J. A., de Ferranti, S. D., Hayman, L. L., Van Hare, G. F., Matherne, G. P., Davis, C. K., Joy, E. A., & McCrindle, B. W. (2013). Promotion of physical activity for children and adults with congenital heart disease: A scientific statement from the American Heart Association. *Circulation*, 127(21), 2147–2159. <https://doi.org/10.1161/cir.0b013e318293688f>
- Loucks-Atkinson, A., & Mannell, R. C. (2007). Role of self-efficacy in the constraints negotiation process: The case of individuals with Fibromyalgia Syndrome. *Leisure Sciences*, 29(1), 19–36. <https://doi.org/10.1080/01490400600983313>
- Lowther, M., Mutrie, N., & Scott, E. M. (2007). Identifying key processes of exercise behaviour change associated with movement through the stages of exercise behaviour change. *Journal of Health Psychology*, 12(2), 261–272. <https://psycnet.apa.org/doi/10.1177/1359105307074253>
- Lynch, B. M., Owen, N., Hawkes, A. L., & Aitken, J. F. (2010). Perceived barriers to physical activity for colorectal cancer survivors. *Supportive Care in Cancer*, 18(6), 729–734. <https://doi.org/10.1007/s00520-009-0705-4>
- MacCosham, B. (2017). Negotiating leisure constraints: The case of an amateur musician with epilepsy. *Leisure Studies*, 825–837. <https://doi.org/10.1080/02614367.2017.1285955>
- MacCosham, B., Gravelle, F., & Morin, J. (2019). Towards a better understanding of physical

- activity behavior in adults with congenital heart disease. *American Journal of Health Education*, 50(5), 267-271. <https://doi.org/10.1080/19325037.2019.1642812>
- MacCosham, B., Webb, E., Hamidi, W., Oey, J., & Gravelle, F. (2021). A qualitative exploration of factors influencing physical activity behavior for individuals with Parkinson's disease using the Social Ecological Model. *European Journal of Adapted Physical Activity*, 14(4), 1-17. [doi:10.5507/euj.2020.012](https://doi.org/10.5507/euj.2020.012)
- MacCosham, B., Webb, E., Oey, J., & Gravelle, F. (2019). A qualitative phenomenological exploration of the experiences of individuals with Parkinson's disease engaged in a boxing program. *The Qualitative Report*, 24(6), 1460-1477. <https://doi.org/10.46743/2160-3715/2019.3570>
- MacCosham B, Webb E, Oey J, Gravelle F. (2018). Constraints, facilitators, and stages of behavioral change in physical activity for individuals with Parkinson's disease. *American Journal of Health Education*, 49(3), 179-189. <https://doi.org/10.1080/19325037.2018.1449684>
- Maley, M., Warren, B., & Devine, C. (2013). A second chance: Meanings of body weight, diet, and physical activity to women who have experienced cancer. *Journal of Nutrition Education and Behavior*, 45(3), 232-239. <https://doi.org/10.1016/j.jneb.2012.10.009>
- Marcus, B. H., Nigg, C. R., Riebe, D., & Forsyth, L. H. (2000). Interactive communication strategies: Implications for population-based physical activity promotion. *American Journal of Preventive Medicine*, 19(2), 121–126. [https://doi.org/10.1016/s0749-3797\(00\)00186-0](https://doi.org/10.1016/s0749-3797(00)00186-0)

- Marcus, B. H., Pinto, B. M. Simkin, L. R., Audrain, J. E., & Taylor, E. R. (1994). Application of theoretical models to exercise behavior among employed women. *American Journal of Health Promotion*, 9(1), 49–55. <https://doi.org/10.4278/0890-1171-9.1.49>
- Marelli, A. J., Mackie, A. S., Ionescu-Ittu, R., Rahme, E., & Pilote, L. (2007). Congenital heart disease in the general population: Changing prevalence and age distribution. *Circulation*, 115(2), 163–172. <https://doi.org/10.1161/circulationaha.106.627224>
- Martinez-Quintana, E., Miranda-Calderin, G., Ugarte-Lopetegui, A., & Rodriguez-Gonzalez, F. (2010). Rehabilitation program in adult congenital heart disease patients with pulmonary hypertension. *Congenital Heart Disease*, 5(1), 44–50. <https://doi.org/10.1111/j.1747-0803.2009.00370.x>
- Maxwell, J. A. (2004a). Causal explanation, qualitative research, and scientific inquiry in education. *Educational Researcher*, 33(2), 3-11. <http://dx.doi.org/10.3102/0013189X033002003>
- Maxwell, J. A. (2004b). Using qualitative methods for causal explanation. *Field Methods*, 16(3), 243-264. <https://doi.org/10.1177%2F1525822X04266831>
- Maxwell, J. A. (2013). *Qualitative research design: An interactive approach* (3rd ed.). Sage Publications.
- McDonagh, J. E., Southwood, T. R., & Shaw, K. L. (2004). Unmet education and training needs of rheumatology health professionals in adolescent health and transitional care. *Rheumatology (Oxford)*, 43(6), 737–743. <https://doi.org/10.1093/rheumatology/keh163>
- McLeroy, K. R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An ecological perspective on health promotion programs. *Health Education Quarterly*, 15(4), 351-377. <https://doi.org/10.1177/109019818801500401>

- Mead, S., Hilton, D., & Curtis, L. (2001). Peer support: A theoretical perspective. *Psychiatric Rehabilitation Journal*, 25(2), 134–141. <https://psycnet.apa.org/doi/10.1037/h0095032>
- Menting, M. E., Cuypers, J. A. A. E., Opic, P., Utens, E. M. W. J., Witsenburg, M., van den Bosch, A. E., van Domburg, R. T., Meijboom, F. J., Boersma, E., Bogers, A. J. J. C., & Roos-Hesselink, J. W. (2015). The unnatural history of the ventricular septal defect: Outcome up to 40 years after surgical closure. *Journal of the American College of Cardiology*, 65(18), 1941–1951. <https://doi.org/10.1016/j.jacc.2015.02.055>
- Merriam, S. B. (2009). *Qualitative research: A guide to design and implementation*. Jossey-Bass.
- Moons, P., Bovijn, L., Budts, W., Belmans, A., & Gewillig M. (2010). Temporal trends in survival to adulthood among patients born with congenital heart disease from 1970 to 1992 in Belgium. *Circulation*, 122(22), 2264–2272. <https://doi.org/10.1161/circulationaha.110.946343>
- Moschovi, D., Kapetanakis, E. I., Sfyridis, P. G., Rammos, S., & Mavrikaki, E. (2020). Physical activity levels and self-efficacy of Greek children with congenital heart disease compared to their healthy peers. *Hellenic Journal of Cardiology*, 61(3), 180–186. <https://doi.org/10.1016/j.hjc.2019.01.002>
- Moustakas, C. (1994). *Phenomenological research methods*. Sage Publications.
- MyHeart (2016, September 17). Aortic regurgitation: A leaky aortic valve. Retrieved from <https://myheart.net/articles/aortic-regurgitation-a-leaky-aortic-valve/>
- National Cancer Institute (NCI) (2020, September 24). Perceived benefits. Retrieved from <https://cancercontrol.cancer.gov/brp/research/constructs/perceived-benefits>
- Newitt, R., Barnett, F., & Crowe, M. (2016). Understanding factors that influence participation in physical activity among people with a neuromusculoskeletal condition: A review of

- qualitative studies. *Disability and Rehabilitation*, 38(1), 1-10.
<https://doi.org/10.3109/09638288.2014.996676>
- Nigg, C. R. (2003). Technology's influence on physical activity and exercise science: The present and the future. *Psychology of Sport and Exercise*, 4(1), 57-65.
[http://dx.doi.org/10.1016/S1469-0292\(02\)00017-1](http://dx.doi.org/10.1016/S1469-0292(02)00017-1)
- Nigg, C. R., & Courneya, K. S. (1998). Transtheoretical Model: Examining Adolescent Exercise Behavior. *Journal of Adolescent Health*, 22(3), 214-224. [https://doi.org/10.1016/s1054-139x\(97\)00141-9](https://doi.org/10.1016/s1054-139x(97)00141-9)
- O'Brien, M., Dodd, K. J., & Bilney, B. (2008). A qualitative analysis of a progressive resistance exercise program for people with Parkinson's disease. *Disability and Rehabilitation*, 30(18), 1350-1357. <https://doi.org/10.1080/09638280701614546>
- Obrusnikova, I., & Cavalier, A. R. (2011). Perceived barriers and facilitators of participation in after-school physical activity by children with autism spectrum disorders. *Journal of Developmental and Physical Disabilities*, 23(3), 195-211.
<http://dx.doi.org/10.1007/s10882-010-9215-z>
- O'Byrne, M. L., Mercer-Rosa, L., Ingall, E., McBride, M. G., Paridon, S., & Goldmuntz, E. (2013). Habitual exercise correlates with exercise performance in patients with conotruncal abnormalities. *Pediatric Cardiology*, 34(4), 853-860. <https://doi.org/10.1007/s00246-012-0556-5>
- Ockene, I. S., Hayman, L. L., Pasternak, R. C., Schron, E., & Dunbar-Jacob J. (2002). Task force #4: Adherence issues and behavior change: achieving a long-term solution. *Journal of the American College of Cardiology*, 40(4), 630-640. [https://doi.org/10.1016/s0735-1097\(02\)02078-8](https://doi.org/10.1016/s0735-1097(02)02078-8)

- Ong, L., Nolan, R. P., Irvine, J., & Kovacs, A. H. (2011). Parental overprotection and heart-focused anxiety in adults with congenital heart disease. *International Journal of Behavioral Medicine*, 18(3), 260-267. <https://psycnet.apa.org/doi/10.1007/s12529-010-9112-y>
- Oreg, S., Vakola, M., & Armenakis, A. (2007, August 3-8). *Organizational member's reactions to organizational change: A review of empirical findings* [Conference presentation]. Academy of Management, Philadelphia, PA, United States.
- Orlowski, M. (2016). *Introduction to health behaviors: A guide for managers, practitioners & educators*. Cengage Learning.
- Orrow, G., Kinmonth, A. L., Sanderson, S., & Sutton S. (2012). Effectiveness of physical activity promotion based in primary care: Systematic review and meta-analysis of randomised controlled trials. *BMJ*, 344, e1389. <https://doi.org/10.1136/bmj.e1389>
- Palys, T. (2008). Purposive sampling. In L. Given (ed.), *The SAGE encyclopedia of qualitative research methods* (pp. 697-698), Sage Publications.
- Park, C. L. & Folkman, S. (1997). Meaning in the context of stress and coping. *Review of General Psychology*, 1(2), 115-144. <https://psycnet.apa.org/doi/10.1037/1089-2680.1.2.115>
- Pate, R. R., Trost, S. G., Dowda, M., Ott, A. E., Ward, D. S., Saunders, R., & Felton, G. A. (1999). Tracking of physical activity, physical inactivity, and health-related physical fitness in rural youth. *Pediatric Exercise Science*, 11(4), 364-376.
- Patel, S. S., & Burns, T. L. (2013). Nongenetic risk factors and congenital heart defects. *Pediatric Cardiology*, 34(7), 1535-1555. <https://doi.org/10.1007/s00246-013-0775-4>
- Pemberton, V. L., McCrindle, B. W., Barkin, S., Daniels, S. R., Barlow, S. E., Binns, H. J., Cohen, M. S., Economos, C., Faith, M. S., Gidding, S. S., Goldberg, C. S., Kavey, R. E., Longmuir, P., Rocchini, A. S., Van Horn, L., & Kaltman, J. (2010). Report of the national heart, lung,

- and blood institute's working group on obesity and other cardiovascular risk factors in congenital heart disease. *Circulation*, 121(9), 1153–1159.
<https://dx.doi.org/10.1161%2FCIRCULATIONAHA.109.921544>
- Pillutla, P., Shetty, K. D., & Foster, E. (2009). Mortality associated with adult congenital heart disease: trends in the US population from 1979 to 2005. *American Heart Journal*, 158(5), 874–879. <https://doi.org/10.1016/j.ahj.2009.08.014>
- Playground Centre (2021). Unstructured vs. structured play. Retrieved from <https://www.playgroundcentre.com/unstructured-vs-structured-play/>
- Plotnikoff, R. C., Hotz, S. B., Birkett, N. J., & Courneya, K. S. (2001). Exercise and the transtheoretical model: A longitudinal test of a population sample. *Preventive Medicine*, 33(5), 441–452. <http://dx.doi.org/10.1006/pmed.2001.0914>
- Plotnikoff, R. C., Lippke, S., Johnson, S. T., & Courneya, K. S. (2010). Physical activity and stages of change: A longitudinal test in types 1 and 2 diabetes samples. *Annals of Behavioral Medicine*, 40(2), 138–149. <https://psycnet.apa.org/doi/10.1007/s12160-010-9193-5>
- Porter, H., Iwasaki, Y., & Shank, J. (2010). Conceptualizing meaning-making through leisure experiences. *Society and Leisure*, 33(2), 167–194.
<https://doi.org/10.1080/07053436.2010.10707808>
- Prochaska, J. O. (1979). *Systems of psychotherapy: A transtheoretical analysis*. Dorsey Press.
- Prochaska, J. O., & DiClemente, C. C. (1983). Stages and processes of self-change of smoking: Toward an integrative model of change. *Journal of Consulting and Clinical Psychology*, 51(3), 390–395. <https://psycnet.apa.org/doi/10.1037/0022-006X.51.3.390>

- Prochaska, J. O., Redding, C. A., & Evers, K. E. (2015). The Transtheoretical model and stages of change. In K. Glanz, B. K. Rimer, & V. Viswanath (Eds.), *Health behavior: Theory, research, and practice* (5th ed., pp. 125-148). John Wiley & Sons Inc.
- Prochaska, J. O., & Velicer, W. F. (1997). The transtheoretical model of health behavior change. *American Journal of Health Promotion*, 12(1), 38-48. <https://doi.org/10.4278/0890-1171-12.1.38>
- Prochaska, J. O., Velicer, W. F., Rossi, J. S., Goldstein, M. G., Marcus, B. H., Rakowski, W., Fiore, C., Harlow, L. L., Redding, C. A., Rosenbloom, D., & Rossi, S. R. (1994). Stages of change and decisional balance for 13 problem behaviors. *Health Psychology*, 13(1), 39-45. <https://doi.org/10.1037//0278-6133.13.1.39>
- Pyke, J., & Atcheson, V. (1993). Social recreation services: Issues from a case management perspective. *Psychosocial Rehabilitation Journal*, 17(2), 121–130.
- Raymore, L. A. (2002). Facilitators to leisure. *Journal of Leisure Research*, 34(1), 37-51. <https://doi.org/10.1080/00222216.2002.11949959>
- Reller, M. D., Strickland, M. J., Riehle-Colarusso, T., Mahle, W. T., & Correa, A. (2008). Prevalence of congenital heart defects in Atlanta, 1998-2005. *The Journal of Pediatrics*, 153(6), 807-813. <https://doi.org/10.1016/j.jpeds.2008.05.059>
- Reybrouck, T., & Mertens, L. (2005). Physical performance and physical activity in grown-up congenital heart disease. *European Journal of Cardiovascular Prevention and Rehabilitation*, 12(5), 498-502. <https://doi.org/10.1097/01.hjr.0000176510.84165.eb>
- Rietveld, S., Mulder, B. J., van Beest, I., Lubbers, W., Prins, P. J. M., Vioen, S., Bennebroek-Everez, F., Vos, A., Casteelen, G., & Karsdorp, P. (2002). Negative thoughts in adults with congenital heart disease. *International Journal of Cardiology*, 86(1), 19-26.

[https://doi.org/10.1016/s0167-5273\(02\)00152-3](https://doi.org/10.1016/s0167-5273(02)00152-3)

Robson, C. (2011). *Real world research* (3rd ed.). Blackwell.

Roche, S. L., Silversides, C. K. (2013). Hypertension, obesity, and coronary artery disease in the survivors of congenital heart disease. *Canadian Journal of Cardiology*, 29(7), 841-848.

<https://doi.org/10.1016/j.cjca.2013.03.021>

Rogers, C. (1951). *Client-centered therapy*. Houghton Mifflin.

Rollnick, S., Miller, W. R., & Butler, C. C. (2007). *Motivational interviewing in healthcare: Helping patients change behavior*. Guilford Press.

Romain, A. J., Attalin, V., Sultan, A., Boegner, C., Gernigon, C., & Avignon, A. (2014). Experiential or behavioral processes: Which one is prominent in physical activity? Examining the processes of change 1 year after an intervention of therapeutic education among adults with obesity. *Patient Education and Counseling*, 97(2), 261–268.

<https://doi.org/10.1016/j.pec.2014.08.004>

Rosenfield, S., & Wenzel, S. (1997). Social networks and chronic mental illness: A test of four perspectives. *Social Problems*, 44(2), 200–216. <https://doi.org/10.2307/3096942>

Rosenstock, I. M. (1974). Historical origins of the health belief model. *Health Education Monographs*, 2(4), 328-335. <https://doi.org/10.1177%2F109019817400200403>

Rosenthal, T. M., Leung, S. T., Ahmad, R., Young, T., Lavie, C. J., Moodie, D. S., & Shah, S. (2016). Lifestyle modification for the prevention of morbidity and mortality in adult congenital heart disease. *Congenital Heart Disease*, 11(2), 189–198.

<https://doi.org/10.1111/chd.12341>

Rossow-Kimball, B., & Goodwin, D. (2009). Self-determination and leisure experiences of women living in group homes. *E-Journal of Adapted Physical Activity Quarterly*, 26(1), 1–20.

<https://doi.org/10.1123/apaq.26.1.1>

Rubin, H. J., & Rubin, I. S. (2005). *Qualitative interviewing: The art of hearing data* (2nd ed.). Sage Publications.

Rundmo, T. (2002). Associations between affect and risk perception. *Journal of Risk Research*, 5(2), 119–135. <https://doi.org/10.1080/136698702753499597>

Saelens, B. E., Sallis, J. F., Frank, L. D., Cain, K. L., Conway, T. L., Chapman, J. E., Slymen, D. J., & Kerr, J. (2012). Neighbourhood environmental and psychosocial correlates of adults' physical activity. *Medicine & Science in Sports & Exercise*, 44(4), 637-646. <https://doi.org/10.1249/mss.0b013e318237fe18>

Sallis J. F., & Owens, N. (2015). Ecological models of health behavior. In K. Glanz, B. K. Rimer, & V. Viswanath (Eds.), *Health behavior: Theory, research, and practice* (5th ed.). John Wiley & Sons Inc.

Sallis, J. F., Cervero, R., Ascher, W., Henderson, K., Kraft, K., & Kerr, K. (2006). An ecological approach to creating active living communities. *Annual Review of Public Health*, 27, 297-322. <https://doi.org/10.1146/annurev.publhealth.27.021405.102100>

Samdahl, D. M. (2007). Similarities are not enough: A response to Schneider and Wilhelm Stanis about coping and leisure constraint negotiation. *Leisure Sciences*, 29(4), 409-413. <http://dx.doi.org/10.1080/01490400701394931>

Sánchez-Lastra, M. A., Ayán, C., Sener, M., & Cancela, J. M. (2020). The use of adapted boxing as a rehabilitation strategy in people with diverse health conditions: A systematic review. *European Journal of Adapted Physical Activity*, 13(1), 6. <https://doi.org/10.5507/euj.2020.004>

Schwandt, T. (1990). Paths to inquiry in the social disciplines: Scientific, constructivist, and

- critical theory methodologies. In E. Guba (Ed.), *The Paradigm Dialog* (pp. 258-276). Sage Publications.
- Sen, A. (1999). *Development as freedom*. Oxford University Press.
- Shefter, L., Uhrman, A. L., Tobin, L., & Kress, J. S. (2017). Inclusion coordinators at Jewish summer camps: Roles and challenges. *Journal of Jewish Education*, 83(1), 69–84. <https://doi.org/10.1080/15244113.2017.1275240>
- Silveira, S. L., & Motl, R. W. (2019). Environmental correlates of health-promoting leisure physical activity in persons with multiple sclerosis using social cognitive perspective embedded within social ecological model. *Preventive Medicine Reports*, 15, 1-6. <https://doi.org/10.1016/j.pmedr.2019.100921>
- Skaal, L., & Pengpid, S. (2012). The predictive validity and effects of using the transtheoretical model to increase the physical activity of healthcare workers in a public hospital in South Africa. *Translational Behavioral Medicine*, 2(4), 384-391. <https://doi.org/10.1007/s13142-012-0136-5>
- Skinner, B. F. (1971). *Beyond freedom and dignity*. Bantam/Vintage.
- Slovic, P. (2016). Do adolescent smokers know the risk? In P. Slovic (Ed.), *The perception of risk* (pp. 364–371). Routledge.
- Son, J. S. (2018). Marginalization in leisure and health resources in a rural U.S. town: Social justice issues related to age, race, and class. *International Journal of the Sociology of Leisure*, 1(4), 5–27. <https://link.springer.com/article/10.1007/s41978-017-0001-7>
- Stout, K. K., Daniels, C. J., Aboulhosn, J. A., Bozkurt, B., Broberg, C. S., Colman, J. M., Crumb, S. R., Dearani, J. A., Fuller, S., Gurvitz, M., Khairy, P., Landzberg, M. J., Saidi, A., Valente, A. M., & Van Hare, G. F. (2019). 2018 AHA/ACC Guideline for the management

- of adults with congenital heart disease: A report of the American College of Cardiology/American Heart Association task force on clinical practice guidelines, *Circulation*, 139(14), e698–e800. <https://doi.org/10.1161/CIR.0000000000000603>
- Stuart, A. G. (2014). Exercise as therapy in congenital heart disease: A gamification approach. *Progress in Pediatric Cardiology*, 38(1-2), 37–44. <https://doi.org/10.1016/J.PPEDCARD.2014.12.008>
- Sun, W., Chen, D., Wang, J., Liu, N., & Zhang, W. (2018). Physical activity and body image dissatisfaction among pregnant women: A systematic review and meta-analysis of cohort studies. *European Journal of Obstetrics & Gynecology and Reproductive Biology*, 229, 38–44. <https://doi.org/10.1016/j.ejogrb.2018.07.021>
- Swan, L., & Hillis, W. S. (2000). Exercise prescription in adults with congenital heart disease: A long way to go. *Heart*, 83(6), 685-687. <https://doi.org/10.1136/heart.83.6.685>
- Takken, T., Giardini, A., Reybrouck, T., Gewillig, M., Hövels-Gürich, H. H., Longmuir, P. E., McCrindle, B. W., Paridon, S. M., & Hager, A. (2012). Recommendations for physical activity, recreation sport, and exercise training in paediatric patients with congenital heart disease: A report from the Exercise, Basic & Translational Research Section of the European Association of Cardiovascular Prevention and Rehabilitation, the European Congenital Heart and Lung Exercise Group, and the Association for European Paediatric Cardiology. *European Journal of Preventive Cardiology*, 19(5), 1034-1065. <https://doi.org/10.1177/1741826711420000>
- Telama, R., Yang, X., Laakso, L., & Viikari, J. (1997). Physical activity in childhood and adolescence as predictor of physical activity in young adulthood. *American Journal of Preventive Medicine*, 13(4), 317-323.

- Thaulow, E., & Fredriksen, P. M. (2003). Exercise and training. In M. A. Gatzoulis, G. D. Webb, & P. E. F. Daubeney (Eds.), *Diagnosis and Management of Adult Congenital Heart Disease* (pp. 145-149). Churchill Livingstone.
- The Marfan Foundation (2014). Bones and joints. Retrieved from <https://www.marfan.org/about/body-systems/skeleton-and-joints>
- Therrien, J., Fredriksen, P., Walker, M., Granton, J., Reid, G. J., & Webb, G. (2003). A pilot study of exercise training in adult patients with repaired tetralogy of Fallot. *Canadian Journal of Cardiology*, 19(6), 685–689.
- Thompson, J. K., Heinberg, L. J., Altabe, M., & Tantleff-Dunn, S. (1999). *Exacting beauty: Theory, assessment, and treatment of body image disturbance*. American Psychological Association. <https://psycnet.apa.org/doi/10.1037/10312-000>
- Thompson, A. M., Humbert, M. L., & Mirwald, R. L. (2003). A longitudinal study of the impact of childhood and adolescent physical activity experiences on adult physical activity perceptions and behaviors. *Qualitative Health Research*, 13(3), 358-377. <https://doi.org/10.1177/1049732302250332>
- Trotter, R. T. II (2012). Qualitative research sample design and sample size: Resolving and unresolved issues and inferential imperatives. *Preventive Medicine*, 55(5), 398-400. <https://doi.org/10.1016/j.ypmed.2012.07.003>
- Tutarel, O., Kempny, A., Alonso-Gonzalez, R., Jabbour, R., Li, W., Uebing, A., Dimopoulos, K., Swan, L., Gatzoulis, M. A., & Diller, G. P. (2013). Congenital heart disease beyond the age of 60: Emergence of a new population with high resource utilization, high morbidity, and high mortality. *European Heart Journal*, 35(11), 725–732. <https://doi.org/10.1093/eurheartj/eh257>

Ubeda Tikkanen, A., Opotowsky, A. R., Bhatt, A. B., Landzberg, M. J., & Rhodes, J. (2013).

Physical activity is associated with improved aerobic exercise capacity over time in adults with congenital heart disease. *International Journal of Cardiology*, 168(5), 4685-4691.
<https://doi.org/10.1016/j.ijcard.2013.07.177>

United States Department of Health and Human Services (USDHHS) (2000). *Healthy People: Understanding and improving health*. Washington, DC: U.S. Government Printing Office.

United States Department of Health and Human Services (USDHHS) (2020a). *Centers for Disease Control and Prevention*. CDC. The social ecological model: A framework for prevention. Retrieved from <https://www.cdc.gov/violenceprevention/about/social-ecologicalmodel.html>

United States Department of Health and Human Services (USDHHS) (2020b). *The health benefits of smoking cessation: A report of the surgeon general*. Rockville, MD: U. S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, Office on Smoking and Health.

University of Pittsburgh Medical Centre (UPMC) (2021). Aortic root dilation. Retrieved from <https://www.upmc.com/services/heart-vascular/conditions-treatments/aortic-root-aneurysm>

UWHealth (2015). Heart care: Innovative treatments. Retrieved from <https://www.uwhealth.org/services/heart-care#:~:text=In%20partial%20anomalous%20pulmonary%20venous,the%20rest%20of%20the%20body>

- van der Bom, T., Zomer, A. C., Zwinderman, A. H., Meijboom, F. J., Bouma, B.J. Mulder, B. J. M. (2011). The changing epidemiology of congenital heart disease. *National Reviews Cardiology*, 8(1), 50–60. <https://doi.org/10.1038/nrcardio.2010.166>
- Vakola, M., & Nikolaou, I. (2005). Attitudes towards organizational change: What is the role of employees' stress and commitment. *Employee Relations*, 27(2), 160-174. <https://doi.org/10.1108/01425450510572685>
- Velicer, W. F., Prochaska, J. O., Fava, J. L., Norman, G. J., & Redding, C. A. (1998). Smoking cessation and stress management: Applications of the transtheoretical model of behavioral change. *Homeostasis*, 38(5-6), 216-233.
- Verschuren, O., Wiart, L., & Ketelaar, M. (2013). Stages of change in physical activity behavior in children and adolescents with cerebral palsy. *Disability and Rehabilitation*, 35(19), 1630-1635. <https://doi.org/10.3109/09638288.2012.748844>
- Vodusek, Z., Khaliqdina, S., Borz-Baba, C., & Scandrett, R. (2019). Sinus venosus atrial septal defect: A challenging diagnosis. *Cureus*, 11(10), e5926. <https://dx.doi.org/10.7759%2Fcureus.5936>
- Wannamethee, S. G., & Shaper, A. G. (2001). Physical activity in the prevention of cardiovascular disease. *Sports Medicine*, 31(2), 101–114. <https://doi.org/10.2165/00007256-200131020-00003>
- Warburton, D. E., Nicol, C. W., Bredin, S. S. (2006). Health benefits of physical activity: The evidence. *CMAJ*, 174(6), 801–809. <https://doi.org/10.1503/cmaj.051351>
- Warner, K. E., Isaacs, S. L., Knickman, J. R., & Lavizzo-Mourey, R. (2006). *Tobacco control policy: Robert Wood Johnson Foundation Series on Health Policy*. Jossey-Bass.

- Warnes, C. A. (2009). Adult congenital heart disease importance of the right ventricle. *Journal of the American College of Cardiology*, 54(21), 1903–1910. <https://doi.org/10.1016/j.jacc.2009.06.048>
- Warnes, C. A., Williams, R. G., Bashore, T. M., Child, J. S., Connolly, H. M., Dearani, J. A., del Nido, P., Fasules, J. W., Graham, T. P., Hijazi, Z. M., Hunt, S. M., King, M. E., Landzberg, M. J., Miner, P. D., Radford, M. J., Walsh, E. P., & Webb, G. D. (2008). ACC/AHA 2008 guidelines for the management of adults with congenital heart disease. *Circulation*, 118(23), e714-e833. <https://doi.org/10.1161/CIRCULATIONAHA.108.190690>
- WHO (2021). *The global health observatory: Explore a world of health data*. Noncommunicable diseases: Risk factors. Retrieved from <https://www.who.int/data/gho/data/themes/topics/topic-details/GHO/ncd-risk-factors>
- Wicker, A. W. (1979). Ecological psychology: Some recent and prospective developments. *American Psychologist*, 34(9), 755-765. <https://psycnet.apa.org/doi/10.1037/0003-066X.34.9.755>
- Williams, D. M., Papandatos, G. D., Napolitano, M. A., Lewis, B. A., Whiteley, J. A., & Marcus, B. H. (2006). Perceived enjoyment moderates the efficacy of an individually tailored physical activity intervention. *Journal of Sport and Exercise Psychology*, 28(3), 300-309. <https://doi.org/10.1123/jsep.28.3.300>
- Winter, M. M., van der Bom, T., de Vries, L. C., Balducci, A., Bouma, B. J., Pieper, P. G., van Dijk, A. P. J., van der Plas, M. N., Picchio, F. M., & Mulder, B. J. M. (2012). Exercise training improves exercise capacity in adult patients with a systemic right ventricle: A randomized clinical trial. *European Heart Journal*, 33(11), 1378–1385. <https://doi.org/10.1093/eurheartj/ehr396>

- Wolff, K., Larsen, S., & Øgaard, T. (2019). How to define and measure risk perceptions. *Annals of Tourism Research*, 79, 102759 <https://doi.org/10.1016/j.annals.2019.102759>
- Wolff, K., & Larsen, S. (2014). Can terrorism make us feel safer? Risk perceptions and worries before and after the July 22nd attacks. *Annals of Tourism Research*, 44, 200–209. <https://doi.org/10.1016/j.annals.2013.10.003>
- Zarshenas, S., Houshvar, P., & Tahmasebi, A. (2013). The effect of eight weeks of aerobic exercise on depression in Iranian women. *Depression Research and Treatment*, 31, 1-6. <https://doi.org/10.1155/2013/132684>
- Zimmerman, G. L., Olsen, C. G., & Bosworth, M. F. (2000). A “stages of change” approach to helping patients change behavior. *American Family Physician*, 61(5), 1409-1416.
- Zipes, D. P., Ackerman, M. J., Estes, M., Grant, A. O., Myerburg, R. J., & Van Hare, G. (2005). Task force 7: Arrhythmias. *Journal of the American College of Cardiology*, 45, 1354–1363. <https://doi.org/10.1016/j.jacc.2005.02.014>
- Zomer, A. C., Vaartjes, I., Uiterwaal, C. S., van der Velde, E. T., van den Merkhof, L. F. M., Bauer, L. H. B., Ansink, T. J. M., Cozijnsen, L., Pieper, P. G., Meijboom, F. J., Grobbee, D. F., & Mulder, B. J. M. (2012). Circumstances of death in adult congenital heart disease. *International Journal of Cardiology*, 154(2), 168–72. <https://doi.org/10.1016/j.ijcard.2010.09.015>

Appendices

Appendix A

Description of CHDs that participants in this study have been diagnosed with

Type of CHD	Description
Pulmonary atresia	Absence of pulmonary valve
Coarctation of the aorta	Blockage of the aorta Narrowing of the vessel
Marfan syndrome	Enlargement of the aorta
Gerbode type ventricular septal defect	Direct communication between left and right atrium
Mitral valve prolapses	Enlarged valves with backwards bend
Tetralogy of Fallot	Hole in muscle wall separating the ventricles Pulmonary valve narrowing Enlargement of the aorta Thick right ventricle muscle wall
Bicuspid aortic valve	Aortic valve with two leaflets
Pulmonary stenosis	Obstruction of right ventricle outflow to pulmonary artery
Atrial septal defect	Hole in muscle wall of heart upper chambers
Transposition of the great arteries D-Type	Aorta and pulmonary arteries connected to wrong chambers
Moderate aortic root dilation	Aneurysm in the aorta
Severe mitral valve regurgitation	Leak in the mitral valve
Ventricular septal defect	Hole in muscle wall separating right and left ventricles
Moderate aortic regurgitation	Leak in the aortic valve
Anomalous left coronary artery	Abnormal form of left coronary artery
Eisenmenger syndrome	Blood flow from right to left ventricle
Severe pulmonary hypertension	High blood pressure in vessels carrying blood from heart to lungs
Dysplastic tricuspid valve	Malformation of the tricuspid valve
Total anomalous pulmonary ventricle defect	Pulmonary veins are abnormal
Sinus venosus atrial septal defect	Anomalous pulmonary venous return
Partial pulmonary vein drainage	Pulmonary veins return blood to right atrium instead of left
Aortopathy	Malformation of the aorta

Note. Descriptions of the diagnoses' were obtained from CDC (2020d), Cedars Sinai (2021), Cove Point Foundation (2020), CTSNet (2012), MyHeart (2016), Vodusek et al. (2019), UPMC (2021), and UWHealth (2015).

Appendix B**PARTICIPANTS NEEDED FOR A STUDY ON PHYSICAL ACTIVITY**

Study title: Physical activity in adults with congenital heart disease

Dear participant,

You have been invited to participate in a research study from the University of Ottawa entitled *Physical activity in adults with congenital heart disease*. The purpose of this study is to explore how engagement in physical activity is initiated and maintained in adults with congenital heart disease. This study could also help with the designing and implementation of physical activity programs that encourage individuals with congenital heart disease to engage and maintain their involvement in physical activity.

To participate in this study, you must be at least 18 years of age, speak English or French, live in the Ottawa region, have been diagnosed with simple to complex congenital heart disease, have the physical capacity to regularly engage in physical activity, and be willing to take part in three semi-structured interviews.

By participating in the study, you will take part in 3 interviews each lasting approximately 60 minutes. The interviews will be scheduled at a time and location that is convenient for you. The interviews will be audio recorded.

Participating in this study is entirely voluntary. If you are interested in participating or have any questions, please do not hesitate to contact Bradley MacCosham by email or by telephone.

This research study has been approved by the Ottawa Health Science Network Research Ethics Board. 20170536

À LA RECHERCHE DE PARTICIPANTS POUR UNE ÉTUDE SUR L'ACTIVITÉ PHYSIQUE

Titre de l'étude: Physical activity in adults with congenital heart disease

Chère participant,

Vous avez été invité à participer à une recherche de l'Université d'Ottawa intitulée *Physical activity in adults with congenital heart disease*. Le but de cette étude est d'explorer comment l'engagement dans l'activité physique est initié et maintenu chez les adultes atteints de cardiopathie congénitale. Les connaissances générées pourraient également aider à la conception et la mise en œuvre de programmes d'activité physique qui encouragent les personnes atteintes de maladie cardiaque congénitale à s'engager et à maintenir leur participation à l'activité physique.

Pour participer à cette étude, vous devez avoir au moins 18 ans, parler anglais ou français, vivre à Ottawa et dans la région environnante, être diagnostiqué avec une maladie cardiaque congénitale simple à complexe, avoir la capacité physique pour s'engager régulièrement à l'activité physique, et être prêt à participer dans trois entrevues semi-structurées.

En participant à l'étude, vous participerez à 3 entrevues d'une durée d'environ 60 minutes. Les entrevues auront lieu à l'heure et à un endroit qui vous conviennent. Les interviews seront enregistrées par appareil audio.

La participation à cette étude est entièrement volontaire. Si vous êtes intéressé à participer ou avez des questions, n'hésitez pas à communiquer avec Bradley MacCosham par courriel ou par téléphone.

Cette étude de recherche a été approuvée par le Ottawa Health Science Network Research Ethics Board. 20170536

Appendix C**PARTICIPANT INFORMED CONSENT FORM****Title of Study: Physical activity in adults with congenital heart disease 20170536****Local Site Principal Investigator (PI): Joanne Morin, RN**

Participation in this study is voluntary. Please read this Participant Informed Consent Form carefully before you decide if you would like to participate. Ask the study team as many questions as you like.

Why am I being given this form?

You are being asked to participate in this research study because you can provide information on how physical activity engagement is initiated and maintained in adults with congenital heart disease (CHD). The information that you provide could potentially be used to design and implement physical activity programs that will encourage individuals with congenital heart disease to engage and maintain their involvement in physical activity.

Why is this study being done?

Congenital heart disease (CHD) is the world's leading birth defect. Roughly 1 in 100 Canadian children are born with CHD. Approximately 98% of individuals born with CHD live well into adulthood, which has resulted in a growing population of young adults who require life-long cardiac care. Across Canada, there are an estimated 100,000 adults with CHD, which now outnumbers youths with CHD. At least of individuals with CHD will experience complications, multiple surgeries, and/or premature/sudden death. According to the Canadian Congenital Heart Network (2013), there are far fewer resources for the care of adult CHD patients than other cardiac patients. As a result, wait times for clinical visits and surgical intervention are much longer than for other cardiac patients, which can lead to increased anxiety, added risk, and even death. Research in the area of adult CHD has not reached the level of sophistication that has been reached in other areas of heart disease research despite CHD research's potential to have a greater impact (Canadian Congenital Heart Network, 2013).

Older patients with CHD need more hospitalizations and interventions than younger patients. Adults with CHD might be exposed to risk factors for coronary artery disease and to consequences of living a sedentary lifestyle. In some instances, their inactive lifestyle is caused by fears, misconceptions, and/or well-intentioned physician reluctance to promote exercise. However, regular physical activity and exercise at recommended levels can be performed and should be encouraged in many patients with CHD. Physical activity is thus considered a safe and low cost intervention for patients with CHD. It is important to recognize, though, that most patients with CHD are relatively sedentary despite the health benefits of physical activity for them. Research on adults with CHD should emphasize the importance of daily physical activity and decreasing sedentary behavior as appropriate for the patient's clinical status. Given that health benefits can come from physical activity of moderate intensity, the health benefits of a physically active lifestyle are within the reach of nearly all patients with CHD. Thus, as a means for understanding

physical activity in adults with CHD, we need to understand the different factors that influence physical activity behavior in this population.

The purpose of this qualitative study is to explore how physical activity engagement is initiated and maintained in adults with CHD. More specifically, this study will seek to understand: the meaning of physical activity in the lives of adult CHD patients, how do meanings evolve throughout different stages of behavioral change in physical activity, the short-term and long-term benefits and risks of physical activity as perceived by adult CHD patients, the stages of behavioral change in physical activity, the perceived constraints and facilitators in each stage of behavioral change, the strategies that adult CHD patients utilize to stay involved in physical activity, and the types of activities that promote long-term engagement in physical activity.

We estimate that 25 to 30 participants will be enrolled in the study.

How is the study designed?

To gain a better understanding on how physical activity engagement is initiated and maintained in adults with CHD, this study will use a qualitative research design. Participants will not be randomly chosen and instead will be chosen if they have had experiences with the different topics covered in the study. As such, participants will be able to provide the necessary information that will help the researcher answer the study's research questions. Data for this study will be collected through three semi-structured interviews to document changes in physical activity engagement over time. Data will also be thematically analyzed meaning information will be grouped with other similar information.

What is expected of me?

You will be asked to participate in 3 audio-recorded interviews that will be scheduled at a time and place of your convenience. The first interview will be scheduled at your earliest convenience, the second interview will take place three months after the first interview, and the third interview will take place six months after the first interview. The rationale for three interviews is because we are seeking to document changes (if any) in physical activity behavior over time. The interviews are to discuss your experiences and involvement in physical activity. The interviews will be approximately 60 minutes long. You may skip any questions that make you uncomfortable or that you do not wish to answer. The interviews will be audio recorded. You may withdraw from the interview at any point and the information that was discussed until that point will be securely destroyed.

How long will I be involved in the study?

The entire study will last approximately 1 year. Your participation in the study will last approximately 6 months. Over this time, you will be required to take part in three semi-structured interviews that will be scheduled at a time and place that is most convenient for you.

What are the potential risks I may experience?

You might find the interviews tiring if they are quite lengthy. You might not like all of the questions that you are asked. You do not have to answer any questions that make you uncomfortable.

Can I expect to benefit from participating in this research study?

It is not guaranteed that you will directly benefit from participating in this study. However, you may benefit from knowing that the information you provide will contribute to understanding the experiences of adults with congenital heart disease in physical activity. The information that is provided could potentially be used to design and implement physical activity programs and interventions that will encourage adults with congenital disease to engage and maintain their involvement in physical activity.

Do I have to participate? What alternatives do I have? If I agree now, can I change my mind and withdraw later?

Your participation in this study is voluntary. The alternative to this study is not to participate.

You may decide not to be in this study, or to be in the study now, and then change your mind later without affecting the medical care or other services to which you are entitled or are presently receiving at this institution.

If you withdraw from the study, you may choose to have all data gathered until the time of withdrawal destroyed and not used for any research purposes.

How is my personal information being protected?

- All information collected during your participation in this study will be identified with a unique study number.
- Interview recordings will be transcribed and anonymized and will not contain information that identifies you, such as your name, address, etc.
- The link between your unique study number and your name and contact information will be stored securely and separate from your study records, and will not leave this site.
- Any documents leaving the Heart Institute will contain only your unique study number. This includes publications or presentations resulting from this study.
- Information that identifies you will be released only if it is required by law.
- For audit purposes only, your original study records may be reviewed under the supervision of Joanne Morin's staff by representatives from:
 - the Ottawa Health Science Network Research Ethics Board (OHSN-REB),
 - the Heart Institute
- Research records will be kept for 10 years, after this time they will be destroyed.

Will I be informed about any new information that might affect my decision to continue participating?

You will be told in a timely fashion of any new findings during the study that could affect your willingness to continue in the study. You may be asked to sign a new consent form.

Who do I contact if I have any further questions?

If you have any questions about this study, please contact Joanne Morin. You may also contact Bradley MacCosham.

The Ottawa Health Science Network Research Ethics Board (OHSN-REB) has reviewed the plans for this research study. The Board considers the ethical aspects of all research studies involving human participants at the Heart Institute. If you have any questions about your rights as a study participant, you may contact the Chairperson at 613-798-5555, extension 16719.

Physical activity in adults with congenital heart disease 20170536**Consent to Participate in Research**

- I understand that I am being asked to participate in a research study about how physical activity engagement is initiated and maintained in adults with CHD.
- This study was explained to me by _____.
- I have read, or have had it read to me, each page of this Participant Informed Consent Form.
- All of my questions have been answered to my satisfaction.
- If I decide later that I would like to withdraw my participation and/or consent from the study, I can do so at any time.
- I voluntarily agree to participate in this study.
- I will be given a copy of this signed Participant Informed Consent Form.

By initialing here I agree to be audio taped. ____

Participant's Printed Name

Participant's Signature

Date

Investigator Statement

I have carefully explained the study to the study participant. To the best of my knowledge, the participant understands the nature, demands, risks and benefits involved in taking part in this study.

Investigator Printed Name

Investigator Signature

Date

FORMULAIRE DE CONSENTEMENT ÉCLAIRÉ À L'INTENTION DU PARTICIPANT**Titre de l'étude: Physical activity in adults with congenital heart disease****Chercheur principal local: Joanne Morin, RN**

La participation à cette étude est volontaire. Lisez attentivement ce formulaire de consentement éclairé par le participant avant de décider si vous souhaitez participer. Demandez à l'équipe d'étude autant de questions que vous souhaitez.

Pourquoi me remet-on ce formulaire?

On vous invite à prendre part à cette étude de recherche parce que vous pouvez fournir des connaissances importantes sur la façon dont l'engagement de l'activité physique est initié et maintenu chez les adultes atteints de cardiopathie congénitale. L'information que vous fournissez pourrait potentiellement être utilisée pour concevoir et mettre en œuvre des programmes d'activités physiques qui encourageront les individus atteints de cardiopathie congénitale à s'engager et à maintenir leur participation à l'activité physique.

Pourquoi effectue-t-on cette étude?

La cardiopathie congénitale est le défaut principal de naissance au monde. Environ 1 enfant canadien sur 100 est né avec la cardiopathie congénitale. Dans le passé, peu d'entre-eux ont vécu passer l'adolescence. Maintenant, environ 98% atteint l'âge adulte, ce qui a entraîné une population croissante de jeunes adultes qui ont besoin de soins cardiaques pour la vie. Dans l'ensemble du Canada, on compte environ 100 000 adultes atteints de cardiopathie congénitale, qui dépassent maintenant les jeunes atteints de cardiopathie congénitale. Au moins la moitié font face à des complications, de chirurgies multiples et/ou de mort prémature ou subite. Il y a beaucoup moins de ressources allouées aux soins des patients adultes atteints de cardiopathie congénitale que d'autres patients avec des maladies cardiaques. En conséquence, les temps d'attente pour les visites cliniques et l'intervention chirurgicale sont beaucoup plus longs que pour les autres patients cardiaques, ce qui peut entraîner une augmentation de l'anxiété, des risques supplémentaires, et même de la mort. La recherche dans le domaine de la maladie cardiovasculaire chez l'adulte n'a pas atteint le niveau de sophistication observé dans d'autres domaines de la recherche sur les maladies cardiaques malgré le potentiel de la recherche liée à la cardiopathie congénitale à avoir un impact plus important.

Les patients plus âgés atteints de cardiopathie congénitale nécessitent plus d'hospitalisations et d'interventions que les patients plus jeunes. Les adultes atteints de cardiopathie congénitale peuvent être exposés aux facteurs de risque traditionnels de la maladie coronarienne et aux conséquences néfastes d'un mode de vie sédentaire. Dans certains cas, leur mode de vie inactif est développé par des peurs, des idées fausses, et/ou une réticence des médecins bien intentionnés à approuver l'entraînement physique. Cependant, l'activité physique régulière et l'exercice aux niveaux recommandés peuvent être effectués et devraient être encouragés chez tous les patients souffrant de cardiopathie congénitale. L'activité physique est donc considérée comme une intervention sécuritaire et peu coûteuse pour les patients souffrant de cardiopathie congénitale. Il est

important de reconnaître, cependant, que la plupart des patients souffrant de cardiopathie congénitale sont relativement sédentaires malgré l'importance des avantages physiques et psychosociaux de l'activité physique pour la santé dans cette population. La recherche chez les adultes atteints de cardiopathie congénitale devrait souligner l'importance de l'activité physique quotidienne et la diminution du comportement sédentaire, selon le cas, pour l'état clinique du patient. Étant donné que les avantages pour la santé découlent d'activités physiques d'intensité modérée, les avantages pour la santé d'un mode de vie actif sont à la portée de presque tous les patients souffrant de cardiopathie congénitale. Ainsi, comme moyen de compréhension de l'activité physique chez les adultes atteints de cardiopathie congénitale, nous devons comprendre les différents facteurs qui influent sur le comportement de l'activité physique dans cette population.

Le but de cette étude qualitative est d'explorer comment l'engagement à l'activité physique est initié et maintenu chez les adultes atteints de cardiopathie congénitale. Plus précisément, cette étude cherchera à comprendre: la signification de l'activité physique dans la vie des patients adultes atteints de cardiopathie congénitale, comment la signification de l'activité physique évolue dans différents stades de changement de comportement, les avantages à court terme et à long terme et les risques de l'activité physique telle que perçue par les patients adultes atteints de cardiopathie congénitale, les stades du changement de comportement dans l'activité physique, les contraintes perçues et les facilitateurs dans chaque stade de changement de comportement, les stratégies que les patients adultes atteints de cardiopathie congénitale utilisent pour rester impliqués dans l'activité physique, et les types d'activités qui favorisent l'engagement à long terme dans l'activité physique.

Nous estimons que 25 à 30 individus participeront à l'étude.

Quelle est la méthodologie de l'étude?

Pour mieux comprendre comment l'engagement à l'activité physique est initié et maintenu chez les adultes atteints de cardiopathie congénitale, cette étude utilisera une méthode de recherche qualitative. Les participants ne seront pas choisis au hasard et au lieu, ils seront choisis s'ils ont eu des expériences avec les différents sujets abordés dans l'étude. En tant que tel, les participants seront en mesure de fournir les informations nécessaires qui aideront le chercheur à répondre aux questions de recherches de l'étude. Les données de cette étude seront recueillies par trois entrevues semi-structurées pour documenter les changements dans l'engagement à l'activité physique au cours de ce temps. Les données seront également analysées thématiquement, ce qui veut dire que l'information sera regroupée avec d'autres informations similaires.

Que serai-je appelé à faire?

Vous devez participer à 3 entrevues enregistrées par appareil audio qui vont prendre lieu à un moment et à un endroit qui vous convient le mieux. La première entrevue aura lieu le plus tôt possible, la deuxième entrevue aura lieu trois mois après la première entrevue, et la troisième entrevue aura lieu six mois après la première entrevue. La raison d'être de trois entrevues est que nous cherchons à documenter les changements (s'il y en a) dans le comportement de l'activité physique au fil du temps. Pendant les entrevues on va discuter de vos expériences et de votre participation à l'activité physique. Les entrevues seront environ 60 minutes. Vous pouvez ignorer

toute question qui vous rend mal à l'aise ou que vous ne souhaitez pas répondre. Les entrevues seront enregistrées par appareil audio. Vous pouvez vous retirer de l'entrevue n'importe quand et les informations qui ont été discutées jusqu'à ce que ce point seront complètement détruit.

Quelle sera la durée de ma participation à cette étude?

Toute l'étude durera environ 1 an. Votre participation à l'étude durera environ 6 mois. Au cours de cette période, vous devez participer à trois entrevues semi-structurées qui vont prendre lieu à un moment et à un endroit qui vous convient le mieux.

Quels sont les risques possibles associés à ma participation à cette étude?

Vous pourriez trouver que les entrevues vous fatiguent si elles sont longues. Il se peut que vous ne voulez pas répondre à toutes les questions qui vous sont posées. Vous ne devez répondre à aucune question qui vous rend mal à l'aise.

Les données recueillies dans le cadre de cette étude seront confidentielles. Toutes les conditions de la Loi 49 sur l'accès à l'information municipale et de la protection de la vie privée de 1989 et de l'énoncé de politique des trois Conseils sur l'éthique de la recherche (version 2) seront respectées. Toutes les copies papier des données d'étude seront stockées dans un bureau verrouillé. Les enregistrements électroniques et les copies des données seront anonymes, protégés par mot de passe et stockés sur des ordinateurs protégés par mot de passe. Seul l'équipe de recherche aura accès aux données. Les seules limites à la confidentialité des données de recherche seront liées aux procédures judiciaires exigeant que les données soient diffusées, ou en cas de dommage imminent à soi ou à d'autres personnes. Les membres de la commission d'éthique de la recherche de l'Institut de Cardiologie d'Ottawa peuvent également examiner ces données dans le cadre des procédures de vérification afin d'assurer l'observation des lois sur la protection de la vie privée et des procédures de recherche Canadiennes établies. L'information codée recueillie au cours de cette étude sera stockée pendant 10 ans après la publication de tous les résultats de cette recherche. Après cette période, tous les données seront détruites.

Puis-je m'attendre à retirer des bienfaits en lien avec ma participation à cette étude?

Il n'est pas garanti que vous bénéficierez directement après avoir participer à cette étude. Cependant, vous pouvez bénéficier de savoir que l'information que vous fournissez contribuera à comprendre les expériences d'adultes atteints de cardiopathie congénitale dans l'activité physique. L'information fournie pourrait potentiellement être utilisée pour concevoir et mettre en œuvre des programmes d'activités physiques et des interventions qui encourageront les adultes atteints de cardiopathie congénitales à s'engager et à maintenir leur participation à l'activité physique.

Suis-je tenu de participer? Quelles sont mes autres options?

Votre participation à cette étude est volontaire. L'alternative à cette étude est de ne pas participer.

Vous pouvez décider de ne pas participer à cette étude, ou d'être dans l'étude maintenant, puis de changer votre décision plus tard sans affecter les soins médicaux ou d'autres services auxquels vous avez droit ou vous recevez présentement dans cette institution.

Si vous retirez de l'étude, vous pouvez choisir d'avoir toutes les données recueillies jusqu'au moment du retrait soit détruit et non utilisé à des fins de recherche.

À quel type d'indemnisation puis-je m'attendre si je devais subir un préjudice ou tomber malade en lien avec ma participation à cette étude?

- Toute information recueillie au cours de votre participation à cette étude sera identifiée à l'aide d'un numéro unique de l'étude.
- Les enregistrements d'entrevue seront transcrits et anonymisés et ne contiendra aucune information qui pourrait servir à vous identifier.
-
- La liste maîtresse et les dossiers codés de l'étude seront entreposés de manière sécuritaire.
- Une liste maîtresse servira de lien entre vos renseignements personnels et votre code numérique de l'étude. Seuls le personnel de l'étude pourra accéder à cette liste et cette dernière ne sera pas transmise à l'extérieur du site.
- La divulgation de vos renseignements d'identification ne sera permise que si requise par la loi.
- Les représentants des établissements suivants pourront procéder à l'examen de vos dossiers médicaux originaux, sous la supervision de Joanne Morin, uniquement à des fins de vérification:
 - Le Conseil d'éthique de la recherche du Réseau de science de la santé d'Ottawa (CÉR-RSSO), et
 - L'Institut de Cardiologie d'Ottawa].
- Aucune publication ou présentation résultant de cette étude ne pourra servir à vous identifier.
- Les dossiers de recherche seront conservés pour une période de 10 années, conformément aux exigences de [CÉR-RSSO/Santé Canada].
- Une fois la période de rétention terminée, tous les dossiers papier seront déchiquetés ou jetés aux rebuts confidentiels, et les fichiers électroniques seront supprimés.

Serai-je informé de nouveaux renseignements qui seraient susceptibles d'influer sur ma décision de continuer à prendre part à cette étude?

Nous vous informerons dès que possible de tout nouveau renseignement qui serait susceptible d'influer sur votre volonté de continuer à prendre part à l'étude. Il est possible que vous soyez alors appelé à signer un nouveau formulaire de consentement.

Avec qui communiquer si j'ai d'autres questions?

Pour toute question au sujet de l'étude, ou si vous croyez avoir été victime d'une blessure découlant de cette étude, veuillez communiquer avec Joanne Morin ou Bradley MacCosham.

Le Conseil d'éthique de la recherche du Réseau de science de la santé d'Ottawa (CÉR-RSSO) a révisé ce protocole. Le CÉR-RSSO est chargé de l'ensemble des aspects éthiques de toutes les études de recherche menées auprès de sujets humains effectuées à l'Institut de Cardiologie. Pour toute question au sujet de vos droits à titre de sujet de recherche, veuillez communiquer avec le président du Conseil d'éthique de la recherche du Réseau de science de la santé d'Ottawa, au 613-798-5555, poste 16719.

Physical activity in adults with congenital heart disease

Consentement à la participation à la recherche

- Je reconnais que l'on sollicite ma participation à une étude de recherche sur comment l'engagement à l'activité physique est initié et maintenu chez les adultes atteints de cardiopathie congénitale.
- _____ m'a fourni les explications nécessaires au sujet de cette étude.
- J'ai pris connaissance de chacune des pages de ce Formulaire de consentement éclairé à l'intention du participant.
- On a répondu à toutes mes questions de manière satisfaisante.
- Si je décide plus tard au cours de l'étude de retirer mon consentement, il me sera possible de le faire en tout temps.
- Je consens volontairement à prendre part à cette étude.
- On me remettra un exemplaire signé de ce Formulaire de consentement éclairé à l'intention du participant.

En mettant mes initiales, je suis d'accord avec l'enregistrement audio. ____

Nom du participant

(en caractères d'imprimerie)

Signature du participant

Date

Énoncé du chercheur ou du délégué

J'ai expliqué soigneusement au participant de la recherche la nature de l'étude susmentionnée. Pour autant que je sache, le participant apposant sa signature à ce consentement reconnaît la nature, les exigences, les risques et les avantages que comporte sa participation à l'étude.

Nom du chercheur / délégué

(en caractères d'imprimerie)

Signature

Date

Appendix D

Interview Guide 1

Participant

What is it like to live with congenital heart disease?

Can you talk to me about your daily living habits?

Probe: What are some of the challenges that you encounter in relation to your daily living habits?

Probe: How do you overcome these challenges?

Physical Activity

Can you talk to me about your experiences/history in physical activity?

Probe: What are physical activities that you have enjoyed in the past? What made this activity enjoyable for you? What physical activities have you not enjoyed in the past? What made this activity not enjoyable for you?

Do you feel as though physical activity is good for people?

Probe: Why? What do you think the benefits of physical activity are for people?

Do you feel as though physical activity is good for you?

Probe: Why? What do you think the benefits of physical activity are for you?

What do you hope to achieve from participating in physical activity?

Meaning of Physical Activity

What does physical activity mean to you?

Probe: Why do you associate this meaning to physical activity? What factors have led to you associating this meaning to physical activity?

Probe: What is it that makes physical activity meaningful or non-meaningful to you?

Can you discuss what is going on when you are having a significant experience in physical activity?

Probe: Can you describe a significant experience in physical activity? What activity(ies) are you involved in? What is it about the activity(ies) that makes it significant?

Can you discuss what is going on when you are having a non-significant experience in physical activity?

Probe: Can you describe a non-significant experience in physical activity? What activity(ies) are you involved in? What is it about the activity(ies) that makes it non-significant?

What factors make physical activity personally meaningful to you (e.g., motivation, attitude, challenge)?

Constraints, Facilitators and Strategies

What stops you from participating in physical activity?

Probe: What barriers influence your engagement in physical activity the most and why?

What prevents physical activity from being personally meaningful to you?

What strategies do you use to overcome barriers that prevent you from engaging in physical activity?

What facilitates or allows you to participate in physical activity?

What facilitates or allows you to make physical activity personally meaningful?

Probe: How does the meaning you give to physical activity influence your perception of barriers?

Probe: Do you perceive barriers the same way when a physical activity is meaningful or non-meaningful to you?

Fearless Physical Activity Program

Can you discuss your perception (or knowledge) of the Fearless program?

How would you advertise the Fearless Physical Activity program?

Probe: What would be the most important factors to get people to come to attend this program?

Do you feel as though the Fearless program is good for people with congenital heart disease?

Probe: Why?

Do you feel as though the Fearless program is good for you?

Probe: Why?

Fearless Physical Activity Event

Have you ever taken part in a Fearless event?

Probe: How many?

Can you tell me about your experience at the Fearless event?

Probe: What activities did you enjoy the most and why? What activities did you not enjoy and why?

What is it about the activity(ies) in the Fearless program that make you want to or not want to stay engaged in physical activity?

What barriers influenced your ability to participate in a Fearless event?

Probe: What barriers influence your ability to participate in a Fearless event the most and why?

What prevented activities from being personally meaningful to you at the Fearless event?

What strategies did you use to overcome barriers that prevented you from participating in a Fearless event?

What facilitated or allowed you to participate in a Fearless event?

What facilitated or allowed you to make activities from the Fearless event personally meaningful?

Probe: How does the meaning you give to those activities influence your perception of barriers?

Guide d'Entrevue 1

Participant

Qu'est-ce que c'est vivre avec la cardiopathie congénitale?

Probe: Quels sont les défis que vous rencontrez?

Pouvez-vous me parler de vos habitudes de vie quotidienne?

Probe: Quels sont les obstacles que vous rencontrez par rapport à votre habitude de vie?

Activité physique

Pouvez-vous me parler de vos expériences/histoires en activité physiques?

Probe: Quelles sont les activités physiques que vous avez aimées dans le passé? Qu'est-ce qui a fait que vous avez aimé cette activité? Quelles sont les activités physiques que vous n'avez pas aimées dans le passé? Qu'est-ce qui a fait que vous n'avez pas aimé cette activité?

Croyez-vous que l'activité physique soit importante pour le monde?

Probe : Pourquoi? Quels sont les bienfaits de l'activité physique pour le monde?

Croyez-vous que l'activité physique soit importante pour vous?

Probe : Pourquoi? Quels sont les bienfaits de l'activité physique pour vous?

Qu'espérez-vous réaliser en participant à l'activité physique?

Signification de l'Activité physique

Qu'est-ce que l'activité physique signifie pour vous?

Probe: Pourquoi associer cette signification à l'activité physique? Quels sont les facteurs qui vous ont amené à associer cette signification à l'activité physique?

Probe: Qu'est-ce qui rend l'activité physique significative ou non significative pour vous?

Pouvez-vous discuter de ce qui se passe lorsque vous avez une expérience significative dans l'activité physique?

Probe: Pouvez-vous me décrire une expérience significative? Dans quelle(s) activité(s) participez-vous? Qu'en est-il des activités qui la rendent significative?

Pouvez-vous discuter de ce qui se passe lorsque vous avez une expérience non significative dans l'activité physique?

Probe: Pouvez-vous me décrire une expérience non significative? Que voyez-vous? Dans quelle(s) activité(s) participez-vous? Qu'en est-il des activités qui la rendent non-significative? Comment vous sentez-vous? Que font les autres (s'il y en a d'autres)? Quels événements ont eu lieu?

Quels facteurs la signification que vous donnez à l'activité physique influence-t-elle personnellement (par exemple, motivation, attitude, adhésion)?

Contraintes, Facilitation et Stratégies

Quelles sont les barrières qui vous empêchent de participer à l'activité physique?

Probe: Quels sont les obstacles qui influencent le plus sur votre participation dans l'activité physique et pourquoi?

Qu'est-ce qui empêche l'activité physique d'être significatif pour vous?

Quelles stratégies utilisez-vous pour surmonter les obstacles qui vous empêchent de participer dans l'activité physique?

Qu'est-ce qui facilite ou vous permet de participer à l'activité physique?

Qu'est-ce qui facilite ou vous permet de rendre l'activité physique significative?

Probe: Comment la signification que vous donnez à l'activité physique influence-t-elle votre perception des obstacles?

Probe: Percevez-vous les barrières de la même façon lorsqu'une activité physique est significative ou non significative pour vous?

Programme de Fearless Physical Activity

Pouvez-vous discuter de votre perception (ou connaissance) du programme Fearless?

Comment feriez-vous la promotion du programme de Fearless Physical Activity ?

Probe: Quels seraient les facteurs les plus importants pour amener les gens à venir assister à ce programme?

Vous sentez-vous comme si le programme Fearless est bon pour les personnes atteintes de cardiopathie congénitale?

Probe: Pourquoi?

Avez-vous l'impression que le programme Fearless est bon pour vous?

Probe: Pourquoi?

Évènement Fearless Physical Activity

Avez-vous déjà participé à un événement Fearless?

Probe: Combien?

Pouvez-vous me parler de votre expérience à l'évènement Fearless?

Probe: Quelles activités avez-vous aimées le plus et pourquoi? Quelles activités n'avez-vous pas aimées et pourquoi?

Quelle(s) l'activité(s) dans le programme Fearless qui vous donne envie ou non de rester engagé dans l'activité physique?

Quelles barrières ont influencé votre capacité à participer à un événement Fearless?

Probe: Quelles barrières ont influencé votre capacité à participer à un événement Fearless le plus et pourquoi?

Qu'est-ce qui a empêché les activités à l'événement Fearless d'être significatives pour vous?

Quelles stratégies avez-vous utilisées pour surmonter les obstacles qui vous ont empêché de participer à un événement Fearless?

Qu'est-ce qui vous a facilité ou permis de participer à un événement Fearless?

Qu'est-ce qui vous a facilité ou permis de rendre les activités de l'événement Fearless significatives?

Probe: Comment la signification que vous donnez-vous à ces activités influence-t-elle votre perception des obstacles?

Appendix E

Interview Guide 2 and 3

Participant

What is it like to live with congenital heart disease?

Can you talk to me about your daily living habits?

Probe: What are some of the challenges that you encounter in relation to your daily living habits?

Probe: How do you overcome these challenges?

Physical Activity

Can you talk to me about your current physical activity?

Probe: What are physical activities that you have enjoyed? What made this activity enjoyable for you? What physical activities have you not enjoyed? What made this activity not enjoyable for you?

Do you feel as though physical activity is good for people?

Probe: Why? What do you think the benefits of physical activity are for people?

Do you feel as though physical activity is good for you?

Probe: Why? What do you think the benefits of physical activity are for you?

What do you hope to achieve from participating in physical activity?

Meaning of Physical Activity

What does physical activity mean to you now?

Probe: Why do you associate this meaning to physical activity? What factors have led to you associating this meaning to physical activity?

Probe: What is it that makes physical activity meaningful or non-meaningful to you?

Can you discuss what is going on when you are having a significant experience in physical activity?

Probe: Can you describe a significant experience in physical activity? What activity(ies) are you involved in? What is it about the activity(ies) that makes it significant?

Can you discuss what is going on when you are having a non-significant experience in physical activity?

Probe: Can you describe a non-significant experience in physical activity? What activity(ies) are you involved in? What is it about the activity(ies) that makes it non-significant?

What factors make physical activity personally meaningful to you (e.g., motivation, attitude, challenge)?

Constraints, Facilitators and Strategies

What stops you from participating in physical activity now?

Probe: What barriers influence your engagement in physical activity the most and why?

What prevents physical activity from being personally meaningful to you?

What strategies do you use to overcome barriers that prevent you from engaging in physical activity?

What facilitates or allows you to participate in physical activity now?

What facilitates or allows you to make physical activity personally meaningful?

Probe: How does the meaning you give to physical activity influence your perception of barriers?

Probe: Do you perceive barriers the same way when a physical activity is meaningful or non-meaningful to you?

Fearless Physical Activity Program

Can you discuss your perception (or knowledge) of the Fearless program?

How would you advertise the Fearless Physical Activity program?

Probe: What would be the most important factors to get people to come to attend this program?

Do you feel as though the Fearless program is good for people with congenital heart disease?

Probe: Why?

Do you feel as though the Fearless program is good for you?

Probe: Why?

Fearless Physical Activity Event

Have you ever taken part in a Fearless event?

Probe: How many?

Can you tell me about your experience at the Fearless event?

Probe: What activities did you enjoy the most and why? What activities did you not enjoy and why?

What is it about the activity(ies) in the Fearless program that make you want to or not want to stay engaged in physical activity?

What barriers influenced your ability to participate in a Fearless event?

Probe: What barriers influence your ability to participate in a Fearless event the most and why?

What prevented activities from being personally meaningful to you at the Fearless event?

What strategies did you use to overcome barriers that prevented you from participating in a Fearless event?

What facilitated or allowed you to participate in a Fearless event?

What facilitated or allowed you to make activities from the Fearless event personally meaningful?

Probe: How does the meaning you give to those activities influence your perception of barriers?

Added

What do you see in your future down the road in terms of physical activity? Do you think that is realistic? Will it be possible to achieve this?

Do you think you are active enough?

What are the risks of being active as someone with CHD?

What do you gain (life skills) from being involved in this physical activity/program?

What is the role of physical activity in your life?

No longer asked during third interview

What can you tell me about physical activity events/programs for people with CHD?

What are your thoughts about engaging in this type of thing?

Physical activity guidelines

Taken together then since you are doing less quantifiable activities do you think you are active enough? What do you think about these guidelines?

Individualized questions

Last time you mentioned you were going to register for X program, how did that go?

Third interview

Go over stages with participants and what stage they felt they were in and why after each interview.

Pre-contemplation: No intention on changing, not considering to change their physical activity behaviour within the next six months

Contemplation: Intend to make a change to their physical activity behaviour within the next six months, weigh the pros and cons

Preparation: Intend to change their physical activity behaviour within the next month, small actions of change where individuals will experiment with the behaviour

Action: made significant changes to their physical activity behaviour in the last six months

Maintenance: Continue physical activity behaviour that they adopted over an extended period of time, example 6 months+

*Go over findings with participants.