

Looking at the Physical and Psychosocial Outcomes after Participation in a Community Physical Activity
Program among Children with Congenital Heart Disease

Angelica Blais

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School of Human Kinetics
Faculty of Health Sciences
University of Ottawa

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Legend

ASD = atrial septal defect
ADHD = attention deficit hyperactivity disorder
AVSD = atrioventricular septal defect
AV-VA = atrioventricular-ventriculoarterial
BMI = body mass index
B-T Shunt = Blalock-Tausig Shunt
CAMSA = Canadian Agility and Motor Skill Assessment
CAPL = Canadian Assessment of Physical Literacy
CCTGA = congenitally corrected transposition of the greater arteries
CHEO = Children's Hospital of Eastern Ontario
CHD = congenital heart disease
CoA = coarctation of the aorta
CSAPPA = Children's Self-Perceptions of Adequacy and Predilection for Physical Activity
DORV = double outlet right ventricle
DTGA = dextro-transposition of the greater arteries
HRQoL = health-related quality of life
IAA = interrupted aortic arch
MVPA = moderate to vigorous physical activity
PA = physical activity
PAr = pulmonary artery
PACER = Progressive Aerobic Cardiovascular Endurance Run
PAPVR = partial anomalous pulmonary venous return
PS = pulmonary stenosis
QoL = quality of life
RV = right ventricle
SCT = social cognitive theory
ToF = Tetralogy of Fallot
TGA = transposition of the greater arteries
TV = tricuspid valve
VSD = ventricular septal defect

Abstract

Background: Children with congenital heart disease (CHD) often face barriers unique to their diagnoses, making participation in community physical activity programs difficult. This pilot, feasibility study evaluated the appropriateness (i.e. feasibility and enjoyment) of the *Sportball* program among a group of children with CHD. This study also sought to observe any changes in physical literacy outcomes and to explore physical activity perceptions of participants, in order to better inform the future use of community-based interventions for this population.

Methods: This study employed a mixed-methods evaluation of a 10-week community-based intervention. Data from two focus groups (baseline and post-intervention) and field notes after each intervention session were collected. Physical literacy outcomes were determined using the Canadian Assessment of Physical Literacy.

Results: Participants with CHD ($n=9$) successfully participated in *Sportball*, as demonstrated by the ability of all participants to complete program activities, participants' overall enjoyment of the program and fair attendance (approximately 80% of intervention sessions). Improvements in motor skill and torso strength were observed, with a statistically significant difference ($p < 0.01$) in motor skill classification. Participation in *Sportball* facilitated positive social interactions during sport and was influenced by personal, social and environmental factors.

Conclusion: Overall, participation in *Sportball* is appropriate for children with CHD who may have motor development delays and/or activity restrictions.

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Preface

Without the help and support of numerous colleagues and peers, this project would not have been realized. I would first like to extend my immense gratitude to my supervisor, Dr. Patricia Longmuir. Thank you for allowing me to pursue this opportunity and for pushing me to bring out my creativity throughout this experience. I'm especially grateful for your patience during countless meetings and long conversations, as we worked through the many pieces of this puzzle. As well, to my co-supervisor Dr. Kristi Adamo: thank you for your valuable feedback, words of encouragement and overall support. I would not have come this far without either of you. To my committee members: Dr. Michelle Fortier and Dr. Judy King, thank you for taking the time and dedication to review this project; your expertise and perspectives have greatly contributed to this work.

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Introduction

Background

Due to recent and ongoing advancements in medical treatment and technology, the number of children living with complex diagnoses of congenital heart disease (CHD) who survive into adulthood is greater than ever before. As almost 90% of children born with heart defects survive into adulthood¹, the literature has shifted accordingly to examine which approaches are best suited to maintain the long-term physiological and psychosocial health of these individuals. Previous research indicates low levels of self-reported health-related quality of life (HRQoL)^{2,3}, as well as an overall decrease in self-esteem, mood, and behavioural issues^{2,4} among individuals with CHD. From a physiological perspective, individuals with CHD are at a greater risk than otherwise healthy peers for developing atherosclerotic disease and obesity as they approach adulthood⁵⁻⁸. It is hypothesized that factors such as activity restrictions and motor skill deficits may contribute to relatively inactive lifestyles, which increases the risk and prevalence of co-morbidities associated with a sedentary lifestyle⁹.

Unfortunately, a stigma is often placed upon children with CHD, where many believe an adverse cardiac event is more likely to occur while participating in physical activity (PA). There are only a few diagnoses or sequelae which warrant strict restrictions from PA, including ventricular arrhythmias or moderate aortic stenosis or dilation⁹. From a patient's perspective, warranted restrictions may create an adverse psychological barrier for children with CHD, potentially leading them to self-impose further restrictions and discouraging an active lifestyle^{7,10}. In an attempt to prevent "stress" placed on the heart by avoiding PA, individuals with CHD may inadvertently be placing greater pressure on their cardiovascular system as a result of a largely sedentary lifestyle.

Specific guidelines for exercise training and recreational sport exist for children with CHD, including descriptions of appropriate activity intensities by cardiac diagnoses and possible sequelae^{9,11}. The use of the terms “physical activity” and “exercise” are often synonymous; both can be defined as any type of bodily movement¹². However, the distinction between these terms in the context of clinical recommendations is important, given their principled differences: PA is often less structured, repetitive, and goal-oriented than exercise training, making it more feasible and enjoyable for most people¹². Recreational sport then borders along the distinction between exercise and PA, as an activity where the primary goal of enjoyment and participation is accompanied by structure and repetition¹³. Given the paucity of supporting evidence, many healthcare providers are hesitant to offer recommendations for recreational sport or PA, despite the risk of acquiring co-morbidities as a result of prolonged sedentary behaviour far outweighing that of an adverse cardiac event associated with casual play or PA^{9,11,14}.

Most activity interventions evaluated among children with CHD focus on exercise training, instead of recreational or habitual PA, and are typically situated within clinical contexts (i.e. cardiac rehabilitation centres). Although they do have a positive impact on overall health outcomes¹⁵, such interventions are not likely to encourage individuals with CHD to adopt an active lifestyle. No studies to date have looked at outcomes of a community-based PA program for children with CHD within the multi-faceted perspective of physical literacy. Given the knowledge on health benefits of recreational activity programs in healthy populations^{16,17}, it is worth exploring the potential outcomes of similar programs among children with CHD. Therefore, a gap currently exists in the body of research, where the overall appropriateness (i.e. safety, enjoyment, feasibility) of recreational, community-based activity programs for children with CHD is unknown. Clinicians should be aware of the potential benefits these programs have,

as they may give children with CHD the right skills, knowledge and encouragement to remain physically active for life. Finally, to generate positive, long-term physiological and psychological health outcomes, facilitators of community-based PA and sport among this population should be identified.

Study Objectives and Hypotheses

This pilot, feasibility study sought to evaluate the overall appropriateness of a popular, community-based recreational activity program among children with moderate to complex diagnoses of CHD. Appropriateness of the intervention was evaluated by two main factors: feasibility and enjoyment. Participation in the intervention was hypothesized to be feasible for children with CHD, as determined by their ability to regularly attend and safely participate in the full intervention. It was also expected that participants would demonstrate and communicate positive feelings towards the program and be willingly engaged in the intervention activities, indicating their enjoyment of the intervention.

As a secondary objective, the potential impact of the intervention on physical literacy outcomes was evaluated among participants with CHD. It was hypothesized that changes in individual physical literacy domains (physical competence, motivation and confidence, daily activity behaviour) would be observed between baseline and post-intervention. With regards to overall physical competence, it was expected that participants' scores would improve on measures of musculoskeletal fitness and motor skill, but not cardiorespiratory endurance. Daily time spent in moderate-to-vigorous physical activity (MVPA) was also hypothesized to improve after completion of the intervention. Finally, the hypothesis that self-reported motivation and

confidence towards engaging in PA would improve after participation in the intervention was evaluated.

To our knowledge, the current study is the first to evaluate a community-based activity intervention among children with CHD. Thus, it is important to understand any facilitators and barriers informing participants' overall participation in the intervention. A final, tertiary objective of this study was therefore to explore the influences and perceptions of PA experienced by school-aged children with CHD who participated in the intervention. Bandura's social cognitive theory¹⁸ was used as a framework to identify and explain any environmental, personal and behavioural influences towards PA participation which presented themselves in the data.

Chapter 1: Review of the Literature

1.1) Physical Literacy

Physical literacy is a multi-faceted concept involving multiple components of engaging in a physically active lifestyle. Physical literacy, agreed upon by the International Physical Literacy Association, is defined as “the motivation, confidence, physical competence, knowledge and understanding to value and take responsibility for engagement in physical activities for life”¹⁹. The model for physical literacy, based on consensus agreement, suggests that an individual’s overall engagement in PA is dependent on both physiological (motor skill, muscular endurance, etc.) and cognitive (motivation, knowledge, etc.) components^{19,20}. Physical literacy is often present in community sport, which aims to systematically develop physical skills and competence so that children are able to move efficiently, safely and effectively, while understanding how their engagement in PA is related to healthy living²¹. Physical literacy is a fluid concept, where its components can change over time and are dependent on a variety of circumstances, such as changes in health and/or environment²². Therefore, it is important that children are continuously engaged in the different components of their physical literacy journey. It is expected that individuals who are physically literate (i.e. display high levels of physical competence, motivation, etc.) are more likely to continue to engage in PA throughout adulthood, as they are equipped with the components that encourage and contribute to a lifetime of PA²².

A largely sedentary lifestyle has been observed among individuals with CHD^{23,24}, potentially supporting the hypothesis that children with CHD have lower levels of physical literacy than their healthy peers⁹. This hypothesis stems from known motor skill and developmental delays that are prevalent in children with CHD²⁵⁻²⁷, as well as varying

physiological and cognitive factors which influence the inactive lifestyles observed among this population^{9,28}. A small pilot study that assessed the physical literacy of children with CHD identified decreased motor skill and muscular endurance when compared to healthy, age-matched peers²⁷. These pilot results suggest that, in order to encourage the adoption of healthy PA behaviours, interventions for children with CHD should focus on improving components of physical literacy, specifically motor skill, muscular endurance, and daily PA behaviour²⁹.

1.2) Motor Skill Development

It is well-established that children with CHD may experience significant motor development delays when compared to their healthy age-matched peers^{25,30–32}. One study by Bjarnason-Wehrens et al. looked at the development of gross motor coordination across a broad range of congenital heart diagnoses, from mild to severe³³. They found that 26.8% and 31.9% of CHD participants showed moderate and severe motor deficits respectively, compared to only 16.5% and 5.5% of healthy controls³³. Holm and colleagues³⁴, using the Movement Assessment Battery for Children, found that children with complex diagnoses of CHD were more likely than healthy age-matched peers to show deficits in overall motor competence. Many of these children were diagnosed with conditions such as Tetralogy of Fallot (ToF) or transposition of the great arteries (TGA) at birth, which severely affect blood flow and require complex corrective surgeries in the first year of life. Children with CHD who undergo complex surgeries earlier in life typically require cardiopulmonary bypass during surgery, have a lower overall cardiac output and experience hypoxemia for brief or prolonged periods of time, which could impact their early cognitive and motor development³⁴. The authors concluded that their findings of impaired motor competence may be attributed to a combination of deficits in muscular strength, balance, and fine and gross motor skills³⁴, resulting from delayed motor development. Such complications are

common neurologic sequelae observed among children with complex diagnoses of CHD who require early surgical intervention.

To gain an understanding of known neurologic sequelae over time, one systematic review conducted by Snookes and colleagues looked at longitudinal studies that have evaluated developmental outcomes in children with CHD²⁶. The twenty-five studies that were found showed consistent delays in standardized assessments of cognitive and motor outcomes in CHD patients who underwent complex cardiac surgery during infancy²⁶. Researchers at the Children's Hospital of Boston examined the development of neurological characteristics, including fine motor skills and visuo-motor tracking, among school-aged children who were born with dextro-transposition of the greater arteries (DTGA)³⁵. This study was part of a larger series on the neurodevelopmental outcomes of children born with DTGA, a particular type of structural heart disease typically treated by completion of the arterial switch operation during infancy. The importance of this longitudinal study was that it provided detailed information surrounding the long-term neurodevelopmental effects of a procedure that was thought to “normalize” the heart structure and function. Children who have undergone surgery for DTGA typically have minimal longstanding consequences; exercise restrictions are minimal to none (i.e., can participate in all types of competitive sport if there are no residual lesions) and risk of re-hospitalization for a serious cardiac event is rare³⁶. However, surgical intervention for DTGA typically requires some type of cardiopulmonary bypass, briefly altering the patient's cardiopulmonary circulation and potentially affecting central nervous system function. It was found that more practical implications could be drawn from deficits observed at the preschool age among this population, including difficulties with visual-motor and visual-spatial tasks³⁷. At 8 years old, there was a continued impairment observed in visual-spatial skills as well as fine motor function among the

same group of children³⁵. Finally, at 16 years of age, reassessment of visual-spatial skills showed significantly lower results than population-based normative values³⁸. Based on these longitudinal results, it became clear that continued care of CHD patients should include targeting interventions to improve neuro-motor sequelae, as these could have an impact on long-term psychological, physiological and behavioural outcomes³⁹.

1.3) Daily Physical Activity Behaviour

Many patients who have moderate or severe diagnoses of CHD may require restrictions on activity intensity^{5,9}, which are discussed in detail in the following section. However, such circumstances do not mean that children with CHD should be discouraged from engaging in a physically active lifestyle. In fact, there is strong support for the promotion of PA at every clinical encounter⁹. Although current evidence supports the importance of daily PA, there is conflicting literature with regards to observed PA behaviours of children and youth with CHD.

It has been reported that 15% of children living with CHD engage in approximately 30 minutes of daily (>3 times per week) PA after school hours⁵, which is still only half of the recommended dose for children. These findings along with other studies have found that children with CHD, regardless of diagnosis, are not meeting current physical activity guidelines of 60 minutes of MVPA per day⁴⁰⁻⁴³, as determined by objective measurements (i.e. accelerometer). It has also been found that individuals CHD spend less time participating in MVPA than age-matched healthy peers^{24,44,45}. In contrast, it has also been suggested that any lack of observed or reported differences in activity level are due to the high prevalence of sedentary behaviour in the general pediatric population⁴⁶. For example, adolescents in a study by Falk and associates with mild to moderate diagnoses of CHD (e.g., atrioventricular defects, isolated valve defects) reported similar activity levels to age-matched healthy controls⁴⁷. However, 27.3% of

participants in this study believed a lower exercise intensity was appropriate for their diagnosis, compared to what was actually recommended by their responsible cardiologist⁴⁷. Regardless of whether their activity levels are similar to, or different from healthy peers, children and youth with CHD are consistently below the recommended amount of daily activity for optimal health outcomes⁴⁸.

Self-efficacy, defined as an individual's belief that he or she is able to adequately perform a task or behaviour⁴⁹, is an important predictor of PA behaviour among children⁵⁰ and adolescents⁵¹. Studies looking at self-reported PA among children and adolescents with CHD have reported a positive association with self-efficacy^{52,53}. Falk and colleagues⁴⁷ also evaluated the relationship between perception of disease severity and PA behaviour among young individuals with CHD. Those who believed their condition was trivial or mild reported higher amounts of daily activity⁴⁷, indicating a potential relationship between perceived medical status and perceived ability to be physically active²⁴.

1.4) Recommendations and Guidelines

Currently there are few evidence-based guidelines which provide PA recommendations and guidelines to clinicians to assist them in counseling their paediatric patients with CHD. Only 13% of published recommendations are evidence-based⁵⁴. An overwhelming 45% of current publications are reviews or opinion pieces, while the remaining 42% are consensus or position statements by an expert panel or recognized organization⁵⁴. The first series of published guidelines determined by expert consensus for young individuals with CHD are the highly referenced Bethesda Guidelines^{55,56}, which apply specifically to young individuals with heart disease who are engaged in highly competitive sport (high school or college level) requiring high intensity training. Although these guidelines are based on participation in competitive sport

exclusively, they are commonly cited and often referenced by healthcare providers who provide activity recommendations to patients with CHD⁵⁷. One study by Roston and colleagues⁵⁷ surveyed Canadian cardiac clinicians and found that respondents were either under- or over-restricting patients with various types of CHD. To address this gap, Takken and colleagues¹¹ published comprehensive recommendations for recreational sport, PA, and exercise training in children and adolescents with CHD. For quick reference, the authors included a table summarizing various types of PA recommendations for 17 common congenital heart defects. In the discussion portion of the document, considerations are given for each defect listed, and recommendations for clinical practice are described. In general, it is recommended that a child with CHD engage in approximately 60 minutes of MVPA every day, given that it is enjoyable and developmentally appropriate¹¹. Factors to consider when prescribing individualized PA or exercise to children and adolescents with CHD include: type of PA (static/dynamic components), potential for body contact/collision, level of competition, medications, surgical history and exercise capacity^{9,57}.

The risk of sudden cardiac death during physical activity is rare among children with any severity of CHD⁵⁸. However, the individual's pathophysiology and any sequelae associated with their condition will inform which types of PA are appropriate to prevent adverse activity-related events. For example, children who received the Fontan procedure are often prescribed antithrombotic medication (i.e., Coumadin or aspirin), which increases their risk of haemorrhage upon bodily impact; thus, restrictions from sports where there is regular bodily impact (i.e. football, ice hockey) are often necessary⁹. Restrictions are also often given to patients who acquire residual sequelae following cardiac surgery, such as ventricular dysfunction or arrhythmias⁵⁹. It is important that these patients are able to pace themselves and take breaks

when necessary, in order to prevent deterioration of cardiac function during high-intensity activity⁵⁹. Furthermore, patients who have implanted pacemakers are often restricted from contact sports, in order to prevent a hard impact from possibly causing device malfunction⁹. Extensive activity restrictions are sometimes required for the few individuals with CHD who have more severe cardiovascular sequelae, such as arterial hypertension⁶⁰ or dysfunction of the coronary arteries⁶¹, where high-intensity aerobic or static activities could result in a serious, adverse cardiac event^{11,56}.

In addition to the aforementioned guidelines and recommendations, the promotion of PA to children with CHD is essential to improve daily activity behaviour and subsequently decrease the prevalence of obesity and other physical and psychological morbidities associated with a sedentary lifestyle. The most recent publication offering appropriate guidelines for PA in children with CHD is written by Longmuir and colleagues⁹, from the perspective of PA promotion through counselling. Previous recommendations had not addressed the importance of PA promotion in this population, which is effectively discussed by the authors. As well, important clinical considerations are given regarding appropriate activity types and intensities for individuals with CHD with pathophysiological complications or considerations. As an example, those with aortic dilation are at a higher risk of dissection, meaning that activities involving sudden or progressive increases in blood pressure should be avoided. Given the risk and regardless of the type of activity, it is recommended these individuals be encouraged to limit activity to a moderate intensity⁹. Overall, the work by Longmuir and colleagues⁹ is an important contribution to PA research for children with CHD from a promotional perspective. Preliminary evidence has shown higher levels of adiposity among children with CHD who were told to limit their activity compared to those who were not⁸. Therefore, by providing counselling

recommendations when such restrictions are required, caregivers can focus on what *can* be done by children with CHD, rather than on restricted activities. As well, the authors recommended various counselling techniques to use when promoting PA and when specific activity restrictions are required for individuals with CHD, such as those with ventricular dysfunctions or hypoxia⁹. Examples of counselling techniques include assessing the individual's desire for change, avoiding general statements (i.e., "no competitive sports"), and inquiring about their own PA experiences and concerns⁹.

1.5) Physiological and Psychosocial Outcomes Addressed by Exercise and Physical Activity

The potential physiological and psychosocial benefits for children living with CHD who participate in exercise and PA are well known⁶²⁻⁶⁴. Knowledge of these outcomes can inform the design and promotion of exercise and PA interventions and/or recommendations for children with CHD. From a future health perspective, the prevention of obesity and acquired cardiovascular disease among individuals with CHD is crucial⁶⁵. The physiological burden of co-morbid obesity increases the risk of early, acquired cardiovascular disease among individuals with CHD⁶⁶. When looking at risk factors for acquired metabolic disease among this population, it is important to consider that children with complex diagnoses of CHD will have had extensive palliative and corrective surgery in infancy, resulting in a re-structured circulation (i.e. Fontan procedure, arterial switch). Thus, the cardiovascular pathophysiology of children with complex CHD may limit the exercise capacity and PA levels of this group⁶⁷⁻⁷⁰.

When the initial focus is on improving physiological fitness, exercise interventions facilitated by cardiac rehabilitation programs can be highly effective^{63,71}. Previous research has shown significant improvements in maximal oxygen uptake^{63,72}, which is an important physiological factor contributing to the lifelong well-being of individuals with CHD. A

systematic review by Duppen and colleagues⁶³ looked at the physiological effects of exercise training programs in children and adolescents with CHD. The review identified 31 articles examining both positive and negative outcomes of exercise training delivered either as home-based or supervised training. The average exercise frequency among the programs was 3 sessions per week over a period of 12 weeks, and the average duration per session was approximately 30-60 minutes⁶³. Main outcome measures evaluated were: peak oxygen uptake measured by cardiopulmonary tests (indirect calorimetry), changes in daily activity level and muscular strength⁶³. Of those included, 23 studies (74%) found significant positive changes in main outcome measures, and none found negative effects. Additionally, the systematic review by Duppen et al.⁶³ only found 4 out of 31 studies which detailed the long-term effects of exercise training programs, with 3 out of those 4 reporting sustained improvements in exercise capacity. Maintenance of physical fitness is especially beneficial for the overall well-being of individuals with CHD as they live through adulthood^{65,66}, as it enables them to sustain their cardiac health and continue through activities of daily living with ease. This can reflect directly upon engagement in PA, since maintaining physical capabilities can allow individuals with CHD to pursue more opportunities to be physically active. With supporting evidence from the review, Duppen and colleagues recommend that all patients with CHD should be given exercise prescriptions as part of their regular care⁶³ in order to gain the health benefits associated with improvements in cardiopulmonary function and an active lifestyle.

In addition to physiological benefits, there are potential psychosocial outcomes that individuals with CHD may benefit from while participating in exercise and PA. Based on data collected using a self-report questionnaire⁷³, Varni and colleagues found that psychosocial and physical function quality of life (QoL) were significantly lower among children with cardiac

conditions when compared to otherwise healthy children⁷³. However, one study found that higher psychosocial and physical QoL was present among adolescents with CHD who participated in a wide range of sports (e.g., swimming, dance, volleyball, soccer, etc.) when compared to those who did not⁷⁴. Another recent assessment of a home-based PA intervention provided to children with Fontan circulation (i.e. single-ventricle circulation) found significant improvements in parent-proxy reported physical and psychosocial QoL from baseline, although there were no significant changes in patient-reported QoL⁷⁵. Consequently, the observed associations between PA and well-being have informed consensus statements on the promotion of PA to children and youth with CHD^{9,11}.

Children with CHD also present a higher risk of developing anxiety disorders and attention-deficit/hyperactivity disorder (ADHD)^{76,77}. There is preliminary evidence suggesting that PA and exercise may improve more specific psychosocial outcomes among individuals with CHD, including decreased anxiety. This is especially important to consider, as children with CHD report higher levels of anxiety and medical fears, including physiological anxiety, fear of having breathing difficulties, and fear of injury or a recurring cardiac event⁷⁸. These fears may be covert, and could contribute to the overall sedentary lifestyles and decreased PA behaviour seen in this group⁷⁸. Interest in the impact of PA on psychosocial health for children with CHD may also be, in part, due to existing evidence which supports its effectiveness in physiologically healthy children⁷⁹. Specifically, there is evidence to support the benefits of aerobic activity for individuals with ADHD⁸⁰, and previous research has suggested potential improvements in symptoms of anxiety after participation in PA^{81,82} and team sports⁸³. Among children with single-ventricle circulation, Muller and colleagues⁸⁴ observed a mild correlation between objectively-measured PA and self-reported mental health outcomes, specifically depression and

anxiety. Although the authors attributed this correlation to the over-protective attitudes of parents and care providers, this relationship has also been seen among otherwise healthy children⁸⁵. Therefore, even among those that have little to no activity restrictions, the importance of PA and exercise for children with CHD should be further emphasized when accounting for psychosocial outcomes as well as physical well-being.

Considering their medical experiences, the interaction between physiological outcomes, psychosocial outcomes and PA behaviour among children with CHD can be complex. Using the existing literature, Dulfer and colleagues⁴ conducted a systematic review to look at the associations between physiological/exercise capacity, PA behaviour, and psychosocial functioning observed among individuals with CHD. The potential relationship between these factors is interesting to researchers as it considers both physiological and psychosocial elements associated with participation in PA. To be included in the review, exercise capacity had to be determined objectively by a bicycle or treadmill cardiopulmonary test, producing measurements of peak oxygen uptake, peak oxygen consumption at the anaerobic threshold, and/or heart rate. PA could be assessed either objectively or subjectively, by an accelerometer or self-reported questionnaire respectively. The third parameter, psychosocial functioning, was fragmented into four different domains: QoL, emotional and behavioural problems, self-efficacy, and depressive symptoms. Only 17 studies were found looking at either exercise capacity and/or PA behaviour, with no clear associations reported with psychosocial functioning⁴. Regardless, given the wide range of ages included in the review, from 5 to 73 years, it would be difficult to generalize any associations found. Another challenge relates to the differences between instruments used within studies, as well as the regular use of parent proxy-reports rather than direct measures, which could have influenced the lack of associations found between parameters. When looking for

studies that included all parameters, Dulfer and colleagues⁴ only found 3 studies with inconsistent findings on the relationship between exercise capacity, PA and psychosocial functioning⁴. The first study by Buys and colleagues found that exercise capacity was associated with self-reported PA as well as physical function relating to QoL⁸⁶, however this study was performed within an older CHD cohort (16-40 years), so the findings do not necessarily apply to children with CHD. Muller and colleagues⁸⁴ found that among children younger than 14 years, who had undergone total cavopulmonary connection (completion of the Fontan circulation), higher exercise capacities were indeed associated with higher objectively measured PA levels and higher self-reported psychosocial functioning. In contrast, McCrindle et al.²⁴ found no significant associations between exercise capacity, PA behaviour, and self-reported functional status among children and adolescents with CHD who had undergone the Fontan procedure. The latter study measured both physical (i.e., general health, activity limitations, symptom discomfort) and psychosocial (i.e. emotional concerns, social life, friendship concerns) function combined using the Congenital Heart Adolescent or Teenage (CHAT) questionnaire. In their review, Dulfer et al. mention why such contradictory findings may have occurred, offering different sample sizes, age ranges, and the use of different PA assessment tools (i.e. tri-axial vs. uni-axial accelerometers) as possible explanations⁴. Overall, the findings in the systematic review by Dulfer and colleagues⁴ demonstrate the relevance and importance of PA participation on the physiological and potentially psychosocial well-being of individuals with CHD.

1.6) Current Interventions Addressing Physical Literacy Outcomes of Children with CHD

There are only two types of PA or exercise programs described in the current literature targeting children with CHD; rehabilitation programs^{15,63,87-89} and more recently, specialized cardiac summer camps⁹⁰⁻⁹³. Based on reported outcomes, these interventions theoretically have

the potential to improve individual physical literacy outcomes such as physical competence (i.e., exercise capacity, motor skill) and daily PA behaviour, as well as psychosocial outcomes related to motivation and confidence for PA (i.e. self-efficacy, QoL, PA knowledge). Findings from a recent review of pediatric cardiac rehabilitation programs were described in the previous section, indicating that paediatric cardiac rehabilitation programs result in acute physiological benefits for children with CHD⁶³. However, research on the psychosocial effects of pediatric cardiac rehabilitation is limited by lack of determined outcome parameters and variability in response; some studies show a positive association between psychosocial function and participation in cardiac rehabilitation^{44,94,95} while others have found no change in outcome measures^{75,96}. Rehabilitation programs may also have the potential to significantly improve the motor skills of children with CHD, as observed by a few intervention studies^{97,98}. Muller and colleagues⁹⁷ evaluated a simple motor training task among preschool children with CHD. Once a week, for a total of 12 one-hour sessions, the authors administered a series of obstacle courses for participants to complete either individually or as a group, with an aim to improve motor competence. A pre- and post-assessment of various motor skills (i.e., agility, coordination, balance) showed that there was a significant improvement in the group of participants that scored below the expected motor quotient reference value at baseline⁹⁷.

Fitness-based cardiac rehabilitation programs may also not be feasible for pediatric populations to maintain, as children are less likely to find the repetition and structure of exercise training enjoyable. Therefore an intervention focusing on PA behaviour and play-based activities among children with CHD, rather than exercise training, could produce more sustainable effects in addition to those already seen in current cardiac rehabilitation programs. One study, currently in progress by Zwinkels and colleagues⁹⁹, plans to assess whether or not an after-school PA

intervention can sustain the effects of exercise training in adolescents with a chronic disease or physical disability, including CHD. Another recent randomized trial by Longmuir and colleagues⁹⁸ looked at various outcomes of a home-based rehabilitation program for preadolescent children (6 to 12 years old). Interventions were individualized to meet any activity restrictions placed by cardiologists, and prescribed activities were explicitly “play-based”, incorporating both static and dynamic movements (e.g., Frisbee golf, beach volleyball). A significant (49%) improvement in gross motor skill was observed from the 2-year study, which was positively associated with MVPA⁹⁸. One of the ways in which this particular study was unique was that it prescribed play-based PA for pediatric cardiac rehabilitation (as opposed to traditional, fitness-centric exercises) and monitored the effect on gross motor skill outcomes. However, maintenance of a home-based rehabilitation program, such as the one implemented by Longmuir and colleagues, may not be feasible for children with CHD who do not regularly receive individualized physical activity counselling.

Studies to date have focused predominantly on individualized cardiac rehabilitation programs, either in-clinic^{94,100,101} or home-based^{75,98}, which may not always be enjoyable for participants with CHD and their families. Furthermore, few studies have looked at group-based interventions outside of rehabilitation or home settings. Moons and colleagues⁹⁰ completed the first formal evaluation of the benefits associated with attending a specialized sports camp for children with CHD. Since the camp was only three days long, no significant, objective, physiological findings were expected. Instead, the authors opted to focus on subjective components of PA and perceived general health in children with CHD after attending the camp. They found significant improvements in perceived physical and psychosocial function, as well as general behaviour from before camp to after its completion⁹⁰. Similarly, Simons and colleagues⁹¹

looked at various psychosocial changes that occurred among 29 children with CHD who were enrolled in a five day camp. Using the Revised Children's Manifest Anxiety Scale, they observed that self-reported measures of general anxiety in participants decreased significantly from the first to the last day of camp. Another study found that after children participated in a cardiac camp, parents discussed being less restrictive and protective of their child's physical capabilities¹⁰². These camps were not sports-specific, in contrast to the intervention used by Moons et al., but they did include numerous recreational activities such as swimming, archery, dancing, and horse-back riding. One other recent study by Bultas, Budhathoki, and Balakas⁹² found positive gains in measures of self-esteem in children with CHD who attended camp, as well as improvements in self-perceived physical, emotional, and social functioning. Most of the aforementioned studies used close-ended questionnaires to evaluate outcomes of the cardiac camps, thus limiting any qualitative information available to inform the overall success of each program from the participants' perspective or their likelihood to enroll in a similar program in the future⁹². Such information would be useful for cardiac clinicians who wish to recommend similar programs to their patients. Nonetheless, collectively these studies show the potential psychosocial effects of group-based interventions specific to children with CHD.

Historically, interventions such as cardiac rehabilitation programs and camps have been exclusive to children with cardiac conditions. Unfortunately, such interventions are not widely accessible or feasible for many families. To date, there is no known information about children with CHD who participate in community-based PA programs. The current study aimed to address this gap by evaluating the appropriateness and potential benefit of a widely available, non-competitive PA program (*Sportball*) among a group of children with CHD. Furthermore, this study investigates contributing factors which may influence future participation in the

Sportball program, based on the personal experiences of children living with complex diagnoses of CHD. This pilot, feasibility study contributes to existing literature on the promotion and prescription of PA to pediatric cardiology patients, by evaluating participation in a community-based PA program among a group of children with CHD.

Chapter 2: Methods

2.1) Study Design & Intervention

This pilot, feasibility study employed a mixed-methods approach to evaluate a weekly, community-based PA intervention among children with CHD. Physical and psychological factors that relate to both sport and disease are complex, therefore collecting both qualitative and quantitative information for this study allowed for a more comprehensive evaluation of the intervention. The primary objective of appropriateness was evaluated using combined qualitative and quantitative measures. The secondary objective evaluating physical literacy outcomes was determined quantitatively, with additional qualitative data informing participants' perceptions of these outcomes. The final, tertiary objective was also explored qualitatively. This study was approved by the Research Ethics Boards of the Children's Hospital of Eastern Ontario (CHEO) and the University of Ottawa, in Ottawa, Canada.

Eligible participants (described in section 2.2) met with the researcher once per week over a period of 12 weeks; baseline and post-test assessments took place on weeks 1 and 12 respectively, and the remaining 10 weeks consisted of a 1-hour group intervention at a community facility. Both the assessment and intervention sessions were facilitated by the researcher. During the study period, a group of graduate students assisted the researcher with delivering the assessments. Experienced employees (i.e. minimum 1 year of coaching) for *Sportball* also provided additional support for the intervention (i.e., lesson planning and program delivery). For the purpose of this study, the chosen intervention was exclusive to participants with CHD, although siblings were allowed to participate if they were within the required age range (7 – 10 years). Each intervention session followed a pre-determined lesson plan: a 10-

minute warm-up, instruction of two to three sport-specific skills (one sport per week), one or two cooperative team games and a 5-minute cool-down. The following sports were played during the *Sportball* intervention sessions: basketball, volleyball and soccer were played twice; baseball and tennis were played at least once; ball hockey was played twice in the first intervention group ($n = 7$).

Sportball is a community-based sports program which focuses on the development of basic motor skills common to all sports and allows for the progression towards more complex and sport-specific skills in a non-competitive environment. *Sportball* was chosen for this study because it is a well-organized, highly structured, replicable and widely available program, making it ideal for future use in the promotion of community PA opportunities to children with CHD. Furthermore, the program aims to increase a child's interest in sports and build positive team social skills.

2.2) Participants

Participants were recruited using non-probability, purposive sampling based on age, gender and severity of diagnosis. Potential participants were considered eligible for the study if they: 1) were between 7 and 10 years of age, 2) had a congenital (structural) cardiac condition that was considered moderate to severe in complexity by their responsible cardiologist, 3) required minimum annual, on-going follow-up with a cardiologist, 4) spoke English, 5) lived in Ottawa or the surrounding area, and 6) had a health status that was considered stable for participation in PA. Potential participants were not asked to enrol in the study if they had undergone cardiac surgery or catheterization in the 6 months prior, or if they were diagnosed with a condition that is known to significantly impair motor development (i.e. cerebral palsy, Down syndrome). Medical history and initial eligibility for study participation were determined

by the researcher using EPIC, the electronic health record system used at CHEO. Approval was then given by the child's responsible cardiologist for potential participation in the study. Once considered eligible, parents and/or guardians were initially approached by a CHEO staff member not affiliated with the research project or the CHEO Research Institute (as required by the CHEO REB). If during the initial contact the parents agreed to speak with the research team, potential participants were then approached by the researcher for participation in the study. If the child and parent consented to study participation, the child's responsible cardiologist was then asked to specify any medically necessary activity restrictions. Additional consent for participation in the focus groups was obtained from the child and their parent.

2.3) Qualitative Assessments

2.3.1 Focus Groups

Two focus groups were facilitated by the researcher; the first at baseline and another post-intervention. Data obtained from the focus groups were used to determine the feasibility and enjoyment of the intervention, to inform and provide context to the potential outcomes observed after the intervention, and to gain an understanding of participants' experiences with PA. Purposive sampling, based on age and gender, was used to select a sub-sample of participants for the focus group (n=4), as it is recommended that children participating in focus groups should not be more than two years apart¹⁰³. A small age gap controls for the level of understanding and experiences of school-aged children, who experience large changes in cognitive and social development over a short period of time. After confirming their participation in the study, families of participants were asked to join the focus group if they were between 8 and 9 years of age. Parents were present during both focus groups, which took place in the multi-purpose room of a community centre in Ottawa and lasted approximately 35-40 minutes each. Parents were

seated with participants during the focus groups, but were told not to answer any questions that were directed to their children. Children were given blank pieces of paper and coloured markers to draw their ideas and answer questions, in an attempt to encourage and stimulate participation in the discussion. Following a semi-structured interview guide (Appendix A) during the baseline focus group, the researcher asked initial, open-ended questions while a graduate student directed probe questions to participants. During the post-intervention focus group, the same graduate student asked initial questions while the researcher directed the probes. Data were recorded on a portable audio device and an additional graduate student was present at both focus groups to take descriptive notations.

2.3.2 Field Notes

Field notes were taken by the researcher immediately following every *Sportball* session. These notes provided detailed accounts of how participants approached or completed skills, how they progressed through the various activities and skills, their interaction with the coaches, researcher and other participants, and finally their attendance and reasons for any absences. As well, notable communications during the intervention sessions were documented by the researcher in written quotations. These notes were used to identify themes in conjunction with the focus group data and support the evaluation of whether *Sportball* is an appropriate intervention for participants with CHD. Illustrations drawn by participants during the focus group discussions were also referred to by the researcher during familiarization with the data, to provide context and to support themes discovered in the data.

2.3.3 Data Analysis

The data were viewed from an interpretivist epistemology. This approach has been used previously to look at the involvement and contribution of parents and caregivers to the engagement of youth with CHD in PA²⁸. This epistemology allows for researchers to consider the life experiences and cultural/social backgrounds of participants, while interpreting findings into a broad theoretical perspective¹⁰⁴. Experiences unique to this cohort include their medical background and potential perceived cardiac concerns while engaging in PA. The researcher considered participants' responses from focus groups, field notes, conversations with participants and their families during intervention sessions, as well as their medical history from chart reviews to build a more thorough understanding of their influences and perspectives at the time while participating in the community-based intervention. For the enjoyment component of the primary objective, the researcher looked for enthusiastic verbal responses and engaged participation during program activities as indicative of enjoyment.

Audio recordings from focus groups were transcribed verbatim and pseudonyms were used to protect participants' identity. Braun and Clarke's six steps for thematic analysis¹⁰⁵ were used to identify and report key themes emerging from the focus group discussions. Once familiarized with the data, initial codes were generated from both transcripts by the researcher and an entry-level graduate student, who was not involved with any other component of the study. A social cognitive theory (SCT) framework guided the deductive analysis, in an attempt to recognize potential influences contributing to participants' PA behaviour, as well as their participation in *Sportball* at the time of the intervention. For each transcript separately, similar codes were grouped into possible sub-themes, reviewed, and then further defined within main themes. Main themes were determined by grouping relevant sub-themes into personal,

environmental or social influences for participating in the *Sportball* intervention or general PA. After main themes were established, results were then compared across baseline and post-intervention to determine if there were any changes in how participants perceived their experiences with PA.

A deductive analysis of the data within an SCT theoretical framework, combined with an interpretivist epistemology, allowed for a multifaceted, interactional approach to exploring the PA behaviours and perspectives of children with CHD in this study. SCT explores how various determining factors that are social, environmental or behavioural in scope, interact to influence an individual's behaviour; for example, PA behaviour among children may be subject to social influences (e.g., peers, family), environmental influences (e.g., neighbourhood, school), previous experiences with the behaviour (e.g., perceptions of success or failure) and personal influences (i.e., psychological, physiological)^{49,106,107}. During the analyses, these factors acted as a guide for grouping initial codes together and organizing main themes.

2.4) Physical Literacy Assessments

The Canadian Assessment of Physical Literacy (CAPL) was used to determine the secondary objective of potential differences in physical literacy outcomes among children with CHD who participate in *Sportball*. The CAPL testing was administered by trained graduate students in a large open space (i.e. gymnasium, atrium). The CAPL is a comprehensive tool for evaluating the different domains of physical literacy (i.e. physical competence, knowledge/understanding, daily behaviour and motivation/confidence) – providing meaningful results about a child's likelihood to maintain a physically active lifestyle¹⁰⁸. All domains are given a composite score (appendices B, F and G), which are then summed to produce a total physical literacy score. For each domain as well as the total CAPL score, the numerical value is

placed into one of four classifications to describe that child's progress through physical literacy: beginning, progressing, achieving, excelling. Scores are classified based on normative data for age¹⁰⁹. A 3-round Delphi process was used to determine the CAPL framework, where physical competence, motivation and knowledge are overlapping domains within a daily behaviour domain²⁰. The assessment and its various components were modeled after this framework and the CAPL has been determined to be a valid and appropriate representation of physical literacy among children between 8 to 12 years old¹⁰⁸. Younger school-aged children (i.e. 7 years) have also been successfully assessed with the CAPL, although domain scores are awaiting validation among this age cohort.

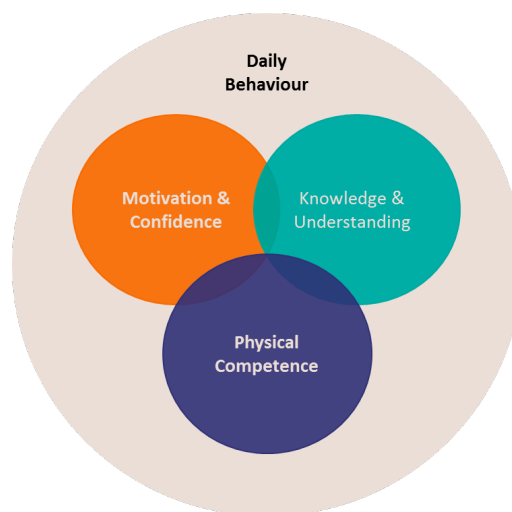


Figure 1. Conceptual CAPL model for the domains of physical literacy.

Taken from the CAPL manual available at www.capl-ecsf.ca

2.4.1 Physical Competence

The physical competence domain in the CAPL includes measures of musculoskeletal fitness, body composition, gross motor skill and cardiorespiratory endurance. Components of musculoskeletal fitness include: strength, flexibility, and muscular endurance. The scoring for the musculoskeletal fitness component is outlined in appendix B. Static grip strength was

assessed using a hand-grip dynamometer¹¹⁰ (Takei Scientific Instruments, Japan), recorded in kilograms. The sum of the highest scores for the left and right hands, based on two trials per hand, was reported as the total grip strength. A sit-and-reach flexometer¹¹⁰ (Novel Products Inc., USA) measured trunk and hamstring flexibility, recording to the nearest 0.5 centimetre. Participants were instructed to sit with their legs extended and feet pressed against the flexometer; with one hand on top of the other, participants were then asked to bend from the waist and push the flexometer with their fingers while keeping their knees fully extended; the best raw score (i.e. farthest distance flexometer was pushed) was used from two trials. For maximum torso endurance, participants were asked to properly hold a prone plank position for as long as possible, supported by the forearms and toes curled under the feet. Participants had one trial to complete this maximal test, which was considered complete upon failure to maintain the proper form after one correction¹¹¹. Time held in the proper plank position was recorded to the nearest tenth of a second.

Anthropometric variables assessed included weight (in kg), height (in cm) and waist circumference (in cm). Waist circumference was measured at the top of the iliac crest (i.e. narrowest part of the waist) while participants stood with their arms raised slightly forward. Raw values for waist circumference were converted into component scores, as per the CAPL. Body Mass Index (BMI) was calculated using the formula: $BMI = \text{weight (kg)} / [\text{height (m)}]^2$. The raw BMI data was then converted to z-scores based on normative values for age and gender¹¹². Each z-score was then converted into a corresponding component score (appendix B)¹⁰⁹. The sum of the component scores for BMI and waist circumference determined the composite score to reflect body composition (appendix B).

The Canadian Agility and Movement Skill Assessment (CAMSA) is an accurate and reliable measure of gross motor skill, as it applies to the overall concept of childhood physical literacy¹¹³. This agility course combines assessments of skill execution and time taken to complete a full series of fundamental complex and combined movements¹¹³. A schematic is provided in appendix C, which illustrates the sequence of skills for the course as described in the CAPL manual¹⁰⁹. As stipulated by the CAMSA protocol, participants were asked to complete two practice trials, followed by two recorded trials. For each trial, a score was given for the quality of each skill (out of 14 total points); when a skill criterion was executed correctly it was given a score of 1 point and when a skill criterion was not observed or performed incorrectly, it was given a score of 0 points. Table 2 outlines the criteria for each of the 7 movement skills within the CAMSA. An additional timing score (time to complete the course) and total agility score (combination of skill and time scores) were determined for each trial (appendix D). The highest overall score from the two trials was used to determine the motor skill component score (appendix D).

Cardiorespiratory endurance was determined using a 15-metre shuttle run field test. Fitnessgram's Progressive Aerobic Cardiovascular Endurance Run (PACER) is a valid and appropriate tool for determining peak aerobic fitness among children, when the use of a graded exercise test is unavailable due to lack of resources¹¹⁴. Participants each completed one trial for the PACER, with the test being terminated upon two failures to complete a lap before the auditory signal or withdrawal from the test due to fatigue. A composite score¹⁰⁹ was then assigned for cardiorespiratory endurance, based on the number of laps completed before test completion (appendix B).

Table 1. Skill Criteria for the CAMSA, *as outlined in the CAPL manual available at www.capl-ecsfp.ca*

Two foot jumping	3 two-foot jumps in and out of the hoops
	No extra jumps and no touching of hoops
Sliding	Body and feet are aligned sideways when sliding in one direction
	Body and feet are aligned sideways when sliding in opposite direction
	Touch cone with low centre of gravity and athletic position
Catching	Catches ball (no dropping or trapping)
Throwing	Uses overhand throw to hit target
	Transfers weight and rotates body
Skipping	Correct hop-step pattern
	Uses arms appropriately (alternates arms and legs, arm swinging for balance).
One foot hopping	Land on one foot in each hoop
	Hops once in each hoop (no touching of hoops)
Kicking	Smooth approach to kick ball and hit target
	Elongated stride on last stride before impact

2.4.2 Daily Physical Activity

Objective and self-reported measures of daily PA were taken throughout the study period to determine overall time spent engaging in PA or sedentary behaviour. PA behaviour was objectively determined using an omni-directional Actical Z-series accelerometer set to 15-second epochs (Respironics, USA). Accelerometers are valid and reliable tools used in pediatric populations to provide accurate data on activity time and intensity¹¹⁵. The devices were distributed by the researcher on weeks 1, 4, 8 and 12 of the study. Participants were instructed to wear a waist belt with the attached accelerometer placed over the right hip during all waking hours, over a period of 7 consecutive days. Participants were also asked to document wear time and reasons for device removal using a log sheet. Valid days had at least 10 hours of recorded data¹¹⁶, and established cut points¹¹⁷ were used to calculate daily minutes spent in MVPA. Self-reported measures of daily PA and sedentary behaviour were assessed at baseline and post-

intervention using questions 15 through 21 from the CAPL questionnaire (appendix E). Results from the CAPL questionnaire, for both daily PA time and sedentary screen time, were summed separately (appendix F).

2.4.3 Motivation and Confidence

Questions 2 and 3 of the CAPL questionnaire (appendix E) evaluated the perceived barriers and benefits associated with PA participation among participants. These questions included various reasons why participants may or may not be active and an indication of their agreement with each reason from a scale of 1 (“disagree a lot”) through 5 (“agree a lot”). Two separate scores are produced for “benefits” (question 2) and “barriers” (question 3). A perceived benefits-to-barriers ratio for engagement in PA was then determined by subtracting the score for question 3 (barriers) from the score of question 2 (benefits)¹¹⁸; a higher ratio indicated more perceived benefits to barriers for PA participation. Confidence was measured by questions 4 and 5 of the CAPL questionnaire (appendix E), where perceived activity level and execution of sport-specific skills were self-reported in relation to age-matched peers; 10-point Likert scales were used, from 1 indicating the lowest perceived confidence and activity level to 10 indicating the highest.

Participants were also asked to complete a section of the Children’s Self-Perceptions of Adequacy in and Predilection for Physical Activity Scale (CSAPPA) as part of the CAPL questionnaire. The CSAPPA is a valid and reliable questionnaire which reports on a child’s capability and willingness to participate in various types of PA¹¹⁹, including play-based, habitual and sport-specific activities (appendix E). Components of the CSAPPA questionnaire have been previously used to measure self-efficacy¹²⁰. Adequacy and predilection are two concepts which

are closely related to self-efficacy, in that an individual will prefer to engage in a particular behaviour if they also feel adequate in their ability to perform the associated tasks¹¹⁹. Each question in the form consists of two mutually exclusive statements regarding participation in PA, of which children choose one statement and decide whether it “really” or “sort of” applies to them. Each answer was given a score of 1 through 4. The CAPL adequacy and predilection sub-scores, respectively, were calculated using the below equations.

$$\begin{aligned} \text{Adequacy} &= (\text{sum of adequacy scores}) \times 1.5 / 7 \\ \text{Predilection} &= (\text{sum of predilection scores}) / 6. \end{aligned}$$

For the current study, the sum of total scores for both adequacy and predilection measured participants’ self-efficacy for participation in PA¹⁰⁸. The total domain score for the motivation and confidence domain was determined as the sum of the adequacy, predilection, benefits-to-barriers, and confidence sub-scores (appendix G).

2.4.4 Statistical Analyses

Statistical analyses were conducted on pre- and post-intervention data to determine if the intervention had any potential impact on raw test scores, component scores or physical literacy classifications. Raw scores for each test were assigned a composite score based on normative data¹⁰⁸. Then, composite scores for each of the four domains were summed to determine an overall physical literacy score (out of 100 total points). Based on consensus agreement from the Delphi process²⁰, the composite scores for daily PA behaviour and physical competence were weighted most heavily (each with 32 total possible points), while the scores for the knowledge and understanding and the motivation and confidence domains were weighted less (each with 18 total possible points). Paired t-tests were used to detect possible changes in physical literacy

outcomes between pre- and post-intervention phases, with significance set at $p < 0.05$. Where skewness or kurtosis was observed in the data, a Wilcoxon signed ranks test was used instead. A repeated measures analysis of variance was conducted on the accelerometer data to determine potential changes in daily PA behaviour throughout the intervention period. 95% confidence intervals were reported to indicate the variability of the outcomes and the range of potential change that could have occurred if the study was repeated.

Total scores for overall physical literacy, as well as composite scores for physical competence and motivation and confidence, were calculated and compared between the pre- and post-intervention phases. Component scores for motor skill, musculoskeletal fitness and cardiorespiratory endurance were also compared between baseline and post-intervention phases. Furthermore, raw data from the musculoskeletal fitness component were compared, including time spent in the plank position and total grip strength, with a Bonferroni correction of $p < 0.025$. Likewise, raw scores for skill execution and time to complete the CAMSA were compared within the motor skill component ($p < 0.025$). To detect potential differences in psychosocial determinants of PA behaviour (i.e. benefits vs. barriers, adequacy and predilection for PA), a Bonferroni correction of $p < 0.016$ was used for the multiple comparisons within the motivation and confidence domain of the CAPL.

A valid week of accelerometer data consisted of at least 4 days of device wear for a minimum of 10 hours¹¹⁶. For each week of device wear, mean MVPA and sedentary time (in minutes) were calculated and compared separately, in order to evaluate the average overall daily PA behaviour of participants. Significance was set at $p < 0.05$. Self-reported time spent in

sedentary behaviour and MVPA were also compared between testing periods, using paired t-tests with a Bonferroni correction ($p < 0.025$).

Figure 2. Participant Recruitment for and Enrollment in the *Sportball* Intervention

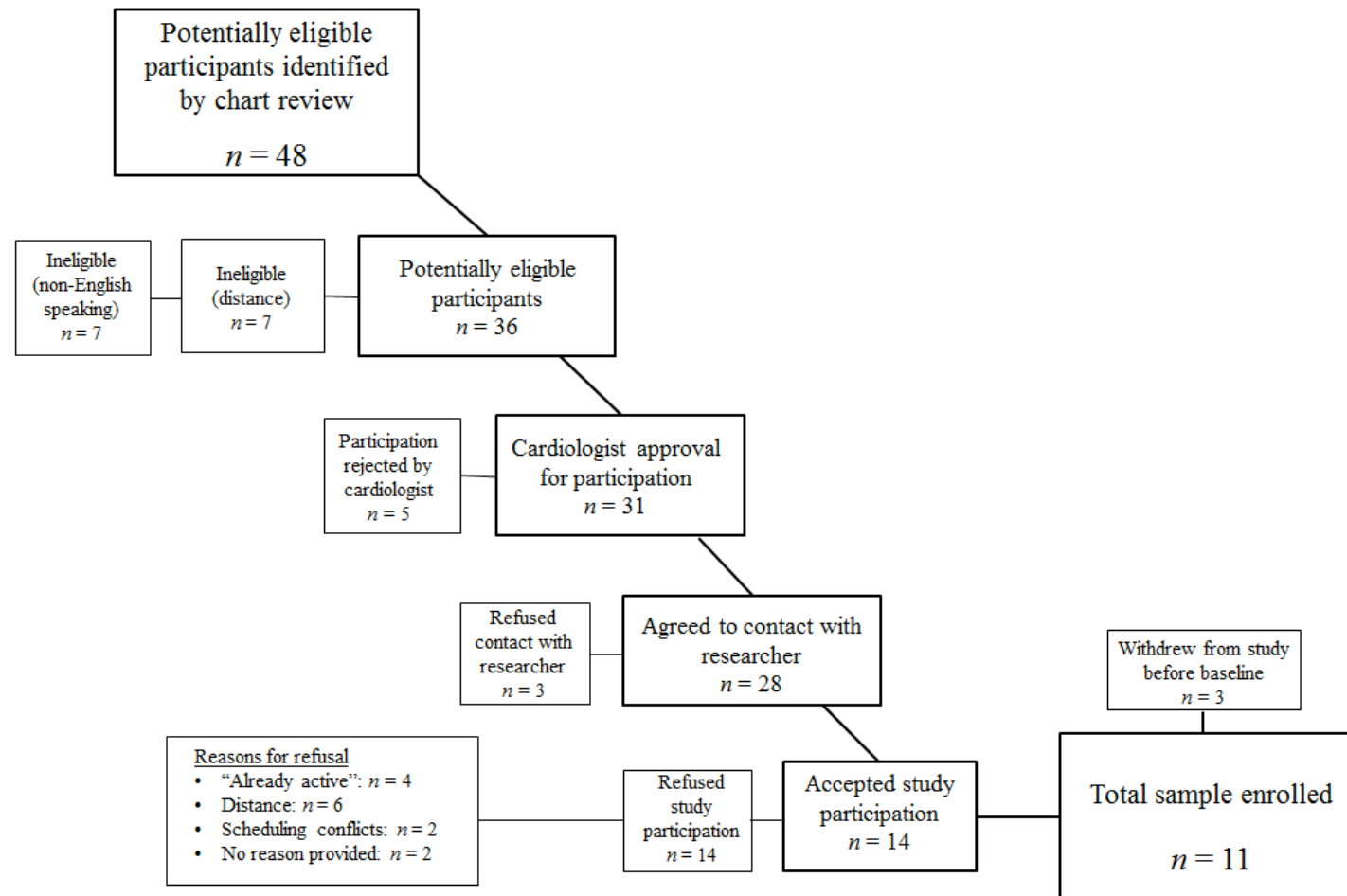


Table 2. Participant Characteristics

Pseudonym	Age	Sex	Diagnosis	Procedure(s)	Developmental/Cognitive Delay	Residual Lesions	Medications	Pacemaker
Charlotte*	8	F	ToF; DORV & AVSD	B-T shunt, Total ToF repair w/ transannular patch, RV-PA conduit	Developmental delay	Sinus node dysfunction, pulmonary hemorrhage, thrombosis	Lansoprazole, Alvesco, Ventolin	No
John*	9	M	TGA, double inlet ventricle, CoA	Glenn procedure, Fontan	ADHD, mild intellectual deficit, speech delay	Chylothorax, Right femoral vein occlusion, pleural effusion & c. difficile colitis	Aspirin, biphentin, Claritin, guanfacine, melatonin	No
Gavin*	9	M	IAA, VSD, Aortic Stenosis	End-to-end anastomosis, patch closure of VSD, aortic balloon valvuloplasty.	ADHD, Language delay	Junctional Ectopic Tachycardia (resolved)	Biphentin	No
Julia*	8	F	Tricuspid Atresia	Glenn procedure, Fontan	None	None	Aspirin	No
Peter	7	M	ToF w/ Pulmonary Atresia & VSD	BT Shunt, RV-PA Conduit, VSD closure	Speech Disorder, Anxiety Disorder, Gross Motor Delays	Branch pulmonary stenosis	Ventolin & Alvesco	No
Adam	10	M	ToF	Transannular patch repair of ToF; VSD closure	Speech Delay	Atrial ectopic tachycardia	None	No
Matthew	7	M	AV-VA discordance, Tricuspid Atresia, Hypoplastic RV & Subaortic Stenosis	Glenn procedure, Fontan	Learning Delay	Persistent desaturation, junctional escape rhythm, Chylothorax	Aspirin	No
Thomas†	7	M	CCTGA, Ebstein's Anomaly, CoA, Complete heart block	Pacemaker insertion, PA banding (palliative), CoA correction	None	None	None	Yes (Complete Heart Block)
Cierra†	10	F	TGA; Mild PS	Arterial Switch	None	None	None	No
Rachel†	9	F	AVSD, heterotaxy	Patch Closure	Complete patch repair, Pacemaker placement,	None	None	Yes (Bradycardia)
Jessica†	9	F	PAPVR & ASD	Patch Repair & Closure	None	Desaturation & Atrial Ectopic Tachycardia	Atenolol	No

* Participated in focus groups; † enrolled in Winter 2017 session. DORV = Double outlet right ventricle; AVSD = atrioventricular septal defect; TGA = transposition of the greater arteries; CCTGA = congenitally corrected transposition of the greater arteries; IAA = Interrupted Aortic Arch; VSD = Ventricular Septal Defect; ToF = Tetralogy of Fallot; CoA = Coarctation of the Aorta; PA = Pulmonary Artery; PAPVR = Partial Anomalous Pulmonary Venous Return; ASD = Atrial Septal Defect; TV = tricuspid valve; RV = right ventricle; AV-VA = atrioventricular-ventriculoarterial; B-T Shunt = Blalock-Tausig Shunt; PS = pulmonary stenosis;; ADHD = attention deficit hyperactivity disorder

Chapter 3: Appropriateness of *Sportball* among Children with CHD: **Feasibility & Enjoyment**

The primary objective of this pilot, feasibility study was to determine if participation in a community-based, multi-sport program (*Sportball*) is appropriate for participants with CHD. Using data collected from field notes and focus groups, quotes from participants and descriptions to provide context are used to report the appropriateness of this intervention. Appropriateness was determined by two main outcomes: 1) Feasibility of the intervention, and 2) Enjoyment of the intervention. Feasibility was defined by the children's ability to safely participate in the activities, as well as parents' ability and communicated willingness to enroll and bring their children to the program. Indicators of enjoyment that were pre-determined included participants' verbal responses to question #6 of the interview guide, as well as enthusiastic verbal responses and engaged participation during the intervention, which were documented in the field notes. Feasibility and enjoyment during the *Sportball* intervention were further explored through a qualitative analysis of the data, where main themes were identified. In this chapter, results for each outcome and related themes are reported in conjunction with a discussion of relevant literature.

3.1) Feasibility of the Intervention

Field notes based on observed and verbal feedback from participants of this pilot, feasibility study demonstrate that participation in a *Sportball* multi-sport program is feasible for children with moderate to complex diagnoses of CHD. Due to the recruitment period being shorter than what was anticipated, two study periods were held: the first in the Fall of 2016 and the second in the Winter of 2017; recruited participants were designated to only one study

period. Out of a total of 11 participants enrolled in both study periods: 9 participants attended at least 80% of the research sessions; one participant had poor adherence to the program, attending approximately 50% of the research sessions, due to personal issues outside of the study; one participant withdrew halfway through the study after receiving treatment for an unrelated condition, which rendered her physically unable to participate. Reasons for absences included: illness (i.e. flu or pneumonia), scheduling conflicts or difficulties traveling to the study location (i.e. poor traffic, far distance, weather conditions).

The structure of the intervention followed the structure of typical *Sportball* classes. In addition to the regular warm-up and cool-down, an average 1-hour intervention session would consist of 2 to 3 skill instructions and either 1 or 2 cooperative team games. Field notes describing each session detail all participants being able to successfully attempt or complete the activities in the program (i.e. skills, races, games) without modifications. All of the skills taught in a *Sportball* program use gradual progressions starting from a basic skill level. Participants were first encouraged to practice and refine the simple execution of a skill (i.e. dribbling a basketball in a straight line). Once they had successfully completed the basic component of that skill, participants were given progressions to work towards (i.e. successfully dribbling a basketball across the room progressed into following a “zig zag” trajectory through pylons, practicing “cross-overs”, etc.). Two themes emerged from the qualitative data, which better inform the feasibility of participation in *Sportball* for children with CHD: 1) physiological and anatomical barriers and 2) the presence of developmental and/or attentional deficits.

Physiological and Anatomical Barriers. There were two identified factors which were hypothesized to affect the feasibility of *Sportball* for children with CHD: 1) cardiorespiratory

fitness capacity and 2) medically necessary restrictions from contact or competitive sports.

Regarding the prior, participants' perceived level of fatigue and exertion would periodically be communicated to the coaches during the intervention sessions. However, the children did not appear to be pushing themselves past their limits and were not showing signs of over-exertion (i.e. no hyperventilation, no disorientation, no chest pain, maintaining the ability to speak, slight perspiration). One participant in particular, John (age 8), held his chest on three separate occasions, all of which were following a running activity (i.e. "marathon", race, running around the gym before class). When this occurred, the facilitator would approach John to ask if he was feeling okay and continuously gave him opportunities to take breaks or slow down. Following these periods of exertion, he would either take a short break or maintain his participation in the activities, stating that he was "just tired". On one occasion, during a brief period of free play prior to the intervention session, John had asked the researcher to "feel my heart beating really fast". Indeed, his heart rate was elevated at the time, but it was not abnormal in rhythm or frequency given his level of activity. John was not the only participant to express fatigue during the class; in the post-test focus group, another participant mentioned feeling "exhausted" while running, while many others ($n=5$) had to take breaks after some of the running activities.

Although some participants showed greater symptoms of fatigue than others, their continued participation in the program was still considered safe. Participants were always given the opportunity to rest if they were feeling tired and a 5-minute water break was taken during every session; both regular occurrences during any community *Sportball* class. Overall, participants did not take additional breaks frequently (i.e. more than one break per session), and such brief interruptions did not interfere with the delivery of the program to the group, nor were individuals excluded from participating in an activity if they needed to take a break.

Physiological limitations are well-documented for children with CHD when participating in sports and PA^{24,28,98}. Although some children with CHD may be restricted from competitive sports based on their cardiologist's recommendation, many more are told to pace themselves according to their own symptoms. In the present study, these limitations were evident from the frequent (one to two times per class) and self-imposed breaks taken by participants - an important component to consider specifically for individuals with CHD wishing to participate in sport. As observed in the current study, children with CHD who require frequent breaks will take them if necessary and if given the opportunity to do so at their own discretion. For community sport programs, this means allowing children with CHD to participate as they choose and not imposing unnecessary breaks. A community leader running a PA session may know about a child's medical background, from registration forms, parent's disclosure or after noticing a child's scar, and potential cues from participants could perhaps influence their decision to restrict children with CHD from certain skills and drills. However, children with CHD who choose to participate in community sport programs should not feel as though they are treated differently from peers when taking necessary breaks. Although John's heart rate was elevated on numerous occasions, it was not unusual given the nature of the activity (running laps around the gym) and he did not want to take a break when asked. Furthermore, his intentions for calling attention to his heart rate were not clear; perhaps he wasn't familiar with the sensation of a faster pulse or he sought validation for running to the best of his capability. Although the *Sportball* coach did not question the researcher for allowing John to continue participating, it is unclear whether or not the coach's response would have been different had the researcher not been present. It is possible that John would have been asked to take a break which he did not want or need, if he had approached a coach or community sport leader who was aware of his CHD in a similar scenario

outside of the present study. This knowledge may be important for parents who are considering enrolling their children with CHD in community sport programs like *Sportball*; open communication with coaches and awareness of activities incorporated into the program could prevent children from feeling excluded from certain sport activities due to fear of an adverse cardiac event, while allowing them to still take periods of rest when necessary.

A potential barrier to participation in the *Sportball* program was specific to those participants who had pacemakers ($n = 2$) or anatomical abnormalities ($n = 1$). These sequelae are known to impact children living with CHD¹²¹ and warrant restrictions from sports where hard bodily impacts are embedded into the objectives of the game (e.g. football, rugby). Regardless of the recreational nature of the program, unexpected bodily impact can still occur while playing many different types of sports. One example from the present study was during a short basketball game; some participants tried using force by pulling or hitting other players to obtain or stop the ball. Sometimes participants would collide with one another unintentionally, resulting from a lack of awareness of their surroundings. During a follow-up discussion with an experienced *Sportball* coach, he mentioned that this type of behaviour was typical among children in this age group, but it was also preventable by an additional level of instruction. This was demonstrated in the next basketball session, as additional instructions for no contact, keeping “hands to yourself” and being aware of surroundings were given to participants. The game that followed had no hard bodily impacts between participants, although whether or not this was actually due to the additional instructions beforehand is not clear. Bodily awareness and motor skill may also be factors to consider when preventing hard impacts during recreational sport sessions. For the first 4 weeks of the intervention, Charlotte (age 9) would use her entire body to dive to the ground and retrieve or stop a ball. Her strategy for keeping control over the ball was through the use of

her whole body, with a stomach- or chest-first approach, instead of using her arms or legs. This was especially evident when she would practice sport-specific skills such as passing a soccer ball or dribbling in basketball. This was cause for some concern, as Charlotte had a deformity of the lower rib cage, resulting in part of her heart being exposed below her chest and requiring a chest plate to protect from hard impacts. On week #3 the researcher spoke with Charlotte about keeping control without diving for the ball, and a noticeable change was observed where Charlotte would only use her limbs to control the ball by the last few weeks of the intervention. The facilitator did not use Charlotte's medical condition as a rationale for this instruction. Rather, it was instructed in a sports-centric manner; telling Charlotte that by not using her whole body, she would gain an advantage in speed during the skills and games. It is likely that Charlotte was able to keep control of the ball before beginning the *Sportball* intervention, as she was capable of executing other sport-specific skills, often requiring more control and attention than trapping a rolling ball. However, the added level of instruction may have prompted her to be more aware of how she was trapping the ball during the classes.

It is important that children with CHD do not feel pressured to continue participation in sport when they may actually require a break. Often, this is why a cardiologist may restrict competitive sports among their patients with CHD. Pressure to perform during sporting activities may prevent children with CHD from taking the breaks they require. This is an important consideration not only for elite sport, but any competitive sport where children are not able to resume participation in a game after taking a break. In the *Sportball* non-competitive setting, participants never missed out on an activity or game because they were taking a break. In this way, *Sportball* succeeded at ensuring participants were not pressured to participate nor were they taking unnecessarily long breaks from the program.

Developmental and Attentional Deficits. The second factor which may have impacted the feasibility of *Sportball* for children with CHD was the presence of attentional and/or developmental deficits among participants. These deficits are more common among children with CHD than the general population, affecting approximately 30%-40% of patients²⁵. Of all study participants ($n = 11$), more than half ($n = 6$; see Table 2) had also been diagnosed with either a developmental delay or attentional deficit hyperactivity disorder (ADHD), based on information collected from medical chart reviews. Therefore, it could sometimes be more challenging to instruct skills and provide proper instruction for games during the intervention. For example, the first learned skill in tennis was how to keep control and manipulate an object on the racquet (i.e. bean bag, small ball, tennis ball). The goal of the activity was to bounce the object ten times consecutively before attempting the same thing with the next object. The participants who had no diagnosed neurodevelopmental delays were able to understand the concept and successfully accomplish the goal. Those who did have some diagnosed delays were swinging their tennis racquets excessively to make the objects go higher, and not working towards the goal of consecutive hits. Perhaps the goal of the skill was perceived to be unattainable by these children and a modified goal (i.e. 3 or 5 consecutive hits) would have been more appropriate.

There were other scenarios observed during the intervention where participants had trouble understanding and/or attending to instructions given by the coaches. When this occurred, participants would usually practice a different skill or play a different game than instructed when given equipment (i.e. ball, hockey stick, etc.). One evident example from week #3 was when participants were learning how to play defensively in ball hockey. Instead of practicing the instructed skill (offensive/defensive stick handling) and playing the game of “hockey tag” with

the rest of the group, Peter (age 7) started taking shots on the wall by himself. In this case, it is possible that he either did not understand the concept or was uninterested in participating in the game. Another example involving Peter was during the first volleyball session (week #4), when his intellectual deficits twice became increasingly noticeable; First, he was the only participant who appeared to have difficulty understanding the difference between a bump, spike and volley and would often just bump the ball or throw it in the air, rather than attempt the other skills; Second, he had difficulty communicating his ideas and struggled to speak to the researcher about sport-specific skills, thus influencing his ability to ask questions and improve his understanding of the movement. Given his difficulties with verbal communication and apparent engagement in other activities, it was not clear why Peter did not want to work on the assigned skills during two of the sessions. Perhaps it was disinterest in the activity which drove Peter to practice his own skills; behaviour which any child could have displayed, regardless of ability, speaking to the structural design of the intervention sessions (the role of program structure on enjoyment of the intervention is discussed in the next section). Another reason for Peter's behaviour could have been attributed to his developmental delay; perhaps he did not know how to execute stick handling or volleys well enough to understand how to do the activities. Furthermore, the hockey skill in particular was the only activity in that week's session where participants were interacting with one another to practice the skill, instead of executing it individually; this differed from stick handling around obstacles and breakaways, the two other hockey skills instructed on week #3, where children could take extra time to practice and work through a skill without interference from other participants. Social factors (i.e. nervous feelings towards interacting with peers) could have also impacted his participation in this team activity, given the interactional component of the skill. Given these observations, participants with known motor delays may benefit more from

continued practice of baseline skills in an individualized sport-specific intervention, such as *Sportball*, instead of activities where various skills and progressions are combined in a more competitive environment.

For another participant with a mild intellectual delay, John, there were no difficulties with executing the sport-specific skills and games. Rather, his delay was more evident during the warm-up and cool-down exercises, when he could not understand some of the functional exercise movements or how to position his body in space; for example, he could not remember how to do a shoulder stretch when it was repeated almost every session, while other participants could easily demonstrate the stretch. One final example was during basketball, when participants were asked to dribble a ball through pylons following a “zig zag” movement pattern. Charlotte had difficulties moderating the force with which she dribbled the ball, making it incredibly difficult for her to control the movement. Although Peter was also focused on this skill, he too was having difficulty keeping control of the ball and used his fist, rather than the palm of his hand, to push down on the ball. During this skill, he would use his voice or clap his hands to produce loud noises, seeming as though he was trying to communicate his frustration or excitement.

During each class, *Sportball* coaches demonstrate skills from a baseline and gradually progress through different levels, depending on the group or individual skill level. With regards to children with developmental delays, becoming comfortable with baseline movements may allow them to better understand how to progress through more complicated, sport-specific skills. Furthermore, a child with CHD who has a significant gross motor delay may require extra attention or further instruction from *Sportball* coaches in order to work through a sport-specific

skill. Although additional coaches are regularly placed in classes, this extra support may not always be possible depending on the location or timing of the program.

Given the higher incidence of hyperactivity disorders¹²² and developmental delays²⁵ among children with CHD, there may be more frequent interruptions and extra support required within a community *Sportball* class. Regarding attentional difficulties, there were two participants who had been formally diagnosed with attentional deficit hyperactivity disorder (ADHD) and were taking medication (biphentin) for symptoms. These children did participate in most of the skills and typically brought a lot of energy and focus to each of the games and skills. However, there were a few situations documented in the field notes where participants had trouble maintaining their attention, especially during the instruction of the skills. Although this can be typical of school-aged children in any *Sportball* class, significant disruptions of the session could interfere with the amount of time spent participating in games and skills. The coaches would often address this issue by allowing participants to demonstrate a skill/movement or by giving them individual feedback and attention while practicing a skill or game. *Sportball* coaches are fairly well equipped for these types of scenarios, having learned a variety of classroom management and education techniques, most acquired through training and practice. Regardless, support in the form of training and an extra coach would likely limit interruptions and allow for more individual feedback to be provided within a session. Overall, despite some attentional difficulties and developmental delays, this group of children with CHD was able to participate in all of the games and learn sport-specific skills from up to six different ball sports throughout the intervention period.

3.2) *Enjoyment of Sportball*

Overall, participants said that *Sportball* was an enjoyable program during the intervention sessions and post-intervention focus group, reflecting participants' initial interest in the program at baseline. Observations made during the intervention sessions included high levels of engagement during the activities and positive attitudes demonstrated by participants. If given the choice, all four participants in the focus group said that they would enroll in the program again. When asked why they would participate in *Sportball*, two participants said: "because it's really fun". Another participant included *Sportball* amongst a long list of activities that she would like to continue and the other mentioned during the intervention sessions that he would like to participate in a basketball-only program with *Sportball*. Participants' accounts of their experiences at *Sportball* revealed two main themes which contributed to their overall enjoyment of the program: 1) Program Structure and 2) Inclusion. One participant, Julia (age 8), touched on both of these themes, in her discussion and illustrations (Figure 3), to describe her overall experience at *Sportball*. An underline has been added in the quote to emphasize the connection between both themes.

"... Before I was happy to go and when I got there I was nervous ... I didn't have that many friends and I didn't really know anybody except Peter... But then at the end I'm really happy because I know everybody and I have lots of fun because I know what we're going to do all the time and I have lots of friends." – *Julia*, age 8.



Figure 3. Participant illustrations in response to the question: "How does physical activity make you feel?"

Program Structure. Focus group and field note data demonstrate that the structure of the program contributed to the overall enjoyment of *Sportball* among study participants. The variety of activities offered within the program was often mentioned as participants expressed their enjoyment of *Sportball*. During the post-intervention focus group, when asked what they enjoyed most about *Sportball*, the first response was “that we played all the sports” – *Charlotte*, age 9. This was agreed upon by all focus group participants, and two mentioned specific sports (tennis and hockey) which contributed to their overall enjoyment of the program. As well, when asked why they might like to participate in more *Sportball* classes in the future, Charlotte repeated: “[because] it’s more fun when we do a new sport”, referring to a different sport being played every week. During the intervention, participants would sometimes communicate their desire to continue playing the sports during a scheduled period of rest in the middle of every session. At the end of each session, when the sport for the following week was announced, participants often expressed their excitement for playing the next sport.

Familiarity with the program also contributed to the overall enjoyment of *Sportball* among study participants. At the start of every session, when asked to repeat a certain muscle group or recall a particular stretch, participants seemed confident and excited to demonstrate what they had remembered from previous sessions. A desire to continue participation in the *Sportball* classes after the completion of the study was mentioned by some individuals, both during the intervention period and assessment sessions. In the focus group, one participant includes *Sportball* amongst a list of other activities when she says: “I would like to do hockey, basketball, more soccer, *Sportball* and I would also like to do swimming again and skating” – *Julia*, age 8. During the ninth week of the intervention, John mentioned to the researcher how much he liked *Sportball*, and proceeded to ask if the organization offered any basketball

tournaments. He mentioned that playing in a basketball league was something he was looking for; at the time, he was also playing in a hockey league for children with special needs, where he was on a team and played in tournaments. He seemed disappointed that he could not join a similar basketball-only class or league with *Sportball*, which he communicated during the focus group when he said: “Because at *Sportball*, I really [wanted to] do basketball, and then I couldn’t do it anymore” – *John*, age 8.

Initially, participants in the focus group said that there was nothing about the program that they would have changed. However, after further probing by the researcher, many participants mentioned running - either in the “marathon” (1-2 laps around the gym) or in the “race” - as a portion of the program they would have changed. During almost every session, the “marathon” was met with long sighs from participants, who communicated their displeasure to the coaches. When first introduced to the “marathon”, participants ran as though it were a race; they attempted to run faster than their peers around the gym, but were exhausted after completing 2 laps. It was emphasized to participants that they had to pace themselves throughout this exercise, and that they could rest at any point by either walking or taking a break for water. For the remaining sessions, the coaches had to continue to remind some participants to stay on the running track and to “just jog, don’t sprint” around the gym. On week #9 of the Fall 2016 program, after participants had reacted negatively to the “marathon”, the researcher decided to change the format of the exercise by adding a variation (i.e. skips or slide for one lap). Although highly structured, the *Sportball* program is flexible enough to allow for such variations in all of the warm-up activities, skills and games. This type of variation to the “marathon” is often used in community *Sportball* programs. Following this addition, there was a perceived improvement in participants’ willingness to run the “marathon” for the last two sessions of Fall 2016. Particularly

Gavin (age 9), who had refused to run the “marathon” during the previous three weeks, participated fully once a sliding or skipping lap was included. There are several reasons why the addition of a different movement could have encouraged children to maintain participation during the “marathon” component. The movements could have been less intense (i.e. sliding at a slower speed versus running at a fast speed); they could have been more interesting or challenging for the children to execute (i.e. criss-crossing feet); or the variation in movement could have shifted their overall focus during the exercise and decreased their perceived level of exertion from running. For children with CHD who have a lower aerobic capacity than age-matched peers, such variations may encourage them to continue participation without feeling discouraged^{24,123}.

The structure of the *Sportball* program gave participants numerous opportunities to practice sport-specific skills in both individual and team settings. The structure of each lesson, including the terminology and instruction of skills, is part of what makes *Sportball* unique from other community-based PA programs. Understanding what to expect from each class and being familiar with the program could have potentially contributed to participants’ expressed desire to continue with *Sportball* after the study. Additionally, a previous interest in sports mentioned in the baseline focus group, could have largely contributed to the overall enjoyment of *Sportball* reported by participants at the end of the study. This may explain why John was looking for a basketball program similar to his hockey league and *Sportball*; enjoying both programs had perhaps spurred his desire to continue with a basketball league that would be similar to his previous experiences.

Inclusion. Feelings of inclusion among participants in the program also appeared to contribute to the overall enjoyment of *Sportball*, as this theme was prevalent in both focus group and field note data. In addition, participants' desires to be included in activities with peers outside of the study were present across both focus groups. After being asked about *Sportball*, Julia mentioned "making friends" as something she liked about the program. To clarify what she liked specifically about making friends in *Sportball*, Julia (age 8) mentioned it was "because we were learning a lot of stuff". There were many opportunities within each session for participants to socialize and work together as a group. For example, there was time to ask questions and share opinions with each other during a 5-minute rest period and a guided group cheer as part of every class ("Life is good, life is fun, we're at *Sportball*, and we're number one!"). As well, participants were put into pairs or teams to practice skills and/or play cooperative games in every *Sportball* class. In doing so, participants would often work together to achieve a common goal (i.e. playing defense successfully while keeping the balls away from the coaches or gaining 100 points by shooting and scoring at a target). One situation in particular where this occurred was when John offered feedback and advice to Julia on how to successfully serve the ball during a short volleyball match. Both participants were playing on the same "team" when John noticed that Julia had difficulties serving the ball over the line; he then took the initiative to demonstrate and describe the skill to her. She seemed receptive to his advice and tried to replicate his execution of the skill when it was her turn to serve the ball again. Exclusive of this situation, John typically kept to himself during games. It was not clear why he chose to take this initiative, but one explanation could be that he was eager to help his teammate be successful during the game (i.e. get the most points). Earlier that day, before the volleyball session had begun, Matthew (age 7) had asked John to play a soccer game with him, which they both enjoyed. After

a few minutes of playing soccer, Matthew decided to create a new, unique game to play with John, who decided to focus instead on practicing his own basketball skills. Matthew seemed disappointed that John did not want to try the game that he had created, while John was instead highly focused on practicing his basketball skills. This example demonstrates how John, who had a competitive nature, may have been willing to interact with others to play games that were structured with known rules and goals, rather than free play. It may also be possible that John felt comfortable enough with his own skill level during the volleyball game, but not during the imaginative game, to interact and play with his peers.

By being in the *Sportball* program, participants were given the opportunity to try numerous types of sports, which was mentioned as an enjoyable component of the intervention. Occasionally during the Winter 2017 study period, siblings who were closely matched in age (i.e. 7 to 10 years) would also participate in the session. When this occurred, the researcher would pay close attention to what the otherwise healthy siblings were doing in comparison with study participants. All participants ($n = 4$) maintained an overall ability to keep up with the skills and games in comparison to the siblings, and communicated their enjoyment of having their siblings participate as well. There were a few occasions where siblings would acquire a skill at a faster pace than study participants, but this usually occurred during individual tasks (i.e. dribbling through obstacles, serving a volleyball, etc.) where enthusiastic encouragement to all participants was maintained by the coach and researcher. Therefore, the supportive environment facilitated by the *Sportball* program is well suited to integrating children with a range of abilities, while simultaneously focusing on achieving individual and team goals.

Chapter 4: Impact of *Sportball* Participation on Physical Literacy Outcomes

Outcomes presented in this chapter inform the secondary objective of this pilot, feasibility study. Specifically, baseline and post-test results for total physical literacy, physical competence, motivation and confidence and daily PA behaviour are described. A separate discussion of the secondary objective and its contribution to current knowledge is provided in section 4.6.

4.1) Participant Characteristics

Sample characteristics are provided in Table 3, describing all participants enrolled ($n = 11$) in this pilot, feasibility study. Of those, 2 participants (18%) did not attend at least 80% of the *Sportball* sessions and another participant only completed the physical competence domain of the CAPL protocol; thus, 3 participants ($n=8$, 27%) were not included in the subsequent analyses, with the exception of physical competence ($n = 9$).

4.2) Overall Physical Literacy

Total physical literacy scores at baseline and post-test were obtained from 8 participants (73% of total sample, 3 girls and 5 boys). According to World Health Organization growth references¹¹², all participants included in the analyses ($n = 8$) were between the 15th and 85th percentiles for height. Furthermore, 6 participants were between the 25th and 75th percentiles for weight and the remaining 2 were above the 97th percentile for weight. There were no statistically significant differences observed in total physical literacy scores after participation in the *Sportball* intervention ($\Delta \text{mean} = 0.35 \pm 7.13$ points, CI 95% [-5.60, 6.31], $p = 0.89$) among this small cohort. There were also no statistically significant differences in any of the CAPL domain scores (Figure 4). However, when participants were grouped into the CAPL classifications, there

was a shift from beginning and progressing at baseline to progressing and achieving at post-test (Figure 5).

Table 3. Sample Demographics and Physical Activity Restrictions

Participants	% or Mean $\pm$ SD (<i>n</i> = 11)	* % or Mean $\pm$ SD (<i>n</i> = 9)	** % or Mean $\pm$ SD (<i>n</i> = 8)
Sex			
<i>Male % (n)</i>	54.5 (6)	55.6 (5)	62.5 (5)
<i>Female % (n)</i>	45.5 (5)	44.4 (4)	37.5 (3)
Age (years)	8.34 $\pm$ 1.21	8.56 $\pm$ 1.24	8.50 $\pm$ 1.20
Height (cm)	128.40 $\pm$ 10.07	130.51 $\pm$ 8.90	132.19 $\pm$ 7.90
Weight (kg)	29.75 $\pm$ 9.13	30.79 $\pm$ 9.03	31.19 $\pm$ 9.57
Waist Circumference (cm)	60.77 $\pm$ 8.92	61.77 $\pm$ 9.19	61.79 $\pm$ 9.57
Activity Restrictions			
<i>None % (n)</i>	36.4 (4)	44.4 (4)	50.0 (4)
<i>Pace self to own symptoms % (n)</i>	36.4 (3)	22.2 (2)	25.0 (2)
<i>No contact sports % (n)</i>	27.3 (3)	22.2 (2)	12.5 (1)
<i>No competitive sports % (n)</i>	9.09 (1)	11.1 (1)	12.5 (1)

Data presented as the mean (standard deviation) or as a percentage of the total sample. Level of activity restriction was derived from participants' medical charts and is also presented as a percentage of the total sample.

* Sample demographics of participants (*n* = 9) with complete physical competence data.

**Sample demographics of participants (*n* = 8) with complete physical literacy data.

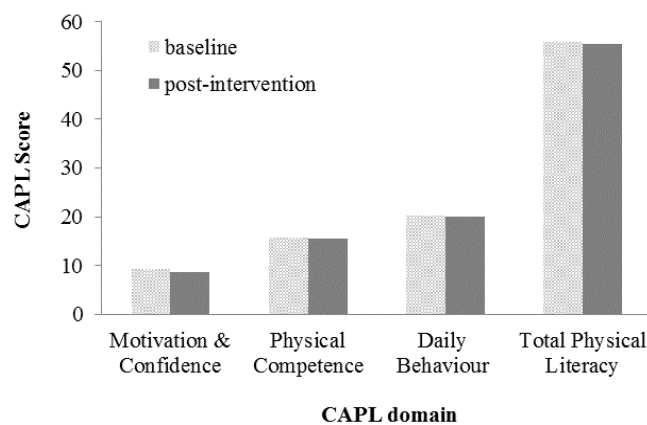


Figure 4. CAPL domain scores at baseline and post-intervention. Standard deviations from the mean are represented by error bars.

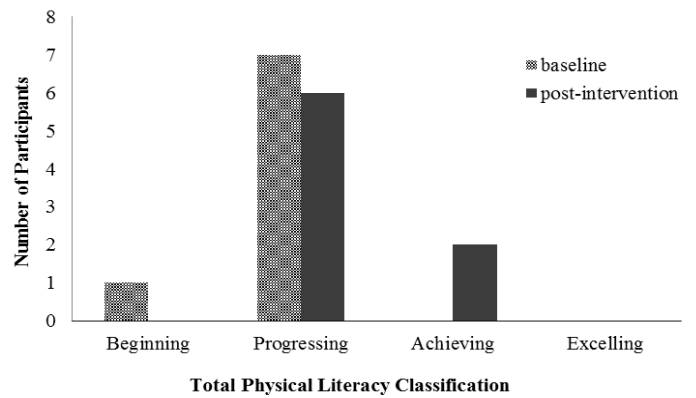


Figure 5. CAPL classifications for total physical literacy at baseline and post-intervention.

Focus group data indicated a perceived improvement in physical tasks among participants during the post-intervention phase of the Fall 2016 study period. Participants in the focus group ($n = 4$) were asked if they noticed any differences in their ability to complete the CAPL assessments between the two testing points. Gavin (age 9) indicated that he may have felt stronger, when he said: “I think I could squeeze [the handgrip dynamometer] harder”. Julia (age 8) experienced some perceived improvement in the obstacle course, as she said “I’m better now because before [*Sportball*], I didn’t really know the obstacle course but now I do know it really well and it’s really fun now...”. John (age 8) also perceived an improvement in his torso endurance and strength, when he said that he “especially [improved] with the plank... I broke the record”; his was the only measured improvement that matched a perceived change as he, spent an additional 27.2 seconds in the plank position compared to baseline. However, looking at the group as a whole, there were noticeable changes in both motor skill and torso strength, reflecting what was mentioned during the focus group discussions. When asked, Charlotte (age 9) simply said that she felt the same about her ability to complete the CAPL assessments before and after the intervention.

4.3) Physical Competence

All participants who remained in the study analyses for physical competence ($n = 9$) were able to complete this portion of the CAPL. Results are reported as the difference between the mean scores from baseline and post-intervention assessments (Table 4). Due to the pilot nature of this study, our sample size did not allow for adequate power to attain statistical significance in the physical competence analyses. There was no observed change in the overall physical competence score between baseline and post-intervention assessments ($p = 0.86$). As hypothesized, there was no change in cardiorespiratory endurance, as determined by the PACER test ($p = 0.67$). There were also no changes observed in the overall musculoskeletal fitness score ($p = 0.73$), nor in the grip strength and flexibility raw scores ($p = 0.59$ and $p = 0.91$, respectively). There was an observed difference in the timed plank hold, with a mean improvement of 5.27 ± 21.6 seconds (CI 95% [-21.9, 11.3], $p = 0.49$), and with 6 of 9 participants showing an improvement between pre- and post-intervention assessments (Figure 6).

Regarding motor skill, there was an observed average improvement of 2.0 ± 3.09 points in overall CAMSA score ($p = 0.07$). When separated into skill and timing components of the CAMSA, there were no statistical differences between baseline and post-intervention (Table 4, $p > 0.025$). However, an overall improvement of 1.0 ± 1.34 points was observed for skills executed properly during the CAMSA ($p = 0.04$) with a slight mean difference in time to complete the assessment (0.85 ± 2.56 seconds, $p = 0.32$). Figure 7 illustrates the individual changes in motor skill score that occurred between baseline and post-intervention. Figure 8 demonstrates the significant improvement in CAPL motor skill classifications ($\chi^2 = 21.94$, $p = 0.001$), as determined by the CAMSA score, between baseline and post-test.

Table 4. Physical competence data

	Baseline ± SD or (IQR)	Post- Intervention ± SD or (IQR)	Δ Mean ± SD	95 % Confidence Interval		P-value*
				Lower bound	Upper bound	
Musculoskeletal Fitness (6 to 42 points) †	9 (6.25)	10 (6.75)	-0.20 ± 2.97	-	-	0.89
Grip Strength (kg)	20.8 ± 5.86	20.8 ± 5.94	-0.55 ± 3.15	-2.802	1.702	0.59
Flexibility (cm) †	26 (10.0)	27 (12.9)	0.32 ± 8.69	-	-	0.91
Timed Plank Hold (secs) †	28.4 (39.9)	27.4 (40.1)	-5.27 ± 21.6	-	-	0.44
Motor Skill (1.5 to 42 points)	13.8 ± 2.94	15.8 ± 2.82	-2.0 ± 3.09	-4.211	0.211	0.07
Skill execution score (0 to 14 points)	6.8 ± 2.74	7.9 ± 1.91	-1.0 ± 1.34	-1.954	-0.046	0.04
Time (secs)	20.6 ± 1.89	19.7 ± 2.32	0.85 ± 2.56	-0.992	2.699	0.32
PACER (laps)	12.9 ± 6.51	12.2 ± 5.31	0.67 ± 4.55	-2.835	4.168	0.67

Mean scores ± standard deviation are presented at baseline and post-test, as well as the difference between mean scores ± standard deviation (SD). † Median scores (interquartile range) are presented at baseline and post-test, as well as the difference between mean scores ± standard deviation. *Statistical significance was set at $p < 0.05$ for the PACER and $p < 0.025$ for the motor skill and musculoskeletal fitness components.

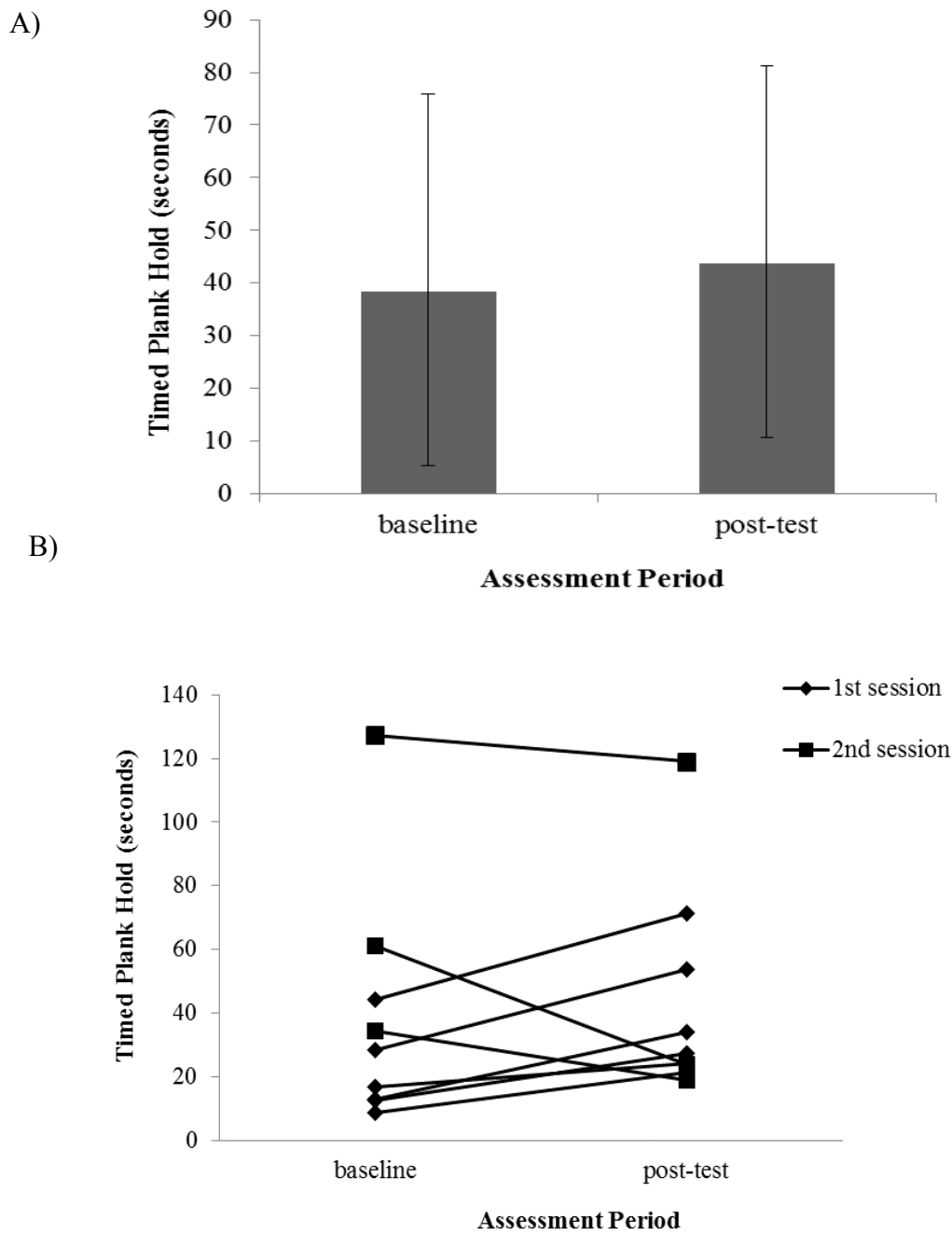


Figure 6. Torso Strength and Endurance. A) Average maximum time held in plank position (seconds) at baseline and post-intervention. Standard deviations from the mean are represented by error bars. B) Individual time, in seconds, held in the plank position at baseline and post-intervention.

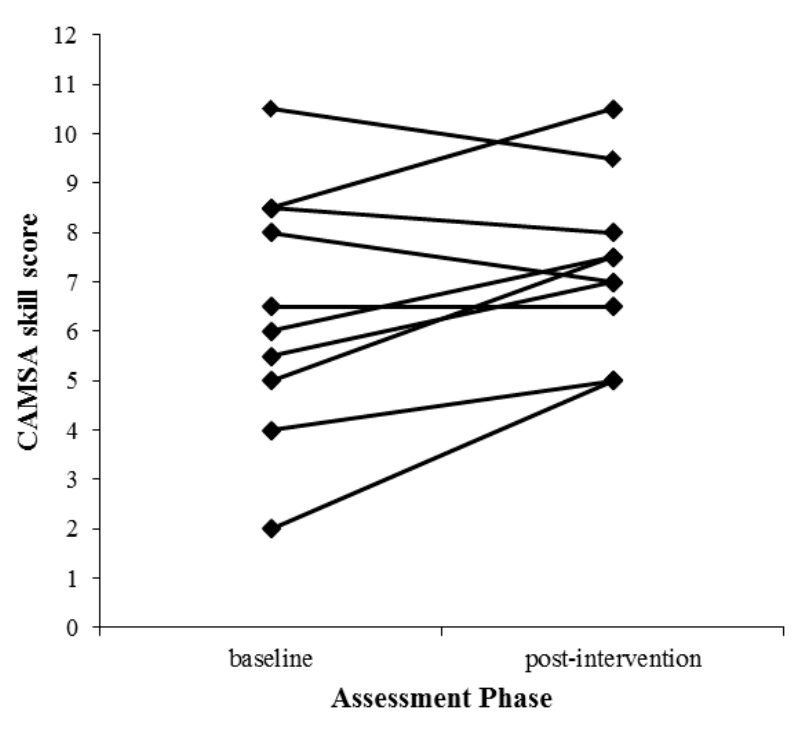


Figure 7. Individual CAMSA score for motor skill execution at baseline and post-intervention.

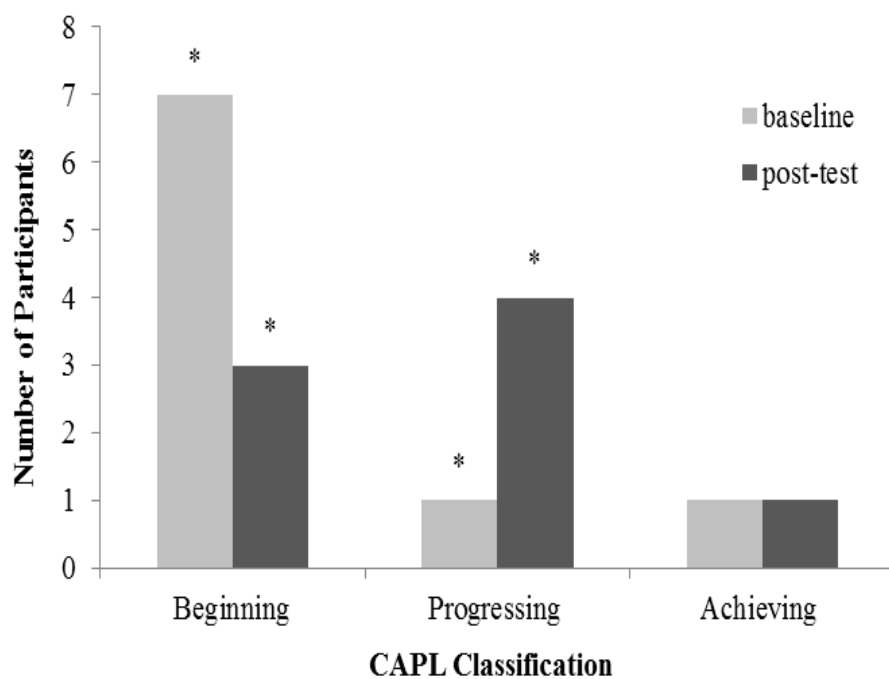


Figure 8. CAPL classification of CAMSA score at baseline and post-intervention assessments.

* $p = 0.001$ indicating statistically significant difference in motor skill classification between tests ($\chi^2 = 21.94$).

4.4) Motivation and Confidence

Of the total number of participants who were included in study analyses ($n = 8$), only 62.5% ($n = 5$) were able to complete the full questionnaire and obtain a motivation and confidence score from the CAPL. One reason for participants' inability to complete the questionnaire was a lack of attentional focus to the questions, even when they were asked aloud ($n = 2$). Another 2 participants were late arriving to the post-intervention session and were therefore not able to complete the questionnaire in the allotted time. Overall, there was a small decline in the motivation and confidence score of the CAPL between paired baseline and post-intervention assessments ($p = 0.69$). Furthermore, there were no changes observed in the individual components which informed the motivation and confidence score of the CAPL (Table 5).

Table 5. Motivation and Confidence for Participation in Physical Activity

Questionnaire Component	Baseline	Post-Test	Δ Mean	p -value
CSAPPA Adequacy (7 to 28 points; $n = 5$)	22.60 $\pm$ 4.45	18.60 $\pm$ 4.16	4.00 $\pm$ 6.40	0.24
CSAPPA Predilection (9 to 36 points; $n = 5$)	23.80 $\pm$ 6.22	25.20 $\pm$ 3.27	-1.40 $\pm$ 8.79	0.74
Benefits : Barriers (-4.7 to 4.0; $n = 7$)	-0.604 $\pm$ 0.625	-0.637 $\pm$ 0.653	0.033 $\pm$ 0.639	0.90
Activity level compared to peers † (0 to 10; $n = 8$)	6.13 (6.75)	5.13 (3.5)	1.00 $\pm$ 3.55	0.73
Skill level compared to peers † (0 to 10; $n = 8$)	6.38 (5.75)	5.38 (5.75)	1.00 $\pm$ 2.98	0.46
CAPL Motivation & Confidence Score † (-1.5 to 18; $n = 5$)	9.23 (3.61)	8.60 (2.09)	0.396 $\pm$ 2.63	0.69

Mean scores $\pm$ standard deviations are presented at baseline and post-test. Statistical significance was set at $p < 0.016$. Ranges are reported in brackets next to questionnaire components.

† Median scores (interquartile range) are presented at baseline and post-test.

4.5) Daily Physical Activity Behaviour

One participant refused to wear the accelerometer device, communicating that she felt uncomfortable since she felt the device resembled a Holter monitor. Another participant forgot to wear the device and only obtained 3 full days of data on week 8. Furthermore, there was a sensor

malfunction with one participant's Actical device at baseline. Therefore, valid PA data, defined as 4 days of accelerometer wear for a minimum of 10 hours per day, were obtained from 6 participants (67%) for all four time points (baseline, week 4, week 8 and post-intervention). Time spent in MVPA did not significantly differ throughout participation in the pilot intervention ($p = 0.41$, Figure 9). The number of self-reported days per week spent meeting current PA guidelines (i.e. 60 minutes per day of MVPA) did not significantly differ between baseline and post-intervention ($p = 0.26$) nor between intervention sessions (i.e., Fall or Spring session, $p > 0.50$). Self-reported time, in hours, spent engaged in sedentary activity also did not significantly differ between baseline and post-intervention ($p = 0.89$).

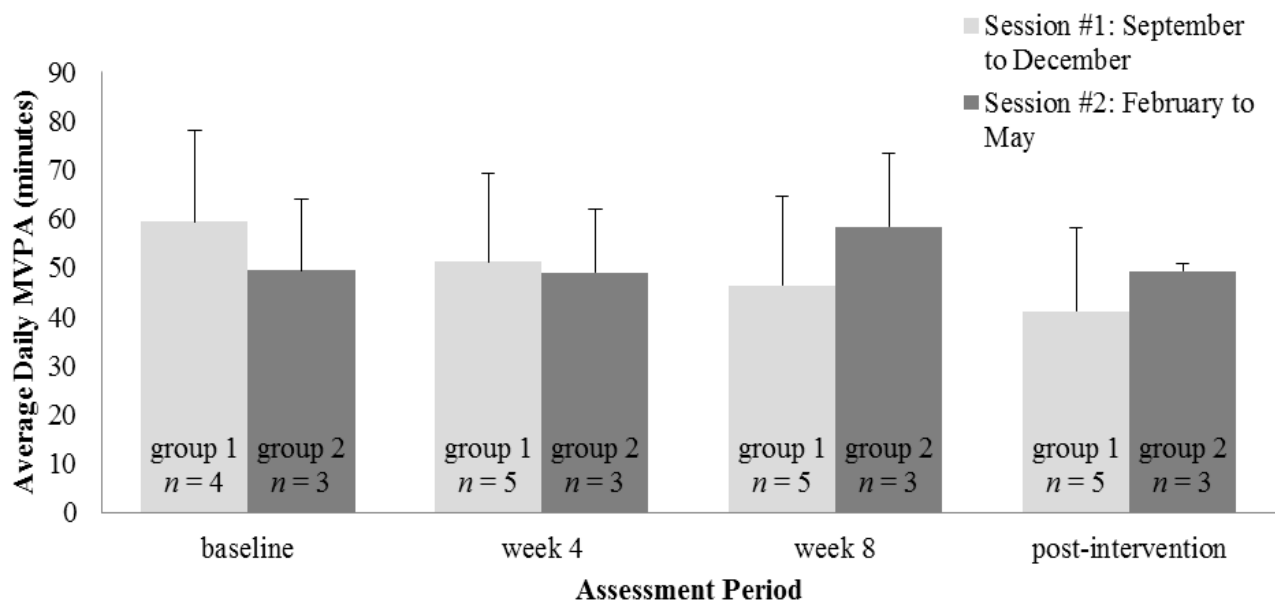


Figure 9. Average time (minutes) spent in MVPA per day. Standard deviations from the mean are represented by error bars.

4.6) Discussion

Data collected from focus groups and field note observations helped determine the appropriateness of a PA intervention for children with moderate to complex CHD. After appropriateness (feasibility and enjoyment), a secondary objective of the current study was to explore the potential effects of participation in the *Sportball* intervention within the context of physical literacy. Low levels of MVPA^{24,40,45}, gross motor skill^{25,34} and self-efficacy for PA^{47,124} have all been previously observed among children with CHD and inform the hypothesis that children with CHD are less physically literate than age-matched peers²⁹. Given the results presented, participation in the *Sportball* program may influence components of physical literacy, specifically gross motor skill and musculoskeletal strength. It is unsurprising that participants' overall physical literacy scores remained unchanged; the short duration and minimal dose of the intervention may not have allowed for significant changes in all of the individual components to occur. Although a complete total CAPL score was obtained from most participants ($n = 8$), one participant was missing data for two domains (daily behavior and motivation and confidence), meaning a total CAPL score could not be derived. Inability to obtain complete CAPL domain results from participants who participated fully in the intervention ($n = 3$; difficulties with device wear and reading comprehension) should also be considered when interpreting the presented results.

A non-significant, but positive trend was observed in the timed plank hold; a functional movement which is positively associated with cardiovascular fitness among school-aged children¹¹¹. This is an important observation, as maintaining cardiovascular fitness can prevent the development of acquired cardiovascular disease in individuals with CHD as they enter adulthood⁶⁵. There were also noticeable improvements in motor skill execution, but not timing,

during the post-intervention CAMSA test. These results align with those of Muller and colleagues⁹⁷, who found that gross motor ability increased significantly among a small sample of participants with delayed motor development, after 12 one-hour intervention sessions. Similar findings have been observed following the *Sportball* program, among a group of younger, otherwise healthy children between the ages of 3 and 6 years¹²⁵. The high prevalence of motor skill deficits observed among children with CHD is hypothesized to contribute to their overall sedentary lifestyles by inhibiting participation in various physical activities¹²⁶. Previous research has shown a positive association between gross motor skill and daily PA among healthy school-aged children³⁹. The changes observed in the current study are therefore promising, specifically with regards to motor skill, as they highlight a potential advantage of participating in PA interventions to improve skill, rather than endurance training. Furthermore, there is practical significance for a child to go from beginning to progressing and eventually achieving the motor skill capability of age-matched peers, as they may become more likely to engage in regular PA and play.

Improvements in torso strength and motor skill were not only found within the CAPL results, but they were also mentioned during the focus group and observed throughout the intervention period. It was especially interesting to compare the focus group data to the CAPL physical competence outcomes, as participants mentioned a perceived improvement in the same tests (obstacle course and timed plank hold) as those where improvements were observed in the objective measures. Such perceptions are important, because the association between perceived physical competence and PA has been consistently observed among children¹²⁷. In a previous study among children with CHD, authors found that participants reported lower motor coordination self-efficacy compared to controls¹⁰⁷. By perceiving such improvements in regular

components of PA (i.e. strength, motor skill), children with CHD may feel more competent and be more likely to accumulate experiences of success while engaging in play. Throughout the intervention, it was noted that participants' perceptions matched the outcomes; individual improvements were observed for many sport-specific and gross motor skills throughout the intervention. Field notes indicated that participants gradually became more comfortable with dynamic exercises such as mountain climbers, squats and push-ups, as well as static lower and upper body stretches during warm-ups. Small improvements were also observed and documented in the field notes as participants became familiar with the sports and overall structure of the *Sportball* classes. For example, some participants improved their dribbling skills during the basketball sessions, gaining better control over the ball and the ability to complete the course of movement ("zig-zag" through the cones) in a shorter period of time. As well, gross motor improvements during obstacle course games, specifically for fast feet and jumping skills, were noted within the intervention. Given the association between self-efficacy and PA participation, which has been documented among children with CHD¹⁰⁷, it is likely that perceived and observed improvements in physical competence may encourage higher levels of engagement in PA among this population.

The physical and psychosocial benefits of regular PA for children are well known¹²⁸ and can further contribute to the overall quality of life of children living with CHD^{73,74}. The potential relationship between motor skill and MVPA may also be partially explained by SCT; as the perceived or actual accomplishment of a skill can influence self-efficacy⁴⁹, which in turn may influence overall PA behavior¹²⁶. Thus, regular participation in a non-competitive PA intervention like *Sportball*, where the focus of instruction is primarily on skill development, may be beneficial to the PA levels of children living with complex diagnoses of CHD. Furthermore,

even though there were observed differences in motor skill, they were not statistically significant in this small study sample. Given the trends observed in the current study, if the *Sportball* intervention were longer in duration or there were a larger number of participants it is possible to hypothesize a statistically significant change in motor skill and torso endurance. Based on the SCT model for changes in PA behavior, a difference in MVPA among participants could be observed following improvements in sport- and PA-specific motor skills.

Chapter 5: Influences and Perceptions of Participation in Physical Activity among Children with CHD: Before, During and After the *Sportball* Intervention

SCT posits that a reciprocal relationship exists between personal factors (i.e. self-efficacy, enjoyment), environmental/social factors (i.e. social support, physical support, physical surroundings) and engagement in behaviour (i.e. participation in PA)⁴⁹. Through a deductive analysis, the researcher was able to identify influences on participants and their PA behaviours, including participation in the *Sportball* intervention, and apply them within an overall SCT perspective (Figure 10). Thus, the findings presented in this chapter demonstrate potential influences upon children with CHD who participate in a community-based PA intervention.

Participants' accounts of their experiences during the focus groups uncovered three overarching themes regarding influences on participation in PA and *Sportball*: 1) Feelings and attitudes towards participation, 2) Social and/or environmental influences on participation and 3) Perceived self-efficacy for sport. Within major themes, any additional sub-themes were identified and described; Feelings of excitement and enjoyment towards participation in PA, frustration, exertion and fatigue during PA as well as nervousness about new PA experiences were identified as sub-themes within the first major theme; Interactions with peers and family members were identified as social and environmental influences, as well as how the environment may influence their perspectives about participating in PA (i.e. known health benefits vs. enjoyment). Included in the following discussion of results are differences in how participants communicated their overall PA experiences between pre- and post-intervention. Finally, the interaction between identified themes are discussed with regards to participation in PA observed among this population. The implications of these qualitative findings for the promotion of

Sportball and other, similar community-based group PA programs to children with CHD are also discussed.

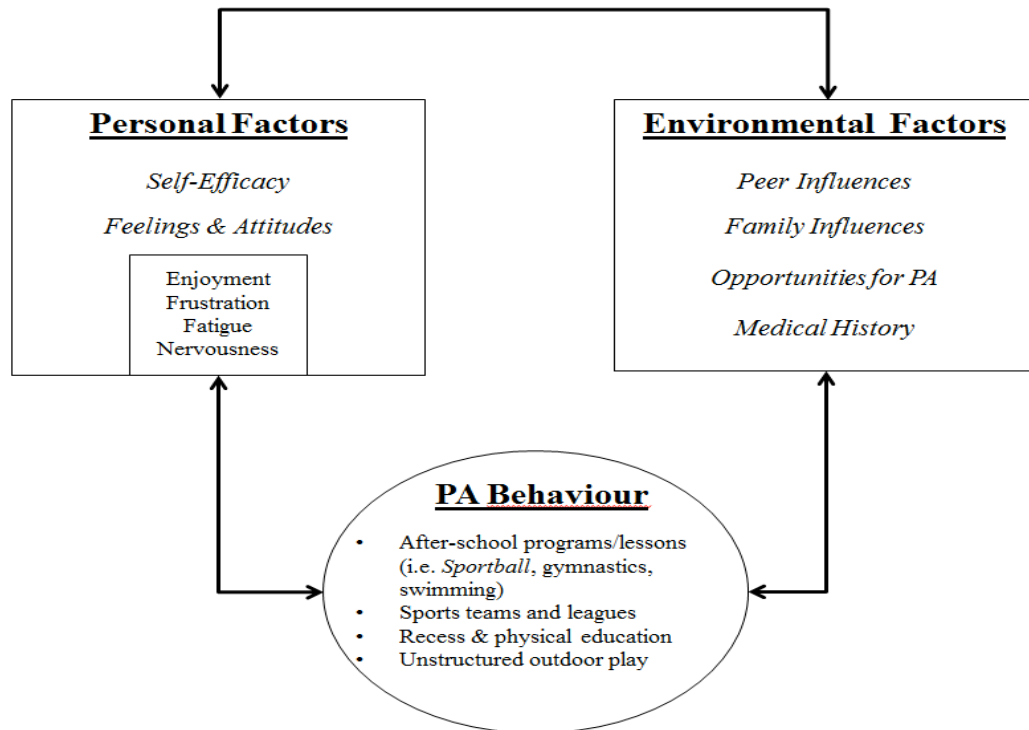


Figure 10. Model of main findings, adapted from Bandura’s causal model of Social Cognitive Theory¹⁸

5.1) Feelings and Attitudes towards Participation

Excitement and Enjoyment. Feelings of excitement towards participation in PA and sport were communicated by all participants in the focus group. Enjoyment of the activity or sport was also mentioned as a reason for feeling excited about that particular activity. In the pre-intervention focus group, Julia (age 8), mentioned that she felt excited when participating in PA “because I like playing sports”. She echoed this post-intervention, when she said “sometimes I’m really excited, like when I do gymnastics or swimming or *Sportball*, because I really like those

sports”. Gavin (age 9) also communicated his feelings during the pre-intervention focus group when he said “I feel excited when I do all of the sports that I do”. Following probes to explain those feelings, Gavin replied “because I just like a lot of sports”. When asked what sports they were most looking forward to playing in *Sportball*, John (age 8) mentioned basketball “because basketball is my favourite sport and I play a lot of basketball now”. It was also suggested that enjoyment of similar activities had an influence on participants’ desires to try new activities. For example, Julia associated her interest in ice hockey to her enjoyment of skating when she said “...I do skating and I really want to try hockey because I think it’s really fun and I really like skating”. Participants also communicated feelings of excitement when beginning a new activity, as two participants spoke about their experiences with gymnastics specifically. Charlotte (age 9) had not yet signed up for lessons when she said “when I [sign up] for gymnastics, I [will be] excited because it’s my first day”. Gavin was reflecting on his feelings about the activity retrospectively when he said “[I was] excited because it was something new that I haven’t tried before”. Excitement for participation in sport was also mentioned as a result of competition; more specifically, after successfully gaining a trophy or winning a game. John played in a recreational ice hockey league for children with special needs and communicated his excitement to play tournament games. One experience in particular he mentioned was “last year in March Break on Tuesday we got to play at the Canadian Tie, [because] all special needs teams were there with the Sens Foundation. And it was kinda fun”. He also spoke about his excitement during competitions “when we win [the games]”, and further described how he went “kinda nuts when we [got] a goal”. Along with excitement, participants mentioned other feelings and perceptions towards the competitive aspect of sport and games, including frustration and nervousness.

Frustration. In the post-intervention focus group, John mentioned how he felt frustrated when he did not successfully shoot and score a point during his hockey games:

John: “I get frustrated if I miss a shot.”

Researcher: “Why do you get frustrated?”

J: “Because I missed a shot and it’ll... like let’s say for example, we’re... in the third period of winning the game and I miss... I get frustrated.”

R: “Okay, because you think that you would have won the game if you had gotten the shot?”

J: “Ya.”

John did not communicate feelings of frustration during the intervention. It was noted that he concentrated on executing every skill correctly. Despite his concentration and his potential feelings of frustration when playing hockey games, John would say that almost every skill was “too easy” during the hockey sessions of *Sportball*. However, he still applied verbal feedback given by the coach and participated fully in all of the games, even after mentioning they were “too easy”. Conversely, Cierra (age 10) would voice her frustration during the intervention for many of the skills and/or sports. Two scenarios, which were reported in the field notes for the volleyball and basketball sessions, demonstrate how Cierra dealt with her frustration at not being able to successfully perform a skill and how it affected her participation in the game and/or session. The first occurred at the end of the first volleyball session, when Cierra looked highly discouraged and emphasized to the researcher that she was not good at volleyball. When practicing “bumps”, Cierra could not hit the ball against the wall at the right angle so that it would come back to her; when learning how to “serve”, she consistently hit the ball vertically instead of serving it horizontally towards the other side of the court. Her perceived failure to

succeed at the volleyball skills appeared to contribute to the feelings of frustration and disappointment that she communicated. Likewise, during the first basketball session, Cierra kept saying that she wasn't "very good at the skills"; she had difficulty coordinating her steps while dribbling the ball and was immediately discouraged when she didn't successfully shoot the ball through an easy target. However, by the end of the second basketball session, Cierra's perspective towards the sport appeared to have shifted, evident from her mentioning that it was the only sport she was good at. Throughout the second basketball session, Cierra was successful at defensive dribbling and passing and was able to set herself up to shoot and score at the basketball net. When it came time to play a short basketball game, Cierra participated fully, took few breaks and took shots towards the net. Cierra's experiences with volleyball and basketball demonstrate how failure to perceive success in a skill may contribute to feelings of frustration towards a particular sport. Low levels of perceived competence and the resulting feelings of frustration could discourage children with CHD from participating in similar activities with peers in community-based settings. However, additional practice in a non-competitive setting to develop mastery for a skill could influence a child's interest towards a sport or activity, as was shown by Cierra's experience with basketball. Although there could have been potential moments of discouragement, participants' experiences with frustration during *Sportball* were minimal and did not impede their overall participation and enthusiasm during the program.

Exertion and Fatigue. Mention of exertion and fatigue during PA, in particular with running activities, was expressed by most (3 out of 4) participants in the post-intervention focus group. As previously mentioned, exertion and fatigue during the *Sportball* intervention was often observed by the researcher and documented in field notes. Gavin commented on this fatigue when responding to the question "How do you feel when you participate in physical activity?"

Gavin: “I feel excited and tired.”

Facilitator: “You feel excited and tired... Okay, explain both of those feelings to me.”

G: “Tired is like... because I’m exhausted.”

F: “Why do you feel exhausted?”

G: “Because I’ve been running a lot.”

F: “Why have you been running a lot?”

G: “Doing the sports.”

F: “Doing the sports that you normally play or doing Sportball?”

G: “Sportball, recess, gym.”

The above conversation mirrors what was observed by the researcher during the intervention sessions when participants, and particularly Gavin, communicated their fatigue over short bouts of running. Furthermore, Gavin mentioned in both focus groups that he ran a lot during his Cub (Boy Scouts) meetings, but did not say that he felt “tired” or “exhausted” from doing so.

Although he did not appear to express these feelings in a negative tone, when asked what he would change about the *Sportball* program, Gavin replied with running during the marathon.

When asked the same question, Charlotte said that she felt “hot” during PA, specifically “because I run”. Finally, when asked about their feelings towards PA, Julia and Gavin chose to

depict them by drawing different faces on a blank page (Figure 11). Along with feelings of excitement, Julia chose to draw faces which represented feelings of exertion and nervousness during PA, to illustrate that “...sometimes when I play some sports I always get really hot”.

John was the only participant in the focus group who did not include fatigue as something he felt while being physically active. However, he still communicated feeling fatigued when he would

hold his chest, breathe deeply and say “I’m tired” during parts of the intervention sessions, as documented in the field notes.

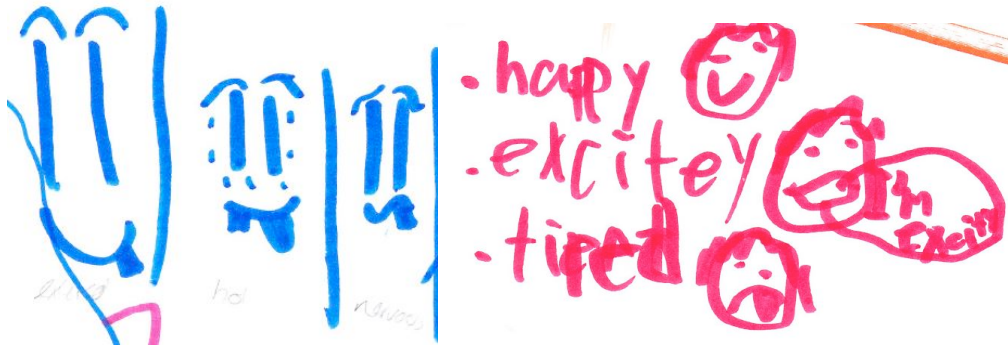


Figure 11. Julia (age 8, left) and Gavin (age 9, right) illustrate their responses to the question: “How does physical activity make you feel?”

Nervousness. Reasons for feeling nervous varied among participants in the focus group, during both pre- and post-intervention phases. Among them were: uncertainty towards the activity, fear of not being included, or lack of confidence for executing an activity-specific skill. Julia described her own nervousness and disinterest in an activity, when comparing it to other activities that were more enjoyable for her:

Julia: “Before I was doing dance and then I was always feeling nervous about it... I don’t know I just didn’t really like dance that much. But sometimes I’m really excited, like when I do gymnastics or swimming or *Sportball* because I really like those sports.”

Julia illustrated these activities in Figure 12; she drew numerous lines through her illustration of a dance class in the bottom left corner of the page, while depicting activities she enjoyed, such as playing ball sports or doing gymnastics, with a check mark. Another example where Julia conveyed nervous feelings towards PA was under the context of competitive sport. At the time before starting the intervention, Julia had just finished one season on a soccer team, which was

an experience she described overall as enjoyable. She reflected upon her experience playing soccer and why she may have felt nervous before playing against another team:

Julia: “I get a little nervous when there are teams that are [better] than us.”

Facilitator: “Do you think that they are better, or do you know that they are better?”

J: “I know that they’re better because sometimes I see them playing against the other teams.”



Figure 12. Julia’s (age 8) illustration of types of PA which she enjoyed (top and bottom right) and which she did not enjoy (bottom left).

Most participants ($n = 3$) in the focus group communicated that trying a new skill or activity caused them to feel nervous. However, it appeared as though none of these nervous feelings arose from their cardiac condition. John, Gavin and Julia all communicated different reasons for feeling nervous about new PA experiences, which included uncertainty and unfamiliarity with trying new group activities. Firstly, Gavin spoke about his feelings during his first gymnastics class when he said: “I was scared because I didn’t know what types of things we were going to

do, like were we going to do a lot of jumping [and] how high was it[?]”. In this case, Gavin was feeling nervous about what he would be expected to do in his gymnastics classes, an activity which he was trying for the first time. Likewise, John communicated his nervous feelings for playing tennis in *Sportball* pre-intervention, because he didn’t “even know how to serve”. John felt nervous because he did not know how to properly execute a skill, and therefore did not think he would find success when trying this new sport (tennis). It became evident throughout the study period that John had a very competitive nature, which could have influenced his nervous feelings about not being able to succeed at tennis. Finally, Julia reflected on why she felt nervous about beginning the *Sportball* sessions, when she spoke about not knowing any of the other participants in the program. Rather than the actions of the intervention itself, Julia’s nervous feelings came from her unfamiliarity with the social environment of the intervention.

5.2) Social and/or Environmental Influences on Participation

Peer Influences and Feelings of Inclusion. All participants in both study periods ($n=11$) mentioned the various types of PA that they engaged in with their friends, siblings and peers. These activities all occurred in different environments, such as recess (i.e. building forts, ball games), gym class, or after school. Enjoyment of PA with friends was often mentioned when participants in the focus groups were asked “what types of physical activity do you currently do?” or “how do you feel about participating in physical activity?”. John spoke about a birthday party he had recently been invited to, where he and his peers played road hockey for about two hours. When asked if he enjoyed playing, his reply was “we all had fun”, suggesting that his enjoyment of the activity was equal to the experiences of his friends, as they played road hockey together. Additionally, when asked what type of PA he did during the school day, John replied that “the only thing I’d say is active is I play with my friends”. Likewise, Charlotte was asked

why she felt “good” playing soccer, with her reply being “because I play with friends at school”. Feeling included among peers and friends could have contributed to participants’ overall enjoyment of PA, as well as their desire to try new types of activities. For example, when asked which activities she was looking forward to, Charlotte said: “I like hockey because my friend’s gonna start and I’m gonna start soon”. With regards to participation in the *Sportball* program, the importance of feeling included with peers was illustrated by Julia (Figure 13), as she spoke about her feelings before and after the intervention. Julia explained her illustration when she said “... Before I was happy to go and when I got there I was nervous ... I didn’t have that many friends and I didn’t really know anybody except Peter... But then at the end I’m really happy because I know everybody”.

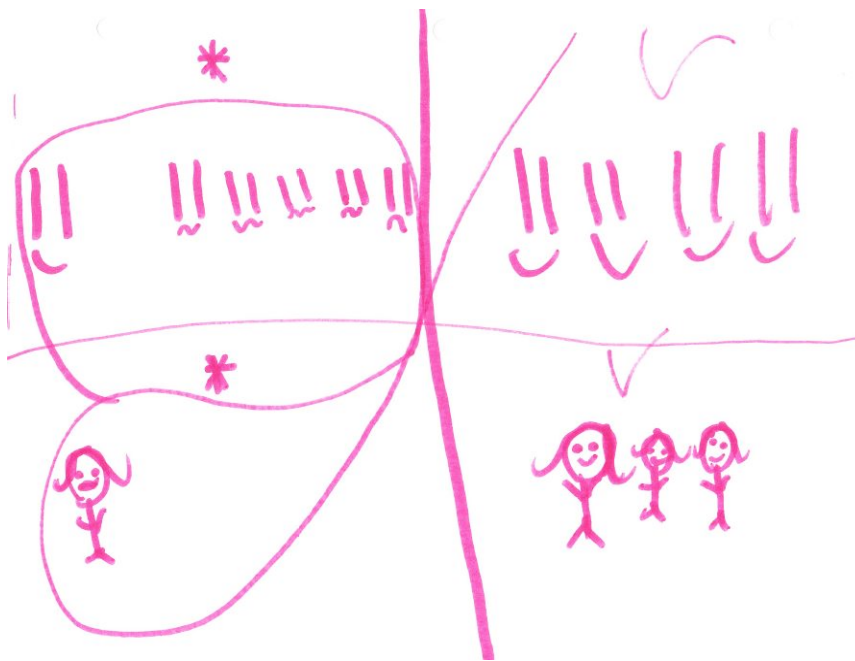


Figure 13. Julia’s (age 8) illustration of her feelings before starting a PA program when she did not know her peers (left), versus finishing the program and making friends (right).

Peer influences towards participation in PA were also described by Julia in the pre-intervention focus group, when she said “I want to try hockey because my neighbours have a hockey net in their ramp, so every day after school they will make new obstacle courses and you have to try to get [the ball] in the net”. Continuing through to the post-intervention focus group, Julia mentioned her interest for playing hockey when she said: “my brother and my neighbour always [play] hockey and it’s really cool... I think it’s really fun”. Julia’s interest in basketball was only communicated during the post-intervention focus group, when she mentioned that it was again her neighbours who interested her in the sport:

“Before when my neighbours had the [basketball] nets and they would always try it and it looked really cool because they’re really good at it and then I thought I wasn’t going to be very good but then when I was at *Sportball* it was really fun and then I thought I would like basketball.” – *Julia*, age 8.

Before having the opportunity to play the game, Julia did not think she was “very good” at basketball. Furthermore, she did not have the confidence to try playing with her neighbours. Thus, this particular example of peer influence differed from her previous dialogue; the desire to feel included with her peers had initially caused Julia to hesitate before trying basketball (out of fear of not being good enough to play), instead of encouraging her to try the sport.

Family Influences and Presenting Opportunities for Physical Activity. Participants often discussed scenarios where they were active with their family members, or when their family members influenced the types of activities they participated in. For example, Gavin said “in the summer, my grandma has a cottage and a beach down the road, so we always swam there and it was really awesome”. Parental influence towards PA was also reflected by Julia’s highly active lifestyle and lack of PA restrictions; her mother was a fitness instructor who valued and

regularly demonstrated healthy active living. Conversely, Charlotte's mother did not appear to lead a highly active lifestyle and was furthermore incredibly hesitant to let her participate in activities where she felt her daughter's cardiac health would be at risk. This became evident during the pre-intervention focus group, as participants began speaking about their experiences with gymnastics. After hearing the perspectives of the other families during the focus group, Charlotte's mother seemed to be more receptive to the possibility that it would be appropriate for her daughter as well, who had always expressed interest in gymnastics:

Mom: "Do you want to do [CanSkate] or gymnastics?"

Charlotte: "Gymnastics"

M: "Ok."

C: "You said I'm not allowed to do gymnastics!"

Facilitator: "What have you always wanted to try?"

C: "Gymnastics... and that's it."

F: "So why haven't you tried gymnastics yet?"

C: "Because I didn't sign up."

M: "Or maybe it's because mom's chicken-poo."

The exchange between Charlotte and her mother demonstrates parental influence on PA when there are potential health risks or activity restrictions to consider.

Health Benefits vs. Having Fun. When asked the question "what does physical activity mean to you?", answers from participants in the focus group varied between the health benefits that come with participation in PA and the specific activities/sports they are exposed to on a

regular basis. During the pre-intervention focus group, many of the responses from participants were health-centric, such as when Julia said “I think [PA is] sports and being healthier and being stronger”. As well, when John was asked to explain his answer (“baseball”), he said “because it’s good for you, it keeps you running... it keeps you healthy”. After being asked the same question in the post-intervention focus group, participants listed many sports and games. When participants were asked why they thought those activities were associated with PA, replies included “because I do it every day” and “because... physical activity is when you move a lot”.

Participants were also asked what they would say to other children in the Cardiology clinic who were afraid of participating in PA. Julia and Gavin’s responses both emphasized the importance of PA “for fun”, and they felt there was no reason for others to feel “nervous”. Instead of referring to the storyline provided by the researchers, Gavin’s reply was simply: “No... I don’t think I should worry about my health”. While replying to the question, Julia also mentioned the importance of fun over competition, when she said: “[it’s just for fun] because... if you win... it’s not a real competition. It’s just practice and even though you practice for a long time and you don’t win, its okay because it’s just about fun”. However, both John and Charlotte struggled to communicate an answer to this question, with John actually stating “it’s a difficult question”. All participants were recruited from the same cardiac centre at CHEO, where there is a small team of cardiologists who regularly consult with patients and their families in the Ottawa and surrounding areas. Although cardiologists reported similar restrictions for their patients (see Table 3), the phrasing was vague and could be subject to interpretation (i.e. no competitive sports). Further, disagreement between patient and cardiologist has previously been found among children¹²⁹ and youth⁷⁴ with CHD. The observed, contrasting responses of both John and Julia demonstrate how similar restrictions can be communicated and interpreted differently between

patients. Both participants underwent the same major surgery (Glenn procedure followed by Fontan) and were given similar activity restrictions (no high intensity or strenuous activities). Julia was told that she was not restricted from any specific activities as long as she was able to pace her intensity to her own symptoms. Contrarily, John was only told that he was restricted from competitive sports. In this scenario, the term “competitive” sport is referring to highly strenuous activity in an environment where John would be expected to train at a high intensity¹¹. It is clear that a child’s interpretation of “no competitive sports” would be quite different than if they were simply told to “pace self to own symptoms”. Although this restriction did not inhibit John from playing in a hockey league or in *Sportball*, it may have influenced his response when asked about other cardiology kids who are nervous about participating in PA; he mentioned it was a “difficult question” and did not provide a response. Julia however replied almost immediately, stating that kids should not worry about their hearts when they are just playing.

Overall, there was less mention of health benefits and more emphasis on participation in PA for the purpose of having fun post-intervention when compared to the pre-intervention focus group. After sorting through all of the qualitative data, there was no clear indication of why this shift in perspective occurred. During the pre-intervention focus group, it can be speculated that participants’ initial responses were influenced by their involvement in the study as children with cardiac diagnoses. By the end of *Sportball*, participants were more familiar with the researcher in a non-clinical context, after facilitating the intervention sessions where cardiac health was rarely mentioned and enjoyment of PA was emphasized. This aligns with the overall purpose of *Sportball*, which is to create an environment where children can learn sport-specific and pro-social skills (i.e. teamwork, positive feedback/encouragement) in a non-competitive and welcoming environment. This observed shift in perspective has important implications for the

appropriateness of the *Sportball* intervention as a short-term intervention (i.e. during early childhood) for children with CHD. *Sportball* encourages an active lifestyle through play, rather than focusing on the associated health benefits, which may be a greater motivator for children to engage in more habitual PA over the long-term. One must remember that despite their medical experiences, these are still children who seek enjoyment from daily activities.

5.3) Perceived Self-Efficacy for Sport

Perceived self-efficacy towards sport is the third main theme which presented itself throughout the study, during both focus groups and as well as the intervention sessions. For example, John would often communicate that he already knew how to do many of the sport-specific skills, demonstrating high perceived self-efficacy. There were sessions where he would say that a skill or game was “too easy”, even though he was not always able to complete the required task successfully. However, some participants were more likely to communicate low perceived self-efficacy for certain sports during the intervention. They did so by saying phrases such as “I’m not good enough”, “I can’t do that”, and “no way, that’s too hard”, during the skill instructions and games. Two participants, Cierra (age 10) and Rachel (age 9), were among the least active within the group and had previously communicated a strong dislike for sports to the researcher. Cierra in particular would often say “I’m not good at this” or mention that she was not a sports-oriented person and easily gave up attempting when she did not accomplish the desired outcome of an activity. Conversely, during the basketball sessions, Cierra’s perceived self-efficacy changed dramatically, which was evident as she communicated that basketball was the only sport she felt she was “any good at” and demonstrated an effort to complete all of the skills and games. It was documented in the field notes that Cierra achieved more goals and successfully executed more skills during the basketball sessions than during any of the other

sports. As well, Rachel found success in the first baseball class of the intervention and brought up her interest in the sport during the following session, when she said “I really didn’t think I would like baseball, but I actually really enjoyed it last week”.

In addition to the field notes from the intervention sessions, perceived self-efficacy for sport also presented itself within the focus group data. In particular, John conveyed high levels of self-efficacy when speaking about a sport he played regularly (baseball) and a sport he would like to try (golf), while conveying low levels of self-efficacy for a sport he had not previously been exposed to (tennis). The facilitator asked John if he ever felt “nervous” about going to baseball, a sport which he had mentioned playing regularly during the pre-intervention focus group. He replied “never. I never do... I don’t get nervous. I can almost hit a home run!”. When asked which sports he would like to try and why, John said that he was interested in golf because it’s something that he felt he would enjoy, adding “I’m really good at mini putt”. Thus, his self-efficacy for putting skills may have contributed to his developed interest in golf. Finally, earlier in the pre-intervention discussion John communicated that he did feel nervous about trying a new sport where he felt he would not be successful:

John: “I’m nervous about tennis... because I’m not that good at it”

Graduate Student: “Have you tried it before?”

J: “Nope”.

GS: “Why do you think you’re not that good if you’ve never tried it before?”

J: “Because I don’t know how to hit... I don’t even know how to serve”.

John was speaking about tennis with regards to the upcoming *Sportball* program, where he was unsure about his ability to successfully complete a skill specific to the tennis session. However,

these feelings did not interfere with his participation in the actual tennis session of *Sportball*, as documented in the field notes; John was eager to continue playing during the class, appeared focused through instructions and found success with skills such as volleys and serves.

Furthermore, during the post-intervention focus group, John mentioned that he would like to learn how to play tennis again. Julia also spoke about her interest in basketball, mentioning that she would be interested in playing basketball along with her peers. Her experience during the *Sportball* intervention likely encouraged her interest in the sport, as she mentioned “[before] I thought I wasn’t going to be very good but then when I was at *Sportball* it was really fun and then I thought I would like basketball”. It was observed during the intervention that Julia completed dribbling exercises with few errors and found some success with shooting and scoring in a hoop. Therefore, she likely perceived success performing basketball-related skills during *Sportball*, where she was able to fully participate and encouraged to continue practicing her skills.

5.4) “*I really like playing games together*” - Influences on participation in physical activity for children with CHD

When there is a need to improve PA behaviour (i.e., increasing levels of PA, decreasing sedentary time), care providers should be aware of the personal and environmental influences which contribute to the overall activity levels of children with CHD. Unsurprisingly, the current study found that social influences (i.e., peers and parents) are of primary importance when engaging in PA, as has been shown in previous studies with children and adolescents^{130–132}.

Furthermore, interventions which target self-efficacy for sport have been found to better promote the development of a sufficiently active lifestyle^{16,133}. Understanding these influences will help

determine the most effective types of interventions and opportunities for promoting active behaviours among children with CHD. The current study highlights some of the influences surrounding school-aged children with CHD, whose ideas are not often featured in qualitative research, as they participate in a community-based group PA intervention. Clinicians should consider such influences when prescribing PA to a child with CHD or when evaluating their PA by patient self-report, a tool which is often relied on to inform the daily PA behaviour of these children⁹.

During the school-aged period of childhood (i.e., 6 to 11 years old) and continuing through adolescence (i.e., 12 + years), parents are a significant influence on their child's overall PA behaviour; providing support, encouragement, and opportunities for PA outside of school hours (i.e., leisure time)^{130,134}. However, parental support can decline when physical competence of the child is perceived to be low¹³⁰; a perception that is likely to occur when the child has a cardiac diagnosis (i.e. known lower cardiorespiratory endurance) or the presence of neurodevelopmental delays. There is a positive association between parents' perceived physical competence of their child and parental support of PA, which in turn is associated with increased regular PA of the child¹³¹. Among adolescents with various complexities of CHD, one study has also found a positive correlation between self-reported PA and the mother's attitude towards PA⁵³. Even without medically-necessary restrictions, parents may perceive their child with CHD as less physically competent than other age-matched children, especially if they present noticeable motor skill delays¹³⁵. Thus, based on parents' low perceived physical competence of their child, parental support of PA may be lower for children with CHD¹³⁰. To this end, participation in PA may be negatively impacted, further emphasizing the importance of the parents' role for promoting PA among their children with CHD. If parents are reminded and

encouraged during clinical encounters to support their children through PA participation, despite demonstrating a lower physical competence, this may encourage children with CHD to participate in more activities and explore available opportunities to be active. Knowing that community-based, non-competitive sport is appropriate and feasible for children with CHD may encourage parents to support them through such programs.

During the focus groups, many participants communicated feeling nervous about certain activities, which manifested differently among each individual. One of the reasons why participants felt nervous before participating in PA was because they did not know other children in group activities or programs, such as the intervention within the current study. This emphasizes the importance of social influences, as engaging in PA with peers has been shown to improve the overall amount of time spent in MVPA among children and adolescents^{79,136,137}. In healthy populations¹³⁸ and those engaged in highly competitive sport¹³⁹, maintaining friendships was found to be a strong influence for children to participate in PA. Contrarily, the concepts of social pressure and exclusion from peers during PA has been previously explored among youth with CHD, where authors suggested that peers' perceptions in physical education settings had a negative impact on their self-efficacy for sport²⁸. Although *Sportball* is a unique setting to engage in sport and PA, it is similar to physical education in that it focuses on building skills, introducing concepts and game play from multiple sports. Findings from the current study therefore, apply the work of Moola et al.²⁸ into an earlier context; where the perceived perceptions of peers during PA can begin to impact self-efficacy for sport at a younger age among children with CHD. This is important to recognize, as young children can be influenced by friends from school or community groups to try different activities and participate in PA^{138,139}. If children with CHD cannot maintain the same intensity or skill level as their peers

while participating in those activities, they may instead feel less encouraged to participate in regular PA with friends^{28,53}. Thus, social perceptions during PA participation could have a negative impact on personal factors such as self-efficacy, which is an important determinant of PA behaviour among children with CHD⁵³ and is consistent with SCT⁴⁹. Reported results on appropriateness, specifically regarding the additional participation of children, indicate that the *Sportball* program may be a suitable program to integrate children of different capabilities in sport. Through this integration, potentially negative social perceptions during participation from children with CHD may be less likely to occur.

When determining appropriate interventions to increase overall PA among insufficiently active children, those which work on improving self-efficacy are thought to be the most effective⁷⁹. Among adolescents with CHD, Bar-Mor and colleagues⁵³ found that an individual's self-efficacy for sport was an important contributing factor to their overall self-reported engagement in PA. Furthermore, it has been suggested that PA programs targeting children with CHD should focus on enhancing self-efficacy in order to encourage long-term improvements in PA behaviour^{24,107}. Findings from the current study demonstrate a potential positive impact on self-efficacy for sport after participating in the *Sportball* program. These findings also align with the previous work of Moons and colleagues⁹⁰, which found a significant improvement among children with CHD in self-perceived physical functioning after participation in a 3-day multi-sport camp. Both interventions were similar in that participants had the opportunity to try various types of activities (multi-sport) and no specific cardiac education sessions were given. In *Sportball*, coaches regularly use positive feedback and provide encouragement towards all participants, while positive words are often repeated by participants to transition from one skill into the next (i.e. “put one thumb up and say ‘oh ya’”, “give your partner a high-five and say

great job”). Such verbal cues by the coaches are part of the *Sportball* program structure, in an effort to encourage children to have confidence in the skills they are learning. Furthermore, each skill is taught from a baseline, allowing participants to start with a component of the skill they are comfortable with, master it, and then progress at their own pace throughout the class. These components of the intervention could lead to an increased self-efficacy for sports among children with CHD, especially as success was observed by the researcher and communicated by participants. Some participants even spoke about their interest to continue playing certain sports outside of the intervention, of which they may have previously perceived themselves as being insufficiently skilled to play.

Chapter 6: Participation in the *Sportball* intervention among children with CHD – General Discussion

The current study has demonstrated that *Sportball* is an appropriate program for children with CHD, while exploring the various factors and influences that contributed to their participation. This chapter provides a general discussion of important considerations for children with CHD who wish to participate in a community-based program such as *Sportball*, including: enrollment in the intervention; perceptions of disease; and activity restrictions. How these factors were considered in the current study are discussed in detail below, including their role in the future promotion of this type of intervention among children with CHD.

6.1) Enrollment & Attendance

Overall attendance during the intervention informs *Sportball*'s appropriateness from the feasibility perspective, particularly families' ability to attend the sessions. Of those determined potentially eligible ($n=48$; Figure 2), 16% declined participation and 6% withdrew from the study before it began, due to distance and/or scheduling conflicts. Although these families were interested in participating, they had too many scheduling conflicts to accommodate in order to plan to attend (i.e. coordinating care for other children, being able to make it to the study on time each week, re-scheduling prior commitments), making the 12-week study period unfeasible for these families. Inability to provide transportation arrangements for regular participation in sport is common among many families in the general population and is also a known barrier for PA among healthy children¹³⁴. Unlike a usual *Sportball* program, parents of children in this particular study did not get to choose a time or location that was suitable for their individual schedules. Therefore, the controlled nature of this intervention (i.e. fixed time and location) limited the number of participants in this pilot, feasibility study. Another 10% ($n = 5$) of

potential participants were deemed ineligible to participate by their responsible cardiologist. Reasons for ineligibility included recent cardiac catheterizations ($n = 2$), complexity of cardiac and/or neurological diagnoses ($n = 2$) and the unstable nature of the CHD diagnosis ($n = 1$; moderate aortic stenosis).

Of particular interest is that 12.5% ($n = 6$) of potential families declined participation in the study because they believed their children already led a highly active lifestyle. These parents felt that their children would not gain any benefit from participating in the program, since they were already perceived as highly active and were enrolled in various other community-based PA programs such as soccer, karate, basketball and cross-country running. One of these children had even participated in a *Sportball* session during their toddler years. This is encouraging, as these families did not appear to be restricting their children from participating in regular PA and competitive sports, contrary to previous findings in this population¹²⁹. However, it should be considered that these parental accounts could have been an overestimation of time spent participating in large doses of daily PA¹⁴⁰. Some participants who were enrolled also reported highly active lifestyles, with activities such as swimming, gymnastics, basketball and hockey being discussed in the focus group and during the intervention sessions. Despite participating in other activities, children enrolled in this study were still not meeting the current PA guidelines and proceeded to enjoy the *Sportball* program. This was communicated when Julia listed activities she would like to try and/or continue, saying “I would like to do hockey, basketball, more soccer, *Sportball* and I would also like to do swimming again and skating”. Since it is multi-sport and skill-based, *Sportball* differs from many other sport programs in its structure and games, meaning it could still be feasible and enjoyable for children with CHD who are already active in other community-based programs. Furthermore, there are many healthy children in the

same age group who are currently participating in *Sportball* classes at various locations throughout the country; many of these children are also likely to have active lifestyles. Given this observation, parents who are interested in integrating their children with CHD into recreational sports with otherwise healthy children should consider the types of children enrolled in community *Sportball* sessions as well as the appropriateness of the program for their own child's health.

Once enrolled, it was important to be aware that personal reasons for participation in the study could have influenced the initial interest and continued attendance of families throughout the intervention. When approached for participation, many parents expressed an interest for their children to have an opportunity to meet other children with CHD who had similar life experiences. Although this was beneficial for recruitment, this is not a typical reason for participating in *Sportball* or other community-based PA programs. Furthermore, whether parents of children with CHD would pay for their child (approximately \$12 to \$18 per class) to regularly attend a weekly *Sportball* session in the community, under a non-clinical context, is not known and would likely be dependent on various factors (i.e., socioeconomic status, distance traveled, number of children, perceived importance of sport). The financial contribution could make it difficult for many families of children with CHD to maintain regular participation, as there are often extra medical expenses to consider (i.e., medication costs, frequent travel to clinic appointments).

Although overall attendance of the program was affected by various external factors (i.e., weather, traffic, prior commitments), illness accounted for the majority of absences (8 of 15 total absences). Two participants (18%) contracted pneumonia during the study period, while an

additional three (27%) had viral illnesses. Absence due to illness is an important consideration for the feasibility of a weekly PA intervention for children with CHD. Acquiring respiratory infections such as pneumonia and bronchitis is more common among individuals with CHD than the general population^{141,142}. Physiologically, individuals who have had previous surgery for complex CHD may have surgical modifications (i.e. Fontan circulation) or damage to the cardio-pulmonary structure, which can lead to poorer lung function and higher susceptibility to acquiring pulmonary infections¹⁴¹. Participants who did have pneumonia missed at least two sessions of the intervention, which affected their overall adherence to the program ($n=1$, insufficient participation). For children with CHD who are more likely to develop respiratory infections, regular and on-going participation in a PA intervention such as *Sportball* may not be feasible, when considering the cost of such programs and the amount of time it takes to recover from respiratory illness.

6.2) Awareness of cardiac condition

Awareness of one's CHD diagnosis within the context of participating in PA was observed among participants in this study, particularly during the post-intervention focus group. The hesitant response of some participants within the focus group may indicate that perceived cardiac health could have had some influence on participants' experiences with PA. It is also important to consider that cardiac function and diagnosis can relate to themes which emerged in the data, such as fatigue, nervousness and social influences^{28,143,144}. This emphasizes the importance of understanding the medical background of children with CHD (i.e., morbidities, restrictions, exercise capacity) when evaluating their overall PA behaviour, especially as they begin to experience social and physiological barriers related to their cardiac diagnosis.

Participants in the current study did not have a large exercise capacity, which led to feelings of

exertion and fatigue during the intervention, particularly the “marathon” component. When asked, participants suggested this component be removed from the intervention, implying that the fatigue experienced during this activity could have negatively impacted their overall experience. However, participants were still able to engage in the “marathon” by going at a comfortable pace and taking a short (approx. < 1 minute) rest period at the end. Their ability to maintain activity at a self-determined pace during the “marathon” was also evident when siblings, who likely had higher exercise capacities, participated in the *Sportball* sessions as well. Despite this finding, it is unclear whether or not children with CHD, being aware of the limitations of their condition, would push past their physiological capacity in an effort to keep up with peers in a community *Sportball* program with otherwise healthy children.

Most of the current literature exploring the physical and psychosocial barriers of PA among individuals with CHD focuses on the experiences of youths or adults^{10,45,144}. For example, youth with CHD have communicated an unwillingness to disclose their cardiac condition, out of fear of exclusion from their peers, leading to over-exertion during PA in an attempt to “keep pace”¹⁴⁴. As well, “social comparison” with peers has been found among youth with CHD during traditional team sports, in that their perceived ability to play a sport is negatively impacted by their perceived inability to keep up with peers during PA²⁸. Given the findings of the current study, it is possible that younger children with CHD also experience self-doubt during participation in sports, as demonstrated by Cierra’s perspective during the first basketball session. However, participating in the *Sportball* intervention allowed Cierra to set and accomplish her own sport-specific goals (i.e., dribbling successfully through the markers, shooting the basketball through the basket on the first try), facilitating perceived feelings of success. Thus, *Sportball* may be an appropriate PA program to encourage feelings of success

among children with CHD at this age particularly; a time when they may begin to compare themselves to their peers and become increasingly aware of their cardiac limitations.

Children with CHD are also highly aware of the various health benefits of an active lifestyle²⁹. Although this knowledge is important, an interesting shift in perspective was observed in the current study between the pre- and post-intervention focus groups. At baseline, participants spoke about the meaning of PA within a health context, where engagement in PA meant being “healthier”. This indicates that engagement in PA may be perceived by children with CHD as a way to avoid spending more time in clinical settings. In contrast, participants spoke more post-intervention about the personal enjoyment they experience while participating in daily PA. This difference in perspective is important, especially with regards to which factors influence children with CHD to adopt physically active lifestyles. Enjoyment of PA is known to have a positive effect on regular participation in PA among children and adolescents^{145–147}, while the association between knowledge of health benefits and MVPA among children is minimal⁷⁹. When promoting PA to children with CHD, it is important to maintain awareness of the health benefits of PA, but also to encourage activities which are preferable and enjoyable, in order to successfully facilitate regular PA into their everyday lives. In the current study, many participants expressed an interest in continuing the intervention, as well as trying other types of sports and activities. One might not expect the same type of positive response towards PA following a traditional cardiac rehabilitation program, where interventions are typically focused on improving health outcomes. Thus, interventions to promote PA among children with CHD should align with their current lifestyle; consisting of more time dedicated to childhood play and socializing with peers, rather than fitness training. Given the observed enjoyment among

participants in the current study, the *Sportball* program aligns well with this perspective, contributing to its appropriateness for children with CHD to participate in PA.

6.3) “*I don’t think I should worry about my health*” - When medically necessary restrictions must be considered.

It is common that children with complex diagnoses of CHD are restricted from competitive sports⁵⁷, as demonstrated by the 8 participants in the current study (73%) who were given activity restrictions by their cardiologist. These restrictions are often based on pathophysiological limitations that are expected with continuous, high intensity PA. There can also be increased risks associated with high isometric or dynamic stress placed on cardiac muscle, altered blood pressure response and coronary artery blood flow. Other circumstances, such as medication (i.e. antithrombotics) or device implementation, require activity restrictions to prevent hard impacts associated with sports (i.e., football, rugby, competitive hockey). Although sudden cardiac death can occur among children with CHD¹⁴⁸, the risk is very small and there is limited evidence of its association with MVPA⁹. Regardless, the immense tragedy associated with such an event warrants restriction as a preventative measure. For their patients with CHD, restriction from sport can become a fine line for physicians; distinguishing potentially harmful, strenuous sporting activities from those which encourage play for “fun”, maintain cardiac health and develop positive psychosocial skills. This line can be difficult to determine and is highly variable depending on individual factors, cardiovascular or cardiopulmonary responses or sequelae and possible co-morbidities^{9,11}. Nonetheless, the current study provides a detailed understanding of what can be expected during a non-competitive, multi-sport program among a group of children with CHD, many of whom are restricted from competitive sports.

If asked to elaborate on what is meant by “competitive sport”, cardiologists usually refer to high intensity, organized team sports which test the physical limits of the participant, particularly during high intensity training regimens¹¹. Unfortunately, this distinction is not always made clear and can result in recreational and/or team games to also be interpreted as “competitive” sports. Thus, the distinction from the cardiologist, whether the restriction is based on intensity or contact, should be made with the patient and their family, in order to decide which activities would be most appropriate⁹. When this distinction is not made, it may cause the child to hesitate and feel nervous when reflecting on their engagement in community sport (e.g., ball hockey with neighbours, basketball with peers at school). In the current study, there was a noticeable contrast between John and Julia’s response to the question: “What would you tell another child in the Cardiology clinic who is worried about their heart when participating in physical activity?”; one was hesitant to reply while the other was quick to mention that there was no need to worry. Throughout the intervention sessions, both participants appeared confident and comfortable with their level of participation, recognizing and seizing opportunities for rest when needed. However, the difference in their responses during the focus group indicates that perhaps John was more hesitant and had complex feelings towards participating in PA and sport after having to reflect on his own experiences with his cardiologist. The contrast between his response during the group discussion and his enthusiasm during the program itself may indicate his comfort level with PA, as he was aware that his participation in *Sportball* was deemed safe by his cardiologist. Similarly, when he spoke about his feelings while playing hockey, he indicated his excitement when he would score a goal with his “special needs” team. As mentioned previously, Julia, who was told by her cardiologist only to pace herself with activities, did not appear to have any complex feelings towards PA when asked the same question above.

One notable observation of the current study was that participants were able to determine for themselves when to take necessary breaks. For children with CHD who are recommended to pace themselves during PA, these self-imposed periods of rest were valuable for informing the appropriateness of *Sportball* among this group. Although they were not implemented into the current intervention, self-regulation techniques may be helpful tools for children with CHD who need to monitor their activity intensity while participating in recreational sport and community-based PA. For example, the use of the “talk test” (i.e. maintaining conversation while engaging in activity) is a valid and reliable method for monitoring exercise intensity in healthy individuals and those with cardiovascular disease¹⁴⁹, and has also been recommended⁹ for children with CHD to maintain activity at a sub-maximal intensity. Once the need for rest is identified by a child with CHD, being in an environment where there is minimal perceived pressure from peers, teachers or coaches to maintain participation is essential. Without emphasizing the importance of winning among participants, *Sportball*’s curriculum focuses on developing individual and team sport skills, making it an ideal environment for a child with CHD who needs to monitor their activity intensity.

The current study also demonstrates that *Sportball* may be an appropriate program for children with CHD who are not permitted to play contact sports, where hard impacts to the body could lead to adverse events (i.e., pacemaker malfunction, damage of cardiac tissue, bleeding injury from anticoagulant use). However, this would not be without some modification. Based on the most current guidelines^{9,11}, there were 4 participants (37%) in the current study with morbidities that warranted restriction from contact sports. When planning the intervention sessions, the researcher purposefully did not include football as one of the weekly sports, given the hard body impacts that are often associated with the sport. This decision did not seem to have

an impact on the overall *Sportball* intervention, as participants did not express their desire to play the sport. Similarly, not all sports would necessarily be played during a regular, community *Sportball* session, which may only run for a period of 6 weeks. In this study, additional instructions had to be given to participants by the coaches during the basketball game in order to prevent harmful collisions between children. Thus, *Sportball* coaches can be aware of these restrictions and attempt to prevent hard impacts to the chest from occurring, without disclosing the medical condition of the participant or impacting the overall delivery of the program.

Chapter 7: Potential Influences on Study Outcomes

7.1) Assumptions

Throughout various stages of this pilot, feasibility study, assumptions were present which could have influenced study outcomes. From establishing the study design, recruiting participants and approaching the analyses of the data, various assumptions (described below) were considered and contributed to the overall results of this project. Future intervention studies for children with CHD should consider such influences when evaluating the outcomes and effectiveness of participating in a community-based PA or sports program.

Participant Recruitment and Demographics. A purposive sampling distribution was used in the current study based on recognized differences in age, sex and cardiac diagnoses, as well as considerations on who would be most likely to benefit from the chosen intervention (i.e., children who have received PA counseling during previous clinic visits). Given the limited sample size, this study was successful at achieving a relatively even distribution of participants by sex and age (Table 2). Children engaged in PA are rarely specialized in one sport or activity during the elementary school years (i.e., 7 to 10 years); more often, children are being introduced to different types of PA available to them through structured, community-based programs (i.e., swimming, skating, gym class.). This assumption informed the age-based inclusion criteria of the current study. Introducing different sport opportunities to children allows them to accumulate various PA experiences, ultimately influencing their future behaviour¹⁵⁰. The current study sought to introduce young, school-aged children with CHD to various activities and sports which they could fully participate in, with the intention of encouraging their continued interest and participation in a physically active lifestyle. This is especially important as children eventually

approach adolescence, where PA behaviour has a tendency to decline¹⁵¹. For children with CHD, the benefits of continued PA throughout childhood and adolescence are crucial to maintaining an overall good quality of life.

Regarding cardiac condition, children with moderate to high complexities of CHD were asked to participate in this study, thus excluding a large demographic of children with simple diagnoses of CHD (i.e., atrial septal defect, isolated valvular disease). Due to the severity and pathophysiology of their diagnoses, children with complex CHD have more frequent clinical encounters and a diminished exercise capacity compared to those with simple lesions. Given those experiences, it was reasoned that children with more complex diagnoses would have different facilitators and more barriers towards participation in PA than those with simple heart defects. Complexity of an individual's cardiac condition, including any medically necessary restrictions from PA, was also considered while informing and interpreting the data. Ability to obtain cardiologist approval for study participation determined which participants were recruited for this pilot, feasibility study and influenced the observed outcomes. No participants in the current study were at risk of syncope during moments of exertion, which would have likely influenced the feasibility of the intervention given the level of exertion reported by participants. Certain diagnoses were also deemed inappropriate for participation by cardiologists, including moderate aortic stenosis and moderate mitral valve regurgitation. Therefore, although there are many other options for children who wish to participate in PA⁹, the feasibility results of this study would likely not apply to children who have specific limitations on exercise intensity (i.e., cannot increase heart rate past a certain threshold), given the variety of highly dynamic and static movements embedded within the games and exercises of the program.

Throughout the study it was noted that, despite not meeting daily activity recommendations (mean MVPA at baseline, 47.72 ± 17.70), most participants were still quite engaged in regular PA. The children spoke about previous experiences with sports and playing with friends or family, as well as from accelerometer data collected. This could have affected secondary outcomes on physical literacy, specifically for the physical competence and/or daily behaviour domains. Increased exposure to and practice with sport-specific skills, particularly in physical education classes or sports teams, could have influenced the trend observed in motor skill at post-intervention. Furthermore, regarding daily PA behaviour, had participants been extremely sedentary at baseline there may have been more defined changes in subjective or objective MVPA after participation in the intervention. One factor which could have influenced activity levels observed among participants in the current study was the perspective of their parents and caregivers. Parents, as discussed in Chapter 6, are instrumental in providing opportunities for PA and influencing the overall activity levels of their children¹³⁰. Reasons why families chose to participate in the study were not specified. One may view the willingness of parents or caregivers to enroll their children with CHD in the current study as speaking to the value they place on the overall importance of PA for their child. Since parents were aware that participation in the intervention had been pre-approved by their cardiologist, it is also possible that they were more inclined to allow their child's participation in the *Sportball* study, versus a similar community sport program. Conversely, parents who were comfortable with their child's engagement in PA and who recognized the many health benefits of participation in PA may have been inclined to enrol in the study in an attempt to contribute to research for other children with CHD.

Study Design. Methodological considerations were made with regards to the selection of the pre/post-test design, frequency and duration of intervention sessions and epistemology. Such considerations influenced the overall experience of participants during the intervention, which in turn, informed the results. The *Sportball* program was specifically chosen for this study as the PA intervention for children with CHD based on previous findings regarding motor skill deficits^{25,26,34}, sedentary behaviour^{24,43,74} and activity restrictions^{8,9,129}. Using the structured, pre-determined lesson plans of *Sportball* allowed the researcher to minimize personal biases while delivering each intervention session, and any changes that were made to the lesson (i.e., changing the format of the “marathon”) were still within the scope of the *Sportball* curriculum. For all activities, there are adaptations or alternatives that can be introduced, depending on the group dynamics of the class; these alternatives were chosen by the researcher when necessary (i.e., obstacle course relay race instead of regular race). Conversely, the curriculum would sometimes limit the amount of time spent in specific activities in an effort to carry out the entire lesson plan for that session. Such decisions on lesson plans and modifications were made based on participants’ overall feedback (i.e., level of fatigue, overall interests) as well as observations made by the researcher. Thus, participants’ communicated feelings and biases of the researcher both influenced when and what type of modifications were made to the original lesson plans. This approach mirrors on-going *Sportball* programs, which are designed to best suit the needs, skill level and understanding of each individual class.

Furthermore, it is hypothesized that a more frequent intervention would have resulted in greater improvements in motor skill and some improvement observed in MVPA. Previous studies evaluating the effectiveness and feasibility of cardiac rehabilitation programs for similar groups of children with CHD reported a duration of 2 to 3 times per week over a period of 6 to

10 weeks⁶³. Although these programs were designed to improve fitness outcomes (i.e. VO₂), some interventions that included motor skill components saw significant improvements after study completion⁹⁸. Given the observed trend in the data towards an improvement in motor skill, when combined with the skill-based activities of the *Sportball* program, it is likely that a greater frequency of intervention sessions would have resulted in statistically significant improvements in gross motor skill among an adequately sized sample. However, the decision to complete study activities within a shorter period required a relatively short term commitment from participants and their families, who were commuting every week to the intervention. With a longer intervention period (i.e., greater than 4 months) it is possible that even fewer children with CHD would have been recruited for participation.

Data Collection. The researcher's involvement throughout the current study had an overall influence on how the data were collected through field notes, focus group questions and possibly during maximal tests. Helping to deliver the intervention as a “coach” enhanced the quality of the field notes, by allowing the researcher to report direct communication with participants while they were engaged in the *Sportball* classes. The field note observations were instrumental to informing the overall appropriateness of the intervention among this cohort. The researcher's involvement also allowed for relationships to be established with participants and their families throughout the 12-week study period. Thus, participants became familiar with the environment in which the testing took place and may have felt more comfortable presenting ideas during the post-intervention focus group, where the *Sportball* program was discussed. Conversely during the baseline testing, participants were only familiar with the researcher from their mutual association with CHEO. This may have influenced what was mentioned during the baseline focus group, as the discourse was more health-oriented. The influence of the

researcher's presence on qualitative data collected is further supported by the greater amount of dialogue in the post-test focus group when compared to the baseline focus group. Furthermore, the shift in discourse from pre- to post-test (i.e. health-oriented to PA for fun) may have been influenced by the researcher's presence and enthusiastic delivery of the PA interventions. We attempted to minimize biased responses from participants by having a graduate student, unrelated to the project and with prior experience interviewing children, deliver the probes at baseline and the main discussion questions at post-test.

Interestingly, participants did not explicitly mention their cardiac diagnosis, living with a heart defect or how it influenced their own experiences. However, their cardiac status was likely implied when some participants pointed to signs of exertion during PA and when one participant discussed parental restrictions. It can be speculated that participants' understanding of the context of the study and the researcher's affiliation with CHEO did not make them feel as though they had to disclose their CHD diagnoses during the discussion on PA. The epistemology used throughout the current study, interpretivism, was selected to consider the lived experiences of children living with CHD as they participated in the study. Therefore, without any indication of how they felt about their cardiac condition, it was difficult to adopt this epistemology for data analyses. Most questions asked during the focus groups were chosen to gain an understanding on the overall PA experiences of our sub-sample of participants (appendix A). However, an extra question was added to the semi-structured interview guide for the post-intervention focus group, in an attempt to probe participants to discuss their experiences with CHD and PA. The question chosen was a hypothetical scenario which allowed participants to think broadly about participating in PA with CHD (appendix A, question #5). Participant illustrations were also included as a way for them to communicate answers and maintain their attention to the

discussion. Having participants explain their answers through illustration provided more context and improved the trustworthiness of the data.

The researcher's presence during the CAPL testing may have also influenced the physical competence outcomes, specifically during the maximal tests. For example, a total of 3 participants held the plank position for a shorter period of time at post-test when compared to baseline (Chapter 5, Figure 2b). One hypothesis for this decline is that participants did not truly hold the plank position to the maximum of their capability, as the researcher administered the plank test to those specific participants. Perhaps their willingness to maintain the plank position for a longer period of time was decreased due to their relationship with the researcher, whom they may have assumed from previous experience during the *Sportball* program, would not push them to their maximal capacity. All other participants ($n = 6$) increased time spent holding the plank position at post-test, which was administered by a graduate student who was not involved in delivering the intervention.

Data Analyses. The theoretical framework used for the thematic analyses of the data was social cognitive theory (SCT). From a glance, SCT is a broad representation of how various factors influence and are influenced by a particular behaviour (i.e. engagement in PA). With any theoretical framework there are numerous assumptions to consider, including SCT; that one's behaviour is goal-oriented, self-regulated and that individuals are self-reflective¹⁵². However, the main and largest assumption of SCT is that an individual's environment, personal attitudes, and behaviour all influence and determine one another in a reciprocal fashion. This assumption is what guided the deductive analysis, throughout the processes of reviewing, defining and reporting emerging themes. Although themes from the current study have been categorized,

determinants of behaviour within the overall SCT perspective are quite broad in nature, allowing the researcher to maintain an interpretivist approach of applying individual experiences to an existing behavioural theory.

Through an extensive review of the literature on PA facilitators, barriers and influences, there were numerous findings on the overall sedentary lifestyles of children living with CHD^{9,24,43,74}. Furthermore, reviewing the medical charts of participants before baseline testing allowed the researcher to be well informed on the physiological considerations, exercise restrictions and presence of any motor skill deficits which may have impacted participation in the *Sportball* intervention. Thus, the researcher began the study holding pre-conceived assumptions about participants' PA behaviours, based on the details which emerged from the literature and medical chart reviews. These assumptions had a clear influence on how the field notes were written (i.e. observing how Charlotte trapped the ball given her restrictions from hard impacts) and how context was added to the focus group data (i.e. restrictions that were placed on some participants but not others, and how those restrictions may have influenced perceptions of PA). However, it can be argued that holding those prior assumptions allowed for a more subtle analysis of the data¹⁵³. For example, knowledge of previous clinical encounters (i.e. PA counselling) was drawn upon to help explain contrasting findings on environmental influences to PA behaviour, such as knowledge of health benefits and parental influences.

The researcher also had to consider her own biases, based on personal experiences participating in PA and living with a mild, corrected CHD. A bracketing interview was conducted prior to recruitment for the current study, in an attempt to uncover any unconscious assumptions which could have unknowingly influenced the data. Assumptions based on the

researcher's own experience with a mild CHD, knowledge of the health benefits of PA and both positive and negative experiences with PA were all recognized and could have influenced what types of themes emerged from the data. For example, the researcher had to recognize that while she could relate to participants in having a cardiac condition, the personal experiences surrounding mild versus more complex CHD are vastly unique. This is why the researcher chose not to disclose her own CHD to participants initially, and was a perspective that she remained aware of throughout the analysis. Furthermore, the positive perspective the researcher held towards PA influenced how she delivered the intervention. For example, the researcher brought her personal background as a dancer to connect with one of the participants, who felt discouraged about her ability to play sports. This participant communicated that she preferred dance over sports, prompting the researcher to connect her own experiences in dance to similarities in sports and games, in an attempt to keep the participant engaged in the program. By recognizing and remaining aware of her biases, the researcher was able to consciously seek alternative perspectives which existed outside of her own experiences with CHD and PA as she went through analyzing the data.

7.2) *Group Dynamics*

Interactions between individuals present during the intervention (i.e. participants with CHD, siblings, coach, researcher) influenced the primary study outcome of appropriateness, for both enjoyment and feasibility. Firstly, interactions between participants could have made the intervention experience more or less enjoyable. In the current study, field note data detail friendships formed between participants which likely influenced overall enjoyment of the program. Furthermore, most observed friendships were not necessarily between participants of a similar age or ability. Although not observed among this group, it is likely that negative

interactions between children (i.e. fighting, bullying), which are rare in *Sportball* classes, would have made the intervention less enjoyable for participants.

Weekly interactions between facilitators (i.e. coach, researcher) and participants also influenced the feasibility component of the primary outcome. Parents were not permitted to remain in the gymnasium during the intervention; a policy which is typical of *Sportball*'s programming. Thus, the researcher and/or the coach were the main authoritative figures and supervisors throughout the intervention sessions. Positive reinforcement was often given to participants, in an attempt to encourage them through activities and skills. This type of reinforcement is typical of regular *Sportball* coaches and could have influenced individuals' continued participation and engagement in the intervention; a positive perception towards the researcher, but perhaps not the intervention itself, may have also made the study enjoyable for participants. It is important to recognize that each *Sportball* coach has their own unique approach to connecting and instructing their classes. Therefore, the positive relationship between the participants and the coaches/researcher may have changed had another coach been instructing the session.

Finally, participants' siblings were sometimes engaged in the intervention session activities, which helped inform the appropriateness of the intervention for children with CHD. Although initially intended for children with CHD, some parents communicated an unwillingness or inability to participate in the study without having the siblings present. However, by allowing siblings of a similar age (between 7 to 10 years) into the intervention, the researcher was able to observe interactions and differences between participants and their siblings during the games and skills. These observations were added to the field notes and helped

inform the appropriateness of the intervention for children with CHD who may participate in an integrated *Sportball* program outside of the current study. Furthermore, close relationships between siblings could have influenced the enjoyment of the intervention for some participants, who communicated their excitement about including their brothers or sisters in the program.

7.3) Limitations

Although the main objective of the current study did not require a minimum number of participants to obtain adequate power for statistical analyses, presented outcomes are still limited by a small sample size. Based on the results of the current study, a sample of 28 participants would provide sufficient power¹⁵⁴ for observed differences in motor skill. Low enrollment in the study was largely due to scheduling conflicts and the inability to commit to 12 weeks of study participation at a fixed date and time. Only four participants were included in the focus group component of the first *Sportball* session, due to the purposive, age-based sampling method enforced by the researcher (i.e., 8-9 years of age). Despite only having 37% of the total cohort participate in the focus group, important information emerged from the dialogue regarding participation in *Sportball* and PA behaviour. Although these statements cannot be generalized to represent the whole cohort or population, they do provide insight on how different lived experiences may impact some children with CHD as they participate in community-based PA programs. Additionally, findings from the detailed field notations taken at the end of every intervention session contributed to determining the primary objective, appropriateness of the intervention, for the remaining 63% of participants.

The frequency and duration of the intervention also limited the results of the current study. A small decline in MVPA was observed (Chapter 5, Figure 4), which could have been due

to the seasonal timing of the study. Variation in PA across different seasons is well documented¹⁵⁵ and most participants ($n = 6$) were enrolled in the *Sportball* intervention during the Autumn months; a time when children are in school during the majority of the day and outdoor play is less accessible (i.e., requires proper attire, sunset occurs earlier). Data from the post-intervention focus group indicated that this decline in MVPA may not have been perceived subjectively, as participants mentioned frequently playing outside in the snow. It is hypothesized that improvements in MVPA may have also occurred with more frequent interventions, as observed in previous studies with otherwise healthy children¹⁶ and children with CHD¹⁵⁶. Due to scheduling conflicts and barriers from family dynamics observed during the study and upon recruitment, it is unlikely that a longer time commitment would have been feasible for this study. However, most *Sportball* programs are scheduled once per week for a period of 6 to 12 weeks. Therefore, the duration and frequency of the intervention sessions in the current study accurately imitated a regular, community-based *Sportball* program.

Finally, the researcher was not able to obtain complete CAPL data from all participants, limiting the secondary results presented on physical literacy outcomes. Not all participants completed the questionnaires; two participants began, but refused to complete the questionnaire due to difficulties with reading comprehension and attentional focus; another two participants arrived one hour late for the testing session, which did not leave enough time for them to complete the questionnaire. Although a shorter CAPL questionnaire now exists, at the time of the current study only the long form was available. For those who arrived late to the testing session, questionnaires were distributed to be completed at home and follow up was pursued. However, one form was sent back incomplete and contact with the second participant was lost. Future studies using the same assessment protocol should consider designating more than the 2 hours to

complete the CAPL and/or scheduling an alternative testing session to account for any missing data. The motivation and confidence domain of the CAPL was determined via questionnaire and completed by 56% ($n = 5$) of those who participated in the full study protocol ($n = 9$). Despite this missing component, a total physical literacy score was still derived for most ($n = 8$) participants using a statistical approach defined by the CAPL¹⁰⁹. One participant was missing complete data from two components, therefore preventing a total score from being calculated. The daily behaviour domain of the CAPL was the other component which yielded incomplete results among participants, due to a device malfunction with the accelerometer ($n = 1$) and the perceived similarity of the device to an intrusive medical device (i.e. Holter monitor, $n = 1$). The researcher was, however, able to collect complete data on physical competence outcomes and evaluate overall trends in physical literacy components. This knowledge contributed to a preliminary understanding of the potential advantages on physical literacy outcomes associated with participation in a community-based PA intervention, *Sportball*, among a group of children with CHD.

Conclusion and Future Considerations

During a time when Canadian children are experiencing dangerously sedentary lifestyles, it is imperative to provide inclusive opportunities for them to regularly engage in and enjoy PA. Regular participation in sport and PA can give children the foundation to remain active throughout their lifespan, thereby reducing their long term risk of acquiring further cardiac disease. Unfortunately, children with moderate to complex diagnoses of CHD are among those with the greatest risk of developing serious morbidities from highly inactive lifestyles. The current pilot, feasibility study sought to explore the appropriateness of implementing a community-based PA program, *Sportball*, among school-aged children with CHD. The knowledge gained from this research contributes to existing literature on the promotion and prescription of PA to children living with cardiac disease, while providing evidence of an appropriate and potentially beneficial, community-based program for participants with CHD.

For most participants enrolled in the intervention, attendance was well maintained throughout the study period. Despite known physiological and anatomical barriers, attentional deficits and motor skill delays, children with CHD in this study were able to maintain participation in *Sportball* without requiring major modifications to program delivery. Enjoyment of *Sportball* by participants was an important consideration in determining the appropriateness of the intervention among children with CHD, who may feel discouraged while participating in regular PA with peers. The modality of the *Sportball* classes and feelings of inclusion communicated by participants were found to contribute most to their overall enjoyment of the program.

A secondary objective of this pilot project was to evaluate the potential effect of *Sportball* participation on physical literacy outcomes among children with CHD. Given the limited number of participants and minimal dosage of the intervention, it is unsurprising that the null hypotheses remained true: no large changes were observed for total physical literacy or any of the individual domains evaluated (i.e., daily activity behaviour, motivation and confidence and physical competence) after participating in *Sportball*. However, there were differences observed in two separate outcomes within the physical competence domain; motor skill and torso strength improved in most participants with CHD. An observed difference in motor skill is an especially important preliminary finding for this population, whose motor skill deficits are well-documented and believed to further contribute to the overall sedentary lifestyles observed among individuals with CHD. Results suggest that more frequent participation in *Sportball* could improve the motor skills of children living with CHD, potentially attenuating the gap between healthy age-matched peers.

Qualitative findings from the current study also contributed to a tertiary objective, which explored the perceptions of children with CHD on their PA behaviour and what may have influenced their overall participation in the community-based intervention. Using SCT as a theoretical framework, it was found that social interactions, personal feelings and attitudes, environmental factors and one's perceived self-efficacy for sport were some of the main influences on participation in overall PA as well as during the *Sportball* intervention for participants with CHD. Having an understanding of these influences is beneficial because it can help identify which programs or modalities offering community-based PA may be most effective in promoting active lifestyles among children with CHD as they approach adolescence and adulthood. Participation in the *Sportball* intervention; facilitated positive social interactions

during sport, was set in a non-competitive and inclusive environment, and elicited feelings of enjoyment and success. Although it was not reflected by questionnaire results, positive influences surrounding the experience of the intervention may contribute to some improvement in perceived self-efficacy for sport among participants with CHD.

Overall, participation in the *Sportball* program is feasible for children with CHD who often have lesser capabilities in motor skill and/or cardiorespiratory fitness than age-matched peers. Findings also suggest that *Sportball* is an appropriate alternative when restrictions to competitive sport apply. For children whose cardiac condition requires them to avoid hard bodily impacts (i.e., presence of pacemakers), *Sportball* is an appropriate option for PA provided this information is disclosed to the coaches; a session can easily be modified to prevent the risk of impact without compromising the general content or enjoyment of the lesson. Finally, many children with moderate to complex diagnoses of CHD are required to pace themselves while engaging in PA or sport. In such cases, *Sportball* was shown to be appropriate for children with CHD who wish to engage in PA and sport, while allowing sufficient opportunities for rest.

Future Considerations. The current study was a preliminary evaluation of the potential benefits children with CHD may gain from participating in a skill-based, non-competitive, community PA program. The components that make up the *Sportball* curriculum make it ideal for children living with heart disease that are cleared for participation in PA but restricted from competitive sports. Results showed a trend in motor skill improvement, which is of particular interest to this population whom often have motor skill delays in childhood. A randomized controlled trial evaluating observed differences between participation in *Sportball*, other community-based PA programs and no intervention could help identify appropriate motor skill interventions for this population. Outside of the study, many participants spoke of their

engagement in other sports within recreational or semi-competitive settings (i.e., leagues for children with special needs). Future studies should explore other community-based physical activities and recreational sports, so that care providers who are involved in the promotion of PA are aware of the factors which contribute to the appropriateness of these interventions for their patients with CHD.

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Appendix A

Focus Group Semi-Structured Interview Guide

Icebreaker: “What are some of your favourite things to do with family and friends?”

Q1: “When I say ‘physical activity’, what does that mean to you?”

- What about when you’re using your imagination or creating something?
- Is there movement involved?
- Could that be a type of physical activity?

Q2: “What types of physical activity are you currently doing?”

- Are there lessons that you take at school or outside of school?

Q3: “How do you feel about participating in physical activity?”

- During gym class? At recess? On weekends? After school?
- Excited? Nervous?
- When participating in physical activity, do you find it difficult to keep up with your friends?

Q4: “Is there any activity that you’ve always wanted to try but haven’t?”

- Why not?

Q5: “Some kids that I’ve spoken to in the Cardiology clinic at CHEO say that sometimes when participating in physical activity, they worry about their heart.”

- What would you say to these kids about participating in physical activity?

Q6 (baseline): “Why do you want to participate in the Sportball classes? Are you excited or nervous about starting?”

Q6 (post-intervention): “What did you enjoy most about being in Sportball this year?”

- Is there anything that you would change about Sportball?
- Did you feel there was a difference doing the testing today compared to when we did the testing in September?
- Do you think that you would want to sign up for more after-school programs, like *Sportball*, in 2017?

Appendix B

CAPL Physical Competence Score

Taken from the “Canadian Assessment of Physical Literacy Manual for Test Administration”, pages 46 to 96; www.capl-ecsfp.ca. Permissions obtained from Dr. Patricia Longmuir of the HALO Research Group.

Physical Competence Domain Score:

$$\begin{array}{ccccccc}
 \text{Body} & & \text{Musculo-} & & \text{PACER score} & & \text{Overall} \\
 \text{composition} & & \text{skeletal fitness} & & \text{(range 10.5 to} & & \text{obstacle} \\
 \text{aggregate} & + & \text{aggregate score} & + & \text{42)} & + & \text{course score} \\
 \text{score} & & \text{(range 6 to 42)} & & & & \text{(range 1.5 to} \\
 \text{(range 8 to 34)} & & & & & & \text{42)} \\
 & & & & & = & \text{Physical} \\
 & & & & & & \text{competence} \\
 & & & & & & \text{domain score} \\
 & & & & & & \text{(range 26 to 160)/5} \\
 & & & & & & = \\
 & & & & & & \text{(range 5.2 to 32)}
 \end{array}$$

Body Composition Aggregate Score:

$$\begin{array}{ccccc}
 \text{BMI component} & & \text{Waist circumference} & & \\
 \text{score (range 3 to 17)} & + & \text{component score (range} & = & \text{Body composition} \\
 & & \text{5 to 17)} & & \text{sub-score} \\
 & & & & \text{(range 8 to 34)}
 \end{array}$$

BMI Component Score:

BMI z-score	Corresponding WHO category	Component Score
> 2.0	Obese	5
> 1.0 to ≤ 2	Overweight	12
≥ -2.0 to ≤ 1.0	Recommended	17
≥ -3 to < -2.0	Thinness	10
< -3.0	Severe Thinness	3

Waist Circumference Component Score:

Waist circumference component score

Waist Circumference (cm)	Classification	Component Score
> 84.9	Obese	5
75 to 84.9	Overweight	11
50 to 74.9	Recommended	17
<50	Thinness	11

**Based on data collected by HALO Research Team

Musculoskeletal Fitness Aggregate Score:

Grip strength (range 2 to 17)	+	Plank (range 2 to 17)	+	Flexibility (range 2 to 8)	=	Musculoskeletal fitness score (range 6 to 42)
----------------------------------	---	--------------------------	---	-------------------------------	---	--

Grip Strength Score:

Total grip strength	Component score
> 45	17
39 to 45	12
33 to < 39	7
< 33	2

Plank Score:

Plank Time(s)	Composite Score
> 127	17
86 to 127	12
46 to < 86	7
< 46	2

Flexibility Score:

Flexibility (cm)	Composite Score
> 33.7	8
> 27.7 to 33.7	6
24.1 to 27.7	4
< 24.1	2

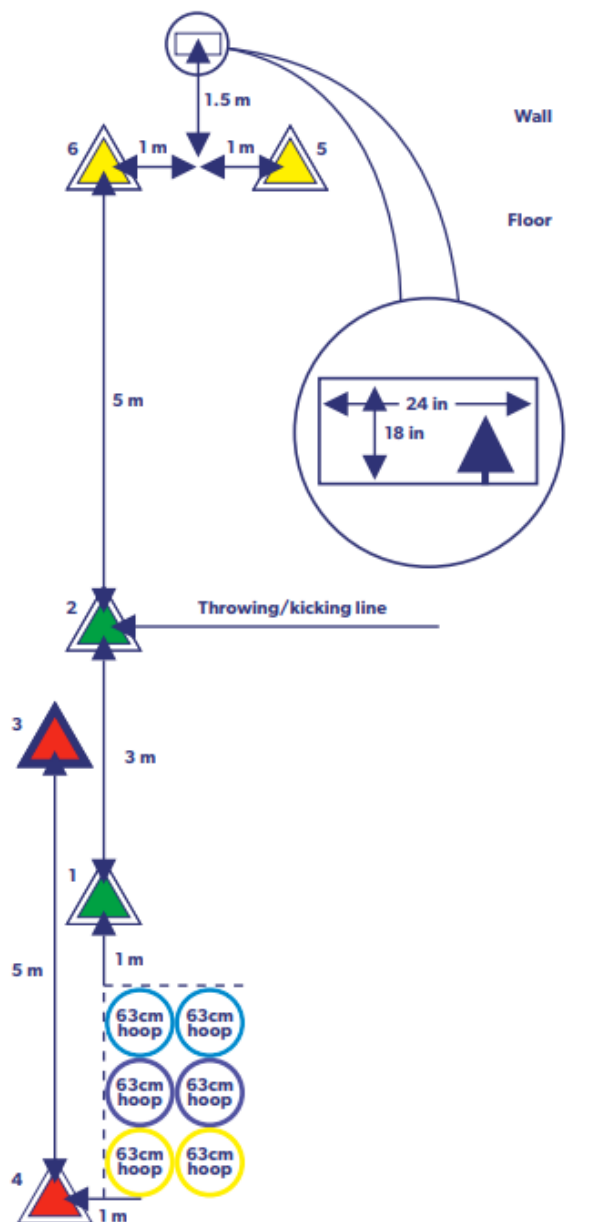
PACER Score:

20m PACER (laps)	Composite score
> 44	42
31 to 44	31.5
19 to < 31	21
< 19	10.5

Appendix C

CAMSA Schematic

Taken from the “Canadian Assessment of Physical Literacy Manual for Test Administration”, page 51; www.capl-ecsfp.ca. Permissions obtained from Dr. Patricia Longmuir of the HALO Research Group.



Appendix D

CAMSA Score and CAPL Motor Skill Score/Class

Taken from the “Canadian Assessment of Physical Literacy Manual for Test Administration”, page 58-59; www.capl-ecsfp.ca. Permissions obtained from Dr. Patricia Longmuir of the HALO Research Group.

Overall CAMSA Score:

$$\begin{array}{ccccccc} \text{Time Score} & & & & & & \\ \text{(range 1 to 14)} & + & \text{Skill Score} & = & \text{Total Obstacle} & = & \text{Best Score from Trial 1} \\ & & \text{(range 0 to 14)} & & \text{Course Score (range} & & \text{and Trial 2} \times 1.5 \\ & & & & \text{1 to 28)} & & \text{(range 1.5 to 42)} \end{array}$$

CAMSA Skill Score:

The point distribution between skills performed is as follows:

1. 2-foot Jump (range 0 to 2)
2. Sliding (range 0 to 3)
3. Catching (range 0 to 1)
4. Throwing (range 0 to 2)
5. Skipping (range 0 to 2)
6. 1-foot Hop (range 0 to 2)
7. Kicking (range 0 to 2)

The skill score is simply the total number of skills that were correctly performed, so the skill score will range from 0 to 14.

CAMSA Time Score:

Time (sec)	Score
< 14	14
14 < 15	13
15 < 16	12
16 < 17	11
17 < 18	10
18 < 19	9
19 < 20	8
20 < 21	7
21 < 22	6
22 < 24	5
24 < 26	4
26 < 28	3
28 < 30	2
≥ 30	1

CAMSA Score Classification:

	Beginning	Progressing	Achieving	Excelling
Boys and Girls (combined time and skill score)				
8 years	< 14	14 to 18	> 18 to 23	> 23
9 years	< 17	17 to 21	> 21 to 24	> 24
10 years	< 19	19 to 23	> 23 to 26	> 26
11 years	< 20	20 to 24	> 24 to 27	> 27
12 years	< 21	21 to 24	> 24 to 27	> 27

Appendix E

CAPL Questionnaire

Taken from the “Canadian Assessment of Physical Literacy Manual for Test Administration”, page 133 - 144; www.capl-ecsf.ca. Permissions obtained from Dr. Patricia Longmuir of the HALO Research Group.

Physical Activity Questionnaire:

What school grade are you in: (please circle one)

1 2 3 4 5 6 7 8

Are you a: (please circle one) boy girl

What month is your birthday: (please circle one)

Jan Feb Mar Apr May Jun Jul Aug Sept Oct Nov Dec

How old are you: (please circle one)

5 6 7 8 9 10 11 12 13 14 15

In this project, when we talk about physical activity, we mean when you are moving around, playing or exercising. Physical activity is any activity that makes your heart beat faster or makes you get out of breath some of the time.

Why are we asking you these questions? We want to know what kids like you think about physical activity, sports and exercise.

Please remember:

- There are no right or wrong answers. We only want to know what you think.
- If you do not know an answer, please write your best guess.
- There is no time limit, so please take all the time you need.

1. **How many minutes each day should you and other children do physical activities that make your heart beat faster and make you breathe faster, like walking fast or running? Count the time you should be active at school and also the time you should be active at home or in your neighbourhood.**
 - a) 10 minutes
 - b) 20 minutes
 - c) 30 minutes
 - d) 60 minutes or 1 hour

2. **Kids say there are many different reasons that they like to be active or play sports. Being active is anything that you do when you are moving, exercising or not sitting still. Below are some reasons that other kids have told us why they like to be active. For each reason, tell us what you think. If you think it is a good reason then you would "Agree a little" or "Agree a lot". If you do not think it's a good reason, then you would "Disagree a little" or "Disagree a lot". If you are not sure or you don't think the reason is good or bad then you are "in between".**

A reason that I might be active is because when I am active. . .	Disagree a lot	Disagree a little	In between	Agree a little	Agree a lot
...I look better	1	2	3	4	5
...I have more energy	1	2	3	4	5
...I feel happier	1	2	3	4	5
...I have fun	1	2	3	4	5
...I make more friends	1	2	3	4	5
...I get stronger	1	2	3	4	5
...I like myself more	1	2	3	4	5
...I get in better shape	1	2	3	4	5
...I feel healthier	1	2	3	4	5

3. Kids say there are also reasons that make it hard for them to be active. For each reason, tell us what you think. If you think it is a good reason then you would "Agree a little" or "Agree a lot". If you do not think it's a good reason, then you would "Disagree a little" or "Disagree a lot". If you are not sure or you don't think the reason is good or bad then you are "in between".

I might <u>not</u> be active if. . .	Disagree a lot	Disagree a little	In between	Agree a little	Agree a lot
...I didn't have enough time to be active	1	2	3	4	5
...I have too many chores to do	1	2	3	4	5
...I didn't have a good place to be active	1	2	3	4	5
...If the weather was too bad	1	2	3	4	5
...I didn't have the right clothes/shoes	1	2	3	4	5
...I didn't know how to do the activity	1	2	3	4	5
...I didn't have the right equipment	1	2	3	4	5
...I had too much homework	1	2	3	4	5
...I didn't have anyone to be active with	1	2	3	4	5
...I didn't like to be active	1	2	3	4	5

4. Compared to other kids your age, how active are you? (circle one number)

A lot less active Same A lot more active

1 2 3 4 5 6 7 8 9 10

5. Compared to other kids your age, how good are you at sports or skills? (circle one number)

Others are better Same I'm a lot better

1 2 3 4 5 6 7 8 9 10

6. Sometimes children watch television, play video games or play on the computer or on a smart phone. What is the most time that children should look at a screen each day? Do not count the time that you have to look at a screen to do your homework.

- a) 30 minutes
- b) 60 minutes or 1 hour
- c) 2 hours
- d) 4 hours

7. There are many different kinds of fitness. One type is called endurance fitness or aerobic fitness or cardiorespiratory fitness. Cardiorespiratory fitness means... (circle the right answer)

- a) How well the muscles can push, pull or stretch.
- b) How well the heart can pump blood and the lungs can provide oxygen.
- c) Having a healthy weight for our height.
- d) Our ability to do sports that we like.

8. Muscular strength or muscular endurance means... (circle the right answer)

- a) How well the muscles can push, pull or stretch.
- b) How well the heart can pump blood and the lungs can provide oxygen.
- c) Having a healthy weight for our height.
- d) Our ability to do sports that we like.

9. Draw a line to all the words you think describe what "Healthy" means.



10. This story about Sally is missing some words. Fill in the missing words below. Each word can only be used to fill one blank space in the story.

Fun

Endurance

Good

Pulse

Strength

Sally tries to be active every day. Running every day is good for her heart and lungs. Sally thinks that physical activity is _____ and is also _____ for her. At her sport team's practice she does more running to improve her _____. The team also does exercises like push-ups and sit-ups that increase her _____. After exercising, she checks her heart rate which is also called a _____.

11. Circle each activity that you do. If you always or almost always wear safety gear (like helmet or shin pads) when you do the activity, add a check mark inside the circle.



Snowmobiling



Swinging



Baseball



Sledding



Monkey Bars



Skipping



Swimming



Inline Skating



Skiing



Biking



Ice Skating

12. If you wanted to GET BETTER AT A SPORT SKILL like kicking and catching a ball, what would be the best thing to do? (circle one answer)

- a) Read a book about kicking and catching a ball
- b) Wait until you get older
- c) Try exercising or being active a lot more
- d) Watch a video, take a lesson or have a coach teach you how to kick and catch

13. If you wanted to IMPROVE YOUR FITNESS, what would be the best thing to do? (circle one answer)

- a) Read a book about improving your fitness
- b) Wait until you get older
- c) Try exercising or being active a lot more
- d) Watch a video, take a lesson or have a coach teach you how to improve your fitness

14. If you were allowed to pick what you do after school, which activity would you pick? (circle only one activity)

Play video/computer games

Go to my sports team's practice

Read

Walk my dog

Do homework

Chat with friends online

Play outside with my friends

Watch television

When answering the following questions (questions 15-21), please tell us about what you did LAST WEEK.

15. On a school day, how many hours did you watch TV?

- ☐ I did not watch TV on school days
- ☐ Less than 1 hour ☐ 1 hour ☐ 2 hours ☐ 3 hours ☐ 4 hours ☐ 5 or more hours

16. On a school day, how many hours did you play video or computer games or use a computer for something that was not school work?

- ☐ I did not play video/computer games or use a computer other than for school work on school days
- ☐ Less than 1 hour ☐ 1 hour ☐ 2 hours ☐ 3 hours ☐ 4 hours ☐ 5 or more hours

17. On a weekend day, how many hours did you watch TV?

- ☐ I did not watch TV on weekend days
- ☐ Less than 1 hour ☐ 1 hour ☐ 2 hours ☐ 3 hours ☐ 4 hours ☐ 5 or more hours

18. On a weekend day, how many hours did you play video or computer games or use a computer for something that was not school work?

- ☐ I did not play video/computer games or use a computer other than for school work on weekend days
- ☐ Less than 1 hour ☐ 1 hour ☐ 2 hours ☐ 3 hours ☐ 4 hours ☐ 5 or more hours

19. During the past week (7 days), on how many days were you physically active for a total of at least 60 minutes per day? (all the time you spent in activities that increased your heart rate and made you breathe hard)

- a) 0 days
- b) 1 day
- c) 2 days
- d) 3 days
- e) 4 days
- f) 5 days
- g) 6 days
- h) 7 days

20. On a school day how many hours did you spend sitting down doing non-screen based activities (e.g. reading a book, doing homework, sitting and talking to friends, drawing, etc.). Do not count the time that you sit at school.

☐ I did not spend time sitting down in non-screen based activities (e.g. reading a book, doing homework, sitting and talking to friends, drawing, etc.) on school days

☐ Less than 1 hour ☐ 1 hour ☐ 2 hours ☐ 3 hours ☐ 4 hours ☐ 5 or more hours

21. On a weekend day how many hours did you spend sitting down doing non-screen based activities (e.g. reading a book, doing homework, sitting and talking to friends, drawing, etc.). Do not count the time that you sit at school.

☐ I did not spend time sitting down in non-screen based activities (e.g. reading a book, doing homework, sitting and talking to friends, drawing, etc.) on a weekend day

☐ Less than 1 hour ☐ 1 hour ☐ 2 hours ☐ 3 hours ☐ 4 hours ☐ 5 or more hours

Thank you for your help!

CSAPPA Component Questionnaire:

For the rest of the questions you have to read 2 sentences and then circle the sentence you think is **MORE LIKE YOU**.

Try the following **SAMPLE QUESTION**:

Some kids have one nose on their face!	BUT	Other kids have three noses on their face!
--	------------	--

That shouldn't be too hard for you to decide! Once you have circled the sentence that is more like you, then you have to decide if it is **REALLY TRUE** for you or **SORT OF TRUE** for you.

Here is another sample question for you to try. Remember, first circle the sentence that is more like you and then put a check in the correct box if it is really true or only sort of true for you. THERE ARE NO RIGHT OR WRONG ANSWERS, JUST WHAT IS **MOST LIKE YOU**.

SAMPLE QUESTION #2:

Some kids like to play with computers	BUT	Other kids don't like playing with computers
☐ REALLY TRUE for me ☐ SORT OF TRUE for me		☐ REALLY TRUE for me ☐ SORT OF TRUE for me

Now you are ready to start filling in this form. Take your time and do the whole form carefully. If you have any questions, just ask! If you think you are ready you can start now.

BE SURE TO FILL IN EACH PAGE!

What's most like me

Some kids can't wait to play active games after school

☐ REALLY TRUE
for me

☐ SORT OF TRUE
for me

BUT

Other kids would rather do something else after school

☐ REALLY TRUE
for me

☐ SORT OF TRUE
for me

Some kids don't like playing active games

☐ REALLY TRUE
for me

☐ SORT OF TRUE
for me

BUT

Other kids really like playing active games

☐ REALLY TRUE
for me

☐ SORT OF TRUE
for me

Some kids don't have much fun playing sports

☐ REALLY TRUE
for me

☐ SORT OF TRUE
for me

BUT

Other kids have a good time playing sports

☐ REALLY TRUE
for me

☐ SORT OF TRUE
for me

Some kids are good at active games

☐ REALLY TRUE
for me

☐ SORT OF TRUE
for me

BUT

Other kids find active games hard to play

☐ REALLY TRUE
for me

☐ SORT OF TRUE
for me

Some kids don't like playing sports

☐ REALLY TRUE
for me

☐ SORT OF TRUE
for me

BUT

Other kids really enjoy playing sports

☐ REALLY TRUE
for me

☐ SORT OF TRUE
for me

Some kids always hurt themselves when they play sports

☐ REALLY TRUE
for me

☐ SORT OF TRUE
for me

BUT

Other kids never hurt themselves playing sports

☐ REALLY TRUE
for me

☐ SORT OF TRUE
for me

Some kids like to play active games outside

☐ REALLY TRUE
for me

☐ SORT OF TRUE
for me

BUT

Other kids would rather read or play video games

☐ REALLY TRUE
for me

☐ SORT OF TRUE
for me

Some kids are among the last to be chosen for active games. ☐ REALLY TRUE for me ☐ SORT OF TRUE for me	BUT	Other kids are usually picked to play first. ☐ REALLY TRUE for me ☐ SORT OF TRUE for me
Some kids do well in most sports ☐ REALLY TRUE for me ☐ SORT OF TRUE for me	BUT	Other kids feel they aren't good at sports ☐ REALLY TRUE for me ☐ SORT OF TRUE for me
Some kids learn to play active games easily ☐ REALLY TRUE for me ☐ SORT OF TRUE for me	BUT	Other kids find it hard learning to play active games ☐ REALLY TRUE for me ☐ SORT OF TRUE for me
Some kids think they are the best at sports ☐ REALLY TRUE for me ☐ SORT OF TRUE for me	BUT	Other kids think they aren't good at sports ☐ REALLY TRUE for me ☐ SORT OF TRUE for me
Some kids find games in physical education hard to play ☐ REALLY TRUE for me ☐ SORT OF TRUE for me	BUT	Other kids are good at games in physical education ☐ REALLY TRUE for me ☐ SORT OF TRUE for me
Some kids like to watch games being played outside ☐ REALLY TRUE for me ☐ SORT OF TRUE for me	BUT	Other kids would rather play active games outside ☐ REALLY TRUE for me ☐ SORT OF TRUE for me
Some kids like to take it easy during recess ☐ REALLY TRUE for me ☐ SORT OF TRUE for me	BUT	Other kids would rather play active games at recess ☐ REALLY TRUE for me ☐ SORT OF TRUE for me

Some kids aren't good enough for sports teams	BUT	Other kids do well on sports teams
☐ REALLY TRUE for me		☐ REALLY TRUE for me
☐ SORT OF TRUE for me		☐ SORT OF TRUE for me

Some kids like to read or play quiet games	BUT	Other kids like to play active games
☐ REALLY TRUE for me		☐ REALLY TRUE for me
☐ SORT OF TRUE for me		☐ SORT OF TRUE for me

Some kids like to play active games outside on weekends	BUT	Other kids like to relax and watch TV on weekends
☐ REALLY TRUE for me		☐ REALLY TRUE for me
☐ SORT OF TRUE for me		☐ SORT OF TRUE for me

Thank you for your help!

Appendix F

CAPL Daily Behaviour Score

Taken from the “Canadian Assessment of Physical Literacy Manual for Test Administration”, pages 26 to 43; www.capl-ecsfp.ca. Permissions obtained from Dr. Patricia Longmuir of the HALO Research Group.

CAPL Daily Behaviour Domain Score:

Pedometer steps component score (range 0 to 21)	+	Total screen time component score (range 0 to 8)	+	Weekly time spent in MVPA component score (range 0 to 3)	=	Daily behaviour (range 0 to 32)
---	---	--	---	---	---	---------------------------------

Step Count Component Score:

A given number of steps on an **individual day** are assigned a numerical value:

Number of steps	Numerical value
15,000 or more	6
12,000-14,999	5
9,000-11,999	3
6,000-8,999	1
Fewer than 6,000	0

After any missing days are estimated using the random number process described above, the numerical values for each day are summed and then divided by 2 to give the final pedometer score (range from 0 to 21 points).

For example:

Day	Number of steps reported	Score for the day
Monday	14,365	5
Tuesday	9,504	3
Wednesday	12,003	5
Thursday	7,461	1
Friday	16,221	6
Saturday	15,000	6
Sunday	6,978	1
	Sum of scores	27
	Pedometer composite score (sum of scores/2)	13.5

Screen Time Component Score:

To calculate the sedentary behaviour score, screen time is inferred from the responses to the following questions on the physical activity questionnaire:

Q15: On a school day, how many hours did you watch TV?

Q16: On a school day, how many hours did you sit down to play video or computer games or use a computer for something that was not school work?

Q17: On a weekend day, how many hours did you watch TV?

Q18: On a weekend day, how many hours did you sit down to play video or computer games or use a computer for something that was not school work?

The total screen time on a school day is summed (Q15 + Q16) and assigned a component score:

Number of hours of screen time on a weekend day (TV + computer/video games)	Component score
< 2 hours	4 (meeting guidelines)
2 to < 4 hours	2 (above guidelines)
≥ 4 hours	0 (excessive screen time)

Then the total screen time on a weekend day (Q17 + Q18) is summed:

Number of hours of screen time on a weekday (TV + computer/video games)	Component score
< 2 hours	4 (meeting guidelines)
2 to < 4 hours	2 (above guidelines)
≥ 4 hours	0 (excessive screen time)

Component score for weekend day (range 0 to 4)	+	Component score for weekday (range 0 to 4)	=	Total screen time component score (range 0 to 8)
--	---	--	---	---

Self-Perceived Activity Score:

Boys and Girls (measures in # of days)	
Number of days child reports at least 60 minutes of physical activity	Component score
6-7	3
4-5	2
2-3	1
0-1	0

Appendix G

CAPL Motivation & Confidence Score

Taken from the “Canadian Assessment of Physical Literacy Manual for Test Administration”, pages 109 to 112; www.capl-ecsfp.ca. Permissions obtained from Dr. Patricia Longmuir of the HALO Research Group.

Overall Motivation & Confidence Domain Score:

CSAPPA* adequacy score (range 1.5 to 6)	+	CSAPPA* predilection score (range 1.5 to 6)	+	Benefits: Barriers ratio (range -4.7 to 4)	+	Q4 (range 0.1 to 1)	+	Q5 (range 0.1 to 1)	=	Motivation & Confidence domain score (range -1.5 to 18)
--	---	--	---	---	---	------------------------	---	---------------------------	---	--

Benefits-to-Barriers, Q4 & Q5 Scoring:

Q2: Reasons to be physically active

- Scale 1-5 (9 questions)
- Possible total of 45

Q3: Reasons not to be physically active

- Scale 1-5 (10 questions)
- REVERSE SCORED (i.e., if a child circles a 1, they score 5; if they circle a 5 then they score 1 etc.)
- Possible total of 50

Scoring Q2 and Q3:

- The scores for the responses to the “reasons to be physically active” and “reasons not to be physically active” questions are combined to create a perceived benefit to barrier ratio towards physical activity (Garcia et al., 1995)
- Benefits to barriers ratio (-41 to 35) = Total for Q2 (9-45) – Total for Q3 (10-50)
- Total score (-4.7 to 4) = (benefits to barriers ratio/8.75)

Q4: Activity level compared to peers

- Divide the number circled by 10
- (1-10)/10

Q5: Skill level compared to peers

- Divide the number circled by 10
- (1-10)/10

CSAPPA Adequacy Score:

	Really true for me	Sort of true for me	Really true for me	Sort of true for me	
Some kids are good at active games	4	3	1	2	Other kids find active games hard to play
Some kids are among the last to be chosen for active games	1	2	4	3	Other kids are usually picked to play first
Some kids do well in most sports	4	3	1	2	Other kids feel they aren't good at sports
Some kids learn to play active games easily	4	3	1	2	Other kids find it hard learning to play active games
Some kids think they are the best at sports	4	3	1	2	Other kids think they aren't good at sports
Some kids find games in physical education hard to play	1	2	4	3	Other kids are good at games in physical education
Some kids aren't good enough for sports teams	1	2	4	3	Other kids do well on sports teams
Total adequacy score (sum of questions)					

CSAPPA Predilection Score:

	Really true for me	Sort of true for me	Really true for me	Sort of true for me	
Some kids can't wait to play active games after school	4	3	1	2	Other kids would rather do something else after school
Some kids don't like playing active games	1	2	4	3	Other kids really like playing active games
Some kids don't have much fun playing sports	1	2	4	3	Other kids have a good time playing sports
Some kids don't like playing sports	1	2	4	3	Other kids really enjoy playing sports
Some kids like to play active games outside	4	3	1	2	Other kids would rather read or play video games
Some kids like to watch games being played outside	1	2	4	3	Other kids would rather play active games outside
Some kids like to take it easy during recess	1	2	4	3	Other kids would rather play active games during recess
Some kids like to read or play quiet games	1	2	4	3	Other kids like to play active games
Some kids like to play active games outside on weekends	4	3	1	2	Other kids like to relax and watch TV on weekends