Understanding Physical Activity from the Perspectives of Children with Complex Heart Defects, Their Parents and Their Cardiologists

by

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Abstract

Children with complex heart defects lead sedentary lives that limit involvement in peer activities, impact their growth and development, and jeopardize their long-term health. The goal of this research was to better understand the factors that influence daily moderate-to-vigorous physical activity (MVPA), which is associated with physical and psychological health. The physical activity levels of 64 children (25 female, 5 to 11 years of age) with a single pumping chamber in the heart were measured by accelerometry. Fitness and gross motor skill measures and medical history information were analyzed to identify factors associated with MVPA participation. Increased activity was related to the use of antithrombotic medication, spring season of the year, better motor skill and male sex. Group and individual discussions further explored psychosocial influences on the children’s level of MVPA. The children indicated physical activity was primarily motivated by having fun and being with their friends, while other children being more skilled discouraged participation. Parents of children with complex heart defects had dramatically different perceptions. They believe their child’s activity is primarily influenced by
the heart condition and report often feeling uncertain about which activities are appropriate for their child. Finally, sources of parental uncertainty were examined by comparing the physical activity advice provided by the cardiologist to parent reports of the child’s activity restrictions, a content analysis of published activity guidelines and interviews with paediatric cardiologists. Parent uncertainty about activity was supported by the lack of agreement between parent and cardiologist reports of medically necessary activity restrictions. Parent reports of vague or variable activity advice were reflected in the published literature and cardiologist perspectives on activity counselling. These results suggest enabling children with complex heart defects to achieve an active lifestyle may rest on ensuring that the child and parents have appropriate physical activity beliefs and expectations.
Acknowledgments

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The support and guidance of my primary supervisor, Dr. Brian McCrindle, and my advisory committee members, Dr. Mary Corey, Dr. Guy Faulkner and Dr. Beverley Antle, was also critical to the success of this research. I will always appreciate their willingness to guide my research interests in a way that greatly increased my expertise and independence as a researcher.

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Chapter 1
Research Overview
Background and Rationale

Children with complex heart defects lead sedentary lives that limit peer interactions and impact their growth and development. Their sedentary lives also have the potential to jeopardize their long-term health, by increasing their risk for atherosclerosis, diabetes, hypertension and obesity. Exercise training programmes can increase the physical fitness of these children, but such training appears to have little long-term impact on daily physical activity. Research has demonstrated that daily moderate-to-vigorous physical activity is associated with physical and psychological health. The goal of this research was to better understand the factors that influence physical activity in the lives of children with complex heart defects in order to identify effective targets for future interventions to increase the daily physical activity of these children.

Functional single ventricle is the most complex type of congenital heart defect. Most congenital heart defects can be surgically treated by closing holes, replacing valves or repositioning blood vessels. For the child born with only one functional pumping chamber (ventricle), instead of the normal two, there are only two treatment options. Either they receive a heart transplant or they undergo a series of surgeries culminating in the Fontan procedure. The Fontan procedure separates the pulmonary and systemic circulations so that blood returns directly to the lungs and the one pumping chamber of the heart is used to pump blood to the body. As they are living with the most complex heart defect, children who have had the Fontan procedure were the focus of this study to investigate the factors that influence their physical activity participation.

Identifying Factors Associated with Physical Activity Participation

Initially, the physical activity levels of children with a single ventricle (Fontan) were objectively measured via accelerometer. Additional measurements of physical fitness and gross motor skill, and detailed information about each child’s medical history were analyzed in order to identify factors associated with moderate-to-vigorous physical activity participation among children who have the Fontan procedure. The 64 children (25 female, ages 5 to 11 years) completing the accelerometer assessments performed 356 ± 136 minutes of moderate-to-vigorous physical activity per week. Higher levels of physical activity were related to the use of antithrombotic medication, spring season of the year, better motor skills, and male sex. Taken together, these
factors explained 28% of the variation in time spent in moderate-to-vigorous physical activity each week by this group of children.

Understanding Parent and Child Perspectives

Group and individual discussions further explored the variability in activity participation among children with complex heart defects. Focus groups were held separately with children who have complex heart defects and their parents. Additional child/parent dyads were interviewed individually until saturation of the responses was achieved. The children indicated that their physical activity participation was primarily motivated by having fun and being with their friends. Feeling that other children were better or having other children comment on their limited abilities were reasons that discouraged the children’s active participation. The parents of children with complex heart defects had dramatically different perceptions. They believe that their child’s physical activity participation is primarily influenced by their medical condition. Parents indicated that they often feel unsure about whether a particular activity is appropriate for their child. Results of this study suggest that uncertainty about appropriate physical activity influences not only the types of physical activity experiences that parents provide for their child, but also the child’s perception of their own ability to be physically active.

Influence of Professionals and Medical Treatment

In order to explore the source of parental perceptions of uncertainty, the influence of medical professionals and the impact of treatment were investigated in greater detail. Initially, the physical activity guidance provided by the cardiologist was compared to parent reports of a child’s physical activity restrictions. Subsequently, a content analysis of published activity guidelines for children who have the Fontan procedure and interviews with paediatric cardiologists responsible for their care were completed. Parental perceptions of uncertainty about physical activity were supported by a lack of agreement between parent and cardiologist reports of the medically necessary activity restrictions. Parental reports of vague advice that is difficult to interpret were reflected in the guidelines available in the published literature, which are the basis for the recommendations made by the cardiologists. Interviews with cardiologists indicated that they are aware of the important role that they play in establishing physical activity expectations for the children under their care. They also indicated that they believe their ability
to provide effective physical activity counselling is often hampered by factors that are beyond their control. These factors include poor quality or conflicting published guidelines, that people only hear what they want to hear or only retain 10% of what they hear, and that parents prioritize receiving information about or discussing their child’s medical status rather than their physical activity or play with peers.

**A Future of Physical Activity Priority and Certainty**

Results from this research suggest that the most effective way to enable children with complex heart defects to adopt and maintain a physically active lifestyle may lie not in physical fitness or exercise training, but in ensuring that the child and parents have appropriate physical activity beliefs and expectations. Effective strategies for encouraging physical activity are particularly important for children whose health status makes a sedentary lifestyle more probable, and for the maintenance of active lifestyles through all seasons of the year. Cardiologists need clear, consistent published guidelines so that they are able to provide appropriate, unambiguous physical activity recommendations for each patient, regardless of treatment status or where the child falls on the spectrum of medical complexity. Effective methods for ensuring that cardiologists and parents see physical activity as a high priority are needed to ensure that physical activity counselling will be routinely addressed within a brief and hectic clinic visit. Enabling cardiologists to provide effective physical activity recommendations and to prioritize discussions about physical activity should allow parents to feel more confident about appropriate physical activity for their child. Ultimately, parental support and encouragement of appropriate activities should lead to more physically active lifestyles among children with complex heart defects. Further research is required to establish widely accepted guidelines for the physical activity participation of children with complex heart defects and to determine the most effective strategies for conveying appropriate expectations for physical activity within the setting of a paediatric cardiac clinic.
Chapter 2
Understanding the Research Context
2 Importance of Physical Activity for Children

“Play is a simple joy that is a cherished part of childhood”\(^a\). For a child, enjoyment and quality of life are synonymous with play. It has also been said that play is the “work” of children. That is, children should be involved in play with the same intensity and for a similar proportion of time as adults devote to their employment. Play is how children, even at a very young age, interact with the world around them. Research to date indicates that play enhances the cognitive, linguistic, emotional and social development of children by up to 67\%\[^1\]. The importance of play for children cannot be underestimated. In fact, play has been explicitly recognized by the United Nations High Commission for Human Rights as a basic human right of every child \[^2\] because it is so essential to optimal growth and development. Play also contributes to the physical, social, cognitive and emotional well-being of children \[^3\], and school-age children may benefit more than other age groups \[^1\]. Through play children can be creative, develop their personal interests and explore their world in a way that matches their skills and interests. Child-directed play enables children to learn skills such as cooperation, sharing, problem solving, decision-making and leadership.

2.1 Play or Physical Activity

While play is not synonymous with physical activity, for young children play is predominantly active. As such, play contributes to the development of active, healthy lifestyles \[^4\], improves endurance, strength and flexibility \[^5\], enhances readiness for academic learning \[^6\] and is a key component of language and cognitive development \[^7\]. Establishing the “habit” of physically active play during childhood can also reduce the risk of acquiring diseases that are associated with a sedentary lifestyle in adulthood \[^8\]. Recommendations from major health agencies, such as the Centers for Disease Control \[^9\] and the Public Health Agency of Canada \[^5\], highlight the importance of encouraging physically active lifestyles for all children.

Physically active play is important for children with heart defects for the same reasons that it is important for all children. When play opportunities are limited, children miss out on opportunities for social, cognitive, emotional and physical development. For children with heart defects, play opportunities can be limited directly by their reduced capacity for physical activity or indirectly as a result of time allocated to treatment or attempts to shield the child from infection or other complications. Children with congenital heart defects who are restricted from “competitive sport” are 2.5 to 9 times more likely to become obese than children with similar heart defects who are not restricted [10]. The benefits of physically active play may be particularly important for children with complex heart defects who have an increased risk for accelerated atherosclerosis [11]. Children with complex heart problems are also more likely to experience behaviour or learning problems [12, 13]. Research has demonstrated that physical activity can improve academic performance [12], psychosocial health and school performance and behaviour [13]. The Public Health Agency of Canada recommends that children perform 60 minutes of moderate (3 to 5 times resting energy level) activity and 30 minutes of vigorous (6 or more times resting level) activity daily.

2.2 Physical Activity among Children who have the Fontan Procedure

Children born with the most complex types of congenital heart defect are often treated through a series of surgical interventions, culminating in the Fontan procedure. These children are born with only one effective pumping chamber in the heart, instead of the normal two.

Figure 1: Cardiac Anatomy Before and After Fontan

Illustration of circulation within a heart with a hypoplastic left ventricle before (left) and after the Fontan procedure
Through the Fontan procedure, venous blood returning from the body is sent directly to the lungs so that the one pumping chamber in the heart can be used to send newly oxygenated blood throughout the body. Until the past two decades, children needing the Fontan procedure were unlikely to survive past early childhood. However, most of these children now survive into adulthood because of changes to surgical and treatment procedures.

In keeping with the historic mortality of this condition, previous research has focused on utilizing measures of exercise capacity as a surrogate measure of cardiac function and on improving cardiac function through exercise training. Exercise is a specific type of physical activity that involves planned, structured and repetitive activities primarily designed to elicit changes in physiological fitness. In contrast, physical activity can include any type of bodily movement that results in energy expenditure [14]. Exercise is only one small component of the wide range of physical activities that a child can undertake. Only recently, as mortality has been reduced, have researchers turned their attention to the morbidities that survivors experience. To date there have been only two reports [15, 16] that have examined whether children who have the Fontan procedure participate in the daily physical activity that is so essential to childhood growth and development. Since childhood physical activity typically occurs in short, intense bursts, and seldom requires a maximal effort, the limited maximal endurance of children who have the Fontan procedure would not be expected to have a significant influence on their participation in physically active play. Since exercise is only a small subset of the many types of physical activity that are typical in childhood, the current knowledge regarding exercise capacity and physical activity participation among children who have the Fontan procedure will be discussed separately.

2.2.1 Exercise Capacity and Training after the Fontan Procedure

Considering the abnormal cardiopulmonary physiology after the Fontan procedure, it is not surprising that maximal exercise capacity is significantly reduced [17-19]. Research indicates that cardiopulmonary function after Fontan is reduced to two-thirds of normal and that peak oxygen consumption, work rate, exercise time and exercise heart rate are all significantly reduced. These decreases in exercise performance are attributed to lower stroke volume, an
abnormal tissue carbon dioxide to ventilation relationship, and greater dependence on anaerobic metabolism.

Exercise training rehabilitation programmes are routinely provided to adults with acquired heart disease, but are relatively uncommon for children with congenital heart defects [20]. Participation in an exercise rehabilitation programme significantly increases the physiological fitness of children who have the Fontan procedure [21-23]. Longmuir et al [21] were the first to demonstrate the benefits of a post-operative, home-based exercise training program for increasing the physical fitness of children with heart defects. The 60 study participants, 5 to 18 years of age, included children with a wide range of cardiac defects, from simple to complex. The children completed a standard test of fitness immediately prior to their surgery. A programme to encourage movement began when the children was discharged from the intensive care unit and continued until the child returned to school without activity restrictions (2 to 3 weeks after surgery). At the time of discharge from the hospital, the parents were also given a physical activity programme for their child to do at home. The programme required 20 to 30 minutes per day. Half of the programme was activities targeting fitness deficits identified during the pre-operative assessment, with the remainder being age-appropriate, physically active pursuits. Children who complied with the intervention at least one day per week had significantly higher fitness scores at the three-month post-operative assessment. Subsequently, the authors demonstrated that the fitness gains from the home-based training programme were maintained (Figure 2) for a period of 5 years [24].

**Figure 2: Long-term Benefits of Post-operative Exercise Training for Children with Congenital Heart Defects**

<table>
<thead>
<tr>
<th>Compliant group</th>
<th>Subjects in original study</th>
<th>Subjects in long-term test</th>
<th>Preop vs healthy</th>
<th>6 months vs healthy</th>
<th>Long term vs healthy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal*</td>
<td>15</td>
<td>14</td>
<td>$p &lt; 0.01$</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Abnormal</td>
<td>5</td>
<td>3</td>
<td>$p &lt; 0.01$*</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Control group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Normal</td>
<td>14</td>
<td>5</td>
<td>$p &lt; 0.01$</td>
<td>$p &lt; 0.01$</td>
<td>NS</td>
</tr>
<tr>
<td>Abnormal</td>
<td>17</td>
<td>11</td>
<td>$p &lt; 0.01$</td>
<td>$p &lt; 0.01$</td>
<td>$p &lt; 0.01$</td>
</tr>
</tbody>
</table>

Reprinted from Longmuir PE, MS Tremblay, RC Goode, 1990, Postoperative exercise training develops normal levels of physical activity in a group of children following cardiac surgery, Pediatric Cardiology, 11:129, Table 3, with kind permission of Springer Science+Business Media..
Rhodes et al [22] demonstrated the fitness benefits of a supervised exercise training programme, similar in design to the programmes offered routinely to adults with heart disease, for 16 children 8 to 16 years of age, 11 of whom had a Fontan procedure. Their training programme was held at a central location, and children attended the programme for one hour, two times per week for 12 weeks. The training programme resulted in a 15% increase in peak aerobic exercise capacity (26.4 to 30.7 ml/kg/min), which was subsequently shown to be maintained for 6 months after the training programme was completed [25]. Opocher et al [23] demonstrated that similar changes to peak exercise capacity (27 to 30 ml/kg/min) could be obtained using a combination of supervised and home exercise training sessions over an 8-month period. The 10 children in that study were 7 to 12 years of age and had undergone a Fontan procedure prior to the age of 4 years.

It has been suggested that the lower maximal exercise capacity of children who have the Fontan procedure is the cause of their sedentary lifestyle [19]. However, children who have the Fontan procedure can improve their exercise capacity through training [21, 22]. Therefore, it would seem that at least a portion of their reduced exercise capacity results from a sedentary lifestyle (i.e., lack of training), rather than the physiological limit imposed by their abnormal cardiopulmonary anatomy.

2.2.2 Physical Activity after the Fontan Procedure

Amount of Physical Activity

Research indicates that accelerometers can be used to accurately measure the free-living physical activity levels of children with congenital heart disease [16]. Fredriksen, Ingjer & Thaulow [16] examined primarily young adolescents (mean age 12.1 ± 1.8 years, range 8 to 16) randomly selected from a large database of children with congenital heart disease. Results of that study indicated that, as a group, children with congenital heart disease are less active than their healthy peers. However, the authors did not indicate the types of heart defect that occurred among children in the study sample. Only one previous study specifically measured the free-living physical activity of children who have the Fontan procedure. In that study [15], which assessed the physical activity of 147 children and youth, 6 to 18 years of age, moderate-to-vigorous physical activity (MVPA) participation was extremely low in comparison to published data for healthy children of similar age (Figure 3). The low levels of MVPA occurred in both males and
females, and were particularly prominent before 12 years of age. The observed amount of MVPA was not significantly related to maximal exercise capacity, self-reported activity level or health-related quality of life. Interestingly, there was a small proportion of the children studied who achieved recommended levels [5] of MVPA, suggesting that more physically active lifestyles are present for at least some of these children.

Figure 3: Minutes of Daily Moderate-to-Vigorous Physical Activity of a) Males, and b) Females who have the Fontan Procedure Compared to Healthy Peers (red)

Factors Influencing the Activity of Adolescents with Heart Defects

Factors associated with physical activity participation have been studied among adolescents, but not children, with congenital heart defects. In a study of 100 adolescents, Bar-Mor and colleagues demonstrated that self-efficacy for physical activity is the primary factor influencing physical activity participation [26]. Self-efficacy is the individual’s belief about their own effectiveness in performing a behaviour. In relation to physical activity, self-efficacy is the person’s belief in their ability to achieve an active lifestyle. In the study by Bar-Mor and colleagues, self-efficacy for activity was better explained by the cardiologist’s recommendations and the mother’s attitude toward the adolescent’s physical activity, rather than the severity of the cardiac defect. A strong correlation was also found between the cardiologist’s activity recommendation and the adolescent’s attitude towards activity participation. Unlike the severe defects that occur among children with a functionally univentricular heart after the Fontan
procedure, participants in Bar-Mor’s study had heart defects that were considered trivial, mild or moderate in severity. Trivial defects were primarily shunt lesions. Cyanotic lesions were typically considered moderate, while obstructive lesions occurred across all severity categories.

Moola and colleagues [27] utilized qualitative research techniques to study the physical activity and sport perceptions of adolescents with congenital heart defects. The participants in their research interviews were 11 to 17 years of age. The authors categorized three participants as being “cured” via their previous surgery while 10 other participants had palliative surgery for a single heart ventricle or surgery that was intended to repair the heart defect but resulted in residual heart defects. They identified four key themes that influenced the participation of these adolescents. Sport, which was synonymous with physical activity for these adolescents, was not a valued pursuit although it was recognized for its benefits in maintaining good health. Teens categorized by the authors as having curative surgery perceived themselves to be good athletes and had positive attitudes toward sport. In contrast, the adolescents with on-going cardiac problems saw themselves as “not good at sports” and felt that they were often unable to keep up with their peers due to fatigue. The authors suggest that providing enhanced education about and opportunities for non-traditional physical activities, particularly those that can be successfully enjoyed in spite of limited endurance, should be a priority for the professionals who work with these adolescents and their families.

**Impact of Sedentary Lifestyles**

For children with heart defects, Rhodes and colleagues have suggested that perceptions of fragility may unnecessarily restrict physical activity participation. They suggest that a sedentary lifestyle resulting from unnecessary restrictions would be expected to exacerbate any exercise limitation created by a residual heart defect [22]. A comprehensive review paper [28] of the physical activity participation of adults with congenital heart defects draws a similar conclusion. Reybrouck and Mertens concluded that a “hypoactive lifestyle” makes an important contribution to the reduced exercise capacity that occurs frequently with both simple and complex heart defects. They suggest that sedentary lifestyles result from overprotection and therefore they recommend that cardiologists strongly encourage all patients to adopt a physically active lifestyle. This proposed link between perceptions of the person with the heart defect as fragile and physical activity participation is of concern given the results reported by Casey et al [29].
They examined the quality of life of 26 children, 5 to 15 years of age, with a surgically palliated single ventricle who had not yet had the Fontan procedure. When asked to describe their child’s capacity for physical activity, 15 parents indicated that their child could not walk more than 100 yards. In contrast, treadmill exercise testing of the same children identified only two children who could not walk at least 100 yards. Overall, 80% of the parents significantly underestimated their child’s capacity for exercise. Given that parents appear to perceive the child as being much more fragile than objective measures of exercise capacity would suggest, the perceptions of parents regarding their child’s capacity for exercise require further investigation.

Taken together, these studies suggest that the physical activity levels of children with complex heart defects are influenced by a variety of psychosocial factors, rather than being primarily determined by the cardiac physiology. It would appear that factors other than exercise capacity have a significant influence on the child’s physical activity participation, although these other factors have yet to be identified. Existing knowledge also suggests that the perceptions of the child and parents regarding physical activity play an important role in determining participation, and that the family’s perceptions are influenced by the perspectives of the child’s cardiologist.

2.3 Factors Associated with Childhood Physical Activity

Existing knowledge regarding the correlates of physical activity for healthy children can be used to inform research into the factors that influence the physical activity of children with complex heart defects. Factors that influence childhood physical activity can be categorized as fixed or flexible. Fixed influences, such as sex, age, surgical history, or previous activity experience, are those that cannot be changed by an intervention. Flexible influences on activity, which could potentially be influenced by an intervention, include activity intentions and enjoyment, perceived physical competence, facility access, parent support, and perceived activity barriers. Research indicates that each of these flexible factors is significantly related to a child’s actual level of physical activity participation [30-32].

Known Factors that Influence the Activity of Healthy Children

Sallis, Prochaska and Taylor [30] have provided a comprehensive overview of the state of knowledge regarding the correlates of childhood physical activity. For children up to 12 years of
For their meta-analysis, a minimum of three studies were required in order for a variable to be included in their analyses. The strength of the evidence was based on an evaluation of the research methods used and the consistency of results across studies. The review included 54 studies, with up to 31 variables tested in each study, all of which used a cross-sectional design. The validity and reliability of the measures of physical activity used in each study were highly variable, from untested subjective assessment tools to objective measurements. Among demographic variables, male sex and parent overweight/obesity were positively associated with the child’s activity and there was no association between the child’s activity and socioeconomic status, or single parent status. Three psychological variables were associated with physical activity participation. The intention to be physically active and a preference for physically active rather than inactive leisure pursuits were the psychological variables positively associated with physical activity. The number of perceived barriers to physical activity was negatively associated with participation. They reported no association between activity and self-esteem, body image, attitudes to sweating, after school activity interests, dislike of physical education classes, or perceptions of activity benefits in the child age group. Among behavioural attributes, only previous activity experience and eating a healthy diet were positively associated with higher levels of physical activity. There was no established association with cigarette or alcohol use or caloric intake. In terms of the physical environment, access to facilities or programmes and time spent outdoors were positively associated with the child’s activity participation. The available research was insufficient to establish an association between activity level and the provision of transportation by the parent or neighbourhood safety. Sallis and colleagues’ [30] also concluded that there was insufficient evidence to draw overall conclusions regarding the influence of social/cultural factors on the physical activity participation of children up to 12 years of age. Social/cultural factors that have been investigated include parent perceptions of activity barriers and benefits, parental encouragement for activity, whether a parent is expected to provide transportation to the activity or pay for registration, peer influence or subjective cultural norms within this age group. However, Sallis and colleagues concluded that the number of high quality studies was very limited and the results were often conflicting.
Impact of Parental Beliefs and Expectations

The impact of parental socialization on children’s attitudes, beliefs and expectations for achievement has been elucidated by Eccles Parsons, Adler and Kaczalla [33]. Their research examined parent and child beliefs regarding the children’s math abilities. The results demonstrated the foundational importance of parental expectations and beliefs in determining the child’s own beliefs and actual behaviour. Parent perceptions of their child’s abilities for math and parent expectations for their children’s performance of math activities were strongly related not only to the child’s perception of parental expectations but to the child’s own self-perceptions, self-concepts and expectancies for math activities. In fact, parent attitudes and expectations for the child were a stronger influence on the child’s attitudes about his/her own performance than the child’s actual past performance of math activities or parent modeling of math activities.

Continued development of the expectancy model of activity choice, which identifies parental belief systems (parent value of activity and expectations for child’s success) as the primary determinant of the child’s activity choices, has demonstrated its applicability to children’s sport [34] and physical activity [35] participation. The model has as its foundational premise the expectation that over time, children will adopt their parents’ expectations and then reflect those expectations in their own actual behaviour. Figure 4 is the modified version of Eccles’ model that underpins our approach to this research. It incorporates the influence of the guidance parents receive from their child’s cardiologist and other health care professionals, as well as the influence of the reduced capacity for physical activity that the child experiences from birth until completion of the Fontan procedure.

Based on the expectancy value model, the relationship between children’s activity preferences and intentions and their actual participation identified by Sallis and colleagues [30] would, theoretically, reflect the parents’ expectations for their children’s activity. Unfortunately, the Sallis review did not identify existing research that directly examines the influence of parental expectations for the child’s activity on childhood physical activity participation. Sallis and colleagues did identify studies examining the impact of parental participation in activity with the child, and the results of these studies were inconclusive (50% positive association, 50% none).
Figure 4: Expectancy Value Model of Physical Activity for Children with Congenital Heart Defects

Physical Activity Recommendations from Cardiologist
- can try any type of activity (unrestricted)
- expect that child will stop & rest as needed
- probably won’t play in the NHL (child will not excel at activity)

Cultural Milieu
- activity expectations of society (gender, age, importance)

Socializers’ Beliefs & Behaviours
- parent beliefs about and support for child’s activity

Aptitudes, Talents & Temperament
- child’s natural activity skill & inclination

Previous Achievement
- experience of child during past attempts of physical activity

Child’s Interpretations of Experience
- how child attributes activity outcomes to self or external factors
- child’s perception of personal control or influence on activity participation and outcomes

Child’s Perceptions
- parent beliefs
- cardiologist beliefs
- expectations of friends and family
- expectations of society

Capacity Prior to Fontan
- decreased oxygen saturation resulting in limited endurance and fatigue

Expectations of Success
- child’s expectations of positive outcomes based on goals, self-concept of own abilities, perception of task demands, and view of ideal self

Child’s Activity Choices

Subjective Task Value
- how the child values physical activity (incentive and attainment value, utility value, cost) based on affective memories

Modified from Eccles et al, 1991 [34]
Dempsey, Kimiecik and Horn demonstrated the appropriateness of applying an expectancy-value model to the moderate-to-vigorous physical activity of healthy, elementary school-aged children[35]. Their Family Influence Model for activity participation used Eccles’ expectancy-value theory as a framework. In developing the Family Influence Model, the authors examined the correlations between parent behaviour, parent beliefs about their child’s activity and the child’s beliefs about their own activity. Questionnaires were used to gather information on the belief systems of parents and their 4th or 5th grade children. They assessed the level of physical activity through child and parent self-reports, a method that is recognized as reporting erroneously high activity levels. Parent perceptions of their child’s activity competence and children’s expectancies for activity were strong predictors of the children’s actual behaviour. Parents as role models of a physically active lifestyle were unrelated to the child’s actual behaviour.

The expectancy value model also fits nicely with the current state of knowledge regarding factors that influence physical activity behaviour as summarized by Sallis, Prochaska and Taylor [30]. Widely-held expectations that boys will be more active than girls are reflected in the identified sex differences for participation. Physical activity intentions and preferences, which are significantly related to activity participation, are factors that most likely reflect long-held beliefs or expectations of the type that the expectancy value model would link to the child’s adoption of parent values and expectations for the child’s activity. As predicted by the expectancy value model, parent modeling of activity behaviour, peer or societal expectations, tangible parent support through providing transportation or paying fees, and perceptions of the benefits of activity do not significantly influence the child’s actual physical activity behaviour. Based on the expectancy value model, one would also expect that children’s perceived competence for activity (a reflection of parent expectations of the child’s competence) would be strongly related to actual physical activity behaviour.

In spite of the theoretical link, current research evaluating the relationship between perceived competence and actual activity behaviour has been designated equivocal or indeterminate [30]. The review by Sallis, Prochaska and Taylor [30] identified four studies that have examined the link between perceived competence and activity behaviour. A closer examination of these studies suggests that the differing results may actually reflect differences in study design and that each
study is not, in fact, comparable to the others. One study examined factors related to changes in activity behaviour over time and another was focused on exercise behaviour (specific to fitness training). It seems reasonable to assume that the factors influencing these aspects of physical activity behaviour may be different from those that influence the more global concept of physical activity. The two cited studies that address global physical activity correlates, one in healthy children and one in obese children, found a positive relationship between perceived competence in physical activity and actual behaviour, as would be predicted from the expectancy value model. Therefore, it appears that although one additional study would be needed in order to reach the threshold of three positive studies established for the review article, the limited existing evidence appears to support the importance of perceived competence in determining physical activity participation. Based on this information, the expectancy value model appears to be an appropriate framework for identifying the primary factors that influence childhood physical activity.

2.4 Context for this Research

This programme of research is based on the existing body of knowledge about childhood physical activity in both healthy children and those with complex heart defects. It also reflects my own experiences, assumptions and perspectives (2.4.1) and the influence of the professionals in, and the setting of the Labatt Family Heart Centre (2.4.2), where these projects were planned and conducted. As explained in the following sub-sections, it was assumed that the medical condition would not be the primary limiting factor in determining the level of daily physical activity. It was also expected that families would understand what the child could or could not do, and that the observed sedentary lifestyles were primarily a reflection of the low priority attached to physical activity. Finally, I expected that the children’s limited capacity for physical activity in the early years (prior to the Fontan procedure) would frequently result in less sophisticated motor skills at an older age and predispose the family to expect and accept a more sedentary lifestyle.
2.4.1 Researcher Perspectives Brought to the Study

As with all research, the design and conduct of this project reflects the knowledge, assumptions and expectations of the researchers. In designing this study I relied extensively on my existing knowledge about childhood physical activity participation. My knowledge and beliefs about childhood physical activity reflect my post-secondary education in physical activity, my extensive experience in providing physical activity opportunities for children, and my previous physical activity research with children with heart problems and other medical conditions. My education and previous experience has convinced me that physical activity is a critically important component of childhood quality of life. I believe strongly that all children have the right to be involved in play with their peers, and I also believe that for young children peer play almost always involves physical movement. As such, I believe that a young child who is unable to move in a manner comparable to his/her peers faces significant barriers to peer interactions and socialization, in addition to the negative health effects associated with sedentary lifestyles.

Based on my existing knowledge and previous experience, I made the following assumptions in designing this research:

- Physical activity levels would be low among children with complex heart defects.
- The maximal exercise capacity of these children would be lower than normal but most children would have sufficient exercise capacity for participation in peer play (which typically requires 40-60% of maximum effort).
- Children who are less active and their parents would see vigorous physical activity or fitness activities as a low priority in the child’s life.
- Parents would perceive childhood physical activity recommendations from the Public Health Agency of Canada as not relevant or appropriate for their child with a heart problem.
- Children with heart problems often have limited gross motor skills, particularly for more advanced motor skills such as throwing and catching, jumping, or balance tasks. Children with a univentricular heart are cyanotic prior to the Fontan procedure which severely
limits their ability to perform the physical activity needed to develop age-appropriate motor skills.

- Young children are highly dependent on their parents for participation in physical activity. Being active around the home typically requires parental approval and often parental encouragement to reduce screen time. Activity outside of the home is dependent on the parent arranging physical activity opportunities for the child, being available to supervise the child, or transporting the child to a physical activity setting.

- In order to raise the activity levels of children with complex heart defects it would be necessary to convince the child and family that physical activity should be a much higher priority. Once it was a priority, it would be possible to educate the family about methods of increasing daily activity and the wide range of activity options that could be pursued.

2.4.2 Labatt Family Heart Centre at The Hospital for Sick Children

The design and conduct of this research was also influenced by its implementation within the Labatt Family Heart Centre at The Hospital for Sick Children. Our Centre is the largest tertiary care paediatric cardiology centre in Canada. Children with complex heart defects who are well are typically followed once per year by cardiologists in our Centre. Families typically have a long history of care from our Centre, with many children having been diagnosed and followed starting several months prior to their birth. Typically the children have had all of their previous surgeries, major procedures and periods of hospitalization in our institution. Children with complex heart defects are also typically followed by a paediatrician, often with a cardiology specialty, because family doctors are uncomfortable with the complex nature of their heart defect. The paediatrician and family rely extensively on recommendations from the cardiologist in determining the child’s health status. Recommendations for physical activity participation are usually provided by the cardiologist, rather than the paediatrician, because of the perceived link between physical activity and changes in heart rate and function. This "medicalization" of physical activity would be expected to have both positive and negative impacts. The positive impact would come from physical activity being given a higher priority by the family if they perceived that the cardiologist considered it to be important. The potentially negative impact would be an expectation that the child should not participate in any types of physical activity that
were not specifically mentioned or approved by the cardiologist, or activity being given a low priority if it is not emphasized by the cardiologist.

Supervisory Personnel

This project was also influenced by the past research and assumptions of Dr. McCrindle, my primary supervisor, and the many health care professionals involved in the care of the children who were willing to participate. Prominent among these influences was a research project, which had just been completed, that investigated the relationship between exercise capacity, health-related quality of life, daily physical activity and current health status among children and teens that had the Fontan procedure [15]. The results from that study indicated that health-related quality of life and current medical status were related to maximal exercise capacity, but not to daily physical activity. These findings were surprising to the professionals working in the Labatt Family Heart Centre, presumably because of an assumption that the observed low levels of daily physical activity were an outcome of the lower exercise capacity that has been well-documented among these children. It was also assumed that children who were well past their final Fontan procedure would have normal motor skills. Published research on the acquisition of basic motor skills (crawling, walking, running) indicates that these children typically lag considerably behind age-appropriate norms prior to their final surgery [36]. However, there is also a rapid “catch-up” phase after the final Fontan procedure so that by the time that the child starts school, she/he has acquired age-appropriate basic motor skills [37]. Cardiologists also assume that their patients, and their parents, know what types of physical activity are or are not appropriate. The majority of children who have the Fontan procedure without additional complications are allowed to participate in any type of physical activity of interest to them, although parents are told they should not expect the child to be able to keep up with their peers in highly competitive or vigorous sports and that the child should be allowed to rest if desired. Small proportions of these children have implanted devices (e.g., pacemaker, internal defibrillator) or continue to take anticoagulation medication for stroke prevention. For these children body contact sports (e.g., tackle football, ice hockey) are not allowed.
2.5 Objectives for this Research

Children who have a functionally univentricular heart after the Fontan procedure have low levels of physical activity that inhibit their socialization, growth and development, participation in peer activities and quality of life. Their reduced physical activity also leaves them at higher risk of morbidities, such as obesity and diabetes, which are more common among adults with sedentary lifestyles [38].

Research completed to date suggests that socialization factors play a significant role in determining a child’s physical activity behaviour. In particular, parental expectations for the child’s activity and activity recommendations provided by the cardiologist seem to be related to the child’s self-efficacy for physical activity, which in turn is related to the child’s actual physical activity behaviour. However, questions remain regarding how a complex heart defect or its treatment influences childhood physical activity. We do not yet know how children with complex heart problems and their families perceive physical activity. We also do not understand the role the cardiologist plays in the development of the family’s perceptions or what factors unrelated to the heart defect play influence the child’s daily physical activity participation.

Research Goals and Objectives

The goal of this research was to better understand how physically active play relates to the lives of children with complex heart defects, such as those who have the Fontan procedure, and their families. The longer-term goal of my research programme is to develop effective interventions to improve the daily physical activity participation of these children so that they can successfully participate in peer activities and develop the active lifestyles associated with long-term health. I felt that enhancing my understanding of the physical activity experiences of these children would enable me to identify potential targets for future interventions. To enhance my understanding, I chose to use both quantitative and qualitative research methods. Quantitative research methods are effective for summarizing the characteristics of a group and understanding the correlations between variables. Qualitative research methods enable an in-depth understanding of the perspectives of specific individuals or groups. Thus, I chose to selectively use both approaches in order to better understand physical activity in the lives of these children.
The first study presents a descriptive, cross-sectional overview of some of the factors associated with the physical activity participation of children who have the Fontan procedure. Study #2 utilizes parent and child interviews to expand on important psychosocial factors with a view to understanding the context in which children are (in)active. The final study investigates the role of cardiologists and published guidelines in relation to parent perceptions of physical activity for the child with a complex heart defect. The specific objectives for the research reported in the following chapters were:

- Identify the physical fitness, exercise and medical factors associated with weekly moderate-to-vigorous physical activity among children who have the Fontan procedure for a functional single ventricle.
- Describe the physical activity experiences, opinions and beliefs of children with complex heart defects and their parents by listening to their perceptions and their own accounts of the child’s physical activity.
- Examine the physical activity perspectives and the influence of the cardiologists who care for these children on the family’s physical activity expectations and perceptions.

Research Questions

In order to achieve these objectives, the research studies developed were designed to address the following research questions:

- What medical, health, fitness or exercise factors are associated with higher levels of physical activity among children with the most complex heart defects (such as univentricular heart after a Fontan procedure)?
- What are the physical activity, rather than exercise, perceptions and expectations of children with complex heart defects and their parents?
- What are the physical activity perceptions and expectations of the cardiologists who care for children with complex heart defects?
- How do the expectations and experiences of the child, parent and cardiologist interact in influencing the child’s physical activity participation?
2.6 Theoretical Framework

Interpretive Interactionism

Interpretive interactionism, as described by Denzin [39], is the theoretical framework that most closely aligns with the conduct and analysis of this research. However, I readily acknowledge that the research reported in the following chapters does not follow all of the precepts and procedures of a strict interpretive interactionist approach. Rather, I have chosen to develop my own approach, informed by interpretive interactionism, in order develop an approach to this research that would be appropriate and practical in relation to the age of the children participating in the study and the setting of the Labatt Family Heart Centre at The Hospital for Sick Children.

Denzin [39] developed his method of interpretive interactionism based on his strong belief that it is essential to understand the perspectives and experiences of the people you wish to serve before you can develop effective programmes of support. His basic premise was that social life revolves around interpretations. People making judgements or interpretations of the behaviours and experiences of themselves and others is how our social life and interactions develop. Denzin’s research and experience was focused on the relationship between personal problems, such as alcoholism or abuse, and the social institutions and policies developed to address them. As such, Denzin developed interpretive interactionism to examine the interrelationship between “private lives and public responses to personal trouble” [Denzin, 1989, p. 10].

On that basis, he elucidated four ways in which an interpretive approach could contribute to evaluation research:

- Identification of different definitions of a problem or programme.
- Documentation of the assumptions made by the people involved.
- Identification of strategic points for intervening in social situations.
- Suggestion of alternative points of view for the programme or policy.
Denzin’s belief that understanding the perspectives of the people you wish to serve is central to our ability to develop effective programmes and services is the premise which lead me to adopt an interpretive point of view. Over my professional career I have personally observed many examples of programmes and services that were ineffective precisely because they were based on the assumptions of those providing the service rather than the perspectives and needs of the people being served. My own Master’s thesis work is a prime example. The study was based on our assumption that the observed low levels of fitness could be seen as isolated effects from a lack of exercise training. On that basis, we designed a post-operative exercise training programme to increase the children’s level of fitness. The pre- and post-intervention evaluations were standard measures of fitness. The results of the study [21], whereby children who did the exercises only once per week saw significant gains in fitness, made it very clear that factors other than the actual performance of the exercise routines significantly influenced the children’s fitness scores. We had assumed that the low levels of fitness observed among children with congenital heart defects resulted from a lack of training and that providing a suitable training programme would remedy the situation. Perhaps if we had asked the children and families about their perspectives on the children’s low fitness levels we might have developed an intervention that more accurately targeted those key issues. At the very least, we would have selected more appropriate evaluation methods for documenting all of the benefits or changes resulting from the intervention.

Research Approach

Given this previous experience and the long-term research goal to develop appropriate supports to enable children with complex heart problems to enjoy a physically active lifestyle, I felt that the first step in my programme of research must be to gain a better understanding of physical activity in the lives of children with complex heart defects. Thus, the research reported in the following chapters examines objectively measurable factors associated with physical activity, and then the perspectives of the children, parents and cardiologists. The first phase of this research was focused on clarifying the factors associated with physical activity among the target population, since previous research has left this largely unexplained. For this study, a broad range of factors potentially related to physical activity participation were examined. The measures included standardized tests of gross motor skill and fitness (body composition,
muscular strength and endurance, aerobic exercise capacity) in addition to data from the child’s medical history (e.g., age at Fontan procedure, complications, current medication, maximal exercise capacity).

In implementing an interpretive approach Denzin describes a process of initially listening to the stories that people tell each other when they are in a group, and then supplementing that information with individual interviews to create thick descriptions and personal experience stories. Denzin’s approach is very similar to the methods that I used to learn about the perspectives of children with complex heart defects and their parents. In speaking with parents and children it quickly became clear that the physical activity recommendations being followed varied significantly from family to family, or even between parent and child. In order to better understand these variations in perspective, we asked the cardiologist responsible for each child to provide us directly with the physical activity recommendations for that child. We also examined published guidelines about physical activity for children who have the Fontan procedure and conducted brief interviews with each cardiologist regarding their activity recommendations and counselling procedures.

Modified Approach Based on Interpretive Interactionism

Where my research diverges from Denzin’s framework for interpretive interactionism is in relation to the connection with social structures (i.e., policies, programmes). The purpose of my research was to understand the perspectives of children, parents, and cardiologists so that appropriate and effective support programmes can be developed. It was not my purpose to evaluate the impact of existing clinic support programmes, although the low levels of physical activity found among patients attending our clinic [15] clearly suggest that the supports necessary for children who have the Fontan procedure to achieve physically active lifestyles comparable to their peers are not yet in place. I also diverge from the work of Denzin in terms of the methods used to learn about the perspectives of children, parents and cardiologists. Although the parent discussions went into significant depth, I did not attempt to complete lengthy, in-depth discussions with the children because of their age and attention span. The interviews with cardiologists were also deliberately limited in scope. The shorter length was successful in encouraging all available cardiologists to participate in the interviews. The depth of the cardiologist interviews was also somewhat limited by the use of a standard patient profile as the
basis for the discussions. Although the standard profile enabled us to directly compare the activity recommendations between cardiologists, it also limited the cardiologists’ ability to discuss the needs of the “child” in the same depth that would be possible had we been discussing one of their own patients.

Although my research differed from Denzin’s theoretical tradition in terms of the depth of the child and cardiologist interviews, like Denzin, my focus remained on identifying those critically important life experiences that significantly alter or shape meaning. For my study, the focus was the meaning which children who have the Fontan procedure and their parents attach to childhood physical activity. This focus on life-changing experiences differentiates Denzin’s interpretive interactionism from other interpretive approaches that focus primarily on routine parts of everyday life. Families of children who have the Fontan procedure share the life-changing experiences of a critically ill newborn, two or three major heart surgeries, numerous cardiac catheterizations and other invasive tests, a broad menu of medications and the responsibility for tracking a long list of signs and symptoms of heart failure, arrhythmias, or other indications of decreasing heart function. As such, I anticipated that using Denzin’s approach would enable me to develop a better understanding of how physical activity is experienced by children who have the Fontan procedure.
Chapter 3
Factors Associated with Physical Activity Participation
3 Associations Between Fitness, Motor Skill and Medical Factors and Physical Activity Participation

For optimal health, children should be physically active for 60 to 90 minutes per day [5, 40]. Unfortunately, almost 90% of Canadian children do not achieve this recommended level [12]. Physical activity is important for childhood growth, development, socialization and quality of life [3, 41]. Children with congenital heart defects are often sedentary [28]. Among children with functional single ventricle after a Fontan procedure, activity is very low relative to peers, particularly during the early school years [15]. These inactive lifestyles have an immediate impact on socialization and peer interactions. They also hinder the development of sophisticated motor skills [42] and increase the risk of morbidities (obesity, diabetes, hypertension, and atherosclerosis) associated with a sedentary lifestyle [43].

Identifying factors associated with activity participation in this population is the essential first step towards effective interventions that will enable these children to achieve higher levels of physical activity participation. Factors associated with physical activity that can be modified via an intervention would be the key targets for interventions designed to raise daily activity levels. Research has demonstrated that the exercise capacity of children with congenital heart defects can be increased through training programs [24, 25]. However, the ability to participate in peer activities depends primarily on daily physical activity rather than specific levels of fitness. The Public Health Agency of Canada also recommends minutes of daily physical activity rather than measures of fitness in order for children to increase the probability of good health [5]. The purpose of this research was to identify factors associated with participation in moderate-to-vigorous physical activity (MVPA) among children who have the Fontan procedure. The hypotheses for this research were:

- Time spent in moderate-to-vigorous physical activity would be positively related to gross motor skill (both mobility and object manipulation skill sets).
• Time spent in moderate-to-vigorous physical activity would be positively related to health-related fitness. Health-related fitness is defined as the fitness parameters (strength, flexibility, endurance and body composition) associated with a healthy lifestyle.

• Time spent in moderate-to-vigorous physical activity would not be related to exercise capacity or medical status.

3.1 Methods

The study protocol (Clinical Trial #NCT00363363) was approved by the Research Ethics Board of The Hospital for Sick Children and conducted in accordance with the Tri-Council Policy Statement [44]. The approved consent form was mailed to each family prior to the assessment date. Written informed consent was obtained from the parent and informed assent was obtained from the child upon their arrival for the assessment.

3.1.1 Subject Selection

Children known to the Labatt Family Heart Centre at The Hospital for Sick Children were eligible if they were at least one year post-Fontan procedure for functional single ventricle, were 6 to 11 years of age, attended full-day elementary school, and had no other conditions that would contraindicate physical activity. Permission to approach the family was sought from the responsible cardiologist for each of the 122 children (47 female) meeting these criteria. Twelve children (6 female) were not approached because the child no longer met the criteria (n=5) or the family was not living in Canada (n=6) or had requested they not be approached for research (n=1). Study invitation letters were sent to all remaining families (n=110) and contact by telephone determined their interest in participating. The families of 71 children (26 female) consented to study participation, 31 families refused, 7 families could not be contacted and 1 additional child was found to be ineligible. Seven families who consented withdrew from the study before assessment completion because the child’s medical status changed to ineligible (n=6) or the child was unable to cooperate with the assessment (n=1). The overall participation rate was 67% of eligible children (n=64/95).
3.1.2 Measurements

Detailed medical record reviews abstracted patient demographics and current and previous cardiac history. During the assessment visit, children completed standardized measures of self-perception for physical activity [45], physical performance, including gross motor skill [46], cardiopulmonary capacity [47] and health-related fitness [48]. Children refrained from eating for two hours prior to the cardiopulmonary exercise test. Otherwise, rest breaks and snacks were provided as required.

The Children’s Self-perceptions of Adequacy and Predilection for Physical Activity (CSAPPA) scale was used to assess the participants’ attitudes towards physical activity participation [45]. The scale presents children with 22 pairs of dichotomous statements describing children who have two different views of physical activity. For example, “Some kids learn to play active games easily but other kids find it hard learning to play active games”. The child is asked “Which kids are more like you?” and then after a description is selected they are asked to indicate whether it is “really” or “sort of” true for them. The statement pairs address a variety of different aspects about physical activity, including active games, sports, skill, injuries, peer attitudes and school physical education classes. Each item is assigned a score from 1 (least active response) to 4 (most active response). A total score and three sub-scores (adequacy, predilection, enjoyment) are calculated.

Mobility and object manipulation skills were assessed using the Test of Gross Motor Development – Version 2 [46] which required the child to perform 12 gross motor skills. Six mobility skills (run, jump, slide, gallop, hop, and leap) and six object manipulation tasks (strike, kick, dribble, roll, catch, and throw) were evaluated. Performance criteria for children 3 to 10 years of age were used to score each skill.

Cardiopulmonary capacity was assessed at rest (5 to 10 minutes, lying semi-supine in a quiet room) and during a continuous, graded exercise test with continuous monitoring of oxygen consumption (Physiodyne MAX-2 metabolic cart, Quogue, NY), 12-lead ECG (GE Medical Systems CASE 8000, Milwaukee, WI) and body movement (Actical 2.1 omni-directional accelerometer). The exercise test was performed on a GE T-2000 treadmill, with blood pressure measurements completed during each stage. The protocol began with two, 2-minute warm up
stages (6% grade at 1.0 km/hour; 8% grade at 2.0 km/hour) followed by the standard Bruce protocol. The additional slow stages enabled younger children to become accustomed to the treadmill and monitoring equipment.

Five protocols measured health-related endurance, strength, flexibility and body composition [48]. The Canadian Aerobic Fitness Test measured aerobic exercise capacity as the child walked up and down two steps for three minutes at a pre-determined pace. A 10-second post-exercise pulse count determined whether additional, faster stepping stages would be completed. The step test was terminated when the pulse count exceeded 80% of the child’s peak heart rate during the Bruce treadmill protocol, unless the child voluntarily stopped sooner due to fatigue. Blood pressure and pulse count were measured prior to, and during recovery from the stepping test. Strength was assessed as maximal hand grip strength (separate measures of right and left hand via Smedleys dynamometer) and trunk strength (number of partial curl-ups at a rate of 25 per minute). The sit-and-reach protocol assessed flexibility as the distance between the outstretched fingers and the soles of the feet while the child was seated with legs extended and ankles dorsiflexed to 90 degrees. Body composition was assessed with measures of standing height and weight.

**Measurement of Weekly Physical Activity**

After the assessment visit, an omni-directional accelerometer (Actical 2.1) was used to objectively measure the child’s physical activity [49]. The accelerometer measures changes in movement speed (acceleration or deceleration) and records the information as activity counts. Larger or faster changes in speed are indicated as higher counts. The validity of accelerometer measurements of children’s physical activity has been previously established [50]. The Actical 2.1 was selected because it is very small and lightweight. It is shock and waterproof so it is suitable for use in all types of childhood physical activity, including bathing or swimming activities. The Actical 2.1 is designed so that the person wearing the device is unable to stop, start or change the recording functions. The researcher completed repeated bouts of activity wearing multiple accelerometers simultaneously in order to ensure that all of the accelerometers were functioning and recording similar activity counts before the data collection began.
Participants were asked to wear the accelerometer during all waking hours for one week. One week was defined as five days when the child attended school (weekdays) and on two days with no school (weekend or holiday days). Families were asked to complete the seven assessment days consecutively. Log sheets enabled the family to record any unusual events that might have influenced the accelerometer results (e.g., accelerometer taken off for sport participation). A review of the log records indicated that unusual events were rare, and did not significantly influence the data although family member illness or special circumstances (e.g., school field trip with an unusual level of activity) sometimes resulted in a short gap between assessment days. Participants and their parents were shown how to attach the accelerometer to the belt provided and how to position the device at the mid-axillary line, just above the iliac crest. Participants were required to have at least 3 weekdays and 1 weekend day of valid and recorded activity measurements. The criterion for a valid day of data recording was operationally defined because of the varying ages, and therefore sleep/wake habits, of the participants. A valid weekday was defined as having accelerometer counts prior to the start of school that continued until the evening hours. For younger children with earlier bed-times, that typically comprised at least 10 hours. For older children, a valid day typically comprised at least 12 hours. Weekend days required at least 10 hours of monitoring. The majority of participants (61/64 or 95%) achieved at least 3 weekdays and 1 weekend day of monitoring.

3.1.3 Data Analyses

Calculation of Minutes of Moderate-to-Vigorous Activity

The accelerometer was programmed by the researcher before it was given to the family to store the acceleration data at 15-second intervals, which is the shortest epoch available on the Actical 2.1. Short epochs were selected because of the high-intensity, short burst pattern of movement that is common for young children. Previous research has established a threshold of 400 counts per 15-second epoch [51] as representing activity that is moderate-to-vigorous (MVPA) in intensity (3 to 6 times resting energy expenditure). Activity counts for each 15-second interval throughout each day were exported from each accelerometer for analysis in a spreadsheet. The number of 15-second epochs which exceeded the threshold of moderate activity (400 or more counts per 15-second epoch) was counted for each day. The minutes of MVPA per day were
calculated by dividing the number of epochs at 400 or above by four. Minutes of MVPA were calculated separately for each weekday and weekend day recorded. Finally, total minutes per week were calculated using the following equation: \[5 \times \text{weekday average} + 2 \times \text{weekend average}\]. Repeat analyses with/without the 3 participants who had minimal accelerometer data were unchanged so all data were retained in the analyses.

**Calculation of Standardized Scores**

Normative data for healthy children was used to convert the gross motor skill and anthropometric assessment results to age and sex-matched percentile scores. Measures of height and weight were used to calculate body mass index, and all measures were converted to a percentile score normalized for age and gender [52]. Results from the 12 gross motor skill tests were used to calculate mobility and object manipulation sub-scores, according to published procedures [46]. The mobility and object manipulation sub-scores were standardized by age and gender and combined to determine the overall gross motor skill percentile score. Raw scores were analyzed for health-related endurance, strength and flexibility because normative data are not yet available [53]. Cardiopulmonary exercise test results were converted to Z-scores based on published data for children with innocent heart murmurs [54]. Although the normative data from Cumming et al [54] are now over 30 years old, they are the most relevant reference values for this study as the data were compiled using Canadian children attending a paediatric cardiac clinic. The only other study to report normative data for children performing the Bruce protocol [55] utilized a smaller population of children. Wessel et al [55] report that their data were equivalent to the established values from Cumming et al at sub-maximal levels, and that the maximal heart rates of their study participants were 2% lower than previously reported. Their significantly lower endurance times (decrease of 15%) may reflect a lack of motivation to continue exercising after attaining a near-maximal heart rate or a decrease in the fitness capacity of the children tested. Since the maximal heart rate values were similar to those reported by Cumming et al [54], the Canadian data were used to calculate the heart rate Z-scores used in this analysis.

**Data Entry and Cleaning**

Raw scores were entered into a spreadsheet. Multiple sorting and filter procedures and preliminary descriptive statistics were used to check for out-of-range values. The clean data set
was imported into SAS Version 9.1 for statistical analyses. Descriptive statistics (means, frequency distributions) were used to verify the data import and identify variables with cells less than 5 counts. Variables with counts less than 5 were dropped from subsequent analyses unless the data could be recoded by collapsing one or more categories within the variable that were not significantly different from each other.

The distribution of the dependent variable (weekly minutes of MVPA) was evaluated to determine whether it was normally distributed. Each variable was plotted separately against weekly minutes of MVPA (moderate-to-vigorous activity) to evaluate the linearity of the univariate relationships and identify significant outliers that might influence the results.

Correlations were calculated between weekly minutes of MVPA and individual variables that could potentially be included in the multi-variable model. Correlations related or tending to be related (p<.10) to weekly minutes of MVPA were retained in subsequent analyses. Multi-variable models with pairs of retained variables that were highly correlated were used to further reduce the number of variables considered for the final model.

Variables retained for the final model included a very small amount of missing data. Resting heart rate data were missing for two children and maximal RER (respiratory exchange ratio) was missing for 13 children. Once reduction of the variable list was complete, missing values were imputed prior to the development of the final multivariable model. Through the imputation procedure used, the missing values were replaced with the mean score for that variable. It is recognized that using the mean to replace the missing value would reduce the overall variability of each variable. The distribution and relationship with the dependent variable (minutes of MVPA per week) of each variable with and without the imputed values were evaluated to identify the impact of the imputed values.

Multi-Variable Modelling

Multi-variable modeling was completed using least square estimates. The dependent variable was weekly minutes of MVPA. The predictor variables were added to the model one at a time, in the order of the magnitude of the correlation with MVPA. Variables which decreased the mean square error of the model and increased the model R² were retained in the multi-variable model.
Variables which increased the mean square error or decreased the model $R^2$ were removed from the multi-variable model until the final multi-variable model was identified. I performed all analyses using SAS software, Version 9.1.3 (SAS Institute, Cary, NC, USA). Statistical significance was set at $p < 0.05$ unless otherwise specified.

3.2 Results

3.2.1 Variable Characteristics

Four technicians worked in pairs to conduct the cardiopulmonary exercise testing. Three additional technicians completed the remaining protocols. Analyses indicated that the staffing was not significantly associated with the child’s score ($p = .65$, $p = .64$, $p = .23$, for gross motor, fitness and exercise capacity respectively).

The dependent variable (minutes of moderate-to-vigorous physical activity per week) was normally distributed, as indicated by the box plot shown in Figure 5. Summary statistics are presented as median ($1^{st}$ quartile, $3^{rd}$ quartile) because some of the predictor variables were not normally distributed. A linear relationship was suitable for all predictor variables.

Based on the single variable plots, the following changes to variable coding were completed:

a) Removal of variables with cells $n < 5$ (pacemaker, Actical estimation, calcium channel blockers, parent reports of competition restriction, final stepping speed) and variables with a high percentage of missing values (resting RER (64%), VO2 at anaerobic threshold (50%), RPE after the stepping fitness test (27%)),

b) Season recoded to dichotomous variable, Spring (March, April, May) versus other seasons

c) Income by postal code was changed to a categorical variable to provide meaningful interpretation ($<$50,000, $50,000-$100,000, $>$100,000) and because of one extreme value (family income $>$ $250,000$ when all others $<$ $110,000$), and

d) Male and female adults in the child’s home were recoded as none, biological parent, other adult because of small cell numbers with more specific codes.
In addition, the following extreme values were identified that required additional investigation.  
i) Five children whose Fontan repair occurred at 6 to 9 years of age, and  
ii) One child who was highly active and a significant outlier among the participants whose parents reported that their level of exertion was restricted because of their heart condition.  
Extreme values for arrhythmia history, cardiologist report of a body contact restriction, resting VO2 more than 7 ml/kg/min, maximal heart rate and treadmill stage VO2 Z-scores less than -20, and final stepping heart rate less than 80 beats/min did not influence the relationship between the variable and weekly minutes of MVPA. After the final model had been developed, a comparison of results with and without the extreme values for age at Fontan repair and parent report of exertion restriction were completed. The results from the analyses of extreme values are reported in Section 3.2.5.  

3.2.2 Patient Characteristics  

Sixty-four patients (25 female (39%)), having a mean age of 9.0 ± 1.7 years (range 6.0 to 11.7) completed the study.
The participants were $5.7 \pm 2.0$ years (range 1.0 to 9.6 yrs) after their Fontan procedure, which was performed at $3.3 \pm 1.4$ years of age (range 1.6 to 9.1 yrs). Participants had a range of cardiac diagnoses, resulting in a functional single left (33/64 or 52%) or right ventricle, and status as summarized in Table 1. Family income estimated by postal code was diverse (median: $74,813,
The 31 children who chose not to participate were similar to the study participants in terms of sex (20 male, 11 female) and age (median: 9.8 yrs, q1:7.5, q3:10.7).

**Gross Motor Skills**

The children’s exercise capacity, health-related fitness and gross motor skill varied substantially. Gross motor percentile scores (median: 42%, q1:16%, q3:79%) indicated that, as a group, the participants were similar to healthy children. However, the quartile scores indicate that the distribution of individual scores is broader than the normal range. Figure 6 demonstrates the significantly different distribution of scores by gender. There were a large percentage of boys who had very poor (below the 20th percentile) gross motor skills relative to healthy children their age. The higher percentile scores for girls reflected primarily better than expected scores for object manipulation skills (batting, throwing, etc.). Total gross motor percentile scores could not be calculated for four children (3 girls) because they did not perform all 12 of the activity skills.

**Figure 6: Distribution of Gross Motor Percentile Scores by Gender**

![Figure 6: Distribution of Gross Motor Percentile Scores by Gender](image)

**Anthropometry**

Anthropometry measurements indicate the children were shorter (median: 128 cm, q1:120, q3:138) and lighter weight (26.0 kg, q1:22.3, q3:32.5) than expected for their age (median percentiles of 22 and 23 for height and weight, respectively). Median body mass index percentile score was 53% indicating that the ratio of height to weight was typical for children of this age.
(Table 2). Nine children (7 boys) exceeded the 85th percentile for body mass index. One of these boys played highly competitive soccer and performed over 600 minutes of physical activity per week. His high body mass index reflected greater muscle mass. The remaining eight children (13%) were overweight or obese. Flexibility (median 16 cm, q1:11, q3:22) test results indicate that only 7 children (6 girls, 1 boy) were able to reach to or past their toes when they were seated on the floor with both legs extended and the feet dorsiflexed to 90 degrees.

Musculoskeletal Fitness

The two protocols used to assess musculoskeletal strength indicated that there was substantial heterogeneity of performance among the study participants.

Figure 7: Grip Strength Scores by Age and Gender

The median handgrip score was a total of 26 kg of force applied (q1:20, q3:32), calculated as the sum of the right and left hand scores. Handgrip dynamometry scores increased with age (Figure 7), for both boys (r=.60) and girls (r=.70). The partial curl-up protocol to assess trunk strength was successfully completed by 44 (69%) of the children (27 boys, 17 girls). The median number of curl ups completed was 11 (q1:5, q3:20). There were no significant differences between children who could and could not correctly perform at least one curl up. The children unable to perform the curl up protocol tended to be slightly younger (mean 8.4 and 9.3 years, respectively, p=.06), although the age range was the same between groups. Number of curl-ups completed increased with age among the girls, but there was no relationship with age for the boys (Figure 8).

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Cardiopulmonary Exercise Capacity

Cardiopulmonary exercise test results indicate that the children typically performed to their peak voluntary effort rather than their true maximal capacity. Five children (4 girls, 1 boy) had peak heart rates less than 110 beats/min, with a change from their resting heart rate of less than 20 beats/min. In spite of their muted heart rate response, these children achieved peak oxygen consumption values of 20.0 to 37.3 ml/kg/min, with respiratory exchange ratios of 0.96 to 1.05. Peak oxygen consumption could not be measured in 7 children (2 girls, 6.1 to 10.3 yrs) who were unable to tolerate the mouthpiece and nose clips during the exercise test.

Results for the 59 children with a substantial heart rate response to the cardiopulmonary exercise test are shown in Table 2. Peak values for heart rate were 165 beats/minute (q1:150, q3:179), while peak oxygen consumption was 28.4 ml/kg/min (q1:24.9, q3:32.8). That 41% of the children tested had a peak respiratory exchange ratio (RER) less than 1.0 and 36% (20/55) attained less than 80% of predicted maximal heart rate indicates the heterogeneity of participant response. Twenty children (31%) achieved a peak heart rate of at least 90% of predicted.
Table 2: Cardiopulmonary Exercise Test Results

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>Median</th>
<th>Interquartile Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resting heart rate (beats/minute)</td>
<td>58</td>
<td>85</td>
<td>q1: 75, q3: 97</td>
</tr>
<tr>
<td>Resting VO2 (ml/kg/min)</td>
<td>49</td>
<td>5.3</td>
<td>q1: 4.7, q3: 6.2</td>
</tr>
<tr>
<td>Peak heart rate (beats/min)</td>
<td>59</td>
<td>169</td>
<td>q1:151, q3:179</td>
</tr>
<tr>
<td>Peak VO2 (ml/kg/min)</td>
<td>52</td>
<td>28.9</td>
<td>q1:25.2, q3:32.9</td>
</tr>
<tr>
<td>Peak RER</td>
<td>46</td>
<td>1.02</td>
<td>q1:0.95, q3:1.06</td>
</tr>
<tr>
<td>Height (cm)</td>
<td>64</td>
<td>128</td>
<td>q1:120, q3:138</td>
</tr>
<tr>
<td>Height percentile</td>
<td>64</td>
<td>22</td>
<td>q1:7, q3:59</td>
</tr>
<tr>
<td>Weight (kg)</td>
<td>64</td>
<td>26.0</td>
<td>q1:22.3, q3:32.5</td>
</tr>
<tr>
<td>Weight percentile</td>
<td>64</td>
<td>23</td>
<td>q1:11, q3:64</td>
</tr>
<tr>
<td>Body mass index percentile</td>
<td>64</td>
<td>53%</td>
<td>q1: 27, q3: 75</td>
</tr>
</tbody>
</table>

3.2.3 Level of Moderate-to-Vigorous Physical Activity

The children in this study performed an average of 356 minutes (5.9 hours) of weekly moderate-to-vigorous physical activity (MVPA). Two boys (3%) achieved the recommended 90 minutes of daily MVPA [5], and two additional boys achieved over 85 minutes of MVPA daily. The most sedentary children (1 boy, 1 girl) accumulated less than 15 minutes of MVPA per day. Participants were significantly more active (p<.001) on weekdays (median: 55 minutes) than on weekends (median: 39 minutes) (Figure 9).
Figure 9: Activity by Age, Sex and Day of the Week
3.2.4 Factors that Influence Physical Activity

Initial Correlations

Pearson correlation coefficients were calculated between weekly minutes of moderate-to-vigorous physical activity (MVPA) and each demographic and physical performance variable measured during the study. Significant correlations were identified between MVPA and season of testing (children tested in the Spring were more active, r=0.30, p=.02), daily aspirin therapy (children taking aspirin were more active, r=0.28, p=.02), antithrombotic medication (children taking the medication were more active, r=0.41, p=.001), the presence of an open fenestration connecting the pulmonary and systemic circulations (children with an open fenestration were less active, r=-0.26, p=.04), and total score for the Children’s Self Perception of Adequacy and Predilection for Physical Activity (CSAPPA) scale (children with a higher CSAPPA score were more active, r=0.30, p=.03). Trends for a relationship with MVPA were identified for age (older children tended to be less active, r=-0.24, p=.06), the age when the Fontan procedure was completed (children who had the Fontan at an older age tended to be less active, r=-0.22, p=.09), parent reports of a body contact restriction (children tended to be more active if the parent reported that their body contact was restricted, r=0.21 p=.10), motor skill percentile score (higher motor skill related to higher activity, r=0.24, p=.05), resting heart rate (lower resting heart rate related to higher activity, r=-0.22, p=.09), maximal respiratory exchange ratio (higher activity with lower maximal RER, r=-0.24, p=.08), and CSAPPA sub-scale for predilection towards physical activity (higher activity with higher predilection score, r=0.25, p=.07).

Correlations and linear relationships between identified variables and clinical decisions were used to reduce the list of variables used in developing the final model. The CSAPPA predilection score and daily aspirin therapy were removed because they were sub-sets of other variables (CSAPPA total score and antithrombotic therapy, respectively). Age was removed because it was highly correlated with antithrombotic medication use (children are on warfarin immediately after surgery and then are gradually weaned to aspirin and then no medication as long as there is no history of clotting), and the influence of age on minutes of MVPA was eliminated when antithrombotic use was included in the model. Similarly, the age of the child when the Fontan procedure was completed and whether the child had an open fenestration were highly correlated.
Fenestration status was maintained and age at Fontan removed because the relationship with minutes of MVPA was stronger for fenestration status. Season of testing and total CSAPPA score were also significantly related. Season was retained because of a stronger relationship to minutes of MVPA. Gender was retained for the final model even though it was not correlated with MVPA ($r=0.13$, $p=.30$) for two reasons. First, gender has a well-established influence on the physical activity of healthy children [30]. Second, gender was strongly correlated with the motor skill percentile score and the relationship with weekly minutes of MVPA was much stronger with both gender and motor skill percentile in the model.

**Missing Values**

The dataset contained very few missing values. Measures of resting heart rate were missing for two boys (8.3 & 10.8 yrs) because of limited laboratory time during their assessment. Four children (3 girls) were missing one item of the 6-item object manipulation sub-score on the test of gross motor skill. Eleven children (7 boys) were missing the CSAPPA scores. Eight of these children were among those initially tested, before the CSAPPA instrument was included in the testing battery. Maximal RER (respiratory exchange ratio) was missing for 13 children, primarily those who were unable or unwilling to tolerate the mouthpiece and nose clips required during the cardiopulmonary exercise test.

Missing values were replaced with the mean value for the variable prior to development of the final model. Although it is recognized that the use of means in the place of missing values will decrease the sample variability, the procedure did not seem to have a significant impact on the results of this study. There was no change in the relationship between weekly minutes of MVPA and maximal RER, with or without the imputed values, although the standard error and the level of significance were slightly higher with the imputed values. Similarly, the imputed values for resting heart rate ($n=2$) did not influence the relationship (parameter estimate, standard error, level of significance) between weekly minutes of MVPA and resting heart rate.

**Final Model**

The factors most strongly associated with total weekly minutes of MVPA among children who have the Fontan procedure are current use of antithrombotic medication, spring season of the
year, gender and motor skill percentile score. Children who were taking antithrombotic medication performed 1.9 more hours of activity per week than children not on medication. Children assessed in the spring performed 1.5 more hours per week of MVPA than those assessed during the fall or winter seasons. The weekly MVPA of boys was 0.5 hour per week higher than the weekly MVPA for girls (Figure 10). Each increase in motor skill percentile score was associated with an additional 1.1 minutes of MVPA per week, or a difference of 1.8 hours per week from the 0 to 100th percentile.

Figure 10: Factors Strongly Associated with Weekly Activity

Estimated weekly minutes of MVPA by antithrombotic use, season3, and gender.

3.2.5 Impact of Extreme Values

During the initial evaluation of variable versus MVPA plots, extreme values were identified for two variables that required further investigation. Four children had the Fontan procedure at 6 years of age and 1 additional child was nine years old when the Fontan procedure was completed. The other extreme variable was 1 very active child whose parent reported that a

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3 No accelerometer measurements were completed during the summer because children were not attending school. Weekly minutes of MVPA calculated as: (5 x weekday average) + (2 x weekend average)
restriction of the child’s level of exertion was required. The final model was evaluated with and without these extreme values in order to investigate the impact of these unusual cases.

Table 3: Factors Associated with Weekly Moderate-to-Vigorous Activity (MVPA)

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>Estimate (SE)(^3)</th>
<th>p</th>
<th>Estimate (SE)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antithrombotics</td>
<td>64</td>
<td>113.12 (32.43)</td>
<td>.001</td>
<td>87.18 (32.18)</td>
<td>.01</td>
</tr>
<tr>
<td>Spring Season</td>
<td>64</td>
<td>91.38 (37.55)</td>
<td>.02</td>
<td>69.05 (35.18)</td>
<td>.05</td>
</tr>
<tr>
<td>Motor Percentile</td>
<td>64</td>
<td>1.14 (0.58)</td>
<td>.05</td>
<td>1.11 (0.55)</td>
<td>.05</td>
</tr>
<tr>
<td>Male Sex</td>
<td>64</td>
<td>36.15 (34.58)</td>
<td>.30</td>
<td>52.75 (32.13)</td>
<td>.11</td>
</tr>
<tr>
<td>Total Score(^1)</td>
<td>53</td>
<td>3.70 (1.65)</td>
<td>.03</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Predilection(^1)</td>
<td>56</td>
<td>5.33 (2.85)</td>
<td>.07</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aspirin</td>
<td>64</td>
<td>75.70 (32.81)</td>
<td>.02</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fenestration</td>
<td>64</td>
<td>118.77 (56.41)</td>
<td>.04</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maximum RER</td>
<td>51</td>
<td>-325.9 (185.3)</td>
<td>.08</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>64</td>
<td>-18.91 (9.91)</td>
<td>.06</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rest Heart Rate</td>
<td>62</td>
<td>-2.12 (1.22)</td>
<td>.09</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age at Fontan</td>
<td>64</td>
<td>-21.24 (12.25)</td>
<td>.09</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent Contact(^2)</td>
<td>64</td>
<td>54.90 (33.33)</td>
<td>.10</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

\(^1\) Score from CSAPPA  
\(^2\) Parent report of body contact restriction  
\(^3\) Estimated change in MVPA for each unit of change in the dependent variable
When children who had the Fontan procedure at 6 or more years of age were excluded, the motor percentile score in the final model was no longer significantly related to minutes of MVPA (p=.22). The mean square error for the model decreased (from 14132 to 13644), as did the model R² (0.28 to 0.26).

Removing the one very active child among those whose parents reported an exertion restriction had a substantial influence on the relationship between parent-reported exertion restriction and minutes of MVPA. With that child included, there was no significant relationship between exertion restriction and MVPA (r = -0.13, p=.30). When that child was removed, there was a strong trend towards decreased activity among children whose parents reported an exertion restriction (r = -0.24, p=.06). When the child was excluded and the final model was repeated, both season and gender were no longer significantly related to minutes of MVPA (p=.14 and p=.17, respectively). The mean square error for the model decreased (from 14132 to 13259), as did the model R² (0.28 to 0.24).

3.2.6 Influence of Season

Seasonal variations in MVPA participation are widely recognized [47]. Activity levels are higher in summer due to amenable weather and children not being in school. To minimize seasonal variations, MVPA measurements were not obtained during school holidays (July, August, late December, mid-March), since physical activity levels are different during the summer months or when children are not in school. Nevertheless, a significant relationship between season and weekly MVPA remained. Children assessed during the spring (March to June) completed 1.5 hours of activity more per week than those assessed in the winter or fall.

3.3 Discussion

This study identified physical and performance factors associated with MVPA for children after the Fontan procedure. Existing knowledge regarding cardiac function and exercise capacity [56] and published training studies [25] have assumed that cardiac function would be the primary influence on the MVPA of children who have the Fontan procedure. However, the only previous
study to directly measure MVPA among this population [15] found that MVPA was not related to exercise capacity, medical history or functional health status. This study demonstrates that many factors influence the daily MVPA of children after a Fontan procedure. Some factors are unique to this population, while many are similar to the activity correlates of healthy children [30]. Current use of antithrombotic medication and assessment during the spring season are associated with levels of MVPA that are higher by 1.5 or more hours per week. Our multivariable model (Table 3) explains 28% of the variance in weekly MVPA among our participants.

3.3.1 Factors Influencing the Physical Activity of All Children

Most demographic and physical performance factors associated with MVPA are similar between healthy children and those who have the Fontan procedure. The activity patterns of children after a Fontan procedure reflect those of healthy children. Weekly minutes of MVPA are higher among boys [30] and among those with better gross motor skills [57]. Activity levels were also higher among children tested during the spring, in comparison to those tested in the fall or winter months. Other variables that are related to MVPA among healthy children, such as age, fitness (as reflected in resting heart rate) and self-perceptions about physical activity were correlated with weekly MVPA but did not contribute significantly to the multi-variable model.

These results suggest that although measures of cardiopulmonary exercise performance are important for assessing morbidity and changes in health status, physical activity counselling for children with complex heart defects can be based on the well-established factors that are known to influence the physical activity of healthy children. Given the very large variation in activity level with season, interventions designed to attenuate declines in physical activity during the fall and winter months may be particularly effective. Since the children are already more active during the spring (and presumably summer) months, it may be difficult for children to achieve significantly higher levels of activity during that time of year. However, since their activities levels are much lower during the fall and winter, an appropriate intervention at that time may be more successful at enabling the children to maintain a higher level of activity throughout the year. These results also suggest the need for specific support to encourage physical activity among girls and those who have lower levels of motor skill.
3.3.2 Physical Activity Variables Associated with the Fontan Circulation

The use of antithrombotic medication was the only variable in the final model that was specific to children who have the Fontan procedure. Immediately after the Fontan procedure children receive warfarin to prevent the formation of blood clots in the new circulatory pathway. Children are transitioned from warfarin to daily aspirin therapy several months or years after their Fontan and eventually the aspirin therapy is discontinued if there continues to be no evidence of clot formation. Children who develop a clot at any point typically remain on warfarin indefinitely. Our measurements of weekly minutes of MVPA indicate that children taking warfarin (n=6) were the most active (424 minutes of MVPA per week (q1: 386, q3: 436). Children taking aspirin (n=35) were slightly less active (403 minutes; q1: 297, q3: 477). Children not taking antithrombotic medication (n=23) were much less active (317 minutes; q1:250, q3:366).

Given the progression of medication from the time of surgery and the young age at which the Fontan procedure is typically performed, it was not surprising to find a correlation between antithrombotic medication use and age (r = -0.29, p=.02). This relationship raises the question of whether the observed relationship between antithrombotic medication and minutes of weekly MVPA was actually a reflection of the younger age at which most children take antithrombotic medication. However, when both antithrombotic medication use and age were modeled with weekly minutes of MVPA, the significant relationship with antithrombotic use was maintained (p=.004) but there was no significant relationship with age (p=.28). Therefore, the use of antithrombotic medication is significantly associated with weekly minutes of MVPA when controlling for the relationship between age and MVPA.

The step-wise increase in activity with daily aspirin and then warfarin therapy likely reflects differences in physical activity counselling associated with these medications. All children on warfarin are restricted from body contact activities. In light of this restriction, cardiologists counsel families quite extensively about both restricted activities (e.g., tackle football, ice hockey with body checking) as well as appropriate physical activities such as bicycling, walking, and swimming. Since bicycling and walking can easily occur on a daily basis, it may be that the activity-specific counselling leads to more frequent and regular participation in moderate-to-vigorous physical activity. It is also possible that the specific counselling provided to these
families enables the child and family to be more confident and supportive of the child’s activity participation. Whether body contact activities are restricted for children on daily aspirin therapy differs by cardiologist (Section 5.4). None of the cardiologists interviewed for this research restrict body contact activities for children who do not take any type of antithrombotic medication. Cardiologists seldom provide specific counselling about appropriate activities to the families of children who are unrestricted for physical activity. Families often report that general guidelines such as “he can do whatever he wants” or “no competitive sports” are difficult to understand and interpret in relation to the wide variety of physical activity opportunities available to the child. Families who report feeling uncertain about appropriate activities for their child have children who perform fewer minutes of MVPA each week (refer to 4.7). Children on aspirin therapy may, as a group, demonstrate intermediate levels of weekly MVPA because some cardiologists restrict body contact activities among these children, and therefore extensively counsel these families, while others do not. Overall, these results suggest that detailed physical activity counselling may be particularly beneficial for children no longer taking antithrombotic medication.

Other variables specific to the Fontan procedure that were correlated with MVPA were age when the Fontan procedure was completed, the presence of an open fenestration between the pulmonary and systemic circulation, and body contact restrictions because of antithrombotic medication or implanted medical devices (e.g., pacemaker). However, none of these variables contributed significantly to the multi-variable model.

3.3.3 Physical Activity of Children after a Fontan Procedure

Children in this study performed 356 minutes (5.9 hours) of MVPA per week. The measured quantity of MVPA was comparable to the only previous report among children after the Fontan procedure [15]. More activity was performed on weekdays (median 55 minutes per day) than on weekends (median 39 minutes). This amount of MVPA is 2 to 4 times lower than the 800 to 1400 minutes per week observed in healthy children of similar age [58-61]. It is also significantly lower than the minimum of 90 minutes per day (630 minutes per week) recommended for optimal health [5].
Children who have the Fontan procedure are often small in stature at a young age (as shown in this study), but come to have a weight for height that is higher than their peers during adolescence [62] when MVPA is typically low [58]. The increasing risk of overweight and obesity during adolescence highlights the importance of enabling these children to develop the “habit” of physical activity at a young age. If daily physical activity can be established as a key lifestyle component in childhood, there is a higher probability of an active lifestyle becoming a lifelong pursuit. Since our participants performed 16 additional minutes of activity on weekdays, interventions designed to target sedentary weekend lifestyles may be particularly effective.

The MVPA of children who have the Fontan procedure, although typically low, is highly variable. Two children in this study achieved the recommended minimum of 90 minutes of MVPA per day, while two others performed less than 15 minutes of activity per day. Similarly, age and sex-matched gross motor skill scores also ranged from the 1st to the 95th percentile. Clearly, it is possible for some children who have the Fontan procedure to achieve excellent motor skills and live the active lifestyles recommended for life-long heart health [5]. However, it is equally evident that some children adopt the very sedentary lifestyles which, in adults, are associated with atherosclerosis, diabetes, and obesity [43]. The results of this study suggest that having a Fontan circulation does not restrict a child to a sedentary lifestyle. Rather, effective interventions based on the well-established correlates of physical activity for healthy children are needed in order to enable most children who have the Fontan procedure to adopt and maintain the physically active lifestyles associated with optimal health outcomes.

3.3.4 Study Limitations

The results of this study must be viewed in light of its limitations. The children in this study had only the most complex form of congenital heart defect. Whether the factors associated with sedentary lives would be similar among those with other types of congenital heart defects [28] cannot be determined from these results. It is also possible that there was a selection bias among the study participants. Although all eligible children known to our clinic were approached, we could not assess the activity levels or review the medical records of the children who chose not to participate. However, the age range and sex distribution were similar between participants and non-participants. One might hypothesize that if a selection bias occurred, it would favour the
participation of more active children, while those who are inactive or do not enjoy physical activity would be more likely to refuse. If that assumption were true, the population as a whole may be even less active and even more in need of an effective intervention to encourage higher levels of daily MVPA than the group of children who completed this study. There may also have been an issue of multiple comparisons, given the large number of variables assessed. For that reason, the results presented are from a multi-variable analysis which establishes the relationship of each variable with MVPA while controlling for the impact of all other variables in the model. Finally, we assessed self-perceptions of physical activity, fitness, motor skill, demographic and treatment factors. There may be important differences between healthy children and children with a Fontan circulation in unmeasured factors such as activity attitudes or parent modelling of physical activity.

3.4 Conclusions and Implications

Children who have the Fontan procedure can be physically active at levels that meet, or are close to, recommended guidelines. Current use of antithrombotic medication (1.9 hours/week) and the spring season (1.5 hours/week more than fall or winter) are strongly associated with the level of MVPA. These factors, along with male sex and motor skill performance, primarily reflect the known activity correlates for healthy children [30]. Therefore, interventions to increase MVPA among children who have the Fontan procedure should be based on strategies known to be effective for healthy children. Interventions that target girls and children with lower gross motor skills, and encourage activity on weekends and throughout the year may be particularly effective for developing active lifestyles among children who have the Fontan procedure. Although children with complex heart defects are often sedentary, this research demonstrates that they can obtain the active lifestyles associated with optimal childhood growth, development, peer interactions and health benefit. Their ability to lead a physically active lifestyle appears to be unrelated to measures of their health-related fitness or cardiopulmonary exercise capacity. Health care providers caring for these children should actively counsel their patients about increasing their participation in activities that are appropriate for their age, interests and medical treatment. The counselling provided should be based on factors known to be associated with MVPA for healthy children and the child’s use of antithrombotic medication.
Chapter 4
Understanding Child and Parent Perceptions
4 Activity in the Eyes of Children with Complex Heart Defects and their Parents

4.1 Introduction

The importance of a physically active lifestyle for children is widely recognized. As previously explained (2 Importance of Physical Activity for Children), physical activity is essential for the child to grow and develop, both physically and cognitively. The socialization of young children, including the majority of peer interactions, is also highly dependent on the child’s ability to be physically active. Finally, a physically active lifestyle in adulthood is associated with a lower risk for health problems such as diabetes, obesity, and coronary artery disease [38]. Developing a physically active lifestyle in childhood also increases the likelihood that the person will continue to be active during adolescence and adulthood.

Children who have the Fontan procedure currently have very sedentary lifestyles. They are significantly less active than their healthy peers, particularly prior to 12 years of age [15]. Both boys and girls are similarly inactive, and their activity levels even at a young age are so low that, unlike healthy children, they have a muted decline in physical activity with increasing age. Children with other complex congenital heart defects, as a group, show a similar pattern of lower physical activity levels relative to healthy peers, with little to no difference by sex or age [16]. These very sedentary lifestyles are particularly troublesome given that the majority of healthy Canadian children are not sufficiently active for optimal health [12]. Previous research has demonstrated that exercise training programmes can increase the physical fitness of children with heart defects [24, 25]. However, compliance with training programmes is very low unless the programmes are done at home or located nearby, are for a short duration and are encouraged or supervised by appropriate staff. All of these requirements make such programmes resource intensive, and limit their availability outside of large urban centres. There is also no indication that improving physical fitness via these structured programmes will alter the long-term daily physical activity habits that are most closely associated with health benefits.
Identifying Targets for Intervention

The development of effective interventions depends on an understanding of the factors that influence the target behaviour. Through the study reported in the previous chapter, we identified a series of factors associated with physical activity that, when taken together, explain 28% of the variation in activity level between children who have had the Fontan procedure. We know that many of these factors are similar to those identified for healthy children [30]. Of these, the most likely targets for an intervention would be physical activity preferences and intentions, barriers and time spent outdoors. Other factors, such as sex or access to facilities, would be outside the child’s sphere of influence and therefore would not be expected to be directly influenced by an intervention focused on the child.

Research with adolescents with congenital heart defects and their parents has identified several issues related to physical activity participation that may also influence the activity of younger children. Adolescents with a range of congenital heart defects identify lower self-efficacy for physical activity (one’s own perception that successful participation is less likely), being quicker to fatigue, and a lack of knowledge about physical activity options as issues that lead to lower levels of sport participation [27]. In a separate study, parents of adolescents with congenital heart defects identified uncertainty about appropriate activities and teacher or coach overprotection as issues that reduce the physical activity of their children [63]. Other researchers have found that 80% of parents underestimate the exercise capacity of their child with a congenital heart defect [29].

There is also existing literature on the adaptation and psychosocial adjustment of children with complex heart defects to other spheres of life that can help us to identify additional potential intervention targets. DeMaso and colleagues [64] demonstrated that the emotional adjustment of children with congenital heart defects was primarily determined by maternal perceptions of parenting stress (33% of variance), with the medical severity of the defect contributing very little (3% of the variance). Casey et al [65] obtained similar results by asking teachers to rate the child’s ability to perform school physical activities. They found that higher measures of family strain were associated with lower teacher ratings of activity performance. The influence of family strain was stronger than the influence of the exercise limitation imposed by the heart defect. Taken together, these studies suggest a strong link between the attitudes and adjustment
of the parents and the adjustment of the child with a complex heart defect. These results support Eccles’ expectancy value model which suggests that, over time, the child’s behaviour gradually comes to conform to parent expectations as the child’s values are shaped by parental expectations. Given that Eccles’ model has also been supported through research examining the sport participation of healthy children [34], the potential influence of parent perceptions and expectations for the physical activity participation of a child with a complex heart defect requires further investigation.

**Purpose of the Study**

The purpose of this study was to learn about the physical activity perceptions, including preferences, intentions, barriers and outdoor play, of children with complex heart defects and their parents. The goal was to better understand the perceptions of these children and their parents in order to elucidate how those perceptions might influence the child’s actual level of physical activity.

The research questions to be answered through this research are:

1. How do children with complex congenital heart defects perceive physical activity?
2. How do children with complex heart defects perceive their own activity levels relative to the activity of their healthy peers?
3. How do parents of children with complex heart defects perceive their children’s physical activity?

**4.2 Method**

**4.2.1 Rationale for Research Approach**

The physical activity perceptions of children with complex heart defects and their parents were investigated using a modified interpretive interactionist approach [39] designed to identify how physical activity is understood and experienced by these families. The interactionist approach emphasizes the importance of “life-changing” experiences in determining current behaviour.
Families of children with complex heart defects experience numerous “life-changing” experiences, such as multiple major heart surgeries for their child and responsibility for monitoring a myriad of symptoms that might suggest decreasing heart function. Therefore, I felt that a modified version of Denzin’s theoretical framework would be an appropriate approach to understanding the physical activity perceptions of these families. My research differed from Denzin’s theoretical approach in that in-depth interviews with the children were not completed. Like Denzin, my focus was identifying those critically important life experiences that shape the meaning which these children and their parents attach to childhood physical activity.

**Constructivist Approach**

Interpretive interactionism is grounded in a constructivist view of the world. In contrast to the positivist view of traditional “science”, which seeks to learn the one “truth” that governs a specific situation, a constructivist view sees not just one truth, but many. From that perspective, what is “real” at each point in time is constructed from the many influences that interact with each other. In terms of the physical activity participation of a child with a complex heart defect, a positivist approach would seek to identify one or more determinants that ultimately control the child’s choice to be active or sedentary. In contrast, the constructivist view assumes that whether or not a child is active at a particular point in time will be influenced by many different factors, and those factors are likely to be different or have different influences at different times or in different settings. For example, having an open fenestration is associated with a more sedentary lifestyle (3.2.4). A positivist view would say that any group of children with open fenestrations would be less active than a group of children without fenestrations. A constructivist view would allow that having an open fenestration makes an active lifestyle less likely, but that in the right circumstances (e.g., an activity setting that does not require aerobic fitness), children with open fenestrations as a group may or may not be more sedentary. Given the very complicated array of variables that potentially could influence the physical activity of children with complex heart defects, and knowing that the impact of those variables can change considerably over time, I felt that a constructivist viewpoint would be the most appropriate basis for this aspect of my research.
Benefits of Qualitative Research Methods

Qualitative research methods were chosen in order to investigate the physical activity perceptions of children with complex heart defects and their parents. Words and pictures, rather than numbers, are the data that are systematically analyzed using this approach. Qualitative methods recognize and incorporate the social context that impacts the individuals or situation under investigation. Thus, I felt that qualitative methods would offer the most appropriate avenue for investigating the physical activity perceptions and beliefs of children with complex heart defects and their parents from a constructivist approach. We know that words or images can be significantly influenced by the social context in which they occur. For that reason it is critically important that the qualitative researcher recognize her own influence on the social milieu in which data are generated. The researcher must also recognize the impact of personal experiences, biases and expectations.

Qualitative research is more than just the collection of verbal, written, or pictorial material but rather it is a systematic examination of that material according to established procedures. The goal is to learn how those who experience a situation, such as physical activity for a child with a complex heart defect, understand and make sense of that experience. This focus on the meaning of physical activity for children with complex heart defects and their parents provides a unique opportunity to understand how their perceptions and experiences may influence the child’s participation. The spotlight of research is focused on the understandings, beliefs and expectations of the children and their parents, rather than on the observable behaviours (e.g., minutes of physical activity per week) or other factors (e.g., medical history) that may be the primary interest of the positivist researcher [66]. Qualitative methods are recognized as being particularly suited to developing an understanding of the meaning that individuals attach to the experiences that they have had [66]. They are also effective for hypothesis or theory generation in new areas of research, examining issues and beliefs that are subject to social influences, and collecting in-depth information about a narrow topic of interest [67].

4.2.2 Research Design

This research project was designed to generate an understanding of the physical activity perspectives of children with complex heart defects and their parents by gathering information
directly from the children and families themselves. Information was gathered through both focus groups and individual interviews.

The purpose of the focus groups was to generate discussion regarding perceptions of and experiences with physical activity among group members who shared the experience of a complex heart defect. The goal was to identify significant issues that should be explored further through individual interviews. It was expected that the setting of a group discussion would enable an evaluation of the consensus among group members for the particular views expressed by individuals and an examination of the influence of group members in shaping the responses provided [68]. Two focus groups were conducted, one with children and the other with their parents.

The information obtained from the focus groups was utilized to design the semi-structured interview framework that was subsequently used with children who have the Fontan procedure and their parents. The goal of the interviews was to understand their perceptions of the child’s physical activity participation. In particular, I sought to understand the types of activity in which the child participated, activities that the child would like to learn, and the typical activities performed at home and school, throughout the year. From the parents, I also sought to gather their perceptions of the factors that influence their child’s physical activity, either positively or negatively, as well as the guidance that the parents have received from health care professionals.

I led each of the focus groups, with assistance from other research staff not known to the participants, and independently conducted all of the interviews. None of the participants were known to me prior to the research study and I have no clinical connection to the participants apart from the research study. Details of the methods used for the focus groups and individual interviews are provided in subsequent sections. The modified interpretive interaction framework previously described (4.2.1) was used to guide the data analysis and interpretation.

4.2.3 Research Participants

Focus Group Participant Recruitment

Purposive, rather than random, sampling [69] designed to maximize the variation among focus group participants was employed in order optimize the probability that the views expressed
would represent the diverse opinions in the larger population. Although purposive sampling limits one's ability to generalize the findings, it was felt to be beneficial for the purposes of elucidating the wide range of issues that should optimally be addressed during the individual interviews. The goal of purposive sampling is to identify participants whose perceptions are of interest to the topic under study [70]. It is a powerful tool for identifying “information-rich cases” suitable for in-depth study [68].

A maximum variation sampling strategy [68] was used to identify potential focus group participants from the patient records of Dr. Brian McCrindle. Dr. McCrindle has over 20 years of experience as a paediatric cardiologist at The Hospital for Sick Children and his practice is representative of the range of children with complex congenital heart defects typically seen in the cardiac clinic as a whole. Children 6 to 11 years of age were eligible to participate in the focus group if they had a significant heart defect that would require life-long monitoring and care. The age group of 6 to 11 years was selected to represent children who would be attending full-day elementary school. Previous research has established the ability of children at this age to effectively participate in focus group discussions about topics related to their health [69, 70]. The maximum variation sampling strategy sought to include children who had one or multiple surgeries, children repaired as infants or at an older age, children who had reparative and palliative surgeries, and a range of abnormal cardiac anatomy (both right and left sides of the heart). The purpose of these variation criteria was to obtain a focus group sample that would be representative of the full range of children with complex heart defects and their parents who would subsequently be interviewed. Families who lived more than 100 km from the Labatt Family Heart Centre were excluded because it was felt to be unlikely that they would be willing to travel that distance (more than 1 hour drive each way) in order to participate.

The age and diagnosis of all patients who had been seen by Dr. McCrindle in the preceding 8 months were reviewed to identify potential study participants who met the inclusion criteria. The list of potential participants was then reviewed by Dr. McCrindle to remove any families who, in his judgement, were inappropriate to approach for this research. Families were identified as inappropriate if the family had previously indicated that they did not want to be approached for research, if the child’s health was unstable, if the family was in a period of particularly high stress, or if the child had other developmental or medical issues. Letters of invitation to the focus
group were distributed to the parents of Dr. McCrindle’s patients that could be approached for the study (n=10).

The parent support network of the Labatt Family Heart Centre (KidPACES) and the cardiac clinic were also used to recruit focus group participants. Letters requesting families to participate in the focus groups were distributed to members of the executive of KidPACES, who then distributed the letters of invitation to suitable families within their own network. A flyer about the focus group was also posted in the Labatt Family Heart Centre so that patients of other cardiologists also had an opportunity to participate.

Two weeks after the letters were distributed, the families of Dr. McCrindle’s patients were contacted by telephone in order to answer any questions that they had about the focus groups and to determine whether or not they wished to participate. Five parents from four families and their children with complex heart defects who were patients of Dr. McCrindle agreed to participate (4/10 invited families). Of the six families who did not participate, two declined the invitation, three were interested but unavailable due to vacation schedules, and one child had a physical disability (cerebral palsy) that the parents felt significantly limited his physical activity participation. In addition to the four invited families, one parent participant was identified through the KidPACES network (at 5 years of age her child was too young to be included in the focus group) and one parent and child dyad was recruited from the posted flyer. Although 5 children is considered ideal for focus groups with elementary school-aged children [70], one child and parent did not show up on the day of the group. Therefore, the participants were four children, four mothers and 2 fathers from 5 families.

Demographics of Focus Group Participants

Demographic information for the focus group participants is shown in Table 4. Clearly, the focus group participants represented a wide range of complex heart defects. For this study, a census sampling strategy was used to recruit the focus group participants. That is, all eligible families were contacted and all interested families were able to participate. The possibility of selection bias must be considered because the families who agreed to participate may differ in some way from the families who declined the focus group invitation (n=2) or who were interested but unavailable (n=3). However, a review of the demographic attributes of the participants suggests
that the focus group participants were an accurate reflection of the range of variability that occurs within the population of children with complex heart defects. There was a fairly equal balance by sex and age of the children, two had undergone surgical repair while three were palliated, and two had a pacemaker because of surgical complications. Thus the demographic attributes of the participants closely reflected the desired distribution across the maximum variability observed in this population.

Table 4: Demographic Description of Focus Group Participants

<table>
<thead>
<tr>
<th></th>
<th>Mother A</th>
<th>Father B</th>
<th>Mother C</th>
<th>Mother D &amp; Father D</th>
<th>Mother E (non-participant)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child Sex</td>
<td>Female</td>
<td>Female</td>
<td>Male</td>
<td>Male</td>
<td>Male</td>
</tr>
<tr>
<td>Child Age</td>
<td>11.5 yrs</td>
<td>9.75 yrs</td>
<td>10.5 yrs</td>
<td>8.6 yrs</td>
<td>4.9 yrs</td>
</tr>
<tr>
<td>Child Diagnosis</td>
<td>Tetralogy of Fallot</td>
<td>Pulmonary Atresia, Hypoplastic Tricuspid Valve</td>
<td>Ventricular Septal Defect, Coarctation of Aorta</td>
<td>Aortic Stenosis</td>
<td>Hypoplastic Left Heart Syndrome</td>
</tr>
<tr>
<td>Child Surgical History</td>
<td>Repair</td>
<td>Fontan</td>
<td>Coarctation &amp; VSD repair</td>
<td>Valvotomy</td>
<td>Fontan</td>
</tr>
<tr>
<td>Pacemaker</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>
Interview Participant Recruitment

Individual interviews were conducted with a select group of children who have had the Fontan procedure and their parents. The children were enrolled in the study of factors associated with physical activity participation among children who have the Fontan procedure (3.1.1). Children and their parents were interviewed in the order that they arrived at the hospital for the baseline assessment visit for that study. Recruitment of this convenience sample of children with complex heart defects and their parents continued until saturation of the interview results was achieved. Although in quantitative research a random sample of participants is preferred, randomization of the families interviewed was limited to the order of assessment visits. This method of sampling is less problematic in qualitative research because data collection continues until no new information is generated by the completion of additional interviews (i.e., saturation is achieved). Therefore, the order in which study participants are interviewed is much less relevant because additional interviews will be conducted until all viewpoints have theoretically been obtained. That is, no new information or themes emerge during subsequent interviews with additional participants [68]. A total of 10 girls and 10 boys and their parents were interviewed. Ten family dyads within each strata by child gender is within the range of 6 (saturation for major themes) to 12 (saturation for sub-themes) interviews that is expected to produce saturation of the results [71].

Interview Participant Demographics

The demographic attributes of the interview participations are summarized in Table 5. A review of the demographic attributes of the interview participants indicates that the families chosen to participate in the individual interviews were representative of the total population of participants in the larger study. The interview participants were also representative of the population of children who have the Fontan procedure as a whole, except that boys and girls were equally represented among the interview participants. The overall population is predominantly boys (75%), due to fact that almost all children with hypoplastic left heart syndrome (one of several diagnoses leading to the Fontan procedure) are male.
Table 5: Demographic description of interview participants

<table>
<thead>
<tr>
<th>Child</th>
<th>Parent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>Age</td>
</tr>
<tr>
<td>M</td>
<td>9.6</td>
</tr>
<tr>
<td>M</td>
<td>10.5</td>
</tr>
<tr>
<td>M</td>
<td>10.8</td>
</tr>
<tr>
<td>M</td>
<td>8.6</td>
</tr>
<tr>
<td>M</td>
<td>7.2</td>
</tr>
<tr>
<td>M</td>
<td>9.0</td>
</tr>
<tr>
<td>M</td>
<td>10.4</td>
</tr>
<tr>
<td>M</td>
<td>7.1</td>
</tr>
<tr>
<td>M</td>
<td>8.3</td>
</tr>
<tr>
<td>M</td>
<td>11.4</td>
</tr>
<tr>
<td>F</td>
<td>10.5</td>
</tr>
<tr>
<td>F</td>
<td>7.7</td>
</tr>
<tr>
<td>F</td>
<td>7.1</td>
</tr>
<tr>
<td>F</td>
<td>7.0</td>
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<tr>
<td>F</td>
<td>6.0</td>
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<tr>
<td>F</td>
<td>10.6</td>
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<tr>
<td>F</td>
<td>6.7</td>
</tr>
<tr>
<td>F</td>
<td>11.1</td>
</tr>
<tr>
<td>F</td>
<td>6.1</td>
</tr>
<tr>
<td>F</td>
<td>10.2</td>
</tr>
</tbody>
</table>

DORV = double outlet right ventricle; HLHS = hypoplastic left heart syndrome; Tri. Atresia = tricuspid atresia; Pulm. Atresia = pulmonary atresia; DILV = double inlet left ventricle; GP = grandparent
4.2.4 Focus Group Methods

Rationale for Focus Groups

Focus groups were initially used to obtain the physical activity perspectives of children with complex heart problems and their parents. Such group discussions, developed initially for marketing research, are a recognized data collection tool for generating hypotheses and developing survey questions [68]. They were developed in response to the realization that many decisions that people make are influenced by the social context in which they occur, and that discussions with other people are particularly powerful influences. More recently, the feasibility of using focus groups with elementary school-aged children with chronic illnesses and medical conditions and trustworthiness of the data thus obtained, have been established [69, 70]. Trustworthiness is the concept in qualitative research that embodies data that are reliable, valid and useful and not unduly influenced by the personal opinions of the investigator [70].

The focus group sessions were intended to provide me with first-hand information about family priorities, participation, and expectations for the physical activity of these children. The focus group format was chosen to encourage interactive discussions between group members, which often lead to synergistically created insights that would not have otherwise been identified [68, 69]. Research also suggests that people will answer questions in more detail during a focus group than they would in an individual interview. Being in a group they feel less pressure to answer every question, because others are also participating, and therefore they contribute more detailed responses when they choose to participate [69]. Group discussions typically focus on the most important issues, and provide checks and balances to clarify or negate false or extreme views [68]. Focus groups also provide the flexibility to investigate emerging, unanticipated responses and to observe how opinions and views are shaped by social influences (i.e., other group members). Finally, the use of preliminary focus groups is an effective method for identifying terminology and frames of reference relevant to the population under study so that questionnaires can be developed with appropriate wording and content [70]. It was expected that the group discussion would be particularly suitable for facilitating discussions with the child participants. Group discussions are a widely used strategy in current educational practices [67] and focus
groups have previously been used with children to explore their understanding of health information.

Focus Group Environments

The focus groups were held at the hospital in the early afternoon. Families arrived and were introduced to the research staff and each other. The goal of the focus group was explained to each child and their assent to participate was obtained. Informed consent for their own and their child’s participation were also obtained from the parent in accordance with the requirements of the hospital’s Research Ethics Board. Staff for the focus group included the researcher (P. Longmuir), the child life specialist who provided the play activities, and a research student who took notes of the key points of conversation. In the play room used for the children’s focus group, the children were provided with craft and drawing materials and drinks and snacks that they could access at any time in order to provide familiar experiences and a more comfortable setting [70].

It was intended that the parent and child focus groups would be separate, so that both parents and children could more easily provide their own personal opinions. However, one child (D) was not willing to be separated from his parents. As a result, his father was present during the child focus group and he (child D) was present during the parent focus group.

In each focus group, the researchers and participants were seated in a circle for ease of discussion. Two Sanyo digital recording devices were placed at either end of the circle in order to maximize opportunities for recording all voices and to provide a backup recording in the event of equipment malfunction. The researcher explained that the devices would record what people said, and that the research assistant sitting at a separate desk would also be making notes on her computer. When all participants agreed to having the conversation recorded the tape recorders were turned on and the student note taker began her work. The rules for participating in the discussion (e.g., allowing everyone to speak, respecting each person’s opinion, there was no right or wrong answer), the importance of confidentiality and the voluntary nature of research was reiterated to the participants at the beginning of each group. The moderator ensured that each participant had similar opportunities to share thoughts with the group. Participants were invited to ask questions at the end of the focus group and the moderators clarified any information
discussed that might be misunderstood (e.g., incorrect or misleading statements from other participants).

**Focus Group Questions**

The research questions to be investigated via the parent and child focus groups were initially formulated as:

1. In which physical activities do children with complex heart defects participate at home, at school and in the community?

2. What are the physical activity expectations of children with complex heart defects and their families?

3. How do cardiologists and their heart condition influence the child’s physical activity?

4. What are the barriers to physical activity experienced by these families?

The research questions were designed to gather a broad range of information about the child’s current and potential physical activity participation. The questions were intended to document the types of physical activities in which these children participate (#1) and the barriers or factors that reduce or hinder their participation (#4). I also felt it was important to learn more about the physical activity perceptions of these children and their parents regarding the child’s ability to be physically active (#2) and the influence of their cardiologist and the child’s heart condition (#3).

The focus groups followed a semi-structured interview format that both guided the discussion and allowed new themes or issues to emerge. The questions posed during each focus group were developed in order to gather data related to the identified research questions. The choice of topics reflected constructs known to influence the physical activity of healthy children [30], with a particular focus on topics which had not yet been addressed in literature regarding children with complex heart defects. The comprehensive master list of all potential questions was then reviewed by two researchers (B. Antle, B. McCrindle) with expertise in focus group research and paediatric cardiology, respectively. The final list of questions was then organized into a focus group script, which grouped related or follow-on questions and enabled a logical flow of topics for discussion from simple (e.g., What do you like to do?) to more complex (e.g., What has your
doctor told you about physical activity?). The questions of interest were preceded by “warm-up” questions to initiate the discussions and the final question regarding advice for others was added as a debriefing opportunity to enable participants to feel that they were contributing expertise and assisting others through their contributions [69].

Children’s Focus Group

The topics addressed during the children’s focus group were activities done at home, at school or in the community, the experience of participating in activities with other children, what information medical professionals and family members had provided about the child’s physical activity, the types of activities that the children feel are difficult and their perceptions of experiencing a new activity. The relationship between the research questions and the specific questions asked during the child and parent focus groups is provided in Table 6. The semi-structured framework of questions that guided the child focus group discussions is provided in Appendix A. The questions were designed to be concrete (e.g., What physical activity do you do at home?) rather than abstract (e.g., Are you an active person?) in keeping with the developmental level of the participants [65].

The child focus group began with introductions and discussions of what the children liked to do when they are not at school. The initial questions about their activities at home, school and in the community were designed to establish whether the focus group participants had the predominantly sedentary lifestyles that characterize children with complex heart defects. Questions about participating in activities with other children were designed to identify the importance of peer influence. Peers are known to be important influences on the activities of older children, but peer influence is more equivocal at younger ages [30]. We also anticipated that influence of healthy peers might be lower among these children because their heart defects prevent them from participating in the full range and intensity of activities enjoyed by their peers. Questions about the activity guidance received from doctors and parents were intended to investigate the children’s understanding of their own activity potential and the impact of adults who are known to influence the child’s beliefs about physical activity [34].
<table>
<thead>
<tr>
<th>Child Focus Group Questions</th>
<th>Research Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Can you draw the activity you like to do most when at home?</td>
<td>1.</td>
</tr>
<tr>
<td>What other physical activities do you do at home?</td>
<td>X</td>
</tr>
<tr>
<td>2. Can you draw the activity you like to do most when at school? What other physical activities do you do at school?</td>
<td>X</td>
</tr>
<tr>
<td>3. What physical activities do you do at other places? (neighbourhood, park, playground, daycare, etc.)</td>
<td>X</td>
</tr>
<tr>
<td>4. What is it like when you do activities with other kids?</td>
<td>X X</td>
</tr>
<tr>
<td>5. What have your doctors told you about physical activity?</td>
<td>X X X</td>
</tr>
<tr>
<td>6. What have your parents told you about being active?</td>
<td>X X X</td>
</tr>
<tr>
<td>7. What activities are hard for you to do?</td>
<td>X X X</td>
</tr>
<tr>
<td>8. If you tried a new activity you had never done, what would it be like?</td>
<td>X</td>
</tr>
<tr>
<td>9. Do you have any advice for other kids who have had a heart operation?</td>
<td>X X X</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Parent Focus Group Questions</th>
<th>Research Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What activities are popular in your family?</td>
<td>1.</td>
</tr>
<tr>
<td>2. Which of your child’s activities would contribute to the recommended 90 minutes of daily activity for children?</td>
<td>X</td>
</tr>
<tr>
<td>3. What have you been told by health professionals about your child’s ability to participate in physical activity?</td>
<td>X X X</td>
</tr>
<tr>
<td>4. What activities does your child do at school?</td>
<td>X</td>
</tr>
<tr>
<td>5. What makes it difficult for you to take your child to activities, lessons, teams or clubs?</td>
<td>X X</td>
</tr>
<tr>
<td>6. What advice would you give other parents?</td>
<td>X X</td>
</tr>
</tbody>
</table>
Questions regarding activities that are difficult and perceptions of trying new activities were intended to elicit beliefs related to self-efficacy for physical activity (i.e., the children’s perceptions of their own effectiveness for performing childhood physical activity) which is an important mediator of a child’s participation [34].

Parent Focus Group

The parent focus group began with introductions and a general discussion of the typical activities that the participants enjoyed with their children. Examples of both active and sedentary activities were provided to encourage parents to identify those activities that their family typically enjoyed without a bias towards physically active pursuits. Subsequently, Health Canada recommendations for childhood physical activity [5] were described and parents were asked about the appropriateness and relevance of the guidelines for healthy children for their children with complex heart defects. Parents were asked about the guidance or information that they had received from health professionals about their child’s activity in order to understand parental expectations for the child’s participation [34]. Questions about the activities that their child is involved in at school and in the community were intended to identify resources and opportunities available to the family. It also acted as a second data source to corroborate the children’s own reports of their activity participation (triangulation of the data to establish its reliability [66]).

Parents were asked about the barriers they experience in supporting their child’s participation in physical activity because parental support and facilitation of activity is an important determinant of childhood activity in this age group [30]. The parent focus group concluded with the researcher asking the participants for their advice to other parents of children with similar heart problems. The wording of the specific questions posed during the focus group is provided in Appendix B.

4.2.5 Individual Interview Methods

Rationale for Individual Interviews

In-depth interviews are the primary source of data when using Denzin’s interpretive interactionist approach [39]. The goal of open-ended interviews is to find out how the person being interviewed views the world. Interviews enable us to learn about things, such as attitudes,
beliefs, and expectations, that cannot be directly observed [68]. Direct observation/measurement has clearly demonstrated the sedentary lifestyles of children with complex heart defects (3.2.3). However, the lack of a correlation between medical history variables or exercise tolerance and the child’s level of moderate-to-vigorous activity suggests that factors other than the cardiac defect itself are the primary determinants of activity participation. Therefore, interviews were selected as the most appropriate method to learn more about how physical activity is “viewed” by children with complex heart defects and their parents.

Interview Environments

Interviews were conducted during the baseline assessment visit for the study to identify factors associated with physical activity participation among children who have the Fontan procedure (3.1). When each family arrived they were introduced to the researcher who explained the goal of the interview and obtained informed consent in accordance with the requirements of the hospital’s Research Ethics Board. Interviews were conducted in a seating area within or adjacent to the physical activity testing area in the hospital. A Sanyo digital recording device was used to record each interview. The researcher also made written notes of the discussion during the interview in order to document non-verbal communication, record researcher observations and perceptions, and to provide a backup of the interview content in the event of equipment malfunction. Additional notes were recorded by the researcher at the end of the interview as required to fully document the interview content and experience.

It was intended that the parents and children would be interviewed separately. However, given the relatively young age of the children they were given the option of completing their interview with or without the parent seated nearby. In order to minimize the influence of the parent on the child’s comments, the parents were given a lengthy questionnaire to complete just before the child interview began. The questionnaire was a combination of published instruments used to assess the child’s physical activity participation and the factors that are important influences (either positive or negative). The questionnaire addressed topics such as neighbourhood safety, activity of their child relative to friends, and the child’s participation in lessons or classes at school and in the community. By providing this questionnaire just as the child was beginning the assessment, it was hoped that parent attention would be primarily focused on the questionnaire, making it less likely that the parent would actively participate in the child’s interview. Although
most children chose to remain in the same room as their parents, many children reacted very positively to being asked for their own opinion (as distinct from the opinion of their parents). In most cases the children made clear statements to indicate their own opinion on those occasions when a parent did attempt to contribute their own thoughts during the child interview (e.g., “Pat already asked you about this, now she wants to know what I think”).

**Individual Interview Questions**

Research with healthy children has demonstrated that there are many variables in the psychological, socio-cultural and behavioural realms, such as activity beliefs and parent support, which play a significant role [30]. The published literature about childhood physical activity and the information gained from the initial focus groups were combined to develop the following questions for the individual interview phase of this research:

1. How does the child participate in physical activity within the home/family setting?

2. How does the child participate in physical activity within the school setting?

3. What are the child’s preferences for physical activity?

4. What are the child’s perceptions of physical activity?

5. How do parents understand the physical activity options for their child?

6. What are the physical activity priorities and preferences of parents of children with complex heart defects?

7. What are the supports for and barriers to physical activity for the child with a complex heart defect?

Table 7 provides a matrix of these research questions and the categories of questions posed during the individual interviews (child and parent).
Table 7: Research Questions/Individual Interview Questions Matrix

<table>
<thead>
<tr>
<th>Child Interview Questions</th>
<th>1.</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
<th>5.</th>
<th>6.</th>
<th>7.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Since we’ve never met, can you tell me about yourself?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>2. What things do you really like to do? What are your favourites?</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. What do you usually do after school or on weekends?</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>4. What do you do during the winter or during summer vacation?</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>5. Do you take any lessons, play on teams or go in races or games with winners?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>6. How do you get to and from school?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>7. What do you do in gym and at recess/lunch?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>8. If you had to pick one word to say how you feel about being active, what word would it be?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>9. What activities would you like to learn or do better?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>10. Do you like playing on teams or with friends? Winners and losers or playing for fun?</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Do you like being outside or inside or both?</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Do you like activities music or pretending?</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. What advice about activity would you give to other children?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>
Table 7 (cont’d)

<table>
<thead>
<tr>
<th>Parent Interview Questions</th>
<th>Research Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. What equipment or places for physical activity are available to your child?</td>
<td>1. X 2. X 3. X</td>
</tr>
<tr>
<td>3. What have you been told by health professionals about your child’s physical activity?</td>
<td>1. X 2. X 3. X</td>
</tr>
<tr>
<td>4. What activities would you like your child to learn or do?</td>
<td>1. X 2. X 3. X</td>
</tr>
<tr>
<td>5. What activities are not recommended or do you not want your child to do?</td>
<td>1. X 2. X 3. X 4. X</td>
</tr>
<tr>
<td>6. How important is physical activity to your family?</td>
<td>1. X 2. X</td>
</tr>
<tr>
<td>8. What is your child’s opinion regarding physical activity?</td>
<td>1. X 2. X</td>
</tr>
<tr>
<td>10. What makes it’s hard for your child to participate?</td>
<td>1. X 2. X 3. X</td>
</tr>
<tr>
<td>11. What would make it easier for you to support your child’s activity?</td>
<td>1. X 2. X</td>
</tr>
<tr>
<td>13. If you could ask an expert about activity for your child, what would you ask?</td>
<td>1. X 2. X 3. X</td>
</tr>
</tbody>
</table>


Mistaken Assumptions

The parent and child focus groups provided interesting results and required me to give further consideration to the development of the specific research questions for the individual interviews. In analyzing the focus group data I quickly realized that my assumptions had led me to ask only about the barriers to physical activity and so little information was gathered about factors that have a positive influence on the child’s participation. Both barriers and supports were discussed during the individual interviews to provide a more comprehensive picture of the full range of issues and influences. Focus group discussions with the children about their activity clearly indicated that there were substantial differences between the home and school environments. Therefore, the children were asked specific questions about their physical activity at a variety of times in both the home and school environments. One parent-child dyad at the focus groups spoke extensively about the child’s preference for sedentary activities, and several parents commented that some children are more naturally active, sedentary or competitive. These comments highlighted the importance of investigating both parent and child perceptions, priorities and preferences for the child’s physical activity during the individual interviews. Finally, the extensive discussions in the parent focus group about the lack of clarity and uncertainty that parents feel when trying to decide whether a particular activity is appropriate for their child was a completely unanticipated result. To further investigate the issue of parent perceptions of uncertainty the individual interviews included questions designed to elicit parents’ understanding of the physical activity options available to their child.

Individual Interview Design

Initiating each interview with questions about the participants’ current behaviour was also designed to encourage highly descriptive responses. Most of the interview questions were designed to be open-ended, in order to minimize the influence of research assumptions about the types of responses. However, for the children’s interviews, the final questions were designed to be dichotomous (e.g., indoor versus outdoor play) in order to provide more concrete questions that could be used to gather specific information about important variables. The dichotomous questions in the child interview were omitted from an interview if the child had previously provided an answer while responding to an open-ended question.
The interviews followed a semi-structured format that both guided the discussion and allowed new themes or issues to emerge. The topics addressed during the children’s interviews were activities done at home, school or in the community, activities done in structured programmes (e.g., teams, lessons), activity variation by season, how the child feels about physical activity, desired new activities or improvements, preferences for activities outdoor/indoor, with music or as competition. The interview guide for the children’s interviews is provided in Appendix C. The child interviews began by allowing the children to introduce themselves to the researcher (“getting to know you”) and concluded by asking the children what advice about physical activity they would give to other children who had the same heart operation. Drawing and colouring activities were available to the child throughout the interview in order to provide a more comfortable and familiar setting.

The parent interviews began by asking the parent about typical activities that they enjoyed with their child. The researcher emphasized that the activities could include any type of activity, not just sports or physical activity. Subsequently, the parents were asked about the activity options available to their child (guidance provided, places available, equipment, etc.), their priorities and interests for the child’s activity, the supports and barriers they experience in relation to their child’s participation in physical activity, and how they do or would like to support their child’s participation. Similar to the children’s interviews, the parent interviews concluded by asking the parents what advice they would give to other parents of children with heart problems. The interview guide for the parent interviews is provided in Appendix D.

### 4.2.6 Data Safety and Storage

All of the interviews were digitally audio recorded using Sanyo digital recorders. The recorders are USB port compatible for ease of transfer to the researcher’s hospital owned, encrypted computer. Immediately after each group or individual interview, the recording file(s) were transferred to the encrypted computer and then a back up copy was filed on the cardiology main computer which is also password protected. After verification that the copied files functioned correctly, the original data files on the Sanyo recorders were erased.

Each recording was stored using a specific file naming protocol to ensure the anonymity of the participants. Each family was assigned a coded identification number. The numbers were
sequential with participants starting with A for the focus group participants, 1 for the male boys participating in the individual interviews and 101 for the individual interview participants who were female. The name of the computer file containing the recorded interview also indicated whether it was a parent or child interview. The master list that connected the participant names to the coded identification numbers was kept in a locked drawer in a locked room. Only the researcher (P. Longmuir) had access to the master list.

Confidentiality and anonymity was preserved through a variety of procedures. During the group discussions, participants chose their “name for the day”, so that other group participants would not know the true identity of the other participants. Focus group participants were also reminded at the beginning and end of each focus group that what was said should be considered confidential, and therefore it should not be discussed or repeated outside of the focus group setting. One exception was made for the participants in the child focus group who were told that they could tell their parents what they said during the group, and that they could ask their parents about what other people said as long as they didn’t tell them who actually made the statement. This exception was felt appropriate to ensure that children could ask their parents about any statements that other children might make that would cause them concern. Confidentiality and anonymity was also preserved by selectively erasing names used during the interviews from the audio computer file and ensuring that names and identifying information (e.g., cardiologist’s name, name of child’s school) were anonymized in the written transcript.

4.2.7 Data Analyses

The goal of all research is to enhance our knowledge about the topic under study. To that end, it is the data analyses, rather than data collection, that are of greatest importance. Qualitative research depends on the skill, training, and insights of the researcher at each step of the research process. Thus, the findings of qualitative research are intimately linked to the style and intellect of the researcher [68]. Throughout these analyses I monitored and documented my impact on the development of the research findings.
Sampling Strategy

The maximum variation sampling strategy, used for the focus groups, was intended to produce detailed descriptions of the perspectives of each participant as well as shared patterns of beliefs and understandings that are significant because they emerge from such a heterogeneous group [68]. Therefore, the analysis of the focus group data was designed to identify information that would elucidate the variation in physical activity perceptions among children with complex heart defects and their parents, in addition to significant common patterns. In contrast, the purposeful stratified random sample used for the individual interviews was intended to enhance the credibility of the interview results. Such a small sample size does not allow the interview results to be generalized to a larger population. However, the random selection procedure (i.e., participants determined by the schedule for the larger study) reduces the potential for selection bias, and therefore enables increased confidence in the interview results [68].

Recording and Transcription

The digitally recorded focus group discussions and individual interviews were transcribed using pre-determined transcription conventions (see Appendix E). The initial notes recorded by the research assistant during the focus group and the notes of the researcher from each interview served as the starting documents for developing the transcripts. Each recording was replayed in short sections of one sentence or less so that the initial notes could be accurately expanded to create verbatim transcripts. Multiple reviews of the transcription files while listening to the audio-recordings were used to maximize the accuracy of the written transcripts. The completed written transcripts were imported into the NVivo qualitative research software programme for analysis. Version 7 of NVivo was selected because all researchers at The Hospital for Sick Children have agreed to utilize the same software in order to facilitate the sharing of qualitative data and analyses between all project collaborators. Each group or individual interview was coded separately, in the order that they were completed. Initially, data from the two focus groups were analyzed in order to inform the development of the individual interview structures. Subsequently, the individual interviews were conducted and the transcripts for those interviews were created and analyzed in the order that they were completed.
Patterns and Variation in the Data

The goal when analyzing interviews is to “make sense out of what people have said”⁴. It involves paying close attention to what is said as well as what is not said. For example, imagine that none of the parents or children had mentioned video games, computers or television as an activity that their children enjoyed. It is very unlikely that none of the participating children would like at least one of these activities. By recognizing what had not been said the researcher may interpret the data as indicating that the participants were providing only socially desirable responses about physical activity rather than a true picture of their children’s interests and activities.

The analysis of the interviews also involves looking for patterns and integrating what is said by different people. The first step is to summarize or describe the data in order to answer basic questions. For this study, this initial descriptive phase focused on describing the physical activity participation of the children and the perspectives of their parents in order to answer the specific research questions developed for the focus group (4.2.4) and individual (4.2.5) interviews. A primarily inductive approach was taken to the descriptive analysis of the group and individual interview data. During the focus group sessions I had learned how inaccurate my original assumptions, such as low priority for or interest in activity, were about the perceptions of physical activity among children with complex heart defects and their parents. Based on that new understanding, I felt that it would be inappropriate to develop a specific coding structure into which the data would be categorized. Rather, the inductive approach selected allowed patterns and themes to emerge from the data within the categories of questions included in the interview guides.

By examining the natural variation in the data, both within and between individuals and groups, the analysis identified categories and themes articulated by the study participants. The inductive analysis of the interview data began with the identification of key phrases or terms that were present in the transcripts, phrases or terms that could provide a brief summary of a single thought or statement. For example, the phrase “I only walk around the house and watch TV” produced codes for the concepts of a) walk and b) watch TV. During the second level of analysis I brought

sensitizing concepts (concepts brought to the data by the researcher [68]) from the research literature and Eccles expectancy-value model to the data. For example, the sample phrase shown above was also assigned to the sensitizing concept of “winter activities”, since the physical activity levels of these children vary with the seasons of the year (3.2.6). The final level of analysis utilized typologies, or classification systems to systematically organize and report the findings of the study. Typologies can be both indigenous and analyst-constructed [68]. The analyst-constructed typologies used in this study emanated from the research questions posed to the interview data. For the focus group data, the analyst-constructed typologies were types of physical activity participation, physical activity perceptions (experiences and priorities), medical influences (cardiologist and heart condition), and barriers to physical activity. For the individual interviews, the analyst-constructed typologies were physical activity participation at home and at school, preferences for activity of the child and parents, perceptions of physical activity of the child and parents, and supports for and barriers to the child’s physical activity participation. Examples of the indigenous typologies expressed by the study participants include having fun, uncertain expectations, and the child’s heart function/status. The descriptive analysis of the child and parent interviews, which provides a rich description of physical activity in the lives of children with complex heart defects and their parents, is reported in detail in sections 4.3 (child interviews) and 4.5 (parent interviews).

Interpretation of Results

The second step in the analysis of qualitative data focuses on the interpretation of the results [68]. The goal of interpretation is to explain the study findings in a way that addresses “why” the findings occurred. For this study, the goal of the interpretive phase of the analyses was to answer the overall research questions for this research (4.1), which sought to understand why children with complex heart defects do or do not lead sedentary lives. As previously indicated, the primary research questions to be answered through the interpretive phase of the analysis were:

1. Why do most children with complex congenital heart defects lead sedentary lives?

2. Why are children with complex heart defects less active than their peers regardless of their level of heart function?
3. Why do parents of children with complex heart defects allow their children to be sedentary given the importance of physical activity for health?

To assist with the interpretive analysis of the data, situational maps were created. The maps represent how I interpret what the participants said and the common themes that emerged from the descriptive analysis. Naturally, there is a tremendous amount of overlap between the three primary research questions and the factors that influence them. Eccles expectancy-value theory suggests that the child’s perception of physical activity emanates from parental beliefs and expectations. The overlap between parent and child-based influences on the child’s physical activity participation is particularly large for the participants of this study because the younger age of the children makes them particularly reliant on parental input, support and encouragement. Given the significant overlap, I have chosen to present the results of the interpretive analysis in two parts. Section 4.4 - Relationships Between the Children’s Themes summarizes the interpretive analysis of the child interviews. Section 4.6 - Relationships Between the Parents’ Themes reports the results of the interpretive analysis of the parent interviews. The findings from the child and parent interviews were then combined (as reported in 4.7) in order to answer the three primary research questions.

4.2.8 Ethical Considerations

The research protocol for conducting the interviews and analyzing and reporting the results was reviewed and approved by the Research Ethics Board of The Hospital for Sick Children. Informed consent was obtained from all parents, for their own participation as well as their child’s participation. The purpose of the interviews and the intended topics for discussion were explained to each child and then the child’s verbal assent to participate was obtained. In addition, a separate consent form was administered to the parents in relation to the digital audio recording of the interviews, as required by the hospital’s Research Ethics Board.

The nature of interview research also carries additional ethical considerations beyond those typically identified for other types of research (e.g., confidentiality, risk assessment, autonomy, informed consent, data access and ownership). Interviews are not a passive form of data collection, but one that requires the active involvement of each participant. As such, it is essential to be aware of the possibility that the interview will illuminate thoughts and feelings not
only to the researcher but also to the research participant [68]. While conducting the interviews I attempted to remain neutral (not judging the responses provided) and focused on gathering high-quality data. As a “research trainee” at the hospital, I was not permitted to give advice or recommendations to the study participants or to comment on their health, care or treatment. This restriction was, in fact, very helpful in enabling me to re-focus the interview on the area of study when a participant asked for information or my personal opinion. At the same time, the restriction often created an ethical dilemma for me as a physical activity professional because I was required to refer questions about the child’s physical activity participation back to the responsible cardiologist who in many instances, I believed, would not actually be able to answer the question in as much detail. Ultimately, I resolved the ethical dilemma for myself by focusing on the completion of the study, which was designed over the long term to enhance the physical activity information and counselling provided to these families. Thus, I chose to focus on the long term outcome which was intended to answer the questions and provide the guidance that the families were seeking through the questions that they posed to me during the study.

I also recognized that as I developed rapport with the family, they would likely be more willing to discuss their child’s physical activity. In each situation where that openness appeared to create tension or stress, I attempted to provide empathy to the participant’s feelings while offering the opportunity to pause the interview or otherwise change the focus in order to alleviate their concern. For example, one child in the study particularly liked the t-ball activity that was part of the gross motor skill testing (Chapter 2). During the interview with his parents, I posed the questions about the activity recommendations and restrictions that the child’s cardiologist had provided and the types of activity that they might support for their child. In response to the former question, the parents indicated that the cardiologist had told them that the child was not restricted from any type of activity except that he was not allowed to go upside down. When I subsequently asked the parents about the activities that they would support, the mother indicated that she was going to try to find a t-ball league for her son since he enjoyed that activity so much. The father instantly and vigorously reacted to the mother’s comment by stating that the child was not allowed to play t-ball. The discussion between the parents quickly escalated to an argument. It became apparent that the father was adamantly against t-ball because the child might get hit in the chest (where his sternum was cut during his heart surgery) with the hard ball. As their discussion became more heated the mother attempted to end the discussion by reminding the
father that the audio recorder was recording everything that was said but the father responded that it didn’t matter because the purpose of the interview was to find out what they both thought. I responded by acknowledging her discomfort and offered to turn off the recorder while they completed their discussion, an offer that was rejected by both parents.

By following the REB approved protocol, in most interviews I was able to clearly communicate the degree of confidentiality I could provide, the study results that could be shared with the participant (and the timelines for doing so), and the separation between participation in the research project and the child’s on-going medical care at the hospital. On those occasions when unanticipated ethical issues did arise, I discussed the issue (without identifying the family) with the nurse manager of the Labatt Family Heart Centre in order to identify the most appropriate avenue for follow up.

4.2.9 Trustworthiness of the Data

In quantitative research, the quality of the research is evaluated by the validity and reliability of the results. Validity is how well the data match the world being investigated. Research results that are reliable will produce the same result regardless of who conducts the research (inter-rater reliability) or when the research is conducted (test-retest reliability). For qualitative research, the standards are similar although the terminology and methods used to determine and report the quality of the research differ.

For qualitative research, the adequacy or completeness of the data is evaluated not by the number of cases under study or statistical procedures applied to the data, but by the comprehensiveness of the data relative to the issue being studied. In qualitative research, results that are of good quality are considered trustworthy. Trustworthiness is established based on the evidence provided to demonstrate that the descriptions and interpretations provided are an accurate reflection of the situations and persons studied [72]. In qualitative research, the study findings are described in extensive detail to enable readers to both understand the interpretations subsequently reported and develop their own interpretations if desired [68].
Credibility and Dependability

Credibility and dependability are the cornerstones of trustworthiness. Credibility is the match between the participants’ perceptions and the researcher’s portrayal of those perceptions. Has the researcher accurately represented what the study participants think, feel, believe or do? Dependability is similar to reliability in that it assesses whether different researchers would derive the same result. However, dependability is not demonstrated through a statistical analysis but rather through a clear and detailed report of all of the processes and procedures used to collect and interpret the data combined with detailed examples of the data collected in the participants’ own words.

In order to establish the credibility of my research I have described the beliefs and assumptions that I brought to the research process (see 2.4.1) and I have continually re-visited those assumptions throughout the study in order to recognize their influence on the data collection and analyses. Where possible, the data collected were corroborated from multiple sources. For example, parent and child reports of the child’s physical activity participation were used to corroborate the accuracy of the information obtained. Similarly, the reported physical activity level of each child was verified by comparing the parent and child reports to an objective measure of the child’s weekly minutes of moderate-to-vigorous physical activity (as assessed by accelerometer) collected as part of the randomized clinical trial (3.2.3). In addition, throughout all levels of the analyses I considered the impact of the limitations of interview data (either individual or group) on the results obtained. Recognized limitations of interview data include participants shaping their answers to present an enhanced picture of their own capabilities (self-serving responses) or in response to their perceptions of the interviewer (interviewee reactivity) or responding in the way that they believe would be most helpful or acceptable to the researcher (social desirability) [68].

To establish the dependability of my research findings I have provided thick, rich descriptions of the data resulting from the interviews, including detailed quotations directly from the study participants. Detailed descriptions of the methods used throughout all phases of the research and the study sample have also been provided. Although it is not possible to provide copies of all of the data obtained as part of this thesis, the raw data will be provided to other researchers for review and analysis if requested. Taken together, the detailed methods and rich descriptions
illustrate that the results and conclusions are intimately connected to (or grounded in) the information provided by the participants. Saturation of the data was also achieved in order to enhance the dependability of the study results. Individual interviews continued with dyads of male/female children and their parents until no new hypotheses or information were generated by subsequent interviews [66]. Achieving saturation makes it more likely that the data obtained represent the full range of opinions, topics and issues related to the study purpose. All of the group and individual interviews were conducted by the same interviewer, ensuring that each interview was administered in a consistent (i.e., reliable) fashion [70].

Transferability of the Study Results

The small number of participants in this qualitative research project does not allow the study results to be “generalized”, in the quantitative research sense, to the larger population of all children with complex heart defects at large. However, research results are only useful if they can be applied to other groups or settings or in different times than the specific setting in which the data were originally collected. For qualitative researchers, this application of the results beyond the study participants is termed transferability. I have endeavoured to enhance the transferability of my research findings by providing thick descriptions of the research processes, study environment and data collected, and by discussing the relationship between these findings and published research from others. These detailed descriptions provide the reader with a holistic and realistic picture of this research.

Limitations of the Interview Study

All research studies have limitations imposed by the study design, topic under investigation or the available resources, and this interview study is no exception. Many of the limitations of this research, for example the limitations of interviews and focus groups and the potential impact of researcher bias, have been discussed as part of the relevant sections of this thesis. However, two additional considerations merit discussion here.

The sample size for this interview study would be considered very small in relation to quantitative research methods. The resources, such as time and personnel, needed to conduct, analyze and interpret the volume of data generated through a series of interviews restricted the
proposed sample size for this research. However, for the type of in-depth investigation inherent in qualitative research the sample size is relatively robust. Research has established that saturation of the data typically occurs within the first 6 interviews for major themes, and within 12 interviews for more variable concerns [71]. Therefore, it is not surprising that saturation was achieved in this study after 10 child-parent dyads were interviewed, particularly given that the issues of interest were originally derived from the focus group discussions.

Participant reactivity, how participants react to the interviewer, is also a recognized limitation of studies that rely on interviews for the generation of data. Since I personally conducted all of the interviews, both group and individual, all of the participants were reacting to the same researcher. It is not possible to determine how I, as an older woman, influenced the information that the study participants were willing to provide. Since children in elementary school primarily interact with female teachers, it is possible that the families found the discussions with me to be relatively familiar. I also sought to minimize the influence of participant reactivity by considering the issue throughout each phase of the study and by manipulating my comments and actions. For example, I learned about Pokemon, Yugio and video games so that I could carry out equally meaningful conversations about sedentary activities as well as those more popular with boys.

4.3 Findings from the Child Focus Group and Individual Interviews

The interviews with children with complex heart defects covered a variety of topics. Initially the children were asked what they liked to do. I emphasized that they could identify any type of activity as their favourite and that it didn’t have to be sports or exercise. Children were also given the opportunity to draw or colour during the interview to increase their comfort with the setting. The drawing activity at the start of the focus group and the initial interview questions about “who you are” or “what do you like” were intended to get the children talking and involved in comfortable activities and discussion. In hindsight, one or two additional “icebreaker” activities would have been helpful to make the children more comfortable with the interview and enhance their responses to the initial questions. With only one introductory activity, the responses to the questions early in the interview schedule were typically answered
very briefly or with “I don’t know”. As the interview progressed and the children became more comfortable responding to the questions, the length and amount of detail in their responses increased. Starting the focus group with the individual drawing activity was helpful because it appeared to make the children more comfortable with the situation and provided a format that was familiar for sharing their thoughts. The children enthusiastically chose to create a drawing when they were offered the opportunity to talk about or draw what they liked to do. However, as each child focused on their own artwork, it was difficult to draw the children into shared discussions. Ultimately, the information shared during the child focus group was more like a group interview rather than a shared discussion among the participants.

The Influence of Interview Context

It is also important to consider the circumstances surrounding the interviews that may have influenced the findings that emerged. The potential influence of factors such as participant reactivity, socially desirable responses, etc. have previously been discussed. In addition, although the focus group participants were balanced by sex, willingness to participate in the discussions was not similarly balanced. Both of the girls who participated were active participants, responding to each question and activity, and often to the comments made by others. However, both of the boys had very limited independent participation in the discussions. One boy (the youngest of the four children) participated in the drawing activity to illustrate his favourite activity (video games), but otherwise did not engage in conversations with other children. Through repeated encouragement and support he eventually did contribute some ideas via head nods and a few one-word responses whispered to the researcher, however his overall contribution to the discussions was very limited. The second boy did answer most questions that he was asked, although initially he required a lot of prodding from his father who was present throughout the focus group because his son otherwise was not willing to participate. Although the other children never referenced the father’s presence in their responses, it is possible that the information obtained from all of the children was influenced by the presence of the one boy’s father. The potential influence of parents must also be considered in relation to the individual child interviews. Although the children were encouraged to answer the questions independently, the transcripts clearly indicate that many responses were moderated by or through the parents. That is, children would ask for parental input in order to develop their response or to confirm that
they had responded correctly. At other times, parents would interject into the child’s interview their own perceptions or to correct what they perceived to be as errors in the child’s recall or perceptions. However, the presence of the parents was also clearly beneficial to the child interviews as it clearly made most children much more comfortable talking to “a stranger” (the researcher). In addition, parents would often provide prompts (e.g., what’s the other thing with wheels that you like to ride in the driveway) to assist the child in recalling activities done at other times of year or planned for the future.

Coding of Transcripts

The data from both the focus groups and interviews were integrated for analysis. Focus group participants are identified by alphabetical letters (e.g., Child B). Participants interviewed individually are identified by numbers (e.g., Mother 5).

Coding of the transcripts generated a large number of phrases and terms. Initially, I began to analyze the phrases within categories based on the concepts included in the research questions and expressed by the children. The initial categories included activity likes and dislikes, who was involved (family, friends, etc.) and where the activity occurred (home, school, etc.). However, as I continued to work with the data it became more and more difficult to stay within the original structure. For example, there was a comment that the doctor had said “that we have to be active” and another referring to monkey bars “I’m not that good at hanging onto them that long, so that’s kinda hard for me”. As I considered how to fit these comments into the overall findings I realized that often the children were commenting on abstract rather than concrete concepts or key issues that were not directly addressed by the research questions. They were often expressing their thoughts and perceptions about an activity, rather than providing strictly descriptive information. With that realization, I re-organized the emerging themes into three categories: preference, guidance, and opportunity (Figure 11). Preference reflects the child’s personal choices or preferences for different types of activity. Guidance is the encouragement, discouragement or advice that they receive about activity from other individuals, such as parents, doctors, or teachers. The category of opportunity represents the available activity options, both within the family and in the community, of which the child is aware. Each of these three major themes contribute to how the child’s activity perceptions develop and are, in turn, shaped by the influence of self (the child), family, friends, school, community and physicians.
4.3.1 Children’s Activity Choices or Preferences

The children spoke about activity choices in relation to their own personal choices as well as the choices of others with whom they interact, such as family or friends. They identified their favourite activities, some of which were active while others were sedentary, what they did on their own and what new activities that they would like to learn. They also identified the activities that were favourites of other family members and friends.

The active activities that the children identified as favourites were almost exclusively informal activities done alone or with siblings or friends. The activities mentioned by the children included swimming or water play, bike and scooter riding, dancing, hopscotch, backyard swings, trampolines, and climbers, rollerblading, karate, walking, and skipping rope. Favourite winter activities were tobogganing, ice skating, skiing and building snowmen and snow angels. Team or group activities mentioned included basketball, volleyball, baseball and soccer. The sports were more often mentioned by the boys, of all ages, and the older girls. The children indicated that the sports were primarily done with siblings or at a sport camp. Sedentary activities were almost exclusively watching television, games on the computer or video games, such as puzzles, checkers, or games where you travel through different situations that test your skills. Playing with toys, looking after or playing with pets, talking with friends, playing music, doing art or crafts, reading or doing puzzles by hand were also mentioned. One boy (hockey) and one girl (volleyball) indicated that they were involved in competitive sport.
Active Pursuits with Friends

An initial review of the activities done with friends indicated that they were primarily active pursuits, such as skipping, soccer and playing on the monkey bars. The activities done with family were also fairly active, such as playing in a backyard swimming pool or going sledding in the winter. The children were much more likely to identify sedentary activities when they were commenting on what they do when they are playing alone. Most children indicated that when they are playing by themselves they are usually watching TV or playing video or computer games. None of the children indicated that they would play video or computer games when they were with their friends. Skipping, bicycling, and hitting a tennis ball were also identified as activities that were done alone.

Although many of the activities reported by the children appeared to be quite active, several comments suggested that perhaps the children were not as actively involved as their friends or family. They also indicated that they typically played goal (in soccer) or just did the batting (in baseball) when they were involved in sports with other children. One child (Boy3), who had mentioned liking tennis, later indicated that he liked watching tennis on television but had never actually played. Another child who talked about going into a neighbour’s pool was quite adamant that she wasn’t swimming. The conversation with the focus group researcher was:

ChildB: I went in a pool yesterday.
Researcher: Nice, you went swimming yesterday?
ChildB: No, in a pool.
Researcher: Oh that sounds like a good place to be on a day like today for sure.

And then a few minutes later:

Researcher: I think ChildB was saying that yesterday she went swimming in a pool.”
ChildB: Nooo, playing in the pool.

Similarly, the child who indicated that she went for boat rides with her Dad and floated on an inner tube with her sister described the experience as being primarily sedentary. She described their family outings as:
ChildA: My dad lives right on the lake. Sometimes we’ll go boating to this area
where me and [sister’s name] can, um there’s the tubing string in the water that way
we can’t float away, because the thing is pretty heavy and cause the boats, like the
waves will tip you away, yea, and we stay there. Me and [sister’s name] we just hang
on to the rope.

These comments suggest that even activities that appear to involve significant physical activity
may actually be quite sedentary. Most of the activity choices identified by the children were also
ones that typically do not require competition between the participating children. Playing in a
neighbour’s pool, going sledding in the winter and skipping rope are all activities that can easily
incorporate rest breaks, can adapt to different children moving at different intensities, and readily
accommodate variations in skill level among the participating children.

4.3.2 Children’s Perspectives of Encouragement and Discouragement

Encouragement or discouragement provides guidance to the child about participating in physical
activity. Based on Eccles expectancy-value model, encouragement or discouragement from the
child’s parents will also contribute to the child’s activity preferences as the child gradually
adopts parental beliefs over time. In analyzing the interview data, therefore, factors that
encourage or discourage a child from participating in physical activity were considered within
both of these realms (preference and guidance).

Having fun and being with friends were definitely the dominant themes that the children
identified in relation to encouragement for physical activity. Many children indicated that
playing or being with their friends was their “most favourite” activity or that being with friends
would encourage them to do activities that they would not otherwise do.

ChildA: I don’t like moving that much and my mom wants me to get active more, so
she’s, my friend [name], one of my daycare, the owner of my daycare’s daughter, she
baby-sits me and [sister’s name] and we’re really good friends with them and um,
[friend’s name]’s gonna play tennis with me every month, uh, one day a week.

The children indicated that enjoyment of the activity would even encourage them to participate
in activities such as household chores. One child emphasized that she really enjoyed doing
housework with her mother, and she contrasted her opinion of chores with the opinions of her
other family members.
ChildA: It’s not so bad because me and my mom love cleaning, my Dad and my sister hate it.

Availability of Opportunity

The availability of play spaces and equipment was also mentioned by many children. Having opportunities for active play at or close to home definitely seemed to encourage the children to be more active. One child indicated that proximity to play spaces was important in both summer and winter.

Girl10: Cause there’s a hill and when you get out of the door and there’s steps over here and then there’s grass and that over here there’s a big hill.
Researcher: uh hmm
Girl10: And then ground and then um in the winter time it’s a lot like on the hill there’s snow and we can slide down
Researcher: Slide down oh cool that’s
Girl10: And in the summer time we go to the park we have a really, really, really close park.

While having fun, being with friends and having opportunities readily available were the dominant themes that emerged about encouragement for physical activity, there were also comments from individual children that indicated other factors can also have an impact. One child indicated that she did a lot of skipping in order to raise money for the Heart and Stroke Foundation (to help fix children’s hearts). Another child indicated that she was active at recess (playing soccer baseball) because that is what all of the other children were doing. She also explained that the reason that she was going to play tennis once a week with an older child at her daycare was because her mother really wanted her to be more active. Another boy indicated that being outside was always much more fun than being inside.

Factors that Discourage Activity Participation

The concerns that the children raised in relation to factors that discourage their participation in physical activity were widely varied. All of the children indicated that there were times when it was difficult to do the activities enjoyed by their friends. That the children recognized that their skills and/or endurance are lower than their peers were illustrated through comments about not being as good as their peers or getting tired. For example:
ChildA: Because me, I like to stay less active. I don’t really like to be active, active, active, cause sometimes I get tired out or something like that and I watch TV, and I mostly watch TV and go on the computer, that’s all.

Many of the children spoke about being outside in the summer but staying inside most of the winter because they would get cold.

Girl6: Yeah I usually stay inside and in the summer I usually go out more. But in the winter I usually stay inside.
Researcher: Does being outside, do you get cold when you are outside?
Girl6: Yeah and I turn purple and I get cold. They say I’m cold blooded.

Having choice about the type of activity and whether or not to be active seemed important to a couple of children. Comments such as “I don’t like running cause we have to do it in school” and “I always have to do something I don’t want to do” suggest that being required to do an activity leads to a less than favourable impression. Given the importance of enjoyment and fun to encouraging activity, their comments suggest that forcing specific activities that are not of the child’s choosing may ultimately be counterproductive to their level of activity participation.

Parent Comments about Physical Activity

Interestingly, all of the children commented on what their parents said to them regarding physical activity. One child, who described herself as not liking to be active, talked about how much her mother wanted her to do more activity. Her rationale for being inactive was that being really busy would interfere with her school work. In contrast, all of the other children spoke about their parents in relation to discouragement of activity. One child expressed his frustration at not being allowed to play on a soccer team in the summer because of his father’s concerns.

Mom: His father is like, oh I am scared.
Boy3: Nothing will happen. I play soccer everyday and I’m good at it. I got like nine goals.
Researcher: At school.
Boy3: Yeah.
Researcher: So did you play on a team this summer for soccer.
Boy3: ummm [shakes head]
Researcher: No okay.
Boy3: My dad and uh, and uh, like when we play soccer it’s rough.
Researcher: Well, it can be.
Boy3: Yeah, but I just keep passing. I just stand there and two persons coming and I just go right then go through them and then they bump into each other.
During the focus group, several children commented that their parents told them to settle down, pay attention or sit still.

   Researcher: Well ChildB, did you say your Mom tells you that you are too active all the time?
   ChildB: Yeah.
   Researcher: Do you run around all the time?
   ChildB: I thought so.
   ChildD: I don’t listen.
   ChildB: Me either.
   Researcher: what about you ChildC, what do your parents tell you about being active, do they tell you to be more active or less active or about the same?
   ChildC: Less.

Clearly, from the children’s perspectives, parents are very aware and tuned into their child’s physical activity. The child who described herself as not liking to be active reported that her mother made significant efforts to encourage her participation. The remaining children described themselves as being active in spite of perceiving that their parents often wanted them to slow down or sit still.

4.3.3 Children’s Recollections of Activity Advice or Guidance

Information that guided the children in their physical activity participation was reflected in their personal definitions of physical activity, the activity advice they would offer to other children with similar heart problems, and the counselling or guidance that they remembered from their parents or doctors. As indicated above, the children indicated that their parents were often telling them to slow down or be less active. Only the child who described herself as not liking to be active indicated that her parent frequently said that she had to be more active.

Relatively little information about how the children defined physical activity was available in the focus group transcript. One child asked whether basketball was a physical activity. However, a second child responded to the question “what is physical activity” with a very in-depth answer. She had recently been to see her cardiologist and she indicated that he had made it very clear that she needed to do at least one hour of physical activity each day. Her explanation of her drawing about physical activity and how it was defined clearly reflected the information that her cardiologist had recently provided.
ChildA: Actually doing stuff like that’s movement. Right now I have me doing hip hop, playing with my friend, bicycling, and soccer and then cleaning my house.

For most children, their recommendations about being active were much more hesitant cautious. When offering advice to another child with a heart problem, they spoke of trying an activity and slowing down or taking breaks as needed.

Girl8: Just keep trying and if you need a break just slow down or stop.

Girl10: Try not to get hurt in activities like hockey or baseball or something, and have fun.

Boy1: I think you need to be careful sometimes like me.

Boy6: Run about a 100m and then stop.
Researcher: Uh huh a hundred.
Boy6: A hundred yeah, and then run again.

No Memory of Guidance from the Cardiologist

Only a few children recalled that their doctor had talked to them about physical activity. One boy indicated that he could not remember what the doctor had said. Another indicated that he was not allowed to do activities upside down.

Boy4: I can’t hang upside down. Which stinks.
Researcher: What happens when you hang upside down?
Boy4: The blood goes into my head and never comes out.

One girl whose cardiologist had recently counselled her about physical activity provided a very detailed response.

ChildA: that we have to, that we have to be active, more active.
Researcher: How about you ChildD? Has your doctor here at Sick Kids or your doctor at home ever told you anything about physical activity?
ChildD: [shakes head]
Researcher: How about you ChildC, has your doctor ever told you anything about physical activity?
ChildC: [nods head]
Researcher: Do you remember what he told you?
ChildC: [shakes head]
Researcher: Did your doctor ever tell you anything about it ChildB?
ChildB: No.
Based on the parent focus group discussions (4.5), the cardiologists responsible for the care of these children had discussed their physical activity participation or restrictions with their parents. However, given that the children were now at an age where they would be primarily responsible for determining their own activity at school or with friends, it is surprising how little information they could recall. It would seem that the children are largely unaware of the physical activity discussions that have occurred between their parents and cardiologist. A review of the cardiac diagnoses and treatment history of the participating children indicates that often children’s recollection of physical activity advice from their physician was exactly the opposite of what would be desired and expected. For example, two of the children who were certain that their doctor had never spoken to them about physical activity would actually have specific activity restrictions. One child had a pacemaker (which restricts participation in body contact activities) and the other child’s heart problem carries a higher level of risk for sudden death during strenuous isometric exercise (muscle force without body movement). Both of these physical activity restrictions (body contact and isometric exercise) are relatively common among children with complex heart problems. Although they reduce the options for physical activity available to a child, the children are still strongly encouraged to participate in a wide variety of suitable activities.

4.3.4 Recognition of Activity Opportunities

The activity opportunities that the children recognized were considered within three venues: home, neighbourhood and school. Only seven of the 24 children interviewed indicated that they went to a daycare or babysitter after school. The remaining children all indicated that they come home after school. Children who go to a daycare or babysitter indicated that they were often involved in physically active pursuits with the other children or the equipment that was provided.

Girl10: I go to my babysitter’s house, and sometimes we play hide ‘n seek.
Researcher: Oh ok. What else do you usually do when you are at the babysitters?
Girl10: Um sometimes I play soccer, not with a soccer ball but with a bouncing big bouncy ball.

Boy7: We play soccer, and play basketball at 6:30.

Children who go home after school were much more likely to mention sedentary activities and were less likely to mention activities with friends.
Girl7: I usually come home after school.
Researcher: What do you do when you get home?
Girl7: Do our homework
Researcher: Do you get a lot of homework.
Girl7: No No.
Researcher: Not too bad. Well that’s good. What else do you do after school?
Girl7: Mmmm. Go on the computer.
Researcher: Ohh. You have a computer at your house. Wow. Anything else you like to
do in the evening after school.
Girl7: I like to watch T.V.

Although most of the children did not mention physical activity with a family member, most of
the children were able to draw or describe a variety of physical activities that they enjoy doing at
home. In responding to the question about activity at home, one boy drew a picture of himself
playing video games. The other drawings and discussions were of more active pursuits.

ChildD Father: Draw what you like to do baby. What do you like to do?
ChildD: Go in the pool.
ChildC: Bicycle.
ChildB: Dancing.
ChildA: Hip Hop, and I used to do jazz.
ChildB: Me playing in the pool. I’m going to draw my friends.
Researcher: What do you like to do when you’re at your house, ChildD?
ChildD: I like to play in the pool.

All of the children indicated that they like to play in a park or playground in their
neighbourhood. Swimming or playing in a pool and sledding in the winter were also mentioned
by the children as favourite activities that they could do at home or in their neighbourhood.

Team and Group Sports at School

In contrast to the primarily individual activities that the children identified at home or in their
neighbourhood, the activities they reported doing at school focused primarily on team sports or
group games, both at recess and during physical education class. Tag, hide and seek, skipping,
soccer baseball, dodgeball, mini-sticks, soccer and touch football were commonly mentioned as
were playing on hills or playground equipment. Two children indicated that they did a lot of
running during gym class and one mentioned skipping (Jump Rope for Heart, a fundraising event
for the Heart and Stroke Foundation of Ontario). Despite the range of activities mentioned, many
of the children’s comments also indicated that they did the activity because they “had to” rather than because it was enjoyed.

4.4 Relationships Between the Children’s Themes

The creation of a situational map (Figure 12) was used to further analyze how the themes of opportunity, guidance, and preference work together to influence the child’s perceptions of activity as well as their actual participation. It is important to recognize that the relative importance of these themes will vary, with time, location, and the other people involved.

Four Spheres of Influence for Children

There appear to be four spheres of influence on the physical activity of children with complex heart problems: the child him/herself, the family/home environment, the school/community environment, and the influence of doctors. It was somewhat surprising to hear how little influence medical professionals had in relation to the child’s activity. One child who said that she was very sedentary vividly recalled her cardiologist encouraging her to be more active and another knew he was not allowed to do upside down activities. The remaining children either had no recollection of a discussion about physical activity with their doctor or remembered a discussion but could not remember what was said. These findings suggest that, contrary to what might be expected, discussions with medical professionals have very little influence on the children’s perceptions of, or participation in physical activity.

Similar to their healthy peers, children with complex heart defects participate primarily in activities that they enjoy. In contrast to issues of body image and peer acceptance that influence the activity of adolescents, for young children having fun is the primary motivational factor for increasing physical activity [30]. Perceptions of whether an activity was enjoyable were influenced by experiences of fatigue and their own assessment of their abilities relative to their peers.

Family/home and school/community environments also appear to have a very influential role, a finding which is again similar to healthy children of the same age. The availability of physical activity options at home, at school and in the community, the amount of screen time or
homework, and having friends with whom they can participate are factors that strongly influence the physical activity patterns of these children. Unlike their healthy peers, children with complex heart defects who consider themselves active report that their parents often encourage them to slow down or take it easy. Conversely, a few children indicated that their parents always wanted them to “go outside and play” or “be more active”.

Ultimately, as shown in Figure 12, activity will be viewed as either positive (green) or negative (red) at a particular point in time. Typically it would be expected that participation would be higher when activity is seen as positive. However, the children clearly indicated that at times they participate in physical activity “because they have to”, even though it is not seen as enjoyable. Thus, children with complex heart defects travel a road that is influenced by many factors as they journey toward a decision regarding physical activity participation. The results of this study suggest that most of the influencing factors are similar to the influences for healthy children of similar age, such as having fun, friends and a place to be active. However, children with heart defects are also influenced by factors unique to their experience, such as perceived limitations of endurance or skill, the presence or absence of comments from medical professionals and comments from parents about whether they should “slow down”.
Figure 12: Situational Map from Child Group and Individual Interviews

Medicine
- MD Advice

Family/Home
- Home PA Options
- Parent PA Equipment
- Parent PA Counselling
- Screen Time
- Parent Says Slow Down

Child
- Fatigue
- PA Enjoyment
- Advice to Others
- PA Ability Compared to Friends
- PA Meaning
- Charity

School/Community
- Neighbourhood PA Opportunities
- School PA Mandatory
- School PA Opportunities
- Homework
- Peer Critics
- Friends to be Active With

Opportunity
Guidance
Preference
Activity
4.5 Parent Focus Group and Interview Findings

The primary finding from the parent interviews was the realization that the assumptions that we had made while designing the research project were largely invalid. We knew that children with complex heart problems are very inactive. Medical staff and parents emphasize that they try to give the child as “normal” a life as possible [63]. However, children with pacemakers, taking antithrombotic medication or with obstructive left-sided lesions (e.g., aorta stenosis) do have some medically necessary activity restrictions. In our clinic, medically necessary restrictions of physical activity are conveyed to the family by the child’s cardiologist. Based on that knowledge, we had assumed that the activity of children in this study would be largely unrestricted. We expected that parents of children who require activity restrictions would clearly understand and be able to implement those limitations. We also assumed that parents would have a positive view of the child’s involvement in peer play, which given the age of the study participants would largely be focused around physical activity. Finally, we recognized that many children would have limited endurance relative to their healthy peers and therefore parents would likely feel that the recommended 90 minutes of moderate-to-vigorous activity daily [5] would be seen as an inappropriate target for their children. What we learned from the parents was that their perceptions were largely the opposite of what we had assumed. They expressed uncertainty about their child’s future and how physical activity might influence their health. They also felt that it would not be difficult for their children to achieve the recommended level of 90 minutes of daily physical activity.

4.5.1 Importance of Activity

All of the parents realized that physical activity was very important for their child, particularly in relation to keeping their heart strong. Most of the parents felt that their child was already sufficiently active. They described their children as participating in a wide variety of age-appropriate activities, such as swimming, skipping, bike riding, soccer and video games. They also emphasized that the children were often very active at school, such as at recess, during gym class, and because of the new mandatory daily physical activity requirement.
Dad B: Oh yeah, they walk around the school every morning.
Mom A: They do. DPA it’s called DPA. They do that everyday. It’s 20 minutes mandatory now, every day that they have to do activity. If that’s all she had to do that’s all she would.

In fact, many children were described as having a high level of activity even though objective measurements of their weekly activity by accelerometry subsequently completed indicated that it was actually very low (3.2.3). The parents also indicated that the activity level of their children had changed over time as the repair of their heart condition progressed.

Dad D: He’ll be playing game cube and he can’t sit he’s got to be standing and walking or doing something.
Mom D: Or jumping on the couch.
Dad D: He never sits [chuckles].

Mom C: He just went from basically no mobility to going like crazy.

Given the perception that their children are already quite active, it is not surprising that the parents also felt that the recommended level of daily physical activity was very achievable for their children.

Mom A: I think it’s totally realistic
Mom E: Yeah I think it’s reasonable. I think any physical activity sounds like a lot because as an adult I think I wouldn’t work out for … [laughter]
Mom E: but it’s different right? I think that it is very important for their bodies to stay mobile, and it can be broken up I would assume right?
Researcher: Oh yeah, that’s just the total in 24 hours that they have to accumulate.
Mom A: They have lunch, they have two recesses. Then they have the 20 minutes. In school alone they’re almost getting an entire hour of activity a day and if they have gym it’s even more. They almost do it without us even being involved in it.

Barriers to Encouraging Activity

The parents also commented on factors that made it more difficult to encourage their child’s physical activity. One parent spoke about her child as having a natural preference for reading, Sudoku puzzles and other types of sedentary activities. Other parents spoke about the impact of hot and cold weather on their children, and how often the children are kept inside at recess or even kept at home from school on very cold or hot days in order to avoid teacher concern about the child “turning blue” or having the child feel sick or have a headache due to extreme heat. Of
course, all of the parents commented on the growing interest in computers and video games as a significant factor that limits their child’s activity. The parents reported that, like their peers, the children with complex heart defects were increasingly interested in “screen time” as they got older. As one parent said:

    Mom A: You know that’s we’re heading into that lazy zone of life.

4.5.2 Importance and Impact of the Family

Almost all of the parents of children who participated in the study measuring moderate-to-vigorous physical activity levels (3.2.2) indicated that activity was a “very important” priority for their whole family, in addition to recognizing its importance for the child with the heart defect. Only four families indicated that physical activity was not important or only somewhat important to the family.

Positive Impact of the Family

Regardless of the level of importance, all parents recognized the role that they play in influencing their child’s activity. From their comments, the parents recognized that the family had a significant influence on the child’s physical activity participation. Many parents also recognized that their influence could be both positive (supporting activity) and negative. For example, one mother indicated that she teaches high school physical education and therefore she had a lot of resources and expertise that she was able to use when her daughter became concerned that being active might be too much for her heart. Many of the parents also indicated that they were interested in having their children involved in activities that they enjoy. Several families spoke about going on hikes or bike rides together, and how the child’s heart problem would limit what the family could do together. Parents also indicated that they wanted their children to experience the activities that they particularly enjoyed when they were young. Conversely, they were also interested in ensuring that their children had opportunities for physical activity that were not available to them as children.

    Mom9: I’d like her to try, cause I was involved in a lot of sports.
    Mom10: I want her to be aware of the importance of her physical activity.
    Researcher: Okay.
Mom10: Because we weren’t really raised with “go out and get exercise”. Just go out and have fun. So we didn’t have to do sports. So I want her to know the value of it.

**Impact of Sedentary Parent Lifestyles**

Other parents indicated that their own sedentary lifestyles, or the sedentary lifestyles of their spouse, were a barrier to the child being involved in physical activity. One father indicated that his wife did not enjoy physical activity and was content to have the children in the house when they were home. He was hoping that the research study would encourage his wife to make more of an effort to take the children to the local park or community centre. Other parents recognized the influence of themselves or siblings on the physical activity of the child with a heart defect.

Dad9: What I need is to encourage the other family members to participate in physical activity.

Dad5: Convincing him that it’s a good thing to do. Sometimes he really digs his heels in and absolutely refuses to do it.
Researcher: [child’s name] doesn’t do things?
Dad5: When [name] is comfortable that’s when he engages in activity. If you try to force him, its impossible. He freaks out.
Mom5: There’s something else that happens. It’s either peer modeling or something else that allows him engage in the activity.
Dad5: His brothers help.
Mom5: It opens the opportunity for him. It opens the model for him. [child’s name] has just been very, very cautious.
Dad5: When he's ready, he does the activity.
Mom5: So his younger brother, when he came along, he just kind of started doing a lot more then because if he can do it then I can do it.

4.5.3 Fragile Children

One common story for all of the parents was the high stress experience of having a critically ill baby. The parents provided many examples of how the fragile health of their child had impacted the lives of everyone in the family. One mother described the difficulty of finding daycare for her child when “you had to ask the daycare to read a book” about all of the potential symptoms of heart failure. Another mother very clearly identified how the fragile health of her child with a heart defect had changed the whole family’s socialization.

Mom5: I think part of the problem was when he was younger. We couldn’t really plan much cause we were coming here and going back and forth so much. This was taking up
a lot of our time, and going to different appointments. I couldn’t get him on a routine or a
schedule.

Although all of their children had successfully come through that period, it was clear that the
experience still played a large role in the parents’ perceptions of the children’s capacity for
physical activity. One mother described herself as having separation anxiety in trying to adjust to
the change in her child’s activity since his previous surgery. Several other parents readily agreed
that they shared her concerns.

Mom E: I have to remember when he’s running, he’s going to sweat. Profusely,
potentially, if should that be just his natural thing as a person. But then I get scared
because then I see the sweating and then I have to [chuckle] remind myself that his heart
rate will increase cause he’s physically active. But I’m always going there and I’m
checking it and you know seeing what his heart rate is and things. He does sometimes
pale out a bit, but he’s got a big tan right now and I am really like this is major tan for me
right so I have to remind myself there’s all those normal things with [child’s name], but
it’s always in the back of my mind if I’m in a public place and he’s playing. Honestly I
don’t hear anything. I’ve got one eye trained on him [chuckle] watching for some sign
that tells me something inside’s not going right.
Mom D: Yeah.
Mom E: So it is very anxious for me. And I think I’m growing out of it cause you can see
by his scraped knees and stuff that [chuckles] he is getting active. But I’m having
separation anxiety between the role of constantly mother hen-ing over him
Dad D: Yeah
Mom E: and realizing that exercise is good and I have to allow him to do that. So it’s a
balancing act for me.

While all of the parents indicated that their child’s health had significantly improved since those
early critical months, they also clearly knew that their child’s health was still at risk. For some of
the parents, the spectre of the heart suddenly stopping or a medical crisis with a sudden onset is a
very real concern. For others, the deterioration in their child’s heart condition will be gradual
over a period of time.

Mom A: In terms of sleepovers you know, [child’s name] just reached an age where
there’s sleepovers happening. And I know that a couple of parents will say “Do I need to
know anything? If anything were to happen what do I do?” [chuckle] You know we have
the ability to say “Nothing’s going to happen but, or it’s not going to happen over night”.

Mom D: That’s our concern with the teachers. They were “Well, what will happen to
him?” You call 9-1-1, there is no you call us. You call the ambulance you know.
Dad D: You call 9-1-1.
Mom D: You go [chuckles]. There would be no “Do we have time?”. Well, there is no time you just have to go.

It is also clear that concerns over the child’s health extend well beyond family members. The concerns shown above indicate that parents must also deal with the fears and concerns of other adults in the child’s life, such as teachers, daycare staff and parents of the child’s friends. It is easy to see how their past experience, and the real risks that they live with on a daily basis, could easily be transferred to participation in physical activity given that all physical activity requires a significant change in heart function from the resting or non-exercising state.

Parent Choices and Concerns

While there are definitely valid and substantial concerns regarding the heart function of their children both now and in the future, the fragility of their child’s health can also lead to restrictions of activity that are not medically justified. For example, one family indicated that they had not gone back to visit family in the country where the parents were born because they did not believe that there would be adequate medical facilities if something should happen to their child during the trip. They indicated that they had made this decision on their own even though their child’s cardiologist had said that such a trip would be fine. Other parents spoke about their own difficulties in trying to balance protecting their child from further health problems with enabling them to have a “normal” childhood. Concern over body contact activities, and in particular contact with the child’s chest, was particularly common.

Mom6: I’d be concerned about high contact sports or anything like that, like football maybe. But other than that. Rugby I’d say would be another example. Wrestling.

Several parents also indicated concern about their children’s ability to continue participating in physical activity with peers as they got older. They indicated concern about the influence of sedentary activity choices by peers (e.g., computers, video game), but they also recognized that their children would be increasingly disadvantaged by their small size as they got older.

Mom4: No the doctor hasn’t said no competitive sports. It’s something that I won’t do. He’s smaller than most kids his age and they are too rough. Especially boys, you know and I can’t deal with that.

Mom8: I really don’t think he should be limited, but when he gets older, like in grade four or five. Playing baseball and stuff like that, which he can do now, and hockey he can
do that now because it’s all kids play. But when he gets older, he might not to be too happy about that. Do you know what I mean?

The Stress of Promoting Activity

The parents also recognize that their responsibility to encourage their child to be involved in childhood activities was often a struggle with their own or their spouses’ fears in relation to their child’s fragile health.

Mom3: When we were going to the soccer game but his father is like oh I am scared.
Boy3: Nothing will happen. I play soccer everyday and I’m good at it. I got like nine goals.
Mom: He plays soccer every day at school. We feel like we are scared, because his heart problem we are scared.
Boy3: They don’t let me try out for any teams.

Mom A: Even though it’s hard as a parent. You try not to, you know, hermetically seal them in a bubble.
Mom D: Yeah.
Dad D: Yeah exactly.
Mom A: Because of our fears.

Dad10: Yeah, we put my son in hockey which would be five years ago. It was like, okay, it’s no body contact, put him out there. Well, we had to make the decision whether we were going to put him in contact hockey. There’s two leagues, you can go either way.
Researcher: Oh okay
Dad10: So you keep him in no body contact. I said to [wife’s name], my wife, the wrestling and the stuff that the two kids do with no equipment on is a lot more, there’s a lot more body contact there than there is on the ice. So, and you know what he’s adapting.

Anxious Children

Several parents indicated that high levels of anxiety related to physical activity occurred in the child rather than the parent. One family indicated that they wanted to enrol their child in the research study because they could not convince him to do any type of sport or exercise. They said that they had tried to convince him to try a wide range of activities and although he would do things with them as family he consistently refused to join in with other children because he would get hurt and have to go back to the hospital. Another mother expressed her frustration at knowing that her child needs to be more active but not being able to make that happen even with the help and influence of her daughter’s friends.
Mom B: How do you motivate a child who isn’t a sports-oriented child. She’s more artistic. So how do you convince a child to be more active. What sort of things would fall under the artistic side rather than … you know soccer doesn’t do anything for her.

Mom A: All depends too on their friends, who they hang out at school.

Mom B: Oh no, they all play soccer. They’ve all tried to talk her into it.

Dad A: Oh okay.

Mom B: They’ve all tried to talk her into baseball. [chuckle] You name it and I’m right behind her, but she doesn’t.

4.5.4 Parent and Child Uncertainty about Activity

All of the parents were easily able to recite the physical activity advice, recommendations or restrictions that they had received from the child’s cardiologist. For most parents, the advice was that few if any restrictions were required. The restrictions recounted by the parents related to isometric exercise (e.g., weight lifting), being able to stop and rest as needed, and body contact restrictions for the children with pacemakers or those taking blood thinning medication.

Mom D: No, they’ve given us no restrictions except not lifting weights.

Dad D: No weights, no smoking.

[laughter]

Researcher: No smoking goes for everybody.

Mom D: No drugs.

Dad D: No drugs. [chuckles]

Mom A: We were told by Dr. [cardiologist’s name] that if she is physically not capable of doing something her body will just naturally slow down or suggest that she sit down and rest. She won’t have a choice. So she can go as hard as she wants, as much as she wants. That body itself will let her know if it’s had too much or can’t do something, but no limitations.

Researcher: What about [child’s name] have you been told anything about her activity?

Dad B: Oh, not that I know of.

Mom C: Just like maybe contact sports, like karate or anything like that. Anything that could put risk to getting hit where his pacemaker is, but that’s really about it. But I let him decide when enough is enough.

Mom E: We were told with [child’s name] that he most likely would be able to participate in a school physical activity class like a physical education class, but he probably won’t ever go into like a professional sport or anything like that or potentially a sports team. We were thinking maybe he could do golf or something like that cause it’s not too crazy, but they did tell us that he probably wouldn’t be able to participate in a high level of sport activities.
Child’s Activity Differs from Expectations

Several parents indicated that they felt there was a significant discrepancy between their child’s actual participation and the activity expectations that they originally held for their child based on the activity recommendations that they received from their child’s cardiologist or other health professionals. When their children were infants, the parents indicated that they had been told that their child would be relatively inactive and they contrasted that expectation with the active lives that they perceive their children to lead.

Dad D: When he was at Sick Kids they said he’s going to be lethargic. They said he’s going to be tired all the time or like …
Dad B: Exhausted like [child’s name].
Dad D: It’s like okayyy?
Researcher: You’re still waiting for that to happen.
Dad D: He went out, yeah.
Mom D: It hasn’t happened.
Dad D: It never happened.

Uncertainty in Decision Making

In spite of the guidance given, the parents also made it clear that decision-making around specific activities could be difficult, particularly if participation resulted in the child showing signs of exertion. One parent described her difficult “parenting moments” in relation to her child expressing concern about being too active.

Mom A: I don’t want, if she says “I can’t do something cause I’m tired” or you know she’ll put her hand to her chest, and of course I immediately think oh so here’s one of those parenting moments. Do I force her to do it cause I think she’s playing with me or you know or do you allow her that opportunity or not to let her do it.

The same feelings of uncertainty were expressed by several other parents even in situations, such as emotional stress, when the child was not physically active.

Mom C: If he’s crying, I find that if he’s crying or he’s mad I feel like I should stop him. Researcher: Yeah.
Mom C: I don’t know how much he can take as far as crying goes. I think he’s going to hurt himself.

Their comments make it clear that these parents often feel that they are in situations of uncertainty regarding how much stress and strain (either physical or emotional) that their child’s
heart can take. Similar feelings of uncertainty also occur around other types of activity, particularly those involving body contact or impacts to the chest.

   Dad1: Oh I’m kind of scared about hockey and um football, getting hit in the chest or anything.

It was interesting to hear even the parents of the boy who plays ice hockey with body checking express concern about the possibility of him being hit in the chest:

   Dad10: Like he said about the lacrosse. We’ve told him that he couldn’t play football because of the contact, and lacrosse is just as rough. Without the padding so, we walked away from that one by going to the baseball, the rep baseball. So as we keep him busy there and then, but you know as they get older they get their own opinions and if he wants to start something new we’ll just go with the flow.

Researcher: Uh huh. Now has Dr. [cardiologist’s name] told you no contact sports?

   Dad10: Be careful with the contact sports. That he told us not to hold him back, but to try and not to have direct blows to the chest.

These parents clearly know what doctors have said about their child’s activity. In spite of that knowledge they indicate that they are often uncertain about whether or not a particular activity is appropriate for their child. It is not surprising, given their previous and on-going experiences with their child’s fragile health, that they naturally “err on the side of caution” whenever they are uncertain about the potential impact of an activity on their child’s heart. These results are similar to those previously reported by Sparacino and colleagues [63]. Their research with the parents of adolescents with congenital heart defects identified similar feelings of uncertainty in relation to the child’s participation in sports. Those parents also reported significant stress in relation to the ambiguity and lack of specific advice about physical activity contained in cardiologist recommendations to let the children “limit themselves”. The authors concluded that the intention of the cardiologists to allow the children to develop to their full potential, without preconceived limits, resulted in parents feeling that they did not clearly understand what was or was not safe and appropriate activity for their child.

4.6 Relationships Between the Parents’ Themes

Parents of children with complex heart defects must balance a wide variety of influences in trying to encourage their child to adopt a healthy, physically active lifestyle. The situational map created to illustrate the interaction between the many important influences that parents’ identified
through this research is shown in Figure 13. The most dominant themes to emerge from the parents’ comments were the importance of physical activity, the fragility of their child’s health and their uncertainty about what types of physical activity are appropriate for their child. They also recognized that the child’s family (both parents and siblings) could have a positive, negative or no influence on the activity level of the child with a complex heart defect. Ultimately, they described a delicate balancing act between encouraging healthy activity and ensuring that their child’s fragile health was not negatively impacted by the stresses and strains, both physical and emotional, which can result from physical activity.

Families Want their Children to be Active

Families clearly want their child with a heart defect to be able to participate in physically active peer play. They also believe that physical activity is important for their child with a heart defect, and most believe that their child has already achieved that active lifestyle. Parents recognize that peer interactions involve physical activity, and they also know that exercise is an important part of maintaining a healthy heart. Recognition of the importance of physical activity, therefore, has a strong positive influence on the child’s actual level of physical activity.

Many Factors Influence the Child’s Activity

As indicated in Figure 13, the parent participants identified numerous factors that influence the physical activity of their children. Only one of these influences, activity importance, seemed to have a clear, unidirectional (positive) influence on the child’s level of physical activity. All of the comments made by parents about the importance of activity were supportive. That is, all of the parents felt that activity was very important for their child and none indicated that it was a low priority or unimportant. Even the parents who indicated that physical activity was not important to the family as a whole felt that activity was very important for their child with a heart defect. Of course, the issue of participant bias must be considered in that parents who feel that physical activity is not important would probably be less likely to make the effort to attend a focus group or volunteer for a research study on the topic.

The potential impact of the other factors identified by the parents could be seen as both positive and negative. For example, parents indicated that the child’s developmental age could encourage
activity because the child becomes stronger and gains new skills with increasing age. However, they were also aware that increasing age typically leads to greater interest in sedentary pursuits, such as video games or computer networking, and also a greater disparity in size and skill between their child and others. Similarly, parents who were themselves very active indicated that their own participation was a strong motivating factor for encouraging their child’s involvement. In contrast, parents who were not particularly active in their own lifestyle found it much more difficult to prioritize physical activity, particularly if their child did not wish to participate.

Impact of the Child’s Medical History

The child’s medical history, current health and uncertain future clearly played a very dominant role in parent decision-making regarding physical activity participation. Parents perceive that their child’s heart is fragile or more vulnerable to stress from either physical activity or emotional strain. These perceptions are a logical, natural conclusion given their past experiences of a critically ill child and the knowledge that their children continue to have serious heart problems. Like all parents, the health and well-being of their children is their primary concern. They are constantly on guard for signs that their child’s health is being compromised and always alert and proactively evaluating the risks and benefits of the activity options that their child encounters.

That they continue to encourage their children to be involved in physical activities, both with family and friends, illustrates the skill that these parents have developed for their “balancing act”. Through this continual balancing act, physical activity becomes a barometer of their child’s health. Successful participation in physical activity is seen as a sign that their child is stronger and healthier. At the same time, on-going concerns about a possible deterioration in their child’s heart function encourages parents to set boundaries around the type and intensity of physical activity in which their children participate.
Figure 13: Influences on Parent Perceptions of Physical Activity for Their Child with a Complex Heart Problem
Uncertainty About Appropriate Activities

The parents of children with complex heart defects in this study clearly indicated substantial uncertainty about the appropriate types of physical activity for their children. They indicated that they often feel very uncertain about what decisions they should make when trying to implement their doctor’s recommendations for physical activity participation. At a basic level, they know what physical activity restrictions, if any, apply to their child. However, making the day-to-day decisions of how that advice should be implemented can be fraught with uncertainty. For example, parents indicated that they often restricted the physical activity of their child in ways that were beyond the recommendations made by their cardiologist. Activity restrictions different from those specified by the cardiologist were particularly common for body contact sports. For example, many parents indicated that they would not allow their child to play a sport that might result in a blow to the chest or that they would not allow any contact sports, even though those types of restriction are only required during the early post-operative period or if the child remains on anticoagulation therapy. In contrast, the parents of a boy who played hockey decided to allow him to continue in the league with body checking because of the way he was regularly involved in very vigorous wrestling matches with his sister on an almost daily basis. As parents navigate their feelings of uncertainty related to the physical activity of their child with a complex heart defect, it is not surprising that they “err on the side of caution” whenever they do not feel certain about the appropriateness of an activity in relation to their child’s health.

Multiple factors, both measurable variables and individual perceptions, are associated with the level of physical activity achieved by children with complex heart defects. The child’s past, present and future health experiences interact to create a picture of a child whose health is somewhat fragile. Physical activity is both encouraged in order to strengthen the child’s heart, and discouraged to prevent perceived adverse health consequences from either the physical or emotional strain. Unfortunately, the physical activity recommendations and advice provided by the child’s cardiologist typically sheds very little light on where the “safe ground” for a healthy, active lifestyle can be found. Although intended to provide simple, clear guidance about appropriate physical activity, general advice such as “no competitive sports” appears to add to parental feelings of uncertainty. This unintended consequence contributes to the difficult
balancing act these parents perform of ensuring sufficient physical activity for improved health while protecting against activities that might be detrimental to the child’s heart.

4.7 Why Children with Complex Heart Defects are Inactive

Activity perceptions and reports about physical activity were obtained from children with complex heart defects and their parents through this research. Their ideas and opinions have contributed important new knowledge as to why they are largely inactive. Although these results must be viewed in light of several limitations, such as bias toward socially desirable answers, lack of awareness of limited ability to verbalize complex thoughts, they provide the first glimpse into the psychosocial factors that influence the physical activity participation of these children.

In summarizing the results of this research, it is important to return to the research questions originally posed. When we first embarked on this project we knew that children with complex defects were inactive, but measures of fitness, medical history and heart function could explain less than 50% of the variability in their physical activity participation (3.3). Therefore, the goal for this research was to identify answers to the following three research questions:

1. Why do most children with complex congenital heart defects lead sedentary lives?

2. Why are children with complex heart defects less active than their peers regardless of their level of heart function?

3. Why do parents of children with complex heart defects allow their children to be inactive given the importance of physical activity for health?

Uncertainty and Inactive Lifestyles

Based on the information gathered through the parent and child interviews, I would suggest that we have enhanced our ability to answer these questions by considering the psychological, social and emotional factors that influence childhood activity. Children with complex congenital heart defects are predisposed to inactive lifestyles in the same way that the majority of Canadian children get insufficient activity for optimal health [12]. For a small proportion of those children, such as those with open fenestrations or taking blood thinning medication, their medical status or
treatment will play a significant role. However, for the majority of children with complex heart defects feeling uncertain about physical activity, on the part of either the parent or child, is an important contributor to more sedentary lifestyles. The uncertainty does not appear to be related to care of the child’s heart condition. Parents can report the guidance provided by the child’s cardiologist and none of the parents indicated that they received equivocal advice from the cardiologist. Rather their uncertainty stems from trying to interpret the guidance in relation to their child’s daily activity. Is soccer or t-ball a “contact sport”? Is the lunch-time floor hockey league at school a “competitive sport”? What if the ball hits him in the chest? Providing answers to these questions and enhancing parent and child certainty about the physical activities that are both appropriate and important may be an effective method of intervening to enhance the daily physical activity of these children.

Impact of the Heart Defect

Children with complex heart defects are less active than their sedentary peers for a wide variety of reasons. In small part, their lower level of activity is related to their heart function. They do have less endurance and the children are typically shorter and lighter weight than their peers because of limited growth prior to their surgery. Their size can inhibit their activity both directly (“I’m not that good at hanging onto the monkey bars that long”) and indirectly via parent and child concerns about “keeping up” or “getting hurt”. Their lower level of physical activity may also result from factors unrelated to their heart condition. For example, the majority of children reported that they go home after school rather than to daycare or a babysitter. The proportion of families with one stay-at-home parent is much higher than the general population. Therefore, children with heart defects may have less access to the physical activity supportive environments provided by child care programmes (being with friends and having organized physical activity opportunities). Several families indicated that their children were less willing to be involved in physical activity now than in the past. Parents perceived their children to be increasingly anxious about physical activity, even the activities enjoyed previously, and many children commented that they did not enjoy physical activity because they were unable to “keep up”.
Inactive Lifestyles Go Unrecognized

The answer to the final research question seems to be the understanding that the question itself was based on incorrect assumptions. Parents of children with complex heart defects do not “allow” their children to lead sedentary lives, rather they are unaware that their children are inactive. All of the parents in this study firmly believed that physical activity was very important for their child, and for most families they also believed that their children lead active lives. These results suggest that enabling parents to accurately perceive their child’s inactive lifestyle is an important first step toward encouraging the higher levels of the physical activity that they recognize are critically important. The final research project reported in the following chapter begins to address the first of these issues, that is, understanding why the physical activity guidance provided by cardiologists seems unclear or difficult to interpret.

4.7.1 Study Limitations

Impact of the Researchers on the Data Constructed

Of course, the interpretation of these results must always be considered in light of the influence of the researchers on the focus group participants and discussions. That parents feel uncertain about appropriate physical activities was a very unexpected finding. Given a similar opportunity in the future, I would hope to ask more questions and encourage more discussion about what guidance parents are given and the specific types of guidance or physical activity situations that cause them the greatest concern. It is clear that cardiologists need to change how they communicate with parents about the child’s physical activity. However, without more detailed information from the parents’ perspective it is difficult to determine exactly what changes are required.

The children’s focus group was the first such group that I conducted with younger children. Although I had incorporated drawing activities and games in order to keep the attention of the children on the task at hand, my efforts were only partly successful. Given that the girls were much more willing to respond to the activities that I had provided, I wonder whether different types of activities might be more appropriate for focus groups with boys. In order to optimize the participation of both boys and girls, some researchers have recommended that the moderator and
all participants in each focus group be of the same sex of [69]. Others have found that mixed
gender groups are not disadvantaged among this age group [70]. Holding two separate groups for
the children may have improved the participation of the boys, but it would have also required me
to recruit a male moderator for the second session.

I also learned the importance of allowing the children to get to know one another. While it is
relatively easy for parents to meet other parents and create a connection because of their shared
experiences, the way the children’s focus group was designed did not allow the children to
develop similar connections. There was a significant amount of time for informal interactions
(while the parent focus group was held), but the schedule had that time after the children’s focus
group. I think if I had given more consideration to developing connections between the children
before beginning the focus group discussions, I might have been able to encourage a greater
contribution from, and interaction among all of the children.

**Limitations of Focus Groups**

The limitations associated with focus group research must also be recognized. Focus group
participants, as in this study, are generally not randomly selected and therefore focus group
results cannot easily be generalized to a wider population. The results obtained using focus group
methods are also highly dependent on the skills of the moderator leading the group, and
collecting and analyzing focus group data is very labour intensive. Since the purpose of these
focus groups was a preliminary investigation of issues and topics to be explored in further depth
during individual interviews, being unable to generalize results to a broader population was not a
significant concern. The labour intensive nature of qualitative data collection and analysis was
considered an appropriate investment in order to generate novel information about the physical
activity perceptions of children with complex heart defects and their parents [69]. As an
independent consultant I had considerable experience conducting focus groups with adults prior
to embarking on my PhD programme of research. However, I recognized that my lack of
experience facilitating a focus group for children might be a significant limitation for this
research [69]. At the same time I was encouraged to pursue the child focus group in order to
enhance my own expertise and expand my research skills and the methods I would have
available for future research. Prior to conducting the focus groups, I met with a researcher in the
Child Life department of the hospital (D. Koller) who had extensive experience in conducting
focus groups with children. She provided me with strategies and suggestions for facilitating the group and offered to have one of her staff members co-facilitate the children’s group. Unfortunately, it wasn’t until the group was in progress that I realized the child life staff member selected had not had any previous experience conducting research with children. Rather, she had been assigned to work with me in order to gain experience in focus group research. As such, our mutual lack of experience in facilitating focus groups with children was a significant limitation to the results obtained (see more detailed discussion of this limitation in 6.2).

**Limitations of Interviews**

The interviews conducted for this research used a standardized, open-ended approach [68] because of the limited time available to conduct each interview. Although the interviews conducted for this research were quite lengthy and detailed, they were, by design, much shorter than the extensive interviews recommended by Denzin [39]. The shorter duration of the interviews was primarily due to the time constraints imposed by the attention span of younger children. The depth of the child interviews was directly influenced by the children’s attention span. However, the attention span of the children also limited the length of the parent interviews. Complex congenital heart defects are uncommon, and therefore the Labatt Family Heart Centre provides care to children living in a very large geographical area (limited to the province of Ontario for this research). The families participating in this research reside up to 600 km away from the hospital. I decided that it was not appropriate to ask parents to return to the hospital for the research interview on a separate date without their child, particularly since the additional trip would be at their own time and at their own expense. Therefore, the depth of the parent interviews was limited by the time available outside of clinic appointments and the children’s willingness to play by themselves while the parent interviews were completed.

The quality of interview responses is affected by the types of questions that are asked, how the questions are sequenced, the wording of specific questions, and the length of the interview. As previously indicated, the length of the parent and child interviews in this study were deliberately shortened in comparison to the traditional in-depth interviews of the interpretive interactionist approach. While limiting the depth and breadth of discussions, this shorter length would be expected to enhance the participants’ active engagement throughout the each interview. The questions included in the interviews were selected to represent the participants’ experience,
behaviour, opinions, feelings and knowledge related to the child’s physical activity. The sequencing of the questions was designed so that the participant was initially asked to describe what they currently do. Such questions are considered to be relatively straightforward and easy to answer because they require minimal recall or interpretation [68]. Questions about opinions, feelings, and beliefs were asked later in the interview, after rapport had been developed between the researcher and participant and the participant was comfortable with the interview setting. Questions about the child’s medical history and family demographics were not included in the interviews because they represent the types of questions that people find boring or even uncomfortable [68]. Instead, demographic information about the participating families was collected from a review of the child’s medical chart.
Chapter 5
Medical Influences on the Children’s Physical Activity
5 Paediatric Cardiology and Physical Activity Uncertainty

5.1 Introduction

Children who have had the Fontan procedure for functional single ventricle are much more sedentary than their healthy peers. Their low levels of physical activity participation are not related to their exercise capacity [15] or measures of health-related fitness [73]. This research has identified factors associated with the child’s physical activity participation, as reported in 2.3, such as age, sex, season of the year, the child’s gross motor skill and fitness, and medical history factors (age of Fontan procedure, use of antithrombotic medication, fenestration status). Parent or child reports of uncertainty about the appropriate type and intensity of physical activity are also correlated with sedentary lifestyles [74]. Although these factors are related to sedentary lifestyles, whether there is a causal effect is currently unknown. Low levels of gross motor skill could be either a cause or effect of reduced physical activity participation. Similarly, perceptions of uncertainty about physical activity may lead to or be the result of lower levels of activity participation.

Children from families that indicate uncertainty about activity are significantly less active than children in families that are confident about appropriate activities [74]. When the parents of the 64 children whose physical activity was directly measured by accelerometry (see section 2) were asked “If you could ask your cardiologist or another expert for more information about physical activity and your child, what would you ask?” the responses focus almost exclusively on questions that suggest uncertainty about activity. Many parents directly indicate their uncertainty by asking questions about the impact of activity on life expectancy, whether activity should be encouraged if the child feels tired or the heart condition becomes problematic, whether vigorous activity can trigger heart problems or what would happen if the child received a hard blow to the chest. Parents also indicate their uncertainty indirectly, by asking questions about the types or levels of activity considered safe or recommended, the effect of medications on activity and how much activity the child is capable of performing.
Family Uncertainty as a Cause of Sedentary Lifestyles

It is my assumption that parent or child uncertainty about appropriate types or intensities of physical activity would be a causative effective for, rather than an outcome of, sedentary lifestyles. It is understandable that parents would “err on the side of caution” by restricting activity if they are unsure of its appropriateness. It is also unlikely that participating in physical activity would increase feelings of uncertainty about whether the activity is appropriate. That is, it is unlikely that uncertainty is an outcome of previous activity participation. Certainly if participation was successful, increased feelings of uncertainty about activity are unlikely. In the unlikely event that the child’s activity participation has a detrimental impact on the child’s health (e.g., a child taking blood thinning medication is hospitalized for internal bleeding after going tobogganing), it still seems more likely that uncertainty about the appropriateness of the activity would be reduced. As a result, this research assumes that activity uncertainty is a causative agent in the development of sedentary lifestyles. Given that assumption, identifying factors that contribute to activity uncertainty is the first step to developing effective interventions that will allow these children to achieve and maintain higher levels of physical activity.

Purpose of the Study

The purpose of this study was to explore the role that paediatric cardiology plays, if any, in relation to parent and child perceptions of uncertainty about appropriate physical activity. For this research, “paediatric cardiology” was defined as the child’s cardiologist, other staff in the tertiary cardiac clinic (e.g., nurse, fellow), and the guidelines and literature that define the “standard of care”. A greater understanding of the role of paediatric cardiology would enable cardiologists and cardiac clinic staff to better support parents and children to make appropriate choices about the child’s physical activity participation.

Making Physical Activity Recommendations to Patients

In making physical activity recommendations to individual patients, health professionals in the cardiac clinic utilize their expertise to balance information from a variety of sources. First and foremost, they utilize the information that they know about each patient’s health status. They also rely on the knowledge and recommended practices contained in the scientific literature.
Finally, they must convey the physical activity recommendations to the family (parents and child) as well as to the child’s family physician or other health professionals involved in the child’s care. It was assumed that the child’s cardiologist would determine the physical activity guidance provided to the family, regardless of whether the information was conveyed to the family directly or via other clinic staff. Published guidelines and expectations for the standard of care would be expected to inform the cardiologist’s decision-making.

Research by Falk et al [75] suggests only a low level of agreement between cardiologist and adolescent reports of physical activity restrictions. Those results, combined with parent and child reports of activity uncertainty suggest the need for greater understanding of the role of paediatric cardiology in developing the family’s physical activity expectations for their child.

Research Questions

Our understanding of the cardiologist’s role was sought through answers to the following research questions:

1. How do the reports of activity restrictions for the child differ between the cardiologist, parent and other health care providers?

2. Why do cardiologists provide advice, such as “no competitive sports”, that families feel is vague and difficult to interpret when making daily decisions about their child’s physical activity participation?

3. How is physical activity information conveyed by cardiologists to patients and their families?

Each of these research questions is addressed separately in the sub-sections of this chapter.

5.2 Disagreement Between Parent, Cardiologist and Medical Record Reports of Physical Activity Restrictions

Previous research has established that children with complex heart defects and their families rely heavily on the guidance provided by their cardiologist in making decisions about daily life. For example, advice about physical activity from the cardiologist plays an important role in
determining the self-efficacy for activity of adolescents with congenital heart defects. The adolescent’s belief about their own ability to be successful (positive self-efficacy) and the activity attitudes of parents are both primary correlates of the adolescent’s actual physical activity behaviour [26]. Feelings of connection to and reliance on the paediatric cardiologist and concerns about the knowledge of adult cardiologists are often so strong that the child and/or family will refuse attempts to transfer the care of the teenage or adult patient to an adult cardiologist [76]. Given the family’s strong bond with the paediatric cardiologist, it would be expected that the family would make significant efforts to follow the cardiologist’s recommendations regarding physical activity participation. It would also seem reasonable to assume that the family would choose to follow advice received from the cardiologist over advice from other health care providers.

A recent study by Falk et al [75] was the first to demonstrate that there is often a discrepancy between the physical activity recommendations of the cardiologist and the activity participation and restrictions reported by adolescents, 12 to 18 years of age, with trivial, mild or moderate congenital heart defects. Adolescents with postoperative cyanotic congenital heart defects were considered to have defects that were moderate in severity. Falk et al found that 31% of the adolescents rated their heart defect as less severe and 15% rated it as more severe than the rating provided by the cardiologist, resulting in a low overall rating of agreement (Kappa=0.295). Cardiologists and adolescents were asked to rate their allowed physical activity as light effort only, somewhat intense effort (no competitive sports), or intense effort (unrestricted). The actual physical activity participation of the adolescents was estimated from the adolescents’ responses to a standard self-report physical activity instrument (7-day Physical Activity Recall Questionnaire). Agreement between the cardiologist and adolescent reports of physical activity recommendations was low (Kappa=0.32). Only 60% of the adolescents provided the same response as their cardiologist. Another 27% reported they were more restricted than what the cardiologist had recommended. Thirteen percent of the adolescents reported that they are allowed to participate in more vigorous activity than recommended. Of concern, 80% of the adolescents who were restricted to only light activities by their cardiologist reported that they could do more intense physical activity. These results suggest that adolescents in need of the tightest activity restrictions have a very high rate of under-reporting the recommendations of their cardiologist.
Purpose of the Study

The purpose of this study was to evaluate the consistency of reported activity restrictions for children who have had the Fontan procedure for palliation of a univentricular heart. Differences between parent and cardiologist reports of a child’s activity restrictions would support parent perceptions of uncertainty. The hypothesis was that reports of the child’s physical activity restrictions would not vary based on the information source.

5.2.1 Patient Descriptions

This cross-sectional study evaluated reports of physical activity restrictions for 64 children (25 female) that had previously undergone the Fontan procedure. The study population was all children, mean age 9.0 ± 1.7 years, range 5.9 to 11.7 years, enrolled in a randomized clinical trial to evaluate the impact of two cardiac rehabilitation programmes on the children’s physical activity participation. The age range of 6 to 11 years was selected to represent children who attended full-day elementary school over an age range where sex differences in physical activity participation are minimal [47]. Children were excluded if they had a disability or medical condition that limited their physical activity participation (n=5), if the family declined to participate (n=1) or if the family was lost to follow-up (n=6). The study protocol was approved by the Institutional Research Ethics Board. Informed consent was obtained from the parent. The child’s assent to the parent providing information about the child’s medical history and the review of the medical record was also obtained.

5.2.2 Methods

The responsible cardiologist completed a questionnaire about the physical activity participation restrictions that applied to the child. The cardiologist specified whether the child was restricted or unrestricted in four categories: “level of exertion”, “level of competition”, “amount of body contact”, and “other”. If restrictions were indicated, open-ended questions were used to obtain specific information about the type of restriction. Parent reports of physical activity restrictions were obtained via questionnaire and interview. The open-ended question “What, if any, types of activities are not recommended for your child because of his/her heart condition?” was part of the parent questionnaire used to gather information about the child’s and family’s perception of,
support for, and participation in physical activity. During a subsequent interview, parents were also asked to identify any types of physical activity that they would not want their child to learn or perform as part of the cardiac rehabilitation intervention. A comprehensive review of the child’s medical chart was completed to identify the physical activity restriction information available to other health professionals. The review included dictated letters from clinic visits, catheterization and surgical procedures as well as hospitalization notes and discharge instructions.

Whether or not a restriction was indicated for level of exertion, level of competition, and amount of body contact was determined for each data source. Open-ended responses that identified additional restrictions were also coded into categories (Table 8). Kappa statistics were used to calculate the agreement between sources beyond that expected by chance. Initially, restrictions reported from each source were described. Subsequently, the presence of any type of restriction, pairwise comparisons of each type of restriction by data source and the influence of demographic factors (e.g., sex, age, cardiac status) on each variable were evaluated.

5.2.3 Results

Study Participants

Physical activity restrictions were obtained from 19 responsible cardiologists (7 female (37%)) for the 64 children included in these analyses. Table 8 provides a summary of the 8 categories of activity restriction identified and whether or not each type of restriction was found in the cardiologist reports, parent reports or medical charts. Fourteen cardiologists were staff at our own institution, 2 were staff at other paediatric tertiary cardiac centers and 3 were in community practice. Activity restrictions were reported by both parents for 19 children, by mothers only for 33 children, by fathers only for 7 children and by grandparents for 3 children. Parent reports of activity restrictions were unavailable for two children.
Table 8: Physical Activity Restriction Categories that Occurred by Source

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
<th>Card.</th>
<th>Parent</th>
<th>Chart</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exertion</td>
<td>Limited intensity or level of effort.</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Competition</td>
<td>Exclusion from some or all competitive or house league sports.</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Contact</td>
<td>Restriction from activities with a high risk of body contact or impact.</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Comfort</td>
<td>Activity as tolerated, within comfortable limits or rest as needed.</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Isometric</td>
<td>Isometric/heavy lifting activities are restricted.</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Upside Down</td>
<td>Upside down activities not permitted.</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Chest</td>
<td>Activities where an impact to the chest might occur are not permitted.</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Parent</td>
<td>Parent must supervise child’s participation in physical activity.</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

1 Card. = Cardiologist report of activity restriction

Activity Restrictions Reported by Parents

A majority of the parents (45/62, 73%, 2 parent reports missing) reported that their child’s physical activity was restricted in some way. One fifth (12/62, 6 female children) of parents reported that their child’s level of exertion was restricted. Parents of 24 children (8 female) reported that their child was not allowed to participate in body contact activities. Only 7 parents (1 female child) reported that their child’s participation in competition was restricted. Many other activity restrictions were reported by parents. Avoiding a blow to the chest (n=7), not “overdoing it” or stopping when tired (n=9) and not doing heavy lifting (n=4) were most common. Participating in activity only with parent supervision (n=2), avoiding upside down or
gymnastics activities (n=2), staying inside when the weather is hot/cold or pollution is high (n=2), no activities with a sudden change of speed (n=1), no team sports (n=1), and requiring the child to stop any activity that causes pain in the chest (n=1) were mentioned by only one or two parents. In addition, one child who has epilepsy was required to have supervision when swimming.

Activity Restrictions Reported by Cardiologists

Half of the study participants (34/64) had some type of physical activity restriction specified by their cardiologist. The responsible cardiologist indicated an exertion restriction for 11% (7/64, 4 female) of the children included in the study. Thirty children (12 female) had restrictions on their level of competition. Some children were allowed only moderate competition. Others were restricted from competition involving body contact or to a house league level of competition. Cardiologists indicated that 37 children were unrestricted for body contact while 26 (11 female) were not allowed to participate in contact sports. Other restrictions reported by the cardiologists included activity only as tolerated (n=6), no heavy lifting or isometric activity (n=3), no upside-down activities (n=1), and no activity in extremes of temperature (n=1).

Activity Restrictions Documented in the Medical Chart

Eighteen children (31% of 58 children, 22 female, 6 medical charts missing) had activity restrictions documented in their medical chart. The medical charts of 6 children (3 female) were not available for review because they were located at other institutions. Almost all of the medical charts that contained restrictions (17/18, 4 female) indicated that the child’s participation in competition was restricted. Children restricted from competition represented the age, cardiac anatomy and type of Fontan procedure of the study participants as a whole and were followed by 8 different cardiologists. Two eight-year old boys had a body contact restriction specified in their medical chart but neither child was on anti-coagulation therapy at the time of the study, although one child was taking aspirin. The boy taking aspirin was the only child that had a restriction for isometric exercise (weightlifting) recorded in the medical chart. None of the medical charts reviewed indicated a restriction of the child’s level of exertion, and none of the other restrictions mentioned by the parents or cardiologists were recorded in a medical chart.
Agreement of Exertion Restrictions by Source

The responsible cardiologist and parents agreed on whether or not the child’s level of exertion should be restricted 74% (46/62) of the time (Table 9), a level of agreement that would occur by chance (Kappa 0.02). Of the 7 children whose exertion was restricted by the cardiologist, only one parent reported an exertion restriction. Eleven parents of children reported an activity restriction that was not reported by the cardiologist. Comparisons with the medical chart were not possible since none of the medical charts included exertion restrictions.

Table 9: Comparison of Exertion, Competition and Contact Restriction Reports by Reporting Source

<table>
<thead>
<tr>
<th>Activity Restriction</th>
<th>Comparison</th>
<th>% (#) Agreement</th>
<th>Kappa</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exertion</td>
<td>Cardiologist &amp; Parent</td>
<td>74% (46/62)¹</td>
<td>0.02</td>
</tr>
<tr>
<td></td>
<td>Cardiologist &amp; Chart²</td>
<td>90% (52/58)</td>
<td>n/a ³</td>
</tr>
<tr>
<td>Competition</td>
<td>Cardiologist &amp; Parent</td>
<td>57% (35/62)</td>
<td>0.05</td>
</tr>
<tr>
<td></td>
<td>Cardiologist &amp; Chart</td>
<td>66% (38/58)</td>
<td>0.26</td>
</tr>
<tr>
<td>Contact</td>
<td>Cardiologist &amp; Parent</td>
<td>60% (37/62)</td>
<td>0.16</td>
</tr>
<tr>
<td></td>
<td>Cardiologist &amp; Chart</td>
<td>57% (33/58)</td>
<td>0.06</td>
</tr>
</tbody>
</table>

¹ Parent reports of activity restriction were missing for two children. These children are excluded from all comparisons of parent reports but were included in the cardiologist and medical chart comparisons because those data were available.

² Chart = Restriction identified during review of the medical chart.

³ n/a = Kappa statistic not calculated because no medical charts indicated an exertion restriction. Therefore there was agreement (52/58) only for children whose cardiologist did not specify an exertion restriction.
Agreement of Competition Restrictions by Source

The agreement between cardiologist and parent for restrictions on competition was not greater than would occur by chance (Kappa = 0.05). Only one parent (3%) reported a competition restriction among the 34 children whose cardiologist indicated that competition was not restricted. In contrast, only two parents (7%) indicated that their child’s level of competition was restricted among the 28 children whose level of competition was restricted by their cardiologist. Level of competition reported by the cardiologist and recorded in the medical chart did agree more often than would be predicted by chance (Kappa = 0.26), but the relationship was relatively weak. The competition restriction was recorded in the charts of 12 (3 female) of the 30 children whose competition was restricted by their cardiologist. Five medical charts indicated competition restrictions not reported by the cardiologist. These results indicate that restrictions of competition occur frequently, based on cardiologist reports, but the restrictions are generally not recognized or reported by parents.

Agreement of Body Contact Restrictions by Source

There was a tendency for parent and cardiologist reports of body contact restrictions to agree more often than chance (Kappa = 0.16) as shown in Table 10.

Table 10: Body Contact Restrictions Identified by Cardiologist, Parent and Medical Chart

<table>
<thead>
<tr>
<th>MD Restriction</th>
<th>Parent Restriction</th>
<th>Medical Chart Restriction</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Yes</td>
<td>12</td>
<td>13</td>
</tr>
<tr>
<td>No</td>
<td>12</td>
<td>25</td>
</tr>
</tbody>
</table>

Two-thirds of parents (25/37) agreed with the cardiologist when body contact was unrestricted. In contrast, 50% (13/25) of parents reported that body contact was not restricted when the cardiologist had specified a body contact restriction. Data from the medical chart did not reflect the body contact restrictions reported by the cardiologist (Kappa = 0.06). The medical charts did
not indicate a body contact restriction for any of the 26 children (0%) for whom the cardiologist had specified a body contact restriction. Two children had a body contact restriction specified in their medical chart that was not specified by their cardiologist.

Agreement between parent and cardiologist was much stronger among children on anticoagulation therapy (Table 11). Parent and cardiologist agreement for body contact restrictions was higher than would be expected by chance (Kappa=0.33) for children taking either aspirin or warfarin. There was also significant agreement between parent and cardiologist for children not taking anticoagulation therapy (Kappa=0.34).

Table 11: Cardiologist and Parent Agreement by Anticoagulation Therapy

<table>
<thead>
<tr>
<th>Activity Restriction</th>
<th>Warfarin or Aspirin</th>
<th>Warfarin</th>
<th>Aspirin</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Exertion(^1)</td>
<td>0.04</td>
<td>0.13</td>
<td>0.00</td>
</tr>
<tr>
<td>Competition(^2)</td>
<td>0.04</td>
<td>0.10</td>
<td>0.33</td>
</tr>
<tr>
<td>Body Contact(^3)</td>
<td>0.33</td>
<td>0.34</td>
<td>5/6(^4)</td>
</tr>
</tbody>
</table>

\(^1\) Exertion = Restriction of vigorous activity
\(^2\) Competition = Restriction of competitive sport
\(^3\) Body Contact = Restriction of activities that result in contact with players or equipment
\(^4\) All children taking warfarin had body contact restrictions specified by the responsible cardiologist.

Other Restrictions

The cardiologist, parent and medical chart reports of activity restrictions identified five additional types of restriction. A restriction of isometric activity or heavy lifting was the only additional factor that was included in all three data sources. One child had a restriction of isometric activity reported by the cardiologist and recorded in the medical chart, but the parent of that child did not report a restriction of isometric activity. Three parents and one medical chart reported restrictions of isometric activity that were not reported by the cardiologist. However, overall there was no significant agreement between the reports of isometric activity restriction
from the three data sources (Kappa = 0.03). The medical charts did not mention any of the other additional restrictions identified by parents or cardiologists.

There was much stronger agreement than would be expected by chance for restrictions of upside down activities (Kappa = 0.66) reported by the cardiologist (n=1) or parents (n=2). Both cardiologists (n=6) and parents (n=9) reported that the activity of a small number of children was restricted to comfortable limits or as tolerated. However, there was no significant agreement, beyond that expected by chance (Kappa = 0.13), between the parents’ and cardiologists’ reports of this restriction. None of the parents reported a restriction for the 6 children that were restricted to comfortable limits by their cardiologist and 9/56 parents (16%) indicated a restriction of their child to comfortable limits that was not indicated by the cardiologist. A few parents also reported restrictions on activities that could result in an impact to the chest (n=5) or that parents must supervise all of the child’s activities (n=2), but these restrictions were not reflected in the cardiologist or medical record reports. Overall, other restrictions were primarily for isometric activities or staying within comfortable limits, but there was no agreement regarding these restrictions when comparing the three data sources.

Factors Related to Activity Restriction

Sex, type of Fontan, underlying cardiac anatomy, child’s current age and child’s age at the time of Fontan were not related to the presence or absence of activity restrictions as reported by either the cardiologists or parents. Whether or not an activity restriction was reported by the child’s cardiologist varied significantly (Chi-square=33.8, df=18, p=.0135) by cardiologist (Table 12). Eight cardiologists reported at least one activity restriction for 100% of their patients, while 5 cardiologists did not restrict any activities of their patients. There was no relationship between parent-reported activity restrictions and the child’s cardiologist.

Factors Influencing Restriction Agreement

The agreement between cardiologist and parent reports of activity restriction were evaluated to determine whether demographic variables were related to the strength of agreement. Sex, type of Fontan, original cardiac anatomy, and responsible cardiologist were related to the agreement of
parent-cardiologist reports. There was no significant relationship between age at study testing or age at Fontan procedure and the measures of parent-cardiologist agreement.

The influence of sex on parent-cardiologist agreement was relatively weak for body contact (Kappa = 0.20) and exertion (Kappa = 0.18) restrictions. Sex did not influence competition restrictions (Kappa = 0.001). Parent-cardiologist agreement was more likely among male children for exertion restrictions (82% and 61% for male and female children, respectively) and among female children for body contact restrictions (51% and 74% for male and female children, respectively).

The type of Fontan also influenced the amount of parent-cardiologist agreement. There was a moderately strong level of agreement (Kappa = 0.36) about exertion restrictions for children (n=7) who have an extracardiac lateral tunnel, but not for children (n=54) who have an extracardiac conduit (Kappa = 0.10). The same pattern emerged for body contact restrictions, with moderately strong parent-cardiologist agreement (Kappa = 0.46) for children who have an extracardiac lateral tunnel but no agreement beyond chance for children who have an extracardiac conduit (Kappa = 0.11). Parent-cardiologist agreement about competition restrictions were not influenced by the type of Fontan connection.

In terms of the children’s underlying cardiac anatomy, the parent-cardiologist level of agreement was significantly greater than chance for exertion restrictions among children with double inlet left ventricle (Kappa = 0.33, n=15), and body contact restrictions for children with tricuspid atresia (Kappa = 0.38, n=11) or double inlet left ventricle (Kappa = 0.70, n=15). Parents and cardiologists of the four children with pulmonary atresia never agreed on body contact restrictions (Kappa = 1.00).

Parent-cardiologist agreement varied significantly by cardiologist for competition restrictions (Kappa = 0.29). There was also a trend toward variation by cardiologist for exertion restrictions (Kappa = 0.17), but no relationship for body contact restrictions (Kappa = 0.08). Seven cardiologists had very high or even 100% of their parents report exactly the restrictions specified by the cardiologist (Table 12).
<table>
<thead>
<tr>
<th>Cardiologist</th>
<th># of children</th>
<th>Any MD restriction</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Exertion</td>
<td>Competition</td>
<td>Body Contact</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>3</td>
<td>100%</td>
<td>100%</td>
<td>67%</td>
<td>67%</td>
</tr>
<tr>
<td>2</td>
<td>4</td>
<td>100%</td>
<td>100%</td>
<td>0%</td>
<td>100%</td>
</tr>
<tr>
<td>3</td>
<td>5</td>
<td>40%</td>
<td>40%</td>
<td>60%</td>
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<td>8</td>
<td>50%</td>
<td>75%</td>
<td>63%</td>
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</tr>
</tbody>
</table>

* Parent reports of activity restrictions were missing for 2 parents
5.2.4 Discussion

The results of this study suggest that parental reports of uncertainty about the appropriate types and intensity of physical activity for their child are accurate. Separate pairwise comparisons (e.g., cardiologist-parent, cardiologist-medical chart) identified only a few factors with agreement better than would happen by chance. However, none of the activity restrictions demonstrated consistent agreement, beyond that expected by chance, when the data from all three sources (cardiologist, parent and medical chart) were compared.

Exertion Restrictions

The responsible cardiologist and parents agreed about restrictions on the child’s level of exertion for 74% (46/62) of the children in the study. Where there was disagreement, parents (11/62, 18%) were more likely to report an activity restriction that was not specified by the cardiologist. Previous research with healthy children has found that parental beliefs about the child’s competence for moderate-to-vigorous activity are significantly related to the child’s level of participation [77]. Our research has shown that parents who are uncertain about appropriate physical activities for their child have children who are more sedentary [74]. Others have found that 80% of parents significantly underestimate the exercise tolerance of their child with a complex congenital heart defect [29]. Assuming that parental beliefs similarly impact the participation of children with and without complex heart defects, then enhancing the accuracy of parental perceptions could enable children (almost 1 in 5) who are unnecessarily restricted in their level of exertion to achieve a higher level of physical activity. Since the medical charts did not mention exertion restrictions, other health professionals involved in the child’s care may heighten parental uncertainty by providing information that contradicts the restriction specified by the cardiologist.

Competition Restrictions

Competition restrictions were the type of activity restriction most likely to be accurately reflected in the medical chart. The more frequent documentation of competition restrictions probably reflects the published guidelines for physical activity participation for children with congenital heart disease that frequently focus on restrictions related to competitive sport [78].
That only 7% of parents (2/28) were able to report the competition restriction specified by the cardiologist is of significant concern. Overall, over 40% (26/62) of the parents of children who have had the Fontan procedure are unaware that their child should not be participating in some types of competitive sport. This is a high level of misunderstanding that could have significant consequences for the child. Although published reports differ, some authors suggest that functional single ventricle anatomy is a risk factor for sudden death during competitive sport [79].

Body Contact Restrictions

Restriction from participation in body contact sports occurs relatively frequently (25/62, 40%) among children who have had the Fontan operation. Body contact restrictions apply primarily to children on anti-coagulation therapy, but they can also be applied to children with pacemakers or other types of implanted treatment devices [79]. The finding that 50% (13/25) of parents are unaware of the body contact restriction specified by the cardiologist is of significant concern. These children may be at risk for significant bleeding injuries or damage to vital medical devices if they participate in body contact sports. It is also of concern that among the children whose participation in body contact sports was not restricted by the cardiologist, almost 60% (22/37) of parents reported that their child was restricted. These results suggest that there is a significant lack of clarity among parents regarding the ability of their child to participate in body contact sports. This finding may be related to the routine use of anti-coagulation therapy after the Fontan operation to prevent stroke or thrombus formation, which are among the most common post-operative complications [18]. Anti-coagulation therapy is discontinued at a later time if there has been no evidence of thrombolytic complications. Almost all children would have been under body contact restrictions when on anti-coagulation therapy immediately after surgery. Parental over-reporting of body contact restrictions may reflect a lack of understanding about the physical activity implications of changes to the child’s anti-coagulation therapy.

Other Restrictions

Additional activity restrictions reported by parents or cardiologists included no isometric activities, restriction of activity to “comfortable limits” or “as tolerated”, restriction of upside down activities, requiring parental supervision of activity and restriction from activities that
might result in a blow to the chest. In most cases, parent reports of these restrictions were more frequent than indicated by the cardiologist, although the differences were not significantly different from what would be expected by chance. Based on cardiologist reports, these additional restrictions applied to 10% or less of the study participants. Parent reports of restrictions related to blows to the chest and a requirement for parental supervision of all physical activity were particularly interesting given that these restrictions were not reflected in the cardiologist or medical reports for any children. Like the unnecessary restrictions of body contact discussed previously, the restriction of activities that might result in a blow to the chest likely reflects the continuation of a previous activity restriction that is no longer required. All children are restricted from blows to the chest at the time of post-surgical discharge for a period of 6 to 8 weeks in order to allow the sternum to heal. However, beyond that initial period the restriction from blows to the chest is unnecessary, and in fact surgeons report that the repaired sternum will be as strong as or stronger than it was prior to surgery (Dr. W.G. Williams, personal communication). These results suggest that the reason for restricting blows to the chest and the temporary nature of the restriction are not clearly conveyed to many parents. That two parents believed that their child should not participate in physical activity unless the parents’ themselves were present suggests that a very small proportion of parents (3%) have very significant concerns about their child’s ability to be physically active. Given the relationship between parent perceptions and the child’s activity participation previously discussed, these results suggest that, for a small proportion of children, the risk of a sedentary lifestyle is very high.

5.2.5 Conclusion

Reports of physical activity restrictions for children who have had the Fontan procedure vary, depending on the source. Activity restrictions reported by the cardiologist are not reflected in the medical chart, and therefore are not available to other health professionals caring for the child. In addition, parental reports of activity restriction often do not reflect the cardiologists’ reports, providing support for parental feelings of uncertainty about appropriate activities for their child. These results suggest that increased attention to accurately conveying the required activity restrictions to parents and other health professionals could lower the parental uncertainty that is associated with a more sedentary lifestyle for the child. Particular attention needs to be paid to
providing parents with clear explanations of what activities are not restricted and how physical activity recommendations will change with the child’s medical status or treatment.

5.3 Vague In, Vague Out: How Published Activity Guidelines Make it Difficult for Cardiologists to be Specific

5.3.1 Introduction

When asked, parents of children who have had the Fontan operation can report the activity recommendations and restrictions provided by their child’s cardiologist. Despite their ability to re-state the recommendations, parents of children who have had the Fontan procedure indicate that they are often unsure or anxious about whether or not their child’s participation in a specific activity is appropriate (4.5.4). They explain their uncertainty by providing examples of how it is difficult to interpret the recommendations made by the cardiologist when making decisions about their child’s activity participation on a day-to-day basis. Parents indicate that they are uncertain about how general recommendations should be translated into daily decisions about their child’s play with friends or participation in school or recreational activities. The following examples are anecdotal evidence, gathered from discussions with the parents of children participating in this research, of the issues of uncertainty that typically occur:

- Parents are told that their children cannot play “competitive sports”, they understand that means the child cannot join a local team (e.g., soccer, hockey) but parents are unclear whether lunch-time or after-school “leagues” at their child’s school, or even “competitions” between classes or teams within the same gym class must also be avoided. Parents also indicate they have been told “no competitive sports” but they are unsure why preventing the child from joining a local bowling or archery team is necessary.

- Parents report difficulty believing general statements such as “she can do whatever she wants as long as she can rest when she is tired”. Some parents believe that the child can play any activity as long as the parent is present to enforce rest times as needed (e.g., taking the child off of the field). Other parents report they do not believe such statements because it contradicts specific information provided by another health care professional or at a different
time (e.g., a cardiologist who previously looked after the child, a nurse on the in-patient ward). A small number of parents indicate that they do not allow or encourage their child to do any activity unless the parent is present. They explain their decision by stating they do not feel that the child, other children, or other supervising adults can be relied upon to ensure that the child rests appropriately.

- Parents clearly understand that “no contact sports” means no tackle football, ice hockey with body checking or kick boxing. However, they are often uncertain about whether that restriction applies to activities where unintentional contact may occur (e.g., skiing) or where contact can occur but is relatively infrequent (e.g., volleyball, cycling). Parents also wonder why boys cannot play ice hockey but they are allowed to play road hockey, which does not have the benefit of rules, referees or equipment for protection. Parents are also uncertain about whether sports such as hockey would be allowed in leagues (e.g., girl’s hockey) where the body contact element is prohibited.

The above examples make it clear that parents often find it difficult to implement advice they feel is vague in relation to the wide range of activity opportunities available to their child. The goal of this research was to examine how the published literature about physical activity for children who have the Fontan procedure may contribute to the advice provided by cardiologists. In order to address this issue, a content analysis of the scientific literature related to guidelines for exercise, sport and physical activity participation for children who have had the Fontan operation was completed. The goal of the content analysis was to determine what knowledge and recommendations the scientific literature provides to health professionals.

### 5.3.2 Methods

A classical content analysis [80] was completed to evaluate the “data” or “facts” that are readily available in the published literature to guide the physical activity recommendations that cardiologists make for their patients. “Content analysis is a research methodology that utilizes a set of procedures to make valid inferences from text” [Weber, 1985, p. 9]. Classical content analysis of written text recognizes that what people know about a situation or event can be conveyed through both oral (e.g., interview) and written records. Written documents are created for many purposes, such as recording information, establishing norms and rules or to set out a
specific argument in relation to a controversial issue [80]. In this way, written texts reflect the
authors’ thoughts, feelings, beliefs, and arguments. As such, analyzing the content of written text
can offer insights into the authors’ understandings of an issue in the same way that the authors’
thoughts could be obtained via interview or questionnaire. In fact, it has been suggested that
written texts can often be more revealing of the authors’ perspectives than even the authors
themselves realize [80].

Purpose of the Study

The purpose of this content analysis was to systematically summarize, using explicit and
replicable procedures, the scientific literature addressing physical activity guidelines or
recommendations for children who have had the Fontan procedure. The goal was to examine the
scope, content, clarity and consensus of recommendations published in the past 17 years. The
resulting summary of the information was used to enhance our understanding of the texts
themselves, the authors, and the intended audience. The content analysis was designed as a
cross-sectional study that compared texts from different sources that were created in a similar
time frame. The time frame was chosen to represent the “current era” of the Fontan procedure
when childhood mortality and morbidity have been significantly reduced [81].

Literature Search Strategy

The scientific literature relevant to this content analysis was comprised of two types of
documents. The most commonly recognized document type is the one that presents empirical
findings, such as a report of research results. However, the scientific literature also contains
many documents that express opinions. Examples of opinion documents are review papers,
position statements, consensus documents and practice guidelines that are created to summarize
or convey the authors’ expert interpretation of the current state of knowledge.

Both types of texts were included in this analysis, as long as they contained guidelines or
recommendations about the physical activity participation of children who have the Fontan
procedure. The texts were analyzed in two ways. Initially, the focus of the analysis was on the
texts as the outcome to be explained (i.e., as the dependent variable). The goal of this focus was
to learn more about the “source” of the texts, such as the knowledge, beliefs and understandings
of the authors and organizations that produced the publications. The second analysis focused on the intended audience for the texts. From this second perspective, the texts themselves are an independent variable that influences, and can be used to explain the attitudes and beliefs of the “intended audience”. In this case, the intended audience is the cardiac clinic health professionals who treat children who have had the Fontan procedure.

The scientific literature included in these analyses were identified through searches of medical databases (PubMed, MedLine, CINAHL, Web of Science, EMBase) using the terms “Fontan”, “child” and either “exercise” or “physical activity”. The term “Fontan” could be anywhere within the article, not just in the title or abstract, in order to identify publications that would specifically apply to the children that were the focus of this research. Publications from 1992 to 2008, published in or translated into the English language, were included in the search. References within and citations to the identified publications were used to expand the list of relevant publications. The searches identified over 300 articles. Following references and citations for the original search results identified an additional 20 potentially relevant publications. From a review of these, 8 position statements, 1 consensus conference report, 1 report of original research, and 13 articles containing author recommendations for physical activity for children who have the Fontan procedure were identified. The vast majority of the identified articles contained empirical research documenting the children’s lower exercise capacity or the beneficial effects of exercise rehabilitation for this population. However, these bodies of literature were not included in the content analysis unless recommendations or guidelines for physical activity participation were provided.

Data Analysis Procedures

The content analysis was completed by initially conducting a qualitative analysis of the selected texts that served as the data for this research. Careful thought and consideration of multiple viewpoints guided these analyses. Content analyses avoid the issue of reactivity during primary data collection because the information in published articles could not be influenced by the questions that the researcher poses to the data. However, the analysis was nevertheless a constructed process of interpretation that incorporated my own beliefs, knowledge and expectations in the selection of data and units of analysis, creation of the coding frame and the application of codes to the raw data. The coding frame used for this analysis is provided in
Appendix F. It was derived from the exercise and physical activity science literature, as well as clinical physical activity guidelines for children who have had the Fontan procedure. The coding frame was structured so that each unit of analysis would fit a single value within a code and each code was independent of all others.

**Study Sampling Strategy**

All identified, peer-reviewed articles that made recommendations about participation in sport, physical activity or recreation for children who have had the Fontan operation were included in the content analysis. A census sample design was made possible by the small number of relevant publications identified through the database searches. Titles and sample relevant text from the articles included in the content analysis are provided in Appendix G. During this analysis there was no attempt to make inferences based on a single reading of a text. Rather, the interpretations offered are based on data compiled across multiple texts. Ultimately, the analyses were summarized using both quantitative and qualitative measures.

**Reliability of the Coding Procedure**

The accuracy of the coding structure was established by conducting the coding procedure twice, after an interval of 6 months. The agreement between the codes I assigned in November 2008 and those assigned in May 2009 was calculated for each theoretical concept using a Kappa statistic. The coding definitions for variables that did not have a significant kappa statistic (i.e., did not agree more often than would occur by chance) were then revisited along with the codes assigned in order to clarify differences in interpretation of the codes from the first coding to the second. By expanding the coding definitions and explanations, I was able to finalize a single code to be assigned for each variable and each article reviewed. The initial coding structure and the revisions completed in May 2009 are shown in Appendix F.

The reliability of the coding framework was established by having two research staff from the Cardiovascular Clinical Research Unit at The Hospital for Sick Children (F. Wong, S. Wellman) independently repeat the data coding process [72]. Members of the research staff involved in the reliability evaluation were familiar with content analyses, although not with this specific project. I reviewed the coding framework with them and provided a list of the publications to be
reviewed. From that point, they independently assigned codes to all of the identified publications using the revised (May 2009) definitions.

Validity of the Coding Procedure

Sampling validity, the relationship between the samples of text analyzed to the entire body of text, was established by the design of the analysis. That is, all relevant documents and all text within each document were analyzed and coded so that the sample represented 100% of the relevant documents rather than a selected subset. The semantic validity of the coding frame, that is the relationship between the codes and the words used in the analyzed texts, was established through a constant comparison methodology. The text being analyzed and the coding frame were always adjacent to each other and within the same viewing area during the analysis. I referred back and forth from the text to the coding frame and vice versa throughout the coding process in order to ensure that the codes accurately represented the text provided by the document authors. Construct validity, the relationship between the coding frame and relevant theory, was established by comparing the terminology used in the coding structure to the terminology used in the texts and in general publications and texts about exercise science and paediatric cardiology. The identification of aerobic/dynamic and muscular strength/static types of physical activity is consistent with the exercise science literature, and the same categorization was used in the majority of reviewed publications (17/23 or 74% aerobic/dynamic, 14/23 or 61% muscular/static). The balance of the coding framework was based on terminology commonly used in paediatric cardiology, both in general care (e.g., implants, hypertension, anti-coagulation) and specific to physical activity participation (e.g., competitive sport, recreation, participation screening).

5.3.3 Results

Intra-Rater Coding Reliability

Agreement between the initial (November 2008) and final (May 2009) codes was significantly better than chance for 15 of the 20 codes (Kappa statistics ranging from 0.23 to 1.00). Whether the guidelines covered individuals with hypertension, implants or on anti-coagulation therapy, whether participants could easily stop their activity as needed, recommendations regarding the
need for screening prior to physical activity participation and the type of authorship had the highest level of agreement (Kappa > 0.60), as shown in Table 13. The five codes that agreed only by chance were permitted amount of body contact, ventricular function, rhetoric for aerobic and muscular recommendations, and argumentation. Differences between the initial and final coding were reconciled by a detailed review of each discrepant code. The final reconciled codes by article for each theoretical concept are provided in Appendix H.

Five of the coding discrepancies for amount of body contact reflected coding pairs that seemed mutually exclusive. Each of these articles was coded as allowing all types of body contact on one occasion, while the other code indicated that body contact was prohibited or the article did not mention body contact. In reviewing these articles it was found that they all discussed the need for body contact restrictions, but the restriction was in relation to a cardiac condition other than the Fontan procedure. Most commonly the articles mentioned the need for body contact restrictions for people with implants, those with Marfan syndrome or those on anticoagulation medication. My initial coding had been inconsistent in relation to these articles probably based on my interpretation of whether the author would feel that the specified restriction would likely apply to a child with the Fontan procedure. By changing the description for a body contact coding value of “1” to “All types and forces of body contact allowed unless additional factors (e.g., implant) other than Fontan circuit” I was able to reconcile these discrepancies so that all five articles were coded consistently. This recoding increased the Kappa to 0.56 (p=.001).

The coding for ventricular function was considered acceptable despite the lack of agreement that was statistically beyond chance because 20 of the 23 articles were given the same code. The kappa statistic was not significant because only three of the articles made mention of ventricular function. The high proportion of articles that did not address the issue of ventricular function gave the three coding errors substantial weight in the statistical analysis. A more detailed review of the three discrepant cases indicated that activity recommendations related to ventricular function were mentioned, but the recommendations were not specific to the use of medications to enhance ventricular function. By changing the code to “guidelines related to ventricular function”, rather than the original code that was specific to ventricular function medication, the coding discrepancies were resolved.
Table 13: Agreement Between Initial and Final Content Coding

<table>
<thead>
<tr>
<th>Code</th>
<th>Kappa</th>
<th>P</th>
<th>Proportion (%)&lt;sup&gt;1&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level of aerobic/dynamic exertion</td>
<td>0.46</td>
<td>.001</td>
<td>14/23 (61%)</td>
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<tr>
<td>Level of muscular/static exertion</td>
<td>0.41</td>
<td>.001</td>
<td>13/23 (57%)</td>
</tr>
<tr>
<td>Level of competition</td>
<td>0.35</td>
<td>.02</td>
<td>13/23 (57%)</td>
</tr>
<tr>
<td>Voluntary participation</td>
<td>0.79</td>
<td>.001</td>
<td>21/23 (91%)</td>
</tr>
<tr>
<td><strong>Amount of body contact</strong></td>
<td><strong>0.01</strong></td>
<td><strong>.93</strong></td>
<td><strong>16/23 (70%)</strong></td>
</tr>
<tr>
<td>Guidelines for implants</td>
<td>0.65</td>
<td>.001</td>
<td>16/23 (70%)</td>
</tr>
<tr>
<td>Guidelines for anti-coagulation</td>
<td>0.68</td>
<td>.001</td>
<td>21/23 (91%)</td>
</tr>
<tr>
<td>Guidelines for hypertension</td>
<td>1.00</td>
<td>.000</td>
<td>23/23 (100%)</td>
</tr>
<tr>
<td><strong>Guidelines for ventricular function</strong></td>
<td><strong>0.00</strong></td>
<td><strong>.</strong></td>
<td><strong>20/23 (87%)</strong></td>
</tr>
<tr>
<td>Authorship</td>
<td>0.63</td>
<td>.001</td>
<td>18/23 (78%)</td>
</tr>
<tr>
<td><strong>Rhetoric for aerobic recommend</strong></td>
<td><strong>0.21</strong></td>
<td><strong>.31</strong></td>
<td><strong>15/23 (65%)</strong></td>
</tr>
<tr>
<td><strong>Rhetoric for muscular recommend</strong></td>
<td><strong>0.08</strong></td>
<td><strong>.68</strong></td>
<td><strong>15/23 (65%)</strong></td>
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<tr>
<td><strong>Argumentation</strong></td>
<td><strong>0.09</strong></td>
<td><strong>.65</strong></td>
<td><strong>10/23 (43%)</strong></td>
</tr>
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<td>Breadth of guideline application</td>
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<td>.001</td>
<td>17/23 (74%)</td>
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<td>Guideline activity scope</td>
<td>0.34</td>
<td>.004</td>
<td>15/23 (65%)</td>
</tr>
<tr>
<td>Adult application</td>
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<td>.02</td>
<td>13/23 (57%)</td>
</tr>
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<td>Child application</td>
<td>0.37</td>
<td>.001</td>
<td>20/23 (87%)</td>
</tr>
<tr>
<td>Physician/cardiologist counselling</td>
<td>0.23</td>
<td>.04</td>
<td>11/23 (48%)</td>
</tr>
<tr>
<td>Teach self monitoring</td>
<td>0.35</td>
<td>.03</td>
<td>20/23 (87%)</td>
</tr>
<tr>
<td>Comprehensive screening</td>
<td>0.65</td>
<td>.001</td>
<td>19/23 (83%)</td>
</tr>
</tbody>
</table>

<sup>1</sup> Proportion of references given the same initial code
All but one of the coding discrepancies for the rhetoric provided in support of the aerobic/dynamic or muscular/static exertion recommendations were related to differences in interpretation between a statement of claim and the provision of backing or support for the claim. The eight articles that were discrepant were reviewed again in detail in order to make a final determination as to whether the authors’ claims were backed up by evidence. In each discrepant case there was found to be evidence of backing for the stated claim. The coding discrepancy reflected differences in my interpretation of how claims (“1”), backing (“2”) and data (“3”) were distinguished. The coding definitions were clarified to make clear that a claim code (“1”) was only assigned when the authors made no reference to data or other publications. The backing (“2”) code was used when the article being reviewed referenced other publications but did not provide the specific data from those publications within the article under review. The data (“3”) code was reserved for articles that provided data (either from the author or a cited publication) within the text of the article being reviewed.

The substantial discrepancy in coding of the level of argumentation provided in each article was the most difficult to resolve. The results indicated that the code of pathos (“2”), an argument based on stirring the emotions of the audience, although theoretically possible was never actually used in any of the articles reviewed. Thus, all of the codes represented my interpretation of the difference between logos (drawing conclusions based on premises and observations) and ethos (claims based on the authors’ authority or claim to fame). Initially, 13 of the 22 codes were concordant. Most of the discordant codes (9/13) were instances were I had initially indicated that the argument was based on logic (“1”) but during the second coding I had determined that the argument was based on a display of the authors’ own authority (“3”). After reviewing each discordant article a third time, 5 of these articles continued with their original coding (2 logos, 3 ethos) and the remaining 8 articles were assigned the second code (1 logos, 7 ethos). Changes to the coding for argumentation were primarily due to more detailed consideration of the cited references. Initially, if references to other published documents were provided to substantiate the recommendation then the logos (“1”) code was applied. However, an inspection of the referenced articles indicated that in many cases the reference did not substantiate the logic coding. Frequently, the reference was to a previous publication by the same author. Alternatively, the referred source was also a statement based on the authors’ own authority. For these reasons, the coding for these articles was changed to ethos (“3”).
Inter-Rater Reliability of Coding

The comparison of my final codes (May 2009) with the codes assigned by the research coordinator was completed through the calculation of kappa statistics for each of the 20 identified codes. Agreement between the two sets of codes (Table 14) was significantly better than chance for 19 of the 20 coding categories (Kappa statistics ranging from 0.29 to 0.91). Type of authorship, level of aerobic/dynamic exertion, voluntary participation, guidelines for implants and hypertension, argumentation, adult application, and whether comprehensive screening was recommended had the highest level of agreement (Kappa > 0.60).

The one code that had agreement only at the level of chance was rhetoric for aerobic activity recommendations. A review of the coding discrepancies for this item indicated that the research coordinator (F. Wong) was much more likely to identify the article as containing or referencing data in support of the stated recommendations. A more detailed review of the articles, and discussions with the project coordinator, indicated that she had coded articles that referenced other publications as based on data, without considering the content of the referenced publication. As a result, several statements were incorrectly coded as being supported by data when in fact the referenced publication was a consensus statement or opinion article. For example, the recommendations by Koster [82] was coded as being supported by data within the article, but the table of recommendations provided was reprinted from a recommendation by a committee of the Council on Cardiovascular Disease in the Young rather than on empirical data supporting the recommendation. Revising the coding for these articles increased the kappa statistic for the rhetoric for aerobic activity to 0.42 and the agreement was statistically higher than would be expected by chance (p=.03).
Table 14: Inter-Rater Reliability of Content Coding

<table>
<thead>
<tr>
<th>Code</th>
<th>Kappa</th>
<th>P</th>
<th>Proportion (%)^1</th>
</tr>
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<tbody>
<tr>
<td>Level of aerobic/dynamic exertion</td>
<td>0.69</td>
<td>.001</td>
<td>18/23 (78%)</td>
</tr>
<tr>
<td>Level of muscular/static exertion</td>
<td>0.48</td>
<td>.001</td>
<td>14/23 (61%)</td>
</tr>
<tr>
<td>Level of competition</td>
<td>0.56</td>
<td>.001</td>
<td>16/23 (70%)</td>
</tr>
<tr>
<td>Voluntary participation</td>
<td>0.68</td>
<td>.001</td>
<td>20/23 (87%)</td>
</tr>
<tr>
<td>Amount of body contact</td>
<td>0.31</td>
<td>.02</td>
<td>17/23 (74%)</td>
</tr>
<tr>
<td>Guidelines for implants</td>
<td>0.71</td>
<td>.001</td>
<td>20/23 (87%)</td>
</tr>
<tr>
<td>Guidelines for anti-coagulation</td>
<td>0.47</td>
<td>.01</td>
<td>21/23 (91%)</td>
</tr>
<tr>
<td>Guidelines for hypertension</td>
<td>0.65</td>
<td>.001</td>
<td>22/23 (96%)</td>
</tr>
<tr>
<td>Guidelines for ventricular function</td>
<td>0.48</td>
<td>.001</td>
<td>21/23 (91%)</td>
</tr>
<tr>
<td>Authorship</td>
<td>0.92</td>
<td>.001</td>
<td>22/23 (96%)</td>
</tr>
<tr>
<td><strong>Rhetoric for aerobic recommend</strong></td>
<td><strong>0.19</strong></td>
<td><strong>.16</strong></td>
<td><strong>13/23 (57%)</strong></td>
</tr>
<tr>
<td>Rhetoric for muscular recommend</td>
<td>0.35</td>
<td>.01</td>
<td>15/23 (65%)</td>
</tr>
<tr>
<td>Argumentation</td>
<td>0.70</td>
<td>.001</td>
<td>19/22 (86%)</td>
</tr>
<tr>
<td>Breadth of guideline application</td>
<td>0.37</td>
<td>.007</td>
<td>14/23 (61%)</td>
</tr>
<tr>
<td>Guideline activity scope</td>
<td>0.57</td>
<td>.001</td>
<td>16/23 (70%)</td>
</tr>
<tr>
<td>Adult application</td>
<td>0.74</td>
<td>.001</td>
<td>19/23 (86%)</td>
</tr>
<tr>
<td>Child application</td>
<td>0.45</td>
<td>.005</td>
<td>18/23 (78%)</td>
</tr>
<tr>
<td>Physician/cardiologist counselling</td>
<td>0.36</td>
<td>.001</td>
<td>12/23 (52%)</td>
</tr>
<tr>
<td>Teach self monitoring</td>
<td>0.33</td>
<td>.005</td>
<td>20/23 (87%)</td>
</tr>
<tr>
<td>Comprehensive screening</td>
<td>0.73</td>
<td>.001</td>
<td>20/23 (87%)</td>
</tr>
</tbody>
</table>

^1 Proportion of references given the same code
Type of Physical Activity

Two broad categories of physical activity are identified within the body of knowledge related to exercise science. Dynamic activities are those that result in movement of the body or limb segment when energy is exerted. Most commonly these types of activity involve the larger muscles of the body and the activity continues over a period of time (e.g., one minute or longer). As a result, dynamic activities usually rely on the aerobic metabolic system, where oxygen is used to release energy from ATP, to provide the energy required for the activity [47]. Jogging, swimming, bicycling and cross-country skiing are examples of dynamic activities that rely primarily on aerobic metabolism. The second broad category is static physical activities where energy is expended but the body or body segments do not move (or move very little). Static activities are typically of very short duration, and as a result they usually rely most heavily on anaerobic (without oxygen) metabolism to supply the required energy [47]). Wrestling, power lifting, tackle football and gymnastics are examples of activities that typically have a higher proportion of static activities.

Most of the published guidelines provide recommendations for the intensity of aerobic/dynamic and muscular/static activities (Figure 14). The majority of recommendations (14/17) indicate that the intensity of aerobic or dynamic activities should be light to moderate. Two publications [28, 83] indicate that vigorous aerobic activities are acceptable for children with congenital heart defects. However, it is unclear whether these recommendations would apply to children who have had the Fontan operation. While the Fontan operation is included in the congenital heart defects described by Reybrouck & Mertens [28], it is not included in the table of recommendations provided for specific diagnoses. Colonna et al [83] included children who had a Fontan procedure in their study, but the physical activity guidelines are specified by New York Heart Association status (I to IV) rather than by diagnosis. Presumably a child who had the Fontan operation could fit into categories II, III or IV depending on the percentage of normal function available. However, the criteria listed by Colonna et al specify a particular degree of function for both right and left ventricles.
There is much less consensus among the recommendations relating to muscular strength or static activities. Of the 14 guidelines that make mention of these types of activity, 1 indicates that all types of static activities are allowed, 4 indicate that light or moderate intensity static activities are recommended and 6 recommend only light static activities. Three publications indicate that static activities are prohibited and 9 (39%) make no mention of guidelines for muscular/static activities.

Psychological Influences

Psychological influences are factors, such as competitive drive or peer pressure, which may encourage individuals to push themselves to extreme levels of exertion. For children with congenital heart defects, the prospect of psychological influences pushing the child to continue vigorous exercise despite symptoms (e.g., chest pain, or feelings of nausea, dizziness or palpitations) is a frequently discussed issue. However, published guidelines more often refer to limits on participation in competitive sport (Figure 15) than specifically limiting the child to activities where participation can be voluntarily terminated at any time. Sixteen (70%) reviewed publications specified whether restriction from competitive sport was required. Those
publications were equally split between requiring and not requiring restrictions from competitive sport.

**Figure 15: Publication Coding for Level of Competition Permitted**

![Code 3 - Level of Competition](image)

1 = All types of sports, including competitive sports, allowed  
2 = All recreational sports, but not competitive sports, allowed  
3 = Unorganized physical activity allowed but no organized sports (competitive or recreational) allowed  
4 = Level of competition is not mentioned

In contrast to competitive sport recommendations, only 7 articles (30%) specified a participation restriction in terms of activities that allow the participant to voluntarily terminate their participation, temporarily or permanently, as needed or desired (Figure 16). Where a competitive sport restriction is specified, it is explained in terms of the potential for the child being pushed by psychological factors to extreme levels of exertion, where potential harm could occur. Nevertheless, it is the broader “no competitive sport” restriction that is commonly recorded in letters from the cardiologist to the family physician [73]. That “competitive sport” is identified, rather than the specific ability to stop and rest or withdraw as needed, creates opportunity for the intended restrictions to be misinterpreted. It would be helpful if all published guidelines were specific to the issue of voluntary participation so that it is clear that competitive sports that allow participants to rest as required or require little to no physical effort (e.g., archery, bowling) remain unrestricted.
Figure 16: Coding for Being Able to Voluntarily Terminate Participation

<table>
<thead>
<tr>
<th>Code Value</th>
<th>Number of Publications</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>3</td>
<td>16</td>
</tr>
</tbody>
</table>

1 = All types of activity are allowed  
2 = Participation if participant can voluntarily stop (temporarily or permanently) at any time but not where rules or social pressure may lead to continued participation beyond participant level of comfort  
3 = Level of voluntary participation is not mentioned

Potential for Injury and Influence of Treatment

Theoretically, many of the treatments used for children with congenital heart defects may increase their risk of injury during physical activity participation. Impacts that occur during contact sports could result in bleeding injuries to children taking anti-coagulation medication or damage to implanted wires, pacemakers and defibrillators. In spite of the theoretical risks, only a small minority of guidelines (3/23 or 13%) mention whether children should participate in sports where body contact is likely to occur (Figure 17). A small, but slightly larger percentage (6/23 or 26%) states that activity recommendations should be different for children with implanted pacemakers or defibrillators. The remaining guidelines included in this review were silent on this issue.

The published documents included in this review were surprisingly silent about the potential impact of commonly prescribed medications on the physical activity guidelines provided. Only three publications [84-86] (13%) indicated specific guidelines that apply to children taking anti-
coagulation medication. Two publications [79, 87] were the only ones to mention that the guidelines provided would not apply to children taking medications to support ventricular function. Pelliccia et al [85] were the only authors who provided guidelines for children taking ventricular function or anti-hypertensive medication. The dearth of information regarding the potential for anti-hypertensive medications to cause post-exertional hypotension among these paediatric guidelines is surprising, given that the concern is well documented in the adult cardiac rehabilitation literature [88].

**Figure 17: Coding for Restrictions of Body Contact or Implanted Devices**

1 = All types and forces of body contact OK  
2 = Only light or moderate, unintentional  
3 = Only light unintentional body contact  
4 = Physical contact is not allowed  
5 = Amount of body contact not mentioned

**Level of Authority or Recognition**

It must be recognized that the impact of published guidelines or recommendations will vary, depending on the source (i.e., author). Of the 23 publications providing recommendations for the physical activity participation of children who have the Fontan procedure, the majority (13/23 or 57%) are review or opinion articles published by a small group of authors. The remaining articles were primarily position statements from a recognized organization or the results of a consensus conference (9/23 or 39%), with one being a report of original research [89].

Surprisingly, most of the guideline articles (16/23 or 70%) stated the recommendations for aerobic/dynamic or muscular/static activity participation without providing any evidence or supporting documentation (Figure 18). One article qualified the muscular/static recommendations provided [56], and the remaining publications provided evidence in support of
their recommendations. The type of argumentation presented in the publications was primarily ethos (14/23 or 61%), or conclusions supported by a display of the authors’ own authority. The remaining publications (9/23 or 39%) relied on logos, which is a logical deduction to the conclusion from premises or observations. None of the publications attempted to stir the emotions of the reader in support of the authors’ claims (pathos).

**Figure 18: Type of Authorship**

<table>
<thead>
<tr>
<th>Code Value</th>
<th>Number of Publications</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>8</td>
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<tr>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>4</td>
<td>8</td>
</tr>
</tbody>
</table>

1 = Position statement of recognized national or international organization  
2 = Report of consensus conference or expert panel  
3 = Research study by a small group of authors  
4 = Review or opinion of a small group of authors

**Intended Application**

The publications reviewed for this analysis varied widely in terms of the population to whom the guidelines should be applied (Figure 19). In order to be included in this review, published documents had to contain information relevant to the physical activity participation of children who have the Fontan procedure. The majority of these publications (15/23 or 65%) provided physical activity guidelines for children with congenital heart defects in general, and indicated that children who had the Fontan procedure were included within that population. The remaining publications were equally divided between those that provided recommendations specifically for
children who had the Fontan procedure and those that did not specify that children who had the Fontan procedure should be included.

**Figure 19: Breadth of Guideline Application**

The guidelines provided in these publications addressed a wide variety of physical activity settings (Figure 20). A majority of the publications (13/23 or 57%) indicated that the guidelines applied to all physical activity settings, including both recreational and competitive activities. Five publications (22%) applied only to recreational activities or therapeutic exercise training programmes, while three (13%) addressed only competitive sport participation. The setting to which the guidelines apply was moderately correlated (r=-0.54 and r=-0.55 for aerobic/dynamic and muscular/static activities, respectively) with the intensity of activity allowed. Guidelines that applied only to highly competitive sport settings provided recommendations for a lower intensity of activity. Guidelines specific to recreational activities tended to allow a higher level of activity intensity.

1 = Guidelines specific to patients who have had the Fontan procedure
2 = Guidelines for patients with congenital heart defects, including those who have had the Fontan procedure
3 = Guidelines for patients with congenital heart defects, excluding those who have had the Fontan procedure
4 = Level of guideline application was not mentioned
Figure 20: Type of Activity Setting for Guideline Application

The application of the guidelines to individuals at different ages also varied between the publications. Almost all of the publications (19/23 or 83%) indicated that the guidelines applied to children or youth. One publication [90] specifically indicated that it did not apply to children or youth who had a Fontan procedure, and three publications (13%) did not indicate whether or not the guidelines applied to children or youth. The articles reviewed varied significantly in terms of whether the published recommendations should apply to adults who have had a Fontan procedure. Ten articles (43%) indicated that the guidelines would apply to adults, 5 (22%) indicated that the recommendations did not apply to adults, and 8 articles (35%) were silent on the applicability for adults.

Role of the Cardiologist

The reviewed publications were relatively consistent in terms of the responsibilities that were ascribed to the cardiologist in relation to the physical activity participation of children with congenital heart disease. A large majority of the publications (17/23 or 74%) indicated that pre-participation screening (via history, ECG, echo, etc.) should be completed for any type of
physical activity and one additional publication [78] recommended that screening was required only for competitive sport participation. Only 4 publications [28, 90-92] recommended that the child should be taught a technique for self-monitoring their participation in physical activity. Most commonly the technique recommended was the “talk test” (exercising only at a level where it is possible to comfortably talk while participating [21]).

The articles reviewed had diverse views regarding counselling about physical activity. Half of the publications (11/23 or 48%) indicated that the cardiologist should counsel about the child’s activity options, and one additional article [93] indicated that only the activity restrictions should be explained. The remaining 11 publications either made no mention of the cardiologist’s role in activity counselling (8/23 or 35%), or counselling about activity was not included among the cardiologist’s responsibilities that were described (3/23 or 13%).

5.3.4 Discussion

Vague and Inconsistent Guidelines

The physical activity guidelines and recommendations currently available to cardiologists regarding children who have had the Fontan procedure are typically vague and often contradictory. While a substantial portion of the reviewed documents specify that the child can do light or moderate intensity aerobic/dynamic (14/23 or 61%) and muscular/static (10/23 or 43%) activities, the recommended practices in relation to other facets of the physical activity setting are highly variable or largely absent. For example, there was a 50/50 split regarding whether a child could participate in competitive sport or only recreational activities after the Fontan procedure. Guidelines that specified only recreational activities tended to permit a higher intensity of activity than guidelines that allowed participation in competitive sport.

To further illustrate the ambiguity within and between the existing publications, consider the recommendations contained in the 10 publications that indicate children who have the Fontan procedure can participate in aerobic/dynamic activity of either light or moderate intensity. Six of these publications also make recommendations about competitive sport participation, with 3 recommending no competitive sport participation and 3 indicating that all types of sport including competitive sport are permitted. Only 2 of these publications indicate that body contact
activities are not permitted [90, 94] and 3 indicate that guidelines will differ if the child [94, 95] or adult [90] has an implant. The remaining publications make no mention of body contact restrictions or the physical activity implications of having an implant. One of these publications provides guidelines only for competitive sport, another only for exercise rehabilitation, and a third does not mention the scope of application. The remaining publications are divided between those that apply only to recreational activities (3/10) and those that apply to both recreational and competitive sports (4/10). Clearly, the variation in the recommendations and how they are to be applied is substantial even though all of these publications specify the same limitation for moderate or light aerobic/dynamic activity. As these examples clearly illustrate, there is a substantial need to clarify and reconcile existing guidelines to create a reputable source for information that is clear, unambiguous and relevant to a variety of physical activity opportunities.

Relationship Between Guidelines and Cardiologist Advice

The vague and contradictory nature of the published guidelines for the physical activity participation of children who have the Fontan procedure might be expected to lead to inconsistencies in the recommendations made by cardiologists. In the previous section (5.2.3), the activity advice specified by the cardiologists responsible for the children in this study was described. Just over half (34/64) of the children in this study had some type of physical activity restriction specified by their cardiologist. Therefore, although only two of the reviewed publications indicated that these children could participate in all types and intensity of activity, the cardiologists indicated that 47% (30/64) of the children had no restriction of their activity whatsoever. Approximately half of the children in this study (30/64) were restricted in their competitive sport participation. That finding reflects the 50:50 split among the published guidelines regarding whether or not children who have the Fontan procedure should participate in competitive sport.

The majority of the published guidelines recommend activities of light or moderate intensity. However, only a small proportion of the children in this study (7/64 or 11%) were restricted from participating in strenuous physical activity by their cardiologist. Thus, it would appear that the cardiologists caring for children in this study typically provide advice that reflects the 2005 recommendations from Reybrouck & Mertens [28], which are written for adults with congenital
heart defects, or the 2007 guidelines from Colonna et al [83]. Both of these sets of guidelines indicate that these children are able to participate in all types of activity, including activities that are very strenuous.

The cardiologists responsible for 41% (26/64) of the children in this study indicated that they were restricted from physical activities involving body contact even though only 7 children (11%) were currently taking antithrombotic medication or had a pacemaker (n=4). The high proportion of children restricted from body contact suggests that the recommendations specified by the European Society of Cardiology [90] and Maron et al, 2004 [94] are given significant weight by the cardiologists in this study. These two publications were the only ones identified that indicated that body contact should be restricted for children with complex heart defects, regardless of whether or not the child was taking antithrombotic medication or had an implanted medical device (e.g., pacemaker). The high rate of body contact restrictions seen in this study occurred even though the two referenced publications do not directly apply to the population of children in this study. The former citation [90] is specific only to adults with congenital heart defects, rather than children, while the later [94] is specific to genetic heart problems that were excluded from this study population.

In contrast to the high rate of adoption of the body contact restrictions, restrictions based on level of exertion were relatively uncommon. Five publications [85, 90, 92, 94, 96] recommend that children with complex heart defects participate only in activities that allow them to stop and rest as needed, while two indicated that any intensity of activity was permitted. Despite recommendations for intensity restriction in 5/7 (71%) of the available guidelines, the cardiologists in this study only required a restriction of intensity for a small proportion (6/64 or 9%) of the children in their care.

These results suggest that the ambiguity and gaps in the published literature regarding the physical activity recommendations for children with complex heart defects is reflected in the variability of the restrictions applied by paediatric cardiologists. Most certainly, some of the variation from published guidelines undoubtedly reflects considerations that are unique to each patient and family. However, the variability also likely reflects other factors, such as attitude toward physical activity or potential liability for sport-related injury, which influence the decision-making required of each cardiologist in the absence of clear consensus guidelines.
As discussed in the previous chapter, parents report that their uncertainty about their child’s activity typically emanates from one of two factors. Either the parents report being given different advice at different times or by different cardiologists, or they indicate that they have been given advice such as “no competitive sports” that they feel is difficult to understand and interpret. Given the variability observed in the published guidelines as well as the variability of activity restrictions applied by the cardiologists caring for the children in this study (5.2.3), it is not surprising that parents report uncertainty due to conflicting advice across time or from different cardiologists. It is clear that the cardiologists caring for the children in this study differ in the physical activity advice that they provide. The expectation that there would be a higher probability of a cardiologist giving different advice across time, even with no change in the child’s medical status, seems reasonable given the current situation. The current literature provides little to no guidance on the impact of medication and requires the cardiologist to select among conflicting guidelines. Perhaps if cardiologists consistently asked families about perceived discrepancies or uncertainties, the reasons for changes or discrepancies could be addressed and families would subsequently feel more confident about following the advice provided on a daily basis.

Gaps in Current Guidelines

The lack of consistent and clear guidelines for participating in the full spectrum of physical activity opportunities creates a climate where ambiguity can flourish. There appear to be some very important gaps in relation to the current guidelines, and how they are understood by both cardiologists and families.

The majority of guidelines rely solely on the authors’ own claims, without the provision of evidence in support of the recommendation. Although there is a large body of literature regarding the exercise capacity of children with complex heart defects, there is virtually no scientific evidence as to the whether these children can safely participate in the wide variety of activities and physical activity settings readily available to young children. Additional research is needed to document the types of physical activity in which these children successfully participate, the safety and physiological and psychological impact of those activities, and the extent to which decreased exercise capacity results from a lack of training. Once the strength of the evidence is increased in these areas, it will be possible to develop physical activity
recommendations based on the exercise capacity of the child and the physiological and psychological demands of the activity.

“No competitive sports” is a guideline that appears in 50% of the publications and is applied by a similar proportion of cardiologists. However, it is also frequently cited by parents as an example of a guideline that is very ambiguous and difficult to implement. They wonder why participation on a bowling or badminton team is prohibited, when the same child is allowed to play soccer at school, is not restricted from playing street hockey with children in the neighbourhood or is allowed to do a strenuous activity like mountain biking. Parents also wonder why a child with a naturally competitive personality is restricted from team sports but not restricted from the same activity with peers. They recognize that their children’s competitive personalities make them equally likely to push beyond a safe limit whether the sport is formally or informally organized.

When an explanation for a restriction from competitive sport is provided, published guidelines indicate that the intention is to restrict situations in which the child might be pushed to ignore important symptoms or continue exercising when rest is required because of social or peer pressure. It is not the competition per se that is the problem, but rather the psychosocial pressures that are typically connected with physical activity settings that emphasize excellence. However, since parents report being unclear about why competitive sports are restricted it would appear that the rationale or explanation for the restriction is not being passed on in a way that parents can understand. The lack of explanation may be because the cardiologist is trying to simplify the advice (by “simply” restricting competitive sports) or it may reflect the ambiguity of the published literature regarding restriction from competitive sports in general. Regardless of the reason, it would seem that addressing the difference between competition and psychosocial performance pressure would enable cardiologists to more clearly specify the required restriction. A clearer explanation would better enable parents to apply the restriction on a daily basis.

Appropriate guidelines for children who have other treatment considerations are also largely absent from the current publications. Only 3 publications (13%) indicated that the guidelines provided would apply to children taking anti-coagulation medication. Only one of these publications stated that body contact activities were not permitted [90], while the others made no mention of body contact restrictions. Only 6 publications indicated whether or not the guidelines would apply to children with implanted devices (e.g., pacemaker), and just one [85] addressed
the impact of anti-hypertensive or ventricular function medications. Since many children who have the Fontan procedure require various medications or implanted devices, there is a significant gap in the current literature regarding the recommendations that would apply to children who have less than an optimal post-operative status.

5.3.5 Conclusions

Need for Guideline Consensus and Clarity

There is clearly a need to improve the physical activity guidelines currently available to cardiologists caring for children who have the Fontan procedure. Discrepancies between different recommendations, such as the European restriction from all competitive sport [90] and the North American guideline allowing participation in some types of competitive sport [95], must be reconciled. However, it is equally important that the consensus guidelines to be developed are supported by strong, research-based evidence. The current lack of evidence regarding whether children with complex heart defects can safely participate in the broad spectrum of physical activities across different settings makes it very difficult for cardiologists’ to actively advocate and promote appropriate physical activity to these children and their parents. Currently, the guidelines only enable cardiologists to indicate activity restrictions, but telling a child/family only what absolutely should not be done does not provide any information about the importance of the activities that should be done.

Recommendations for physical activity, and any required activity restrictions, must also be clearly delineated across the full range of physical activity opportunities in which children participate. Currently, there is very little evidence available to indicate that it is safe for these children to participate in recreational sport, physically active childhood games, school physical education, or active play with family and friends.

This author suggests that it would also be prudent for the guidelines to recognize that peer or self-applied pressure for a maximal effort could be significant, not only in organized leagues, but also in informal “pick up sport” settings. Similarly, recognition that teachers or coaches may demand excellence even in a casual physical activity setting is important. Theoretically, a child
may also more easily succumb to peer or self-applied pressure in a casual setting, where there is no oversight by an adult or coach.

Effective Counselling of Families

It would be helpful if the published guidelines provided more specific examples and recommendations on how the guidelines can be most effectively explained to children and their parents. Education of physicians regarding effective methods for counselling about physical activity should enhance the clarity of the advice provided to families. I would recommend that physical activity professionals be extensively involved in the development of appropriate counselling and educational materials. Physical activity professionals, such as me, have an in-depth understanding of the wide variety of physical activities that children are involved in during play. Those activities extend far beyond the competitive sports that are most commonly referenced in current guidelines. Developing guidelines that include the broad range of childhood physical activity would assist parents in applying the cardiologists’ advice when making decisions on a daily basis about their child’s physical activity participation. In addition, from a relatively young age, children can be involved in physical activity without the direct involvement of a supervising adult (e.g., neighbourhood play with friends, recess activities). Therefore, although parents will continue to be responsible for the child’s overall physical activity participation, it is essential that the children themselves understand the advice provided by the cardiologist and how it should be applied in a variety of settings. There is currently no published research that examines how information about physical activity participation can be most effectively communicated to and understood and implemented by children and youth with complex congenital heart defects. Methods of enabling the referral of children with complex heart defects and their families to the services of physical activity professionals with expertise in facilitating the adoption of physically active lifestyles are required. Training in techniques such as motivational interviewing is also recommended for professionals working in paediatric cardiac clinics, and in particular the cardiologists who parents look to for the child’s physical activity recommendations, to enhance their ability to utilize behaviour change strategies with proven effectiveness in relation to increasing physical activity behaviour.
Recommendations Needed for Children At Risk for Activity

Considerable additional research is required to clearly define the physical activity recommendations for children who require implants or on-going medication. Very few of the current publications address the issue of how implants or medications can impact the child’s physical activity participation. Among the few publications that do address some aspect of implants or medications, only one article [97] provides support for the claims made by the authors. The other 5 articles rely solely on the claims stated by the authors, without providing any supporting information.

Counselling Role of Cardiologist

Finally, the role of the cardiologist and other health professionals in encouraging children who have the Fontan procedure to lead physically active lives needs to be elaborated. The role of the cardiologist in identifying children who are potentially at risk for adverse effects from physical activity participation is relatively well delineated, particularly in publications from Italy where pre-participation screening is mandatory. However, very few publications address the counselling and education facets of the equation. Current recommendations emphasize that children should participate in activities of light or moderate intensity. In order to follow that recommendation, the child and family must clearly understand the recommendations and how to implement them. Only half of the current guideline publications address the issue of counselling about appropriate physical activity. One publication indicates that the cardiologist should clearly explain any activity restrictions to the family. The 8 other publications that mention counselling emphasize the need to encourage activity, answer questions or address concerns about activity, or explain appropriate and inappropriate activity options.

Enable Families to Determine Activity Intensity

The child and family must also have a reliable method to determine the intensity of an activity, and in particular to recognize when activity becomes too vigorous and participation should be scaled back. Expecting that restrictions of activity can be equated to specific types of activities is inappropriate. Badminton, for example, is often assumed to require a lower intensity of effort. However, it can actually become very vigorous as skill is acquired. Similarly, the intensity of
casual activities such as playing at the beach or tobogganing can vary significantly, depending on how the activities are actually performed and the child’s motivation. Therefore, children should be taught to monitor the intensity of their activity participation using readily understood cues such as breathing (i.e., being able to talk comfortably) and pulse rate. Recommended methods of self-monitoring and the involvement of exercise professionals in teaching these skills should be included in future guidelines.

A Way Forward

Based on the identified needs for greater consistency in published guidelines, specificity in advice to families and counselling to encourage activity and process to enhance published recommendations and resources is recommended. Initially, a systematic review of the evidence is required to clarify the risk of morbidity and mortality across the full spectrum of physical activity settings. Recently completed reviews focus exclusively on the exercise capacity and response to fitness training of children who have the Fontan procedure [98, 99], but do not address the safety of participation in physical activity outside of a structured exercise setting. Once additional research evidence across the broad spectrum of physical activity settings typically enjoyed by young children was available, the data could be reviewed by an expert panel in order to develop consensus recommendations regarding the physical activity participation of children who have the Fontan procedure. The required content could then be incorporated into appropriate formats for dissemination to and use by cardiologists. Finally, specific counselling strategies to effectively convey the guidelines to patients and their families should be provided.

5.4 Cardiologists Describe Their Role in Guiding Activity Participation

5.4.1 Introduction

The American College of Preventive Medicine position statement on physical activity counselling recommends that physicians incorporate physical activity counselling as a routine part of their standard of patient care [100]. The position statement emphasizes the on-going relationship and trust between a patient and the family physician, as well as patient expectations
for obtaining preventive health information from their physician as key factors supporting the call for routine physical activity counselling. Although the statement is specific to the role of family physicians in relation to the counselling of their adult patients, a similar expectation of paediatric cardiologists regarding children with complex heart defects would seem warranted. Most children with complex congenital heart defects are seen at least annually by a paediatric cardiologist, who typically cares for them until they reach adulthood. The family’s reliance on and trust of the cardiologist is emphasized by the resistance that patients and families often exhibit when attempts are made to transition the young adult to an adult cardiology practice [76]. That parents are certain that they can readily restate any comments made by the child’s cardiologist about physical activity (4.5) is evidence of the priority and attention given to the cardiologist’s comments and advice. Thus, the relationship between a family that includes a child with a complex heart defect and the child’s paediatric cardiologist would seem to offer a particularly effective environment for the provision of counselling designed to encourage the child’s physical activity participation.

Research evaluating the effectiveness of physical activity counselling by physicians has produced equivocal results. Typically, the counselling provided by physicians is very directive or prescriptive. It provides information to the family based on the physician’s interests and priorities, rather than evoking the behaviour change priorities of the family that includes a child with a complex heart defect. A systematic review of the physician activity counselling literature [101] indicates that physician counselling can effectively increase the physical activity level of the patient, at least in the short term. Adolescents also benefit from physical activity counselling from their family physician [102, 103]. However, many physicians find it difficult to provide effective physical activity counselling because of barriers, such as time or fiscal constraints, inadequate training about behavioural change counselling and the lack of simple and effective counselling tools [104, 105]. Research indicates that only 1/4 to 1/3 of physicians provide physical activity counselling to their patients on a regular basis [105]. Current research is investigating the benefits of incorporating a physical activity professional as part of the clinical care team on the effectiveness of providing physical activity counselling through primary care [104].
Cardiologists and Parents Differ on Activity Recommendations

As previously discussed (5.2), the agreement between written physical activity recommendations provided by the cardiologist and parent reports of what they have been told about their child’s physical activity participation is seldom better than what would occur by chance. Parents also report that the physical activity advice provided by the cardiologist often seems ambiguous or is difficult to implement on a day-to-day basis (4.5.4). Parent reports of ambiguity are supported by the content analysis of published guidelines for children who have the Fontan procedure, which indicate a substantial lack of consensus about appropriate physical activity opportunities for these children (5.3.4). These results suggest that the methods currently used by paediatric cardiologists to provide physical activity recommendations and counselling may be less than optimal.

In my personal discussions with health care professionals, I have found that they often assume that, where there is a discrepancy between family and professional reports, parents are uniformly over-protective of their child. That is, they restrict the child’s activity to a greater extent than the cardiologist believes is necessary because of the child’s heart condition. However, our comparison of parent and cardiologist reports of activity restrictions indicates that parents are equally likely to be unaware of required activity restrictions (5.2.3), that is they often under-restrict their child’s physical activity participation. Comments during the focus group from the one child who described herself as sedentary (4.3) suggest that the children themselves may also be a significant source of uncertainty or hesitation to participate even when the parents are supportive of physical activity. Being overly restrictive or permissive regarding the child’s physical activity participation could potentially have a negative impact on the child’s health and quality of life. Therefore, we sought to learn more about the perceptions of cardiologists regarding counselling about physical activity and the physical activity participation of their patients.
5.4.2 Methods

Study and Interview Design

There are 20 full and 2 part-time cardiologists who see patients with complex congenital heart defects in the Labatt Family Heart Centre at The Hospital for Sick Children. In order to learn more about the perceptions of cardiologists regarding the physical activity counselling of their patients, we developed a short survey that was completed with each cardiologist via an interview format. A brief, verbal questionnaire format was selected in order to encourage all cardiologists to participate. It was assumed that a longer, semi-structured interview format would limit the participation to those cardiologists who were so supportive of physical activity that they would be willing to clear a substantial amount of time in their schedule. Our strategy to maximize the number of participating cardiologists was successful in that 20 out of the 22 cardiologists completed the verbal questionnaire. Two cardiologists were not available for interviews due to sabbatical/maternity leaves.

I met individually with each cardiologist, at a time and place of convenience to them, to verbally pose the survey questions. The interview questions addressed the cardiologists’ expectations regarding who provides physical activity information to the patient, when that information is provided, what advice they generally provide to patients who have the Fontan procedure without complications, whether they would provide written as well as verbal physical activity information to their patients, and their perceptions of or explanations for the discrepancy between cardiologist and parent reports of the child’s activity restrictions (as reported in 5.2). All questions (Appendix I) used an open-ended format which asked for a rationale or explanation of the response. The cardiologists were assured that their responses would remain confidential and their agreement to participate in the interview was considered implied consent. Each interview to complete the questionnaire was completed within 10 to 30 minutes, depending on the length and detail of the responses.

Data Analysis Procedures

Responses to each question were recorded in writing by the interviewer. After all interviews were completed, the responses were coded into a computerized spreadsheet for analysis. Given
the highly structured format of the interview questions, I chose to summarize the interview results by tabulating response frequencies.

The cardiologists’ perspectives on physical activity counselling were also compared to the parent-cardiologist agreement about physical activity restrictions previously discussed (5.2.3). Cardiologists with only 1 or 2 patients in the study were excluded because a discrepancy with one family would dramatically change the rate of agreement. Therefore, we compared the cardiologist interview responses to the cardiologist-parent agreement for exertion, competition, and body contact restrictions for the 8 cardiologists who had 3 or more participating patients. Initially, cardiologist-parent agreement about activity restrictions for exertion, competition and body contact was calculated as the proportion of parents who reported the same restriction provided by the cardiologist. Interview responses from the cardiologists were then evaluated to identify interview responses that were related to high and low levels of agreement.

5.4.3 Results

Demographics of Participating Cardiologists

Five female and 15 male cardiologists completed the research interviews. One male and one female cardiologist were not available due to long-term leave. One female and one male were part-time cardiologists who also have their own practices outside of the hospital. The cardiologists graduated from medical school between 10 to 35 years prior to the interview.

Activity Counselling Practices

Counselling or monitoring of patient physical activity participation is routine for almost all (19/20) cardiologists. Twelve (63%) indicated that they routinely counsel all of their patients, while 7 indicated that counselling was routine only for specific diagnostic groups. The one cardiologist who does not do routine counselling indicated that he does counsel patients to participate in whatever activity they were interested in, but that the counselling is done as needed rather than on a routine basis.

Almost all of the cardiologists (19/20) indicated that they would be willing to provide written information about physical activity to their patients. They stressed that it was important to provide general information specific to the diagnosis, but that the written information also
needed to be flexible in order to allow for individualized requirements specific to each child. Five cardiologists emphasized that the information should focus primarily on what the child can do, rather than just providing a list of what is not appropriate. Three cardiologists felt that any written information about physical activity should be provided in the form of a personal letter to the family or child’s paediatrician, and two felt that only general, very generic advice about the importance of activity should be provided in writing.

Among the 7 cardiologists who counsel specific sub-groups of patients the content or focus of the counselling is highly varied. Some cardiologists (4/7) indicate that they routinely ask about the child’s physical activity participation and performance as part of the history done at each visit. Others (3/7) indicate that they focus their counselling primarily on children with obstructive lesions of the left side, such as coarctation of the aorta or aortic stenosis. Other diagnostic sub-groups that were identified for specific physical activity counselling included tetralogy of Fallot, children with complex defects including those who have had the Fontan operation, those with heart failure, sedentary children, those taking warfarin and children who require restriction from competitive sports. One cardiologist indicated that counselling was focused on those patients that in the cardiologist’s opinion are likely to have problems related to physical activity participation.

Counselling by Other Health Professionals

The involvement of other health professionals in providing physical activity counselling was highly variable. Nine (45%) cardiologists indicated that they do all of the physical activity counselling themselves. They indicated that although information might be provided by other health professionals they do not rely on that happening. They feel that families want to hear advice and recommendations directly from the cardiologist and that being directly involved was the best way to ensure accuracy and respond to family questions. The 11 cardiologists who indicated that other health professionals were involved all identified the role of their clinic nurse. Nurses are expected to ask about the child’s physical activity participation and/or provide activity recommendations. The involvement of fellows or family doctors in physical activity counselling was also mentioned by one and two cardiologists, respectively.
Activity Counselling by the Age and Stage of Child

A majority of the cardiologists (14/20) felt that there were specific points in the child’s care when physical activity counselling was particularly important, with the remaining 30% of cardiologists (6/20) indicating that it was equally important throughout the child’s life. At time of diagnosis (7/14), after surgeries or other procedures (6/14), and when the child is starting school (5/14) were the most commonly identified times that activity counselling was a high priority. Other times that were mentioned by 3/14 cardiologists were when the child would be changing schools, during adolescence, and when the child or parent requests information. Counselling if the child was overweight by history, had a history of arrhythmias or expressed an interest in becoming involved in organized sport were additional reasons that were each mentioned by 1 cardiologist.

Activity Restrictions for a Child After Fontan

Physical activity restrictions for a child with an uncomplicated Fontan repair varied between cardiologists (Table 15). Although the overall rate of restriction was very consistent for the different types of activity (Figure 21), the restrictions were actually selectively applied by 40% (8/20) of the cardiologists. Only one cardiologist mentioned all four restrictions and one other mentioned three of the four. Most of the cardiologists who mentioned restrictions (6/8) specified only one or two restrictions.

**Figure 21: Rate of Activity Restriction for Uncomplicated Fontan Patients**

![Activity Restrictions for Uncomplicated Fontan Patients](chart.png)
Table 15: Type of Activity Restriction by Cardiologist

<table>
<thead>
<tr>
<th>Cardiologist</th>
<th>Contact</th>
<th>Comfort</th>
<th>Competition</th>
<th>Isometric</th>
</tr>
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<td>0</td>
<td>1</td>
</tr>
<tr>
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<td>0</td>
<td>0</td>
<td>0</td>
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<td>1</td>
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<td>0</td>
</tr>
</tbody>
</table>

1 = Restriction specified

Among the 12 cardiologists (60%) who indicated at least one restriction, 42% (5/12) indicated that activity would be restricted to the child’s comfortable limits, 33% (4/12) indicated that competitive sports would be restricted and 42% (5/12) would restrict isometric exercise. Six cardiologists indicated that body contact activities would be restricted if the child also had a pacemaker or was taking anti-coagulation medication. There was no relationship between the likelihood of a restriction of physical activity and the sex of the cardiologist. All of the
cardiologists who obtained their medical degree in 1982 (5/20) or earlier identified activity restrictions that could apply to Fontan patients. Those who obtained their medical degree after 1982 (15/20) were equally likely to restrict or not restrict their uncomplicated Fontan patients.

**Explanation of Parent/Cardiologist Discrepancy of Reported Activity Restrictions**

At the end of each interview, we briefly outlined the results from our research comparing cardiologist and parent reports of the child’s physical activity restrictions (5.2). The cardiologists were not surprised to find that there was a discrepancy, but did express surprise that parents could either under or over-report restrictions. They indicated that they would have anticipated any discrepancy to be related to parental overprotection of the child. Two cardiologists did not comment on the research findings because they were certain that the results would not apply to their own patients.

Explanations for the discrepancy in reported physical activity restrictions varied tremendously. Most cardiologists (12/18) provided two or more reasons for the discrepancy. Almost all of the explanations (6/8) were related to communication about physical activity between the cardiologist and the parent and/or patient. A lack of communication was proposed as an explanation by almost 40% of the cardiologists (7/18). That is, the discrepancies occur because information about physical activity is not routinely discussed at each visit, or it is only shared at key points (e.g., after surgery) even though over time the recommendations may change.

Parent interest in and receptivity for information about physical activity were also commonly cited explanations for the discrepancy of activity restriction reports. Four cardiologists (22%) indicated that “people hear what they want to hear”. Four others indicated that they felt that parents and cardiologists see physical activity as a very low priority in comparison to medical test results. As a result, in a hectic clinic setting, information about physical activity is either not provided or not attended to. Three cardiologists (17%) suggested that the explanation for the discrepancy may be related to inaccurate sharing of information. For example, a cardiologist may say more to the family about physical activity than what is recorded in the chart. It was also suggested that what the family or patient says to the cardiologist about the child’s physical activity may not be accurate, particularly in relation to what adolescents report about their own physical activity. That people only retain 10% of what they hear was also mentioned as a
possible explanation by 3 cardiologists. Potential explanations mentioned by two cardiologists include the family receiving conflicting advice about physical activity from different doctors, parents not wanting to discuss restrictions or the implication of the heart problem with the child, and the lack of officially recognized position statements or guidelines that provide a reliable basis for recommendations.

Comparing Cardiologist Perspectives and Cardiologist/Parent Agreement

Eight of the interviewed cardiologists had 3 or more patients involved in the study that compared cardiologist and parent reports of activity restrictions (previously reported in 5.2). Cardiologist-parent agreement by type of activity restriction for these 8 cardiologists is reprinted in Table 16. Cardiologists with 3 or 4 patients were considered to have a high level of agreement (white letters on black background in Table 16) if there was agreement on all parent-cardiologist reports of a specific activity restriction. Cardiologists with 5 or more patients were considered to have a high level of agreement if all or all but one parent reported the same activity restriction as the cardiologist. Cardiologists were considered to have a low level of agreement (grey shaded boxes in Table 16) if none or only one parent reported the same activity restriction as the cardiologist.

Table 16: Cardiologist-Parent Agreement for Interviewed Cardiologists

<table>
<thead>
<tr>
<th>Cardiologist</th>
<th># of study participants</th>
<th>Any restriction</th>
<th>Exertion</th>
<th>Competition</th>
<th>Body contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>15</td>
<td>3</td>
<td>100%</td>
<td>33%</td>
<td>67%</td>
<td>67%</td>
</tr>
<tr>
<td>1</td>
<td>3</td>
<td>100%</td>
<td>100%</td>
<td>67%</td>
<td>67%</td>
</tr>
<tr>
<td>2</td>
<td>4</td>
<td>100%</td>
<td>100%</td>
<td>0%</td>
<td>100%</td>
</tr>
<tr>
<td>3</td>
<td>5</td>
<td>40%</td>
<td>40%</td>
<td>60%</td>
<td>60%</td>
</tr>
<tr>
<td>5</td>
<td>5</td>
<td>0%</td>
<td>100%</td>
<td>100%</td>
<td>60%</td>
</tr>
<tr>
<td>16</td>
<td>7</td>
<td>100%</td>
<td>100%</td>
<td>0%</td>
<td>29%</td>
</tr>
<tr>
<td>19</td>
<td>8</td>
<td>50%</td>
<td>75%</td>
<td>63%</td>
<td>63%</td>
</tr>
<tr>
<td>12</td>
<td>8</td>
<td>50%</td>
<td>75%</td>
<td>88%</td>
<td>63%</td>
</tr>
</tbody>
</table>

As previously discussed, cardiologist-parent agreement was very good for restrictions of exertion but very limited for restrictions of competition or body contact. Half of the cardiologists (4/8) achieved a high level of agreement for exertion restrictions. Only one cardiologist had a low
level of agreement in relation to exertion restrictions. There was no relationship between cardiologist sex or year of graduation from medical school and the rate of cardiologist-parent agreement about exertion restrictions.

**Attribution of Cause of Exertion Restriction Discrepancy**

Interviews with 8 cardiologists were analyzed to evaluate the perspectives of cardiologists with high and low rates of parent-cardiologist agreement (Table 16). A review of the interview responses for the cardiologists with high exertion agreement indicated that they were a diverse group. Two of them indicated that they ask every patient about physical activity at every visit while the others routinely counsel their patients who have the Fontan procedure. They were all personally involved in providing physical activity counselling, and did not rely on other health professionals, even though they recognized that nurses and fellows might also be involved. Most of the cardiologists (3/4) with a high level of exertion agreement restricted the physical activity of their Fontan patients in some way. Physical activity restriction to the child’s comfortable limits was most common (2/4), with restrictions of isometric exercise, body contact and competition also indicated.

Physical activity counselling was felt to be particularly important at specific times in the child’s care by the majority of cardiologists with a high exertion agreement rating (3/4). Time of diagnosis and time of procedures or changes in medical status were the most commonly mentioned points in care when physical activity counselling should be a higher priority. All felt that counselling information should be individualized for each patient. Half of the cardiologists with a high level of agreement (2/4) emphasized that the counselling should focus on what could be done rather than only restrictions, a rate that was double that among the total of 20 cardiologist interviews. Limited communication and families receiving different activity advice from different doctors were the most commonly mentioned explanations for the discrepancy between parent and cardiologist reports of activity restrictions. The one physician who had a low rating for exertion agreement said that all of his patients were counselled at every visit and that he and/or his clinic nurse were involved in delivering the counselling. He indicated that his Fontan patients have no restrictions, unless there are body contact restrictions for implanted devices or anti-coagulation. He felt that counselling should be individualized for each child, and that information about specific activity options should be provided. The observed discrepancies
in activity restriction reports were attributed to the lack of clear guidelines or recommended practices and the expectation that families hear only what they want to hear.

**Attribution of Cause of Competition Restriction Discrepancy**

Two cardiologists achieved a high rating for parent-cardiologist agreement about competition restrictions for physical activity and two had a very low rating (0% agreement). The high rating cardiologists were both female with approximately 20 years of experience since graduation. The cardiologists with a low competition agreement rating were both male and female, and had 20 or 30 years of experience.

The cardiologists with a high agreement rating for competition restrictions indicated that they ask every patient about their physical activity at every visit. They also indicated that their clinic nurses also typically ask about activity, although they do not require them to do so. Neither of them requires any physical activity restrictions unless the child has additional complications (beyond the Fontan). They responded differently when asked about times when activity counselling would be particularly important, reasons for the observed discrepancy in reports of activity restriction and whether counselling should be general or specific to the child. The cardiologists with a low rating of agreement on competition restrictions indicated that they routinely counsel their Fontan patients about physical activity but do not routinely counsel patients with simple defects. One cardiologist indicated that all of the physical activity counselling was done directly with the patient, while the other indicated that a consistent message from all health professionals (nurse, paediatrician, etc.) was extremely important. The cardiologists with low competition agreement ratings also differed in relation to the activity restrictions required. One permitted Fontan patients to do any activity, unless there were other considerations such as anti-coagulation. The other restricted physical activity to comfortable limits and restricted adolescents from competitive sport. They both indicated that physical activity counselling was important at any change in medical status or phase of life (e.g., starting school), and that the counselling should be individualized for the patient. One felt that activity options as well as restrictions should be discussed and conveyed to the patient in a letter.

Cardiologists with a low rating for agreement about competition restrictions indicated either that people hear what they want to hear or that family’s will forget previous information if it is not constantly reinforced.
Attribution of Cause of Body Contact Restriction Discrepancy

Almost all (6/8) of the cardiologists had agreement ratings for body contact restrictions of 40% to 60%. These moderate levels of observed agreement are somewhat surprising. Body contact restrictions are important for certain patient groups, such as those with implanted devices or taking anti-coagulation medication. The modest level of agreement is also surprising given the consistency with which cardiologists indicate the need for body contact restrictions and that body contact restrictions were the only type of restriction to have levels of parent-cardiologist agreement that were better than chance (5.2.3). Only one cardiologist achieved a high rating, and one had a low rating.

Cardiologists with high and low agreement ratings for body contact restrictions both indicated that they routinely counsel patients who have the Fontan procedure about physical activity participation. The cardiologist with the high rating indicated that she did all of the counselling herself, that it emphasized what the child was able to do and that there were no activity restrictions unless the child had other considerations. The cardiologist with the low rating indicated it was important for all health professionals to provide a consistent message and that after the Fontan procedure children should be active within their comfortable limits and not be involved in competitive sport as teenagers. Both indicated that physical activity counselling was important at key points in the child’s medical course or life stages and that counselling should be individualized for each child.

5.4.4 Discussion

In general, cardiologists routinely counsel patients about physical activity. Sixty percent counsel all of their patients, with the remainder focusing on patients who may be at risk for physical activity or who need a lot of encouragement to be active. Cardiologists generally do the counselling themselves, whether or not their clinic nurses are also involved. The focus of the counselling is primarily the activity restrictions required by the child’s medical status but discussions about appropriate expectations for the child’s participation also occur, particularly at the time of diagnosis or when the child starts school.
Variable Physical Activity Restrictions After Fontan

The physical activity restrictions that are provided for a child who has had an uncomplicated Fontan procedure were highly variable. The most common restrictions were “no competitive sports”, “no isometric exercise” or physical activity within “comfortable limits”. In addition, restrictions for body contact sports were mentioned for children with implanted devices or on anti-coagulation therapy. Unfortunately, the most commonly reported activity restrictions were largely the restrictions that parents indicated were the most problematic. During the previously discussed focus group for parents (4.5), participants indicated that they closely monitor their child’s physical activity participation. For example, they reported measuring their children’s heart rate or breathing at intervals while their child was involved in a sport. The parents indicated that they often felt that the child’s young age would not enable the child to accurately self-monitor activity to remain within “comfortable limits”. During those discussions, parents had also indicated that “no competitive sports” was a very difficult restriction to interpret on a daily basis because casual activities with friends, such as street hockey or backyard soccer, often become highly competitive depending on the nature of the people involved. Clearly, more specific guidance regarding participation in strenuous or competitive activity settings would assist parents in their daily decision-making about appropriate activities for their child. These results indicate that the activity advice most commonly provided by cardiologists is what parents feel is most problematic. Therefore, frequent feelings of uncertainty could be anticipated as parents’ try to interpret and apply advice that they feel is problematic in the daily life of their child.

Variable Restrictions Reflect the Published Guidelines

The restrictions reported by the interviewed cardiologists reflect the diverse and somewhat contradictory information contained in published guidelines (5.3.3). The varying recommendations raise the possibility that a family might receive different physical activity recommendations when they interact with or the child is cared for by different cardiologists. For example, when children are hospitalized the cardiologist responsible for the in-patient ward temporarily assumes responsibility for the child’s care. Similarly, prenatal care and counselling may be provided by one cardiologist while another assumes the child’s care after birth. The care of children can also be transferred between cardiologists if the child develops additional
complications (e.g., arrhythmias, pulmonary hypertension) that require specialized expertise. Given that the Fontan procedure requires 2 or 3 major surgeries, it is easy to see how one family may receive physical activity recommendations from 5 (prenatal, postnatal, 2 surgeries, ongoing) or more different cardiologists at different points in the child’s care. When different recommendations are provided without an explanation for the change, parents must decide for themselves how the discrepancy can be reconciled and which recommendations will be implemented. As one cardiologist explained, the physical activity decisions of the parents may ultimately reflect their perceptions about which cardiologist is more experienced or who they “trust” the most. Another cardiologist suggested that given conflicting advice parents may tend to retain the information that is closest to what they would prefer to hear.

Need for More Effective Physical Activity Communication with Parents

The cardiologists suggested that more effective communication between cardiologist and parent regarding the child’s physical activity participation would assist in resolving the discrepancy between parent and cardiologist reports of activity restrictions. That almost all cardiologists would be willing to share written as well as verbal information about physical activity suggests the need to develop knowledge transfer resources suitable for use in a busy clinic setting. A simple system for documenting and tracking the physical activity recommendations for the child, from diagnosis to transition to adult care, could potentially reduce the probability that parents would receive different information from different cardiologists. Several cardiologists suggested a system that would prompt them to update the child’s physical activity recommendations at each visit. They felt that type of reminder would enhance their ability to explain the physical activity implications of changes in the child’s medical status. Such a system could also increase the probability that accurate and timely information about the child’s physical activity restrictions would be included in the documentation shared with other health professionals, such as paediatricians, involved in the child’s care. Research by Faulkner and Biddle [106] supports the concept of providing “cues” to health care providers in order to facilitate the promotion of physical activity participation. In evaluating how intention and readiness for change impacts physical activity promotion by mental health professionals, they identified past behaviour and intention as strong predictors, with intentions being based in turn on attitudes and perceived behavioural control. They indicate that a plan for promoting physical activity, which takes into
account the environment in which the plan will be delivered, facilitates more consistent performance of the desired counselling behaviour. Their research is supported by our interview results. The paediatric cardiologists interviewed in this project also suggested that a plan, such as cues or prompts, would improve their ability to promote physical activity within the context of a busy tertiary care clinic.

**Physical Activity Encouragement Needed**

The small proportion (25%) of cardiologists who counsel about specific activities that are recommended for the child raises the possibility that parents may underestimate the importance of physical activity for the child’s health. Being told that it is important not to do certain activities does not automatically mean that doing other types of activity is important. That virtually all cardiologists routinely counsel all or some of their patients regarding physical activity suggests that they believe that appropriate physical activity is important for the children’s health. However, when counselling includes only discussions of inappropriate activities parents may mistakenly assume that a broader interpretation of the restrictions would be as, if not even more beneficial. For example, parents often provided examples such as tackle football and ice hockey when indicating that their children were restricted from body contact sports. However, in the absence of specific activity recommendations it could be anticipated that parents would naturally “err on the side of safety” and extend the body contact restriction to other activities, such as baseball, soccer or volleyball, which also may involve contact between players or with equipment. Further research is required to investigate whether enhancing the specificity of the cardiologist’s activity recommendations would be an effective means of increasing the physical activity participation of children with complex heart defects.

**Cardiologist-Parent Agreement Reflects Guidelines Consensus**

Cardiologist-parent agreement was higher for level of exertion restrictions and lower for restrictions of competition or body contact (Table 16). The differences in level of agreement appear to reflect the degree of consensus within the published guidelines regarding the need for exertion, competition or body contact restrictions (5.3.3). Only 2/17 published guidelines indicated that the level of exertion was unrestricted. The consistency within published guidelines that children who have the Fontan procedure should exert themselves only within comfortable
limits may provide cardiologists with greater certainty in communicating that advice to parents. In contrast, competition was restricted in 50% of the guidelines that addressed the issue of competition and 74% (17/23) of the publications made no mention of whether or when body contact activities should be restricted. The lack of consistent recommendations regarding competition and body contact may lead cardiologists to be less authoritative or consistent in conveying the need for these restrictions to parents.

Enhance Understanding of Communication Limitations

All cardiologists recognized the role of limited communication in relation to the observed discrepancies between parent and cardiologist reports of activity restrictions. However, the identified source of the communication difficulties appeared to differ between those with high and low levels of parent-cardiologist agreement. Cardiologists with high levels of parent-cardiologist agreement emphasized factors related to the communication from health professionals. A lack of discussion about physical activity during clinic visits, the potential for conflicting information from other health care providers, and the need for written materials to support verbal comments were the reasons most commonly cited. In contrast, cardiologists with low levels of agreement more commonly reported communication limitations that were beyond the control of health professionals. The most common explanations were the lack of clear guidelines or recommended practices, the belief that without constant reinforcement families forget information previously provided, and the expectation that people hear only what they want to hear. These results suggest that cardiologists who prioritize their own role in effectively communicating physical activity information to parents may be more likely to achieve higher levels of parent-cardiologist agreement than those who attribute poor communication to external influences.

Study Limitations

By design, the cardiologist interviews were very brief. The brevity of the interviews enabled us to gain full participation from all available cardiologists connected to The Hospital for Sick Children. The breadth of participation allowed us to accurately assess the range of opinions and responses that exist among a large sample of paediatric cardiologists. However, the brevity of the
interviews also significantly restricted our ability to gather in-depth information about specific issues.

It must also be recognized that the number of cardiologists participating in the interviews was relatively small (n=20), even though it represented almost all of the full and part-time cardiologists associated with our institution. In order to gather more comprehensive data from a larger number of cardiologists, similar interviews would need to be implemented through a multi-institutional study.

Cross-referencing of the cardiologist interviews with the measures of parent-cardiologist agreement about activity restrictions further reduced the number of cardiologists included in the analysis. Although parent-cardiologist agreement data were available for patients followed by 19 cardiologists, only 8 cardiologists had at least 3 patients whose parents were involved in the study through which parent reports of the child’s physical activity restrictions were recorded. Therefore, the results of the comparison must be interpreted with great caution because of the small number of cardiologists and small number of parents per cardiologist.

5.4.5 Conclusions

The results of the cardiologist interviews suggest several potential sources of uncertainty as parents attempt to guide their child’s physical activity participation. The activity recommendations of the cardiologists reflect the published guidelines, both in the type of activity restrictions and the ambiguity of their application. The competitive sport restrictions that have the greatest ambiguity in the published literature are also the advice that parents indicate is the most difficult to interpret. Cardiologists routinely provide physical activity guidance, but the content focuses primarily on medically required activity restrictions. The importance of activity participation and specific suggestions regarding the types of activity that should be encouraged are provided less often, leaving parents with limited information about how to prioritize or select activities that are appropriate. Simple tools that prompt cardiologists to address and document the child’s physical activity recommendations at each visit are required. Written resources that encourage physical activity in conjunction with verbal counselling are recommended in order to reduce parent uncertainty, and enable them to prioritize the promotion of healthy active lifestyles for their children.
Chapter 6
Directions for Future Research
6 Opportunities for the Future

In order to better understand physical activity in the lives of children with complex heart defects, this research is the first to examine factors that influence the physical activity of elementary school-aged children with complex congenital heart defects. Children who have the Fontan procedure for a functional single ventricle have the most complex form of congenital heart defect and were the focus of this research. Therefore, I sought to document the physical activity participation and perceptions of children with complex heart defects, and the perceptions of their parents and a large group of paediatric cardiologists.

Physically active lifestyles are critical to the healthy growth, development and socialization of young children. For children with complex heart defects, maintaining a physically active lifestyle is even more important because they also have a higher risk for atherosclerosis and other morbidities associated with a sedentary lifestyle. The results obtained through this series of research projects has identified important factors related to the physical activity levels of children with complex heart defects that have not been previously recognized. The children’s beliefs about physical activity strongly influence their own desire for (in)activity. Given their relatively young age, and the importance of parental beliefs for the child, parental beliefs about the child’s capacity for physical activity are also very important.

The parents’ own beliefs emanate both from their own perceptions and experiences as well as the information, attitudes and expectations provided by the cardiologist responsible for their child’s care. Figure 22 provides a graphical representation, based on the results of this research, of how these various influences may interact.
Support for Eccles Expectancy Value Model

Eccles expectancy value theoretical framework [34] suggests that a child’s behaviour is primarily influenced by the child’s own belief in their ability to be successful. Children who believe that participating in physical activity will be a positive experience and that they will have fun and be successful, are the most likely to actually participate. The beliefs of the child, according to Eccles, are determined by the beliefs and expectations that the parent holds for the child’s participation. Results from these investigations suggest that a similar model applies to children with complex heart defects. Children who have the Fontan procedure have highly variable levels of physical activity. There are also substantial variations in their self-perceptions for physical activity participation. That is, some children see themselves as a “sports guy” (Boy1) or “competitive athlete” (Girl6), while others see themselves as “a more sedentary person” (ChildA). In this study, children often indicated that they were aware of the activity beliefs and expectations of their
parents. The parents of children with complex heart defects indicated that their expectations for their child’s abilities and life expectations are significantly influenced by the information provided by the child’s cardiologist.

6.1 It’s Not the Heart!

Factors associated with the physical activity levels of children who have the Fontan procedure are more similar to, than different from, the factors that are important for their healthy peers. Physical activity varies throughout the year, with the warm weather periods being the most active and the winter being the most sedentary. Boys are more active than girls and motor movement skills are better among children who are more active.

Conspicuously absent from the final model (Figure 22) are factors related to the abnormal cardiopulmonary physiology of children who have the Fontan procedure. Surprisingly, measures of the child’s current medical status or previous medical history were not related to their current level of moderate-to-vigorous physical activity (3.2). Diagnosis, type of Fontan repair, history of complications or the use of medications to support cardiac function were not related to MVPA level. The only factor related to their heart defect that was significantly related to weekly minutes of MVPA was the use of antithrombotic medication. Children taking these medications are often restricted from participation in body contact activities. As a result, cardiologists are careful to clearly discuss the details of which activities should be encouraged and which should be avoided. The need for antithrombotic medication will always be determined by factors other than the child’s future physical activity participation. However, understanding the benefits obtained from the more specific physical activity counselling provided to children taking antithrombotic medication suggests that a counselling intervention may be effective for increasing the activity of children with complex heart defects.

Research Needed to Identify Effective Interventions

Research is needed to determine the effectiveness of interventions designed to increase the physical activity participation of children with complex heart defects. These results suggest that physical activity counselling may be an effective intervention because many important influences are in the psychosocial realm. Results from the individual and group interviews (4.7)
indicate that many parents are uncertain about what activities are appropriate for their child. They report that it is difficult to implement general phrases such as “she can do whatever she wants” or “don’t expect him to play in the NHL” when they have heard differing recommendations from other health professionals. The higher activity levels of children taking warfarin (3.3.3) suggest that the specific activity counselling that they receive effectively allows not only the avoidance of contraindicated activities but greater certainty about the child’s ability to participate in permitted activities. Future research should investigate the benefits of this more specific type of physical activity counselling on the participation of children with complex heart defects who do not need antithrombotic medication.

6.2 It’s About Fun, Isn’t It?

For children with complex heart defects, the desirability of physical activity is strongly influenced by having fun, being with friends, and being successful (Figure 22). The individual and group interview results indicate that children and parents differ very substantially in their views regarding the key factors that influence the child’s physical activity participation. The children themselves report factors influencing physical activity that are similar to those reported by healthy children of similar age (4.3). The primary consideration is having fun. Other important influences are physical activity opportunities readily available at home or in the community, having family or friends to be active with, and an expectation that attempts to participate will be successful. Factors associated with lower activity levels include screen time (television, video games, computers), homework, peers who criticize their activity participation and perceptions that other children are “better” at physical activity.

The children also believe that their parents provide them with consistent guidance about their physical activity participation. The one sedentary child in the focus group indicated that her parent was always trying to get her to be more active. Other children who described themselves as active indicated that their parents were always telling them to slow down. Based on these results it seems that children clearly perceive messages from their parents about whether their physical activity level is appropriate and how it needs to change. However, whether those messages determine the child’s activity level or result from it has yet to be determined.
Parents Think About Heart Health

In contrast to the children themselves, parents of children with complex heart defects identified primarily medical-condition related factors as influencing their child’s activity participation (4.5). They emphasized that their child’s medical history, current health, and unknown future health significantly influenced their own perceptions and expectations. They also accurately linked the activity guidance that they received from physicians with their child’s health history. For example, antithrombotic medication or pacemaker implant was linked to restriction of body contact. Their past experiences and future expectations lead them to perceive their child’s health as somewhat fragile, and in need of protection from unnecessary stress, both physical and emotional. They also know what doctors have advised about physical activity recommendations for their child. However, they indicated that the general nature of the comments provided often made day-to-day decision-making about their child’s activity participation very difficult. Parents reported that they felt like they were constantly trying to balance on a fine line. They knew that activity was very important for their child’s health. However, their uncertainty about how to implement the general advice from the physician combined with their desire to ensure that their child’s “fragile” health status was protected left them with tremendous uncertainty about how much activity should actually be permitted or encouraged. Cardiologists need to counsel families about physical activity keeping in mind that parents need to feel confident about appropriate physical activities for their child.

The parent of the child who described herself as sedentary also indicated that she often felt uncertain about her own decision making regarding her child’s physical activity. However, she indicated that her uncertainty stemmed primarily from her child’s anxiety and uncertainty about physical activity. The parent indicated that she herself, the child’s cardiologist and all of her child’s friends had repeatedly tried to engage the child in a wide variety of physical activities. However, in recent years her daughter had consistently limited herself because it “might be too much for my heart”, even for activities that she really enjoyed at a younger age. This family’s experience suggests that uncertainty about how physical activity could impact the child’s heart function can be a concern for the child with the heart defect as well as the parents.
Investigate Impact of Parent/Child Differences in Perception

It would have been interesting to share with participating parents the children’s perspectives about being told to be “more active” or “slow down”. Although several parents spoke about how hard they have tried to encourage their sedentary children to be more active, none of the parents gave any indication that they tried to get their children to slow down. Unfortunately, the question of whether they felt their children were too active or should slow down was never asked. My initial assumption for this research that the parents would recognize the sedentary lifestyles of their children but would feel that a normally active lifestyle was not realistic for their children (2.4.1), were clearly inaccurate. To our surprise, the parents typically felt that their children were normally active. Our prior assumptions had not prepared us to question the accuracy of parental perceptions of the child’s activity. However, from the parent conversations about the importance of physical activity and all of the activities in which their children were involved, most parents seem to feel that their children are physically active. Although the parents recognize that they struggle to determine when activity is excessive or inappropriate, they do not seem to recognize how often they convey messages to their children about decreasing their physical activity.

Like their parents, the children recognized the impact of their heart condition on their physical activity participation. However, the medical influence appeared to play a much smaller role from the children’s perspective. Only the child who described herself as a sedentary person recalled her physician talking to her about how important it was for her to be more active. Apart from the physicians’ influence, the children also recognized that their heart condition could influence their activity in other ways. They indicated that sometimes it was hard to play with their friends because they would get tired. They also are discouraged from participating when they feel that their friends are stronger or more skilled, or if their peers are critical of their abilities.

Parents Have Limited Recognition of Other (i.e., non-heart) Influences

Having fun and playing with family and friends, which were of highest importance for the children, were not identified as significant influences by parents of children with complex heart problems. The parent participants did mention some influences not specific to their child’s heart problem, but they related primarily to parent perceptions of the importance of physical activity. Parents who enjoy physical activity themselves indicated that it was important to share active
experiences with their child. Parents who were less active or who placed a higher priority on school work indicated that they were less likely to strongly encourage their child’s participation, particularly if the child resisted being active.

**Children have Accurate Perceptions of Their Own Activity**

The child and parent interviews provided very important information that significantly enhances our ability to care for these children. Most children with complex heart defects appear to have a very accurate and appropriate view of their own physical activity participation. They indicated that their participation was primarily influenced by the factors that are important to all children, such as having fun and being with friends and family (4.3). While they did recognize that their heart condition placed some additional limitations on their ability to participate in certain types of physical activity, their views seemed to accurately reflect experiences of being quicker to fatigue or having less skill or experience. Therefore, it is important for the health professionals who care for these children to consistently and positively reinforce the importance of physical activity, and to encourage and support their participation in physically active peer play to the greatest extent possible.

It is also clear that health professionals need to communicate more effectively with parents about the importance and priority of physical activity in their children’s lives. The results of this study suggest that parents need much more specific, detailed information about their child’s physical activity capabilities in order to feel confident in making daily decisions about appropriate activity participation. Rather than focusing on activity restrictions, these results suggest that health professionals need to emphasize the importance of daily physical activity. In addition, they need to provide specific information about the type, amount and intensity of physical activity that is appropriate for the child.

**6.3 Kids are Naturally Active, Aren’t They?**

There is no doubt that physically active lifestyles are very important for children with congenital heart defects. Physical activity not only benefits their long-term health, but it is also essential for their childhood growth, development and socialization with peers. The inactive lifestyles adopted by most children with complex heart defects (3.2.3) indicate a need to re-think current
approaches for encouraging physical activity for these children. The results from this research suggest that a more effective approach would be focused on removing uncertainty about the type or amount of physical activity that is appropriate or should be expected from a child with a complex heart defect.

**Importance of Parental Beliefs**

Eccles’ expectancy value model suggests that a child’s behaviour is determined by the child’s belief about the behaviour, and that the child’s beliefs are largely a reflection of parental beliefs and expectations for the child. Parents of children with complex heart problems indicate that they often feel very uncertain about the type or amount of physical activity that is appropriate for their child (4.5.4). Given their uncertainty about what is or is not appropriate, parents indicate that they are often in a position of wanting to encourage their child’s participation with peers while at the same time fearing that the activity might be detrimental to their child’s health. One mother indicated that she often struggled with how to respond when her child resisted physical activity by saying that “it might be too much for my heart”. The mother commented that in these situations she mentally struggled with whether or not she should push her daughter to participate. The question for her was whether her daughter’s concern was legitimate or whether she was “playing” her mother just to get out of doing the activity.

The expectancy value model would suggest that the daughter’s hesitation about physical activity is a reflection of the mother’s own ambiguity. It was clear from the mother’s comments that she herself was not certain that the activity was completely safe and appropriate. Had she felt more certain, she would have pushed her daughter to participate without hesitation since the mother clearly stated that she knew how important activity was for her child’s health. Eccles’ theory would predict that the mother’s hesitation and uncertainty regarding the child’s physical activity would gradually be adopted into the child’s own beliefs. As the child adopted the belief that the safety and appropriateness of physical activity was uncertain, the child’s behaviour would gradually conform to that belief. The predicted result would be exactly what was observed, the child’s sedentary lifestyle reported by both mother and child. Based on the expectancy value model, the key to achieving physically active lifestyles for children with complex heart defects lies in ensuring that parents believe that physical activity is beneficial and important for their child, and that they have strong expectations for their child’s active participation.
6.4 Our Clinic Visit is About How My Child’s Heart is Functioning

Time is a very precious commodity in a tertiary care paediatric cardiac clinic. Time is precious for paediatric cardiologists who must assess the complex health issues of the child, respond to new or on-going concerns, and convey the results and implications of recent tests or procedures, all while they are also training future cardiologists. Typically the cardiologist’s interaction with the family has to fit within a once yearly visit of 15 to 20 minutes duration. The clinic visit time is also very precious to families, who understand that they have this one short window of time each year when they can “find out how their child is doing” and get answers to their questions and concerns. Given these intense time pressures, and the cardiologists’ belief that parents want activity restrictions to be provided directly from the cardiologist (5.4.3), it is not surprising that discussions about physical activity are often very limited.

Interventions to Optimize Parental Beliefs and Expectations

If parental beliefs and expectations for the child’s physical activity are paramount for enabling the child to adopt a healthy active lifestyle, the next step is to understand how cardiologists, or other health care providers, can support the development of appropriate parental beliefs and expectations. Research in a variety of psychosocial spheres has clearly indicated that parental expectations for a child with a complex heart defect are largely determined by the information provided by the cardiologist [22, 26]. Results from my parent interviews (individual and group) indicate that the counselling provided by the cardiologist has a tremendous impact on parental decision-making for the child. The priority that parents attach to comments from their child’s cardiologist suggests that cardiologists could play a very significant role in the development of parental beliefs and expectations that would support the child’s physical activity participation. On that basis, cardiologists are uniquely positioned to provide recommendations about physical activity to the child and parents.

Cardiologists interviewed for this research recognize their central role in providing physical activity guidance for the child (5.4.4). However, they also identify very significant barriers that limit the effectiveness of the counselling that they currently provide. The primary barriers identified were the need to prioritize clinic time for test results and more immediate health
issues, and the perceived disconnect between the information that they provide and what parents’ understand or hear. Further research is required to determine whether a different model of care might be more effective at conveying the importance of physical activity participation and providing families with specific activity recommendations that they can implement on a daily basis. Given the time pressures on the cardiologist, it may be more effective for the cardiologist to introduce the topic of physical activity and then refer the family to a physical activity professional for more in-depth discussions and recommendations.

**Increasing Awareness of Immediate Physical Activity Benefits**

From my interactions with families and health professionals in the cardiac clinic, I believe that the relationship between physical activity and health is currently viewed from a long-term perspective. The immediate impact of inactivity on the child’s current health or quality of life is under-appreciated. Living with a child with complex heart problems provides enough challenges in the present day that families are unlikely to feel the need to prioritize matters that they perceive as being important at some future, distant time. As a result, cardiologists indicate that parents ask questions about physical activity at specific times when the connection between the child’s current health and physical activity is brought to the fore. When the child starts school and information is requested about the child’s participation in physical education classes or when an older child expresses an interest in organized sport or fitness training are times when there is a current and immediate connection between physical activity and the child’s heart problem. At these times, parent questions about physical activity emerge and discussions about the child’s physical activity are given a higher priority. More detailed and frequent guidance about physical activity is needed in order to develop appropriate parental beliefs and expectations. To that end, the priority of physical activity counselling must be increased within the long list of issues addressed during a clinic visit. Alternatively, a method of addressing physical activity counselling and issues with a minimal use of clinic time is required.

**6.5 Parents Don’t Understand – Cardiologists are Unclear**

It is interesting to consider the myriad of ways in which cardiologists identified communication barriers as relevant to the effectiveness of their physical activity counselling with families
(5.4.4). For some cardiologists, the communication barrier was primarily related to physical activity being a low priority and a casualty of the limited clinic time. From this perspective, the cardiologists readily agreed that they typically focus only on the bare essentials, those being the medically necessary activity restrictions, and that their advocacy for a physically active lifestyle was typically very limited or even non-existent. For other cardiologists, the communication barrier was situated within the family. Comments such as “people only retain 10% of what they hear” or “what I say isn’t necessarily what they hear” indicate an expectation that communication is a two-way street. Even if time is taken to advocate for physical activity, some cardiologists’ expect that the information may not be received or may be received very differently by the parent and child.

Parents “Know” Activity Recommendations but Struggle with Decision-Making

From the cardiologists’ perspective, differences between parent and cardiologist reports of activity restrictions result from the parent not having received the information communicated by the cardiologist (5.4.4). However, data from the parent interviews suggests an alternative explanation. None of the parents indicated any uncertainty about what the cardiologist had told them about their child’s physical activity participation. They could clearly recall the physical activity advice that had been provided to them on different occasions. Rather, their uncertainty emanated from the difficulties they encounter in actually using the information to support their daily decision-making.

Parents feel there is a need for more specific guidance than what is currently provided (4.5.4). It may be difficult to resolve the ambiguity in published guidelines (5.3.3) without significant additional research on the impact of physical activity participation for children with complex heart defects. However, educating physicians or providing them with more effective tools for accurately conveying their intentions regarding the child’s physical activity would likely address the majority of parent concerns. For example, each cardiologist would need to choose the activity recommendations for each child based on their knowledge of the child’s medical condition and their beliefs regarding the published guidelines. However, once that decision is made, the cardiologist or a physical activity colleague working with the cardiologist needs to take the time to educate the child and parents about the child’s physical activity participation. Providing specific examples of recommended and restricted activities would seem to be of benefit. For
example, does “no body contact” mean only sports where there will deliberate and repeated contact are restricted, or are activities where inadvertent contact might occur also included. These results suggest that a brief discussion about how day-to-day decisions should be made and why the current advice may differ from information previously provided would greatly enhance parent confidence for guiding their children into appropriately active lifestyles.

Cardiologists’ Activity Recommendations Vary

The nature and variability of activity restrictions reported by the cardiologists seem to reflect the wide range of recommendations available in the published literature (5.3.3). Equal numbers of publications indicate that restriction from competitive sport is or is not required, and the cardiologists who reported at least one activity restriction were similarly divided. The much greater consensus about the restriction of vigorous activity (activity within comfortable limits) also reflects the majority of publications that recommend only activities requiring light or moderate effort. The availability and consensus within published guidelines also seems to parallel parent-cardiologist agreement about activity restrictions. Restrictions on the child’s level of exertion had a high level of parent-cardiologist agreement, while agreement regarding restrictions for competitive sport was much lower. These results suggest that the counselling provided on this topic was very effective. Taken together, these findings suggest a link between the content and degree of consensus within published guidelines and the ability of cardiologists to confidently and consistently counsel children with complex heart defects and their parents regarding appropriate physical activity. In contrast, the very equivocal nature of the published guidelines regarding competitive sport participation makes it more difficult for cardiologists to provide definitive advice. As a result, there is a much lower level of agreement between parent and cardiologist reports for restrictions from competitive sport (5.2.3). Developing consensus guidelines about physical activity for a child who has the Fontan procedure appears to be an important first step toward addressing the parental uncertainty that is so strongly linked to the sedentary lifestyles of these children.

Minimal Guidance Does Not Lead to “Normal” Activity Expectations

Cardiologists interviewed for this research emphasized the need to provide clear, simple advice about physical activity that would be easy for parents to implement (5.4.3). I believe their
emphasis on simple, minimal advice typically emanates from two perspectives. One view is that children are naturally active, so that children with heart defects will automatically be as active as their heart condition allows. Based on this view, there is no need for activity promotion. The second view attempts to minimize the restrictions or concerns conveyed in order to avoid the phenomenon of the “cardiac cripple”\(^5\). Unfortunately, it is exactly these minimal, simple and general statements about physical activity that parents indicate are the source of much of their uncertainty about the child’s physical activity participation. Parents of children with complex heart defects indicate that there is a tremendous need to steer away from over-simplified or very general statements, such as “no competitive sports” or “no contact sports”, that are difficult to implement in daily decision-making about the child’s physical activity participation. As previously discussed, parents often find it extremely difficult to know what is actually meant by “no competitive sports” or “no contact sports” when it is applied to the wide variety of physical activity opportunities available to their child (4.5.4). More effective methods of physical activity counselling are required in order for parents to understand how these general restrictions should guide their decisions. Parents need to be able to consider their child’s potential participation in activities as diverse as a long distance “fun run” versus a highly competitive youth bowling team, or girl’s hockey which prohibits body contact versus figure skating with its inevitable falls and collisions. Another simple statement that parents often hear is that the child “can do whatever he or she wants”, or that no restriction of physical activity participation is required. Objective measures of the physical activity levels of children with heart defects have clearly demonstrated that they are significantly less active than their peers (3.2.3)[15], who in turn often do not achieve the level of daily physical activity associated with long-term health [5]. Apparently being allowed to “do whatever you want” does not necessarily mean that the child with a heart defect will actually perform the desired amount of physical activity. “Doing whatever you want” only leads to a healthy active lifestyle if what you “want” is physical activity.

\(^5\) Cardiac cripple is the term coined to describe a child who is restricted from most normal childhood activities because of a previous referral to a cardiologist for an innocent heart murmur. In the 1970’s, research recognized that many children who had been seen in a cardiac clinic were extremely overprotected and limited in daily life even when the cardiologist’s assessment had definitely shown that the child had absolutely no heart abnormality.
6.6 Recommendations for Future Research

The results of this research have implications for clinical practice as well as for future research. While much has been learned about the factors that influence the physical activity of children with complex heart defects, much more must be understood if we are to ensure that each child is able to enjoy all of the benefits of daily involvement in physical activity. These results indicate that more time and attention to physical activity, from both parents and cardiologists, is required if children with complex heart defects are to achieve the physically active lifestyles that are so critically important. There is a clear need to develop consensus around simple and logical physical activity recommendations that can advocate for physically active lifestyles and be accurately conveyed within a hectic clinic visit. The recommendations must also enable parents to feel certain that the activity choices that they make for their child are safe, appropriate, and important for their child’s health and quality of life.

The next study in this programme of research will investigate methods of effectively advocating for physically active lifestyles and enabling parents to feel confident in their ability to make decisions regarding their child’s physical activity participation within the setting of a tertiary paediatric cardiac clinic. The study will seek answers to the following key questions:

1. **How can outpatient physical activity counselling practices and tools be changed so that cardiologists prioritize activity counselling and children with complex heart defects and their parents feel certain about which physical activities are appropriate for the child?**

Higher levels of physical activity among children taking antithrombotic medication suggests that when more time is allocated to discussing physical activity options and providing specific advice, the child is more likely to adopt a physically active lifestyle. The hypothesis to be tested is whether training in effective counselling techniques and skills, such as motivational interviewing, would better prepare cardiologists to advocate for physical activity with the children and families under their care.
2. **What information or education would enable families to encourage physical activity during the Fall and Winter months or among those children whose medical status carries a higher risk of a sedentary lifestyle?**

   Children with an open fenestration and those who had the Fontan procedure at an older age are more likely to be sedentary. Children with complex defects are similar to their healthy peers in that their physical activity declines substantially during the Fall and Winter months. The hypothesis to be tested is that providing a programme of home-based, physically active play opportunities, that are specifically designed for the needs of the child, will increase the physically activity participation of the child both during and after the intervention.

3. **What are the physical activity guidelines or restrictions that apply to children with complex heart defects?**

   The published literature regarding guidelines for the physical activity of children with complex heart defects is very ambiguous. Clear recommendations are available for highly competitive sport participation but not for the wide range of physical activity that is typical for young children. New educational materials that explain the physical activity options available during leisure-time and in house league and school settings are required. The hypothesis to be tested is providing specific information about the child’s active participation in a variety of settings will significantly increase school and community physical activity participation.

4. **How do the physical activity perceptions of children with simple heart defects and their parents compare to the results from this study given that they also have very sedentary lifestyles in spite of no activity restrictions?**

   Results from this study clearly indicate that being told “she can do whatever she wants” does not necessarily result in a physically active lifestyle for the child. Similarly, with the exception of fenestration status, age of repair and antithrombotic medication, medical history variables are unrelated to the child’s activity level. The hypotheses to be investigated are: a) whether uncertainty about physical activity is prevalent among parents of children with less complex heart defects, and b) whether similar changes to education and advocacy practices within the cardiac clinic (refer to #1, #2 and #3 above) can enhance the children’s level of moderate-to-vigorous physical activity.
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Appendix A: Questions for Child Focus Group

Warm up question: What types of things do you like to do when you are not in school?

Today we are going to talk about physical activity. “Physical activity” means everything that you do when you are not sitting still.

1. Can you draw the physical activity that you like to do the most when you are in your house?
   What other types of “physical activity” do you do in your house?

2. Can you draw the physical activity that you like to do the most when you are at school?
   What other types of “physical activity” do you do when you are at school?

3. What types of “physical activity” do you do at other places (e.g., in your neighbourhood, at the park or playground, on a sports field, in a recreation centre, at daycare)?

4. What is it like when you do activities with other kids?
   Probe: Some kids with heart problems are teased during activities. What sorts of things have happened to you, or have you heard about from others?

5. What have your doctors, either here at Sick Kids or at home, told you about physical activity?

6. What have your parents told you about being active?

7. Kids with heart problems often find it hard to do some kinds of physical activity. What activities are hard for you to do?

8. If you were to try a new activity that you had never done before. What do you think it would be like?

9. Thanks a lot for your help. Do you have any advice for other kids with heart problems?
Appendix B: Questions for the Parent Focus Group

1. What sorts of activities are popular in your families?
   a. What activities do you like to do as a family?
   b. What activities do your children like to do (alone or with their friends)?
   c. What influence has having a child with a heart condition had, if any, on your families’ activities?

2. For optimal health, Health Canada recommends that children participate in “physical activity” for at least 60 mins/day. What types of activity do you think would be counted as “physical activity” toward that goal?
   a. The Health Canada guideline is intended for children in general. What are your thoughts about the 60 mins/day guideline for your child with a heart condition?

3. What have you been told by health professionals (e.g., cardiologist, family doctor, nurse) about your child’s ability to participate in physical activity?
   a. What has been your approach in handling these recommendations?
   b. Some parents have told us they worry when their child with a heart defect participates in physical activity. What worries do you have about your child’s participation?

4. What sorts of activities is your child involved in at school?
   a. We’ve talked about the activities your child is involved in at school. Can you comment more specifically about the participation of your child with a heart defect participate in gym class at school?
   b. What about in recess or after school activities at school?

5. Parents often find it difficult to take their child to activities, lessons, teams or clubs in their community.
   a. What makes it difficult for you?
   b. Is it any more or less difficult for your child with a heart defect?

6. What advice would you give to other parents of children with heart conditions regarding physical activity?
Appendix C: Questions for the Child Interviews

Familiarizing the Child with the Interview

1. Since we’ve never met before, I would like to get to know you. Can you tell me about yourself?

2. Imagine that I had called you on the phone last night, before we saw each other. What would you have said to me so I would know what you look like (so I would have recognized you when you arrived)?

3. Now that I know what you look like, I’d like to know more about you as a person. I’d really like to know more about the things about you that I cannot see (e.g., your feelings, your thoughts). What can you tell me how you usually feel or what you think about yourself?

4. What things do you really like to do?

Child’s Activity Participation at Home

5. Think about a school day. What do you usually do after school?

6. Think about a weekend day. What do you usually do on the weekend?

7. Are your activities any different in the winter? If so, what do you do in winter?

8. Are your activities different during summer vacation? If so, what do you do then?

9. Do you take any lessons or classes?

10. Do you play on any teams?

11. Do you ever compete in races or games where one team wins?

Child’s Activity Participation at School

12. How do you usually get to school?

13. What activities do you like to do in gym at school?

14. What activities do you like to do in your free time at school (e.g., recess, lunch)?

15. What do you usually do during the winter at free time?
Child’s Perception and Understanding of Physical Activity

16. If you had to pick one word to say how you feel about being active, what would that one word be?

17. Are there any activities that you do that you would like to do better?

18. Are there any activities that you don’t do that you would like to learn?

19. Do you like activities on a team or with just a couple of friends?

20. Do you like doing stuff outside or inside?

21. Do you like activities with winners and losers or just playing for fun?

22. Do you like activities with music or pretending?

Child’s Summary and Recommendation

23. If you met another child with the same heart problem as you, what advice would you give him/her about physical activity?
Appendix D: Questions for the Parent Interviews

Familiarizing the Parent with the Interview

1. What do you and your child like to do when you spend time together?

Parent Recognition of Activity Options

2. What activity equipment do you have available to your child (e.g., balls, hoops, bat)?
3. What places for activity do you have at home?
4. What places for activity are in your neighbourhood?
5. What has your child’s cardiologist told you about your child’s involvement in physical activity?
6. What, if any, activities are not recommended for your child because of the heart condition?

Parent Priorities and Preferences for Physical Activity

7. What activities are you interested in having your child do or learn about in this study?
8. Are there any activities that you would not want your child to do or learn?
9. How important is physical activity to your family?
10. How important is it to you that your child is physically active?
11. What do you think is your child’s opinion about the importance/value of physical activity?

Potential Barriers and Supports for Physical Activity

12. What makes it hard for your child to participate?
13. What makes it hard for you to support your child’s participation?
14. Do other people in your child’s life (e.g., teacher, coach, friend) ever make it more difficult for your child to participate?
15. What do you expect will happen when your child tries a new activity?
16. If you could ask your cardiologist or another expert for more information about physical activity and your child, what would you ask?
Parent Support for the Child’s Participation

17. Typically, what are you able to do to help or support your child’s participation in physical activity?

18. What would you need in order to be ready for your child to be more active?

19. What support or resources would you need to make this happen?

Parents’ Summary and Recommendation

20. If you met the parents of other children with similar heart problems, what advice would you give them about physical activity participation?
Appendix E: Transcription Conventions for Focus Groups and Interviews

Data Layout

Continuous prose layout will be used to position the data on the page. Each new concept will be placed on a separate line, starting at the left edge of the page. The same font will be used for all speakers so that the questions or statements of the researcher will not be highlighted. All comments will be in the same column so that each speaker is given equal emphasis.

Unit of Measurement

The basic unit of measurement will be an individual idea or concept. Depending on the speaker, one concept may be expressed in a relatively long narrative or several concepts may be expressed in one phrase. Therefore, the concept as the unit of measurement will not necessarily correspond to sentences, the speech between subsequent pauses, or changes from one speaker to the next. The concept as the basic unit of measurement will allow each idea presented by the participants to be identified. At this point, there is no previous research to suggest what concepts or ideas may emerge or be important. Therefore, having each concept as a separate entity, physically separated on a separate line, will help to ensure that all concepts are highlighted equally and unique or multiple concepts are not lost within a long narrative from one person.

Verbatim Transcription

The words spoken by each speaker will be recorded as accurately as possible, although limits of audiotape clarity may make it difficult to achieve this goal of 100% transcription. No attempt will be made to impose the sentence structure, punctuation and grammar typical of written text onto the transcript of the spoken information. Each concept will be represented by the words use to express it, whether or not that concept represents a complete or partial sentence or phrase.
Transcription of laughs, coughs, sighs, etc.

Laughs, coughs, sighs, etc. will be recorded within the text in square parentheses [ ]. These data will only be recorded if it occurs within the expression of a single concept. For example, background coughs by non-speakers would not appear in the transcript. However, if the speaker laughs, or the speaker’s expression of a concept is interrupted by the laughter of others, the action would be recorded. For the purposes of this research, it is assumed that the fact that someone who is not speaking coughs in the background is probably not relevant to the identification of key concepts. However, laughs or sighs that are part of the speaker’s expression, or are made by others in response to the speaker’s comments, will be noted because they may be a source of information about the speaker or listener’s reaction to the concept being expressed.

Transcription of overlaps, interruptions, pauses and inaudible segments

Inaudible segments will be noted in square parentheses [ ]. Overlaps and interruptions will not be recorded because each concept will be recorded separately, regardless of the speaker or timing of the comment. Pauses that occur within one speaker’s expression of an individual concept will be recorded as short (< 2 seconds) or long (2 or more seconds). Pauses between speakers or between expressions of different concepts by the same speaker will not be recorded in the transcript.

Contextual Information

Contextual information will be recorded separately from the narrative text. General contextual information about the physical setting will be described at the beginning of the transcript, in a separate section. Changes to contextual information that occur during the interview will be recorded in the right hand column, adjacent to the narrative that occurred at that time. For example, a child may notice the arrival of a clown or celebrity to the patient area. This change in context could have a significant impact on the child’s attention and the subsequent conversation. Notes about contextual information made after the end of the interviews (i.e., based on the investigator’s memory or impressions of what happened) will be recorded in a separate section at
the end of the transcript. Very detailed contextual information will not be recorded, but rather
the recorded information will focus primarily on contextual factors that may inform or influence
the concepts being discussed.

Audit Trail

The conventions described in this document are the beginning of the audit trail that will be used
to document the transcription process. This document will remain a work in progress, that will be
updated throughout the transcription process as additional decisions and distinctions are made.

Verification of the Transcripts by participants

Five randomly selected parent participants within each diagnostic group will receive the
transcript of their own interview for the purposes of verification of content. The transcripts will
not be returned to the child participants for verification. Children will be told during the
interview that what they say will be held in confidence by the researchers, and that it would not
be conveyed to their parents, friends, doctors, etc. Ethical permissions for our study do not
permit direct contact with children without parental agreement. In order to maintain the
confidentiality pledge made to the children, it is not possible for the parents to see the transcript
for their child. It would be possible for the researcher to contact the parents and ask permission
for the child’s assistance with verification. However, asking to share information with the child
that cannot be viewed by the parent may unnecessarily raises concerns about the content of the
information among parents. There are also potential issues of ethics if the parents perceive that
their children’s comments were being withheld or hidden from them or the children feel pressure
to reveal their comments to their parents.
Transcription Personnel

During the interviews, the staff person conducting the interview will create real-time notes of the key concepts and session content by recording key points as the discussion evolves. After the interviews have been completed, the audiotapes and notes will be reviewed to ensure that all of the ideas mentioned have been included in the real-time notes. The detailed transcripts will build off of the real-time notes to represent the actual words and phrases used by the participants. All interviews will be transcribed by the Project Transcriptionist.
Appendix F: Content Analysis Coding Frame

<table>
<thead>
<tr>
<th>Theoretical Concept</th>
<th>Derived Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of physical activity</td>
<td>Aerobic/dynamic, muscular strength/static</td>
</tr>
<tr>
<td>Psychological influences</td>
<td>Level of competition, voluntary participation</td>
</tr>
<tr>
<td>Potential for injury</td>
<td>Amount of body contact</td>
</tr>
<tr>
<td>Influence of treatment</td>
<td>Implants, anti-coagulation, anti-hypertensive, cardiac support</td>
</tr>
<tr>
<td>Level of authority/recognition</td>
<td>Authorship, rhetoric aerobic, rhetoric strength, argumentation</td>
</tr>
<tr>
<td>Specificity for Fontan circulation</td>
<td>Breadth of guideline application</td>
</tr>
<tr>
<td>General scope</td>
<td>Guideline scope, adult application, child &amp; youth application</td>
</tr>
<tr>
<td>Physician role</td>
<td>Physician or cardiologist role, teach self monitoring</td>
</tr>
</tbody>
</table>

**Type of Physical Activity**

Code 1: Level of aerobic/dynamic exertion

1 = All types of aerobic/dynamic activity, including very strenuous aerobic/dynamic activities, allowed

2 = All light or moderate intensity aerobic/dynamic activities, but not strenuous aerobic/dynamic activities, allowed

3 = Only light intensity aerobic/dynamic activities are allowed

4 = Aerobic/dynamic physical activity is not allowed

5 = Level of aerobic/dynamic exertion is not mentioned

Code 2: Level of muscular strength/static exertion

1 = All types of muscular strength/static activity, including very strenuous muscular strength/static activities, allowed

2 = All light or moderate intensity muscular strength/static activities, but not strenuous muscular strength/static activities, allowed

3 = Only light intensity muscular strength/static activities are allowed
4 = Muscular strength/static physical activity is not allowed
5 = Level of muscular strength/static exertion is not mentioned

**Psychological Influences**

Code 3: Level of competition
1 = All types of sports, including competitive sports, allowed
2 = All recreational sports, but not competitive sports, allowed
3 = Unorganized physical activity allowed but no organized sports (competitive or recreational) allowed
4 = Level of competition is not mentioned

Code 4: Voluntary participation
1 = All types of activity are allowed
2 = Participation is allowed in activities where the participant can voluntarily choose to stop their involvement (temporarily or permanently) at any time but not in activities where there may be rules or social pressure to continue participating beyond what the participant feels is appropriate
3 = Level of voluntary participation is not mentioned

**Potential for Injury**

Code 5: Amount of body contact
1 = All types and forces of body contact allowed
(revised to: All types and forces of body contact allowed unless restrictions are required because of cardiac factors other than the Fontan surgery (e.g., implants))
2 = Only light or moderate, unintentional body activities are allowed
3 = Only light unintentional body activities are allowed
4 = Physical contact is not allowed
5 = Amount of body contact is not mentioned
Influence of Treatment

Code 6: Guidelines differ for implants (pacemaker, defibrillator)
1 = Yes, guidelines differ for those with implants
2 = No, guidelines do not differ for those with implants
3 = Guidelines for implants are not mentioned

Code 7: Anti-coagulation medication use
1 = Activity guidelines apply to all patients, regardless of medication use
2 = Activity guidelines apply to all patients, except those taking anti-coagulation medication
3 = Activity guidelines apply to patients taking anti-coagulation medication
4 = Anti-coagulation medication use is not mentioned

Code 8: Anti-hypertensive medication use
1 = Activity guidelines apply to all patients, regardless of medication use
2 = Activity guidelines apply to all patients, except those taking anti-hypertensive medication
3 = Activity guidelines apply to patients taking anti-hypertensive medication
4 = Anti-hypertensive medication use is not mentioned

Code 9: Ventricular function medication use
1 = Activity guidelines apply to all patients, regardless of medication use
2 = Activity guidelines apply to all patients, except those taking ventricular function medication
3 = Activity guidelines apply to patients taking ventricular function medication
4 = Ventricular function medication use is not mentioned

Level of Authority/Recognition

Code 10: Authorship
1 = Position statement of recognized national or international organization
2 = Report of consensus conference or expert panel
3 = Research study by a small group of authors
4 = Review or opinion of a small group of authors
Code 11: Rhetoric for aerobic or dynamic exertion recommendations
1 = Claims (makes a claim)
   (revised to: Makes a claim without any supporting data or references to other publications)
2 = Backings (provides support backing a claim)
   (revised to: Provides references to other publications or other support backing the claim)
3 = Data (statement of data)
   (revised to: Provides data from the authors or other publications within the article being reviewed)
4 = Qualifiers (qualifies a claim or backing)
5 = Rebuttal (rebuts a claim or backing)

Code 12: Rhetoric for muscular or static exertion recommendations
1 = Claims (makes a claim)
2 = Backings (provides support backing a claim)
3 = Data (statement of data)
4 = Qualifiers (qualifies a claim or backing)
5 = Rebuttal (rebuts a claim or backing)

Code 13: Argumentation
1 = Logos (drawing conclusions from premises and observations)
2 = Pathos (stirring the emotions of the audience)
3 = Ethos (display of the author’s or source’s own authority and claim to fame)

Specificity for Fontan circulation

Code 14: Breadth of guideline application
1 = Guidelines specifically for patients who have had the Fontan procedure
2 = Guidelines for patients with congenital heart defects, including those who have had the Fontan procedure
3 = Guidelines for patients with congenital heart defects, excluding those who have had the Fontan procedure
4 = Level of guideline application is not mentioned
**General Scope**

Code 15: Guideline scope
1 = Competitive athletics with regular training and competition only
2 = All types of activity including competitive sport
3 = Recreational and leisure activities and/or exercise training/rehabilitation
4 = Exercise rehabilitation/training only
5 = Guideline scope is not mentioned

Code 16: Adult application
1 = Yes, guidelines apply to adults
2 = No, guidelines do not apply to adults
3 = Adult application is not mentioned

Code 17: Child or youth application
1 = Yes, guidelines apply to children and/or youth
2 = No, guidelines do not apply to children and/or youth
3 = Child or youth application is not mentioned

**Physician Role**

Code 18: Physician or cardiologist role
1 = Cardiologist explains activity options and restrictions
   (revised to: Cardiologist counsels about activity, such as options and/or restrictions)
2 = Cardiologist explains restriction but not options
3 = Cardiologist does not explain, role of general practitioner
4 = General practitioner or cardiologist does not explain
5 = Physician role not mentioned or not specified
Code 19: Teach self monitoring
1 = Yes, suggestions for methods of self-monitoring activity intensity are provided
2 = No, suggestions for methods of self-monitoring activity intensity are not provided

Code 20: Comprehensive screening recommended
1 = Yes, for competition or high intensity physical activity only
2 = Yes, for competitive or recreational physical activity
3 = Yes, for recreational physical activity but not competitive physical activity
4 = No, not recommended regardless of type of activity
5 = Not mentioned
Appendix G: Titles and Sample Relevant Text of Content Analysis Articles

American Heart Association Expert Panel on population and Prevention Science, Councils on Cardiovascular Disease in the Young, Epidemiology and Prevention, Nutrition, Physical Activity and Metabolism, High Blood Pressure Research, Cardiovascular Nursing, and the Kidney in Heart Disease; and the Interdisciplinary Working Group on Quality of Care and Outcomes Research. Cardiovascular Risk Reduction in High-Risk Pediatric Patients. Circulation, 2006, 114, 2710-2738.

Congenital Heart Disease

Tier III, At risk, high-risk setting for accelerated atherosclerosis: epidemiological evidence
Assess cardiovascular risk factors/comorbidities (fasting lipid profile, smoking history, family history of early CAD in expanded 1st-degree pedigree (M<=55y, F<=65y), blood pressure interpreted for age/sex/height, BMI, fasting glucose, physical activity history) If less than two of: BMI<=95th %ile for age/sex & BP < 95%ile+5mmHg for age/sex/ht %ile + LDL cholesterol <=160mg/dL + FG < 100 mg/dL, HgbA1c < 7%, then counsel healthy lifestyle modifications

Traditional Risk Factors/Comorbidities

All the known risk factors for accelerated atherosclerosis will occur at the same incidence as seen in the general population. In the setting of a repaired congenital defect, these may represent even more potent harbingers of premature cardiovascular disease. Some children with repaired congenital heart defects may have limitation in their ability to perform physical activity. A sedentary lifestyle is an independent risk factor for accelerated atherosclerosis. In addition, such children may be even more prone to obesity in our current obesogenic environment.

Cardiac rehabilitation has been shown to improve the exercise performance of children with congenital heart disease, even those with known residual cardiac dysfunction. Published guidelines can be used to determine the level of exercise considered appropriate for specific congenital diagnoses.
Recommendations for Children With Congenital Heart Disease

Because children with congenital heart disease have other abnormalities that may make the heart more vulnerable to both the development of atherosclerosis and the adverse sequelae of a cardiovascular event, it seems prudent to be aggressive about the evaluation of their cardiovascular disease risk status. This is particularly true of those with the congenital cardiac defects presented above. Children, adolescents, and young adults with these specific congenital heart diseases are at risk (tier III) for premature cardiovascular disease. The algorithm in the figure and Table 2 provide specific management guidelines. Future research will clarify which additional congenital cardiac diagnoses require specific attention to cardiovascular risk reduction.


6.4 Physical activity/sport

Participation in sports and regular physical exercise have well documented beneficial effects on fitness, psychological well-being, confidence and social interaction as well as on the later risk of acquired cardiac disease. Recommendations on exercise in grown-ups with congenital heart disease need to be based on the ability of the patient as well as on the impact of physical training on cardiac haemodynamics (e.g. ventricular remodelling, myocardial ischemia). Counselling should include an appreciation of the type of energy expenditure involved in different sports and teaching of a method to enable the patient to limit his or her activities (Table 2). These include the Borg scale of perceived effort, a target heart rate range (60–80% of maximum heart rate achieved during testing without symptoms or haemodynamic deterioration) and a simple breathing rule (activity can be carried out safely as long as breathing still permits comfortable speech). Impact sport should be avoided in patients with Marfan’s syndrome or other aortic anomalies, those on oral anticoagulants or those with pacemakers. Formal testing, assessing the impact of exercise levels relevant to the patients’ expectations during normal day life, should be
undertaken and protocols derived from conventional adult exercise testing programmes need to be adapted. Doctors should use these results in discussion with patients. In general, medical practitioners are conservative and are often unnecessarily proscriptive in their recommendations; this may have important adverse effects on quality of life. Exercise may have acute, chronic and potentially harmful haemodynamic effects in patients with congenital heart disease. These include fluid depletion, blood pressure rise or fall, tachycardia and/or arrhythmia as well as long-term effects on ventricular hypertrophy and function. Of most concern is the risk of sudden death during or after exercise. Most cases of sudden death during physical activity in the young are due to a previously unrecognized cardiac disorder and sudden death in patients with known congenital heart disease is very rare (1 in 10 000 patients in a recent survey in nine specialist centres for grown-ups with congenital heart disease). Potentially lethal situations may occur with arrhythmia and haemodynamically vulnerable circulations (e.g. preload jeopardized circuits such as after Mustard/Senning or Fontan operation or with heart failure. Advice to perform social exercise to a level of comfort, but not to attempt competitive sports is applicable in most situations.

Fontan

13. Sport/physical activity

- recreational sports only


The focus of this 36th Bethesda Conference is the trained athlete with an identified cardiovascular abnormality. The goal is to formally develop prudent consensus recommendations regarding the eligibility of such individuals for competition in organized sports, and to present these considerations in a readily usable format for clinicians. This document constitutes an update of the 16th (in 1985) and more recent 26th (in 1994) Bethesda Conferences.
As before, we define the competitive athlete as one who participates in an organized team or individual sport that requires regular competition against others as a central component, places a high premium on excellence and achievement, and requires some form of systematic (and usually intense) training. Therefore, organized competitive sports are regarded as a distinctive activity and lifestyle. An important component of a competitive sports activity concerns whether athletes are able to properly judge when it is prudent to terminate physical exertion. For example, the unique pressures of organized sports do not allow athletes to demonstrate strict control over their level of exertion or reliably discern when cardiac-related symptoms or warning signs arise. However, the panel recognizes that this definition is most easily applied to high school, college, and professional sports. Clinicians may want to use individual judgment in defining competitive forms of physical activity for participants in many youth sports activities, particularly those for children less than age 12 years. Athletes may be regarded as competitive in many sporting disciplines—at almost any age or level of participation, including involvement in high school, college, professional, and master’s sports. The recommendations in this document do not apply to (and are not specifically designed for) non-competitive recreational sports activities; such appropriate guidelines appear elsewhere. Nevertheless, we also recognize that some practitioners will choose to extrapolate or translate the recommendations for competitive athletes selectively to some recreational sports, and to non-athletes with occupations that require vigorous physical exertion (e.g., firefighters or emergency medical technicians), or to cardiac rehabilitation programs. Furthermore, it is emphasized that these Bethesda Conference recommendations should not be regarded as an injunction against physical activity in general; indeed, the panel recognizes the well-documented health benefits of exercise. In particular, regular recreational physical activities should be encouraged. Excessive and unnecessary restrictions could potentially create physical and psychological burdens (particularly in young children).

Postoperative Fontan operation.

The Fontan operation is characterized by systemic venous return bypassing the right ventricle. The operation is used for the long-term palliation of patients with tricuspid atresia or other complex types of single ventricle. Although many patients improve clinically after the Fontan operation, they usually have limited exercise capacity and reduced cardiac output at rest and during exercise. Postoperative arrhythmias have been associated with significant morbidity and
mortality. Diagnostic evaluation before sports participation should include a chest radiograph, ECG, echocardiography or CMR, and exercise testing with oxygen saturations.

Recommendations:

1. Athletes can participate in low-intensity competitive sports (class IA).

2. Athletes can engage in class IB sports if they have normal ventricular function and oxygen saturation.


Overprotection is common in children with CHD. The resulting sedentary lifestyle leads to diminished physical work capacity and places them at risk for early development of cardiovascular disease and other illnesses associated with physical inactivity. Children have a natural need for motor activities and this should not be interrupted or discouraged. Perception and motor activities in children with CHD are catalysts not only for the child’s physical development but also for the emotional, psychosocial and cognitive skill. As regards adolescents, we know that physical activity in youth is a major predictor of maintained fitness throughout life. International recommendations suggest at least 60 min of moderate to vigorous physical activity daily. On the other hand not all adolescents with CHD are eligible for competitive sport. If the adolescent needs to be restricted in his or her physical activity, information about this should be given at an early adolescent stage (10–12 years), allowing both the child and the parents to adapt to the new rules before things get too serious. The purpose of this review is to give the reader a comprehensive, though practical, tool to guide patients with all relevant CHD, including both children and adults, in leisure and competitive sport participation. The recommendations represent the consensus document of an international expert panel appointed by the European
Society of Cardiology. The recommendations are based on published scientific evidence, if available, and on the personal experience of the contributing authors.

Table 1

Eligibility for non-restricted participation in competitive sports in congenital heart disease patients: Univentricular hearts are not eligible.

Classification of sports

Sports are usually classified as isotonic/dynamic or isometric/static and to the level of intensity. Our group previously reported an overview of the commonest sports in Europe in respect to the classification above. In general static exercise causes mainly pressure overload and can be difficult to control and is therefore less suitable than dynamic exercise in patients with CHD.

Univentricular hearts/Fontan circulation

Single ventricle function is most commonly a result of double inlet ventricles, atrioventricular atresia or hypoplastic left or right heart syndrome. With only one pumping chamber the systemic venous return is passive, bypassing the heart. Patients with Fontan circulation all have moderate to severe impaired exercise capacity. MaxVO2 is in the range of 15–30 ml/kg per min in most studies. This is due to reduced cardiac output response to exercise, abnormal heart rate response both during exercise and in the recovery phase, lower oxygen saturation due to shunting at different levels and abnormal ventilatory response. Although arrhythmias are common in these patients, exercise has not been shown to trigger fatal episodes. As regards exercise recommendation, these patients are not eligible for competitive sport. They benefit from regular light and moderate strenuous sport. See also Table 2.

Table 2

Recommendations for sport participation in congenital heart diseases

Univentricular Hearts/Fontan circulation

Low to moderate dynamic and low static sports
Genetic cardiovascular diseases (GCVDs) include hypertrophic cardiomyopathy (HCM), arrhythmogenic right ventricular cardiomyopathy (ARVC), Marfan syndrome, and the ion-channel diseases, including long-QT syndrome (LQTS), Brugada syndrome, and catecholaminergic polymorphic ventricular tachycardia (CPVT).

The practicing clinician is frequently confronted with the dilemma of designing non-competitive exercise programs for those athletes with GCVDs after disqualification from competition, as well as for those patients with such conditions who do not aspire to organized sports. Indeed, many asymptomatic (or mildly symptomatic) patients with GCVDs desire a physically active lifestyle and participate in recreational and leisure-time activities to take advantage of the many established benefits of exercise. Recently, published guidelines have focused narrowly on individuals participating in recreational sports settings such as health and fitness facilities or in Master’s sports competition. The conflict between the known benefits and potentially adverse consequences of exercise and the desire of young individuals to participate in various levels of physical activity creates a demand for appropriate information to resolve such uncertainty. At present, no systematic practice recommendations are available concerning the risk of recreational (non-competitive) exercise in adolescents and young adults with GCVDs. Therefore, there was a clear and present need to develop the present consensus recommendations governing recreational exercise for patients with known GCVDs. It is the aspiration of the panel that this document will be useful for cardiology subspecialists and practicing clinicians in pediatrics, internal medicine, primary care, or sports medicine. Conversely, individuals participating in a variety of informal recreational sports and circumstances engage in a range of exercise levels from modest to vigorous on either a regular or an inconsistent basis, which do not require systematic training or the pursuit of excellence and are without the same pressure to excel against others that
characterizes competitive sports. The lack of systematic athletic conditioning in the definition of recreational sports is expected to decrease the risk of cardiovascular events.


Given the severity of univentricular heart disease, obesity and overweight (in 15.9% of the Fontan group) in this high-risk population are likely to have a negative impact secondary to the risks associated with increased afterload and ventricular mass. Pediatric cardiologists are frequently asked to provide recommendations for physical activity restriction in their patients with congenital and acquired heart disease or potentially life-threatening arrhythmias. These recommendations are extrapolated from published guidelines for competitive athletics in children with heart disease. In a retrospective study reviewing patients over a median of 8 years, Stefan et al reported that activity restriction in children with congenital heart disease was associated with the development of obesity. Even children who were of healthy weight at baseline had a higher risk of becoming obese over time if their activity was restricted. Physical activity limitation is a risk factor unique to children with heart disease. Importantly, physical activity restrictions in children with heart disease are not solely determined by practitioner recommendations. Indeed, these limitations may sometimes be initiated by parents or be self-imposed. Children with heart disease are often sedentary even when not limited by their physiology. Massin et al reported recently that children who had undergone the arterial switch operation were much less likely than their peers to participate in moderate or vigorous activity even when no restrictions had been placed by their cardiologists. Decreased activity may lead to deconditioning, decreased exercise capacity, and lower quality of life. A sedentary lifestyle associated with congenital heart disease is known to carry into adulthood and predict increased morbidity and mortality in this population. Several recent studies have shown the benefits of physical training programs in both adults and children with congenital heart disease. Practitioners may need to refocus counselling during outpatient visits, providing careful instructions for appropriate and safe exercise regimens with regard to the underlying condition, in addition to more traditional counselling regarding exercise restrictions. Given the fact that patients with acquired and congenital heart disease have
not escaped the epidemic of obesity, it is especially important for practitioners to adapt current activity guidelines from the American Heart Association and Bethesda conference for this purpose.

Conclusions

Obesity is a common significant additional risk factor for long-term cardiovascular disability in children with congenital and acquired heart disease, a population that is already at increased risk of shortened life expectancy. Although this study has important implications for the practice of outpatient paediatric cardiology, additional investigation is required to identify both common and potentially unique contributors to this problem, such as formal or perceived exercise restriction. Additional study is also required to truly understand the impact of overweight on the long-term outcome and cardiovascular health of children with underlying heart disease. Appropriate interventions for obese pediatric cardiac patients need to be developed. Given the known benefits of normal weight and exercise participation, advising against inactivity, obesity, and other unhealthy lifestyle choices and communicating these concerns to the referring physician should be important parts of the paediatric cardiologist’s care of children with cardiac disease.


Abstract

AIM: To review exercise performance and exercise habits in patients with congenital heart disease (CHD). BACKGROUND AND METHODS: Physical exercise and physical activity has shown beneficial effects on the physical, psychological and social level in adult patients with cardiovascular disease. Favourable effects have also been documented in children with CHD. Exercise testing is preferentially performed on a treadmill in children, with the measurement of gas exchange. RESULTS: An overview of the literature showed that formal exercise testing has frequently documented reduced or suboptimal values for aerobic exercise performance in children with left-to-right shunts (atrial septal defect, ventricular septal defect), valvular heart
disease and obstructive anomalies (aortic stenosis, pulmonary stenosis, coarctation of the aorta). Subnormal values for exercise tolerance have also been observed in patients with successfully repaired cyanotic heart disease (tetralogy of Fallot, transposition of the great arteries, Fontan operation). An important contributing factor to the impaired exercise performance is the hypoactive lifestyle, as often observed in patients with CHD. This frequently results from parental or environmental overprotection. CONCLUSION: These patients should be stimulated to be physically active, unless medical restriction is imposed. Fortunately, this represents only a small fraction of the total number of congenital heart defects for which sports participation is allowed.

Introduction

The beneficial effect of physical exercise on the cardiovascular system has been documented in many reports, both in healthy individuals as well as in patients with cardiovascular disease. Physically active individuals are known to have a lower incidence of ischemic heart disease and a greater life expectancy. Regular physical exercise has also been shown to have a beneficial long-term effect in patients with congenital heart disease (CHD). Despite this evidence a large number of patients are physically inactive because they are overprotected by their parents and their environment. The main reason for this attitude is the fear of sudden cardiac death, although only a small number of cases have been reported during physical exercise in patients with CHD. On the basis of this experience, children with CHD are currently encouraged to be normally active and to participate in recreational sport activities, also after corrective cardiac surgery. These recommendations are based on the experience that physical exercise in children with CHD has favourable effects on the physical, psychological and social level, both for the children as well as their parents. In the majority of cases, these children do not need to participate in formal rehabilitation programmes. Even after corrective surgery, formal rehabilitation is mostly restricted to the hospitalization period, and consists mainly of chest physiotherapy (breathing exercises) and early mobilization. As soon as the children are discharged from the hospital, they are encouraged to resume their normal physical activities at home, and are stimulated to be as active as their healthy peers. There are only a few contraindications to exercise for non-operated cardiac defects as for operated defects. The final decision to allow a child with CHD to participate in physical exercise should always be based on a full cardiological evaluation. A few
controlled studies in patients with CHD have shown that maximal exercise capacity can be improved after a period of physical training. Cumulative medical experience has shown that the risk of physical exercise in patients with CHD is very low. Only a few defects (hypertrophic cardiomyopathy, congenital abnormalities of the coronary arteries, aortic stenosis y) have been associated with sudden cardiac death during physical activity. Fortunately, these anomalies represent only a small percentage of the total number of congenital heart defects for which sport participation is allowed.

Assessment of the habitual level of physical activity in children with congenital heart disease

The reported hypoactive lifestyle in children with CHD, which is frequently present during daily life, is often the result of overprotection by the parents or relatives. In the majority of cases no medical restriction is imposed on the patients being fully active. A medically imposed restriction on competitive sports is justified for a number of pathologies, such as aortic stenosis, obstructive cardiomyopathy and malignant arrhythmias. Despite this, previous studies on patients with a small left-to-right shunt showed a significantly decreased level of physical activity when assessed with a standard questionnaire. This decreased activity level correlated with reduced aerobic exercise performance. This reduced activity level is considered to be incidental to the disorder. A low level of physical activity is also generally found in patients with unoperated aortic stenosis, but this results from a medical restriction on performing intensive and competitive exercise and sports.

Fontan operation

In a number of conditions there may be a single functioning ventricle, such as in tricuspid atresia. To survive, a communication between the caval veins and the pulmonary artery is made, bypassing the right ventricle. This means that there is no effective right ventricular pump. Although the survival of these patients is dramatically improved, the majority of them have a strikingly reduced exercise tolerance. In a study by Driscoll et al. the maximal exercise performance in this patient group amounted to only 37% of the normal control value.

Exercise recommendations in patients with congenital heart disease
As it is impossible to predict how much energy will be expended by an individual patient when practising exercise or sports, some general guidelines can be formulated for different pathologies. Recommendations are generally based on clinical experience, which has shown that physical exercise has beneficial effects on the physical, social and psychological level in children with CHD. A classification of the intensity of sports has been made by the American College of Cardiology. Exercise intensity is classified as low, moderate and high dynamic with a low, moderate and high static component. Detailed tables with typical sports have been published elsewhere. Exercise recommendations as formulated by the European Society of Cardiology are presented in Table 1*. These recommendations are intended to support the clinician and to offer some guidelines in making clinical decisions. An easy rule to define a safe exercise intensity is the use of the ‘talk test’. This means the children should exercise at an intensity level at which they still are able to talk to their peers or parents during exercise.

* There is no mention of guidelines for Fontan patients within Table 1 content.


Abstract

It is well documented that children with a Fontan circulation have a reduced exercise capacity. One of the modalities to improve exercise capacity might be exercise training. We performed a systematic literature review on the effects of exercise training in patients with a Fontan circulation. Six published studies were included that reported on the effects of exercise training in 40 patients. All studies had a small sample size and/or did not include a control group. Based on the six published studies we can conclude that children who have undergone a Fontan operation and who are in a stable haemodynamic condition can safely participate in an exercise training programme and that exercise training results in an improved exercise capacity. However, more research is needed to establish the optimal exercise mode, dose-response
relation, and the effects of exercise training on cardiac function, peripheral muscle function, physical activity, and health-related quality of life.

Rationale/Background

Patients with a Fontan circulation who are in good condition are advised to participate in regular low intensity aerobic exercise to increase their physical fitness. However, in another study the combination of strength and aerobic exercises was advocated. These differences in exercise programming highlight the need for a better understanding of the trainability in Fontan patients and the need for practical exercise guidelines.

As exercise capacity is an important predictor of health outcome and survival in adult patients with cardiovascular disease,24 children with pulmonary diseases, as well as in healthy subjects, the purpose of this systematic review is to summarise the effects of exercise training in patients with a Fontan circulation and to provide practical guidelines concerning exercise counselling for the practitioner.

Picchio FM, Giardini A, Bonvicini M, Gargiulo G. Can a child who has been operated on for congenital heart disease participate in sport and in which kind of sport? Journal of Cardiovascular Medicine (Hagerstown), 2006, 7, 234-238.

Exercise training and sports participation is an important part of the physical, psychological and metabolic growth of any child and adolescent, and this is also true for patients with congenital heart disease (CHD). As one can expect, exercise tolerance varies widely according to the CHD and to the treatment received, but the functional result achieved in the single patient is more important. Individual counselling is necessary and should be based on observations/results of thorough cardiovascular assessment. Exercise testing is the ideal tool to identify patients in whom exercise may induce arrhythmias or haemodynamic instability. In general, some degree of aerobic, isometric exercise training can be granted to most patients operated on for CHD. Serial evaluations may be required because of changing haemodynamic and functional status with time.

General considerations
Because of its beneficial effects, exercise training is nowadays considered as an integral part of the therapeutic programme of rehabilitation of the patient with heart disease. The recommendation for exercise training regarding the type, the intensity, and the modality of exercise, largely depends on the individual functional condition and on the arrhythmogenic risk. These general rules are also valid for patients operated on for congenital heart disease (CHD). In this particular population of children and adolescents, physical activity and sports competition have an important educative and formative role, both from strictly physical and psychological points of view. In general, CHD can be divided into two main categories: 'simple' CHD, that can be effectively cured by surgical or transcatheter treatment, and 'complex' CHD, in which the heart lesion can be treated with palliative surgery and only sometimes be truly repaired. The category of simple CHD includes, with some exceptions: atrial (ASD) and ventricular septal defects (VSD), patent ductus arteriosus (PDA) and pulmonary valve stenosis, especially when these conditions have been treated early in infancy and complete normalization of cardiovascular function can be anticipated. Coarctation of the aorta may often be included in this group if significant sequela is absent. A word of caution is necessary when aortic stenosis/regurgitation is considered, as coping with these lesions during exercise may sometimes be troublesome.

The group of complex CHD includes heart lesions with complex anatomy but capable of anatomical correction, such as the tetralogy of Fallot (ToF) and transposition of the great arteries (TGA) after arterial switch operation (ASO). It also includes complex lesions for which anatomical repair is impossible or has not been achieved and the ultimate result is a palliative repair that restores a normal physiology of the circulation, as in TGA patients after an atrial repair and Fontan palliation for single ventricle physiology. According to these hypotheses, it becomes clear that, even when extremely good technical and functional results are achieved, physical capacity can be very different according to CHD type and treatment, and therefore the recommendations for the modality and intensity of exercise training will be different.

Exercise training and sport competition should be seen in its widest meaning, with a range of intensity that goes from recreational exercise training, to more organized forms of exercise, and to the extreme of competitive sports with its specific regulations. In Italy, consensus recommendations for the selection process for participation in competitive sports have been published to guide sports medicine physicians to judge the eligibility of candidate subjects. A
specific section of these recommendations has been devoted to patients with CHD. Similar guidelines have been proposed by the American College of Cardiology in the USA.

It is known that, from a physiological and metabolic standpoint, exercise training can be classified as aerobic (dynamic or endurance exercise) or anaerobic (with sudden increases in work-load, blood pressure and heart rate). From a practical point of view, exercise training can be classified according to the magnitude of cardiovascular involvement needed in terms of heart rate, blood pressure, cardiac output, peripheral vascular resistances, sympathetic activation and emotional participation. Therefore, the different types of exercise training may range from the one with a prevalent neurogene and emotional component with only slight increase in heart rate, blood pressure and cardiac output, to those with high cardiovascular involvement and substantial increase of heart rate, blood pressure and cardiac output. Generally speaking, in the subject operated for CHD, as in adult patients with other heart lesions, aerobic exercise with slow and progressive increase in heart rate, blood pressure and cardiac output is preferred. In some specific categories (aortic valve disease, pathology of the ascending aorta, systemic ventricular dysfunction) anaerobic exercise, with its typical sudden increase in blood pressure subsequent to increased systemic vascular resistance, should be strongly discouraged. In fact, it can further trigger left ventricular hypertrophy and is associated with increased risk of sudden cardiac death.

In addition to the type of exercise, other factors that influence the overall energy expenditure are exercise intensity and time spent in that particular exercise. For example, in patients with excellent or good anatomical and functional results, exercise training with a low-to-moderate cardiovascular involvement, with a 30-60 minute duration, repeated three times a week is appropriate and recommended.

Therefore, to evaluate which type and which intensity of physical exercise can be tolerated and therefore recommended to the specific patient, a complete clinical and instrumental evaluation is required. The useful tools to accomplish this task are listed here: a knowledge of the type and physiopathology of CHD, treatments performed and potential complications that can be encountered; clinical inspection and presence of symptoms; twelve-lead electrocardiogram and continuous electrocardiographic monitoring; echocardiography; magnetic resonance imaging (especially useful since it provides information about anatomy and function); exercise testing and
cardiopulmonary exercise testing; and an electro-physiological study, in some specific conditions.

Sport participation for children and adolescents operated on for complex congenital heart disease

The results of surgical correction of complex CHD are nowadays excellent and a good quality of life and survival into adulthood can be anticipated for most patients. . . . Evidence exists that, in patients operated on for CHD, arrhythmias often represent a clinical manifestation of haemodynamic sequela.

Fontan operation is intended for definitive palliation of a wide variety of heart lesions with functionally one ventricle. Therefore, Fontan patients represent a heterogeneous group of patients. Indeed, they may have different types of CHD (single or dominant ventricle, one or two atrioventricular valves, of right or left morphology), and they may have undergone different surgical techniques (atrio-pulmonary connection, intra-cardiac or extracardiac total cavo-pulmonary connection). Functionally, in the Fontan circulation, there is no sub-pulmonary ventricle and the systemic ventricle has an increased afterload. Moreover, especially when there is a dilated atrium included in the Fontan circuit, total vascular resistance can be further increased and a lack of preload can take place. In this condition of limited preload, the increase of cardiac output during exercise depends only on an appropriate increase in heart rate.

Data from our own and other centres show that exercise capacity is markedly reduced in Fontan patients as early as in the second decade of life (Fig. 2) and there is a progressive trend to reduction thereafter (Fig. 3). Specific factors that can lead to severe exercise intolerance in this setting are the presence of sinus node dysfunction and bradycardia, ventricular dysfunction, especially if the systemic ventricle has a right morphology. Due to these limitations, Fontan patients in good condition should be encouraged to only take part 'in aerobic, low-intensity sport activities.

Conclusions

In children and adolescents, as well as in the young adult operated on for CHD, physical exercise and sport practice have an important beneficial effect on cardiorespiratory function and on psychological and general well-being. Therefore, in general, some recreational, non-competitive,
preferably aerobic exercise training should be permitted and encouraged. The intensity of exercise training should be adapted according to the specific lesion in question and to the functional result obtained. Competitive sports with medium to high levels of cardiovascular involvement should be reserved for selected individuals in excellent functional condition; that is, mainly those patients that have been 'cured' by medical or surgical treatment. Some patients successfully treated for aortic coarctation or aortic valve disease and who have an excellent functional status can also be eligible for competitive sports, but limited to those sports with aerobic, purely isotonic physiology. Patients with complex CHD should be carefully evaluated, taking into account not only aerobic capacity and functional status but also the risk of exercise-induced arrhythmias. If in excellent/good condition, some type of non-competitive low-intensity sport activity can be allowed under regular medical supervision. In selected cases of repaired ToF patients, eligibility for competitive sports with mild-to-moderate cardiovascular involvement can be considered. Children and adolescents with a physiological, non-anatomical repair, such as those with atrial repair for TGA or those with Fontan physiology, are eligible for low-to-moderate-intensity recreational activities if in good functional status. As a general important rule, type and intensity of exercise and sport activities should be tailored individually, especially in those patients with haemodynamic residua, poor functional condition and increased arrhythmic risk. Cardiopulmonary exercise testing represents the ideal test in this setting since it can measure global cardiovascular performance, and provides information about the intensity and duration of exercise that can be suggested to the patient. Finally, all operated patients should be re-evaluated every 6-12 months to assess the persistence of eligibility criteria for participation in competitive and non-competitive sports.


The success of surgery for congenital heart disease which has been performed since many years has created a population of patients who require careful follow-up in order to determine their clinical progress and to establish the type and intensity of physical activity which they can safely perform. The authors illustrate the opinion of the European Community regarding children, sport
and organizational aspects and also problems concerning the management of pediatric cardiac patients in Europe and Italy. Cardiological and surgical aspects are considered together with the practice of physical activity, with emphasis upon the differences between the various countries. Particular attention is paid to the Italian legislation regarding the certification to participate in competitive or non-competitive sport in such a population of patients. Great importance is given to paediatric cardiac rehabilitation programs which aim at improving the aerobic fitness of patients operated upon for complex congenital heart disease and at illustrating their own cardiovascular limitations so that they can perform physical exercise with the utmost safety.

In Italy, the legislation regarding sports and health is very strict. The law defines two kinds of activity, competitive and non-competitive sports. With regard to competitive sport, there is activity performed within a tournament and recognized by a league. This level of sport involves training during the week and games during the weekend and necessitates a higher physical and psychological effort by the participant. Two committees, one of the Italian Society of Sports Cardiology and one of the Italian Society of Pediatric Cardiology, have produced, in the last few years, guidelines for the correct management of these patients in relation to the practice of physical activity, both competitive and non-competitive.

In children with complex congenital heart disease (tetralogy of Fallot, transposition of the great arteries, etc.), even the most expert heart surgeon cannot completely restore the anatomy of the heart. We have to understand that these patients have been treated but that they have not been cured. It is with this philosophy in mind that the Italian legislation does not permit the practice of competitive sport in these patients. In this context, great importance has been given to paediatric cardiac rehabilitation programs for patients operated upon for congenital heart disease with the aim of improving their aerobic fitness and in order to illustrate their own cardiovascular limitations so that they can achieve the greatest safety during physical activity. However, numerous problems limit these programs, in particular the distance from home to the hospital, the traffic delays and, most important, the family’s desire to make the effort that is needed if their child participates in such a rehabilitation program.

Among young individuals, variously defined as <30 or <40 years of age, the most frequent pathological findings are hereditary or congenital cardiovascular abnormalities, including hypertrophic cardiomyopathy; coronary artery anomalies (e.g., anomalous coronary artery origin, acute angle takeoff and ostial ridges, or intramyocardial course); aortic stenosis; aortic dissection and rupture probably associated with connective tissue defects such as Marfan syndrome; mitral valve prolapse; arrhythmogenic right ventricular cardiomyopathy; and arrhythmias, including those resulting from accessory atrioventricular pathways and channelopathies such as the long-QT syndrome. Myocarditis also is associated with exercise-related deaths in young individuals. Ventricular arrhythmias are the immediate cause of death in these conditions, except for Marfan syndrome, in which aortic rupture is often the proximate cause (Table 1).

Individuals With Diagnosed CHD

The incidence of exercise-related cardiovascular complications among persons with documented CHD has been estimated by at least 5 reports with data derived from exercise-based cardiac rehabilitation programs. Haskell surveyed 30 cardiac rehabilitation programs in North America and reported 1 nonfatal and 1 fatal cardiovascular complication per 34 673 and 116 402 hours, respectively. The rate appears lower in contemporary exercise-based cardiac rehabilitation programs (Table 2) because an analysis of 4 reports estimates 1 cardiac arrest per 116 906 patient-hours, 1 myocardial infarction per 219 970 patient-hours, 1 fatality per 752 365 patient-hours, and 1 major complication per 81 670 patient hours of participation. This low fatality rate applies only to medically supervised programs that are equipped to handle emergencies because the death rate would be 6-fold higher without the successful management of cardiac arrest. Furthermore, patients typically are medically evaluated before participation, which could decrease event rates, as could the serial surveillance provided by rehabilitation staff. Such
considerations support the use of supervised exercise-based cardiac rehabilitation programs for patients after acute cardiac events.


Recommendations for participation in competitive sports in athletes with congenital heart disease

General considerations

Patients with congenital heart disease (CHD) who participate in competitive sports may expose themselves to an upper limit of physical and mental stress. Because the available literature regarding exercise and sports participation in patients with CHD is limited, a restrictive attitude seems wise. As a general recommendation, exercise physical tolerance in children with CHD is better than in adults with CHD, and dynamic exercise seems to be more suitable than static exercise. Some lesions are not compatible with competitive sports, due to their morphologic severity/complexity and tendency to serious arrhythmias, including Eisenmenger syndrome, secondary pulmonary hypertension, univentricular hearts, coronary artery abnormalities, Ebstein anomaly, congenitally corrected transposition of the great arteries, and transposition of the great arteries corrected by the Mustard, Senning, or Rastelli procedure.
Patients with PM

Patients with heart disease and PM implantation can participate only in sports consistent with the limitations of the arrhythmia and the underlying heart disease. Athletes with a PM and no signs of heart disease will be allowed to participate in competitive sports with only minor CV demand, provided that exercise testing and 24-hour holter monitoring show an appropriate increase in the paced heart rate during exercise, and no occurrence of significant arrhythmias. However, subjects with PM should be restricted from sports with a risk of body impact, because of the possible disruption of the electro-catheters and damage to the pacing unit. Furthermore, the possible risk of electromagnetic interferences should be closely evaluated.

Patients with ICD

Most patients with ICD have a cardiac disease which represents per se a contraindication for competitive sports. Indeed, the efficacy of the ICD to interrupt malignant ventricular arrhythmias during exercise remains to be established. Because ICD patients may benefit from low-intensity and supervised exercise programmes, it seems wise that individuals with ICD and no evidence of structural heart disease (or with mild morphologic abnormalities) and preserved cardiac function can be allowed to participate in sports with only low dynamic or static demand, which do not pose a risk of trauma to the device, and do not specifically trigger malignant VTs (such as torsade de pointes in congenital long QT syndrome and polymorphic catecholaminergic ventricular tachycardia). Sports participation can be allowed at least 6 months after the ICD implantation, or after the most recent arrhythmic episode requiring defibrillator intervention (including pacing, antitachycardia pacing, or shock). Furthermore, to reduce the risk of inappropriate shocks related to sinus tachycardia induced by exercise, the cut-off heart rate for the ICD needs to be appropriately set by exercise testing and 24 h Holter monitoring.

Tricuspid Atresia

Symptom/Finding – dyspnoea, intolerance of high-level activity
Activities/Treatments – low-to-moderate level activity, CPET for high-level activity, consider supplemental oxygen
Comments – Usually paired with ASD, Fontan repair (right atrium to pulmonary artery)


Fontan procedure

Exercise

Following the Fontan operation, patients have an abnormal cardiorespiratory response to exercise. They have a decreased aerobic exercise capacity that decreases further with age and a lower-than-normal anaerobic threshold. Multiple factors contribute to the exercise limits experienced by these patients. They have a blunted heart rate response, so their heart rate increases more slowly with exercise and they reach lower maximal heart rates. Their ability to increase stroke volume with exercise is limited and may be related to impaired ventricular function or residual Fontan obstruction. They also experience mild systemic desaturation with exercise, with O2 saturations of approximately 90%. Those with an open fenestration have more pronounced desaturation with exercise. Children should be encouraged to be physically active and allowed to set their own exercise limits. Parents, teachers, and other adults should be aware of the child’s exercise limitations, especially with endurance sports, and provide alternate activities and adequate rest periods.

Physical fitness is becoming increasingly emphasized in our society. Everyone is encouraged to participate in routine exercise, and many desire to compete in organized athletics. Patients with heart disease are living longer, healthier lives and may also desire sports participation. Because selected patients may be at risk for sudden death, a thorough evaluation should be performed. The purpose of this article is to familiarize the reader with basic principles of exercise physiology and preparticipation evaluation and to provide a guideline to recommending athletic involvement in patients with heart disease.

Congenital Heart Disease

Congenital heart disease includes patients with left-to-right shunts, obstructive lesions, and cyanotic heart disease. General preparticipation evaluation for patients in this category who have not undergone surgery includes a complete history, physical examination, electrocardiogram (ECG), echocardiogram, and exercise stress test. Selected patients may require cardiac catheterization for further hemodynamic assessment. Postoperatively, patients require the same thorough evaluation.

Cyanotic Lesions

Patients with surgically corrected tetralogy of Fallot or transposition of the great arteries (atrial or arterial switch) are permitted to participate in all competitive sports if only very mild hemodynamic abnormalities persist. The remainder of patients should be directed toward less strenuous activities. Patients who have undergone the Fontan procedure are restricted to low-intensity sports.

Physical activity

The possibility of performing exercise training is a concern of postoperative congenital heart disease patients and, as a rule, should not be excluded. It has been demonstrated that a program of regular physical activity which is adapted to the postoperative hemodynamic situation, increases working capacity and muscular strength and promotes healthy body development and weight control (55,56). On the other hand, the cardiologist should take care of an excessive or inappropriate physical activity which may have detrimental effects, increasing the risk of re-operation or sudden cardiac death [57,58]. An accurate clinical and instrumental evaluation is therefore necessary and the task force of Italian Society of Pediatric Cardiology has divided postoperative conditions into four classes [24]: Optimal, New York Heart Association (NYHA) class I with ability index 1, trivial or absent hemodynamic residua and sequela, normal right and left ventricular function, functional capacity > 80% of normal, absence of arrhythmias at rest or during exercise test. Good, NYHA class I with ability index 1, mild hemodynamic residua and sequela, normal right and left ventricular function, functional capacity between 71% and 80% of normal, absence of sustained or repetitive arrhythmias at rest or during exercise test eventually on medical treatment. If on pace-maker, it should be throughout checked routinely. Sufficient, NYHA—IA class II with ability index 2, moderate hemodynamic residua and sequela, dilation and/or depressed function of the right or left ventricle, functional capacity between 60 and 70% of normal, presence of repetitive arrhythmias at rest or during exercise test not well controlled by medical treat-merit; high degree atria-ventricular block, sinus node dysfunction with pause <3.5 s, Sid minimal heart rate Poor NYHA class III-IV with ability index 3-4, important hemodynamic residua and sequelae, severe dilation and depressed function of the right or left ventricle, functional capacity reduced = 60%, of normal, presence of repetitive sustained arrhythmias not controlled by medical treatment; high degree atria-ventricular block; sinus node dysfunction with pause >3.5s and minimal heart rate <30beats/ in.

As a rule, sports and/or physical activities featuring isotonic stress are always better than exercises with isometric stress. In some congenital anomalies of the aorta, such as coarctation or
bicupid aortic valve with aortic dilation, participation in sports with a high risk of body collision should be discouraged. Patients in class 1 (optimal postoperative status) can participate in all sports, including competitive levels if the defect was a simple one (atrial septal defect, ventricular septal defect, patent ductus arteriosus, valvular pulmonary stenosis) whereas for more complex defects the acceptable level of physical activity should be evaluated individually considering the type of correction performed. Patients in class 2 (good postoperative status) can participate in non-competitive sport of moderate intensity. Patients in class A (sufficient postoperative status) can perform only physical activities of low intensity (swimming, walking or cycling on flat terrain, simple scholastic ability level gymnastics). Patients in class 4 (poor postoperative status) are discouraged from performing any sort of physical activity as it may be dangerous.


Tremendous advances in the diagnosis and medical, surgical, nursing, and long-term management of congenital heart disease (CHD) have resulted in dramatic improvement in patients' physical status. Although many patients can anticipate a productive life, some individuals may be subject to physical limitations. Comprehensive care is needed to assess and counsel patients with CHD as to appropriate physical activity levels through adulthood. The ultimate goal is to promote and optimize the adolescent's future health and well-being.

The advantageous health benefits of exercise and physical fitness are well documented in the general population. Fitness level influences heart disease directly and indirectly through its effects on blood pressure, serum lipids, and obesity. High levels of physical activity in adults also have been shown to correlate with reduced rates of occurrence, and in some instances regression, of different kinds of cancer, osteoporosis, musculoskeletal injury, anxiety, and depression. With these findings in mind, the American Medical Association (AMA) Department of Adolescent Health has recommended that physicians provide health guidance on an annual basis to all adolescents to promote improved physical fitness.
Adolescents and young adults with heart disease lack knowledge regarding appropriate physical limitations. These individuals perceive their physical limitations as worse than medically indicated, and many patients who should not have been restricted or at most mildly restricted have experienced unnecessary restrictions. Exercise is important for psychological and physical well-being and enhances the quality of life. An individualized exercise prescription should be developed for each patient. Following complete and successful repair of most cardiac lesions, participation in recreational and some team sports is allowed. There are, however, a significant number of sports-related deaths in patients with CHD that are preventable. Because of this risk it is important to understand exercise physiology and the cardiovascular adaptation to exercise in individuals with CHD in order to use the many published recommendations.

THE EFFECTS OF EXERCISE ON SPECIFIC TYPES OF CHD

In 1971 the Council on Rheumatic and Congenital Heart Disease of the American Heart Association formed an Ad Hoc Committee on Habilitation of the Young Cardiac. This committee developed "Recreational Activity and Career Choice Recommendations for Use by Physicians Counselling Physical Education Directors, Vocational Counselors, Parents and Young Patients with Heart Disease." A similar committee updated these recommendations in 1986 in a report entitled "Recreational and Occupational Recommendations for Young Patients with Heart Disease." The 1986 recommendations are tabulated in Table 1.

The committee suggested that recommendations be based on specific detailed knowledge of (1) the demands placed on the circulatory system by various activities, (2) present and future functional state of the circulatory system, and (3) the acute and long-term results of the interaction between (1) and (2).

The guidelines are intended to help patients select occupations within which they can function for maximum duration and make optimum use of their capabilities and interests and to advise patients on physical activity in order to protect them from any potential hazardous effects of overloads of the circulatory system without imposing any unnecessary restrictions.

Implicit in the recommendations is a comprehensive assessment of individual functional capacities. The assessment may use graded exercise testing using a treadmill or bicycle. During
this testing three leads of the electrocardiogram are continuously monitored for heart rate and to
evaluate dysrhythmias, and periodically all 12 leads are reviewed for signs of myocardial
ischemia. The blood pressure is measured before, during, and after exercise to detect either
significant hypertension or hypotension, a sign of limited cardiac reserve. Freed" reports a very
low risk of serious complications, a 1.7% incidence in a high-risk group, and no deaths in
patients assessed with graded exercise testing. Contraindications to exercise testing in
adolescents are acute inflammatory disease, severe systolic hypertension (200/100), uncontrolled
congestive heart failure, acute renal failure, and acute febrile disease. Special consideration
should be given to patients who are at risk for sudden death (Table 2) or those with malignant
ventricular arrhythmias. Patient assessment may also include a recent chest radiograph, stress
electrocardiogram, cardiac catheterization, or electrophysiologic evaluation.

One may wish to augment the assessment of functional status with the use of a set of questions to
evaluate how the progression of the heart defect may have influenced the functioning of the
adolescent. Such questions are found in the Functional Status Index, developed by Stein and
Jessop; the Health Status Index, developed by researchers at the Rand Corporation; and the
Health Interview Survey by Bloom.

Once a full assessment of the individual's physical status is completed, recommendations for
activity limitations also should take into account the severity of a given congenital malformation
and the type and success of all surgical interventions. In addition to deficits listed in Table 1, the
following highlights selected congenital heart defects that may be negatively affected by
incorrect recommendations.

Table 1. Recreational and occupational activity recommendations for adolescents and adults with
CHD

Other major defects (unoperated or palliated only, e.g., tricuspid atresia) III
Other major defects (postoperative intracardiac repair) II

Recreational activity classification
III Light exercise. Activities include nonstrenuous team games, recreational swimming, jogging,
cycling, golf
Moderate exercise. Activities include regular physical education classes, tennis, baseball.

Occupational activity classification

III Medium work. Peak load of 5 to 7.5 cal/min. Involves lifting 50 lb maximum, with frequent lifting and/or carrying of objects weighing up to 25 lb.

II Heavy work. Peak load of 7.6 cal/min and above. Involves lifting 100 lb maximum, with frequent and/or carrying of objects up to 50 lb.


The number of young preadolescent and adolescent boys and girls that are active in American sports increases each year. Most boys and girls will require some type of physical and cardiac evaluation before sanctioned sport participation. Findings from such preparticipation exams may cause physician concerns of a cardiovascular anomaly and result in cardiac consultation. Possible cardiac abnormalities, cardiac concerns, and potential medical-legal liabilities make accurate cardiac evaluation of young athletes a high priority for safe sport participation.

Familiarity with the exercise and conditioning demands of a sport can be helpful for the physician who certifies aspiring youth athletes. Patients with a history of cardiac or pulmonary conditions should have cardiovascular consultation to determine participation levels in most, if not all, sports. Most young athletes with milder forms of congenital and acquired heart disease are able to participate fully in most sports without restrictions.

Individual and team sports have been classified as having low, moderate, and high dynamic and static components for actual competition (Table 3 in article). Acute effects from static (isometric) and dynamic exercise were previously measured and compared by Longhurst and Mitchell. They referenced oxygen consumption, heart rate, blood pressure, cardiac output, and systemic resistance changes over time. Static exercise was measured at 40% capacity, and dynamic exercise was based on increasing the workload by 100 kpm/min for the timed duration. Mitchell
and Rowland have both shown similar responses to exercise challenges in young athletes. When certifying a young athlete for a particular sport, one should appreciate these types of static and dynamic exercise demands.

In some instances, postoperative congenital or acquired heart disease patients will continue to have an increased risk for sudden cardiac death. Those patients with poor hemodynamic surgical results are at greatest risk, with some actually higher than before surgery. Many arrhythmias can develop during the first year after surgery. Patients with postoperative tetralogy of Fallot and transposition of the great vessels with non-arterial switch-type operations most often are associated with sudden death.


Successful treatment of patients with congenital heart disease (CHD), combined with population growth, has increased the likelihood that physicians will encounter these patients during the course of daily practice. Because of the known health and psychological benefits of exercise, determining the safety of exercise and prescribing a rational exercise program are important in the evaluation and management of CHD patients.

Classification of sport activities

Assessing the potential impact of competitive athletics on a patient with CHD requires knowledge of the patient’s particular condition and an understanding of the demands of the proposed physical activity. Exercise is typically classified by the type of exercise, either predominantly dynamic or predominantly static, because the cardiac impact differs significantly. Dynamic exercise such as running requires change in muscle length and joint movement with low intramuscular force, whereas static exercise such as weight lifting imposes a different burden of large intramuscular force and less change in muscle length and joint movement. Dynamic exercise imposes a volume load on the ventricles, whereas static exercise produces a pressure load on the heart and arterial circulation.
Most types of activity can be classified easily by the degree of dynamic and static exercise. For example, bowling is a low-static/low-dynamic activity, whereas, at the other end of the spectrum, decathlon is a high-static/high-dynamic activity. Physicians can use this classification combined with knowledge of the patient’s anatomic abnormality and physiology to decide whether a particular sport should be attempted.

A second consideration in athletics is the potential for collisions during sports. Some patients with CHD may be cleared for sports as long as the potential for collisions is low. For example, patients with Marfan syndrome who lack a family history of sudden death and have no evidence of aortic root dilation can participate in low and moderate sports activity, but they are at increased risk of injury with collisions. Thus, archery and fencing would be acceptable, but football would not be allowed. Similarly, patients recovering from cardiac surgery should not engage in sports with the potential for collision until their incisions have healed, sternal stability is re-established, and postoperative complications such as pericarditis and atrial arrhythmias have resolved.

Tricuspid atresia

Patients with tricuspid atresia are born with an incomplete or absent tricuspid valve, typically in combination with an ASD. Because they lack a functioning right ventricle, surgery is palliative and consists of connecting the right atrium to the right pulmonary artery; the most commonly performed operation is called the Fontan procedure. Because blood flow to the lungs is largely passive, exercise performance in these patients will be reduced, although they may still be highly functional. Exercise performance will be particularly compromised if they develop atrial arrhythmias or LV dysfunction.

Clearance for patients with the Fontan operation to participate in greater than low-level athletics requires exercise stress testing to determine functional status and echocardiography to measure LV function. Oximetry may be combined with exercise stress testing to obtain further objective evidence of functional status.
After a Fontan correction for univentricular heart or complex heart defects, there frequently exists a persistent degree of intolerance to exercise, as well as the appearance of precocious or delayed arrhythmias. Only cases with normal ventricular function, absence of hypoxemia, absence of arrhythmias and good tolerance for exercise, demonstrated by means of a maximal exercise test, will be able to do exercises with a low static load and dynamics, other levels are not advised.

Physical and sport activity in cyanotic congenital heart defects:
1. Not palliated or corrected:
   Sport of competition: prohibited.
   Physical Activity:
   - Low intensity: allowed with low static and dynamic component.
   - Intense: prohibited.
2. Palliated:
   Physical Activity:
   - Little intense: allowed if patient asymptomatic and slight hypoxemia.
   - Intense: prohibited.
   Sport of competition:
   - Little intense: allowed if normal PE and patient asymptomatic.
   - Intense: prohibited.
3. Corrected: the particular criteria will be followed for each cardiopathy.


Cyanotic Congenital Cardiac Disease, Unoperated

In most patients, cyanotic congenital heart disease produces exercise intolerance and progressive hypoxemia with increasing effort. Patients are unlikely to want to engage in competitive sports
because of their self-limiting activity. There are rare patients with cyanotic congenital heart
disease who reach adolescence or even adult life with mild resting cyanosis and shortness of
breath only with exercise. These patients may experience a rapid and profound decrease in
arterial saturation during sports participation.
Recommendation: Athletes with unoperated cyanotic heart disease usually can participate only in
low intensity competitive sports (Class IA), but individualized exercise prescriptions are
recommended.

Postoperative Palliated Cyanotic Congenital Heart Disease

Palliative surgery can be performed to increase pulmonary blood flow in patients with decreased
flow or to limit blood flow in those with excessive flow. Often these patients have significant
relief of symptoms at rest but arterial desaturation during exercise frequently persists.
Recommendation: Athletes can usually participate in low intensity competitive sports (Class 1A)
provided the following criteria are met: a) arterial saturation remains above approximately 80%,
symptomatic arrhythmias are not present, there is no symptomatic ventricular dysfunction,
athletes have near-normal physical working capacity on exercise testing.

Postoperative Fontan Operation

The Fontan operation is characterized by a communication from right atrium to pulmonary artery
without an effective right-sided pumping chamber. The operation is used for the long-term
palliation of patients with tricuspid atresia or other complex type of single ventricle. Although
many patients are improved clinically after the Fontan operation, they usually have limited
exercise capacity, as reflected in reduced cardiac output at rest and with exercise. Postoperative
arrhythmias have been associated with significant morbidity and mortality. Diagnostic evaluation
before sports participation should include chest radiograph, ECG, and exercise testing. If there is
a possibility of ventricular dysfunction, echocardiography and/or other modalities to assess
ventricular function should be used.
Recommendation: Athletes can participate in low intensity competitive sports (Class IA).
Selected individuals can engage in sports of either moderate demand or low static demand if they
have normal or near-normal ventricular function, normal or near-normal oxygen saturation, and
near-normal exercise on formal exercise testing.

For children and adolescents, recreational play and competitive sports provide important psychosocial and biological benefits. Exercise in children has been shown to improve self-esteem and academic performance. In some young people with congenital heart defects, however, exercise may produce cardiovascular dysfunction, generate symptoms, or precipitate sudden death. This article reviews previously published guidelines and presents our recommendations for clinicians responsible for decisions regarding sports participation in children and adolescents with congenital cardiovascular disease.

Sudden cardiac death is the most feared consequence of athletic participation for the young individual with a cardiovascular abnormality. Most cases of sudden death in young athletes are due to congenital heart disease. Intense exercise may cause dangerous arrhythmias in some circumstances. Exercise increases serum catecholamines, which decrease the threshold for malignant arrhythmias. In patients with chronic pressure or volume over-load, repeated exercise may contribute to the processes of myocardial hypertrophy and fibrosis. Myocardial dysfunction can be produced by recurrent intermittent episodes of exercise-induced ischemia, particularly in patients with congenital heart defects characterized by cyanosis, pressure overload, or low cardiac output.

Although intending to minimize risk, exercise and sports participation guidelines can cause difficulties for patients with cardiovascular disease and their physicians because of risks of physical and psychological morbidity resulting from restriction of physical activity. Small, but real, risks of catastrophic complications, even for the entirely healthy participant, are associated with many sports activities (e.g., downhill skiing, hang gliding, football, boxing, or motorcycle racing), but the family or the individual athlete may choose to accept these risks. Risks for a catastrophic outcome for the athlete with a cardiovascular abnormality are analogous in some respects. Some element of risk occurs with every sporting activity. After all of the possible risks have been thoroughly discussed, the final decision to participate in exercise and sports activities usually rests with the athlete and the family.
Physical recreational and competitive sport activities can be classified by dynamic and isometric exercise demands. However, the actual demands generated by any one physical activity depend largely on differences in motivation, effort, and environmental circumstances. A category for activities associated with risks for bodily collision is important because some cardiac patients face special risks from injury or abrupt deceleration, such as patients with Marfan’s syndrome, those treated with anticoagulants, and children with permanent pacemakers.

The Appendix summarizes previous exercise guidelines for this population and presents our personal recommendations for these guidelines.

Classification and Authors’ Recommendations

Fontan
No maximally strenuous dynamic or strenuous isometric exercise. No strenuous dynamic exercise if abnormal exercise test or abnormal 24-hour Holter, exercise arterial saturation < 80%, or CHF.

Previous Guidelines Summarized

Selected patients may participate in some of the less-intense sports of either high-dynamic or high-isometric demands if normal exercise test duration, no arrhythmia at rest or during exercise testing, no ventricular arrhythmia, SVT or severe sinus bradycardia on 24-hour Holter, no CHF, exercise arterial saturation > 80%, and nearly normal LV function.


Sports

It is generally accepted that physical fitness through exercise is important for the optimal physical and psychosocial development of children and adolescents. Regular exercise is not only allowed but should be recommended for most patients affected by congenital heart disease,
however, it is important for patients to know which activities are permitted and which are not. Indeed, insufficient knowledge can lead to the selection of harmful sports or inappropriate restrictions. Focused discussions on appropriate sport and exercise activities can remedy such situations.

Sports such as swimming, cycling, walking, dancing, playing tennis, football, and other activities are considered safe. Generally, performing sports at a rate of 2 to 3 times per week for 1 to 2 hours is recommended. Obviously, there is a large personal variation, therefore, patients should learn to recognize their physical limitations and acknowledge signs of physical overexertion. If a patient experiences symptoms such as chest pain, shortness of breath, palpitations, or dizziness, he or she may stop physical activity immediately and must contact the cardiologist. Competitive sports or those that require heavy lifting are prohibited for some patients such as those with obstructive outflow lesions and pulmonary hypertension.
## Appendix H: Results of Content Analysis Coding

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6 Details of the theoretical concepts and codes are provided in Appendix F.
### Appendix H (cont’d)

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Appendix I: Cardiologist Interview Questionnaire

1. Do you routinely counsel or monitor your patients with congenital heart defects regarding their participation in physical activity? Yes No
   If yes, when and in which patient groups?
   If no, when/how do you provide that information?

2. Do you expect other health professionals (e.g., clinic or in-patient nurses, family doctors) to (also) provide physical activity information to your patients? Yes No
   If yes, who and what types of information?
   If no, why not?

3. Assuming a child has no unusual complications or sequelae, what physical activity recommendations do you make for patients who have the Fontan procedure?

4. Are there particular points in a child’s care when you feel that providing physical activity counselling is particularly important? Yes No (e.g., at diagnosis, at surgical discharge, when medical status changes, teen years)
   If yes, what are the key points from your perspective?

   Would you be willing to provide written information or guidelines about physical activity to your patients? Yes No
   Why or why not?

   If so, can you describe what such a form would look like or what information it would provide?
5. We have analyzed data collected during our previous Fontan study to compare the physical activity recommendations that parents provide to those that were provided to us by the responsible cardiologist. We found that there was no agreement between what the cardiologist specified and what the parents reported. Sometimes the parents were unnecessarily restrictive, but just as often they were unaware of restrictions reported by the cardiologist.

What are your thoughts about reasons for the disagreement we have observed?

6. Do you have any other comments or recommendations related to physical activity counselling that we should consider?

Thank you for helping us with our physical activity research plans