

Physical Activity and Sport Participation in Youth With Congenital Heart Disease: Perceptions of Children and Parents

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This study explored perceptions toward physical activity and sport in the lives of youth with congenital heart disease. Thirteen cardiac participants were interviewed in the presence of their parents, and a process of inductive analysis was conducted. Sport was not considered a valued pursuit despite the belief that it is essential for the attainment of good health. Low-self efficacy and fatigue were influenced by covert fears and exclusion and further decreased the value ascribed to sport and physical activity. Nontraditional activities, support from others, and perceptions of mastery played a crucial role in enabling participation and facilitated the journey toward recovery. Findings are discussed within the context of self-efficacy theory and may inform the design of safe and enjoyable physical activity opportunities for this population.

Approximately one in 100 children in North America are born with congenital heart disease every year; although the precise cause is unknown, genetic and environmental factors play a role in the etiology of congenital heart disease (Smith, 2001; Sparacino et al., 1997). As a result of advances in medicine and technology in recent decades, however, the survival of children with cardiac conditions has increased, and today, 85% of those with congenital heart disease are expected to reach adulthood (Sparacino et al., 1997). Illnesses that were once fatal have now become chronic, facilitating a shift from medical to quality of life related issues (Kiernan, Gormley, & MacLachlan, 2004; McCrindle et al., 2006).

Children with congenital heart disease may be at risk of negative psycho-social sequelae, and, within the larger group of youth with chronic illnesses, are characterized by covert fears and anxieties; low self-efficacy and self-esteem; deficits in

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learning and attention; depression and anxiety; and difficulties with peer socialization and school absenteeism (Bar-Mor, Bar-Tal, Krulik, & Zeevi, 2000; Fredriksen, Mengshoel, Frydenlund, Sorbye, & Thaulow, 2004; Gupta, Mitchell, Guiffre, & Crawford, 2001; McCarthy, Williams, & Plumer, 1998; McCrindle et al., 2006; Wright, Galea, & Barr, 2003). Interventions have been designed to address the rehabilitative and psycho-social needs of children with congenital heart disease and other chronic illnesses. The objective of such programs is to attenuate the negative impact of the illness and increase quality of life (Kiernan et al., 2004).

Physical activity has been suggested as one such method of increasing quality of life in youth with congenital heart disease (Fredriksen et al., 2000; Imms, 2004; Smith, 2001). The cardiopulmonary and musculoskeletal benefits of exercise rehabilitation for this population has been researched extensively (Freed, 1984; Galioto & Tomassoni, 1993; Kaminar, Hixon, & Strong, 1995; Kitchiner, 1996; Longmuir, Tremblay, & Goode, 1990; Rhodes et al., 2005; Tomassoni, 1996). Other research has demonstrated a range of psychosocial benefits associated with physical activity participation. These include increased self-confidence, initiative, and independence (Galioto & Tomassoni, 1993); reduced internalizing scores on the Child Behaviour Check List, that is a psychosocial subscale which assesses withdrawal, somatic complaints, and anxiety/depression (Fredriksen et al., 2000); and enhanced self-perceptions of physical functioning and role functioning due to behavioral and emotional problems (Moons et al., 2005). Conversely, when parents of youth with congenital heart disease were asked to assess their child's physical activity and psychosocial profile, a relationship was found between reduced physical capacity and behavioral and emotional problems (Fredriksen et al., 2004). Overall, the few interventions that do exist have occurred primarily in camp settings, making it difficult to isolate the effects of physical activity on quality of life from other interventions at camp. Furthermore, inconsistent and short-term results, as well as the absence of controlled trials, have plagued existing methodology (Epstein, Stinson, & Stevens, 2005).

Youth with congenital heart disease are less active than their healthy, age-matched peers (Burgess, 2003; Lunt, Briffa, & Ramsay, 2003). A recent study examined the relationship between physical activity levels, functional status, and exercise capacity in 147 patients after the Fontan procedure (staged surgical palliation of congenital heart disease that bypasses the right heart to direct blood into the lungs). Objectively measured physical activity levels were markedly lower in this population, and reduced participation was associated with decreased perceived general health (McCrindle et al., 2007). In a cross-sectional study of 100 adolescents with mild cardiac conditions, self-efficacy was found to be a more important determinant of physical activity participation than objective severity of the cardiac malformation and was influenced by advice received from the cardiologist and attitudes of mothers (Bar-Mor et al., 2000).

There is little research that explores the perceptions of youth with disabilities in general (Goodwin, 2001), and we know less about youth with congenital heart disease. Gupta et al. (2001) do not make direct reference to physical activity but note that children with congenital heart disease report higher levels of covert fears and anxieties. These include general medical fears, fear of injury, fear of "being unable to breathe," and increased physiological anxiety scores. Qualitative studies have illustrated some of the dilemmas faced by parents of youth with congenital

heart disease in considering physical activity options. Sparacino and colleagues (1997) reported that parents find it unsettling to receive ambiguous recommendations from health care professionals regarding their child's overall physical activity participation, and some parents are uncomfortable allowing their children to impose their own physical activity restrictions. Parents also discussed the impact of their child's underdeveloped physical stature and note that despite wanting to encourage sport participation, they are uncertain of how much pushing is required (Sparacino et al., 1997).

Overall, evidence for the physical and psychosocial benefits of physical activity for youth with congenital heart disease is developing (Moons et al., 2005). At the same time, research consistently demonstrates that this population is less active than the general youth population. Understanding the perceptions of these youth toward physical activity will be critical in enabling greater levels of safe and enjoyable participation. A qualitative approach is ideally suited to accessing such "insider" perspectives and generating hypotheses during the course of research in response to issues raised by the participants themselves. Inductive analysis of qualitative data is an effective way to develop theory and understanding, which is firmly grounded in participants' own experience (Creswell, 1998; Wolcott, 1994). It is also necessary to capture issues of variability and contextuality in the lives of individual participants and better understand barriers to participation from the unique perspective of youth with complex cardiac conditions (Faulkner & Biddle, 2004).

Furthermore, it has been suggested that illness must be "studied qualitatively if we are to understand how people make sense of its genesis and its consequences" (Radley, 1999, p. 19). Sensitive methodology that does not limit the possible continua of answers, or restrict participant views, is essential when interviewing children who are ill (Eiser & Twamley, 1999). Rather than imposing a priori assumptions and a deductive framework in advance, themes are allowed to emerge inductively from the data, and in this way, the beliefs, attitudes, and perspectives of participants may be used to inform the design of interventions (Maykut & Morehouse, 1994). This exploratory study, therefore, aimed to investigate perceptions of the role of physical activity in the lives of youth with complex cardiac conditions. Providing these youth with an opportunity to discuss their perceptions of physical activity was seen as critical to helping us, as health scientists begin to develop an understanding of how physical activity opportunities may be better shaped and tailored to their needs.

Method

Participants

Eligible participants were identified from cardiac clinic appointment lists in advance. Patients and families were approached for interviews by the clinical nurse manager or researcher at the end of their appointment at the clinic. In a form of convenience sampling, we recruited thirteen participants between the ages of ten and eighteen over a period of three months. To allow reader transferability, participants were classified into three groups on the basis of objective measures of cardiac disease severity and current cardiac status: Fontan (F), Bi-ventricular Repair- Cure (BVR-c), and Bi-ventricular Repair- Residual (BVR-r). Although no exclusion was made

on the basis of gender, geographical region, socio-economic status of the family, ethnicity, or race, assessments of these social factors was beyond the scope of the present project. Table 1 gives a complete description of all participants, and are indicated with the use of pseudonyms. Twelve patients requested that their parents accompany them during the interviews, and parental presence greatly enhanced their comfort. For this reason, some parents participated minimally during the interviews and are included as participants. Verbal consent was obtained from those parents who chose to participate during the interviews.

This study was approved by the Research Ethics Board at the Hospital for Sick Children (SickKids). SickKids is a pediatric care, research, and teaching hospital affiliated with the University of Toronto and is dedicated entirely to the provision of specialized medical care for sick children. All children were informed of the study in the presence of their parents and were required to give written consent/assent prior to participation. This study was facilitated by the Clinical Leader of the Cardiac Program who, in addition to acting as a liaison between the pediatric cardiologist and the researcher, informed the clinic about the study and introduced the researcher to all cardiac clinic staff. Recruitment measures utilized for this study included posting advertisements in the Cardiac Clinic and Echocardiography lab, sending electronic communication messages to staff members, as well as phone calls to potential candidates.

Table 1 Description of Participants

Pseudonym	Age	Sex	Cardiac Diagnosis	Surgical Procedure	Subgroup
Rory	15	F	-HLHS	-S/P Fontan	F
Carmen	14	F	-DORV	-S/P Rev with PS -S/P PV Implant	BVR-r
Casey	18	M	-TGA	-S/P Jatene Switch	BVR-c
Jesse	14	M	-HLHS	-S/P Fontan	F
Aman	17	F	Hypoplastic RV	-S/P Fontan	F
Maddie	17	M	-TGA	-S/P Arterial Switch	BVR-c
Jaime	11	F	-HLHS	-S/P Fontan	F
Jackie	15	M	-Aortic Atresia	-Yasui	BVR-r
Jayden	14	M	Hypoplastic RV	-S/P Fontan	F
Rudy	10	F	-TOF -Stroke	-S/P Repair	BVR-r
Ayden	13	F	Hypoplastic LV, DORV	-S/P Fontan	F
Dylan	16	F	-TOF	-S/P Repair -S/P PA Stents	BVR-r
Lane	14	M	-CoA	-P/O CoA Repair -P/O sub As repair	BVR-c

Note. TOF = Tetralogy of fallot; HLHS = Hypoplastic left heart syndrome; COA = Coarctation of aorta; d-TGA: Transposition of great arteries; F = Fontan; BVR-c = Bi-ventricular cure; BVR-r: Bi-ventricular repair- residual

Data Collection: Interviews and Field Notes

This exploratory study employed a qualitative design combining semi-structured interviews and a thematic analysis (Biddle, Markland, Gilbourn, Chatzisarantis, & Sparkes, 2001) to investigate perceptions of the role of physical activity in the lives of youth with complex cardiac conditions. Interviews and field notes were the primary sources of data used in this study. A semi-structured interview schedule consisting of broad and open-ended questions was designed by the authors. Social cognitive learning theory (Bandura, 1977) provided the conceptual framework in the development of this schedule. Self-efficacy is a central component of this theory and exerts a powerful influence on learning and behavior by affecting choice of activities and level of motivation. It is not an assessment of the skills that one has, but rather, refers to one's belief in their capabilities to utilize these skills in order to execute an action in a variety of situations. The impact of self-efficacy on behavior is thought to be influenced by four primary factors: mastery and vicarious experiences, verbal persuasion, and physiological and affective states. In keeping with the qualitative nature of this study, the schedule was continually adapted on the basis of each interview. Within each interview, however, general interview topic domains included outcome expectations regarding physical activity and sport participation, self-efficacy, and facilitators and barriers to participation.

After informed consent was obtained, participants engaged in a 45-60 min, audio-taped interview in the Cardiac Clinic treatment room. All interviews were conducted by the first author, who has extensive experience interacting with children affected by chronic illnesses. The first author has volunteered at the Hospital for Sick Children for the past six years in the area of multi-organ transplant, cardiology, and critical care, has established rapport with the Cardiac Clinic both in the hospital and therapeutic camp environment, and is very familiar with this particular pediatric institute. Field notes were also recorded by the first author on a daily basis. Observations of the interview process, individual participants, and the cardiac clinic were recorded in a research journal. Field notes provided support for transcribed data, assisted in the generation of themes, and aided in the development of the final conceptual map.

Results

The audiotaped interviews were transcribed continuously during the data collection phase. Inductive data analysis was employed, which involved a process of close scrutinization of the text in order to be immersed in the data and understand the perceptions of participants. The constant comparative inductive data analysis method (Glaser & Strauss, 1967; Maykut & Morehouse, 1994) was used to identify, code, and organize data into themes that arose from the transcripts. The transcripts were read line by line, and quotations were coded to form the basic units of analysis (Coffey & Atkinson, 1996). The responses that occurred most frequently across all participants were documented in tabular format and used to create provisional themes and categories. Data collection was terminated after the thirteenth interview when "saturation" was met in that no new themes, categories, or subcategories were emerging (Glaser & Strauss, 1967; see also Guest, Bunce, & Johnson, 2006).

This method also allowed for the continued process of comparison and contrast between already identified units of data and newly emerging ones. Newly arising data units were either allocated to existing categories or, if they were dissonant, generated new provisional themes. These provisional categories were refined, and a final thematic analysis and response frequency table was created across the participants in order to indicate the frequency with which the most common categories were relevant to individual participants. Lastly, a broad concept map relating to the role of physical activity in the lives of children and adolescents with cardiac disease was derived inductively from the data and illustrates the interrelationship between the most common categories and variables (see Figure 1). Relationships between these themes in the concept map were grounded in the data (Strauss & Corbin, 1994) and formed the basis of the findings and discussion section of this paper.

Although trustworthiness criteria are referred to inconsistently across the exercise and sport science literature (Biddle et al., 2001), we adopted a number of criteria to enhance the “trustworthiness” of our study. First, an audit trail (Lincoln & Guba, 1985) was developed that consisted of the first author’s field notes,

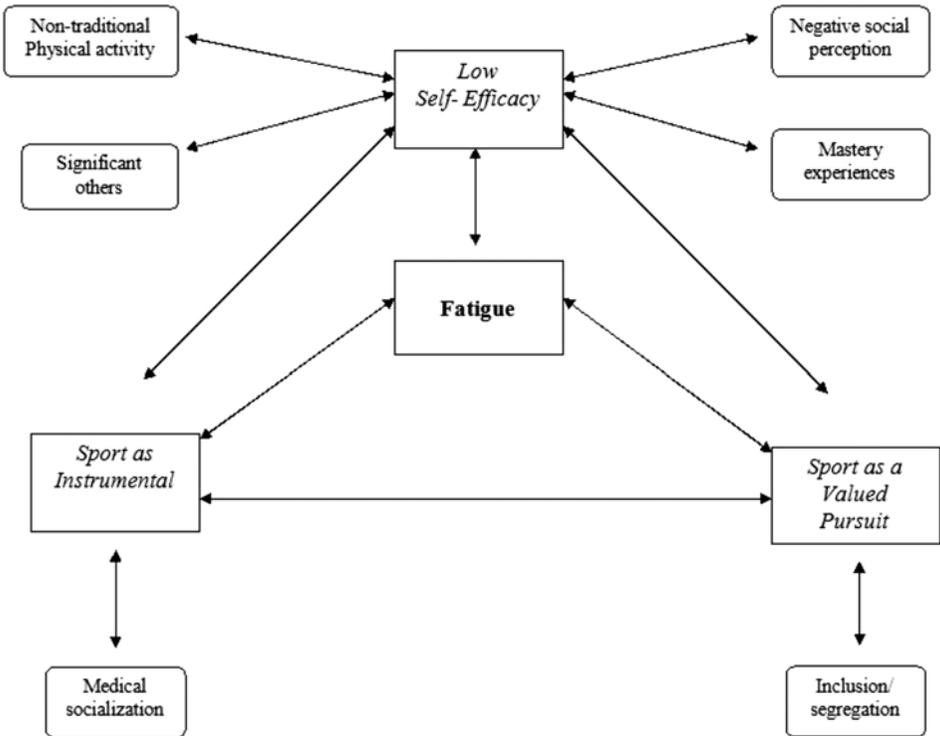


Figure 1 — Perceptions toward sport and physical activity in youth with complex congenital cardiac conditions.

interview transcripts, unitized data, and the concept map. Second, the interview transcripts were also analyzed by the second author. This analysis independently confirmed the four primary outcome themes (see Figure 1) generated through the first author's preliminary analysis. Third, throughout the analysis process, interpretations were also shared and discussed within the research team in order to challenge the identified themes and their connections in a form of peer debriefing (Lincoln & Guba, 1985). Finally, qualitative research is usually characterized by rich description, and narrative is used to more closely represent the experience of participants. Accordingly, we invite readers to ask a range of questions regarding the text. For example, is there enough evidence, in the form of participant voices, to enable the reader to judge our interpretations? Are the findings coherent in that different parts of our interpretation create a complete and meaningful picture (Lieblich, Tuval-Mashiach, & Zilber, 1998)? In terms of authenticity, has the text invited the reader "into a vicarious experience (however brief) of the life or lives being described" (Sparkes, 2000, p. 33). That is, has it provided the reader with a better understanding of youth with complex cardiac conditions and the meaning of physical activity in their lives?

Four interrelated themes as well as their associated variables emerged from this data: (a) sport and physical activity was not a valued pursuit in relation to other, more important activities that youth engaged in; (b) participants indicated low self-efficacy toward being physically active, particularly when engaging in "mainstream" or "traditional sport"; (c) participants displayed an instrumental relationship with sport in which dissonance was evident; participation was only viewed as an important behavior for its instrumental health benefits; (d) physical activity participation was negotiated within an on-going and prevailing experience of cardiac disease related fatigue. Youth with congenital heart disease in this study did not distinguish between sport and physical activity, and for this reason, the terms are used interchangeably throughout.

Sport Not a Valued Pursuit

When questioned about the overall importance of sport and physical activity in relation to other areas of their lives, the majority of participants indicated that it was not a valuable pursuit. Although academics spending time with family and friends and other interests were of higher priority, the reasons as to why sport was not important greatly differed among participants.

For example, sports are "not really that important" for Rory, as educational pursuits are of greater interest. Rory's mother explains that her daughter fell behind academically as a result of the surgical procedures she had to endure as a child. As attention has shifted to helping her to progress academically toward a desired career, sports are less important. School work is more important than physical activity:

Because she has to do catch up. With the surgery she had in elementary, she missed school . . . so she has had to work hard to get back up to the level where she should be. So now she's going toward a career, and she needs to get her academic level to where it should be.

Moreover, responses speak to the role of self-efficacy in determining the extent to which sport is valued. Experiences that provided direct evidence that athletic

efforts were not meeting a desired outcome contributed toward decreased self-efficacy and a change in priorities. Consequently, time and effort devoted toward sport and its value in the lives of youth with cardiac disease has decreased. For example, Jackie suggests that . . .

Sports isn't really high priority on my list, just something fun I like to do. . . . I know that since I'm not that great at sports, I know that I don't have to try as hard, because I know that there probably won't be a career in sports for me.

Aman, Sarah, and Dylan also indicate that sport is not particularly meaningful in relation to the broad range of other activities that are available to them. They express that while sport may be an important and enjoyable pastime for some youth, they prefer to engage in more important activities.

Aman states that "even if I would be able to do it (sports), I would prefer (music) . . . like some people like sports, and some like music." Sarah expresses similar sentiments and explains that "some people like sports, but it's not really interesting when you get into it, no . . . I won't really want to do a lot of sports" (in the future). Dylan also prefers to engage in nonathletic endeavors that are "way more important than sports." Unlike athletic activities, these interests are valuable because they allow for an element of choice and enjoyment. Activities such as singing, computer work, research, and writing are

. . . a good thing to do . . . something that I love to do. I don't do it because I have to, I do it because I want to. . . . I do not always want to go there (gym), and my mom will be like "do you want to go today?" And no I don't want to go—I don't feel like going. So I kind of—I put it off a lot.

For those participants who did value physical activity, participation had been sustained over a long period of time and fulfilled a meaningful social role within the sport setting. Years of experience in horseback riding, as well as the responsibility associated with taking care of her horse are two of the reasons why sports are very important for Carmen . . . "cause I've been doing it so long, and cause I have to look after the horse, cause its owners don't come up that much."

Lastly, although sport was undervalued in this particular sample of participants, segregated physical activity opportunities for youth with cardiac conditions may increase the value they attribute toward sports. Most participants stated that they would be interested in participating in sports with other children with cardiac conditions and/or would prefer both segregated and inclusive sport opportunities. The opportunity of "being the same" as other children who frequently experience fatigue, as well as reducing the skill gap between youth with and without congenital heart disease, was the most frequent reasoning provided.

Jaime discusses the benefits of segregated sport programming for children with cardiac disease: "because that way I could play with kids that have the same thing as me." Similarly, Jackie explains that the common understanding among children regarding the meaning of fatigue in sports would be the most beneficial aspect of a school-based, multisports program for children with heart disease: "they all have, would all have, the same, basically the same cardiac problem, so maybe they've had the same surgery or similar problems with their hearts. So they know all how I feel and why I get tired sometimes."

In addition to feelings of “sameness” and the shared experience of fatigue, participants indicated that segregated sports programs would be beneficial in reducing the detrimental impacts associated with inclusive environments. Segregated sports programs were perceived to reduce the skill gap between youth with and without congenital heart disease, as well as the high performance expectations associated with participation in these contexts. Jaime’s mother explains that it would be “beneficial if there was (segregated sports) programs for kids with heart conditions. . . . I know she has a problem with other kids who can do more. Because they can do more, and she can’t do as much as they can.” Jesse expresses similar sentiments and suggests that engaging in sports with other children who also live with congenital heart disease will “help because they don’t have to be stressed and anything about who’s going to win and who’s going to lose. They’re all the same type of people.” Dylan’s perspective is consistent with Jesse and her mother’s, and she emphasizes both the value of not having to meet a high performance expectation in sports as well as a higher degree of social sensitivity and understanding among youth with congenital heart disease in segregated sport:

That (segregated sport) can be interesting, cause you wouldn’t be around a whole bunch of people who can run as fast as a cheetah . . . you’d be with people who have . . . the same types of conditions as you. . . . So I guess I’d be around a whole bunch of people who knew how I felt. . . . They wouldn’t laugh at me to get up— they’d help me up.

A few participants, however, mentioned that segregated sport opportunities may create a climate in which people are labeled, standards of excellence are lower, there is too much variability within the cardiac conditions for programs to be feasible, or that there are inherent difficulties associated with participation in both segregated and inclusive contexts. Jayden explains that

. . . if I played on a normal team, it’d be hard to play with them. If I played on a team with the same physical cardiac condition as me, it would be the same. . . . I don’t know if we all have the same conditions. Like maybe they’re stronger than me.

Sport appeared to be *undervalued* because of the prominence of educational activities within the context of recovery from cardiac disease. Evidence that confirmed inadequate performances decreased self-efficacy and contributed toward a reorganization of priorities whereby sport was not a valued activity. Where sport was held in high regard, years of successful engagement and the fulfillment of an important role in the athletic setting were essential factors. Lastly, segregated physical activity opportunities may elevate the value and importance of these pursuits in the lives of youth with congenital heart disease.

Physical Activity and Sport as Instrumental

When participants were questioned regarding their beliefs toward physical activity and sport, responses were largely limited to its rehabilitative and instrumental role; participants emphasized the importance of physical activity in the achievement and maintenance of health, as well as the recovery from the pathological heart. A narrow

range of factors was discussed, and emphasis was placed upon the role of sport in protecting against cardiac disease related symptoms such as fatigue.

Jesse believes that it is important to participate in physical activity in order to maintain an adequate level of fitness, as well as avoid fatigue “. . . so they can be fit to do sport, like they don’t get tired easily.” Jaime also speaks of the role of sports in maintaining optimal well-being as well and post-surgical recovery. She states that it is important “because they have bad hearts and stuff like that. . . . (sport) keeps them healthy and helps them to stay healthy . . . it’s important for the heart and the knees and stuff.” Furthermore, Dylan and Ayden discussed the importance of physical activity and proper nutrition in maintaining an ideal body weight, where overweight is believed to further exacerbate cardiac symptoms and endanger health. For example, Dylan suggests that

To be doing physical activities, you’re more likely to live longer . . . Cause no disrespect to anybody, but there’s a lot of obese people these days. And the reason they’re so obese is cause they don’t exercise, and they don’t eat properly.

Sports are also instrumental in avoiding undue weight gain for Ayden, where overweight is believed to place an added burden upon an already weakened organ. (Sport is important) “probably to keep in better health, so for instance, not to get overweight cause then your heart and everything gets all stressed and everything.”

Participants also adopted an instrumental attitude toward the potential skills that may be derived from participation in physical activity. Physical and physiological outcomes, such as strength, speed, and coordination were identified as skills obtained from participation and their role in achieving a healthy and strong body that is not burdened by fatigue was discussed. For example, Maddie proposes that

it (sport) gets you very fit, gets your heart rate down . . . it’s kind of being athletic and just being able to do whatever you want at anytime. Not getting tired as easily as others who don’t play sports.”

A few participants identified rehabilitative assistance as well as specific physical activity related information and monitoring by professionals as the primary type of support that would enable greater participation. Jackie mentions that a highly desired goal “is to be able to run more, longer distances” and believes that family, friends, teachers, community members, and hospital support staff could foster this level of achievement by

giving me examples of other ways that I could get active. And, maybe I could talk to a coach about helping me with a program after school to get me more active . . . especially the cardiac help. Like a cardiac program would help build the stamina up again.

Lastly, Rudy’s mother eloquently expresses that it was difficult to change a deeply ingrained belief regarding the instrumental benefits of physical activity. For several years, sport was conceptualized from a narrow physical perspective, and it

took time, experience, and feedback from daughter Rudy to view physical activity in a more holistic manner. Joelle states that

Years ago in dancing, there were other things I was thinking that she was going to benefit from, rather than the actual fun aspect. So I looked at sports from a different perspective . . . what Rudy could physically get out of it to help her movement improve. . . . And I looked at everything that way. It was a long time before I really, kind of relaxed back.

Although the importance of physical activity was primarily discussed within the context of a rehabilitative domain, not all participants displayed an instrumental relationship with physical activity, and this may be a function of age, maturity, severity of the condition, and post-surgical status. Some participants discussed other aspects of the sport experience that are also of importance to them, such as socializing and recognition. For example, Aman explains that student athletes “feel important . . . they feel like they are a part of something . . . so it’s a team, not a family, but they’re like a team, it’s like their own circle.” Maddie’s comments also illuminate a broader and more encompassing attitude toward sport. He suggests that lessons learned on the playing field can be transferred to other areas, and assist with development in the future: “It (sport) is very important because not only does it build team sportsmanship and all the relationship necessities . . . it’s just really fun . . . (sports can help in) school, when you get older at work, social setting, speeches, public speaking, interacting with people.”

The fact that this participant displays a more integrated attitude toward physical activity may reflect the family’s belief that a “successful” cardiac surgery has been performed. Maddie has been unhampered by postoperative complications that may have resulted in restricted participation. His father expresses that

It is a condition that we’ve come to realize that, after the big shock of when you’re born, that once you fix it, it seems to be fixed. And so we don’t have any kind of lingering concerns, there isn’t any kind of weakness . . . so therefore Maddie, with his particular body type, with his particular drive, determines how much or how little sport he ends up doing.

Attitudes and beliefs toward physical activity were limited to its instrumental role and utility in achieving desired functional and rehabilitative health outcomes, rather than the inherently enjoyable aspects of the activity itself. This discourse of health was evident in beliefs regarding the importance of physical activity, the skills that may be acquired, the type of assistance that would enable greater participation, and the place of physical activity in the future. Where a more integrated view of sport was held, factors such as age and development, as well as the absence of residual cardiac effects, appeared to influence beliefs.

Low Self- Efficacy

Although not all participants displayed low self- efficacy toward sport specifically, this was a common theme across the larger group. Self- efficacy appeared to be shaped by broader factors.

On the Sidelines: Negative Social Interactions, Exclusion, and Social Comparison

Unpleasant social interactions and comparisons in an athletic setting played a significant role in determining low self-efficacy in sport. Jaime believes that she is a poor athlete. She discusses how her heart condition and associated fatigue contribute toward teasing on the part of her peers during physical education. This results in greater fatigue and social exclusion from the activity altogether:

I am not really good at sports . . . cause of my heart. I'm always getting teased by the other kids. Which isn't very nice, and it really bothers me a lot. . . . I try my best but then other people always swipes the ball from me. And I always end up having to chase them. And then I get really tired, so I have to sit down, so someone else has to take my place on the team that I'm on.

Ayden explains how unpleasant social interactions with peers who do not understand her limitations has also decreased perceptions of her physical capabilities:

. . . we were doing high jump. And I was like pushing the mats for people. And it was hard because I couldn't do that. And my friends kept pressuring me to do it. And I said "I can't do it," and she's like "you're just pushing a mat" . . . when I say I can't do something, I don't want them to keep pressuring me. Cause then I feel bad, cause I feel like I'm not doing what everyone else can.

Rory also makes a strong statement regarding self-efficacy in sport by claiming that "I suck at sports," and although she remains silent after the question, her mother asks her if social comparison with peers during physical education has influenced this core belief:

Is it because you cannot go as long as the other children when you are doing sports, or that you get a low number in scores? That's just something that you just decided . . . are you comparing yourself to the healthy, healthy students?

Lastly, Aman also believes that she is not a good athlete and that others share a similar view. She is uncertain of what her peers think of her as a sport participant and dislikes the experience of feeling as though they are judging her in physical education: "Sometimes it feels not fun. I mean it's not really fun to know that people see you lower. Well, not lower, but you don't know exactly how they see you." Negative social interactions, exclusion, and social comparison during physical activity influenced the degree of self-efficacy that participants adopted toward sport.

The Role of Significant Others

Significant others, such as parents, friends, teachers, and coaches functioned as both supporting and limiting factors in the development of physical activity related self-efficacy. Before cardiac surgery, Jayden did not believe that he would be able to run. He explains how unpleasant feelings resulted from watching his peers engage in an activity that he was unable to do:

... And before my surgery, when we were doing track at my school, and it's like running events like 800 m or 1500 m, and I knew that I physically wouldn't be able to finish them ... sometimes I get a little depressed if a lot of your friends are doing it, and you'd like to be doing the events that they're doing.

Alternatively, verbal persuasion from physical education teachers, coaches, parents, friends, and community members appeared to enhance self-efficacy and foster continued participation. For example, receiving positive comments from adult figures has had a role in shaping Jayden's belief that he is a good athlete and instilled within him a desire to continue to participate:

I'd say that I'm a good athlete. ... They're (peers) always mentioning how I'm playing good, and how I had a good game today. ... someone says "you did good today, I hope that you can do that again." And then I want to show them that I can do it again, and I keep playing.

Lane remembers that after undergoing his first cardiac surgery at the age of seven, he was concerned about the amount of time that it would take to heal and the possibility of incurring an injury in sport: "I was really worried about if I got hurt or something (in sport), then I'd probably be in serious condition." However, he explains how consistent, instrumental, and emotional support from his parents and school have influenced his now positive perceptions of his ability in sport:

Yah, I'd say that I'm a good athlete. Basically just my parents keeping me in sports, all the way through, sometime from about two or three years old. ... They encourage me to do every sport that I can ... And, I get a lot of support from my school, with people complimenting, or telling me to keep going with athletic events.

Sports related self-efficacy was low across the majority of participants; however, important figures in the lives of youth with cardiac disease had a role in shaping these beliefs.

Enabling Success: Mastery Experiences

Mastery experiences in physical activity had a beneficial impact on the way the participants felt about themselves in sport, even when low self-efficacy was indicated. Furthermore, participants who perceived themselves to be good athletes all discussed the positive impact of mastery experiences in athletics.

For example, although Ayden asserts that "I don't think I'm a good athlete, because I can't do that stuff (sports)," a successful experience in horseback riding resulted in positive feelings and has motivated her to continue engaging in this activity. She explains that "last summer, I went to a horse show. I won and I felt really happy ... it kind of gave me, like achievement to go farther in it, and to do more in it." Similarly, although Jaime has yet to succeed in sport, a mastery experience is an imagined and desired experience that is believed to impact self-efficacy. She believes that "I'm not really good at sports ... cause of my heart." However, she

states that it will feel “. . . good (to succeed at sports) . . . cause I’m really good . . . the only game I want to succeed at is hockey. Or basketball.”

Participants who perceived themselves to be good at sports, discussed the beneficial impact of a successful athletic experience in enhancing self-efficacy and motivation. Jayden’s first successful experience in hockey has impacted the way he feels about himself in sport and his future desire to participate:

I started hockey this year, and I played many games, and I still hadn’t gotten a goal. And then when I got one, I felt like I had reached the goal I was trying to get, for a very long time . . . it made me feel more confident that I could get more goals playing hockey, and other times, doing other sports.

Single or multiple successes in the sports domain influenced positive feelings toward sport, even when self-efficacy was low. In addition, success in sports was a desired experience for a few participants. Lastly, participants who displayed satisfaction with their athletic performance spoke highly of the role of mastery experiences in facilitating self-efficacy and future interest in sport.

Finding Another Way: The Importance of Nontraditional Sports

The discovery of a “nontraditional” physical activity that limited fatigue and physical and emotional demands required for participation in “regular sports” emerged as an important variable and played a role in enhancing self-efficacy. Unlike other activities, which often result in fatigue and negative affect, some of the participants derived great joy from golf, dancing at home, cycling around the neighborhood, swimming, horseback riding, and triathlon.

For example, even though Jesse states that “I can’t say I’m good at sports, but I’m OK,” riding his bicycle around the neighborhood has resulted in feelings of happiness, fun, and comfort. The fatigue that is encountered when he participates in “regular” sports is not present when he rides his bike: “With my heart problem, it is easy to do, it is easy to drive . . . which makes me feel comfortable . . . it makes me like tired” (to play the other sports). Similarly, Carmen firmly believes that she is only a good athlete when considered within the context of horseback riding. Unlike physical education, the social climate at the riding stable has provided her with an environment where she is free of her characteristic shyness.

I’m not really a good one (sport participant) in school. Because in school I’m shy, but in horseback riding, they all know me up at the barn so it doesn’t really matter . . . I don’t have to be shy around them because I’ve known most of them for three years.

Rudy’s mother explains that the dynamics of horseback riding differ dramatically from other activities, thus enabling success: “I think that it’s the sport too; it puts her on a bit of a different playing level. There’s not the same kind of expertise that would be involved in playing basketball . . . yah, it’s a different thing.” Although

Jackie does not consider himself to be a good athlete, participation in golf has decreased the demand for strength and endurance required in other activities and allowed for family involvement. This has facilitated positive feelings about himself when he is engaged in the activity:

It's (golf) not really a high endurance sport. You don't really have to be really athletic or strong for it. It's not really anything like basketball—you have to be tall or soccer—you have to be really fast . . . and also family . . . most of my whole family plays golf.

Participants may benefit from physical activities that limit physiological and emotional demands and result in personal fulfillment. Even though they are not activities that “typical” North American youth engage in, nontraditional physical activities provided an opportunity to experience “sport” even when overall self-efficacy remained low.

Unifying the Themes: Fatigue

Lastly, the experience of cardiac disease related fatigue provided the undercurrent for all three interrelated categories. Where participants have come to understand that active people fatigue less quickly, physical activity is viewed as instrumental in protecting against or delaying the onset of fatigue. For example, reduced fatigue may be one of the key factors explaining why exercise may enhance quality of life in cancer survivors (Courneya, 2005). In addition, fatigue may limit opportunities for success in physical activity, thereby reducing the degree of self-efficacy. Where self-efficacy is already low, less value will be attached to an activity in which one struggles to overcome fatigue within the boundaries of their physical activity “restrictions.”

For example, Dylan eloquently explains how fatigue mediates her feelings toward sport; she indicates how youth with CHD may negotiate their feelings when they encounter fatigue during active pursuits.

. . . first of all, I hate sports, because I can't run around properly cause of my heart. And I always have to stop earlier than others, cause I get too tired. But on the other hand, I love sports . . . I would love to be able to play basketball for three hours, I'd love to do that but unfortunately I can't.

Similarly, Ayden's comments illuminate the connection between the categories discussed above, as well as the intersecting role of fatigue. Whether or not fatigue in sports is a belief, it is also a very real and everyday reality that has destabilized any certainty regarding the place of physical activity in her future:

I can't even walk up the stairs, so how am I going to run? I hope I can do more (sports) than I am now, but I don't know . . . I . . . that's hard to say since I don't know what is going to happen. . . . I don't know if I'll get better than I am now . . . Even if I'm just sitting at my desk, I get really tired, just being awake I get really tired really fast.

Discussion and Recommendations

Our findings demonstrated some consistency with existing research while offering several novel insights. The failure of the majority of participants to identify the broader aspects of physical activity beyond its physical health benefits is a new finding and may reflect a variety of factors. For example, exposure to the medical environment, which often includes invasive surgical procedures, lengthy hospitalizations, as well as follow-up care at the hospital, may restrict physical activity participation and create the perception that it is an activity that one can engage in when the process of rehabilitation is well under way. In addition, children's attitudes toward physical activity may be shaped by the systems of knowledge that are implicit within medical institutions. Although essential, exercise testing is largely viewed as a tool in which to assess the current functioning of the heart and determine appropriate exercise "guidelines" or "restrictions." Important and potentially influential messages may be produced and communicated from professionals regarding the role of physical activity in maintaining cardiac health. Broader conceptualizations of physical activity may be limited, as patients and families become concerned with following an "exercise prescription" to "stay healthy," and the inherently enjoyable aspects of physical activity outside of its role in exercise rehabilitation may not be apparent.

Although unrelated to physical activity and congenital heart disease, various authors discuss the role of the medical context in shaping patient perceptions. Featherstone, Latimer, Atkinson, Pilz, and Clarke (2005) suggest that medical knowledge, representations, and discourse are characteristic features of modern day medical clinics and have persisted through time. Kameny and Bearison (1999) propose that the biomedical domain is an integral aspect of the "construction of self" in the narratives of adolescents with cancer. Lastly, Brittain (2004) proposes that perceptions of persons with disabilities remain deeply embedded in, and shaped by, the dominance of the medical field.

The impact of exposure to invasive medical environments on perceptions toward physical activity in youth with heart disease begs further exploration; however, health care professionals may influence participation in children with heart disease (Bar-Mor et al., 2000; McCrindle et al., 2007) and interact intimately with families for a prolonged period of time. For this reason, it is advisable to present the social, psychological, and developmental benefits of physical activity, in addition to its instrumental role in enabling increased functional capacity. Emphasis should be placed upon the role of physical activity in fostering social inclusion, fun, friendship, and future development.

Several of the variables associated with self-efficacy in this study are supported by Bandura's (1997) self-efficacy theory. For example, previous and ongoing *mastery experiences* in sport for youth with congenital heart disease exerted a powerful influence on self-efficacy and motivated continued participation. Conversely, adverse sport experiences were characterized by negative social interactions, exclusion, and social comparison and detracted from the desire to participate by confirming inability and inadequacy. *Verbal persuasion* from significant others such as parents, coaches, and physical education teachers were also strong predictors of self-efficacy beliefs (Bandura, 1977; Bar-Mor et al., 2000). Lastly, the impact of *physiological and affective fatigue* was a major determinant of self-efficacy toward

sport in this study. Those children who perceived themselves to be most susceptible to the impact of cardiac disease-related fatigue indicated low self-efficacy toward sport. Bandura (1997) suggests that fatigue and other somatic ills can be read as signals of physical ineffectiveness, and indicators of fatigue in performance-oriented environments such as sport can be viewed as sources of physical inadequacy for youth with congenital heart disease. However, engaging in *nontraditional physical activities* that limited physical fatigue and indicators of physical inadequacy was an effective means of overcoming low self-efficacy as a barrier to participation.

Boys appeared to demonstrate lower sport-related self efficacy than girls; however, the impact of gender on self- efficacy and self-perceptions toward sport in children with congenital heart disease was not explored explicitly. The inability to participate in sport may be a particularly sensitive issue for adolescent boys, given its cultural importance in the development of physical prowess, team building, body image, and self-esteem (Lunt et al., 2003). It is plausible that adolescent boys who are not able to participate in sports experience lower sport related self efficacy than girls do, especially if social constructions of gender continue to perpetuate the notion that sport is a tool to cultivate masculine identity (Pronger, 1999), and few other avenues for success are perceived.

These findings accord with research that uses questionnaires to assess self-efficacy and related constructs in children with congenital heart disease and other chronic illnesses. For example, childhood survivors of acute lymphoblastic leukemia displayed reduced self-perceptions toward physical activity as compared to age-matched controls. The authors discuss the potential role of mastery experiences in sport in enhancing self-perceptions toward physical activity (Wright et al., 2003). In addition, Bar-Mor et al. (2000) found that the verbal persuasion from cardiologists and mothers greatly influenced self-efficacy toward physical activity in children with heart disease. The “disconnect” between subjective and objective reality was apparent, as self-efficacy was found to override severity of the cardiac problem in determining the involvement in sport. Physical educators should be aware of the unique sources of low self-efficacy toward sport in youth with congenital heart disease. In addition, strategies to enhance self-efficacy should be built into physical activity programs (McCrinkle et al., 2006).

Sport did not appear to be a valued pursuit across the majority of participants, and the degree to which it was valued appeared to be influenced by several variables. In this sample, those participants who perceived themselves as poor or mediocre athletes tended to ascribe less value toward physical activity, and other domains of life were more important. It is unclear if deflecting attention away from sport to other activities represents a self-protective mechanism, but similar processes have been documented elsewhere. Upon acceptance of the diagnosis, and expectation that they will not be able to participate, adolescents with cardiac disease may reorganize their priorities. Attention is shifted away from sport toward other activities in order to protect self-esteem (Lunt et al., 2003).

Accordingly, recent research has discussed the benefits and disadvantages associated with both segregated and inclusive sport programming for youth with disabilities (An & Goodwin, 2007; Goodwin, Fitzpatrick, Thurmeier, & Hall, 2006). Here, inclusive sport for youth with disabilities adheres to the philosophy of accepting and valuing diversity, ensuring flexibility, and establishing high standards of excellence for all those involved (Grenier, 2006). A few youth spoke of the

stigma and uncertainty associated with participation in segregated sports programs; however, for the majority of participants, segregated programs that allow youth with congenital heart disease to engage in physical activity together, may increase the value ascribed toward sport. Several participants mentioned their desire to “be the same” as their peers in physical activity settings. Similar observations have been made in other qualitative studies. When youth with heart disease were asked for input regarding their treatment services, a group option, including strategies to increase confidence in sport, was suggested (Kendall, Sloper, Lewin, & Parsons, 2003).

Although unrelated to physical activity and cardiac disease directly, Goodwin and Staples (2005) found that for youth with disabilities, the theme of “not alone” was identified as a primary benefit of attending a segregated recreational camp. Participants valued the opportunity of decreased isolation, a sense of belonging, the shared illness experience, discovering the interests of other youth with disabilities, and negotiating individual identities in a “therapeutic landscape.” Similarly, the coordinators of a peer support group for youth with chronic illnesses in Australia discuss the theoretical role of such programs in enhancing psychosocial adjustment to illness (Olsson, Boyse, Toumbourou, & Sawyer, 2005). Beyond the need to “be the same,” it is necessary to explore whether youth with cardiac conditions would express similar sentiments. The availability of both segregated and inclusive physical education is an ideal way in which to ease the transition from rehabilitation to home, school, and community-based physical activity settings and increase the value ascribed toward sports. This may allow for the shared physical activity and cardiac disease experience in segregated settings and empower youth with the skills necessary to thrive in inclusive physical education (Goodwin & Staples, 2005).

Ongoing, affordable, and accessible programs for youth with congenital heart disease are the conditions required for high quality segregated sports. While some participants suggested that they would prefer segregated teams sports, nontraditional sports may enable mastery and self-efficacy; by reducing the physiological demands of mainstream sports and the detrimental impact of fatigue, such non-traditional activities may render perceived or real limitations invisible. The need for such accessible programs is essential, particularly in light of evidence that the psycho-social benefits of recreational camp programs are short lived (Epstein et al., 2005).

The conditions necessary to facilitate optimal participation of youth with congenital heart disease in inclusive physical education requires further exploration; however, a collaborative, sustained, organized, and focused effort, characterized by ongoing communication between medical professionals, physical educators, parents, and children is necessary in order to accommodate all cardiac needs, provide necessary supports, and develop changing expectations for performance so that multiple ways to succeed are possible.

Such a team oriented approach has been described for youth with other disabilities. This involves recognizing the desire for parents to be actively involved in their child’s physical education and considering them as interventionists who possess illness-related knowledge and strategies to optimize the involvement of their children in sport (An & Goodwin, 2007; Sayers, Cowden, & Sherrill, 2002). As well, physical education teachers are major agents of socialization for children with disabilities, and their willingness to employ creative strategies to establish

inclusive physical education is crucial (Brittain, 2004; Grenier, 2006). It is important to mobilize their potential to act as “catalysts” for inclusion and sensitivity to difference, and view them as possessing the ecological equity required to decrease physical and social barriers encountered by youth with disabilities in sport (Grenier, 2006). Most importantly, a collaborative approach to physical education which seeks to enable inclusion, must consider that teachers, parents, and medical staff are significant sources of verbal persuasion and may exert powerful effects on self-efficacy toward sport and physical activity participation.

Limitations, Future Research, and Conclusions

Qualitative research encompasses exploration and description of a phenomenon in order to understand the individual reality of participants. The goals of qualitative research are unique and different, and the focus of interviews is to capture a rich and detailed narrative (Faulkner & Biddle, 2004). Findings from this small sample cannot be generalized to the larger population of children and adolescents with complex cardiac conditions. Generalizability of the concepts, rather than the sample, may be feasible, however. (Eiser & Twamley, 1999).

The presence of a parent in the room during the interviews may have limited the full scope of participant responses. If participants were guarded in their responses, exploring the ways in which parental attitudes toward sport influence participant beliefs, was problematic, as well as determining whether or not participants believe that parental over-protection in sport is apparent. The presence of parents during the interviews was requested by the majority of participants, however, and their minimal contribution appeared to greatly enhance their comfort and willingness to engage in discussion. This was an uncontrollable limitation of the present study and needs to be considered within the context of interacting with children who have been hospitalized with chronic illnesses.

Unlike previous investigations, this study did not assess the relationship between disease severity and correlates of physical activity (Bar-Mor et al., 2000; Lunt et al., 2003). Although participants that were theoretically higher on the continuum of severity (e.g., Fontan) tended to display reduced participation and lower self-efficacy, this was not always the case. Ongoing research is required to examine the relationship between these two variables and the extent to which other factors mediate the relationship. In recent decades, exercise psychology has been concerned with identifying the mechanisms through which physical activity influences psychological well-being. Physical activity is thought to improve psychological well-being through an interrelationship of physiological, biological, and psychological processes (Faulkner & Carless, 2006). Future research may wish to delineate the extent to which the above mechanisms operate for youth with cardiac conditions.

Despite the numerous physical, psychological, and social benefits of physical activity for children in the general population at large, as well as children with chronic illnesses such as cardiac disease, the majority do not meet recommended levels (Canadian Fitness and Lifestyle Research Institute, 2002/2003; Humbert et al., 2006). Future interventions for this population are essential and the perspectives of participants and families in this study may inform the development of such

programs. Access to both segregated and inclusive sport, strategies to enhance self-efficacy and reduce fatigue, and changing the way we conceptualize physical activity to encompass its multidimensional components may enable increased participation so that children with heart disease can benefit from safe and enjoyable physical activity experiences.

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