

“What I Wish You Knew”: Social Barriers Toward Physical Activity in Youth With Congenital Heart Disease (CHD)

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Despite the benefits of physical activity for youth with congenital heart disease (CHD), most patients are inactive. Although literature has addressed medical and psychological barriers to participation, little is known about the social barriers that youth encounter. This qualitative study explored sociocultural barriers to physical activity from the perspective of 17 youth with CHD. The main theme, “what I wish you knew,” was related to all other themes—youths’ efforts to resolve “disclosure dilemmas,” the barriers they encounter during physical education, and their struggle to understand themselves as normal. The participants’ narratives illuminate the centrality of their sociocultural world to physical activity. The findings call on researchers and educators to attend to the social and cultural environments where these youth live and play.

Keywords: health, pediatrics, qualitative inquiry, physical activity, sociological perspectives, physical disabilities

One in 100 American infants is born with congenital heart disease (CHD) each year (Sparacino et al., 1997). These heart defects range along a continuum from mild lesions to severe defects, which may be palliative and eventually fatal. Several decades ago, the majority of patients died in infancy; however, dramatic advancements in medicine have revolutionized the field of pediatric cardiology, and the majority displays a good prognosis (Green, 2004). For the first time, the number of patients in adult clinics outnumbers those in pediatric centers, and most patients will reach adulthood. Thus, CHD can be considered as a chronic rather than life-threatening childhood illness. Indeed, young adults with CHD are a relatively new population, and, from a medical standpoint, these patients are forging novel health frontiers.

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Improved survival, however, has done little to attenuate lingering psycho-social sequela in youth with CHD. For example, these youth experience negative psycho-social outcomes, such as depression, anxiety, behavioral disorders, and covert fears (Bar-Mor, Bar-Tal, Krulik, & Zeevi, 2000; Fredriksen, Mengshoel, Frydenlund, Sorbye, & Thaulow, 2004; Gupta, Mitchell, Giuffre, & Crawford, 2001). In addition, youth with CHD have reduced health status, quality of life, and academic difficulty associated with neurological deficits. Because they are different, these youth experience negative social experiences such as bullying (McMurray et al., 2001). Thus, there is growing interest in incorporating psycho-social services into the routine care of youth with CHD. The goal of such interventions is to attenuate the psycho-social burden of disease and enhance quality of life.

More specifically, physical activity is one such intervention that may enhance quality of life in youth with CHD. Defined as any bodily movement produced by the skeletal muscles that result in energy expenditure (Caspersen, Powell, & Christenson, 1985), the ability to play and engage in physical activity is central to childhood. Physical activity may be a normalizing endeavor (Taub & Greer, 2000) in which youth develop personal and social skills. The psycho-social benefits include enhanced behavioral and emotional functioning, general health, mental health; attitudes toward illness, self-efficacy, quality of life, coping, and life satisfaction; and perceptions of mastery, independence, normalization, and well-being (Goodwin & Staples, 2005; Moons et al., 2005). Because physical activity is associated with reductions in anxiety, pain, and fatigue (Briery & Rabian, 1999; Kiernan, Gormley, & MacLachlan, 2004), it is an important intervention that can improve quality of life and psycho-social health in youth with CHD.

Physical and Psycho-Social Barriers to Physical Activity in Youth With CHD

Despite the benefits of physical activity, the majority of youth with CHD are inactive (McCrindle et al., 2007). In addition, youth with CHD engage in less vigorous activities (Lunt, Briffa, & Ramsay, 2003). Therefore, in addition to exploring the attitudes of these youth toward activity, uncovering the barriers to participation is an important research endeavor. In particular, parental overprotection has been documented as a barrier to participation for youth with CHD and other chronic illnesses. The vulnerable child syndrome, in which parents worry excessively about their sick child and restrict physical activity, may lead to the construction of a chronic sick role, in which youth are abdicated from responsibilities (Wilkes et al., 2009). Illustrating that youth are susceptible to parental influence, parental beliefs strongly affect youths' self-efficacy for physical activity (Bar Mor et al., 2000). In addition, disease factors, such as breathlessness and exhaustion, are significant barriers. When physical activity leads to exhaustion, youth are unlikely to want to be active (Swisher & Erickson, 2008). Termed the vicious cycle of inactivity, physical activity induced fatigue in populations that are chronically ill results in reductions in activity; in turn, this exacerbates disease symptoms (Nixon, Orenstein, & Kelsey, 2001). Although perceived confidence in one's ability to be active is critical to adherence in youth with disabilities (Martin, 2006), low self-efficacy is another barrier (Moola, Faulkner, Kirsh, & Kilburn, 2008). Moreover, within the

context of reduced self-efficacy and discomfort, youth reprioritize their values and construct physical activity as “not important” (Lunt et al., 2003).

Although researchers have explored social barriers toward physical activity in “able bodied” populations, such as lack of social support, poor access to facilities, low socioeconomic status, negative attitudes toward physical activity from family and peers, as well as contextual or life stressors (Dishman, Sallis, & Orenstein, 1985), only a few studies have discussed the contextual factors in youths’ social worlds that pose barriers to physical activity beyond the disease itself. For example, school liability issues have been discussed within the context of risk (Moola, McCrindle, & Longmuir, 2009). Due to the fear associated with a cardiac emergency occurring on school premises, misinformed teachers and school boards may inappropriately exclude youth with CHD from engaging in the same activities as their peers. In addition, through processes such as bullying and exclusion (McMurray et al., 2001), peer groups can be a significant social barrier during physical activity. Establishing close social relationships and keeping up with peer-related activities is of utmost importance to youths’ health perceptions, thus illustrating the centrality of the social world for youth with CHD (Kendall Sloper, Lewin, & Parsons, 2003). Finally, socioeconomically disadvantaged youth may encounter more health barriers and occupational restrictions (Crossland, Jackson, Lyall, Burn, & O’Sullivan, 2005).

Thus, while there is some literature on the role of parents, schools, and peers, this review revealed a paucity of information that addresses social barriers to physical activity in youth with CHD. Therefore, by primarily addressing the individual, medical, and psychological factors that influence participation, the literature has reproduced discourses of individualism. Physical inactivity in youth with CHD is attributed to personal rather than structural issues, and a critical discussion of potential contextual influences has been obscured (Wheatley, 2005). Beyond the body, those factors in youths’ social worlds that may influence participation remains under researched. In particular, there is a lack of qualitative research that provides a nonthreatening and child-centered approach to talk with youth about their physical activity experiences. Thus, the purpose of this study was to explore social barriers to physical activity in youth with CHD.

Conceptual Framework

This study was conceptually informed by the social model of disability as well as the concept of illness representations. The theoretical framework lent insight into how the interview guide was developed and informed the analysis and discussion. Seeking to wage an attack upon medical model notions, the social model of disability was proposed by grassroots disability activists in the 1970s in Britain (Shakespeare, 1998). Seeking to remove disability from “deviant and pathological bodies” and the lure of individualism, which describes disability as a personal rather than political problem, the social model attempts to remove disability from the person and relocate it in disabling social environments. Thus, the social model is concerned with unraveling the physical, social, cultural, ideological, and institutional barriers which interact with “impairment” to produce disability as a problem. Moreover, these scholars discuss how disability is constituted as a problem within the context of modernization, industrialization, and capitalism, where the

emphasis on normalization marks the disabled body as abhorrent and pathological (Barnes, 1998; Barton, 1998). As a social construct, disability is never removed from the social meanings and structures where it is embedded (Sousa, Corredeira, & Pereira, 2009).

Second, as a concept within the subdiscipline of the sociology of health and illness, this study was also conceptually informed by the notion of illness representations. In addition to dismantling the power imbalances that are an inherent component of the interaction between physicians and patients, acknowledging the health expertise of patients (Kelly & Field, 1996), recognizing the complex narratives that chronically ill patients draw upon in the process of meaning making, and living with illness and thinking about how illness may alter identity (Smith & Sparkes, 2008; Thomas-MacLean, 2004), these scholars discuss the importance of exploring the diverse array of illness representations that illustrate culture's relationship to illness. Indeed, although illness has a medical and embodied dimension, it is also coded within representations, language, and metaphors that speak to our relationship with social life. Although health care providers often fail to recognize the "secret indignation of the sick" (Scheper-Hughes & Lock, 1986, p. 139), sociology of health and illness scholars recognize the importance of attending to the array of social and cultural representations that we bring to illness. Indeed, such representations are a rich site for cultural analysis and are an expression of cultural images and metaphors of illness. They help us to understand the folk theories or common sense knowledge that we bring to illness in culture. Furthermore, in addition to the medical consequences of illness itself, or the "original affliction," cultural representations create a second illness that has been termed "the double." Conjuring up fear, dread, stigma, or exclusion, cultural representations may radically diverge from one's own understanding of illness and, furthermore, be "more ugly, than sublime, more degrading than elevating, more exploitive, than consoling" (Scheper-Hughes & Lock, 1986, p. 137). While illness representations are precarious, and always a site of contestation and change, it is suggested that we take stock of the potency of representation and language in understanding illness, the multiple representational systems, and dramatic metaphors that act as conceptual tools for understanding illness in culture, and, more importantly, the potential to work toward more liberating, ethical, and alternative illness representations (Scheper-Hughes & Lock, 1986; Wallis & Nerlich, 2005). Thus, the social model of disability and the notion of illness representations provided an informative conceptual toolkit to guide this study.

Method

Research Setting, Recruitment, and Participants

This study was approved by the Research Ethics Board (REB) at The Hospital for Sick Children (SickKids) in Toronto, Canada. SickKids was established in 1875 and is dedicated to excellence in pediatrics. As one of the largest pediatric health centers in the world, it has a rich history and has played a pioneering role in the development of medical breakthroughs.

Purposeful sampling was employed to recruit participants; eligible participants were phoned before their appointment in the cardiac clinic to request their

participation. Participants were also approached directly by a nurse or the first author during his/her appointment. Alternatively, some participants requested participation by contacting the researcher. Seventeen youth between the ages of 11 and 17 participated. This number was sufficient to attain saturation in the data and adequately reflect the group's experience of physical activity. Although diagnosis, operative repair, and medical and functional characteristics varied, all participants were complex CHD patients. Thus, they are characterized by cardiac lesions that are more severe and complex, and their medical history is complicated and intensive, often requiring hospitalization. The sample was gender balanced, and, although demographic information on ethnicity was not collected, it was generally reflective of the ethno-cultural diversity that characterizes a metropolitan pediatric facility. The average age of the participants was 14.9 years. The participant descriptions are provided in Table 1.

Qualitative Research Tradition

Grounded theory was the qualitative research tradition that informed this study. Although it continues to engender heated debates (Weed, 2009), grounded theory is a total research design and is understood as both methodology and method. Thus, it is a particular approach for thinking about the social world and the type of knowledge that can be produced about social life. Drawing upon social constructivism and interpretivism, grounded theory adopts an antipositivist stance. It purports that knowledge is historically situated and does not simply await excavation and discovery. Rather, knowledge is cocreated in the complex interrelationship between the researcher and participant (Charmaz, 2003). Thus, rather than reflecting reality, grounded theory allows for a particular interpretation of reality. It allows for the production of theory through data and captures elements of a group's social experience (Bartlett & Payne, 1997).

Data Collection

Because a multimethod approach may allow participants to express their experiences in a variety of ways, it is the preferred manner in which to conduct qualitative research with youth (Darbyshire, MacDougall, & Schiller, 2005). Accordingly, a multimethod approach was adopted in this study. All participants engaged in a semistructured interview and completed an artwork task known as the draw-and-write technique. The results from youths' artwork will be reported elsewhere, and this paper focuses only on youth's verbal data from the interviews. The interview guide was informed by the theoretical frameworks and the authors' clinical experiences. Although the interview guide was semistructured, further questions were informed by the participants' responses such that the interview proceeded like a conversation (Flick, 2006). The interviews occurred in clinic rooms and staff offices. All interviews were conducted by the first author who has clinical, research, and camp experiences working with children that have chronic illnesses. The interviews were approximately 45 min to one hour.

The participants were asked to discuss the barriers that they may encounter during physical activity. The researcher did not define physical activity, and, rather, definitions were left to youths' own interpretations. Interestingly, when asked about physical activity, youth often answered in terms of physical education; this

Table 1 Participants

Pseudonym	Age	Gender	Diagnosis	Procedure(s)	Alone/ Accompanied
Daniella	15	F	Pulmonary atresia	Conduit replacement	Alone
Alicia	11	F	TOF	TOF repair	Accompanied Participated
Kayla	17	F	TOF	TOF repair	Alone
Elsie	13	F	CoA	CoA repair ASD and VSD repairs	Accompanied Participated
Brooke	17	F	TGA	Arterial switch	Alone
Justine	13	F	CoA AS	CoA repair. Dilation of aortic valve	Alone
Maria	17	F	CoA, mild AS	CoA repair	Alone
Elliot	16	M	CCTGA, CoAo, VSD	CoA repair VSD repair	Alone
Maryanna	12	F	Pulmonary atresia	BCPS	Alone
Paulo	17	M	CoA	CoA repair	Alone
Jonah	17	M	DORV	Rastelli procedure Resection of sub AS	Alone
Jordon	12	M	DORV, straddling MV	Fontan	Accompanied No participation
Mindy	14	F	TGA, PS, straddling MV	Fontan	Alone
Aubrey	17	M	DORV, PS	Fontan	Alone
Everett	16	M	TOF	TOF repair	Accompanied
Lisette	15	F	AVSD	AVSD repair MV repair	Accompanied No participation
Jayden	15	M	Hypoplastic RV	Fontan	Alone

Note. AS: Aortic Stenosis; ASD: Atrial septal defect; AVSD: Atrioventricular septal defect; BCPS: Bidirectional cavopulmonary shunt; CCTGA: Congenitally corrected transposition of the great arteries; CoA: Coarctation of aorta; DORV: Double outlet right ventricle; TOF: tetralogy of Fallot; TGA: Transposition of the great arteries; MV: Mitral valve; PS: Pulmonary stenosis; RV: Right ventricle; VSD: Ventricular septal defect

is addressed further in the discussion. For example, questions included the following: Are there any things that make it difficult for you to do physical activity with a heart condition? What would make it easier for you to do more physical activity with a heart condition? Are there things that you would like to tell other people about what it is like to do physical activity with a heart condition? What do

other people think about the physical abilities of youth with heart conditions? Are there things that people should know about the physical abilities of kids with heart conditions that they do not already know? The interviews were audio-taped. Given REB protocol, which emphasizes child-centered research, informed consent was obtained from youth only, rather than parents. All participants were reimbursed with a \$20.00 gift card. Furthermore, although parents did not participate, in five cases, youth requested that their parents accompany them during the interview. This was an uncontrollable limitation and must be considered within the context of conducting ethical research with children. In addition, obtaining objective measures of physical activity or demographic information was not included in this study and is the focus of other interventions with this population.

Data Analysis

The audio-taped interviews were transcribed verbatim, and an in-depth qualitative analysis of the data was undertaken. Grounded theory relies on both inductive and deductive reasoning. Through a process of abduction (Weed, 2009), the researcher is sensitized and informed by the theoretical framework and review of literature. At the same time, a hypothesis is not presupposed a priori; rather, the findings emerge through the data (Weed, 2009). In addition, theoretical sensitivity is central to grounded theory. Displaying metacognition, researchers are encouraged to bracket preconceived notions, technical jargon, and habitual patterns of thinking so as to open themselves to the broad range of social experiences that may arise from the data (Bartlett & Payne, 1997). Finally, grounded theorists are encouraged to use theoretical sampling, such that there are sufficient data and explanation to completely describe the findings. This is an iterative process in which the analysis guides further data collection and emergent themes direct further lines of inquiry (Weed, 2009).

The transcripts were read, reread, and scrutinized individually and as a larger group. During open coding, noticeable units of meaning or important insights articulated by youth were denoted with legible codes. Using contrast and comparison, similar units of meaning were collapsed into preliminary themes, and divergent units of meaning were used to generate new categories. Through the process of axial coding, the transcripts and data were searched for the conditions that give rise to themes and thus consisted of identifying subthemes. Finally, selective coding was performed. This consists of identifying the main theme of the study—"what I wish you knew"—as well as the interrelationships between other themes to the main theme (Maykut & Morehouse, 1994). The themes were carefully refined and offer a general conceptual illustration to explain the physical activity experiences of youth with CHD.

The issue of trustworthiness in qualitative research continues to be a highly controversial one (Seale, 1999). Trustworthiness refers to "truth value," authenticity, credibility, and the degree to which the authors are able to offer a believable account of participants' experiences that are worthy of reader confidence. Indeed, given that knowledge is socially constructed and historically situated, the notion of being able to access "true" knowledge has been critiqued. Indeed, some qualitative researchers even suggest that concerns regarding trustworthiness have been adopted to appease those schooled in the positivist, quantitative paradigm (Seale, 1999). Bearing in mind these important critiques, this study took strides to ensure

trustworthiness. This included maintaining an audit trail, documenting all steps of the research process, recording field notes, and engaging in research team discussions. In summary, by exploring social barriers toward physical activity in 17 youth living with severe heart disease, this qualitative study built upon notable limitations in the existing literature. The results are discussed below and pseudonyms have been used to protect the anonymity of the youth.

Results

“What I Wish You Knew”: Representations of Youth with CHD in Physical Activity and Health

Cultural misrepresentations and misconceptions about the health and physical ability of youth with CHD were experienced as formidable barriers by all youth. Thus, all the participants reflected upon cultural representations of CHD and expressed what they wish that others knew about their health and physical activity. While they all offered a range of things that they would like to tell others about what it is really like to be a youth with CHD, their responses fell into one of two subthemes. More specifically, the youth drew upon (a) realist or (b) resistance narratives to express what they wish that others knew. Thus, realist and resistance narratives should be understood as subthemes under the broader category of “what I wish you knew,” or variations in youths’ understandings of the cultural representation of CHD.

Realist Narratives. Several youth drew upon realist narratives to confirm dominant cultural representations of youth with illnesses. For example, they explained that the hardship associated with CHD is real. Because they experience invasive medical treatments that are distressing, these youth drew upon realist narratives to explain that they are different from able-bodied youth; the stories that they constructed about themselves emphasized pain and hardship. Similarly, by asserting that their physical activity experiences are difficult and distressing when compared with physically competent able-bodied peers, these participants confirmed dominant cultural representations of physical activity among youth with illnesses.

For example, Lisette employs a dominant cultural narrative to explain that physical activity is more difficult and painful for youth with CHD:

I would explain to them that it’s not like we can do everything that you can do. It’s like we have to push two times as hard because our heart does not work as normal as peoples’ and we get out of breath a lot quicker, we need to be hydrated a lot faster . . . and it’s a lot harder than if you are a regular, healthy person, you know? . . . so people just need to give us [youth with CHD] a little bit of sympathy, and it’s not that easy.

Similarly, Danielle draws upon realist narratives to explain that CHD requires her to fight; she constructs herself as a fighter and states that

I know I’m a fighter because I’ve had to fight through so much stuff. I don’t even remember a day when I’ve never fought for my life. Even though I have the condition, and it’s solved or whatever . . . you still feel that you still have to fight for your life.

Thus, in telling us “what I wish you knew” about what it is like to be a child with CHD, some youth drew upon realist narratives to confirm the dominant cultural representation that physical activity is distressing for youth with disabilities.

Resistance Narratives. In contrast, other youth drew upon narratives of resistance to challenge and disrupt dominant conceptualizations of youth with CHD in health and physical activity. These youth self-reflexively contemplated the ways in which other people construct them as weak and helpless, and they positioned themselves in opposition to these interpretations. In addition to explaining that they are no different from youth without CHD, these participants resisted disabling discourses in physical activity. They emphasized that they are strong, competent youth who are able to undertake the same physical tasks as their peers. In addition, they emphasized that CHD could not thwart and undermine their abilities.

For example, by explaining that CHD is not as disabling or uncommon as people think, Elliot draws upon resistance narratives to demystify heart disease:

The biggest thing for them to understand is that it is definitely more common than you think. People try to avoid it, like when they see a person in a wheelchair, you tend to pretend that they're not in a wheelchair . . . other people shy away from it, and I never really understood why . . . so you got to realize that they don't see it as this huge, massive disability that's always right in front of their face.

Everett also debunks notions that youth with CHD are frail. He ponders the cause of such misrepresentations and speculates that others may infer a sick body from a sick heart:

People with heart conditions are not as feeble as they might think in the situation. They're just like normal people, although they should probably keep on the exercise more than the rest of them. I guess it's like putting two and two together. Thinking that “oh, there's a problem with the heart and 'cause the heart is such an important part of the body, obviously if they have a problem with this, they have a problem with the entire body.”

Thus, other youth drew upon resistance narratives to challenge dominant cultural representations. Cultural misrepresentations that emphasize frailty were thought to be incorrect, and youth suggested that they are strong and able and can undertake physical activity. Furthermore, by misconstruing their health and physical activity, inaccurate representations were described as a social barrier for some youth. The participants drew upon their own experiences to correct cultural misrepresentations.

Therefore, “what I wish you knew” refers to the participants' ability to understand cultural representations of childhood illness, and, more importantly, their efforts to explain what it is really like to have CHD and engage in physical activity. What youth wished that others knew slightly varied, however. By agreeing with dominant cultural portrayals, some youth adopted realist narratives. In contrast, other youth took up resistance narratives to refute representations of frailty. Furthermore, “disclosure dilemmas,” barriers in physical education, and contesting the abnormal body also encapsulate the experiences that youth with CHD wished others knew, and these themes are described below.

Secret Keeping: Negotiating Disclosure in Health and Physical Activity

Youth with CHD also wanted others to know about the difficult and complex disclosure dilemmas that they encounter with respect to health and physical activity (Sparacino et al., 1997), and problems related to disclosure were central to their experience of living with CHD. Some youth were worried about the consequences of disclosure and were uncertain to whom CHD could be safely entrusted. Many youth were aware that disclosing their cardiac condition could result in negative consequences. By exacerbating difference, disclosure could potentiate exclusion and marginalization. Conflating the terms physical activity and physical education, physical education in particular exacerbated an already complicated disclosure dilemma. Youth suggested different ways they might personally resolve their own disclosure dilemmas, and decisions were based on the perceived social consequences. In all cases, youth placed a great deal of effort into the resolution of their disclosure dilemmas.

Most youth decided not to disclose their cardiac condition to others, making their desires for “what I wish you knew” all the more poignant. Doing so was thought to result in negative social experiences, such as exclusion, and perpetuated the continued construction of these youth as fragile, weak, and different. Although nondisclosure prevented youth from the “social injury” of being different, youth were aware of the downsides associated with this approach in physical education settings. When physical education teachers and peers did not know about youths’ cardiac conditions, they were expected to do the same activities as others. This often left youth feeling exhausted during physical education, and they devised covert ways in which to rest, such as stopping briefly every few minutes. While negative physical experiences, such as fatigue, were described as unpleasant and unsafe, in the cost-benefit analysis, this was presumed to be less distressing than the social exclusion that youth experienced when they revealed themselves.

For example, Mindy purposefully avoids disclosure. She explains that disclosure may accentuate difference and facilitate inaccurate assumptions about her physical abilities:

I don’t kind of like anybody to know because they would treat me differently and stuff, and they would try to tell me what to do, and what I can is what any kid in the class can do. I don’t really like talking about it and stuff, because I don’t really like bringing attention to myself, and that kind of does . . . there are worse things to worry about.

Other youth described the school climate as uncaring, and they lacked a supportive social network. Because “others do not know or care about me,” disclosure was unwarranted:

No one knows because I am not really close with anybody. I don’t have much friends, actually, I don’t have any at high school at all . . . my decision not to tell someone, is just that I don’t think they know enough about me for me to tell them . . . just because I don’t feel enough closeness, they should not know . . . if I was to, God forbid, fall sick or to have any problems or anything, I don’t think they would care enough . . . like why should they know about me? (Jonah)

In contrast, other youth stated that it was important for teachers and peers to know about CHD. They emphasized that they are “no different” from other youth and that having heart disease should not result in shame. As such, they resolved the disclosure dilemma by sharing the information with trusted friends and teachers, and they articulated that it was important for others to accept them. “It doesn’t matter if they know, I have no problem letting them know. I am not ashamed of it, I’m just normal except that I have a line (cardiac scar) down me” (Elsie).

For these youth, disclosure was also thought to be important in physical education. Youth emphasized that if a cardiac event occurred, it was critical for teachers to act quickly and appropriately, and in this way, disclosure was a precautionary measure that safeguarded health.

Thus, youth appeared to navigate complex disclosure dilemmas that posed barriers to health and physical activity. They were worried about others’ reactions to CHD, albeit to varying degrees; unsure of whom they could trust, they based decisions on the perceived social consequences. While most youth resisted disclosure, others did so to ensure their physical safety and expressed the importance of others accepting them. Conflating the terms physical activity and physical education, youth reported that physical education settings complicated disclosure dilemmas by accentuating physical differences.

The Things That Stand in My Way: Barriers Encountered During Physical Education

Once again, conflating the terms physical activity and physical education, youth with CHD also wanted others to know about the complex physical and social barriers that they encounter during physical education. In all cases, these social and structural barriers resulted in distress; they led to negative appraisals of physical education and detracted from enjoyment. In particular, (a) the physically demanding physical education curriculum, (b) not having sufficient time for rest, (c) inappropriate responses from physical education teachers, and (d) peer bullying were described as barriers that detracted from involvement in physical education.

The physical education curriculum in Brooke’s school emphasizes traditional team sports. She expresses self-doubt and a sense of physical inadequacy when participating in activities such as basketball, and, as she engages in social comparison with her peers, she chastises herself. Her narrative illustrates the interplay between the physical, social, and psychological barriers that youth with heart disease may encounter during physical education. Brooke’s frustration regarding her inability to “keep pace” with her peers in physical education is apparent:

Why do we have to do a sport today? And I’m not any good at basketball. I can’t dribble, and I’ll feel like a loser cause I’m going to mess up all the time, I’m not going to get any baskets. Yah-just feeling left out . . . there’s a group of six girls that were really good at every sport. And I’d be like “oh I wish I could, you know?” At least be good at one—it would make me feel a little better.

Similarly, inadequate time for rest and hydration was experienced as an unpleasant barrier, and youth were particularly distressed by the discrepancy between health providers and physical education teachers’ advice. In particular, when youth had been advised by their physicians to rest when necessary, and teachers did not

accommodate these requests, youth felt distressed, embarrassed, and confused. For example, Lisette explains that when efforts to communicate her physical education needs are unacknowledged, she feels invalidated. Lisette questions her teacher's intent and struggles to understand her failure to accommodate:

My doctor advises me to try to keep up as much as I can . . . if I feel that I can't keep up with the rest of the class, then take a little break, take a breather, get a drink . . . I found that last year when I did ask for a break, I wasn't given it, because my teacher just assumed it was an excuse to stop running. . . . It made me feel really embarrassed and annoyed. My mother has called her, told her about my condition, she knows about my scar, I showed her the prescription for the pills that I take, and she just chose to ignore it.

In addition, socially insensitive responses by physical education teachers were experienced as barriers. For example, teachers often pushed youth excessively, or, rather, excluded them completely. Aubrey explains that when pressured, he is most likely to succumb to it and risks exceeding his own embodied knowledge and perceived activity limitations. For Aubrey, the lack of understanding about the activity needs of youth with CHD makes him angry:

So if they don't know (about CHD), they'll keep pressuring me and pressuring me, and eventually, I'll give in . . . Well, when I stop, I feel exhausted. But if someone is telling me, and I tell them "I can't," I just feel a bit kind of angry 'cause they're not getting it.

While youth were distressed by these excessive performance expectations and inappropriate responses to CHD, they endured them for fear that if others knew, they risked being treated differently and having performance expectations lowered. Mindy balances the demand of high performance standards with the risk of fatigue in physical education. She believes that if teachers and peers knew, they would reduce their expectations and overlook her athleticism:

Complaints that I have about this (physical education)? I think it is too "go, go, go," and you need a few times to catch your breath . . . they might just treat me differently, like I can't do something, instead of, you know. And basically, not set the bar very high for me.

Finally, other participants experienced distressing social interactions with peers during school life and physical education, such as bullying. Interestingly, participants explored the meaning of peer-related teasing and they contemplated why difference is easily targeted and attacked in adolescent social circles:

I've had someone saying "you have a problem, you can't get past me [soccer game], you have this [CHD], you can't do this, right?" . . . I had one time when someone in my school said "yah, you're different than all of us." And I'm like, "no I'm not—I can basically do the same things as anyone" . . . "You got no right saying that, you don't know what I have" . . . Words can actually affect you a lot, more than actions. (Paulo)

Bullying also occurred outside of the context of physical education and required youth to critically consider the meaning and importance of difference:

On our lockers, she wrote something on hers and something on mine, and mine said “scar face” . . . how low can you go to make fun of somebody? It’s like calling somebody ugly—it’s not like they can help it—they were born like that. And after the day went through, it was like “wow that really put it in perspective for me that I’m not like everybody else,” and that I stand out for someone to take something as different as my heart and make fun of it . . . it made me feel like really different than everybody else. (Lisette)

In this regard, both physical and social barriers in youths’ social and cultural environments detracted from enjoyment in physical education.

The Normal/Abnormal CHD Body: Contesting the Normal Body in Health and Physical Activity

Finally, youth with CHD also wanted others to know about their complex struggle to understand themselves as similar or different, and their narratives about normalcy oscillated between being the same or different. Youth were distressed by their nonnormative embodiment, and they either took strides to conceal their cardiac conditions or engaged in normalizing practices to be like other youth. Furthermore, youth often contemplated whether others understood them as normal or not:

I don’t know what people would think mostly about heart conditions. Maybe they would think that they’re fragile or I can’t do things, or we wouldn’t be good at a sport, and they wouldn’t be good for the team. Just because they think they wouldn’t be healthy enough or wouldn’t be able to do it. And I’d say, as long as we’re staying fit and being careful, then we’re pretty much the same as anyone else. (Brooke)

Furthermore, normalcy was associated with youths’ efforts to resolve their disclosure dilemmas. Because youth wanted to be regarded as normal and resisted differential treatment during physical education, they strongly resisted disclosure. “I want him to know [physical education teacher], but I just don’t want him to just take me out of some things” (Jordan).

Similarly, spaces and settings which accentuated difference and nonnormativity, such as physical education, were distressing for youth:

Just like this? [being sidelined in physical education]—‘cause you feel like really, really, odd and you feel really, really weird that you have to sit out just because you were born with it [CHD] . . . you want to live a normal life, but you can’t live a normal life because you have this. And like I said, when you’re not in the hospital, your disease doesn’t exist. So I think that basically, you should just go on and do your normal thing, and you just feel like really left out when people say that “you can’t do these things.” (Mindy)

In this regard, youth with CHD simultaneously constructed themselves as both normal and not, the same and different, at one and the same time; thus, discourses of normalcy were contradictory. Because it exacerbated difference within a context where it is of utmost importance that one fits in, nonnormativity was described as negative. Youth were greatly distressed by perceptions of difference and actively

engaged in normalizing practices, such as nondisclosure of CHD. In all cases, physically active settings increased perceptions of difference. In summary, the themes were interrelated. In telling us “what I wish you knew,” youth dialogued about the significance of disclosure dilemmas in their lives, the difficulties they encounter during physical education, as well as their effort to offset nonnormativity as central to what they wish that others understood about what it is really like to have severe CHD. Below, the findings are discussed within the context of the existing literature base.

Discussion

Children with illnesses have traditionally been excluded from critical dialogues about the meaning of childhood illness in culture; however, it is important that children with illnesses actively participate in the cultural production of illness and be afforded opportunities to shape and comment upon these cultural representations (Barnes, 2006). Indeed, in dialoging about “what I wish you knew,” the participants reflected upon the rich social and symbolic representations and imagery in North American culture that construct youth with CHD and illustrated their capacity to engage in critical dialogue about the cultural representation of children with illnesses. They were cognizant of how they are understood as youth with illnesses through the eyes of others. Challenging the “tyranny of developmentalism” (Mayall, 2000) that emphasizes the apparent immaturity of youth, the participants demonstrated their self-reflexive capacity to think about such representations, and they either supported or contended them. Thus, some participants agreed with dominant representations and explained why CHD is a traumatizing experience. Similarly, they explained that physical activity is more difficult for youth with illnesses. In contrast, some participants were eager to disrupt these dominant representations. Illustrative of their capacity to dialogue about the “double”—or representations of illness—children commented upon how these representations are often demeaning and oppressive (Scheper-Hughes & Lock, 1986). They argued that cultural portrayals that emphasize frailty and weakness are inaccurate, and, by describing themselves as normal and capable youth, they proposed alternative, more liberating representations (Wallis & Nerlich, 2005). Because inaccurate cultural representations and portrayals led others to either underestimate their physical abilities, or, rather, not appreciate how difficult it was for them to engage in physical activity, cultural misrepresentations were experienced as a distressing social barrier toward physical activity for some youth with CHD.

There is scant literature on youths’ perceptions toward how their health and physical activity is represented in society, and this is arguably a novel contribution from the current study; however, this finding, “what I wish you knew,” accords with broader literature on illness representations. For example, in addition to discussing how different illnesses generate different social and symbolic meanings in culture, and the ways in which patients should be considered as the experts of their own illness experiences (Barnes, Mercer, & Shakespeare, 1999), this literature examines how cultural portrayals of illness may misrepresent certain fundamental elements of the illness experience and vary radically from patients’ own embodied and experiential understandings. Therefore, in addition to illuminating their historically and

culturally contingent nature, these scholars suggest that cultural representations of illness can never offer up a true nor authentic account (Barnes et al., 1999; Davis, 1995, 1997). Indeed, by discussing “what I wish you knew,” the findings confirm this conceptual proposition. Specifically, by reflecting on how their understandings of illness vary from broader cultural representations of CHD, and making efforts to correct them, the participants displayed their health care expertise (Barnes et al., 1999) and sophisticated capacity to contemplate these cultural representations.

Furthermore, this study extended the concept of disclosure to youth with CHD. Indeed, participants appear to negotiate complex disclosure dilemmas and resolve this conflict based on the minimization of difference and the consequences of telling. Conflating the terms physical activity and physical education, youth reported that physical education settings accentuate performance differences between youth with and without disabilities. Physical education settings appear less accommodating to youth with CHD and thus further complicate disclosure. It is not surprising that most youth opted not to tell.

Youths’ disclosure dilemmas also accords with the broader literature. For example, Sparacino et al. (1997) documented the complex disclosure dilemmas that are encountered by the parents of youth with CHD. Due to social stigma and misconceptions, these parents are unsure of whom to tell about CHD; fearing social insensitivity, they tolerate the burden of secrecy. Similarly, a study conducted with children with cystic fibrosis (CF) found that these patients struggle with the problem of disclosure. Where social anxiety concerns peak during adolescence, these youth strategically conceal CF as a carefully guarded secret (Christian & D’Auria, 1997).

Indeed, the problem of disclosure for the participants reveals the complex ways in which they carefully navigate their CHD identities. Most youth opt for secrecy and are gravely concerned that disclosure will exacerbate perceptions of difference and abnormality. The possible reasons for these complex identity negotiations require further investigation. However, factors such as the internalization of stigma and disability discourse, the amount of time that youth have spent in hospital environments, the CHD attitudes and beliefs of healthcare providers, and, more notably, the influence of parental perceptions of CHD on youths’ identity negotiations are potential reasons for why most youth do not disclose. In this regard, negotiating the disclosure of a stigmatizing identity appears to be a common experience for those with chronic illnesses and their parents. As clinicians, researchers, and physical educators, it is imperative that we display sensitivity to youths’ weighty disclosure dilemmas, recognizing that the “spectacle of disability” is all the more pressing during adolescence, where the main developmental task is to “fit in” (Christian & D’Auria, 1997).

Conflating the terms physical activity and physical education, participants discussed the network of barriers that they encounter during physical education. The barriers that youth described were physical and social in nature. For example, youth explained how a demanding physical education curriculum organized around sports such as track and field resulted in exhaustion. They wished that the physical education programs provided them with a broader range of activities that facilitated inclusion. Youth were cognizant of their fatigue during physical education; not providing adequate time for rest was another physical barrier that detracted from enjoyment in physical education. Finally, while some teachers were socially sensitive and facilitated inclusion, others demonstrated inappropriate social responses

to CHD, such as excluding youth from the activity or pushing them beyond their perceived limitations. These barriers detracted from youths' enjoyment in physical education and led to negative appraisals.

Within the broader field of pedagogy, that is, a critical intellectual forum for thinking about education, disability has been omitted and disabled students marginalized (Erevelles, 2000). Indeed, although people with disabilities are among the most marginalized in society, critical pedagogues have remained silent around the issue of disability, and it has either been avoided as a social category for analysis, or, rather, simply added to the "trinity" of race, gender, and class. Indeed, termed disability pedagogy, scholars with disabilities and allies aim to further a critical disability dialogue that challenges the larger systems that have constructed disability as a medical and individual category—a critical education that occurs *because* of their disabled bodies, rather than *in spite* of them. In this regard, efforts are being made to address the silences that have occurred around people with disabilities in critical education and pedagogy (Erevelles, 2000; Nocella, 2005).

With respect to physical education and disability, specifically that youth with severe CHD report experiences of marginalization and exclusion during physical education, is a novel finding and calls upon physical education pedagogues and researchers to further explore the physical education experiences of this specific group of youth. Although there is only a small but emerging pedagogy literature that examines the physical education experiences of youth with disabilities more broadly—subsumed under gender, disability remains absent as a lens for understanding difference in physical education (Flintoff, Fitzgerald, & Scraton, 2008)—the narratives of youth with CHD accords with the pedagogy literature. For example, various authors have discussed how physical education spaces are premised upon ablest assumptions that emphasize normal, efficient, and productive bodies. Working to exclude nonnormative bodies, physical education may lead some people with disabilities to feel alienated in such hostile spaces (Sykes, 2009). Similarly, although physical education has the potential to be a normalizing experience for some students with disabilities, other studies have found that it may be a site where social constructions about disability are reproduced and a space in which students with disabilities learn that their marginal activities do not afford them with the same social status and capital associated with mainstream physical education (Flintoff et al., 2008). Furthermore, a lack of opportunities to be active, inadequate equipment, poor teacher education, inappropriate activities, peer exclusion in physical education, liability concerns, and parental overprotection (An & Goodwin, 2007; Swisher & Erickson, 2008) are social barriers to physical education that are encountered by other youth with illnesses and disabilities. In this regard, the experiences of participants closely accords with the pedagogy literature and may speak to a similar experience of marginalization encountered by youth with illnesses and disabilities during physical education.

Clearly, the findings call upon adapted physical activity and pedagogy specialists to prioritize understanding the physical education experiences of youth with severe CHD as an important part of their research agendas. In addition, studies have found that physical education teachers are generally intrinsically motivated to include students with disabilities into the curriculum. Doing so is viewed as a way to better the educational experience for all students, enhance diversity, and change perceptions of students with disabilities. A variety of pedagogical challenges,

however, such as lack of teacher knowledge and training, large class sizes, lack of resources, safety concerns, lack of parental involvement, and uncertainty regarding whether students are experiencing a sense of success during physical education, often impede teachers from being able to include students with disabilities (Hodge et al., 2009). For this reason, studies that address the constraints that physical education teachers may encounter in efforts to include youth with CHD into the physical education curriculum also require further investigation. Finally, physical education teachers must be informed about the specific barriers that youth with CHD encounter during physical education and work with youth to sensitively devise appropriate accommodations that better facilitate enjoyable physical education. Given the activity limitations that this group experiences, and the burden of fatigue, teachers should devise appropriate accommodations that allow youth to rest when required during class while not drawing undue negative social attention.

More importantly, when discussing the barriers encountered during physical education and problems with disclosure, it was interesting to note that there were important discrepancies between the researchers' and participants' understanding of the term physical activity. Although participants were questioned about physical activity during the interview, their answers were framed in terms of physical education. In addition, the terms physical activity and physical education were often conflated. That youth with CHD understand physical activity as a discipline and practice that occurs in institutionalized school settings, is an interesting finding in and of itself and begs further study both by adapted physical activity and pedagogy specialists. Indeed, there may be important discrepancies between dominant, "adultist" (Darbyshire et al., 2005) understandings of physical activity and youths' own situated understandings. For example, the movement that youth do outside of institutionalized and organized physical education spaces may not "count" as physical activity or be memorable and important for youth. Rather, because physical education is by its very nature an embodied practice where moving the body is central to success (Flintoff et al., 2008), physical education may be the most salient experience in which youth with CHD recount their experiences of moving the body. Thus, more research is needed to unravel the incongruence between adult-youth understandings of physical activity and discern the meanings that youth bring to the term physical activity.

Finally, youths' ability to draw upon narratives and past experiences to articulate themselves as normal or abnormal youth was profound. Indeed, youths' relationship to normalcy was contradictory, and they simultaneously constructed themselves as both normal and abnormal. The experience of abnormality was contextual and temporal; hospitalization, doctor's appointments, and times of illness reminded youth all too poignantly that they are not the same. Social activities and times of relative wellness were opportunities to "forget the body." Interestingly, because physical activity accentuated the difference between youth with and without CHD, youths' sense of normalcy was more threatened in these spaces. Because they struggled to keep up, physical activity served as a site for accentuating differences in relation to their peers. Because it made them susceptible to negative social experiences, such as bullying or a diminished social status among their peers, the abnormal cardiac body appeared to be threatening for youth and they took great

strides to conceal nonnormativity. Furthermore, the abnormal body and perceptions of difference are arguably more salient during adolescence when concerns center primarily on fitting in with peers in the dominant social group. Furthermore, they engaged in normalizing practices to diminish the risk of being different.

The struggle to attain a sense of normalcy reported by youth with CHD accords closely with the broader literature. Much like participants in this study, other youth with a variety of chronic illnesses also struggle with the question of normalcy. For example, adolescent girls with CF feel marked as different (Berge, Patterson, Goetz, & Milla, 2007). In addition, because it allows for disability identification and the opportunity to be the same (Goodwin & Staples, 2005), youth with disabilities are eager to engage in physical activities with other children that also have disabilities. Thus, results from this study closely align with the literature.

Similarly, the social model of disability lends conceptual and interpretive insight into the finding that youth with CHD carefully negotiate normalcy within the context of physical activity. More specifically, social model theorists have discussed how stark divisions between normal and abnormal bodies were less emphasized before the rise of industry and modernization (Davis, 1997; Shogan, 2003). Rather, these scholars propose that the marking of disability as different is associated with the rise of modernization, industrialization, and capitalism. Indeed, the working, productive body is culturally revered during periods of economic productivity and the able body epitomizes this. Because the disabled body fails dominant cultural values, such as work and productivity, it arises as a problem in modern capitalist states that are premised upon the assumption of productivity and efficiency (Abberley, 1998; Sousa et al., 2009).

Furthermore, social model theorists purport that the rise of modernization, capitalism, and industrialization was also associated with the ascendancy of normalization and the normal distribution curve. Indeed, the normal curve functions as a tool to enforce particular standards for performance and productivity and is underpinned by modernist assumptions. The normal distribution curve serves as a tool in which to differentiate the normal from the deviant, and corrective techniques are employed to enforce and entrench normalcy (Davis, 1997; Shogan, 2003). Deviant bodies feel the burden of normalcy in such societies. They are incited to conceal deviance and work toward becoming more normal.

Indeed, the normalcy narratives of youth with CHD accord with these theoretical insights afforded by the social model of disability. Specifically, youth were cognizant of the importance of normalcy, and, while their narratives reflected contradiction, they constantly compared themselves against standards in health and physical activity and found themselves lacking. Looming large, the abnormal body threatened youth, and they sought to appear more normal. This illuminates the centrality of discourses of normalcy to the lives of youth with CHD; they are troubled by their nonnormativity and take strides to rectify it. In summary, by dialoging about “what I wish you knew,” their disclosure dilemmas, the barriers that they encounter during physical education, and their efforts to understand themselves as normal, youth with CHD drew our attention to the contextual barriers that affect their health and physical activity and call our attention to the social and cultural environments in which they undertake physical activity.

Conclusion

Despite the physical and psycho-social benefits associated with physical activity, the majority of youth with heart disease are inactive. Most often, individualist discourses are drawn upon to blame the victim, and the problem of inactivity is attributed to the individual pathological cardiac body. In addition, notions of insufficient will power are conjured up, suggesting that youth with heart disease lack will power and sufficient moral development. Too often, biological and psychological explanations are drawn upon to explain physical inactivity in youth with CHD. By exploring the influence of social barriers, this study sought to build upon this limited understanding of physical inactivity. The social barriers that influence the health and physical activity experiences of youth with CHD were explored.

In dialoging about “what I wish you knew,” their problems with disclosure, barriers in physical education, and struggle to understand themselves as normal, this study illuminated the social barriers that constrain the health and physical activity of youth with CHD. In trying to encourage these youth to be active, it is advisable for health professionals to look past individual people with disabilities and attend to the social and cultural environments where these youth live and play. Where there is a move in pediatric cardiology to enhance the psycho-social health and quality of life of these youth through physical activity, it is also important for health professionals to think about how barriers in youths’ social and cultural environments may contribute to reduced psycho-social health and quality of life. By placing the physical activity experiences of a neglected group of youth with heart disease at the center of the research design, this study demonstrates the centrality of social barriers to youth with CHD in their pursuit of physical activity. The voices of youth have, more importantly, contributed to our ongoing interrogation of the sociocultural factors that mediate their everyday health and physical activity.

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