The Perceptions of Caregivers Toward Physical Activity and Health in Youth with Congenital Heart Disease

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Abstract

Medical advances have reduced mortality in youth with congenital heart disease (CHD). Although physical activity is associated with enhanced quality of life, most patients are inactive. By addressing medical and psychological barriers, previous literature has reproduced discourses of individualism which position cardiac youth as personally responsible for physical inactivity. Few sociological investigations have sought to address the influence of social barriers to physical activity, and the insights of caregivers are absent from the literature. In this study, caregiver perceptions toward physical activity for youth with CHD were investigated at a Canadian hospital. Media representations, school liability, and parental overprotection construct cardiac youth as "at risk" during physical activity, and position their health precariously. Indeed, from the perspective of hospital staff, the findings indicate the centrality of sociological factors to the physical activity experiences of youth with CHD, and the importance of attending to the contextual barriers that constrain their health and physical activity.

Keywords

adolescents / youth; caregivers; grounded theory; health; heart health; exercise / physical activity; risk, perceptions

One percent of North American infants are born with congenital heart disease (CHD) each year. CHD is an umbrella term that encapsulates a range of structural defects of the heart that are most often functionally significant. Complicated malformations of the heart can, at best, be palliated, and in some cases they are eventually fatal (Hoffman & Kaplan, 2002; Sparacino et al., 1997). Because of medical advances, however, a growing number of youth with CHD are expected to reach adulthood, and CHD is now considered to be a chronic childhood illness that affects health on a daily basis (Green, 2004).

Despite reduced mortality, most youth with CHD are still plagued by a range of detrimental psychosocial sequelae. These include a high incidence of depression, anxiety, behavioral difficulties, covert fears, and academic failure (Bar-Mor, Bar-Tal, Krulik, & Zeevi, 2000; Fredriksen, Mengshoel, Frydenlund, Sorbye, & Thaulow, 2004; Gupta, Mitchell, Giuffre, & Crawford, 2001; McCrindle et al., 2006). This significant "burden of disease" might also "track" into adulthood. For example, young adults with CHD encounter difficulties with social relationships, independent functioning, and attaining employment. In light of these concerns, pediatric cardiologists are interested in developing interventions that will enhance quality of life in youth with CHD (McCrindle et al., 2006). In particular, undertaking physical activity and exercise is one health intervention that might enhance quality of life in youth with CHD. In addition, as will be demonstrated throughout this review of the literature, caregivers interact with youth over several years and are implicated in making important health and physical activity decisions. Thus, clinical caregivers are central to youths' quality of life, and can be considered as "critical stakeholders" with respect to these youths' physical activity participation. For this reason, addressing caregiver perceptions toward physical activity in youth with CHD is an important research task.

Review of the Literature

Although physical activity and exercise are associated with enhanced quality of life in youth with CHD, their physical activity experiences have been explained through

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dominant biomedical, rehabilitative, and health-psychology discourses. Indeed, sociological investigations studying the impact of social barriers to physical activity in youth with CHD remain absent from the research. For example, the medical model has demonstrated that these youth suffer from reduced exercise capacity, physiological functioning, and levels of physical activity (Lunt, Briffa, & Ramsay, 2003; McCrindle et al., 2007; Moalla et al., 2006; Reybrouck, Boshoff, Vanhess, Defoor, & Gewillig, 2004), thus reducing the problem of inactivity in these youth to individual, pathological bodies. Individualist rehabilitation discourses have also characterized descriptions of physical activity in which youth with CHD are morally compelled and personally responsible for improving their cardiac health through engaging in physical activity. It is assumed that if youth display tenacity and perseverance, they will be able to reverse cardiac deconditioning and improve important health parameters such as maximum oxygen consumption, treadmill walking time, oxygenation of respiratory muscles, muscular endurance, coordination, exercise capacity, cholesterol, and body fat percentage (Galioto & Tomassoni, 1993; Rhodes et al., 2005). Attaining healthy levels of physical activity is another benefit associated with participation in rehabilitation regimes (Longmuir, Tremblay, & Goode, 1990).

Finally, health psychology discourses have also influenced our understanding of health and physical activity in youth with CHD. Indeed, we learn that as a result of the chronic and debilitating nature of CHD, these youth are at risk of acquiring latent individual psychopathology such as depression, anxiety, behavioral disorders, poor self-image, and low self-efficacy (Bar-Mor et al., 2000; Burgess, 2003). Thus, the impact of CHD is not isolated to the body alone, and those youth who lack a robust will and temperament might also succumb to various mental disorders that connote an impaired psyche and flawed constitution. Indeed, because physical activity might attenuate and repair such psychological deficiencies, it is advocated for. The psychological benefits of physical activity—such as enhanced initiative, independence, quality of life, self-efficacy, role functioning, and skill improvement (Fredriksen et al., 2004; Galioto & Tomassoni, 1993; McCrindle et al., 2006; Moons et al., 2005)—also compel these youth to take responsibility for becoming active.

Indeed, there are several limitations associated with psychobiological explanations of physical inactivity in cardiac youth. In particular, by assuming that individuals are responsible for engaging in risk-reducing behaviors such as physical activity, these psychobiological explanations reproduce individualist discourses of healthism. Social and cultural conceptualizations of risk emphasize that concerns about health risks are central to modernity (Vahabi & Gastaldo, 2003). Furthermore, psychobiological explanations of inactivity in CHD youth turn away from the social and contextual factors that produce health risks in cardiac youth, such as physical inactivity. Rather, neoliberal discourses make health a personal responsibility in which good, healthy, and moral citizens take responsibility for attaining health and avoiding risky behaviors that compromise health (Ingham, 1985; Wheatley, 2005). Indeed, for youth with cardiac disease, individualist discourses arguably make for a reductionist and deterministic explanation of physical inactivity. For example, by insisting on individual reparation (Rich, 2006; White, Young, & Gillett, 1995), discourses of individualism reduce the "problem" of inactivity in youth with CHD to personal weaknesses. A critical interrogation of the social and material conditions which also constrain their physical activity is obscured, and rather personal victim blaming, guilt, and reproof are the logical extensions (Kirks & Colquhoun, 1989; Townsend, 2009). Thus, although individual behaviors such as physical inactivity in cardiac youth are constituted as problematic and risky, the social and cultural environment remains unchanged. Notions of insufficient and impaired willpower and morality are conjured up (Townsend), and CHD youth are held personally accountable for engaging in risky behaviors such as physical inactivity. An understanding of the social forces that mediate the relationship between CHD and low levels of physical activity are precluded.

For this reason, although biomedical and psychological explanations are crucial to facilitating an understanding of physical activity in this population, the sociological and contextual factors that might also influence participation beg further study. For example, although literature is scant, a few authors have noted the centrality of sociological factors to the health and physical activity experiences of these youth. These authors suggest that the social world is formative to youths' perceptions of health and the degree to which they understand themselves as able to keep up with peers (Kendall et al., 2001; Wray & Maynard, 2006). Furthermore, research conducted with CHD youth indicates that social comparison with and exclusion from their peers in physical education are significant social barriers. In addition, there are also school-related social barriers to physical activity for youth with CHD. In particular, schools might fear the legal ramifications associated with a cardiac event occurring on school premises. They might inappropriately exclude youth with CHD from engaging in physical education with their peers (Moola, McCrindle, & Longmuir, 2009). Furthermore, parents of youth with CHD might worry excessively about their child's health and physical activity (Bar-Mor et al., 2000). Perceiving them as being at risk,

they might restrict them from engaging in the same activities as their peers.

Thus, although literature that addresses the sociological factors influencing the health and physical activity of youth with CHD is scant, these factors appears to be an important area for investigation. More specifically, clinical caregivers occupy an important and central position in youths' social lives and influence their physical activity participation (Bar-Mor et al., 2000). However, caregiver perceptions toward the social factors that influence CHD youths' physical activity remains a lacunae in the existing literature and is a neglected site for investigation.

Caregiver Physical Activity Perceptions

The perceptions of clinical caregivers toward the health and physical activity of cardiac youth are absent from the existing literature. Indeed, although caregivers occupy a socially dominant position in the health care encounter, garnering the insights of both caregivers and patients might produce a better and more detailed account of the social phenomena in question (Davies, 2005). Arguably, caregivers' understandings and perspectives are central to how youth experience both their health and their health practices. Thus, despite the fact that caregivers are often regarded as neutral vessels of information, the perspectives of caregivers are crucial components of the health delivery chain. Additionally, because the health of youth with CHD is monitored over years, caregivers become an integral component of youths' social lives. Caregivers are able to offer important insights regarding patients' health needs, and their wealth of experience and expertise enables them to provide nuanced and sophisticated "insider" perspectives regarding physical activity for youth with CHD.

Whereas CHD caregivers are an underresearched population, the caregivers of other chronically ill youth operate within a high-stress context characterized by limited funds and a lack of adequate support for their emotional needs, and find their work simultaneously satisfying and exhausting (Clarke & Quin, 2007). In addition, qualitative studies have revealed some of the important moral dilemmas and anxieties that caregiving staff for other chronically ill youth encounter. Caregivers might feel particularly stressed when their personal beliefs and values toward patient care do not accord with clinical recommendations (Jarman, Smith, & Walsh, 1997; King & Turner, 2000). Finally, in a larger study conducted with 17 youth with severe CHD in our cardiac clinic (Moola, Fusco, & Kirsh, in press), youth reported that they regard their caregivers as "health and physical activity experts" who care about them and "safeguard" their health. In addition, youth value their caregivers' opinions about their health and physical activity, and the caregivers appear to occupy a significant social role in the lives of the youth. Because of this, conducting a staff investigation to address caregiver perceptions toward physical activity in youth with CHD appeared to be a logical extension of our previous research endeavors. It allows us to study the question of physical activity in youth with CHD from multiple vantage points.

In summary, by attributing low levels of physical activity to defective bodies and minds, dominant physical activity research for youth with CHD has obscured the influence of broader social factors in their contexts and environments that might also constrain their physical activity. Youth with CHD are held personally accountable for engaging in risky behaviors, such as physical inactivity. Additionally, previous research has also ignored the perspectives of caregivers. Moving beyond biomedical rhetoric (Rich, 2006), in the current study we sought to address these limitations by studying caregiver perceptions toward physical activity in youth with CHD. Working with a group of health care staff at a pediatric hospital in Canada, the purpose of this qualitative study was to gain greater insight into caregivers' understandings of the social, cultural, institutional, and ideological factors that shape the health and physical activity experiences of youth living with CHD. Indeed, this article is premised on the assumption that caregiver perspectives are central to how youth experience health directives, particularly those related to physical activity, and therefore these perspectives are worthy of investigation in their own right.

Method

In addition to offering access to the imaginative lifeworlds of participants, qualitative research is necessary to capture the "humanity of health care" (Clarke & Quin, 2007). Valuing narrative, description, and research in "naturalistic" settings, qualitative methods broaden our understanding of social questions and shed light on the context in which behaviors unfold (Denzin & Lincoln, 2003). By studying caregiver perceptions toward physical activity in youth with CHD, qualitative research extends our limited understanding and captures aspects of their social experiences that quantitative tools might eclipse. By accounting for the ways that this knowledge is socially constructed, qualitative methods offer a self-reflexive entry point into the social lives of participants (Mason, 2002). Moreover, quantitative approaches currently dominate physical activity research (Pearce, 2009). Qualitative inquiry might allow researchers to understand

the role and meaning of physical activity for participants and the social and cultural environment in which it unfolds. Using such in-depth and exploratory approaches, qualitative researchers might be able to address localized and situated physical activity knowledge (Pearce).

Research Setting and Participants

This article is based on a study conducted at a major pediatric hospital in Canada. Bridging research, teaching, and care, the cardiac center in the hospital is committed to attaining excellence in the diagnosis and care of youth with CHD. The current health care context is characterized by a greater emphasis on the development of health care teams, which are thought to facilitate improved organizational effectiveness and shared decision making (Propp et al., 2010). The cardiac center is composed of an interdisciplinary team of professionals, and values family-centered compassionate care.

Cardiac staff were recruited to capture the interdisciplinary perspectives of the cardiac team and similarities and differences between disciplines. Staff were introduced to the study in an information session, and advertisements were posted in the echocardiography laboratory and cardiac clinic. Eligible participants were identified by the nurse manager, and staff were contacted by phone and email to solicit participation. A convenient interview time was arranged for participants. Seven caregivers between the ages of 27 and 60 participated in this study: one man and six women. Participants represented various disciplines such as medicine, nursing, social work, exercise physiology, child-life specialists, physical therapy, and occupational therapy, and years of service ranged from 2 to 30. Participants provided care for cardiac patients from birth to 18 years of age; however, in general, staff reflections and comments about physical activity were in relation to youth with heart disease.

Although this study was approved by the research ethics board at the children's hospital and informed consent was obtained from participants, the first author still encountered particular ethical conundrums during the research investigation which are important to discuss. For example, during the interviews, staff grappled with personal ethical dilemmas as individual staff members working on a larger clinical team, and posed questions about the interview process itself. For example, during the interviews, staff contemplated such issues as deciding how much of a particular patient's story was appropriate to disclose without compromising confidentiality. Some participants also chose not to answer particular questions, questioned the relevance of age on the content form, and used "politically correct" terminology to express their dissatisfaction with other staff members or the institution. Staff also made an effort to display professional expertise. Although the first author made efforts to concede to caregivers' requests, these ethical issues and conundrums were carefully documented and recorded.

Data Collection: Interviews and Field Notes

Individual interviews and field notes were the primary methods used to gather data. These methods were employed to investigate caregiver perceptions toward physical activity in youth with CHD. A semistructured interview schedule was designed and, using a recursive model, the interview proceeded in the line of conversation (Rich, 2006). The social model of disability, the sociology of health and illness, sport sociology studies, and the sociology of childhood offered a general conceptual framework in which to guide interview questions. Thus, concepts such as the social and cultural barriers encountered by persons with disabilities (Barnes, 1998), the illness narratives taken up by chronically ill individuals (Smith & Sparkes, 2008), the notion of children as agentic health care subjects (Mayall, 1998), and the ways in which sport itself can be considered as an "able-bodied institution" (Hoyle & White, 1999) offered important analytical concepts for consideration.

Interview questions were informal, open ended, and guided by participants' responses (Mason, 2002). The interviews were conducted in staff offices by the first author, who has researched and volunteered at the hospital for several years. This experience was relevant to this study in that it facilitated a more comprehensive, nuanced, and detailed understanding of CHD, and contributed toward rapport building with the clinical and administrative staff. The interviews were between 35 and 95 minutes in duration and were audiotaped and transcribed verbatim. The interview guide was relatively short and focused, pertaining to the potential impact of the media, parents, and schools on the health and physical activity of youth with CHD. Thus saturation, or the point at which no new meaningful information was obtained, occurred after seven interviews and repetition in the data was observed.

In addition to conducting interviews, field notes were recorded in a research journal. Important points regarding individual interviews—such as the child life specialist's detailed understanding of the psychosocial benefits of physical activity, for example—were documented, as well as institutional observations. These notes assisted us in better understanding the particular health care context of the project, understanding staff roles and responsibilities, as well as observing status hierarchies between staff (Propp et al., 2010). All interview and field note data were stored in a locked filing cabinet in the cardiac center. Informed by the work of Charmaz (2005),

constructivist grounded theory was employed to generate a thematic analysis.

Research Design and Analysis: Grounded Theory

Concerns have been raised regarding the appropriate use of grounded theory (Weed, 2009). For example, rather than being used by theoretically sensitive and trained researchers, concerns were expressed that it could be used "as a way in which to confer legitimacy on qualitative research by researchers who simply claimed to be doing inductive research" (Weed, 2009, p. 1). Moreover, grounded theory should be used as a means for developing usable theories to better understand poorly developed social experiences. In the present study we bore this in mind. Staff perceptions toward physical activity for youth with CHD remain understudied, and theoretical frameworks are lacking. For this reason, grounded theory provided a suitable framework for analysis.

Debates regarding whether grounded theory is a methodology or method continue, and it is perhaps better considered as a total research design that is characterized by several variants (Weed, 2009). Grounded theory offers both conceptual insights with respect to how knowledge about the social world should be created and practical tools for doing so. For example, use of grounded theory emphasizes the complexity of the social world by suggesting that social life itself is fragmented, splintered, and disordered. Furthermore, in grounded theory it is purported that knowledge is coproduced in a complex interaction between the researcher and the participant (Charmaz, 2005; Miller, Strier, & Pessach, 2009). By breaking with assumptions and technical jargon, grounded theory encourages researchers to display theoretical sensitivity and be open to the broad range of potential phenomena available for exploration in the social world.

In addition, based on a constant interplay between inductive and deductive reasoning, grounded theory equips researchers with a set of practical tools to generate emergent themes and to conduct an analysis of the data (Bartlett & Payne, 1997; Charmaz, 2005; Glaser & Strauss, 1967). In this study, we employed an iterative process in which data collection and analysis occurred simultaneously. A line-by-line analysis of the transcribed data was undertaken, and individual transcripts were read and reread. Through immersion in the data, commonly occurring phrases and units of meaning across all participants' narratives were "bracketed," coded, and grouped into provisional categories. As a form of theoretical sampling, emergent findings were "fleshed out" and refined, and the analysis guided further data collection. The data were scrutinized further and the conditions and properties that gave rise to particular themes were delineated. The data were searched for interrelationships between themes as well as the relationship between each theme and the main category. Although this analysis was undertaken by the first author, the second author read the transcripts. Discrepant interpretations were discussed and consensus developed. By "grounding" the findings in the data, categories were carefully refined (Maykut & Morehouse, 1994). A conceptual illustration of the findings was devised and serves as the basis for the discussion (see Figure 1).

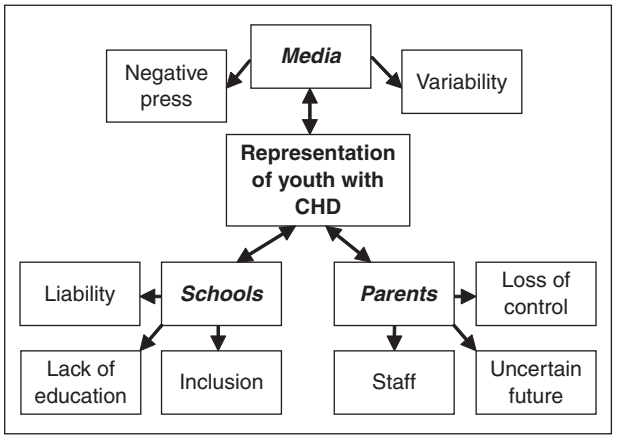

Figure 1. Construction of youth with congenital heart disease (CHD) as at risk in health and physical activity

In this study we attended to trustworthiness in qualitative research, or the degree to which the findings accurately depict the experiences of the lives under study, and "make sense" within the context of participants' social worlds (Creswell, 1994; Spalding & Phillips, 2007). Often employed to appease those schooled in the quantitative tradition, trustworthiness has been critiqued for breaking the fluidity associated with qualitative inquiry (Holloway, 2005). However, a variety of criteria were employed to enhance trustworthiness. An audit trail consisting of the first author's field notes, conceptual maps, and research findings was maintained. Field notes were written daily and discussions were held with the research team to discuss the findings and establish consensus. Questions regarding the data were proposed, such as whether they "invited" the reader into the vicarious experiences of staff and provided a believable account of their experiences.

Grounded theorists encourage researchers to consider how "the self" is always "visible" in research. Thus, the researcher inevitably brings to bear particular frames of reference that influence the findings. In addition, the researcher's social position influences what "counts" as data and what is disregarded (Charmaz, 2005). In this

study, the first author's identity as a 28-year-old South African-Canadian woman researcher who had a decade of experience working with ill youth could not be "bracketed." Arguably, these social positions were constitutive of the research question proposed, delimited the field of study, and influenced the making of meaning. In this regard, although grounded theory provided an analytical framework, efforts were made to employ it self-reflexively.

In summary, caregiver perceptions toward physical activity in youth with CHD were studied and several interrelated themes were generated. Staff suggested that the media, teachers and school boards, and parents construct particular representations of youth with CHD as excessively at risk during physical activity. The results are reported below with the use of pseudonyms for the participants. Occupations and work roles have been removed from the quotes to protect the anonymity of the participants.

Results

Manufacturing Risk

The media played a role in constructing youth with CHD as being excessively at risk during physical activity. Staff prefaced statements about the media by indicating that some youth do have debilitating conditions and might be at risk of incurring negative physical consequences when engaged in certain contraindicated physical activities. However, staff were critical of the media's failure to depict the variability among youth with CHD, and of the media's role in constructing particular representations of youth as excessively at risk in physical activity. Such "fear mongering" incorrectly implied that all youth with CHD are equally at risk of sudden cardiac death during physical activity. The media was also thought to obscure the fact that most youth with surgically repaired lesions can safely engage in enjoyable physical activity. By generating negative press and failing to depict the physical activity success stories of heart patients, media representations were thought to be biased and it was considered that they undermined the abilities of youth with CHD. Devon explained that by failing to account for the variability among youth, the media portrays all youth as equally at risk during activity, and thus reports inaccurate information:

> Sometimes you'll hear the story of a kid dying at school suddenly. And that sort of gets a lot of people saying, "Well, my child has a heart condition. That could happen to my child." And I think the misconception is, there is a lack of understanding of this condition. I think there is a misconception that there is a "blanket" heart condition—that this is the same as that. I don't think they maybe realize how diverse the group is. I think the media may play into that when someone [youth with CHD] has a heart attack.

Laurie concurred with Devon. She suggested that media representations gloss over the variability between youth with CHD, and generalize individual cases. Although most youth with CHD can safely engage in physical activity, the crippling clinical status of some patients cannot be overlooked. Drawing on English literature as an illustrative example, Laurie suggested that media misrepresentations are born out of the failure to adequately describe the variability among youth with CHD and the detrimental impact that one sick child's story might have for all youth:

> You think back to *Little Women,* and the image of Beth dying in her bed. . . . That is a powerful image, and I think really reflects a lot of what people think about heart disease. You know, "Blue babies, they're weak, they're going to die." That sort of thing. The problem is that, although most of the time that's not true, some kids are like that, and some kids are weak, and are fragile, and are going to die. And so, it's hard to combat that stereotype when it is true for a certain amount of kids. Not many, but just enough.

Because cases of cardiac death during physical activity are used to "sell" stories, these are showcased in the media. Martina discussed the dangers associated with negative news coverage and the detrimental impact this has for the parents of youth with CHD:

> One of the things that I do try to help them understand is the differences in etiology in terms of heart problems. . . . Those are profile stories. That kind of stuff sells newspapers. It cannot be a reflection of all patients with CHD. And it emphasizes the negative, and it is emphasizing every parent's worst nightmare: "My kid is going to drop dead."

Martina also explained how, by not discussing impressive achievements, the media undermines the tremendous potential of cardiac youth:

> I think a wonderful example are the heart transplant patients who went to Bangkok and participated in the World Transplant Games in August. These kids and these parents are an absolute testimonial to the fun and to the ability that these kids have. I think if we are looking for media coverage, we need to look at a balance.

Alexis suggested that media coverage of youth with CHD has a sinister side. The portrayal of heart-wrenching stories that emphasize the limitations of cardiac patients are related to economic agendas:

> The stories are usually—they focus a lot on the limitations of the children. . . . The end of the story is not positive, and often they are cases of children that have actually died. So I think that certainly does paint a picture of limitation, barriers, struggle. Certainly, within the stories, there are very inspirational, positive points as well, but they're primarily more heart wrenching. I think purposely so, in some ways driven to—you know, donations and things like that.

Staff proposed that media representations have a detrimental influence in shaping societal understandings of these youth. By not accounting for the rarity of sudden cardiac death, the diversity among patients, and their physical activity successes, the media was implicated as a powerful socializing agent that represented youth as at risk.

Parental Barriers to Physical Activity for Youth With CHD

Staff prefaced their discussion about parents by talking about their interactions with families who have displayed great resilience and adaptive coping. By ensuring that their children lead a "regular life," such families were thought to safeguard their child's precarious survival (Rempel & Harrison, 2007). If familial responses were appropriate, CHD was thought to be the impetus for inner strength. However, staff also detailed interactions with anxious families who worried about the health and physical activity of their child. Because it detracted from their respective child's ability to engage in physical activity and undermined his or her physical competence, parental overprotection was thought to have a detrimental impact. Staff concurred that some parents deter youth from engaging in physical activity and are barriers to participation. Rather than blaming parents, however, staff contemplated the factors that might contribute toward their behaviors and proffered complex rationales. Parental overconcern was thought to be related to loss of control, the uncertainty with respect to long-term outcome, and negative past experiences.

Bailey reflected on parental worry regarding the health and physical activity of youth with CHD. She suggested that parental overprotection is related to the sense of losing control that parents encounter at the hospital, and the perceived threats to their role as parents. Thus, parental overprotection is inseparable from the larger "control battles" parents wage:

> Parents lose all sorts of control when they are here. Not that they are in a struggle with their kids. But then, protecting their kid, and them playing that role for their kid, gives them that control. And sometimes, when you are asking them to give it up so that their kid can have it? It's hard, it's hard. . . . Parents feel so powerless. They don't have control over the care of their children anymore.

Alternatively, Martina attributed the problem of parental overprotection to an uncertain long-term prognosis, as well as the fear that participation in certain activities could have disastrous consequences. If health-related outcomes appear to be out of parents' control, overprotection is the result. In addition to hindering youths' physical activity, Martina suggested that parental overprotection interferes with the attainment of developmental milestones:

> I think that one of the challenges for many of the kids is the level of overprotectedness by their parents. And the real feeling that these kids—that something bad will happen to them if they participate in certain kinds of activities. I think it may come from the uncertainty of long-term outcome. And I think they are so afraid that these kids will die. It [parental concern] may encumber the child from reaching appropriate developmental milestones, like separation and autonomy.

When asked about the cause of parental overprotection, Victoria emphasized that it is difficult to distinguish between the impact of raising an ill child and the ways that hospital staff inadvertently shape parents' beliefs. For example, by failing to facilitate staff–parent communication and by not addressing misconceptions, staff contribute toward parental overprotection:

> I think some of the assumptions or ideas that parents have may come from us, inadvertently or not. And some may just be because their child is sick. I think it is maybe a bit of both, maybe. Maybe parental ideas which may or may not be affected by the medical team.

Participants talked about parental barriers to physical activity and the negative impact this has on activity participation and development. Staff proposed complex rationales to explain parents' behaviors.

Physically Educating a Sick Child

Staff reported stories about patients who derived the benefits of participation in enjoyable physical education. By devising appropriate accommodations that did not

accentuate differences, teachers could be thought of as advocates and allies. They worked toward fostering an inclusive climate and acted as catalysts for inclusion (Grenier, 2006). However, staff also believed that youth with CHD encounter numerous school-related barriers to physical activity. For example, by sidelining and excluding youth, or by ignoring limitations and pushing them, teachers and schools were thought to undermine the physical abilities of youth and detract from the health benefits of inclusive physical education. In addition, such behaviors could result in unpleasant consequences, such as stigma and poor identity development. Staff avoided blaming schools and teachers, and fears were attributed to complex factors. These included a lack of teacher education about the physical abilities of youth with CHD, as well as liability concerns.

Bailey attributed schools' and teachers' fears to multiple problems. In addition to lack of education regarding the physical abilities of youth with CHD and the fear of a cardiac event occurring on school premises, Bailey alluded to the numerous constraints that teachers encounter when trying to include youth in physical education. Large class sizes act as barriers to inclusion, and Bailey addressed a central issue in the inclusion debate, the concern that including youth with illnesses risks lowering the outcome expectations for the entire class:

> Teachers who have had no experience with cardiac patients are like, "Okay, not on my—I'm not having you have something bad happen, when it would be because I have asked you to do something." So I think that they are the most limiting. . . . It's hard too: Teachers now have what, like 35 kids in the class? And you are asking them, if there does need to be modification and limitations, they are going to limit an entire class because of one kid? I think there are a lot of things against being able to include a cardiac kid into a gym [class].

Laurie attributed the problem of school-related worry to liability concerns, and alluded to changing norms regarding this issue. She suggested that we live in an era of liability, and that contemporary culture is characterized by a concern with issues of risk. If schools fear the legal ramifications of a cardiac event occurring on premises, they might inappropriately exclude youth with CHD from physical education, and this undermines their physical abilities:

> I think that that sort of issue is out there. Certainly all the institutions are concerned about liability, and that's a reality of life today; unfortunate. I do feel like the presence of the automatic defibrillators that are becoming more widespread is helping people to feel more comfortable with that in the schools. Just knowing that there are things that they could potentially do if they had to. And I'd say gym teachers on one side, and then parents.

Harriet drew on her clinical experience to discuss the detrimental psychosocial consequences associated with excluding youth with CHD from involvement in physical education. She also suggested that restricting youth from physical education deprives them of the "natural place where children gather." More specifically, Harriet reflected on one patient's story to illustrate how exclusion from physical education heightens stigma and perceptions of difference:

> One patient I had a number of years ago, and they had a color code [a warning system] in the school. It was really very sad. This particular patient had another complex [heart condition]—so he ended up with a special line [percutaneously inserted central catheter (PICC), a form of long-term intravenous access]. And so, they had his picture everywhere, and they had these red, blue, and different color codes they call over the playground. And they would always watch where he was. So that was very sad.

Harriet also speculated that "standing out" in physical education as a result of CHD might thwart youth's identity development and sense of personhood. When youth "become their conditions," the salience of disability is overemphasized and youth are understood as little else other than their disabilities. Harriet stated that "they stand out. They lose their identity. They become a cardiac diagnosis versus this gorgeous child who should go through school with no issues."

Although staff recollected experiences working with patients who had derived the benefits of inclusive physical education, schools' and teachers' concerns were reported as barriers. Staff attributed school-related fears to the representation of youth with CHD in the media, the era of liability, and problems associated with inclusion. Such factors undermined the physical competencies of cardiac youth and resulted in negative consequences.

In summary, all themes were interrelated. Staff suggested that media representations, schools, and parents concomitantly constructed particular representations of youth with CHD as being excessively at risk. In this way, these three social barriers operate in tandem to construct inaccurate representations of youth with CHD (see Figure 1). Although some youth do suffer from the debilitating consequences of severe CHD, most patients with surgically repaired lesions are able to engage in some degree of physical activity and should be encouraged to

do so (Moola et al., 2009). Thus, participants considered the cultural construction of youth with CHD—as fragile and delicate children at risk during physical activity—to be inaccurate. Such images merely serve to perpetuate the continued exclusion of youth with CHD from physical activity, and staff challenged this assumption. Below, the findings from this study are discussed within the context of the existing literature.

Analysis and Recommendations

The social constructivist stance adopted in this study allowed us to study the complex ways in which clinical caregivers understand physical activity for youth with CHD. Indeed, caregivers suggested that the media, parents, and schools construct cardiac youth as at risk during physical activity. Although this finding will make a novel contribution to the research, sociocultural literature on risk informs a better understanding of how and why youth with CHD are understood as being at risk, and the consequences of these constructions. For example, late modernity has been described as a "risk society" (Beck, 1992, p. 19) in which the reflexive individual is charged with minimizing risks through careful management and control of the body. Within this context, the body is constructed as a project that is always unfinished; it is subjected to a litany of body modification techniques and surveillance practices that are deployed to control the body and carefully manage the risks to which it is subject (Lupton & Tullock, 1998). Moreover, the centrality of and concern with the body in modernity opens it up to multiple risks. Indeed, the body in modernity is always vulnerable to threat and, within the context of globalization, those of us in a risk society are constantly concerned with guarding ourselves against invasion and attack from multiple risks, such as nuclear weapons or disease (Lupton & Tullock). In addition, drawing on discourses of individualism, all bodies in modernity must act in risk-reducing ways and proactively work toward circumventing health-related risks. Indeed, risk-taking behaviors, especially with respect to health, are understood as irrational. Responsible individuals act in health-protective ways (Vahabi & Gastaldo, 2003) such that risk avoidance is understood as a moral enterprise (Fusco, 2006) and an indicator of good citizenship.

In a risk society, children's bodies are particularly susceptible. As potentially unruly and unregulated bodies that might easily be led astray (Lupton & Tullock, 1998), children are the coveted "future of tomorrow" and must be schooled and disciplined into proper modes of conduct. Indeed, where risk discourses converge and center on children's bodies, it is evident that in a risk society, teachers, schools, the media, and health professionals are invested in preventing cardiac youth from engaging in potentially risk-taking behaviors and are implicated in the surveillance and monitoring of their health and safety. Within the context of inaccurate information and misconceptions, from staff perspectives it appears that physical activity and exercise have emerged as potentially hazardous for cardiac youth. As such, there is great concern about their involvement in active pursuits.

Moreover, Vahabi and Gastaldo (2003) proposed that there are both expert and lay conceptualizations of risk. Expert notions of risk are reduced to objective concepts and epidemiological statistics. Assuming that humans are rational actors, these realist risk perspectives are oriented toward defining, assessing, managing, and evaluating risks. However, these statistics might make little sense to the social lives of patients, and it is necessary to study how people take up, negotiate, and make sense of risk-related information within the context of their everyday lives (Lupton, McCarthy, & Chapman, 1995; Robertson, 2000). Indeed, a sociocultural understanding emphasizes that risk is the outcome of competing historical, cultural, and political discourses (Vahabi & Gastaldo) and, in this regard, what we come to know as a health risk is itself influenced by social norms as well as idiosyncratic perceptions (Robertson). Such lay perceptions of risk are always lived, experienced, and embodied. As such, the social and cultural interpretation of risk might vary dramatically from epidemiological and medical notions, and provide a framework for examining how patients bring meaning to the concept of risk in social contexts (Lupton et al.).

The construction of youth with CHD as being at risk in physical activity and sport is novel and remains an underresearched lacunae in the literature. From the perspective of staff, the concept of risk was relevant. Staff discussed the factors in the social and cultural lives of youth with CHD that construct particular images of them as fragile, delicate, and at-risk youth who require intensive health-related scrutiny. Staff offered both expert and lay conceptualizations of risk. For example, they drew on statistics and scientific/medical/clinical information to explain how cases of sudden death during physical activity are relatively rare, and that although a subset of youth are at risk, the majority of youth with CHD are not. However, staff also offered their insights on how lay conceptualizations of risk among the media, parents, and schools are mobilized and construct representations of youth with CHD. For example, they self-reflexively considered parental physical activity anxiety and speculated about why schools are concerned about the consequences of a cardiac event occurring on school premises. Thus, they offered up meaningful insights into how risk in physical activity is lived and negotiated by those intimately involved in the care of youth with CHD.

Regardless of whether staff offered expert or lay perceptions of risk, in all cases inaccurate representations of youth with CHD by parents, the media, and schools were thought to have a detrimental impact. Staff suggested that by constructing youth with CHD as at risk, such representations perpetuate their continued exclusion from physical activity and sport. Furthermore, because physical activity was thought to be a healthy and enjoyable pursuit for all children, staff suggested that physical activity restrictions deprive them of a normal childhood. In addition, in keeping with the social constructivist nature of this qualitative inquiry, staff perceptions of risk should not be considered as "true" or "accurate" reflections of physical activity in youth with CHD. Rather, the findings convey how this particular group of health care providers understood and constructed meaningful interpretations within the context of the research setting, domains of professional expertise, and the health care context.

In this study, staff suggested that youth with CHD must contend with a range of social and symbolic images and representations in culture that emphasize notions of fragility, dependency, and vulnerability. Although this has not been documented previously, other studies have illuminated the complex ways in which chronically ill and disabled individuals must manage and cope with representations of illness within a culture. For example, influenced by the formative work of Susan Sontag (1977), who proposed the notion of illness as a metaphor for broader cultural values and concerns, Dixon-Woods, Seale, Young, and Heney (2003) drew on media and parental reports to study how youth with cancer are represented. Childhood cancer is positioned as a relentless battle between good and evil. Cancer is the evil villain and the child is constructed as a courageous, inspiring, and uncomplaining hero who dutifully complies with treatment and is aided by parents who battle feverishly alongside him or her. Moreover, because of the fact that cancer invades the entitlements and activities of childhood itself, such as play, innocence, and future ambitions, it shakes the very ground on which our understanding of childhood is premised, and thus is regarded as particularly insidious. Moreover, although neither account provides unmediated access to the reality of childhood cancer, and there is a need to study their own representations, Dixon-Woods et al. found important discrepancies between media and parental reports. For example, rather than having notions of dutiful compliance, parents emphasized that cancer treatment was often extremely difficult, tedious, and even intolerable for youth. Furthermore, rather than focusing on the moment of recovery and remission as portrayed in the media, parents were much more likely to consider the difficulties that youth might encounter in the future. In their analysis, Dixon-Woods et al. also showed how romanticized notions of childhood cancer treatment are inevitably related to strategic marketing maneuvers that aim to present a gripping human interest story. These representations can be particularly oppressive for those youth and families who are not able to cope in this way.

Similarly, Shakespeare (1994) commented on the rich social imagery and representations through which people with disabilities have more generally been constructed in literature and film. Drawing on Simone de Beauvoir and Mary Douglas to emphasize concepts of Otherness and liminality, Shakespeare illuminated how persons with disabilities are criminalized, dehumanized, patronized, infantilized, medicalized, pitied, and feared. Functioning as the collective "dust" or "waste bin" for the bodily anxieties that able-bodied people wish to disavow, disabled bodies function as "ciphers" for demeaning and limited collective cultural representations. Thus, it is evident that chronic illness elicits a range of stigmas and labels, and its meaning is derived in social contexts (Davis, 1997). Moreover, where different illnesses are associated with different meanings in culture and public evaluations vary based on these understandings (Barnes, Mercer, & Shakespeare, 1999; Bury, 1991; Goodwin, Thurmeier, & Gustafson, 2004), from the perspective of staff in this study it is evident that the notion of illness as metaphor and symbol can also be taken up to understand representations of youth with CHD. Emphasizing notions of fragility, vulnerability, pity, and risk, staff suggested that the potent cultural imagery through which youth with CHD are represented excludes them from physical activity and sport. Indeed, we have reported on staff perceptions toward the media construction of these youth rather than providing actual media reports. However, staff stated that more accurate media reporting is crucial, and that it is necessary to challenge negative and biased reporting. Reporting the physical activity success stories of youth, rather than tragedies, could contribute toward reshaping inaccurate perceptions.

Finally, staff also implicated the parents of youth with CHD in the construction of risk, and this is well supported by the literature. For example, by underestimating their child's physical capacity, many parents might undermine his or her abilities (Fredriksen et al., 2004). In addition, drawing on gendered notions of caregiving for chronically ill youth, there is a close association between maternal anxiety and youths' covert fears (Gupta et al., 2001). Maternal attitudes toward physical activity are a powerful determinant of self-efficacy in youth with CHD, and exert an influence on the actual level of physical activity that is attained (Bar-Mor et al., 2000). Moreover, parental overprotection tends to be a generalized pattern that affects youth with other illnesses as well. For example, by lowering aspirations and not expecting them to achieve the same degree of success as their peers, the

parents of youth with cancer overprotect their youth (Davis, 1997). The findings of this study support and extend this literature.

Although staff talked about their interactions with resilient families who had safeguarded their youth's precarious survival (Rempel & Harrison, 2007), by undermining their youth's physical abilities and deterring them from engaging in the same activities as their peers, the family also posed formidable participation barriers. Parental overprotection was thought to result in detrimental psychosocial sequelae and to interfere with physical activity and health activities. In addition to preventing them from engaging in the same activities as their peers and undermining their ability to lead a normal life, parental overprotection was thought to deprive youth of a voice and to complicate attaining normal developmental milestones.

Staff contemplated why parents acted this way, and they offered many rationales; the parents were rarely dismissed as the problem. Instead, factors such as "living through one's worst fear," loss of control, and a sense of uncertainty regarding the future were thought to contribute toward parental attitudes and behaviors. Similar findings have also been reported following other studies. For example, within the context of receiving inadequate information and a lack of communication with care providers, other study findings have indicated that parenting a child with a chronic illness is experienced as devastating, irrevocable, life-altering, and sudden (Ware & Raval, 2007). Moreover, staff implicated themselves in the problem of overprotective parenting. By failing to communicate or address misconceptions, staff considered whether they contributed toward parents' fears. However, although staff commented on their role in perpetuating the problem of parental overprotection, there appeared to be an ethical tension between organizational standards and the family agenda (Shapira-Lishchinsky, 2009). Although staff espoused the benefits of physical activity for youth with CHD and discussed the detrimental impact of overprotective parenting, they generally did not see themselves as responsible for communicating and disseminating physical activity information and knowledge to families, and it was perceived to be outside of their professional competencies. Thus, because staff perceived parents and youth as ultimately responsible for being active, discourses of individualism were reproduced. To address parental physical activity anxiety, it is advisable for staff to provide venues for parents to communicate concerns related to their child's health and physical activity. Interacting with other parents might provide a forum for social support and understanding. Communicating physical activity education and knowledge with parents should be a continued endeavor for cardiac staff.

In summary, novel findings regarding caregiver perceptions toward physical activity in youth with CHD were produced in this study and will extend the extant literature. In addition, findings from this study are well supported by the literature on sociocultural concepts of risk and the sociology of illness, and were drawn on for explanatory and interpretative value.

Limitations and Conclusions

The primary limitation associated with this qualitative study was its reliance on secondary, proxy reporting. Primary accounts of physical activity among cardiac youth from parents, teachers, and media personnel were absent in this study; rather, staff drew on their experiences to offer their perceptions and perspectives on the social barriers that youth with CHD encounter. Staff also commented on the cultural construction of youth with CHD as fragile and at risk. Although social constructivists counter positivist notions of true and accurate knowledge, this might detract from the legitimacy of the findings. Future researchers should seek direct representations of physical activity in cardiac youth from these important stakeholders as well as from youth themselves.

Physical activity is associated with physical, psychological, and social benefits for youth (Humbert et al., 2006; Sothern, Loftin, Suskind, Udall, & Blecker, 1999). Although declining rates of physical activity are a concern for all youth, youth with chronic diseases such as CHD are a component of this broader trend. Youth with CHD are less active than healthy peers and display poor self-perceptions toward active pursuits (Bar-Mor et al., 2000; Lunt et al., 2003). Biomedical and psychological studies continue to dominate our understanding of physical activity in this population, and although findings from such studies are important, they might suggest that CHD youth are personally responsible for engaging in risky behaviors such as inactivity, and obscure the influence of sociological factors. Few investigators have studied the extent to which social barriers influence the relationship between low levels of physical activity and severe congenital heart disease, and the insights of cardiac staff have not been studied. Working within the context of an interdisciplinary cardiac center, to our knowledge this is the first qualitative investigation into the caregiving experiences of a diverse group of cardiac staff. In addition to offering their insights into their caregiving experiences with chronically ill youth, staff drew upon secondary reporting to discuss how sociocultural barriers—such as the media, parents, and schools—influence the physical activity experiences of pediatric heart patients and contribute towards low participation. More often than not, they construct these youth as excessively at risk. Informed by a constructivist paradigm, staff challenged these powerful assumptions and attempted to portray a more accurate depiction of the physical abilities

of youth with CHD. Thus, "beyond the biomedical," staff broadened our limited understanding of physical inactivity in cardiac youth and exposed some of the social and contextual barriers that continue to constrain their physical activity participation.

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