“No Time to Play”: Perceptions Toward Physical Activity in Youth With Cystic Fibrosis

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Although physical activity may reduce lung function decline in youth with cystic fibrosis (CF), most patients are inactive. Little is known about why youth with CF are inactive or how to facilitate physical activity. This study explored perceptions toward physical activity in 14 youth with CF at a Canadian Hospital. Qualitative interviews were conducted and a grounded theory analysis was undertaken. The participants demonstrated positive or negative perceptions toward physical activity and different experiences—such as parental support and illness narratives—influenced youths’ perceptions. In addition, the participants experienced physical activity within the context of reduced time. Recommendations for developing physical activity interventions, including the particular need to ensure that such interventions are not perceived as wasteful of time, are provided.

Keywords: pediatrics, physical activity, qualitative inquiry, cystic fibrosis

Physical therapy is time consuming . . . I guess that it helps your lung function. The bad thing about that, is like, it also takes away from some of your time—if you wanted to be active, you would not be able to be active, if you had to do your treatment. (Zoe)

The above quote exemplifies how one patient living with cystic fibrosis (CF) negotiates the experience of physical activity within the context of significant temporal loses. Indeed, despite the notable physical and psycho-social benefits of physical activity for patients with CF, the majority of these youth are inactive (Nixon, Orenstein, & Kelsey, 2001). Furthermore, the extant literature is characterized by an

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absence of qualitative studies that help to illuminate why youth with CF are inactive. The study described below explores how one group of youth with CF experience and negotiate physical activity and, in doing so, illustrates the numerous barriers and temporal constraints that limit their participation.

**Review of the Literature**

Cystic fibrosis is a fatal, autosomal recessive genetic disease that affects 1/2500 North Americans (Lowton, 2004). Although the majority of people with CF died in early childhood several decades ago (Nixon et al., 2001), notable achievements in respiratory medicine have dramatically altered the illness course. While treatment remains palliative, novel therapies and procedures such as physical therapy, medications, and nutritional supplementation have reduced mortality with the average life expectancy now being approximately 30 years (Williams, Mukhopadhyay, Dowell, & Coyle, 2007). Indeed, some authors have described CF’s coming of age, and the need to reconceptualize it not solely as a childhood illness but as one that extends into adulthood (Jessup & Parkinson, 2010).

Even though patients with CF are living longer, they are still affected by significant morbidity (Moran & Bradley, 2010). For example, undertaking numerous, time consuming treatments on a daily basis or being hospitalized are particularly arduous for youth with CF and interfere with important social activities (Williams et al., 2007). In addition, youth with CF experience reduced psycho-social health, such as depression, anxiety, body image issues, behavioral disorders, concerns related to health in the future, and prolonged parental dependence (Berge, Patteron, Goetz, & Milla, 2007). Described as “being shipwrecked” (Jessup & Parkinson, 2010), a pervasive sense of impending danger also invades the lives of many people with CF and may compromise psycho-social health. Finally, young people with severe CF may struggle with health providers over the meaning of a good enough death and how to facilitate it in a manner which preserves dignity (Chapman, Landy, Lyon, Haworth, & Bilton, 2005). Indeed, despite an improved prognosis, youth with CF experience compromised physical and psycho-social health (Berge et al., 2007). Interventions to increase quality of life and psycho-social health, such as physical activity and exercise, have been promoted.

**The Role of Physical Activity and Exercise for Youth With Cystic Fibrosis**

Given that it may slow disease progression and contribute important psycho-social benefits, there is growing interest in the use of physical activity as an adjunctive treatment for CF (Moran & Bradley, 2010). Indeed, even for patients with severe disease, regular physical activity, defined as any bodily movement that is produced by the skeletal muscles that results in energy expenditure (Caspersen, Powell, & Christenson, 1985), is strongly encouraged and may be a normalizing pursuit that is central to childhood. For example, several studies undertaken in diverse research sites such as clinical, home, and camp settings have reported beneficial outcomes associated with physical activity and exercise for youth with CF (Stevens
The notable physical benefits include reduced rate of lung function decline, improved physical functioning, enhanced muscular strength and endurance, increased aerobic and anaerobic capacity, and reduced mortality (Gruber, Orenstein, Braumann, & Huls, 2008; Klijn et al., 2004; Moorcroft, 2004; Schneiderman-Walker et al., 2000). Furthermore, physical activity may enhance quality of life and psycho-social well-being in youth with CF (Rose & Sandy, 1986). For example, the ability to engage in activities of daily living, well-being, body image, self-esteem, resilience, acceptance, social functioning, and perceptions of wellness are secondary quality of life outcomes associated with physical activity for youth with CF (Enright, Chatham, Ionescu, Viswanath, & Shale, 2004; Selvadurai et al.; 2002; Stanghelle, Hjeltnes, Bangstad, & Michaelsen, 1998).

Despite the notable physical and psycho-social benefits of physical activity, however, most youth with CF are less active than age-matched peers and activity levels diminish further during adolescence (Prasad & Cerny, 2002). Little is known about why youth with CF are inactive or how to facilitate increased activity. Potentially, the “vulnerable child syndrome” in which parents restrict youth from activity based on false perceptions of illness and adopt negative appraisals toward physical activity, are psycho-social barriers that deter participation (Wilkes et al., 2009). Unpleasant physical symptoms are also deterrents to physical activity (Swisher & Erikson, 2008). For example, termed the “vicious cycle of inactivity,” symptoms such as fatigue and breathlessness may lead to activity avoidance. In turn, physical inactivity only serves to exacerbate CF-related symptoms, thereby entrenching a broader pattern of inactivity (Nixon et al., 2001). Other youth with chronic illnesses also report that experiences such as bullying, social stigma, poor inclusion, liability concerns, and lack of access to physical activity opportunities, impede physical activity (Goodwin & Staples, 2005; Moola, McCrindle, & Longmuir, 2009). More specifically, the inability to keep up with able-bodied peers may increase perceptions of nonnormativity among youth with chronic illnesses (McMurray et al., 2001; Moola, Faulkner, Kirsh, & Kilburn, 2008).

The inherently exploratory and explanatory nature of the qualitative paradigm, however, may help to illuminate why youth with CF are inactive in spite of the notable benefits that physical activity may afford. Thus far, qualitative investigations that explore youths’ perceptions and barriers toward physical activity, and the role of physical activity in their lives, remain a neglected area of research inquiry. Indeed, the voices of youth with CF are absent in the exiting literature. Uncovering such information is critical if we are to more fully grasp the perceived barriers to, and facilitators of, participation. Comprehending the potentially complex reasons why youth with CF are inactive and how to facilitate activity through the design of interventions that are sensitive to their social lives and worlds, is a notable advantage that may be afforded by such a descriptive and exploratory client-centered approach. Thus, the purpose of this qualitative study was to explore the role and meaning of physical activity in the lives of a group of youth with CF. The specific research question was this: What are the perceptions of youth with CF toward physical activity and the benefits and barriers associated with participation?
Method

Conceptual Framework

Since the narrative approach adopted from the sociology of health and illness may provide researchers with a way in which to understand how people with illnesses story and chronicle their health and physical activity experiences—and has rarely been employed with chronically ill children—it was drawn upon as a conceptual framework and lens for interpretation (Smith & Sparkes, 2008; Smith, 2010). In addition to acknowledging that narrative is perennial and integral to the human condition itself, narrative approaches take the following tenets as their epistemic assumptions: (a) we all lead storied lives; (b) we interpret our stories within the sociocultural context in which we live; (c) story telling facilitates a more comprehensive understanding of the complex social world around us; (d) corporeality—and taking stock of the fleshy body—is critical to storytelling; (e) since there are multiple narrative types, it is important to avoid narrative determinism; and (e) rather than emanating from the caverns of our minds or as mere cultural artifacts, stories are constructed in constant interplay between ourselves, our social relationships, and the sociocultural realm in which we live (Smith & Sparkes, 2011). These important epistemological assumptions associated with the narrative approach were critical to understanding how CF youths’ health and physical activity stories are likely cocreated productions between self, social relationships, and sociocultural contexts.

Further to the narrative approach, Bury (1991) suggests that as biographical disruption, the experience of illness may fragment the structures of everyday life, unsettling ones’ sense of self and calling into question ones’ role in the broader social world (Bury, 2005). More importantly, as wounded story tellers in a remission society, people with chronic illnesses may construct stories of their experiences (Frank, 1995). For example, culturally dominant narratives of restitution—that is, “feel-good” stories that are pleasing to hear—emphasize triumph in the face of adversity and the success of individual survivors over illness (Frank, 1995). In contrast, stories of chaos emphasize pain and hardship, in which ones’ life world is dominated by illness and the self, is lost and all consumed (Frank, 1995). Furthermore, some scholars have explored how athletes narratively construct their experiences of illness within the context of sport (Sparkes, 2004). For example, the early stages of elite athlete Lance Armstrong’s battle with an aggressive form of cancer was characterized by much pain and turmoil and the very integrity of the self was threatened. However, drawing upon dominant narratives of restitution, he triumphantly overcame his struggles and returned to sport unscathed (Sparkes, 2004). Thus, concepts from the narrative approach provided a useful conceptual framework. In seeking to explore perceptions toward physical activity in youth with CF, we were aware of how youth may draw upon personal experiences and dominant, sociocultural narratives to construct stories of their health and physical activity experiences.

Research Setting, Recruitment, and Participants

This study was approved by the Research Ethics Board at a metropolitan pediatric hospital in Canada, and the treatment of participants was in accordance with the
ethical standards that are outlined by the American Psychological Association. The study occurred in the Cystic Fibrosis Clinic between July and September 2008 and was facilitated by a physiologist and nurse. Eligible participants were identified using the outpatient clinic registry and the primary investigator (first author) proceeded to contact participants, explain the study, and request participation. Fourteen youth between the ages of 11 and 17 participated. The average age of participants was 14.2 years and ten females and five males participated (see Table 1). The degree of lung function decline and the age of diagnosis varied, and the participants had no other illnesses or disabilities. One youth was hospitalized at the time of the interview and another was receiving home intravenous therapy. However, the remaining participants were receiving routine medical follow-up in the outpatient CF clinic and were medically stable. Although the majority of the sample was Caucasian, one participant self-identified as Black and the other as East Indian. While most participants were from middle class families, three participants were from socioeconomically deprived regions in the Greater Toronto Area. It was our intent to conduct interviews with youth independently of parents. However, three participants requested that their parents accompany them during the interviews. Although this was an uncontrollable limitation of the study, the presence of parents appeared to be comforting for youth and should be considered within the context of conducting ethical research with chronically ill youth.

Table 1 Participant Characteristics

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Gender</th>
<th>Activity Category</th>
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<tbody>
<tr>
<td>1. Rudy</td>
<td>12</td>
<td>F</td>
<td>Inactive</td>
</tr>
<tr>
<td>2. Faisal</td>
<td>16</td>
<td>M</td>
<td>Inactive</td>
</tr>
<tr>
<td>3. Danny</td>
<td>16</td>
<td>M</td>
<td>Inactive</td>
</tr>
<tr>
<td>4. McKayla</td>
<td>15</td>
<td>F</td>
<td>Active</td>
</tr>
<tr>
<td>5. Graydon</td>
<td>15</td>
<td>M</td>
<td>Active</td>
</tr>
<tr>
<td>6. Cassie</td>
<td>15</td>
<td>F</td>
<td>Active</td>
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<tr>
<td>7. Isabella</td>
<td>15</td>
<td>F</td>
<td>Inactive</td>
</tr>
<tr>
<td>8. Harriet</td>
<td>12</td>
<td>F</td>
<td>Active</td>
</tr>
<tr>
<td>9. Koby</td>
<td>11</td>
<td>M</td>
<td>Inactive</td>
</tr>
<tr>
<td>10. Gretchen</td>
<td>12</td>
<td>F</td>
<td>Inactive</td>
</tr>
<tr>
<td>11. Samantha</td>
<td>16</td>
<td>F</td>
<td>Inactive</td>
</tr>
<tr>
<td>12. Zoe</td>
<td>16</td>
<td>F</td>
<td>Active</td>
</tr>
<tr>
<td>13. Diana</td>
<td>15</td>
<td>F</td>
<td>Inactive</td>
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<tr>
<td>14. Celeste</td>
<td>14</td>
<td>F</td>
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Qualitative Research Tradition: Grounded Theory

Since it allows for an exploration of a particular social groups’ experience of physical activity, grounded theory was selected as the qualitative research tradition for this study. According to Weed (2009), grounded theory is characterized by a
process of “abduction” in which the researcher may be theoretically sensitized by the literature and theory yet not wed to a preexisting theoretical framework (Weed, 2009). Theoretical sensitization by the narrative approach was thus considered to be complementary to constructivist grounded theory, theoretically sensitizing us to narrative, while not affixing us to particular ideas entirely. Furthermore, since social constructivist grounded theory and the narrative approach are premised upon similar epistemic assumptions, they may be considered as compatible.

Premised upon social constructivism and interpretivism, grounded theory is understood as both methodology and method (Charmaz, 2003). It is a means for thinking about the complexity of the social world, the ways in which knowledge is cocreated in the interaction between the researcher and the participant, and the potential for new knowledge and theory to arise through data. Grounded theory is characterized by particular epistemic tenets. For example, the researcher is encouraged to be immersed in, and wrestle with, the data as well as to adopt a self reflexive stance by considering how his/her social position and location influence the production of knowledge (Charmaz, 2003). Finally, researchers should display theoretical sensitivity. By bracketing preconceived notions, habitual patterns of thinking, and technical jargon, it may be possible to uncover “what is really there” (Bartlett & Payne, 1997). This is a self reflexive task in which the researcher remains cognizant of the personal assumptions which may influence the research, so as to open oneself to the broad range of experiences that youth with CF may discuss.

Data Collection, Data Analysis, and Trustworthiness

Semistructured interviews served as the primary means of data collection and were 45 min to one hour in duration. To explore the perceptions of youth with CF toward physical activity, the primary investigator devised an interview guide (Creswell, 1994). Although the interview guide was not formally pilot tested before the study, it was informed by relevant literature and sensitizing concepts (Holt & Tamminen, 2010). Furthermore, the interview questions were based on similar guides developed by the authors (Moola et al., 2008) and were approved for appropriateness by members of the research team. For example, commonly understood barriers to physical activity for youth with CF, as well as theoretical concepts from the sociology of health and illness, assisted with the development of questions (Frank, 1995; Swisher & Erikson, 2008). Finally, the primary investigator has worked with chronically ill children in pediatric facilities for over a decade, and her clinical observations informed the interview guide. The interview questions were flexible in nature, unobtrusive, and questions were guided by participants’ responses. For example, questions included the following: Is physical activity important or not important for you? Can you explain whether CF impacts how active you want to be? Can you tell me what physical activity means to you? Furthermore, although participants were asked about what it is like to engage in physical activity with CF, the term physical activity was not defined by the researcher. Rather, youth were left to interpret the term on their own, and participants’ tacit understanding of physical activity shaped their responses. Furthermore, although interviews probed youths’ physical activity experiences, participants conflated health, illness, and physical activity. Thus, as illustrated in the findings, youth explained physical activity in terms of living with CF. The interview guide is available from the first author on request.
The interviews occurred in appointment or patient rooms and were taped and transcribed verbatim. All participants gave informed and written consent to research participation and, by continually asking children how the interview was going and if they wanted to proceed, informed consent was maintained throughout the interview process. Since competent children and youth are able to independently consent irrespective of age at this particular institute, parental consent was not sought. Finally, saturation refers to the point at which no novel data are emerging and redundancy in the data are obtained. Thus, data collection was terminated after 14 interviews (Guest, Bunce, & Johnson, 2006).

To analyze the data, the transcripts were repeatedly read line by line. They were scrutinized for recurring patterns of meaning, which occurred commonly across all of the participants’ narratives. Commonly occurring patterns of meaning were coded and grouped into thematic content areas, and by contrasting and comparing similar and different units of meaning, separate categories were delineated (Maykut & Morehouse, 1994). These content areas were developed, named, and refined. The data were searched for the interrelationship between different categories and the subthemes associated with each category. The process was iterative in that the emerging analysis guided further data collection and directed the researcher to further explore particular areas during the interview process (Grbich, 2007; Mason, 2002).

The issue of trustworthiness in qualitative research—that is, the degree to which the authors offer an authentic and believable account of the lives under study, is an area that is rife with debate. In line with a social constructivist grounded theory and narrative approach, such research quality concerns—or “criteriology”—reflect the concerns of qualitative researchers who are attempting to appease those schooled in the quantitative tradition (Seale, 1999). Given that there is no reality outside of our interpretation of it, that unmediated access to direct and authentic experiences are a fallacy, and that the notion of truth is historically and culturally situated and bound (Smith & Sparkes, 2011), typical approaches to ensuring trustworthiness in qualitative research were not adopted. Such an approach was considered inconsistent with our constructivist ontology and interpretivist epistemology and rather entails taking stock of the interpretive, socially, and culturally contingent production of knowledge.

The study drew upon the creativity of qualitative methods to explore the physical activity perceptions and experiences of youth with CF. The main themes, (a)

![Figure 1 — Perceptions toward physical activity in youth with cystic fibrosis.](image-url)
positive perceptions toward physical activity (see Figure 1), (b) negative perceptions toward physical activity, and (c) “no time to play” are explained below. Generally, youth displayed either positive or negative perceptions toward activity and different experiences (subthemes), such as parental support or illness narratives, were associated with positive or negative activity appraisals. Finally, all participants negotiated physical activity within the context of reduced time. Regardless of youths’ physical activity perceptions, this final theme was central to how all participants interpreted the role of physical activity in their lives. An overview of these themes is presented in a concept map.

Findings

“It Is Kind of Like, My Sanctuary”: Positive Perceptions Toward Physical Activity

Five participants demonstrated positive perceptions toward physical activity and described it as an enjoyable pursuit. In addition, positive perceptions appeared to influence physical activity behavior, and these youth were regularly engaged in a variety of activities, such as walking the dog, walking to school, or participating in activities at local facilities for people with illnesses. More importantly, these youth were characterized by particular experiences which appeared to shape their positive activity perceptions. These experiences included (a) parental support, (b) mastery experiences, (c) enjoyment, and (d) a sense of hope.

**Parental Support: Advocates for Physical Activity.** Youth who displayed positive physical activity perceptions stated that they receive a great deal of family support and described their parents as advocates for physical activity. When these parents encountered obstacles, for example, they engaged in problem solving to seek out activities that their child could successfully participate in and provided encouragement. Youth also suggested that their parents were knowledgeable about the benefits of physical activity. For example, Graydon describes his mother as an educated CF “expert” and states that

> My mom is always reading things about CF—Internet sites and books and all sorts of stuff. She knows a lot about it, and she knows all of the physical activities and sports that I need to do to be healthy.

Similarly, by providing her with physical activity opportunities at an early age, McKayla’s family has positively influenced her physical activity perceptions and behaviors:

> My mom and dad taught me to like sports when I was younger. I have always been that way; I grew up that way. I am used to it. I was never the person who was like, “let’s play Barbie’s.” I was the one who was like, “let’s play football” when I was six. I was always active and with the guys. I was always like that.

Thus, perceived family support and encouragement were the most important experience for those youth who displayed positive perceptions toward activity.
Enabling Success: Mastery Experiences in Physical Activity. Participants who displayed positive perceptions toward physical activity had memorable mastery experiences that empowered them with an enduring sense of competence and achievement. Most often, mastery experiences were derived from participation in individual activities rather than team sports, and youth commented that they were better at such noncompetitive activities. For example, Zoe displays a positive attitude toward dance. In addition to enjoying the social atmosphere in the dance studio and the music, she derives a sense of competence through dance:

I have a lot of friends there, I guess. I really like music, so that allows me to be around it a lot. It (dance) is really exciting. There is a lot of anticipation leading up to it. I like working hard to achieve things.

Similarly, Rudy is cognizant of the activities in which she cannot excel due to CF—related fatigue, and she accepts her physical activity limitations. However, she makes an effort to seek out activities that are personally achievable and likely to result in a sense of mastery:

As I said, track and field— it is harder to run straight for 1000 meters, or to jump as high as other people. But I guess I just try to find stuff that I could do, you know? Things that I can personally achieve.

Thus, youth who regarded physical activity positively were motivated by opportunities to experience mastery, and these experiences promoted a sense of competence.

Enjoyment. An inherent sense of fun and enjoyment during physical activity was another experience associated with positive physical activity perceptions and these youth looked forward to being active. For example, Graydon expresses his preference for individual activities, and, unlike competitive team sports, he suggests that they result in a sense of fun and pleasure:

I do not play soccer or hockey or any of those. I am just not interested in them. I do not have as much fun when I am playing soccer or hockey. I have more fun running, being in the gym, or biking.

Similarly, Rudy emphasizes that a sense of enjoyment and fun is more likely to facilitate activity. She explains that when youth are pressured to be physically active, rather than encouraged, physical activity becomes a burdensome task that resembles “work:”

I like being active in stuff that is fun, not hard work. Hard work is more tiring, and, just “ah, I have to do that now”? I would not mind doing something with my friends because that is fun. But if I had to go run a kilometre all by myself, I would not enjoy that.

Deriving fun during physical activity and a sense that experiences were self-authored rather than forced were experiences associated with positive physical activity perceptions.

A Sense of Hope. Finally, although there are multiple cultural narratives (Smith, 2010), youth who displayed positive perceptions toward physical activity adopted
illness narratives that were characterized by hope and optimism. For them, physical activity was instrumental in the attainment of health and provided proof that CF had not conquered them. For example, Gretchen is resilient and hopeful. Although there are moments when she wishes that she did not have CF, she does not feel limited or regard herself as different from other youth. Gretchen uses physical activity as evidence of her abilities, and participation serves as a way in which to challenge the dominant stereotype that youth with disabilities are incapable of engaging in physical tasks. Since physical activity provides evidence that CF has not defeated her, she draws upon spiritual metaphors and describes it as “sanctuary.”

I do not want to be treated differently . . . so what, I have CF. One of my cousins, he went easy on me in sports and I got really mad. I was like “fine, I have a disability, but I still want competition, so how will I know if I improve or not?” I want to know that even though I have CF, I don’t want that to stop me. I want to be able to achieve . . . when I do sports, I will be like “oh I am not letting this stop me. Even though this is happening, anybody can do sports.” It is kind of like my sanctuary.

Similarly, while Cassie acknowledges that her “lungs may not be great forever,” successful physical activity and sports participation is proof that CF cannot limit her, and she maintains positive perceptions toward physical activity:

I definitely do not think of myself differently, because I have CF . . . I definitely do not lower my self esteem, because of that . . . the CF does not even bother me and there is nothing physical that keeps me from doing anything. As long as I want to, there is nothing that is keeping me behind . . . I know that I can do it as long as I want to.

Thus, those youth who displayed positive perceptions toward physical activity were characterized by experiences of parental support, mastery, fun, and hopeful illness narratives.

“When I Am Really Sick, I Even Find Brushing My Teeth Difficult”: Negative Physical Activity Perceptions

Nine participants displayed negative perceptions toward physical activity. In addition, negative perceptions appeared to influence behavior, and these youth were physically inactive. Interestingly, although these youth were well educated about the benefits of participation, they were ambivalent regarding change and proposed logical explanations for inactivity. The experiences associated with negative physical activity perceptions included (a) the detrimental impact of CF on physical activity, (b) the belief that physical activity is not important, (c) perceived lack of parental support for physical activity, and (d) a sense of despair. Below, these experiences are discussed as subthemes.

The Detrimental Impact of Cystic Fibrosis on Physical Activity. Unpleasant physical symptoms associated with CF, such as breathlessness and exhaustion, were the central experiences associated with negative physical activity perceptions. For example, Faisal explains that CF symptoms make it too difficult to be
active, and he believes that teachers and coaches would prefer to select youth who are stronger and better at sports:

> It (sports) uses all of my energy and it makes me feel tired, yes, it exhausts me . . . exercise makes me very tired. It makes me very drained and makes me cough a lot. When I do exercise and I start to cough, I just continue coughing and coughing and coughing, and then I get a headache and a stomach ache.

Similarly, although she is aware of the benefits of physical activity for her health, Diana explains that CF symptoms make it too difficult to undertake even the basic activities of daily living, let alone physical activity:

> The physical therapist is just like “always stay active because it will increase your stamina.” But it is hard in the first place if you do not have enough stamina. Sometimes, when I am really sick, I even find brushing my teeth difficult.

By making youth feel unwell and resulting in physical discomfort, the unpleasant symptoms associated with CF strongly influenced a negative physical activity orientation.

“**What Is the Point?**": Low Value Ascribed to Physical Activity. Youth who displayed negative perceptions did not conceptualize physical activity as an important endeavor. Within the context of physical discomfort and social comparison, physical activity was not a valuable activity and they questioned the point of being active. For example, Diana states that

> I am not really good at sports. I know enough times from being sick and trying to run on the treadmill, or something. I can’t. I feel really tired, so then I say, “if I am going to be tired, then why do it?” . . . having CF, I know that I should do it (activity)—it should be higher on the priority list. The more important things for me are like work and school . . . But physical activity is just something optional for me. I know that it should not be, but . . . because I know that it is hard, I do not want to make myself work hard.

Isabella concurs; the detrimental impact of CF makes her question whether she should engage in physical activity and whether it is a worthwhile pastime:

> Sometimes, when I am running, I get more tired easily and faster than other people. Sometimes that kind of makes me not want to always do sports . . . it is fun, and I want to, but I feel like it (CF) is kind of slowing me down. If it is slowing me down, then to keep doing the sport, it is not worth it.

Therefore, for the group of youth who were characterized by negative physical activity perceptions, the detrimental impact of CF made them question the point of being active.

**Lack of Parental Support.** A perceived lack of family support and encouragement characterized the experiences of youth who regarded physical activity negatively. These youth stated that parental involvement would facilitate increased physical activity and they expressed their desire to be physically active with their families. For example, Danny describes his family as lazy and expresses sadness when
he remembers how active they were in the past. Danny expresses enthusiasm in becoming active with his family again:

My family does have a big influence on me. My family is pretty lazy . . . we were all really active, but now, nobody does anything. Family is a big influence . . . if we all got active again, like if my dad bought bikes for all of us and was like “we are going to do a family bike ride once a week”—I would be into that. That would be awesome.

Celeste also wishes that her family was more physically active together and she alludes to one of the important benefits of family-based physical activity. Unlike other venues, which may be characterized by competition and performance expectations, family-based physical activity is noncompetitive and supportive . . . “if all of my family is going to go play one time in the week, going to play a sport, and there is no pressure, because it is just your family— I think that it definitely would benefit.”

Overall, youth with CF who relayed negative physical activity experiences were characterized by a perceived lack of family support for physical activity.

A Sense of Despair. Finally, youth characterized by negative physical activity perceptions adopted narratives of despair and hopelessness to articulate their illness experiences. Furthermore, these narratives strongly shaped negative physical activity perceptions. For example, Faisal displays a less hopeful future orientation and his illness narrative emphasizes the ways in which CF accentuates difference; in relation to his peers, he feels thin and frail. He is excluded and ostracized and perceptions toward physical activity are framed through this perspective. As he recounts his experiences of marginalization, he indicates that sports programs are designed for able-bodied youth.

I feel small, I feel skinny. I do not feel like I fit in with other kids. When I walk to school, I am the shortest kid—people ask me, “What grade are you in”? . . . And I feel really sad, that they ask me that. Those are the two things that really keep me down . . . and they think that I am bad and that I have some disease . . . they talk rudely about me to themselves . . . if it (sports programs) is for kids that are not sick—there is no point in going. It is all healthy kids, and they are active, and it is a place for them.

Diana also constructs a despairing illness narrative and her physical activity perceptions are refracted through this lens. Reduced physical functioning and observing that she is no longer able to do the same activities as she did in the past, serve as a painful reminder that her illness is progressing, that CF is “winning”:

I also know that I am not going to live as long as everybody else so that is hard. I feel like it is out of my control, I feel helpless, how I used to be able to do it (physical activity), and now I can’t. It is kind of depressing. It makes me think that it is a progressive disease, and it make me think that it is getting worse . . . it makes me worried.

The negative impact of CF, questioning the point of physical activity, lack of parental support, and despairing illness narratives characterized the experiences of these youth.
“No Time To Play”

Finally, all participants explained that due to the life limiting nature of CF as well as the time consuming and tedious nature of daily treatment, they have less time available to them in relation to their peers and were “running out of time.” They alluded to reduced time in both a literal and symbolic sense. For example, although the average life expectancy for patients with CF is 30 years, and many patients tentatively dream of such things as attaining a career or getting married (Jessup & Parkinson, 2010), participants understood themselves as not living as long as their peers and questioned whether they would ever attain major developmental milestones. For this reason, reduced time had a metaphoric dimension. Similarly, due to the daily hassle of managing CF, such as taking medication and physical therapy, youth discussed reduced time in a literal sense. Youth indicated that while necessary, daily treatments were time-consuming and hateful. Within the context of having to engage in such time consuming treatments, there was a lack of available time for physical activity. Youth preferred to use this little, precious time for more important activities such as spending time with family and friends.

For example, as he describes his experiences at summer camp, Graydon’s narrative is punctuated with anger. By preventing him from engaging in camp activities with his peers, he explains how physical therapy “robbed” him of time:

I hate when it (physical therapy - PT) gets in the way of all of these things. At camp, it really gets in the way when you wake up and the bell goes and you have to go to breakfast. But I have to do PEP (breathing mask), and that holds me back. Or, it is night time and they are all going to go out somewhere. And maybe I have to go back to the cabin and get my PEP which is really far away. It is just annoying . . . that was the worst and I hated it so much . . . I know that I need to do physical activity, but it is just sometimes hard when things interfere, like medicine or PEP.

Gretchen also suggests that physical therapy is time consuming. She imagines that if it were shorter, she would have more time for activities such as outdoor play, exploration, or swimming:

The disadvantage of it is that it takes a while and with extra-curricular activities, there is a time restraint. It would be cool (physical therapy) if it was a little bit shorter, so that I could be able to do some more stuff . . . sometimes, I would rather be outside playing, going for a swim, or playing with my sister or just going outside. But I am OK with it (PT), and I have been able to adjust. But it would be cool if it was shorter.

Danny no longer adheres to PT treatments. Negative childhood associations, the fact that PT is a reminder of living with a fatal condition, and the time consuming nature of PT are experiences which help explain his resistance and constitute a “logical explanation.” Danny worries that PT detracts from time available for physical activity:

I hate doing PT. When I was a kid, there was a round board and I would lie on it while my mom wacked my chest. Like a beating with a cupped hand — I hated it. Ever since I was little and she did that, and I knew that it was PT, I
have despised it. It takes away from my time, and that is something that I do not like. When you have to sit down and do your mask for 30 minutes, and the PEP mask for 20, it drives the nail home that you do have a lung disease and sometimes I just want to forget about it . . . as I am doing it, “wow, I have to do this, to prevent myself from dying.” It takes away from my time for sports, friends, and family.

Youth with CF were aware of reduced life expectancy and how treatment detracted from available time. Physical activity occurred within the context of reduced time, and, in relation to the hassle of CF treatment, there was less available time for physical activity. Youth wished to spend this time engaging in more important activities.

**Discussion**

By employing a theoretically informed qualitative research design, this study addressed crucial limitations in the literature and has attempted to advance our understanding of how youth with CF experience and perceive physical activity. The detrimental impact that CF had on the ability to be active, was one of the most significant experiences associated with negative physical activity perceptions. CF symptoms, such as coughing and breathlessness, were consistently reported as negative experiences and engaging in physical activity was not desirable if it was thought to exacerbate these unpleasant symptoms. Moreover, some youth alluded to the vicious cycle of inactivity that has been documented in the literature—or the “chicken or egg” dilemma, which tends to characterize physical activity participation for youth with CF (Nixon et al., 2001; Selvadurai et al., 2002). Indeed, youth explained that breathlessness and coughing leads to activity avoidance; in turn, inactivity further exacerbates CF symptoms. The finding that disease symptoms are a significant barrier to physical activity for youth with CF and other chronic diseases is well documented (Moola et al., 2008; Swisher & Erikson, 2008). When youth feel unwell, they are unlikely to want to be active and disease symptoms lead to activity avoidance.

Furthermore, informed by the narrative approach, youth with CF adopted various illness narratives that appeared to influence physical activity perceptions (Sparkes, 2004). For example, some youth were resilient and optimistic about CF and displayed a positive orientation toward physical activity. Drawing upon culturally dominant narratives of restitution, these youth believed that the attainment of health was possible and that they would not succumb to CF. Rather, they were convinced that CF-related obstacles would be overcome and that they would garner strength and insight through the process. Moreover, physical activity provided evidence that CF had not conquered them and was a testament to their will and resolve to fight. In contrast, other youth adopted chaos narratives to articulate their negative perceptions toward health and physical activity, and, in doing so, they conveyed a sense of desperation, futility, helplessness, and worry about the future. Recounting experiences of pain, hardship, and exclusion, these youth were deeply cognizant of their suffering and troubled by the terminal nature of CF. In turn, these despairing illness narratives influenced negative physical activity perceptions; it was an unpleasant reminder of CF. Alternatively, physical activity was
regarded as an able-bodied site that emphasized exclusion. As suggested by Smith and Sparkes (2008), these despairing chaos stories engendered fear and lacked a structured plot and feel-good overcoming narrative. For this reason, they invoked a sense of “narrative wreckage” and were difficult to hear. Finally, although quest narratives consider illness as a transformative process that profoundly changes the self, no participants adopted this narrative structure, and, rather, illness narratives appeared to be characterized by the restitution and chaos types only (Frank, 1995). A quest or polyphonic illness narrative is characterized by a philosophy of the present and a fundamental reconceptualization in values and beliefs, making it possible to both enjoy the present without investing in or depending on the future (Ezzy, 2000). While this may ultimately be a very helpful way of storying CF, this narrative structure may evolve over time and did not appear to be accessible to the participants. Other literatures have discussed the despairing nature of the narratives that characterize other chronically ill youth and people with disabilities (Smith & Sparkes, 2008; Yoos & McMullen, 1996), and in this regard, the concept of illness narratives lent interpretive insight into the findings.

Finally, this study provoked novel insights into how youth with CF experience physical activity within the context of reduced time. Indeed, although time was not a concept included in the research question or interview guide, it emerged as an important analytical point for further inquiry and was a concept that youth dialogued about and constantly grappled with. Within the context of living with a terminal illness, youth spoke of time metaphorically and literally and illustrated their capacity to think in nonliteral and abstract ways. Youth perceived their treatments as necessary but time consuming and unpleasant, and as a result of such treatments, they understood themselves to have less time. Indeed, physical therapy was described as an arduous burden that results in less available time for physical activity. Moreover, youth preferred to repartition their limited precious time elsewhere and did not regard physical activity as a worthwhile time investment.

Other qualitative studies have illustrated the complex time tricks that children with CF negotiate and the ways in which their illnesses contribute toward a loss of temporal integrity (Glasscoe & Smith, 2008) or a shattering of one’s sense of time and how it passes. While time in a Newtonian sense is linear, chronic illness illustrates the iterative, cyclical, and fragmented nature of time for these youth. They are described as both diminutive and old souls at one and the same time. For example, having missed critical developmental milestones, they are always lagging behind. However, having experienced traumatic health encounters at tender ages, they are wise beyond their years and have mastered a complicated and technical medical jargon that is uncharacteristically childlike. By moving perceived time forward and backward and highlighting particular health-related time periods as salient, chronic illness may reset the clock (Glasscoe & Smith, 2008). Similarly, by explaining the tentative and precarious nature of the future for patients with CF in their phenomenological study of the body, space, time, and relationships, Jessup and Parkinson (2010) allude to the weighty temporal dilemmas encountered by young people with CF and the salience of time to their lives. For example, at the time of diagnosis, the future is effectively cancelled. Patients with CF and their loved ones are confronted with the finality of the disease and the heart wrenching task of explaining death onto those that one was supposed to
bestow life; however, as patients become aware of the medical advancements in CF care, they are permitted to tentatively dream about a provisional future. Thus, grappling with temporal issues is central to the experience of living with CF and finding the time for physical activity is, arguably, constrained by youths’ weighty temporal dilemmas.

**Recommendations**

Youth reported that disease symptoms restricted them from engaging in physical activity and they often felt too unwell to participate. While the benefits of physical activity for this population are well documented, health professionals must remain sensitive to the physical discomfort which detrained youth experience during initial efforts to become active. Since perceptions of pain, fatigue, and breathlessness strongly influence nonparticipation, health professionals should recommend and promote physical activities that gradually increase fitness while minimizing physical discomfort and remain sensitive to the burden of disease.

In addition, health professionals should be aware that children with CF construct personal stories of living with illness within the sociocultural contexts in which they live (Smith & Sparkes, 2011). In addition to being aware of how illness disrupts a sense of self and identity (Taylor & Field, 2003) and the profoundly intertwined nature of personal stories and the sociocultural realm (Smith, 2010), it is important to understand that the narratives that youth construct to explain their illnesses strongly influence their physical activity perceptions. Since hopeful illness narratives appear to shape positive perceptions toward physical activity, health professionals should work with youth to develop more positive and functional ways of understanding and interpreting their illnesses. More importantly, to avoid the sedimentation of particular story lines as “true” and the delegitimization of others (Smith, 2010), it is necessary to identify and deconstruct the dominant physical activity narratives in the broader social and cultural world that shape CF youths’ individual stories. Indeed, given the self-society story telling relationship, novel societal narrative structures must be made available in order for youth with CF to articulate different and, arguably, more hopeful health and physical activity stories. In addition, given that youth with CF experience physical activity within the context of reduced time, health professionals need to be aware of the complex way in which these youth bring meaning to the concept of time and display sensitivity to their perceived time constraints. Health professionals should devise physical activity programs in a manner that is not perceived to be wasteful of time, and the medicalization of physical activity should be avoided so that youth do not come to regard it as just another time consuming treatment.

Moreover, all participants underscored the importance of parental support. Parental encouragement was integral to physical activity for active youth with CF. In contrast, inactive youth lamented a lack of familial support for physical activity and wished that their parents were more active with them. Health professionals should thus consider family-based intervention approaches, in which parents are actively engaged in youths’ physical activity (Fiese, 2005).

Finally, due to clinical concerns regarding the risk of cross contamination, youth with CF are not advised to engage in physical activity together. This poses
particular challenges for adapted physical activity specialists. Youth with CF are arguably a more socially isolated group and typical approaches to forming physical activity social groups that allow youth to share illness narratives and engage in activity together are not feasible. Indeed, the medical needs of this population must be carefully balanced with the provision of social support and call on health professionals to devise novel physical activity approaches. Internet mediated physical activity—which socially connects youth with CF to each other without compromising physical health—such as face book, skype, or twitter, are potential options.

**Limitations**

Although youth strongly supported the assertion that parental support is integral to physical activity through processes such as role modeling and facilitation (Prasad & Cerny, 2002), the actual level of parental physical activity support cannot be ascertained from the available data. More importantly, although lack of parental support shaped negative perceptions toward physical activity for youth, the numerous barriers that these uninvolved parents may encounter, such as a lack of knowledge about physical activity or socioeconomic constraints, is unknown. Health professionals should resist the urge to blame parents for physical inactivity, and, rather, it is important to consider the barriers that may prevent parents from being able to provide their children with enjoyable opportunities. Clearly, further research is required to explore parental perceptions toward physical activity in youth with CF, and assisting those parents who are not able to support their children’s efforts to be active should be a future priority for researchers and clinicians. The lack of objective indicators of disease severity was another limitation. Without such information, it was not possible to ascertain whether disease severity influences perceptions toward physical activity.

**Conclusion**

The relationship between aerobic capacity and survival has sparked interest in the area of physical activity for youth with CF. Despite the benefits, however, these youth display low levels of physical activity. This field is characterized by the absence of theoretically informed qualitative research, which lends insight into why these youth are inactive, and this study sought to address these limitations. The participants displayed either positive or negative perceptions toward physical activity, and all youth experienced physical activity within the context of reduced time. By illuminating how youth with CF experience physical activity, the findings call attention to how youths’ complex psycho-social realities, such as temporal dilemmas or illness narratives, may operate in tandem with reduced physiological health to constrain physical activity and contribute toward reduced participation. When planning physical activity for youth with CF, programs must consider their complex psycho-social realities and experiences. Doing so may contribute toward the development of more comprehensive and meaningful programs that are sensitive and tailored to the social lives, worlds, and dilemmas of youth with CF.
References


