Youth with Chronic Illness Forming Identities through Leisure

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Abstract

The purpose of this study was to develop an understanding of the ways leisure is influential in identity development and maintenance for youth with chronic illness. Drawing on a symbolic interactionist perspective, semi-structured interviews were conducted with 30 participants who reflected on their chronic illness experiences during adolescence and emerging adulthood. Data were analyzed using a grounded theory approach. The findings suggest that leisure played a role in shaping the identities of participants in three ways. Specifically, chronic illness made it difficult for some participants to (a) present idealized identities through leisure, (b) fit in with peers through leisure, and (c) develop an identity through action.

Keywords: *chronic illness; identity; youth*

People's identities, how they view and describe themselves and others, can play an impor-
tant role in shaping people's relationships, activities, well-being, and social status. Research has
shown that leisure can play an important role in shaping young people's identities because of the
perceived freedom of choice and exploration that exists within leisure contexts (Kleiber, 1999;
Mannell, 2007). Despite leisure being a context of positive identity development, challenges as-
sociated with developing and presenting identities also exist. For example, young people's leisure
choices and involvements can be shaped by how others view them and how they view themselves
(Kivel & Kleiber, 2000; Shaw, Kleiber, & Caldwell, 1995). When young people engage in leisure,
a perceived need to present themselves in certain ways may affect the quality of their experiences
(Fine, 2001; Hilbrecht, Zuzanek, & Mannell, 2008). While many young people face challenges
in developing their identities, certain population groups may be considered at-risk. One such
group is young people living with a chronic illness (Taylor, Gibson, & Franck, 2008). Illness
related challenges are particularly salient in adolescence and emerging adulthood because of the
heightened pressure at this stage of life to "fit in" with peers, cultural associations between youth
and health, and limited experience adjusting to difficult life events (Balfe, 2009; Hilton, Emslie,
Hunt, Chapple, & Ziebland, 2009).

Chronic illness can result in disruptions to people's lives because of the physical challenges
and stigma associated with illness (Hutchison, Loy, Kleiber, & Dattilo, 2003). However, little is
known about the impact of having a chronic illness on the lives of youth, particularly as it relates
to how they use their free time to develop identities (Taylor et al., 2008). The term "youth" will
be used throughout this article to collectively refer to adolescents (12 to 18 years old) and emerg-
ing adults (early twenties). As such, the purpose of this study is to develop an understanding of
the ways in which leisure is influential in identity development and maintenance for youth with
chronic illness.

Literature Review

This study adopts a symbolic interactionist perspective on the concept of identity (e.g.,
Fine, 1993; Prus, 1996). Specifically, identity refers to how people think of themselves and how
they are thought of by others. Through a symbolic interactionist perspective, people's identities
are shaped by their decisions and activities, influenced by relationships with other people, and
shaped by broader cultural practices (see Fine, 1993 for a discussion of nuances within the per-
spective and comparisons with other perspectives). Thus, identities are the result of their own
choices and the social environment in which they are embedded. As people actively construct
their identities, they develop an understanding of appropriate behaviors and seek to display them
to others (Mead, 1934; Stryker & Burke, 2000). Although the social environment can normalize
the development of identities such that people feel as though they must appear in certain ways,
some people resist pressures to conform to social norms and create identities that differ from
the majority (Holland & Lachicotte, 2007; Prus, 1997). Consistent with the focus of this study,
the remainder of this section reviews the roles that leisure specifically plays in the formation and
maintenance of identities.

Leisure and Identity

Leisure plays a role in developing people's identities in at least four ways (Fine, 2001; Kivel &
Kleiber, 2000; Mannell, 2007). First, when people connect with others in a particular setting tied
to the activity they can develop a shared social or subcultural identity (Fine, 2001; Green, 2001;
Snelgrove, Taks, Chalip & Green, 2008). The development of a shared identity tends to develop

through prolonged involvement in a setting and involves a socialization process whereby participants learn, adopt, and reproduce the norms associated with the given identity (Donnelly & Young, 1988; Green & Chalip, 1998). Second, people can receive recognition from peers because of engagement in certain leisure activities, such as becoming known as a "runner." A particular status and related perceptions can also be ascribed to a leisure identity, such that people who perform particular activities are thought of in certain ways (Goffman, 1963; Haggard & Williams, 1992; Kivel & Kleiber, 2001; Shamir, 1992). In fact, popularity based on involvement in certain leisure activities is particularly common in adolescence (Evans & Eder, 1993; Fine, 2001). Third, being able to engage in typical or desired leisure activities plays an important role in making people feel as though they have a place in their social world (Arnett, 2004; Erikson, 1963; Kivel & Kleiber, 2000; Kroger, 2007; Shaw et al., 1995). Limitations to engagement in activities can also lead to what Kleiber et al. (1995) termed a "lost sense of self in action." Fourth, people may compare their involvement in leisure activities to personally or socially desirable images and construct a sense of identity from those comparisons (Arnett, 2004; Goffman, 1963; Kivel & Kleiber, 2000; Prus & Grills, 2003). For example, young people may attempt to emulate the behaviors of an athlete or musician as a way of building a similar identity.

Comparably, much less attention has been given to the potential challenges that exist in forming identities through leisure. Research on women and sport suggests that stereotypes created and reproduced by others can negatively affect women's abilities to use sport to construct identities (Green & Chalip, 1998). In these cases, there is essentially a conflict between the personal identity that these women are attempting to create, and the social identity they have been ascribed by others. Some research has described the sense of empowerment that women feel by participating in sports that have been labeled as masculine (e.g., football, hockey). For example, in a study of a woman's flag football subculture, Green and Chalip (1998) suggested that the ability to engage in behaviors that are not normally socially acceptable for women was one of the driving forces behind participation. The rejection of a stereotypical image of a woman often leads people unfamiliar with the subculture to conclude that all participants are lesbians (Green & Chalip, 1998; Lenskyj, 1994). However, this is a false conclusion as both openly lesbian and heterosexual women often play together on the same team (Green & Chalip, 1998).

The limited number of socially available identities built on leisure can also be seen in an examination of race. Appiah (2000) suggested that for some races, a very narrow number of identities related to leisure are available which result in pre-established "collective identities." Ogden and Hilt (2003) described how for African Americans, particularly those in an inner-city, the sport of basketball has become a collective identity. Through the reproduction of images in the media, and interaction within the African American community basketball "belongs to an African-American, whether she likes it or knows anything about it, because it is culturally marked as black" (Appiah, 2000, p. 612). Ogden and Hilt (2003) noted that the socially acceptable way of acting within the African American community often involves the rejection of leisure pursuits that are not considered Black and engaging in those that are sanctioned. Similar to gender, this situation involving race is another example of the paradox of identity and leisure. That is, leisure can be an arena for resistance and expression that creates a sense of empowerment, while simultaneously reinforcing dominant stereotypes (Boyd, 1997).

Leisure can also help or hinder the development of identities for people with chronic illness (Snelgrove, Wood, & Havitz, 2013). Like adults, some young people with illness avoid social situations whereas others are more social and spend time with peers (Abrams et al., 2007; Hilton et al., 2009; Taylor et al., 2008). Having difficulty engaging in social leisure because of physical

differences that result in physical limitations or social ridicule also serves to reinforce perceived difference or negative identities. Nicholas et al. (2007) found that some adolescents with illness, particularly males, reported being excluded from sports because they were not as tall, fast or strong as their peers. Consequences for many are a reduction in friends. In these cases, it is unclear if and how more private forms of leisure are employed and the meanings those forms of leisure hold for adolescents (e.g., Kivel & Kleiber, 2000). Researchers have found that leisure choices are influenced by people's perceptions of self and their perceptions of the identity images associated with specific leisure activities (Haggard & Williams, 1992; Kleiber, 1999). Young people living with a chronic illness may be no exception (Drew, 2007). Freedom to engage in valued activities can have important implications, as difficulties may be reduced and desired self-images maintained (Abrams et al., 2007; Balfe, 2009; Charmaz, 1983; Hilton et al., 2009; Kleiber, Brock, Lee, Dattilo, & Caldwell 1995; Woodgate, 2005).

Illness and Social Identities

In some cases, when others know the existence of a person's illness there is a risk that a reputation tied to illness will develop and even become what Hughes (1945) termed a "master status." That is, a person can become primarily known as a sick person above all else. Importantly, when people develop an illness-based master status, that status and its cultural associations may shape other people's perceptions about the capabilities and social position of the person with the illness (Fine, 2001; Fine & Fields, 2008; Goffman, 1963). Goffman referred to these perceptions or assumptions as identity imputations, and he suggested that they lead to wide ranging attributions about people's character and competence. Similar imputations can be found in others areas of social life, such as talking louder to blind people or believing that people who are obese have poor character (Nettleton, 2006). Thus, people may choose not to reveal the existence of their illness (Charmaz, 1991; Goffman, 1963; Joachim & Acorn, 2000) as a way of avoiding stigmatization and consequent negative reactions from others (Richards, 2008; Robinson, 1993). Instead, some people attempt to act in ways that are considered normal or avoid situations that may result in suspicion of an illness (Frank, 1991).

Also important to consider is the visibility of the illness. People who have illnesses that are not manifested in visible characteristics have been described as *discreditable*, whereas those people who have visible illness characteristics are considered *discredited* (Goffman, 1963; see also, Joachim & Acorn, 2000; Karp, 1996; Prus & Grills, 2003). Being discreditable means that a person has the ability to cover his or her illness in the presence of people he or she encounters but risks being stigmatized if such actions are not taken. In this sense, people with concealable illnesses are in a situation similar to others who also have an opportunity to conceal an aspect of their identities, such as one's sexuality (e.g., Meyer, 2003). Thus, the central concern is preventing stigmatization and identity imputations by covering or avoiding situations that risk uncovering illness. Conversely, being discredited is associated with having a characteristic that cannot be readily concealed such as a significant mobility restriction, skin condition, speech impairment, or a mental disability that is apparent in social interaction. Building upon existing research related to the roles of leisure in identity development, the purpose of this study is to develop an understanding of the ways in which leisure is influential in identity development and maintenance for youth with chronic illness.

Method

Study Participants and Recruitment

To develop an understanding of youths' experiences with chronic illness, including any changes that may occur throughout the illness experience, participants who were 18 to 30 years old who could reflect on these changes over time were recruited and interviewed. Consistent with university ethics approval, participants were recruited through a number of means including advertisements on various illness-focused group pages on Facebook.com, referrals from study participants and friends, and an advertisement included in a newsletter for the Crohn's and Colitis Foundation of Canada. In all cases potential participants were directed to the study website that discussed the study, their ethical rights as participants, and provided them with an e-mail address for further contact. Snowball sampling was also used to recruit participants. Three people e-mailed for further information about the study, and later declined to participate due to a lack of availability. Also, four people expressed interest in the study but were not interviewed because they did not fit the age requirement. All other participants who contacted the researcher and expressed an interest in participating were interviewed. No compensation was offered or given to participants for their involvement in the study. Ongoing recruitment and interviewing occurred over an eight-month period.

Participants in this study consisted of 30 young people, each of whom was living with a chronic illness. The illnesses were Crohn's disease (11), ulcerative colitis (4), type 1 diabetes (4), multiple sclerosis (3), epilepsy (2), celiac disease (2), juvenile rheumatoid arthritis (1), fibromyalgia (1), lupus (1) and anaphylaxis (1). Attempts were made to recruit participants who had a range of illnesses to allow for the opportunity to make comparisons across illnesses and thereby avoid the assumption that experiences differ by illness, and increase the possibility of developing an understanding of the lived experiences of illness at a more general level. Prior to beginning the study, the goal was to obtain somewhat of a balance in the number of individuals with each illness. However, relying on the snowball sampling method as one of the methods of recruitment contributed to an imbalance in the sample as participants most often referred potential participants who had the same illness. The inclusion of participants with other illnesses was sought by actively seeking out further Web pages on which an advertisement could be posted. This recruitment approach was successful, for example, in adding participants with epilepsy, multiple sclerosis and lupus towards the end of the data collection phase of the study.

The largest challenge of participant recruitment was reaching young men. Of the 30 study participants, 23 were young women, and 7 were young men. Early into recruitment and interviewing, the need to obtain more young men was recognized. At that point only young men were actively recruited. That process resulted in the recruitment of four more young men over the remainder of the recruitment phase. The age of participants at the time of the interview ranged from 19 to 33 years old. For the majority of participants symptoms first appeared in their teenage years.

Interviews

Three types of interviews were conducted. This approach allowed participants to be involved in the study in a way that met their comfort level and geographic location. The majority of participants (24) were interviewed face to face, while the remainder were interviewed by phone (two participants) or electronically (three participants). Initial face-to-face and phone interviews lasted between 45 and 120 minutes, with the majority lasting 60 minutes or longer. Some follow-up interviews were conducted via e-mail and were comparably shorter in length, and acted

mostly to elaborate or clarify certain responses. All face-to-face interviews occurred in locations chosen by the participants. Most typically, interviews were conducted in coffee shops but some also occurred in participants' homes as well as sitting areas at universities and hospitals.

Semi-structured interviews were facilitated in a way that allowed participants to bring up topics that were most salient to their experiences with chronic illness (Lofland & Lofland, 1984). The interviewer was open to the idea that participant experiences would vary and that it would be more productive to explore those issues and experiences that were most salient to the person being interviewed rather than pushing for responses on questions and issues they indicated were not relevant to their life. All interviews began by thanking participants for agreeing to participate, reviewing the information and consent forms, and addressing any questions. Next, participants were asked to take the interviewer back to their earliest memory of when they first noticed their health had changed and to describe what happened (e.g., Karp, 1996). Interviews then followed from participants' initial descriptions of these early experiences. With many participants, issues of interest related to involvement with leisure, work and school naturally flowed out of the conversation as it progressed, with minimal direct questioning needed other than requests for elaboration. In other instances, certain topics required more direct questions, which then typically restarted the flow of the conversation. In a few cases, participants seemed to feel more comfortable with the interviewer leading the conversation by asking questions more frequently than with other participants.

Interviews in an Area of Personal Experience

Leisure researchers often study phenomenon in which they have personal experience (Dupuis, 1999; Henderson, 2009). In this study, the researcher has first-hand experience with a chronic illness and attempted to use that experience to enhance the research process rather than ignore it (Dupuis, 1999). Specifically, the researcher's personal experience with chronic illness was useful in developing rapport with participants, crafting questions in a sensitive manner, and in connection with extant research, developing questions that were hoped to be of relevance to the research participants (Etherington, 2004). Although all participants would have known that the interviewer had ulcerative colitis after reading the information letter on the study website, they were reminded of this at the beginning of each interview when discussing how the interviewer came to be interested in studying chronic illness experiences.

When asking a few sensitive questions to some of the participants, the researcher drew on some personal experiences when framing questions. The researcher always emphasized that the question being asked may not apply to them at all and answering in that way is completely acceptable. Making this clarification and asking for examples helped reduce bias towards answering questions in a particular way. In the few cases where personal experiences were shared by the researcher, a range of experiences resulted from somewhat similar stories to indications the situation did not apply to them. Further, obtaining detailed examples of situations in which an event occurred increased the trustworthiness of the data (Prus, 1997). Participants who at first seemed unsure about discussing experiences with a stranger seemed more comfortable after knowing the interviewer could empathize with their experiences in some way. To ensure the data was not unduly influenced by personal experiences shared by the researcher, the researcher compared answers from unprompted participants with the answers from prompted participants. No differences were found.

Data Analysis

Face-to-face and phone interviews were first transcribed to facilitate the data analysis process. Data analysis followed an inductive analytic approach known as grounded theory

(Charmaz, 2000, 2006). In this context, coding refers to categorizing segments of data with a short phrase that describes what is happening in action terms. The use of action-based phrases also helps connect the analysis to the tenets of symbolic interaction – understanding experiences in a social context. Data analysis began with initial coding, which typically involves reading each transcript and coding line-by-line (or section-by-section) of data free of preconceived categories. Charmaz (2006) suggested that "this method of coding curbs our tendencies to make conceptual leaps and to adopt extant theories *before* we have done the necessary analytic work" (p. 48). These initial codes are considered provisional as further data comparison adds precision to the analysis.

Focused coding followed initial coding which involved an attempt to develop more directed and conceptual codes. Further, it "requires decisions about which initial codes make the most analytic sense to categorize your data incisively and completely" (Charmaz, 2006, pp. 57). Last, theoretical coding was undertaken. This final stage of coding allowed for the development of a coherent analytic story by relating and integrating focused codes. Finally, an overarching theme was developed to collectively represent the analytic story of participants' experiences as described in the three themes. After major themes were developed each section was continually refined to add clarity to the analysis and the quotations that best exemplified the process or sub-process being described were selected. In cases where sub-processes were underdeveloped or supported they were dropped from the final findings section. As the analysis progressed, an evaluation of how often particular participants' quotations were being used over others was undertaken. Consequently, a readjustment of a few of the selected quotations was made to increase the balance amongst participants' voices (Karp, 1996). Where possible this balance involved incorporating different illnesses and genders.

Establishing Trustworthiness

The establishment of trustworthiness was conducted in accordance with criteria established by Lincoln and Guba (1985) and Wallendorf and Belk (1989). Lincoln and Guba developed four criteria that should be addressed in an interpretive research project to work towards establishing trustworthiness: credibility, transferability, dependability, and confirmability. First, credibility addresses the question of having confidence in the findings. Wallendorf and Belk described it as having a sense that adequate and believable representations of the studied phenomena are provided. A number of techniques were employed to address credibility including (a) a substantial number of extended interviews with participants; (b) developing an understanding of a range of participant illness experiences, especially those that differed from the researcher's; (c) sharing transcripts with participants; and (d) follow-up with participants which led to some elaboration and clarification of participant comments. Second, the idea of transferability addresses the question of the degree to which the findings apply in other contexts and was addressed by interviewing participants with a range of chronic illnesses. Doing so facilitated an analysis of the "generic social processes" (Blumer, 1969; Prus, 1996) that would not have been directly possible by interviewing participants with only one chronic illness.

Third, dependability refers to the replicable nature of study findings. Wallendorf and Belk suggested that approaching a study longitudinally could help remove the cross-sectional bias often found in social science research—a challenge to dependability. As questions were asked that focused on both the past and present, an understanding of the experience of living with a chronic illness was more fully developed. Without such an approach, a full range of experiences and changes would not have been fully understood and only present experiences may have been obtained. For example, asking participants to reflect on how things might have changed

if they currently viewed their illness positively reduced the likelihood of drawing conclusions based solely on recent experiences. Last, confirmability refers to the degree to which the findings emerged from the context or participants under study and not the researcher. To address the issue of confirmability, an extensive number of quotations were presented along with short summaries of the concept being described to provide the reader with the ability to judge whether the participants' verbalized experiences were consistent with the researcher's description and summary of the findings.

Findings

Leisure played a role in shaping the identities of study participants in three ways. Specifically, chronic illness made it difficult for some participants to (a) present idealized identities through leisure, (b) fit in with friends through leisure, and (c) develop an identity through action. This section describes these three themes in detail. Pseudonyms are used for all study participants.

Presenting Idealized Identities

Many participants found that having a chronic illness made it difficult for them to present ideal identities, physically and behaviorally. Specifically, challenges were related to increases or decreases in weight and idealized physical appearances tied to gender, expectations around what youth believe they should be doing at their age, and social withdrawal.

One of the ways that participants indicated that self-presentation was made difficult was because of associated weight gain or loss. For some participants, such as Juliet who gained significant weight, changes to their physical appearance through physically active leisure was not always possible because of pain or a lack of energy. Through trial and error, Juliet found that to minimize pain from fibromyalgia she had to limit her exercise to levels that provide little help in reducing weight. Juliet described her increased weight as undesirable and not the ideal appearance of a young woman. Conversely, Amy found that her decreased weight, a symptom of her Crohn's disease, resulted in her describing her frame as frail and not very feminine. Similarly, Will found that he was unable to participate in physically active leisure and would gain weight during bad periods due to a lack of energy. Increasing his body size was important to him because he equated a certain size with being manly. Engagement in leisure activities that showcase one's body are especially problematic and result in avoidance, covering, or careful selection of leisure spaces. Juliet provides a good description of this situation:

> You're always trying to strategically organize what you look like, so people don't think you look huge that day or so you don't feel huge. I swim sometimes because we have a pool here and thankfully this building is 90% gay men, so I don't care so much wearing a bathing suit downstairs. But I don't love wearing a bathing suit in front of anybody else. I wear it, but it's 'throw off my tank top and dive into the pool immediately' kind of feeling. Whereas in my life I have always, no matter what at 130 or 111, I have never been one to feel like I had to cover up.

Negative feelings associated with weight can permeate all social activities, as people withdraw altogether while they "work on" their bodies. As Bree explained, she became really obsessed with watching what she was eating and hardly went out in public with friends.

Challenges in self-presentation were also evident in public behaviors. In addition to idealized physical appearances tied to gender, participants also described expectations around what youth believe they should be doing at their age.

I sit there [on the couch]. Just sit there, wait for tomorrow. There's nothing else that you can really do. I'm sure I could probably get out of here, do the cane [or] wheelchair thing. I'm 27, I don't want that. I don't want a cane, I don't want a wheelchair. I don't want any of that stuff. (Mark, multiple sclerosis)

The possibility that illness symptoms may occur in public places was a strong deterrent for some young people and resulted in social withdrawal. Rebecca's experiences are particularly instructive in this regard.

I used to go down in the middle of a conversation or anything. The noises I make. My eyes would roll to the back of my head. These are not the most pleasant things to see happening to someone. So it was all-around embarrassing. …[My mom and sister] would both tell me what happened after I had woken up from a seizure. They'd be like 'That was scary' or 'You made the noise from the Grudge.' …I remember going down. I was walking my dog a few years ago and I went down in front of a pub. That was just humiliating. …I remember someone from the pub saw me go down and thank god they didn't think I was drunk because I was obviously right outside a pub. He came running out to see if I was ok. It was really embarrassing. (Rebecca, epilepsy)

Because of experiences like the preceding and the anticipation of others, Rebecca responded by spending most of her time in her bedroom because she did not know when she might have a seizure. Her social withdrawal was tied to perceived expectations of how people should behave with epilepsy. She explained that,

It's not pleasant to have something like that in public. I don't know how to describe it. It's something that draws a lot of attention to you…. I think [other people] would have thought that if I wasn't well, maybe I shouldn't be outside of the house or something like that. I think that's the big one; that [other people] think I should just be inside the house. (Rebecca, epilepsy)

The impact of the unpredictability of chronic illness on self-presentation was also evident in Tessa's experiences. When "bad days" arrived and activities were planned, confrontations and disappointment arose when other people held expectations about how people should behave. Tessa recalled an emotionally difficult day for her when her parents had rented a local arena in the summer to host a birthday party for her.

The day the party happened I didn't know if I was going to make it; even though I wasn't sick, my body was so depleted and I remember my parents were just furious at me because my attitude wasn't right. I was trying to be so polite to people, but I felt awful. I could barely hold myself up, I was dizzy, and yet they were like 'You're being selfish right now. Suck it up, you're being selfish, this is why no one wants to hang out with you, this is why you can't have friends. You get sick and then you act like this.' (Tessa, Crohn's disease)

In Tessa's case, her parents expected her to sustain a certain public appearance regardless of her symptoms by attending the party and putting on a normal face.

Fitting In with Friends

Fitting in with peers was very important to participants and chronic illness risked complicating that endeavor. "Fitting in" for this study is defined as being accepted by others. Participants expressed a desire to have others act as though nothing has changed despite them having a

chronic illness. Kristin explained that she's drawn to being around friends "who are just so used to it that they don't bat an eyelash if I pull out my glucose monitor or anything." Even if it is the exception rather than the norm, sometimes people's worst fears are confirmed when they tell others they have an illness—social isolation based on perceived limitations. In Emily's case, she told her boyfriend in confidence about her disease and he then told all of their friends. When asked how she would prefer people to act toward her, Emily did not want to be treated any differently than previously.

> Not differently than they did before. I have MS, I haven't changed. I'm still who I am and they never gave me a chance after that. They were just gone. They were cutting me out of a lot of things like bowling or wherever they were going like mini golf or laser tag. I was never invited to any of these and I only found out about them because they were posted on Facebook. I saw them and then I was pissed off. I'm like why wasn't I invited here, this is stupid. I do think it was because of the MS because they wouldn't let me help them move into their house. It all just spiralled from there. (Emily, multiple sclerosis)

Engagement in social activities centered on eating or drinking alcohol were problematic for participants whose disease symptoms may have been linked to diet (e.g., celiac disease, Crohn's disease, colitis, diabetes). The settings in which this occurred varied but in all cases these participants described the situations as a potential threat to their ability to fit in with friends. When hanging out with others who are unaware of a person's illness, unwanted conversations are often forced upon the person. Further, some people feel as though they become the center of attention because of dietary restrictions.

When situations that participants perceived to be embarrassing occurred, it was how others in the setting responded that influenced how they felt. Mark's description of a camping trip with friends highlights this point well.

> We went up to the north end of Algonquin Park and it was fall time and I had my walking cane, and I could barely stand up straight and I was having a hard time walking because I had been moving around in the bush as much as I could for the last couple of days. We had this log set up across the fire for our grilling of all the food we were cooking, well I come across to go flip it and I fell across the board through the fire and rolled down the hill almost coming into the water. He was like the best friend ever, he didn't say anything. He didn't say anything to me, he didn't say anything about it, he just came and picked me up. All the rest of the guys were laughing, he didn't say anything he looked at me and picked me up, got me back on the cane and picked all the fire wood up. I think that's the example I can give you of someone helping me out. I felt like complete shit, it's utter embarrassment. You have this whole presence of a man, and when you have MS, you just lose it all. You don't have the strength, you lose a lot of it, and he just made it really easy that day. Really easy. …He didn't treat me like I was a cripple, he didn't treat me like I was any different than any other person. And he didn't make me feel like a baby, like, 'Oh, you ok?' He just made me feel like me. He understood without having to say anything. I felt so bad I was on the verge of crying. Not because I'm a whiner or anything. Just because of the situation. He just handled it so well because he knew exactly what to do at the right time, and make me get up and laugh about it. (Mark, multiple sclerosis)

When participants were constrained to their homes because of physical restrictions they risked missing out on social leisure opportunities. When friends were willing to adjust the ways in which they interact with friends, it helped these participants feel good and connected to others.

> I was super active before, I rode my bike everywhere, I did yoga three or four times a week, I went dancing three or four times a week because my boyfriend was a DJ as well as his other job. I was always out doing things. I skied and scuba dived and did a ton of stuff. So I was really active. I kind of thought that people weren't going to want to hang out so much because I wasn't going to be able to go do all these crazy things anymore but everyone always came over for movie nights and still did stuff with me. So I didn't really have a drop off with friends. Actually I got closer to a lot of people who stepped up and really helped and brought things over when they thought it would be nice for me. People actually really stepped up in that respect. I really thought things would change just because my life went from being out all the time. (Juliet, fibromyalgia)

The experiences of Kristin, Emily, Mark, and Juliet highlight the importance of having friends who are willing to treat people no differently than others. In some cases, participants felt as though only people with a similar illness were able to understand them and fit with their lifestyle. At a time when other teens were engaging in common teen activities or embroiled with age appropriate concerns, participants were faced with what they perceived to be more pressing issues. Thus, connecting with others who were also faced with similar challenges because of illness seems like an appealing alternative for many participants.

> There is a part of me that only other IBDers can understand, it's the nature of our existence. I could care less about teenage issues and so I lose a point of connection because I know there are larger things to worry about. ... I also don't have the energy to play and meet up so that interferes. (Regan, Crohn's disease)

Although some people took the step of organizing an illness based club and joining another established one like Amy did at the university, others did not have that same desire or have access to such opportunities. For example, when she was a teenager Myra heard about diabetes camps she had a strong desire to attend.

> I wanted to go because I could meet other diabetics and actually experience things with them. We could take shots together. Shots, not like alcoholic shots [insulin shots]. ... We could talk about things. We could just be. We could be. I'm still sad to this point that I didn't go, but now is my chance. I paid for the trip on my own and it is next week. I'm really excited. (Myra, type 1 diabetes)

In some cases, participants wanted to avoid others with a similar illness because they do not want to draw attention to their illness.

> There are these things called diabetes camps. I *refused* to go to them. I think it was one of the very few times with diabetes-related stuff that I put my foot down against my parents. So they wanted to sign me up to go to diabetes camp and I refused. I said *no,* there is no freaking way. I screamed and cried. I was a really good kid, so for me to put up that much angst against them, they had to give in. Which they did. For me, I didn't really want to know other type 1s. If I came across them naturally, that's great, but I didn't want to be around a bunch of other sick people. It was not what I wanted. Part of my way of being normal and fitting in as much as I could was not going to diabetes camp for a week in the summer. No thank you. (Kerri, type 1 diabetes)

So, in cases such as Kerri's, organized leisure settings that bring people together, like Myra and Steve enjoyed, were not attractive to everyone because of the disruption it caused to feelings of normalcy.

Developing an Identity through Action

Symptoms associated with chronic illness threatened to limit participants' involvement in everyday life. As Mark's quote demonstrates, an inability to engage in desired leisure activities contributes to feeling as though one has no place in the world.

> It felt like everything that was me was ripped away, because you're not the same person. I was an outdoorsman. My canoe sits down at the bottom of the stairs and you can't do any of that. Your whole identity is gone. I was a hand worker, whether it was cars or my job or sitting around the house, and that all stopped. Canoeing stopped, all that stuff stopped. It's like your whole identity is ripped away. (Mark, multiple sclerosis)

Being unable to engage in desired leisure activities can be a very challenging proposition. Symptoms could restrict people from getting out of bed, leaving the house, or having enough energy to engage in physically demanding activities. Although most people described these down times as missed opportunities to engage in sports or socializing with friends because of low energy, others also talked about not being able to play music, or read because of blurred vision. In all cases, these missed opportunities were described as highly meaningful pursuits. Alternatively, where possible other activities were substituted that were generally perceived as less enjoyable and meaningful. Primarily, these activities consisted of watching television or movies. Will's description is illustrative of many people's experiences.

> I was involved in a lot of sports and I remember playing basketball during that time and hockey, and I had no energy. I couldn't play anymore. It was never that way for me. I always wanted to be out there playing. I just couldn't do it. That was a big thing for me at that time, I couldn't push myself anymore. I couldn't play. ... That was a big drawback. Then after I got diagnosed, I was playing basketball, I tried to keep playing during it and then once that season was done I would have played soccer usually and I just quit. There's no way that I could have done it. That was big for me in terms of what I did all of the time. All of a sudden I had to stop, and for me that was really hard. I didn't have depression out of it by any means, but I almost felt lost in that sense, like 'Alright what do you do, watch TV?' It wasn't me as a person. (Will, Crohn's disease)

In addition to physical symptoms that threatened participants' involvement in leisure and resulting identity development and maintenance, mental work also did the same. In less serious cases, people were momentarily interrupted. For example, people might think about what could happen when they are performing on stage like Mimi or when they made travel plans like Sarah. Also, when people like Rebecca felt their muscles flinch they were reminded of past seizures and worry that more may be coming. Similarly, Will explained, "I think about it in some way or another, probably on a daily basis." In other cases, mental work limited leisure activity involvement and enjoyment. As Kristin explained, although a person can become adjusted to the physical challenges of chronic illness, the mental challenge may remain.

> Mentally, it's another job. It's something that you never really totally put out of your mind. It's funny because I sometimes think about what my life without diabetes would be like and for me it's not the thinking about 'Oh, I wouldn't have to do needles, oh, I wouldn't have to change my pump site.' It's 'I wouldn't have to think about this.' All

the mental energy it takes up to manage it and deal with it when it doesn't work out. (Kristin, type 1 diabetes)

Ever since she was young, Kristin's life has been about control. The effort involved in constantly planning for what might happen if she was to go low in certain situations or develop further complications can be difficult to escape. Taking a break from the continual management begets worry that future complications may arise if care is not taken. The thought of engaging in activities forced an evaluation of whether the benefits of participating exceeded the required mental energy.

> Even anything physical that I would want to do. It's still an issue now whether it's I want to go for a walk, or when I would want to sometimes go play tennis. It's always a matter of making sure your blood sugars are right before you start, you have the right snacks available, is it dropping when you're getting the exercise. Sometimes you're like 'My blood sugar is good right now, and as much as I'd like to go do that, it's probably going to mess it up, so I'd rather just not.' So you sometimes end up not doing things that you might want to do because it's just easier not to. (Kristin, type 1 diabetes)

Further, as participants pursued enjoyable activities like partying with their friends or playing sports, full enjoyment may not be achieved because of the associated mental work.

> It can make what I want to do less enjoyable. It's just always there. ...When you're in high school or university and you're partying with your friends. …I never wanted to get out of control because of my diabetes. I didn't want to drink so much that I couldn't control my diabetes anymore. Even if I was going out drinking, I was having to always check my blood sugar to make sure because I couldn't feel the changes if I was feeling the alcohol. I was smart about it, which is probably a good thing, but being smart about it means you're never not thinking about it. How do you let loose and have a party when you're worrying about your body all the time. (Kristin, type 1 diabetes)

> It was always that energy thing. I wanted to be a part of different clubs, whether it was high school or university, but sometimes I didn't have the energy and really had to pull myself there. Even when I was there I really wasn't listening or paying attention because I felt so weak or sick. (Amy, Crohn's disease)

In sum, chronic illness made it difficult for participants to (a) present idealized identities through leisure, (b) fit in with friends through leisure, and (c) developing an identity through action.

Discussion

Findings from this study suggest that having a chronic illness can make it difficult for youth to present idealized identities, fit in with peers, and develop identities through action. In a broad sense, participants experienced identity development through leisure in similar ways as other people. Importantly, within the broader processes of identity development and maintenance, this study addresses the specific challenges faced by youth with chronic illness.

How youth look, act, and are thought of by others contributes to how they are treated by their peers and others in their social world (Adler & Adler, 1998; Evans & Eder, 1993). Treatment may range from achieving high social status to being isolated entirely (Brown, 2004; Merten, 1996). In varying degrees, many of the participants in this study were faced with the threats that chronic illness can bring to looking, acting and being considered similar to the majority of the

population. Thus, the challenges that chronic illness can create for physical appearance, behavior patterns, and reputations highlight the importance of the body in social interaction and in achieving identity (Balfe, 2009; Bourdieu, 1984; Goffman, 1963; Kleinman, 1988; Sanders, 2008; Williams, 2000).

Participants described not feeling as though they were able to achieve the ideal appearance of a young man or woman, or successfully adopt particular roles (e.g., personal trainer) because of their variations in weight. Similar experiences were found with respect to behavioral public appearances. In these cases, participants described feeling as though others would not want them to inhabit public leisure spaces because they were sick, or others looked down on them because they were not engaged in activities that characterized most youth (e.g., attending university). Mead's (1934) notion of a generalized other and Festinger's (1954) processes of social comparison characterize the process that seems to have occurred as participants compared their body to their internalized notions of masculinity (e.g., strength) or femininity (e.g., physical beauty), compared their situations to that of a typical person their age, and anticipated the behavioral expectations of people with chronic illnesses. Indeed, research has found that youth are influenced by idealized notions of a man or woman's body (Kroger, 2007). These influences on body image are potentially problematic because they can narrow the range of free expression, sexualize bodies, and threaten self-esteem (Evan, Kaufman, Cook, & Zeltzer, 2006). Thus, findings of this study suggest that chronic illness intensifies the challenge of achieving a body image and identity with which a person is comfortable rather than creating a unique set of challenges (Fobair, Stewart, Chang, D'Onofrio, Banks, & Bloom, 2006).

The onset of chronic illness also threatened participants' abilities to be viewed as "one of the group." Participants consistently expressed a desire to have friends treat them as though nothing has changed, and it is with that mindset that participants approached social leisure contexts. Connecting with others in social leisure settings was problematic when participants' illness becomes the center of attention because of dietary restrictions or physical impairments. The desire of participants to avoid having their illness become a focal point is consistent with research indicating that some adults feel the same way (e.g., Snelgrove et al., 2013; Parry, 2007). Although it is difficult to compare the experiences of the participants in this study directly with the experiences of adults in other studies, it appears as though the desire to fit in by having an illness downplayed is heightened in adolescence and young adulthood. This conclusion seems reasonable given the importance placed on fitting in with peers during adolescence and young adulthood as compared with adulthood.

During occurrences in social leisure that highlight a person's illness, people transition from being discreditable to discredited (Goffman, 1963). When an illness becomes visible, it is how others in the setting respond that influences its impact on the affected person's ability to fit in. Positively, participants described friends who were willing to treat them as though nothing had changed, particularly during embarrassing situations, as being very important to their ability to feel normal. Pity and over attentiveness were unwelcome. Similarly, when participants were unable to engage in social leisure in public settings because of physical limitations, it was friends who were willing to alter their plans and desired activities to meet the needs of the person with an illness that made a difference. When friends like the ones described were not plentiful, participants often sought out other people their age going through a similar situation. The primary way participants met and connected with others who had the same illness was through their involvement in camps designed for youth with a certain illness. In these leisure settings, participants could, as Myra explained, "just be." Misunderstandings, potential judgment, and fear of

embarrassment were minimized or eliminated (Bluebond-Langner, Perkel, Goertzel, Nelson, & McGeary, 1990; Thomas & Gaslin, 2001). Although a desire to connect with similar others was not universal for all participants (Glover & Parry, 2008), the importance of creating leisure settings for people who do want to connect with similar others seems particularly important for the identity development of many youth with chronic illness.

Participants in this study described in various ways the importance of accomplishing desired leisure activities to their ability to develop desired identities. The participants also described the challenges of accomplishing desired activities and their effect on their ability to develop and sustain identities (Abrams et al., 2007; Balfe, 2009; Hilton et al., 2009; Kleiber et al., 1995; Woodgate, 2005). When symptoms such as fatigue or discomfort were present or heightened, participants were constrained in undertaking daily activities they described as highly meaningful, such as playing sports and music, and hanging out with friends. During this time, leisure activities that were easier to engage in were substituted, such as watching television and movies. This strategy corresponds with research findings that show people will substitute leisure activities when faced with constraints to preferred leisure activities (Brunson & Shelby, 1993; Kleiber, Nimrod, & Hutchinson, 2011; Wood & Danylchuk, 2012). However, among the participants the substitutions were viewed as less personally meaningful and enjoyable activities, even by those participants self-described as aficionados of the new activities.

Participants clearly described their inability to continue to develop or maintain their identity through participation in meaningful and preferred activities as distressing. Kleiber et al. (1995) called this experience a "lost sense of self-inaction" (p. 293). Thus, this finding is consistent with Kleiber et al.'s study of adults' experiences with spinal cord injury. Their findings highlighted the relevance of activities in achieving identity. Further, some participants described the demanding mental work associated with chronic illness that can make it seem as though engaging in leisure activities is not worth the effort. Participants evaluated the perceived benefits against the costs of participating and sometimes activities were not pursued. The psychological and social costs described by participants were related to the constant attention required to manage one's illness, the worry that something might go wrong when participating, and a desire to avoid embarrassment in social settings. This cost-benefit decision-making approach is also consistent with the findings of previous leisure research on the topic (e.g., Baldwin & Norris, 1999; Lee & Scott, 2006). When engaging in leisure activities, participants experiencing this type of mental immersion in illness also indicated that constantly thinking about their illness was like a job and took away from enjoying leisure activities. As Kleiber et al. (1995) found, the mental work involved in illness can cause a consciousness of self or disruption in "flow" that is often described as antithetical to enjoyment and identity development (Csikszentmihalyi, 1991; Fine, 2001).

Implications for Practice

Findings from this study also highlight some implications for practice. First, there is a need to create programs and leisure spaces for this population group. Specifically, programs that bring together people with similar illnesses, and create opportunities to participate in desired forms of sport and leisure are needed. However, as the findings demonstrated it should be recognized that some people with illness will not want to participate in these types of programs because it threatens their ability to develop an identity not encompassing illness. Second, there appears to be a need to enhance understandings of illness among the general public, which would reduce the likelihood of youth with illness being restricted in their identity development through leisure based on misunderstandings about limitations or illness symptoms. Third, there is a need

to create opportunities for youth with illness to participate in leisure in ways that recognize the personal and social challenges they face.

Limitations and Future Research

The findings from this study should be considered along with potential limitations. One of the limitations of this study is that it did not focus its examination on dyadic or group relationships, and thus relationships or interactions could not be observed directly. Future research could study social acceptance and the family unit or other social networks more closely to obtain a more complete picture from multiple perspectives. Also important to consider is the nature of the sample in the study. First, as a result of the use of snowball sampling as one of the methods of recruitment, there was an imperfect distribution of participants by type of chronic illness. Although, no notable differences by illness type were recognized during data analysis there is a possibility that a more evenly distributed sample could have better highlighted differences in how identity develops through leisure for youth with illness. Although challenging in a practical sense, future research would benefit from attempting to address this potential issue and possibly enhance theory in this area. One of the unique aspects of this study, though, was the development of an understanding of how identity develops through leisure for youth with chronic illness in general, rather than for youth with one specific illness. This type of analysis can only be conducted directly by recruiting participants with various types of illnesses. Second, the age and onset of illness varied in this study. Although all participants had an illness during their teenage years, it is difficult to fully draw conclusions about similarities or differences in experiences based on a qualitative analysis of 30 participants' experiences. Thus, future research should consider the use of a large quantitative survey to conduct comparative analysis of identity development based on illness type and age.

A number of areas for future research can also be suggested based on the findings of this study. First, as this study focused on one particular population group, future research is needed to further examine the factors that limit and enable the development of desired identities through leisure for other groups of youth (e.g., Kivel & Kleiber, 2000). Second, following an identification of the ways in which leisure plays a role in shaping identity development for youth with chronic illness, an understanding of how youth are able to cope with illness and negotiate the constraints they face to participate in leisure seems warranted. Third, a number of illness communities were identified in this study including those created online, through organized leisure settings such as volunteer organizations or recreation camps, and informally in hospital settings. An analysis of these communities could be undertaken to address the long-term outcomes derived from involvement and the elements of a program or organizations' design that contributes to desired outcomes.

Conclusion

The purpose of this study was to develop an understanding of the ways in which chronic illness impacts youth's attempts at forming and maintaining identities through leisure. This study identified three ways in which leisure is involved in identity development, including the presentation of idealized identities, fitting in with peers, and developing an identity through action. These three themes reinforce the important role that leisure plays in self-expression, facilitating social connections, and shaping sense of purpose. The experiences of the participants in this study suggest that youth with chronic illness experience successes and challenges as it relates to these three mechanisms of identity development. Successes and challenges of identity develop-

ment for this group can be traced to the person involved, friends, family and others around them, and prevailing societal notions of ideal bodies and health.

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