

Living with a Chronic Illness in Adolescence and Emerging Adulthood

by

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AUTHOR'S DECLARATION

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by examiners.

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ABSTRACT

This study explored the lived experiences of chronic illness during adolescence and emerging adulthood. Previous research has indicated that chronic illness can result in disruptions to people's lives because of the related physical challenges and social stigmas. These challenges may be particularly salient in adolescence and emerging adulthood because of pressure to "fit in" with peers, cultural associations between youth and health, and limited experience adjusting to difficult life events. However, little is known about the impact of having a chronic illness on the lives of young people. Although chronic illness can disrupt identity formation and maintenance, relationships, and involvement in leisure, work and school, people can make adjustments to meet the challenges (if only in part) associated with chronic illness. Thus, this study addresses the over-arching question: *how and when can chronic illness become a problem for young people in their everyday lives (i.e., leisure, relationships, school and work) and what types of adjustments are made as a result?* To develop an understanding of the recent as well as the individual historical experiences of young people living with a chronic illness, people emerging into adulthood were recruited and interviewed who could reflect on these changes over time. The final sample of participants in this study consisted of 29 young people (23 women, 6 men) each of whom was living with a chronic illness. The ages of participants ranged from 19 to 33 years old, and their age of illness onset ranged from 1 to 25 years old. Unstructured in-depth interviews were conducted with 26 participants, as well as 3 semi-structured electronic interviews. Data were analyzed using a grounded theory approach.

The findings suggested that the main challenge for young people with illness is achieving a desired identity. Being able to achieve a desired identity was tied to three processes. These processes included participants' ability to manage their appearances and reputations, accomplish desired activities, and experience positive relationships. Although most adolescents and emerging adults to some degree face these same challenges in attempting to achieve desired identities, experiences associated with chronic illness can intensify these challenges. Further, the factors that contribute to them being challenging seem to be unique to those living with a chronic illness. The findings also suggested that participants' experienced chronic illness in varied ways. Many of the adjustments and factors that contributed to these differences, including how people's experiences changed over time are identified. These adjustments and factors are similar to the coping strategies and constraint negotiation strategies identified in previous research at a generic level. The specific ways in which young people with chronic illness are able to achieve identity is also described, including differences within the experiences of participants.

Study findings also have important implications for the design of programs and leisure spaces for this population group. Indeed, programs that teach coping strategies, bring together people with similar illness, and create opportunities to participate in desired forms of leisure are needed. However, as the findings demonstrate, it should be recognized that some young people with illness will not want to participate in these types of programs because it threatens their ability to achieve identity. Further, at a public policy level there appears to be a need to enhance understandings of illness, and ensure that young people with illness receive opportunities to participate in leisure, work, and school in ways that recognize the personal and social challenges they face. A number of areas for future research can also be suggested based on the findings of this study, including the factors that constrain achievement of identity for other population groups, a focus on social judgment within illness communities, and the emotional change that occurs within dyadic or group relationships in the context of chronic illness.

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CHAPTER I: INTRODUCTION

Although evidence is accumulating that leisure under the right circumstances can have a positive impact on adults' physical and psychological health and well-being directly as well as indirectly through its influence on other domains of life (Mannell, 2007), the roles of leisure in adolescents' and emerging adults' efforts to deal with chronic illness and challenges to identity development have received little attention from researchers. This lack of attention is also true of research on the influence of having a chronic illness on young people's leisure behaviour and experience.

Research clearly supports the idea that physical health outcomes can be improved or maintained through participation in physically active leisure that increases cardiovascular function, reduces the risk of certain diseases, and maintains cognitive functioning (Mannell & Snelgrove, 2012). Further, other types of leisure that do not involve exercise may contribute to health through a variety of social psychological pathways such as enhancing social support that may buffer stress, which in turn reduces physical health risks (e.g., Iwasaki, MacKay, Mactavish, Ristock, & Bartlett, 2006).

Researchers also have suggested a variety of ways in which leisure can positively impact people's psychological well-being. Mannell (2007) classified these ideas into five types of processes: (a) keeping idle hands and minds busy (e.g., directing youth into positive rather than negative activities; diverting attention from distressing life events); (b) pleasure, relaxation and fun (e.g., fun activities that enhance quality of life in the short term and cumulatively contribute to overall life satisfaction over the long term); (c) stress coping (e.g., leisure can minimize the effects of daily hassles and negative life events through positive beliefs and behavioural strategies tied to leisure) (d) personal growth (e.g., activities that facilitate self-determination and

make people feel competent); and (e) identity formation and affirmation (e.g., freedom to explore and engage in leisure activities that are personally and socially meaningful in shaping or maintaining a desired identity).

Yet, leisure is not a panacea for improved health and psychological well-being (Mannell, 2007), and of particular interest in the present study, does it guarantee experiences that positively influence identity development. For example, young people's leisure choices and involvements can be shaped by how they are viewed by others and how they view themselves (Fine, 2004a; Kivel & Kleiber, 2000; Shaw, Kleiber, & Caldwell, 1995). When young people engage in leisure, a perceived need to present themselves in certain ways may sometimes negatively affect the quality of their experiences (Hilbrecht, Zuzanek, & Mannell, 2008). Challenges associated with achieving and presenting identities may also extend to involvements in other areas of life important to young people such as relationships, work, and school (Adler & Adler, 1998; Arnett, 2004; Fine, 2001; Larson & Richards, 1994). Indeed, as adolescents become emerging adults (19 to 30 years old) they not only continue to develop their identities through their leisure involvements, but give increasing importance to work and romantic relationships (Arnett, 2004; Cote, 2000; Konstam, 2007).

While many young people face challenges to identity development in their daily lives, certain population groups may be considered more at-risk. One such group are young people living with a chronic illness (Maslow, Haydon, McRee, Ford, & Halpern, 2011; Taylor, Gibson, & Franck, 2008). In the case of chronic illness, disruptions to people's lives may occur because of the physical challenges and stigma associated with their illness (Hutchison, Loy, Kleiber, & Dattilo, 2003). Stigma refers to the negative associations that accompany being labelled as

having an illness and subsequently being assigned to a devalued or marginalized group resulting in status loss (Link & Phelan, 2001).

This study was an attempt to examine the influence of having a chronic illness and the resulting challenges on leisure behaviour and experience, and identity development. Although leisure and identity development likely influence physical health outcomes in the long term, exploring these health outcomes was beyond the scope of the present study.

As well as being an understudied area, young people's experience of chronic illness, leisure and identity was of personal interest and relevance. Coupled with a theoretical interest in identity development, my experience of having ulcerative colitis, a chronic illness, since I was ten years old drew my attention to this population group. It seemed likely that many people with a chronic illness experience their lives, including their leisure, differently than their "non-chronically ill" peers, due to illness-related physical challenges and the ways in which others define and act towards them and their illness. As described in greater detail in a subsequent chapter, I sought to leverage my personal experience with chronic illness to facilitate participant recruitment and data collection. I also attempt to evaluate the extent to which my own experiences influenced the findings that emerged from my analyses of the data I collected.

Physical and Social Challenges Associated with Chronic Illness

The specific physical challenges often differ amongst illnesses. By way of example, Crohn's disease and ulcerative colitis, which affect youth, can bring about symptoms such as abdominal pain, diarrhea, nausea, weight loss and lack of energy. Both are marked by lifelong fluctuations in flare-ups and remission, and can be managed for periods of time with medications such as anti-inflammatories, steroids, and immunosuppressants. Neither can be cured. Juvenile diabetes, another illness with an early age onset, is characterized by a lack of insulin production

by the pancreas. Insulin is needed to transfer sugar from the bloodstream into the body's cells. Common symptoms associated with elevated blood sugar levels include, extreme hunger, weight loss, fatigue, irritability, and blurred vision. Related complications can also develop such as retinopathy which threatens people's long term vision. Blood sugar management, dietary restrictions, and regular insulin injections are a part of the basic disease management process and the consequences of not adhering to a routine are significant and potentially life threatening. A comparatively less common illness amongst youth is multiple sclerosis. MS is a chronic inflammatory disease of the central nervous system characterized by neurologically based symptoms such as a reduction in balance, mobility, bladder function, energy, vision, hearing, and memory (Romberg et al., 2004). However, the specific symptoms, progression, and severity of MS vary unpredictably from one person to another. Although a majority of people with MS are diagnosed between the ages of 15 and 40, children as young as two years old have been affected (MS Society of Canada, n.d.). Additionally, women are approximately three times more likely than men to develop the illness (MS Society of Canada, n.d.). The cure and significant treatment options remain unknown.

In addition to physical challenges, illness stigma can also impact people's lives because of the potential social rejection that can result (Richards, 2008). In some cases, when the existence of a person's illness becomes known to others 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 (Goffman, 1963; Fine, 2001; Fine & Fields, 2008). Goffman (1963) 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. For this study, use of the term identity is consistent with how symbolic interactionist researchers have conceptualized the term (e.g., Fine, 1993; Prus, 1996a). Specifically, it refers to how people think of themselves and how they are thought of by others. As described in greater detail in the next chapter, identity is socially constructed, resisted and reproduced rather than being an inherent aspect of human life that develops naturally under the right circumstances. Similar imputations can be found in other areas of social life, such as talking louder to blind people or believing that obese people have poor character (Nettleton, 2006). Thus, people may choose not to reveal the existence of their illness (Charmaz, 1991; Goffman, 1963; Joachim & Acom, 2000) as a way of avoiding stigmatization and consequent negative reactions from others (Lather & Smithies, 1997; Robinson, 1993). Instead, some people attempt to act in ways that are considered normal or avoid situations that may result in suspicion of a disease (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; Quinn, 2006). Being discreditable means that a person has the ability to cover their illness in the presence of people they encounter 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 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. In the case of being discredited, people may seek to minimize stigmatization by managing tensions during social interaction (Goffman, 1963). Prus and Grills (2003) observed that ability of people who are discreditable to remain discreditable depends on their: (a) abilities (and willingness) to conceal aspects of their situations; (b) the astuteness of their audiences; (c) inopportune discoveries; and (d) self-disclosures” (p. 82). As noted, becoming discredited can lead to being stigmatized. Goffman (1963) distinguished between two types of stigma – enacted and felt stigma. Enacted stigma refers to stigma that is experienced first-hand (e.g., actually being rejected by friends), whereas felt stigma describes stigma that is anticipated. In keeping with the epistemological perspective employed in this study, as described in a later section, I have taken the perspective that felt stigma, although perception based, is also socially influenced.

Chronic Illness Challenges in Adolescence and Emerging Adulthood

Illness related challenges may be 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). Taylor et al.’s (2008) classified the major themes that have emerged from research involving young people with chronic illness into seven categories. These seven themes are a reflection of a desire to understand the physical health and/or psychological well-being of young people with a chronic illness. More specifically, they include: (1) *developing and maintaining friendships* (e.g., being with friends engaged in leisure has been found to be the most important aspect of life for young people with a chronic illness by was substantially complicated by the illness) (2) *being normal/getting on with life* (i.e.,

trying to make other aspects of life the focal point rather than illness); (3) *the role of family* (i.e., potentially positive impact when parents' positive attitude towards the illness encouraged youths' positive attitudes, and negative when parents were overprotective); (4) *attitude to treatment* (i.e., youth's perspective on taking medications and related side-effects influenced their physical health. Taking medication became easier to handle when youth learned to establish routines and understood the importance of medication to their health); (5) *experiences of school* (i.e., felt isolated from peers and reported being bullied because of changes to their physical appearance and lack of physical skills, and felt isolated from teachers because of poor academic performance due to absence or a lack of energy needed to study); (6) *relationship with healthcare professionals* (i.e., when youth were treated positively healthcare professionals were a source of emotional support); and (7) *the future* (i.e., thoughts about how their illness would affect their ability to gain employment, move away from home, or have children).

Although each of these themes is supported by previous research, this work typically does not provide a detailed description of what it is like to live with a chronic illness during this period of time, and offers limited theoretical development or identification of potential interrelationships amongst these themes. For example, as Balfe (2009) argued in reference to emerging adults with type 1 diabetes, "although we know that students are concerned about being normal, we do not have a strong idea of what normalcy means for these young people" (p. 129). This identification of limitations in extant research extends to work on adolescents and emerging adults with other chronic illnesses (Hilton et al., 2009; Schneider & Fletcher, 2008; Taylor et al., 2008). To provide more of a theoretical framework, previous research involving adolescents and emerging adults with chronic illness will be discussed in greater detail in the next chapter using the concepts of identity, emotions, leisure and health. Further, little is known

about the impact of having a chronic illness, including the experience of stigma, on involvement in desired activities (i.e., leisure, work, school) and relationships during adolescence (12 to 18) and emerging adulthood (18 to 30) (Note: The term “youth” or “young people” will be used throughout the document to collectively refer to the period of 12 to 30 years old; Cote, 2000). The ability to engage in desired activities and form desirable relationships can be considered an indication of one’s quality of life, warranting the attention of researchers.

Responding to Chronic Illness Related Challenges

Although chronic illness can disrupt identities, relationships, leisure, work and school involvements, and daily routines, people can also find ways of adjusting their daily lives to meet the challenges (if only in part) associated with chronic illness (Charmaz, 1991; Hutchinson, Loy, Kleiber, & Dattilo, 2003; Karp, 1996; Maslow et al., 2011; Parry, 2008; Schneider & Conrad, 1983; Shannon & Shaw, 2005). The idea of *adjustment* is particularly important as extant research involving adolescents and emerging adults with chronic illness has focused heavily on the problematic aspects of illness with limited attention on changes (see Taylor et al., 2008 for a review). Thus there is a need for research that develops an understanding of how and when adolescents and emerging adults make adjustments to their lives when faced with illness related challenges, along with an understanding of positive and negative experiences.

The ways in which people respond to illness-related disruptions (e.g., physical, social, emotional) can have significant effects on their well-being. Although physiological changes differ amongst various illnesses, psychological adaptation processes have been shown to be similar (Cassileth et al., 1984; Pollock, Christian, & Sands, 1990), suggesting that research related to illness coping and well-being has implications beyond one particular illness. However, most research on chronic illness has been illness-specific, making it difficult to directly compare

experiences across illnesses and identify any “generic” aspects (Prus, 1996a) of illness experiences. For example, viewing disease in a positive manner can be an extremely powerful coping mechanism, and ultimately lead to self-enhancement (Frank, 1991). Further, when positive possibilities are embraced, the development of new and deeper meanings of relationships between body and self can result (Charmaz, 1995).

In a related area of research, Pennebaker and colleagues (e.g., Pennebaker & Beall, 1986; Pennebaker & Susman, 1988) demonstrated how revealing the occurrence of traumatic experiences (e.g., childhood abuse, losing a job) often has a positive effect on health and well-being. Pennebaker and Keough (1999) theorized that when people write or talk about their traumatic experiences they engage in self-repair and self-rebuilding. They suggested that traumatic experiences are a direct threat to people’s identities, and the disclosure process is a way of renegotiating identities by working the experience into a coherent narrative or life story. However, as Pennebaker and Keough acknowledged, “talking with others is not always possible or positive. Talking to close friends after an upheaval can place great strain on the social network. Because of this, people rely on a variety of strategies and institutions to help them deal with traumas and to rebuild their selves” (p. 117). Conversely, findings from other studies suggest that although psychological well-being may result from disclosing disease, the benefits may be contextual (Gray, Fitch, Phillips, Labrecque, & Fergus, 2000; Hilton et al., 2009). Thus, further research is needed to understand the situations and contexts in which people reveal and discuss illness as a way of rebuilding their identities.

Charmaz (1983) found that differences in how people define the impact of the illness on their lives may be related to the stage of a disease. In her study of people living with chronic illness, participants who were currently suffering from the effects of their illness used a

“language of loss” to describe their experiences. Participants in remission or at a stage of improved health, however, viewed their “earlier suffering as a path to knowledge and self-discovery” (p. 191). Similarly, Mohr et al. (1999) found that people living with multiple sclerosis (MS) tended to respond in one of three ways. They categorized the effects of the illness as demoralization (i.e., distress, helplessness, subjective incompetence, loss of self-esteem, and alienation), deterioration in relationships (i.e., a sense of inadequacy in relationships), and benefit-finding (i.e., deepening of relationships with others, an increased appreciation for life, increased focus on spirituality). However, Mohr et al. provided little direction as to the factors that contributed to experiencing MS in these different ways. Further, very limited research has been conducted linking these types of states to their impact on leisure behaviours and experiences and related constraint negotiation strategies (Kleiber, Nimrod, & Hutchinson, 2011).

Thus, there is a need to understand the adjustments people make to illness challenges within the context of the way in which their illnesses develop over time, such as before people find out they have an illness, after diagnosis, during the present, and as people look to the future (Charmaz, 1991; Karp, 1996; Ohman, Soderberg, & Lundman, 2003). The importance of this historical process also points to the need to understand how adolescents and emerging adults come to adopt a particular lifestyle. Additionally, taking a personal historical view may help understand the ebbs and flows of experiences associated with chronic illness. As Charmaz (1995) explained,

as ill people go through and emerge from crises, complications, and flare-ups, they also reenter mundane adult worlds. Meanings gained through experiencing surrender may fade and recede into the past. Yet these meanings and their accompanying feelings may be reawakened and remembered when illness progresses and health again fails (p. 674).

However, Kleiber (1999) and Snelgrove and Havitz (2010) noted that frequently used cross-sectional studies examining people’s personal histories have not produced as clear a picture as

desired with respect to leisure behaviour patterns over the life course. These difficulties suggest that cross-sectional designs may not create a full understanding of the dynamic processes suggested by Charmaz (1995). Thus, research designs that incorporate strategies to examine the longitudinal aspects of leisure and health experiences, either prospectively or retrospectively are needed. Specifically, a comprehensive and coherent examination is needed that considers the illness-related challenges faced by adolescents and emerging adults, along with the adjustments they make to their lifestyles. Of course, these adjustments occur in a social world and an understanding of others' involvement, particularly family and friends, in the adjustment process is important to representing a reasonably complete picture.

Identity, Emotions and Activities

As research suggests, people's identities and emotions influence and are influenced by experiences in leisure, school and work activities (Fine, 1993; Prus, 1996; Sandstrom, Martin, & Fine, 2010), consequently, they also are potentially useful concepts to consider in developing an understanding of the experiences of adolescents and emerging adults with chronic illness. Illness, much like class, gender, and race, is a marker of social difference (Frank, 1991; Lather & Smithies, 1997). Among other things, social difference shapes the perceived availability or appropriateness of certain forms of leisure (Appiah, 2000; Becker, 1963), and one's social circle of friends (Prus, Dietz, & Shaffir, 1997). This view of social difference suggests that some people are often both "outsiders" and "insiders" (Becker, 1963; Prus & Irini, 1980; Sherif & Sherif, 1964). The effects of social difference may be particularly salient in adolescence, as peer influence is strong, and cliques are common (Adler & Adler, 1998). Whereas research on illness experiences in adolescence and emerging adulthood has highlighted social exclusion, it has not adequately addressed how, if at all, youth with illness connect with similar others or successfully

integrate with peers who do not have an illness. Similarly, it is unclear how, and in what contexts, leisure helps or hinders the development of relationships for this group. Research on adults with illness has shown that leisure-based social groups provide benefits by creating an opportunity to connect with similar others (e.g., Glover & Parry, 2009; Hutchinson et al., 2003; Parry, 2008). However, only limited research has examined the experiences of youth with illness who participate in organized recreation settings (e.g., Bluebond-Langner, Perkel, Goertzel, Nelson, & McGeary, 1990; Thomas, & Gaslin, 2001), and no work has been conducted examining less formally organized leisure contexts.

Understanding the specific forms of leisure in which adolescents with illness engage, and the meanings they attach to them, is important for two main reasons. First, socially based leisure can be psychologically beneficial as social relationships can help adolescents with illness manage the stress associated with the illness (Abrams, Hazen, & Penson, 2007). Second, although private or solitary leisure may be psychologically beneficial as a stress reduction technique, too much isolation can be psychologically harmful (Larson & Richards, 1994). Further, previous research shows that adults sometimes participate in leisure that is not culturally sanctioned as a way of purposefully resisting the labels that others ascribe to them (Dionigi, 2002; Green, 1998; Shaw, 2001); yet, it is not known whether adolescents use leisure similarly.

Potential negative consequences of illness also mean that some people are reluctant to reveal an illness, resulting in a controlled form of behaviour (Lather & Smithies, 1997; Quinn, 2006; Richards, 2008; Robinson, 1993). Karp (1996) suggested that “in the cases of both creating and disengaging from relationships, people are normally very careful not to make public announcements until they are certain they are ready to adopt new statuses and identities” (p. 62). While Karp’s point is important, the situational nature of revealing illness, possible

stigmatization and the impact on people's identities should also be acknowledged. People do not always reveal illness to everyone or in all contexts (Hilton et al., 2009). Rather, people are selective, necessitating a focus on the situational aspects of concealing or revealing illness. Concealing illness, a form of impression management, is particularly possible in cases of concealable chronic disease because the illness is not readily apparent to others (Goffman, 1963; Joachim & Acorn, 2000). Further, the desire to hide illness may be especially salient during adolescence and emerging adulthood because of heightened social pressures towards appearing normal and cultural associations between youth and health (Hilton et al., 2009).

Persons with illness may also engage in impression management through the control of emotions (Schneider & Conrad, 1983). That is, social situations may influence persons with illness to sustain the appearance that "everything is going to be alright," and feel obligated to appear "optimistic," "courageous," and "cheerful" (Frank, 1991). Further, Karp (1996) argued that "one of the strongest norms surrounding illness experience is the expectation that the sick person 'work' diligently at living as normal a life as possible. Even people who are literally dying from chronic diseases are expected to minimize the extent to which they are a burden on others and do whatever they can to normalize their circumstance" (p. 106). The process involved in presenting expected emotions has been called "emotion work" (Hochschild, 1983).

Controlling emotions can also aid in maintaining relationships with others by not negatively impacting others' moods (Karp, 1996). However, it remains unclear as to the emotional or social costs of engaging in emotion work for young people with chronic illness.

Conversely, expressing emotions can be positive when it signals to others that a person is temporarily unavailable for social engagement or if it helps explain the intensity of one's feelings (Karp, 1996). Indeed, the inability to express "what is happening to oneself" to others who do

not have illness is a widespread challenge. Similarly, Frank (1991) called for persons with illness to openly discuss their illness experiences and related emotions as a way of changing public stigmas attached to illness. Although well intentioned, Frank did not acknowledge that relationships can become strained when emotional exchanges between people over-time are one-sided (Charmaz, 1991; Clark, 1987, 1997). Thus, both the potentially positive and negative aspects of emotional control and expression should be considered.

Leisure is often framed in terms of its ability to influence positive emotions and reduce or buffer negative ones (Iwasaki & Mannell, 2000). For example, engagement in leisure can serve as a way of easing transitions faced when dealing with new illness diagnoses by maintaining emotional connections to past identities (Kleiber, Hutchinson, & Williams, 2002; Hutchison et al., 2003) or constructing settings that allow for emotional expression (Parry, 2008). Similarly, Karp (1996) found that adults with depression pursued leisure activities to avoid negative feelings associated with the illness. Indeed, young people make leisure choices based on potential emotional outcomes (Larson & Richards, 1994).

However, little research has been reported examining how this “emotion work” disrupts adolescents’ (Fine, 2001), or even adults’ (Fullagar, 2008), abilities to enjoy and benefit from leisure. Similarly, it is not known whether certain contexts (e.g., leisure, school, work) have greater potential for promoting emotion work, and whether activity choices are made based on the perceived ability to facilitate emotion work. Imagining “generalized others” (Mead, 1934) engaged in various activities can also act as reference points for how one should feel as people compare their experiences with those of others and notice differences such as a lack of joy or ability to pursue a certain activity (Karp, 1996). In sum, it appears that identities and emotions are useful concepts for understanding the activities of young people living with a chronic illness.

Epistemological Perspective and Purpose of Study

This study takes the view that an analysis of young people's experiences with chronic illness in everyday life would benefit from the adoption of an epistemological and methodological perspective sensitive to the interpretive and interactive aspects of human life. It has been argued that symbolic interactionism (SI; Blumer, 1969) is one such perspective (Charmaz, 2008). Through a symbolic interactionist perspective young people are viewed as being capable of simultaneously directing their own lives and impacting others' lives through an interpretive, strategic process (Fine, 2004a). Although this perspective, particularly during adolescence, is increasingly being adopted by researchers (Fine, 2001, 2004a; Howarth, 2002; Oransky & Marecek, 2009), traditionally developmental theories that view adolescents and their transition to young adults as being passively socialized and influenced by social pressures and cultural messages that directly produce some attitudinal or behavioural effect, have dominated the literature (Chu, 2004). With such developmental or structural approaches, adolescents are viewed by some theorists and researchers as being "lost" and in need of help with little evidence of agency (Oransky & Marecek, 2009). Research on emerging adulthood is still relatively limited since Arnett's (2000, 2004) seminal statement on this time period, however researchers have varied in their treatment of this group in terms of agency. Nevertheless, symbolic interactionism emphasizes the need to develop an understanding of adolescents' and emerging adults' activities and experiences within their given social worlds to remain sensitive to localized meanings (Charmaz, 2008; Prus, 1996a).

To date, research investigating the lived experiences of chronic illness in adolescence and emerging adulthood is scant (Hilton et al., 2009; Taylor et al., 2008). Further, much of the work that has been conducted lacks in its (a) epistemological and theoretical bases and development,

(b) contextual description of experiences, and (c) understanding of social processes. Thus, this study seeks to develop an understanding of the lived experiences of adolescents and emerging adults with chronic illness. Specifically, this study addresses the over-arching question: *how and when can chronic illness become a problem for young people in their everyday lives (i.e., leisure, relationships, school and work) and what types of adjustments are made as a result?*

To develop an understanding of the recent and personal historical experiences of young people living with a chronic illness, it was deemed beneficial to recruit and interview participants who were emerging adults so that they could reflect on changes over time. Although retrospective methods are subject to memory concerns, recall tends to be significantly higher when discussions focus on an area that is personally meaningful such as chronic illness and open-ended approaches are used that encourage participants to only discuss what they remember (Snelgrove & Havitz, 2010). Although adolescents and emerging adults may differ in the importance they place on certain areas of life, they still share the goal of developing an identity – whether through leisure, relationships, school or work (Arnett, 2004; Erikson, 1963; Kleiber, 1999; McAdams, 1993). Thus, as the experience of chronic illness may involve both generic elements that cut across all ages as well as specific features tied to age, recruiting participants who have experienced chronic illness in adolescence and/or emerging adulthood may capture both generic and unique processes. Further, these two time periods may not be as “bounded” as described by some researchers since young people often draw upon a “cultural toolkit” that allows them to act both younger and older than their age category suggests depending upon the situation (Fine, 2004).

CHAPTER II: REVIEW OF RELATED LITERATURE

As previously indicated the concepts of identity and emotions are potentially valuable lenses through which an understanding of the lived experience of chronic illness for young people may be developed. Thus, the following chapter describes the theoretical underpinnings of these concepts as addressed in social psychological literature, and integrates related research on young people and what is known about the influence of leisure and illness in particular.

Identity

The concept of identity has received considerable attention in symbolic interactionist research (Sandstrom et al., 2010). Despite various conceptualizations amongst interactionists, all “agree that self is not an object that has inherent meaning, but is a construct that is given meaning through an actor’s choices, mediated by the relationships, situations, and cultures in which she or he is embedded” (Fine, 1993, p. 78). Mead’s (1934) work on selves has been highly influential in interactionist thought. Through Mead’s “generalized other” concept, he constructed a foundation for “active internalization” and “dialogic selves” in which individuals actively construct images of selves and appropriate behaviours. Although the social and cultural shape self, great variation exists. As Holland and Lachicotte (2007) argued, “people have to create selves that ... inhabit the (social) structures and spaces (cultural imaginaries) that collectivities create, but they produce selves that inhabit these structures and imaginaries in creative, variant, and often oppositional, ways” (p. 135). However, a person’s willingness to construct an “oppositional” self that deviates from the norm may be increased when he/she is supported by similar others (Prus, 1997). Although Mead’s (1934) theorizing was highly attentive to the influence of the social on identity formation, it can be critiqued for its lack of focus on the problematic nature of the social. As Edwards (2007) argued of Mead,

His focus, therefore, was far more on the impact of the social on the individual, than on the potentially problematic nature of the social. The greater danger was that one might find oneself without a social world to call forth one's identity, than that a version of the social might be deemed alienating (pp. 84-85).

Subsequent work by Becker (1963) appears to add a more critical focus. Although Becker's work focused on deviance, it is applicable to any potentially stigmatizing identity and is consistent with symbolic interactionism (Prus, 1996a). Specifically, Becker's work pointed to the need to understand the processes by which "social rules" are developed, transmitted and understood, and their subsequent effect on people's behaviours and involvements in community life. Further, Becker drew attention to the process of labelling or constructing deviations from normality as being the work of "rule creators" and "rule enforcers." Thus, in the case of illness, it may be helpful to know the people who create and/or enforce the social rules surrounding illness as experienced by young people.

With respect to illness being a deviation from normality, illness labels pervade adolescence and adulthood (e.g., Karp, 1996; Lather & Smithies, 1997). In adolescence labelled selves are rooted in peer relationships (Adler & Adler, 1998; Prus, 1996b), and are a key constraint to experiencing a desired life for adolescents and emerging adults with illness (Hilton et al., 2009; Taylor et al., 2008). In most cases, labels are tied to deviances in physical appearance that result from illness (e.g., Balfe, 2009; Drew, 2007; Nicholas et al., 2007; Woodgate, 2005). Physical appearance and attractiveness are important to most young people and those perceived as "less" attractive by peers may have to deal with some negative labelling. However, in the case of illness, labelling is highly prevalent as chronic illness appears to be outside the range of expected deviations experienced by young people. As Abrams et al. (2007) explained people's bodies are mostly evaluated against others in a similar age range. Interestingly, labels given to adolescents with a particular illness by their peers may be derived

from another illness. For example, one adolescent male with inflammatory bowel disease reported being called “cancer boy” because of his thin hair (Nicholas et al., 2007). Similarly, a female adolescent recovering from cancer recounted: “I spent many of my high school days being called ‘Anna’ (slang for anorexia) or ‘baldy’” (Drew, 2007, p. 285). This suggests that people who are uninformed about certain chronic illnesses may draw on their existing knowledge of other illnesses or related conditions. The reactions of others has important consequences for self-esteem, and when adolescents perceive they are being treated differently than they otherwise normally would, they feel less like themselves (Woodgate, 2005).

Self conceptions are also self-imposed as adolescents and emerging adults compare their body with their perceptions of normal bodies, and how others might view them (Balfe, 2009; Drew, 2007; Nicholas et al., 2007; Woodgate, 2005). Although it was initially thought that only downward comparisons would be beneficial to a person, and upward comparisons would be detrimental, this belief has not found subsequent support. For example, interaction with someone who is perceived as less fortunate than oneself (i.e., downward evaluation) can result in either positive (e.g., “I am advantaged over that person”) or negative (“I could become like that person”) assessments (Suls, Martin, & Wheeler, 2002). Similarly, interaction with someone who is considered to be of higher status could lead to either positive (“I could improve to be like that person”) or negative (“I am disadvantaged compared to that person”) evaluations (Suls et al., 2002). Research has shown that some young people with illness see themselves as being like healthy peers (e.g., Harris, 2009; Horne, 1999; Snethen, Broome, Bartels, & Waraday, 2001), whereas in other cases they compare themselves to others with a similar illness (Christian & D’Auria, 1997). However, a limited understanding remains as to the social circumstances that influence one type of comparison over another (Suls, Martin, & Wheeler, 2000).

Identities, Illness and Leisure

Identities can be constructed through involvement in various activities such as leisure, school and work. Leisure activities in particular may allow for greater freedom than other contexts because of the perceived freedom of choice and exploration as compared with other contexts (Mannell & Kleiber, 1997). In terms of illness and leisure, Parry's (2007, 2008) work indicated that some breast cancer survivors found that involvement in dragon boat racing provided an opportunity to achieve identities based on shared connections with other breast cancer survivors. Positive outcomes of group identity were not experienced by all participants however as "a few of the women stated that they would not continue dragon boating indefinitely due to the loss associated with being around other breast cancer survivors" (Parry, 2007, p. 67).

In a study of adolescence, Kivel and Kleiber (2000) found that leisure can be both beneficial to exploring identities related to sexuality and a constraint in terms of acceptance. As one male participant put it, in sports "there's a male atmosphere, when they separate the males from the females, there's such a macho attitude and almost, I don't know, it almost translates into like a violent sex attitude in a way" (p. 224). Similarly, one female described her decision to stop cheerleading by stating, "there were times when I didn't want attention drawn to me because you can only hide so much for so long, and I knew that and then people started to suspect that [she was a lesbian]" (p. 225). Thus in these cases, Kivel and Kleiber concluded that the participants used public leisure as a way of confirming their gay or lesbian identity by rejecting stereotypical notions of heterosexuality, masculinity, and femininity. Further, participants used private leisure (e.g., books, television, films) as a way of constructing selves by "identifying with individual characters who [are] having similar experiences with respect to sexual identity" (p. 227). Thus, the socially acceptable ways of acting within certain communities can involve the

rejection of leisure pursuits that are not considered their own and the acceptance of those that are sanctioned.

Although no specific research has been reported, labels appear to have important consequences for the leisure involvements of young people with illness. Like adults, some young people avoid social situations whereas others try to lead normal lives by spending 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. 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 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). Perceptions of the identity images associated with specific leisure activities and the person's self shape people's leisure choices (Haggard & Williams, 1992; Kleiber, 1999). Young people living with a chronic illness may be no exception. For example, a male adolescent participant who had cancer explained his choice of leisure in reference to his body image:

within popular media, even guys are getting skinny now...So it's interesting...because I'm also in a rock band and I know in rock and roll – tall skinny guys with guitars, that's the image – that's the thing. ... so unless you are a sporty type – you don't have to be big and muscular (Drew, 2007, p. 284)

Freedom to engage in valued activities can have important implications, as suffering 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). Research is needed to further explore the role that labels play in influencing the leisure behaviours of young people with chronic illness.

Emotion Rules and Emotion Work

Social rules shape emotions in everyday life such that people are expected to “manage” negative emotions and maximize positive ones, and remain “even tempered” and “balanced.” The acceptability of emotions is contingent on setting, time, and audience. Hochschild (1983) called these feeling rules, and they force an inner dialogue that seeks a resolution between “What do I feel?” and “What should I feel?” How do people become aware of feeling rules? Hochschild explained that, “we do so by inspecting how we assess our feelings, how other people assess our emotional display, and by sanctions issuing from ourselves and from them” (p. 57). The enforcement of social rules often normalizes emotions and “come into play as forms of ridicule or encouragement that lightly correct feeling and adjust it to convention” (Hochschild, 1983, pp. 58-59). Emotions are also important because people use them to make inferences about others based on their display. That is, emotions provide people with clues about others (Hochschild, 1983). For example, when an athlete is upset over a missed play, it conveys that he/she is “serious” and really wants to win. Conversely, people also make inferences about others, themselves, or the meaning of things based on an absence of emotions.

In an interactionist sense, emotions are treated as social activity rather than as having inherent meaning. Emotions are learned, change, and become enacted based on peoples’ senses of a “generalised other”, and through interpretations of interactions with others in particular situations (Denzin, 1984; Prus, 1996a). Prus (1996a) draws attention to three central processes in emotion work: “(1) learning to define emotional experiences, (2) developing techniques for expressing and controlling emotional experiences, and (3) experiencing emotional episodes and entanglements” (p. 176), each of which have a number of sub-processes that warrant attention. Further, Prus suggested that “beyond learning ways of monitoring, expressing, and controlling

their own emotional states, people generally also learn ways of monitoring, assessing, and influencing (affecting) the emotional states that others around them may experience” (p. 178). While symbolic interactionism draws attention to the social, emotions are also experienced in solitude, some of which may be held private. Leisure may be particularly salient to the study of some forms of solitary emotions as it can take solo and private forms as well as social. Further, private leisure may be particularly important for marginalized adolescents and emerging adults seeking to explore selves and emotions in safe spaces (e.g., Kivel & Kleiber, 2000).

Emotions and identities are intertwined, as labels and reputations normalize particular forms of emotional expression (Denzin, 1985; Fine, 2001; Goffman, 1959). This relationship is particularly true in Goffman’s (1959) dramaturgical metaphor that describes everyday life as a theatrical performance in which individual actors seek to manage the impressions of others by presenting themselves in strategic ways. In doing so, “Goffman riveted readers’ attention to the human capacity for *self-reflectivity* in a much more compelling fashion than did Cooley, Mead, or Blumer” (Prus, 1996a, p. 80). Emotion research that follows in the tradition of Goffman’s (1959) dramaturgical metaphor, seeks to understand emotions as a form of strategic control that is intended to manage the impressions of others. As Fine (1993) explained, “in this view, emotions are learned behavior and controllable, and ‘feeling rules’ exist that determine when and which emotions will be performed” (p. 75). Goffman’s theorizing suggests that there are essentially two selves, one that is presented to others in a strategic manner that seeks to manage impressions and is dependent upon a given situation; and a second self that is hidden from public performance (Manning, 1992).

Goffman distinguished between front-stage activity (i.e., public presentations of self), and back-stage activity (i.e., behind the scenes preparation) that aids in the impression management

process. Extending Goffman's work, Hochschild (1983) further distinguished "surface acting" and "deep acting." In the former, attempts are made to manage impressions by altering outward appearances. People may deceive others but not themselves in surface acting. Hochschild attributed this idea of surface-deep acting to Goffman's theorizing. In deep acting, displays of emotion are automatic expressions that stem from prolonged effort at working on feeling. This type of acting, Hochschild suggested, is more problematic than surface acting when social or institutional pressures shape behaviours, because one may forget how one would have felt otherwise and may be profoundly changed. Through his concept of *self-lodging*, Denzin (1969) suggested that differences between Goffman's two selves may be reduced in the presence of others who are familiar with a person's hidden self. However, Hochschild (1983) argued that the perceived need for emotion work does not disappear when close friends and family are involved. Rather, she suggested, "the deeper the bond, the more emotion work, and the more unconscious we are of it. In the most personal bonds, then, emotion work is likely to be the strongest" (p. 68). For example, a person may be more controlled in the expression of frustration with their children because he/she cares more deeply about his/her children's feelings than those of strangers.

Although Goffman's (1959) theorizing is powerful in understanding face-to-face interaction, it may be incomplete in capturing the dynamics of social experience. That is, although Goffman's theorizing may have trans-contextual applicability because of its focus on face-to-face interaction, it fails to take into account the varied influence of social situations (Blumer, 1972; Prus, 1996a). For example, adolescents with illness may find that certain leisure contexts require less emotion work or evoke different presentations of self than other leisure or non-leisure contexts such as school or home. In sum, when the notion of impression management

is considered along with broad principles of symbolic interactionism, the potential shortcomings of Goffman's approach may be mitigated, while its strengths are retained (Prus, 1996a).

Emotions, Illness and Leisure

Emotions are particularly relevant to the study of illness experiences (Charmaz, 1991; Exley & Letherby, 2001; Frank, 1991). They are also central to much social psychological leisure research as leisure has been found to stimulate positive emotions and reduce or buffer negative ones (e.g., Iwasaki & Mannell, 2000; Kleiber et al., 2002). Emotions take varied forms and the concept of emotion "encompasses a wide variety of affective experiences ranging from shame or embarrassment to frustration, anger, jealousy, fear, hurt, discouragement, discomfort, despondency, and distancing, to composure, intimacy, happiness, pride, love, enjoyment, fascination, enthusiasm, and excitement" (Prus, 1996a, p. 174). The "emotional high" that adolescents frequently cited in Fine's (2001) study of high school debate, suggested positive psychological experiences (e.g., flow; Csikszentmihalyi, 1991) and drove a desire to continue with the leisure pursuit. Interestingly though, the emotion rules associated with debate competitions minimize the positive affect. As Fine explained, "while competition has many virtues as a motivation, it produces an emotional wake. The joy that debaters feel is powerful, but after a brief moment of exultation, they must tame their joy to appear pleased but modest" (p. 107).

Although positive emotions may be commonplace in leisure, negative emotions can also occur. After detailing the nervous feelings and related side-effects that many debaters experience, Fine (2001) concluded that "our bodies may subvert the pleasures that one should take from competition with friends in an activity that one treasures. The social psychology of self-presentation can cause pain in debate and in other venues where evaluation matters for one's

identity” (p. 106). Similar to the feeling rules that limit positive experiences in debate, Fine explained that adolescents who lose competitions,

must cope with their frustrations, but do so in a way that suggests that this outcome that clearly matters, does not really matter. Sadness and frustration must be hidden, and tears must be held back—often a difficult assignment for adolescents, who find their reputations on the line (p. 107).

However, Fine did not address whether this emotion work impacted other aspects of adolescents’ lives (e.g., Hochschild, 1983; Larson & Richards, 1994). Similarly, Adler and Adler (1998) described the hurt young people experienced when they did not qualify for elite sports teams. These negative emotions can have lasting effects and alter leisure involvement. As a female adolescent recalled:

I will never forget how bad I felt when I didn’t make the performing dance company. They called the kids who made it before school one day, and when I got there all my friends had gotten calls except me. I cried and cried. And so now I don’t try out for things I may not make. I never want to feel that way inside again (Adler & Adler, 1998, p. 111).

Peer acceptance and the development of friendships are of high importance in adolescence and emerging adulthood (Arnett, 2004; Hilton et al., 2009; Larson & Richards, 1994). Presenting one’s self strategically through emotional control is prevalent in adolescents’ daily lives, if not well studied by researchers (Fine, 2001). As one adolescent male in Chu’s (2005) study reported,

every time, no matter what you do, you’re always, like, under a microscope . . . you’re always being, like, judged ’cause that’s just, like, how the world is. You’re always being, like, looked at, so no matter what you do, you always have to keep up your guard and worry about . . . what other things are happening around you and what other people think.

Further, keeping guard was considered important because “you don’t want to show any vulnerability ...’cause then, like, it’s such, like, a competitive atmosphere that kids just attack with, if they think you’re vulnerable on it” (Chu, 2005, p. 11). Chu found that although adolescents may deny caring what others think of them, they described modifying their

behaviours to avoid peer rejection and ridicule. Ultimately, Chu concluded that the development of close relationships may suffer because of “the decision to be selective in their self-expression and guarded in their interactions, which involves withholding parts of themselves from relationships” (p. 13). Similarly Larson and Richards (1994) found that time spent with friends was the most frequently employed coping strategy to reduce daily stress resulting from school, their number one stressor. Interestingly, though, a failure to obtain positive reinforcement from friends was found to be the second more common source of negative emotions (Larson & Richards, 1994).

For some adolescents with illnesses, fatigue is commonplace. Limited energy not only reduces a desire to engage in social leisure, it localizes leisure experiences to certain settings such as the family room couch or bedroom (Woodgate, 2005). When young people persist in social leisure it requires extensive emotional work (e.g., Hilton et al., 2009; Woodgate, 2006). Even though they may be physically with others, some young people do not feel connected with those around them. Yet, close friendships and social support have been found to play an important role in shaping positive experiences when dealing with illness in adolescence and emerging adulthood (Abrams et al., 2007; Hilton et al., 2009). As Abrams et al. (2007) explained, “in particular the role of peers has significant implications on an adolescent’s ability to renegotiate their social sphere. Adolescents refer to using them as a ‘peer shield’ as a means of protecting themselves when they are in social situations and feel self-conscious about their appearance” (p. 625). Prus and Grills (2003) concluded similarly in reference to protection from labelling in general. Having a friend to talk to about illness is also beneficial, but can be difficult when others do not have a chronic illness (Christian & D’Auria, 1997). Further, emotion work

contains a unique dimension for those with concealable illnesses, as disclosure is not always pursued (Eklund & Sivberg, 2003; Hilton et al., 2009).

Although the amount of theory development and research on the lived experiences of chronic illness is limited, there is some evidence to suggest that young people's involvement in daily activities and relationships can be understood by considering identities and emotions. As previously noted, a symbolic interactionist perspective seems appropriate to the study of the experiences of adolescents living with chronic illness because of its focus on the interactional and processual aspects of human life (Prus, 1996a). The next chapter details this perspective and related implications for the study's design.

CHAPTER III: RESEARCH DESIGN

The purpose of this study was to address how and when chronic illness can become a problem for young people in their everyday lives (i.e., leisure, relationships, school and work) and to understand the types of adjustments made as a result. This chapter describes the epistemological perspective that guided this research, recruitment procedures, study participants, the interview process and data analysis techniques.

Symbolic Interactionism

As previously noted, this study was guided by an interpretive framework most closely aligned with a SI perspective as articulated by Blumer (1966, 1969), and also related work by Goffman (1959) and Becker (1963). Blumer's (1969) description of SI is summarized in this oft-cited passage:

Symbolic interaction rests in the last analysis of three simple premises. The first premise is that human beings act toward things on the basis of the meanings they have for them... The second premise is that the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows. The third premise is that these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters (p. 2).

In sum, SI draws into focus the processual, interpretive, reflective and inter-subjective nature of human life (Prus, 1996a). Through social interaction and reflectivity, people "fit their own acts to the ongoing acts of one another and guide others in doing so" (Blumer, 1966, p. 538). So, social interaction is more than a venue for personal expression, it is also a site of influence and meaning making (Blumer, 1969). Further, as social issues such as identity, stigma, and deviance are collectively defined, there is a need to understand processes of legitimation and continuance in everyday life (Becker, 1963). Similarly, Blumer (1971) argued that a "social problem exists primarily in terms of how it is defined and conceived in society" (p. 300).

Interactionists typically employ multiple forms of ethnographic methods, such as interviews, participant observations, informal conversations, and document analyses, to facilitate a situated understanding of the lives of those under study (Sandstrom et al., 2010). It is argued that these methods allow for a deeper contextual understanding of lived experiences than may be facilitated through other approaches, such as questionnaires, structured interviews or experimental designs (Blumer, 1969; Charmaz, 2008). The combination of ethnography's focus on rich descriptions and understandings of people's lives and settings, and grounded theory's emphasis on theoretical development, may complement and strengthen each approach (Charmaz & Mitchell, 2001). Grounded theory involves inductive strategies for collecting and analyzing data to build theory that explains the phenomenon under study (Charmaz, 2006). Some ethnographic texts have been critiqued as overly descriptive and a theoretical, whereas some grounded theory studies offer little descriptive, contextual information (Fine, 2003; Stern, 1994). Charmaz and Mitchell (2001) juxtaposed ethnography and grounded theory in writing:

Ethnographers can use description to tell stories, form scenes, describe players and demonstrate actions. Grounded theory works typically reverse this emphasis. Conceptual analysis takes center-stage; stories and scenes and, therefore, individuals play minor parts on the illustrative sidelines. Grounded theorists include snippets of stories and fragments of experience rather than entire narratives. Thus, grounded theory works may sacrifice subtlety and nuance for clarity and explicitness (p. 170).

Attention to writing practices may be particularly important to an integration of ethnography and grounded theory; yet there may often be tradeoffs between thick description and conceptual development. Thus, I attempted to follow the approach Charmaz has taken in her study of chronic illness: "I aimed for a coherent analytic story without sacrificing the richness and diversity of my participants' lives. I wove their stories throughout the narrative yet their stories stand in service of the analytic tale" (Charmaz, 2009, p. 59).

Study Participants

Prior to data collection, University of Waterloo ethics approval was sought and obtained. The university ethics application process required a detailed description of the recruitment procedures, targeted study participants, interview process, and follow-up procedures. All procedures described in the approved ethics application were followed. Notably, the ethics application indicated that participants 16 years old and over would be recruited and therefore parental consent was not required. However, the ethics office indicated that it might be beneficial to suggest that participants 16-18 years of age speak to their parents about their involvement in the research, and that I address any of their parents' questions prior to conducting interviews. Another important concern was the way in which any negative feelings that might arise while discussing sensitive issues during the interviews would be handled. Two steps were taken to deal with this potential concern: (a) a phone number for free counselling services was provided in the information letter, and (b) I remained in contact with any participants that I perceived to be having emotional difficulties dealing with their illness.

Consistent with the approach approved by the University of Waterloo ethics research board, 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. Attempts to reach other illness-based organizations (e.g., Epilepsy York Region, Juvenile Diabetes Foundation of Canada) were not successful. In all cases potential participants were directed to the study website (www.ahs.uwaterloo.ca/~rsnelgro/illness) that discussed the study, their ethical rights as participants, and provided them with my University of Waterloo e-mail address for further contact. Three people e-mailed me for further information about the study, and later declined to participate due a lack of availability due to their schedules. Also,

some people expressed interest in the study but were not interviewed because they did not fit the age requirement. All other participants who contacted me and expressed an interest in participating in the study were interviewed. No compensation was offered or given to participants for their involvement in the study. Ongoing recruitment and interviewing occurred between December 2010 and July 2011.

The final sample of participants in this study consisted of 29 young people each of whom was living with a chronic illness. The illnesses were Crohn's disease (11), ulcerative colitis (4), type 1 diabetes (3), multiple sclerosis (3), epilepsy (2), celiac disease (2), juvenile rheumatoid arthritis (1), fibromyalgia (1), lupus (1) and anaphylaxis (1). A brief description of the physiological characteristics of these illnesses can be found in Appendix E. 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 my preference 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. Specifically, some of the first participants with Crohn's disease referred a number of other participants who also have Crohn's or colitis, whereas participants with other illnesses were less helpful in referring potential participants. My goal was to obtain a sample close to 30 participants in number. Since I was bound by time and a limited budget to spend on advertising, I was not in a position to turn down willing participants while hoping to recruit participants with other illnesses. Over time I sought to obtain representation of under-represented illnesses by actively seeking out further Web pages on which I could post my advertisement. 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 29 study participants, 23 were young women and 6 were young men. After two months of recruitment and interviewing, I recognized the need to obtain more young men. At that point I sought to actively recruit only young men, changing the advertisements I posted online and my messages to previous interviewees and friends. That process resulted in the recruitment of four more young men, and another five young women over the next five months. The age of participants at the time of the interview ranged from 19 to 33 years old. Their age of illness onset ranged from two years old to early twenties, with the majority being in their teenage years when symptoms first appeared. As the focus of the study was to be on the periods of adolescence (12 to 18) and emerging adulthood (19 to 30) my preference was to only recruit participants in their late twenties and early thirties who had their illness for a significant period of time. All of the participants in their late 20s and early 30s had had their illness during their early twenties or earlier.

The majority of participants resided in Ontario at the time of the interview (23), but participants living in Manitoba (2), Newfoundland (2), British Columbia (1), and the United States (1) were also interviewed. The size of the town in which participants resided varied from small to very large. Although not the focus of the study, no notable patterns were recognized in terms of participants' experiences and their geographic location, although the size of the sample and uneven distribution of locations make it difficult to arrive at any firm conclusions. Table 1 provides a profile of participants in terms of pseudonym used, illness type, current age, illness onset age, gender, and type of interview conducted.

Table 1

Summary Description of Study Participants

Pseudonym	Illness Type	Current Age	Illness Onset	Gender	Interview Type
Amy	Crohn's disease	24	9	Female	In-person
Angie	Ulcerative colitis	24	17	Female	In-person
Beth	Multiple sclerosis	32	24	Female	In-person
Bree	Ulcerative colitis	25	16	Female	Phone
Chloe	Ulcerative colitis	20	18	Female	In-person
Elle	Celiac disease	31	19	Female	In-person
Emily	Multiple sclerosis	23	19	Female	In-person
Erin	Crohn's disease	21	16	Female	In-person
George	Anaphylaxis	28	6	Male	In-person
Juliet	Fibromyalgia	28	20	Female	In-person
Kerri	Type 1 diabetes	33	10	Female	Phone
Kristin	Type 1 diabetes	31	3	Female	Phone
Mark	Multiple sclerosis	27	25	Male	In-person
May	Celiac disease	28	1	Female	In-person
Melissa	Crohn's disease	22	18	Female	Electronic
Mimi	Crohn's disease	26	23	Female	In-person
Myra	Type 1 diabetes	21	14	Female	In-person
Patrick	Crohn's disease	28	13	Male	In-person
Rebecca	Epilepsy	25	20	Female	In-person

Regan	Crohn's disease	19	12	Female	Electronic
Sarah	Ulcerative colitis	33	22	Female	In-person
Sheila	Epilepsy	22	3	Female	In-person
Steve	Crohn's disease	25	2	Male	In-person
Tendra	Crohn's disease	27	17	Female	In-person
Tessa	Crohn's disease	25	17	Female	In-person
Vera	Lupus	30	15	Female	In-person
Victoria	Crohn's disease	25	23	Female	Electronic
Will	Crohn's disease	28	17	Male	In-person
Zach	Juvenile Rheumatoid Arthritis	33	15	Male	In-person

Interviews

Although ethnographers typically prefer to compliment interviews with observation in a particular setting, Charmaz (1990) argued that it is difficult to study chronic illness through traditional ethnographic methods that involve full immersion in a setting. As she suggested, “interviewing works well in studies of chronic illness since the researcher often wants to obtain detailed individual chronicles. In addition, participant observation may be impossible for certain types of research problems in this area” (p. 1167). Although some recreation settings have emerged that bring together adolescents with a particular illness, they remain relatively limited in number and only accessible in the summer months. Thus, few “natural” settings exist to observe young people with chronic illness in a reasonably accessible and unobtrusive manner. However, I consider this doctoral research project as the beginning of a larger research program in which observation will be incorporated in the future to further develop theoretical understandings of

illness experiences. To allow participants to be involved in the study in a way that met their comfort level and geographic location (e.g., those participants living in the United States, Manitoba, Newfoundland, and British Columbia) three types of interviews were conducted. Although participants were asked to participate in a face-to-face interview, a few participants requested phone interviews (two participants) and electronic interviews (three participants), while the remainder agreed to in-person interviews (24 participants). Initial face-to-face and phone interviews lasted between 45 and 120 minutes, with the majority lasting well over an hour. 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 after I indicated my willingness to meet them anywhere that was convenient for them. Most typically interviews were conducted in coffee shops but some also occurred in people's homes as well as sitting areas at universities and hospitals.

My goal for the face-to-face and phone interviews was for them to be a directed conversation (Lofland & Lofland, 1984), in which participants were able to influence the topics of discussion based on salient experiences. Although I did not use an interview guide, I did have broad areas of interest that I hoped to explore, including how having an illness had impacted participants' relationships with friends and family, their use of free time, their pursuit of school, and their early work life if applicable. These broad areas of interest served as the probes when discussion of them did not arise in the general flow of the conversation. For example, I might have asked "tell me about how having a chronic illness impacted your family life in the beginning, if at all?" If needed, a follow-up question was, "how did that change as you got older?" The most common probe used was to ask participants for specific examples of when a certain experience they were discussing in the abstract happened (e.g., "can you think of a time

when that happened?”). Following advice from Prus (1996a), it was anticipated that an understanding of identities, emotions, and perspectives would naturally fall out of participants’ stories when talking about leisure, school, and work activities and relationships. I was also interested in positive and negative experiences and how things may have changed over time. As a result of my interest in exploring adjustments (i.e., changes over time), I had to ask people to reflect on past experiences as they developed over time in addition to the present time. Thus, as a way of stimulating recall (Prus, 1997; Snelgrove & Havitz, 2010), a few weeks prior to the interviews I sent participants a reminder e-mail indicating my interest in discussing how having a chronic illness impacted, if at all, relationships, free time, school and work.

I 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. As such, and as I mentioned above, I did not use an interview guide. 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 me back to their earliest memory of when they first noticed their health had changed and to describe what happened (e.g., Karp, 1994). Interviews then followed from participants’ initial descriptions of these early experiences. With many participants issues of interest related to involvements and experiences with relationships, 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 on my behalf which then typically restarted the flow of the conversation. In a few cases, participants seemed to feel more

comfortable with me leading the conversation by asking questions more frequently than with other participants.

Although responses to various questions ranged in depth, participants rarely declined to answer any questions. In fact, most participants were willing to share what could be considered the more intimate details of their lives. The only time a line of questioning was left underexplored was when participants appeared visibly upset by the memory associated with the question and they said it was too difficult to discuss. In a few cases, participants cried, or were about to cry, during emotionally difficult descriptions of experiences, such as friends and family who left them or a discussion of current or past desires to commit suicide. However, I did not make the assumption that just because they expressed emotions that they would not want to continue talking about a particular topic. As the interviews tended to be more of a conversation, it was mostly left to the participant to decide whether they would continue their responses. Minimizing discomfort was of importance, and I took direction from Charmaz (2009) in this regard. As she recalled:

I had decided long before embarking on my study that minimizing my participants' discomfort took precedence over asking intrusive questions to obtain compelling data. Talking about having a serious illness and facing uncertainty can evoke participants' unanticipated realizations and unstated ruminations. Interviewing in this area may proceed on shaky grounds (p. 52).

As can be the case with everyday conversations, the tone and rhythm tended to match the situation. For example, follow-up questions to responses delivered cautiously and emotionally were met with equal measure, as were more light-hearted moments.

To end the interviews, I asked all participants if anything positive had come out of having their particular illness with the hope that it would end the interview on a positive note. In all cases, even with those who had just finished discussing challenging or negative experiences,

participants seemed to embrace the question as it was often met with a smile. Many participants remarked that they thought it was a “good question” or not one they had thought of before. The majority of people were able to respond with at least one answer to the question and it seemed to help end the interview positively. Following the interviews, and even though I had recorded them, I took notes of issues that had been raised during the interviews as a way of remembering major themes that seemed to be unfolding in participants’ stories. This exercise was particularly useful as I conducted more interviews and sought to develop some of the themes in more detail by asking new participants about issues raised by others.

The three electronic interviews were approached somewhat differently than the face-to-face and phone interviews. That is, an initial list of questions was developed for these participants with the explanation that any or all questions may be answered. Participants were also given the opportunity to describe illness related experiences not covered by the written questions. Following initial responses by electronic participants, follow-up questions were sent below the initial response to each question, which were then answered and returned by the participants. The length of the electronic transcripts approximated a 45-minute length interview. Although the answers to most electronic questions were not as long as most of the verbal interviews, and therefore less detailed, I decided that they would be better to employ if it meant that participants would otherwise not take part in the study. I felt that not including people who preferred not to be interviewed on the phone or in person might risk excluding certain experiences. Although only a small number of participants (three) chose to be interviewed electronically, there were no notable differences in their experiences with chronic illness when compared with other participants.

Following the interviews many participants expressed a number of positive feelings about being involved in the interview process. These participants thanked me for allowing them to be involved and many remarked at how they had not talked about their illness experiences to that degree with anyone before. Below are two electronic messages I received that are representative of many others:

It was great to have the opportunity to speak more about the social aspects of Crohn's. I never have done this before - or not to the extent that I had with you. It gave me great insight actually - so thank you for the opportunity and reaching out to me. (Amy, Crohn's disease)

Thanks for a great interview today. It was really nice to meet you. Had a couple thoughts this afternoon after you left. First, I was exhausted when I got back home! LOL. I realized I have never spoken so openly to someone I didn't know about my experiences with Lupus. With my Mom and brother, I always try to be optimistic about my condition, especially when I am having a flare, as challenging as the flare may be. I guess I try to reassure them that I'll be okay by putting on a brave face. With [my husband], I'm a little more open about how I am actually feeling, but still with an optimistic or humorous spin. I've never actually spoken to ANYONE about how I've felt about having lupus, what those experiences with flares were really like, and particularly what my fears are. Even with my rheumatologist. So, thanks for that. It feels great to have articulated my thoughts and now as I sit here and think about them, it motivates me even more to maintain my health and balance my work, life, rest balance so that I can avoid having to live out those fears. (Vera, lupus)

Interviews in an Area of Personal Experience

Conducting research in areas in which a researcher has personal experience draws attention to the need for reflexivity. My personal experience with chronic illness provided a lens for observing and developing understanding and theory. Consequently, it was not my intention to eliminate opportunities for insight in the name of objectivity (see Dupuis, 1999). Rather, I attempted to use my personal experiences as a way of relating to participants, crafting questions in a sensitive manner, and developing questions that I hoped to be of relevance to the research participants (Etherington, 2004). It seemed to help in the recruitment process that I was able to say that I had a chronic illness. My experience also helped me build rapport with the study

participants during interviews. Although all participants would have known that I have ulcerative colitis after reading the information letter on my study website (See Appendix A), I reminded them of this at the beginning of each interview when discussing how I came to be interested in studying chronic illness experiences. When asking questions, I drew on some of my experiences when framing questions, particularly when I perceived the topic to be potentially sensitive. In some cases starting off with an example of how I experienced a situation worked effectively, when for example asking about taking medications and related side effects (e.g., “When I took prednisone it really affected how I looked and acted, how did it affect you if at all?”; “When I was sick I lost a lot of weight and it affected how I thought of my body and how I acted when I was around others in settings that emphasized the body like playing sports, have you ever experienced something like that?”). Sometimes, participants would reply that they did not experience things the way I had and would then explain their experiences. In either case, reflecting on my experiences served as a way of developing questions.

Participants who at first seemed unsure about discussing experiences with a stranger seemed more comfortable after I shared some of my own experiences. At times I would share experiences when I read discomfort or as a way of introducing a question that may be met with some trepidation. It is also possible that just knowing that I could empathize with their experiences in some way and that I also had difficult stories to tell, even if left untold, may have increased participants’ willingness to talk. In all cases I asked participants at the end of the interview if they had any questions for me. Many participants were interested in knowing about some of my experiences with illness, and so I answered any questions at that time. Although I wanted to leverage my experiences where applicable, I wanted to ensure that the study reflected participants own experiences rather than mine. Thus, I considered it important to attend to

participants' own verbalized meanings and explanations in an open manner during data collection and analysis with the hope that it would help my findings stay true to their experiences (Charmaz, 2009).

Data Analysis

I first transcribed the face-to-face and phone interviews to facilitate the data analysis process. Data analysis followed a type of inductive analytic approach known as grounded theory (Charmaz, 2000, 2006). Grounded theory analysis first begins with initial coding. 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. Initial coding 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. Two examples of initial coding are presented in the below table.

Initial codes	Excerpt
Being misunderstood Experiencing rejection Defining expectations of relationships Responding to rejection	Excerpt from interview with Regan (Crohn's disease) "Some families that I baby-sat for thought that I was contagious until I explained about the disease. I was systemically discriminated against by my dance school at the time. I was intentionally given awful roles in a ballet, and when I asked why I was told that it was because of my Crohn's. This severely isolated me from my peers and was a very difficult time. ... I had been dancing since I was 2 years old and it would have been the last place I would have expected it to take place. I felt stupid and unworthy, but I did go ahead and dance because I didn't want them to win. I deeply hated going and it was traumatic each time."
Anticipating rejection Defining others' expectations	Excerpt from interview with Rebecca (epilepsy) "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 they 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 they think I should just be inside the house."

Table 2: Samples of Initial Coding Process

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). Continuing with the above examples, social rejection appeared to be a common element amongst excerpts. However, further consideration and comparison with other codes lead me to make a distinction based on a more conceptually appropriate coding scheme. Specifically, the first excerpt was used to develop a theme of “understanding illness,” with responses to that misunderstanding noted. The second excerpt became a part of “sustaining public appearances” with social withdrawal noted as a behavioural response. Last, theoretical coding was undertaken.

This final stage of coding allowed me to develop a coherent analytic story by relating and integrating focused codes (Glaser, 1978). In this stage, codes such as “understanding illness,” “affecting others” and “connecting with similar others” were brought together as they collectively represented the process of “experiencing relationships.” Finally, an overarching theme was developed to collectively represent the analytic story of participants’ experiences as described in the three themes. The term “achieving identity” was that unifying theme.

After major themes were developed, I continually refined each section to add clarity to the analysis and selected the quotations that best exemplified the process or sub-process being described. There were almost always many quotations to choose from for a particular sub-process. In cases where sub-processes were underdeveloped or supported they were dropped from the final findings section. Throughout the analysis I attempted to remain focused on my overall research question to give coherence to the analysis. As I progressed, I evaluated how often I was using particular participants’ quotations over others, and readjusted a few of the selected quotations to increase the balance amongst participants’ voices (Karp, 1996). Where possible this balance involved incorporating different illnesses and genders.

When coding the data and carrying out the analysis, I tried to accurately reflect and capture the participants’ individual verbalized experiences, so that I could develop a broader understanding of illness experiences beyond my own. I also attempted to assess whether my own experiences were represented in some way within the findings and if my experiences with chronic illness shaped my perceptions and interpretations. After careful consideration, I concluded that I did share a number of similar experiences with the study participants. However, the broad range of experiences with chronic illness represented in this study added insights beyond those that would have emerged if I had done autobiographical work. Also, while my

own experiences clearly sensitized me to the issues discussed by the study participants, and perhaps made it easier to understand what they were saying, I felt that a researcher who had not experienced chronic illness during adolescence and emerging adulthood would ultimately report similar findings. However, it is important to note, and as Charmaz (2006) argued, we as researchers still construct the codes and themes and thus at some level my own experiences could have unknowingly influenced the data analysis process. As discussed in the next section, a number of steps were undertaken to establish trustworthiness in the research process as I sought to develop an understanding of chronic illness experiences during adolescence and emerging adulthood.

Establishing Trustworthiness

Following a symbolic interactionist perspective, the establishment of trustworthiness was conducted in accordance with criteria established by Lincoln and Guba (1985) and Wallendorf and Belk (1989). These authors' criteria and suggestions are well cited in interactionist research. 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. Following direction from Wallendorf and Belk, 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. The issue of transferability was addressed by interviewing participants with a range of chronic illnesses. Doing so facilitated an analysis of the “generic social processes” (Blumer, 1969; Prus, 1996a) that would not have been directly possible by interviewing participants with only one chronic illness.

Third, dependability refers to the replicability of study findings. Although idiosyncrasies persist to some degree in much interpretive research (Charmaz, 2006), the extent to which findings are connected or consistent with extant theory in the symbolic interactionist tradition provides some indication of dependability. Establishing dependability by actually replicating a particular study may not always be possible as the willingness of study participants to share experiences may be contingent on establishing trust and rapport with the researchers. In this particular study, my having a chronic illness may have facilitated that trust and rapport in a way that some other researchers may not be able to fully achieve, which might be a challenge to replicability. Wallendorf and Belk also suggested that approaching a study longitudinally can help remove the cross-sectional bias often found in social science research – a challenge to dependability. As I asked questions that focused on both the past and present, I was able to understand more fully the experience of living with a chronic illness. 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 I used an extensive number of quotations 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 my description and summary and of the findings.

The Role of a Symbolic Interactionist Perspective in the Research Process

Finally, before turning to the analyses and findings, it is important to identify the ways in which adopting a symbolic interactionist perspective informed the data collection and my analysis, including sensitizing me to specific social processes at work. In the data collection and analysis phases, I drew on advice provided by Prus (1996, pp. 18-19). He argued that there are at least seven main implications that accompany the use of a symbolic interactionist perspective and to which researchers should attend. First, researchers should consider “the intersubjective nature of human behavior.” In the present study, this statement refers to the idea that chronic illness experiences are socially constructed rather than individually derived or predetermined due to the medical aspects of the illness. Thus, questions and analyses focused on social interaction and meanings derived from those interactions. Second and third, researchers should consider “the viewpoints of those whose worlds they purport to examine” and attend to “the interpretations or meanings that people attach to themselves, other people, and other objects of their experiences.” These considerations were addressed by interviewing participants to obtain their viewpoints on the ways in which their lives were impacted by a chronic illness, and represented using extensive quotations.

The fourth consideration suggested by Prus concerns “the ways in which people do things on both a solitary and interactive basis”. I addressed this point by not only exploring the ways in which chronic illness experiences were shaped through interaction with others, including resulting adjustments and changes in perspectives, but also how chronic illness influenced more private behaviours not in the immediate view of others. Fifth, Prus suggested that researchers

consider “the attempts that people make to influence (as well as accommodate and resist the inputs and behaviors of) others.” This suggestion was addressed by seeking to understand how people’s self-definitions were influenced by others, how the feedback they received might have been resisted, and the types of adjustments they made as a result of challenges they faced. Sixth, “the bonds that people develop with others over time and the ways in which they attend to these relationships” need to be considered. This suggestion led me to focus on questions related to the ways in which relationships were impacted by or formed out of experience with a chronic illness. Last, Prus suggested the need to attend to “the processes, natural histories or sequences of encounters, exchanges, and events that people develop and experience over time.” This strategy in particular shaped the interviews and my concern for how events, experiences, relationships and perspectives had changed over time. It focused my analysis in a way that forced a consideration of whether certain themes (or sub-themes) had sequential or evolving elements.

CHAPTER IV: FINDINGS

The analysis of participants' interview responses was guided by the central research question addressed by the dissertation: how and when does chronic illness become a problem for young people in their everyday lives (i.e., leisure, relationships, school and work) and what types of adjustments are made as a result? Further, the analyses that lead to the construction of the central theme and the sub-themes were shaped by the theoretical perspective adopted in this study – symbolic interactionism. More specifically, the seven implications of symbolic interactionism described by Prus (1996a) were considered including a focus on social interaction and solitary behaviours, socially derived meanings of illness and illness experiences, variations in illness experiences, instances of influence and resistance in shaping identity and behaviours, the formation and maintenance of relationships, and how illness experiences unfolded over time.

The findings clearly suggest that chronic illness threatens young people's ability to fit into their social world. This challenge occurs in subtle and overt ways and elicits a variety of responses, which are described and delineated in the following three sections labelled (a) managing appearances and reputations, (b) accomplishing activities, and (c) experiencing relationships. The themes and sub-themes discussed are intended to tell an analytic story that represents the range of study participants' experiences. For the most part themes are representative of the majority of participants' experiences, with variations being explained primarily by the adjustments undertaken. Where found, themes applicable to only a minority of participants are identified. No notable differences were found across illnesses or based on gender, age, and age of illness onset, although the sample size and distribution of illnesses may have made it difficult to identify patterns related to these differences. Consequently, the findings do not rule out that these types of "variables" may have explanatory power. Future research may

help clarify the ways in which some of these variables help explain variations in illness experiences. Thus, the following analysis focuses on the generic social processes (Blumer, 1969; Prus, 1987, 1996) involved in youth's lived experiences with chronic illness.

MANAGING APPEARANCES AND REPUTATIONS

Appearance-related expectations relative to one's age and gender can make it difficult to fit-in for many people. Chronic illness intensifies the challenge when it creates issues related to how one looks and acts, and contributes to unwanted reputations tied to illness. This section describes how physical and behavioural public appearances and illness reputations have implications for relationships, leisure involvements and enjoyments, and self-esteem. The sources of these pressures and resulting adjustments are also described.

Physical Appearances

Deviations in physical appearance are tied to disease symptoms and medications for young people with illness. As described below, challenges associated with perceptions of physical appearance have implications for romantic relationships, engagement in leisure, and self-esteem.

Treatments that involve taking medications which promote weight gain cause significant challenges for young people. Substantial weight gain rarely goes unnoticed by friends and family. Chloe discussed her use of prednisone for ulcerative colitis, and explained how she "hated getting fat" because friends would say things like "oh your face, you look like a little chipmunk." Other young people, such as Amy recounted similar comments from friends such as "looking pudgy" or "pudgy cheeks." Increased weight breeds self-consciousness particularly when it cannot be hidden. As Amy explained, "it was the moon face that you couldn't hide. I was very self-conscious, and I think too it made me so self-critical. I didn't quite like the way I

looked, and I think I even carry that on to today.” Amy’s self-consciousness about her weight also stemmed from a disconnection between the ideal image of a personal trainer, her job at the time, and her appearance.

The bloating too wasn’t fun throughout high school. Even today I think the worry about it is heightened because when I am training clients, I’m thinking “OK do I really look like a personal trainer?” I’m so self-conscious of that. When I’m feeling bloated it can look like I’m carrying fat. I can notice when people look and it’s not always the easiest thing to hide. (Amy, Crohn’s disease)

Negative feelings associated with weight are further exacerbated when friends and family seem to suggest that the weight gain is controllable. Chloe recounted, “my dad was always like ‘you’re so fat. Why don’t you lose weight?’ I [felt] so awful. It just wouldn’t go away.” As offending medications are reduced or eliminated, and weight gain subsides, others offer previously withheld comments on the improvement of ill people’s appearances, confirming suspicions about unspoken impressions of one’s appearance. “It really just makes you feel like, ‘I look slightly less fat to you than usual?’ It almost doesn’t feel like a compliment because you’re so self-conscious about it, it changes the way you feel” (Juliet, Fibromyalgia).

In other cases, perceptions of one’s ability to achieve the ideal appearance of a young woman or man make it difficult to feel as though one fits-in. Sarah views her disease, ulcerative colitis, which causes symptoms such as bloating, gas, and diarrhea as not being compatible with how a woman should be viewed. She described colitis as not being “a very attractive disease,” which is important to her because, as she suggested, “as a woman you want to be viewed in a certain light and that’s not the light you want to be viewed in.” Similarly, recalling the significant weight loss she sustained while in a flare, Sarah said “I was walking around with my little IV pole and I remember just crying my eyes out because I could see the bones in my wrist. I didn’t have any of my feminine features you could say, I was pretty skinny.” It may be tempting to

conclude, as Juliet did, that young men do not face the same challenges relative to weight as young women. However, Mark's story highlights the challenges guys can face relative to being undersized.

Body size is a big thing. Being that guy to take the lid off the jar. A lot of that stuff you can't do anymore. Sex is not the same anymore because you can't be the [ideal guy]. MS almost robs you completely of it. There are a lot of de-masculinizing things that come with the disease. ... With a guy a lot of the times it comes down to work, or it comes down to hobbies or it comes down to what you are good at, and I've always been good with my hands. I never went to school properly, my dad taught me everything I knew and I was in a millwright program. So I was really good at it and for some reason I just got it, and then to have it all taken away, it's like your whole "who you are." You just exist now, it doesn't feel like you're a man, it just feels like you exist. Just a blip. (Mark, multiple sclerosis)

In sum, young women and men's experiences of body size and illness can be distinguished in that women discussed challenges relative to physical beauty, and men highlighted strength and life purpose.

Responses to perceptions of physical imperfections include withdrawal, covering, and attempted improvement. Following a difficult onslaught of symptoms, Victoria expressed an unwillingness to date.

I have not much been in the dating scene since. I am nervous to get close to anyone and have to explain to them all the baggage that comes along with me, Crohn's, brain tumour, etc. I am also nervous and somewhat embarrassed of the fissures that I have as a result of my Crohn's. I am also not happy with the way my body looks after being sick and feel that guys will only see all of the negative things that I see. So, I have remained very hesitant to date.

Even being in an existing relationship can be made difficult when people are not happy with their appearance. Juliet was in a happy relationship with her partner when she gained 50 unwanted pounds because of medication used to treat her fibromyalgia.

It makes a difference too in your personal life with your boyfriend because when he met me I was 125 pounds and I was relatively fit. I wasn't in as good a shape as before but I was still relatively fit. Now it's not the same, there's a lot of extra stuff going on there. So

you kind of feel like “this is not the body you agreed to when you met me.” I know things change but you still want to be attractive to the person you’re with. And when you don’t feel attractive yourself it affects even how you want someone to see you, [whether] you’re being intimate or just on a regular basis. Before I would have been comfortable wearing something around the house or even just being naked getting out of the shower, whereas now you kind of feel like “oh I don’t look so good like this anymore, I’m just going to make sure this towel is on real quick just in case they come in.”(Juliet, fibromyalgia)

As chronic illness can be associated with periods of remission there may be times when physical activity is more possible than others. Changing one’s physical appearance may be easier during these times as Will’s experience highlights. Unable to exercise and gain weight during bad periods due to a lack of energy, Will has been able to control his Crohn’s more recently through medication, and has begun to lift weights regularly.

Definitely I think you want to be more manly. Now I’ve been trying to make sure I get to the gym, I want to make sure I keep the weight on and I definitely think about that. That guy perspective you don’t want to be the smallest skinniest guy there. Definitely at times I have been when I was really sick. (Will, Crohn’s disease)

For others, such as Juliet who gained significant weight, change to one’s physical appearance through exercise is not always possible. Through trial and error, she found that to minimize pain she had to limit her exercise to levels that provide little help in reducing weight. As she explained:

A big part that deals with pain is when you gain this much weight and you’re overweight for your body type, you’re putting more stresses on your muscles and your joints than you’re used to. You’re now too big for your frame which causes more pain and problems. So you’re stuck in this ridiculous place of not being able to lose it and it not being good for you physically or mentally. It feels awful because I’m used to being really fit. I don’t mind being curvy but this is not just curvy. I’m not a huge person, no, but you’re used to being trim or having some sort of muscle mass and you’re used to looking a certain way in your clothes and fitting in your clothes. Now you have to wear most things stretchy. The way I dress has certainly changed because I can’t wear certain things anymore because I just feel like my stomach is sticking out in a really big way. Or I don’t have any muscle left in my arms; they are really, really flabby so you feel really uncomfortable with your arms. You just start to feel way too big for yourself. It affects you and I would

be surprised to think that any modern person living in North America is not influenced at all by people they see on TV or whatever being a certain size. I certainly don't aspire to be a super skinny person but I'm certainly not comfortable at 160 pounds (Juliet, fibromyalgia).

Juliet's strategy of wearing stretchy clothing to cover unwanted weight is a common approach. While at school, Amy said "I could always try and wear baggier clothes. In high school I went to a catholic high school, so I wore a uniform, so I could always wear a baggier white shirt." 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,

I became really obsessed with watching what I was eating. ...As soon as I started on prednisone I became obsessed, like counting calories, eating salads and carrots, and fruits and vegetables all day long trying to not gain any weight. It was my first experience really with, I guess, dieting for extended periods of time. I hardly went out. (Bree, colitis)

These feelings towards weight can also be one of the challenges that remain after symptoms subside or people learn to handle the pain. After eight years of living with fibromyalgia, Juliet explained that:

I think the weight thing is one of the things that I think about on a daily basis because I'm so used to the pain now. ... I've become so used to the pain it's like "OK whatever" the weight thing is in every time you get dressed and every time you take a shower and every time you think about being with your partner, any time you go out to a club with your

friends, you see a movie, you always feel like “ya I wish I could go down to the gym” or “It’d be nice to fit into or I remember when I used to be that small.”

In contrast, certain physical appearances also serve a function in illness related social interaction. In many cases people seem to associate certain physical markers with illness, causing disbelief and a lack of compassion.

People don’t believe me. They don’t see me as being sick. Because I’m rosy, I have my eyes open, I don’t have bags under my eyes. They don’t pay attention to the little things. Right here I’m ok but I can’t say to somebody, “I’m having trouble getting up now because my legs are tingling” and they just look at you like you’re crazy because they don’t understand what you’re going through. They’re just like “ok whatever maybe your legs are asleep,” and it’s not like that. (Emily, multiple sclerosis)

Juliet’s experiences echo Emily’s:

Nobody really knows what it is and I don’t have a cast, I don’t have a limb that looks crazy, my scarring is pretty minimal now, I don’t walk with a limp, I am working, I do things with my life I’m not sad all the time. Because of all these things there’s no way people believe that I’m in pain 100% of my day. Because people expect well if you’re in pain 100% of your day you shouldn’t be functioning. ...When I had my air-cast on my foot I was *definitely* treated better. I was working at the time in between school semesters and knowing that I got in an accident. ...my boss had come to see me. Seeing me in the air-cast, seeing my wheelchair at the front door it legitimized everything. But the minute, literally the second I didn’t have my cane anymore: “Oh you’re 100% better now right?” “Absolutely not, just the bones in my foot have healed.”... The only thing that people could wrap their minds around was my foot, which is why I had the wheelchair, the walker, and the cane. It was all because of my leg and foot, and those specific injuries. But those specific injuries were kind of dealt with in the first two years. That was not my biggest challenge in those first two years. That was the *least* of my problems, the broken bones that I had to rehabilitate. So when people would only give credit to these things and not the other things, the emotional things or the energy, because you’re energy gets zapped when you’re feeling bad. People wouldn’t get that you’re exhausted even though you’ve just been home all day, you’re just exhausted and you can’t do that thing. That’s frustrating. (Juliet, fibromyalgia)

Thus, because physical markers associated with many diseases, such as weight gain or loss, are not readily associated with illness they do not serve to assist in social interactions.

Behavioural Public Appearances

Not only do young people face challenges relative to their physical appearance, but they also must deal with pressure to sustain certain “public appearances.” How people with illness appear in social situations is challenged when (a) others perceive that they are not acting how they should in terms of their disease management or recovery, or (b) their illness brings about behaviours that deviate from others’ behaviours in a particular setting. These two cases are described below along with related consequences and the adjustments people make along the way.

Following the development of retinopathy, a fairly common vision disorder tied to diabetes, Kristin recalled an encounter with a family friend that describes the expectations that others have relative to one’s role in the disease management process.

I saw her at church and this was just around the time when I started to have problems with retinopathy, and she was asking “how are you doing? How is your diabetes going?” I said “I’m doing pretty well but this year I’m starting to have some problems with retinopathy,” and she said, I couldn’t believe it, she said to me, “too much cheating eh?” I almost throttled the woman in my parents’ church. I couldn’t believe, what other disease do you blame [on someone], except for maybe when a smoker gets lung cancer. That’s the only thing I can think of where you’re actually like “oh you brought this on yourself.” But with diabetes you’re just like a bulls-eye for stuff like that. It’s just ridiculous because I didn’t get retinopathy from cheating too much. I got it because I’ve had diabetes for so long, and because when I started I was on one shot of insulin a day where now they have such good ways to micromanage....But to be in a situation where you’ve done your best all your life and you had developed anxiety because you’re trying so hard, and then you have someone come out and flippantly blame you for the fact that you may some day go blind. It’s just so callous to me that I can hardly believe it. I’m still mad about it in case you can’t tell! (Kristin, type 1 diabetes)

In addition to expectations related to diet management and the use of medication, some people face expectations related to how hard they should be working to feel better. Juliet contrasted her boyfriend who she described as very empathetic with her father who exerted pressure to work past her fibromyalgia.

There are people like my dad who is a really big issue because my dad doesn’t believe in this. He thinks that you can power through anything and people are strong. He gives me

these ridiculous stories like “Christopher Reeves was paralyzed and because he had such strength of will, he was able to wiggle his toes when they said he was never able to wiggle his toes.” And “people that have cancer beat it because of their strength of will.” He takes these stories that he reads and then puts it onto me. Like “if this person can do this and be this super champion, you can do it too.”...My dad and I have always been really close, and when I got injured and he noticed it was taking a long time, too long for him, to get better it became a real problem for us. A lot of arguments. If I needed financial help in the beginning he almost didn't want to give it to me because if he did he thought it would just mean that he's promoting me being weak for longer, rather than helping me when I really needed it, because he just really wanted me to power through and be stronger about it. ...If I answer the phone and I sound tired or I sound sore he'll say “oh what's wrong with you today? You've got to get stronger, you've got to be tough” or “everyone's got bad days.” You just want to slap someone, because “you've never felt this way before in your life, you have no idea what this is. You have no idea how it feels to wake up this way.” And for him to think that you can just power through it is ridiculous, frustrating. (Juliet, fibromyalgia)

For Juliet, these types of expectations were particularly difficult because they came from a close family member. As time passed and she resolved the challenge of working and living with fibromyalgia by following in her father's footsteps and starting a business, he became a bit easier on her. However, she believes that this only served to reinforce the idea to him that she can overcome her illness.

The unpredictability of chronic illness makes it difficult to plan social activities and sustain public appearances. When “bad days” arrive and activities are planned, confrontations and disappointment arise when other people hold expectations about how one 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.”“I'm trying so hard.’ I remember that Monday I went in to work and my mom had sent me an email

saying “this is why you don’t have a boyfriend, you’re like this.” All I could think of was if they had only known how bad I feel in the lowest moments of my illness, how hard it is to be normal at all. (Tessa, Crohn’s disease)

Cancelling social activities may be common for people living with an illness, but it can be particularly challenging to handle when close family or friends do not believe that you are doing your part or acting as expected. In Tessa’s case, her parents expected her to sustain a certain public appearance regardless of her symptoms and attend the party. In contrast, some people perceive that expectations exist around the spaces a sick person should inhabit. In Rebecca’s case, she tended to limit her time in social settings, preferring to stay at home, because of perceived expectations of how one 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 they 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 they think I should just be inside the house. (Rebecca, epilepsy)

The ideal public appearance of a person with illness can also be influenced by organizations that seek to project a particular image. For example, Mimi found that she was restricted in how she presented herself and described the disease to the public as she served as the honorary chair for a fundraising event. When preparing for media interviews, she was told by organization staff not to use words like diarrhea or blood, and not to focus on her positive health; all of which she perceived as attempts at shaping an image of people with Crohn’s as being desirable but in need of help.

Engagement in social activities centered on eating or drinking alcohol can be problematic for young people whose disease symptoms may be linked to diet (e.g., celiac disease, Crohn’s disease, colitis, diabetes). The settings in which this occurs vary (e.g., school, work, local pub) but in all cases young people describe them as a potential threat to their desire 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.

I'll go out and have a drink with people, but when everyone is ordering a pitcher of beer, then you have to explain it. "I have Crohn's." Then you're talking about it, and it's not always something you want to bring up and talk about. Some of that can be awkward. That happens all the time. Even ordering pizza at work. Those types of things. "I'm good, I don't want any." "Really?" Then you try and explain. People are usually fine with it and they just ask questions, but it's not always something you want to sit there and talk about. (Will, Crohn's disease)

Similarly, some people feel as though they become the centre of attention because of dietary restrictions.

The hardest thing for me is to be the centre of attention. When we go out for dinner with friends or family it's always about "oh well, what can Elle eat?" or "where can Elle go," or "is there anything for Elle?" And I appreciate that people are always wondering, and worried but I don't want to have to pick the restaurant. ... Or it's when people forget and I have to say it. Like if someone invites me to dinner I want to be like, "I want to come but" ... I hate feeling that I have to have a say in the menu. "Yes I'll come to your place for dinner but I can't eat anything like this, this, and this," and I feel like I'm a burden for people. So that's been hard. And, even when I first started work at [ABC Company], on my first day, I was very shy and quiet and we were having a team building day later in the week and [my boss] asked, she said "we're going to order pizza for the day so let me know if you have any dietary restrictions." So I had to say, but I'm like that's the first thing that people knew about me, like that's probably the first thing I said and I didn't want to but I had to be like, "um actually I can't." ... I often just say "I'll bring my own, don't worry about me, you guys order pizza and I'll bring something for myself." I either feel like an outcast or I feel like I'm letting the party down because people are like "oh let's order pizza, oh but Elle." I don't want to be ruining anyone's party and so sometimes I feel like I'm a bit of an outcast or I'm causing other people to not do what they want to do. So that's why I'm usually like, no no I'm happy, I'll do something else. (Elle, celiac disease)

Elle's experiences, as well as those of other study participants, highlight the feelings that can result when people feel centered out. Revealing illness helps explain to others the reason behind their deviations in diet with the hope that no further attention will be drawn. However, as Elle and Patrick aptly noted, the process is often repeated numerous times as memories fade or new

people are introduced into a setting. Further, the strategy of explaining dietary differences may be contingent upon other people's capacity to understand illness and the ill person's ability to explain illness. Kristin and Patrick suggested that this is particularly difficult during adolescence as compared with later years. Patrick, now in his late 20s, reflected on early adolescence and said, "It's not like when we're this age and you tell someone and everyone is so understanding. Whereas at that age they don't even know what allergies are for the most part. In the beginning it was definitely tough on that standpoint."

Cultural expectations around drinking alcohol can also heighten the challenge of fitting-in for those whose illness creates restrictions. Bree described the connections that drinking has with the area in which she lives and youth in general. Following her ulcerative colitis diagnosis, she found a reduction in drinking to be difficult because in

Newfoundland we drink a lot here (laughs). So being a young adult, people generally find it weird. Like, people always ask me "why do you always drive?" Or, well they'll ask like a boyfriend or a friend "why is Bree always designated driver?" Or they'll say things like, "oh sure come on have a drink leave your car at home, come on." And it's I guess in some way it would be peer pressure but generally I either just go "nah." Like I don't always want to use the I have a disease excuse, so you know I'll just say well you know I well I live far away or whatever, but that's been an adjustment to not [be] partying and staying out late. (Bree, ulcerative colitis)

As Bree described, people adjust by covering with believable excuses, avoiding situations, or resisting peer pressure altogether. Similarly, drinking beer can be considered a typical guy activity, making it particularly noteworthy when a young man does not drink in social situations. As Patrick recalled, "being a young guy you drink beer with your friends in the park or wherever and it sort of came back up again. I had no problem substituting it for some other alcohol, and it wasn't a big deal after a while. Again it was that initial [period], then it was fine." Fast forwarding to university, Patrick described the prevalence of keg parties and their role as key

social events. Important for him, though, was his friends' willingness to adjust to him not drinking beer, thereby allowing him to comfortably fit-in.

I remember in university, you go to keggers all the time and all of my friends would have a 26er for me of rum or vodka or something like that. Stuff like that makes it so much easier. No one even questions it. They'd just send me an email, we have a "whatever" for you. It was cool. It was great, really nice people like that. ...I've been lucky that people have been really understanding. I think friends were huge. (Patrick, Crohn's disease)

Situations in which friends are supportive and help sustain public appearances stand in stark contrast to the stories of people who have not been as lucky.

In addition to diet, some young people feel as though the uncertainty and potential embarrassment that may result from their symptoms do not make it worth being in social situations. As Rebecca suggested, the importance of being social is heightened in adolescence thereby emphasizing the perception that one must sustain public appearances. "When you think of young people, you think of them as being more social than say a forty year old. Ensuring that your social life isn't ruined or damaged is quite challenging." The possibility that symptoms may occur in public places is a strong deterrent for some young people and results in social withdrawal.

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 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. Similarly, Tessa described how she handled social settings in the face of symptoms from Crohn's disease.

I hung out a lot with my boyfriend. But even then I didn't like going out. Going to the mall would be difficult because I didn't know where a bathroom was going to be. Car trips were awful. I hated being confined in a car. I almost became phobic of being in a car with someone else. Pulling over and getting sick. When I did go somewhere I'd carry plastic bags with me in-case I was going to throw up. It happened. I've been in situations where I've been in the car and my stomach was, there was no time to get to the bathroom, and I'm 22 years old and I just soiled myself. Really, really, humiliating stuff. I didn't want to be around anyone. I didn't have any friends. From the time that I was 18 to 24, I was in basic isolation because I didn't know how to deal with it. I didn't know how to explain it to people. (Tessa, Crohn's disease)

Being young is also associated with other cultural norms such as attending a post-secondary institution. So when Rebecca, Susie, and Erin, had to stop going to university because their symptoms restricted their ability to attend, they found it to be embarrassing because they were unable to live up to the expectation that someone in their late teens should be undertaking such a pursuit. To minimize the pain caused by explaining that one is no longer attending university, young people often avoid situations that are likely to create conversations on such topics.

Engaging in social leisure in which embarrassment can occur brings about questions that need to be addressed if engagement is to occur.

You don't really want to go out and be around lots of people if you're in a flare. I'm always worried about "is there going to be a toilet I can get quick access to if I need it?" I certainly don't like to use public washrooms, where there's stalls and stuff. ... I wouldn't go out downtown doing something. I would maybe go to a movie. Definitely be more low-key....If I'm in a really severe flare, I'm not going anywhere. I'm at home, I'm in way too much pain. I just want to be lying down in bed, then running to the washroom, and going back to bed. And watching TV, and I don't really want anybody around for that. ...If you're over at somebody's house, I'm always worried are people hearing this? Or if you're out, like I said the stalls, you don't want to be having to do anything in the stall with other people in the bathroom. (Sarah, ulcerative colitis)

When situations that people perceive to be embarrassing occur, it can be how others in the setting respond that influences how a young person with illness feels. 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 come pick 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, its 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)

Some people also develop techniques that help them sustain public appearances and allow themselves to fit-in without drawing attention. Juliet described a technique she learned from a friend that allows her to handle her pain associated with fibromyalgia while not standing out.

If he all of a sudden has a strong pain in his stomach, he'll stop look at his watch like he's going "oh what time is it?" He will give himself a second where it's not obvious to those around him that he's actually going 'oh my god' and trying to get his breath back and feel better and keep moving. He kind of gives himself that second so it's not drawing attention to himself. That's actually something I've adopted from him. So sometimes I'll do that, tie a shoe, lean down and give myself a second. Like it looks like I'm doing something else, checking my watch, or "oh my necklace is tangled," or I'll find something to do. The dogs are awesome with that, I can look distracted by my dogs for a few minutes rather than what I'm actually doing. "Oh my god that really hurts, I'm so uncomfortable." It kind of gives you that breather. He taught me that, to have this

moment to have a breather to deal with what you're dealing with then you can move on in a second without drawing attention to yourself. (Juliet, fibromyalgia)

Juliet adopts this technique as a way of avoiding comments that draw attention to her being different such as:

“Oh do you need to lay down, do you need this?” Then it becomes this big thing and you have to talk about it, and you just want to be normal and hang out with your friends. You don't want people to fuss. You're out with a bunch of friends and you just want to be normal, you just want to go do the normal thing. But the minute they know that you're not feeling well, it's a constant “do you need to go home? Do you need a ride? Do you want someone to call you a cab? Do you need this? Do you want to sit down? What if we did this thing instead of that thing?” Everyone starts changing the plan and it's like “no, I can keep going, I just need a second. I just need to collect myself for a second.”(Juliet, fibromyalgia)

In sum, social activities that highlight one's illness may not always lead to avoidance but may be more likely to decrease the enjoyment normally derived from such situations. Conversely, the potential embarrassment perceived to exist from certain social activities may lead others to withdraw to avoid embarrassment.

Illness Reputations

Feeling “normal” as discussed by many of the study participants is sometimes made difficult by reputations built upon illness. Once socially labelled as “sick” or by the name of a disease, reputations tend to persist even when symptoms fade. As Bree explained,

I know the people probably mean well when they do this, but I have a lot of family and the first thing that they ask me is “oh and how are you feeling these days?” And I understand that they're doing it out of concern, but I would love to be associated with something else than being the sick person. ... I would prefer them say “how are things going, what's new?” But a lot of people just ask me how I'm feeling and I do understand that they're doing it out of concern but it's just, I wish sometimes people didn't associate me just with that one particular characteristic that I really have no control over... But that's how people see us, like we are the sick kids. (Bree, colitis)

Myra, living with type 1 diabetes, described a similar experience in that sometimes friends and family can be overly attentive to one's illness. She said “they were very sympathetic. Some of

that pissed me off. ‘Calm down I don’t have cancer.’ Even if I did, they treated me like a baby and I don’t like that.”

In other cases, people develop an idea about what ill people are able to do as a result of their disease. In many cases, these are assumptions that do not involve information obtained from the actual person living with the illness. Mark explained that in his case,

a lot of people found out really fast regardless of what I said or did. Mostly because of the way I walked. It came on really fast “don’t do this, don’t do this” ... before you even had the chance to do it or not, or ask for help or anything. They label you a disease before they even think about you personally. (Mark, multiple sclerosis)

Similarly, Myra described the fallout that resulted after telling her boyfriend that she has diabetes.

I started dating someone a year later after my diabetes, and I was kind of afraid to tell them that I was diabetic. Because I always had this thought in the back of my head that they’re going to think that I’m sick. Sick as if I had cancer or something. How am I going to tell them that I rely on shots? ... One of my boyfriends that I dated for two years, his mom told him that he shouldn’t date me anymore because I’m sick, and he shouldn’t be with a sick person.... “Don’t date a sick person. Someone who has problems with their body. They are not going to be reliable.” Stuff like that. They might not live for long. I was very hurt. I was upset at her. “How dare you. How dare you say that? I’m no different. I’m the same. I’m not different than another girl who doesn’t have it.” (Myra, type 1 diabetes)

In contrast to constant attention on illness or a perception that limitations exist, many young people want others to act as though nothing has changed. 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 the 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 towards her, Emily said:

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 where ever 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)

The potential consequences of illness reputations promote concealment of illness by some people. Concealing can mean withholding information about how one is feeling or simply not telling others about the presence of a disease. Similar to others such as Myra and Sarah, Bree expressed concern over the worry that develops when parents know that bad days are present. Although it is nice to know that others care, it can be stressful to know that others are worrying. In an effort to minimize the stress caused from other people's worrying, and the solidification of one's reputation as being sick, people tend to hide how they are feeling from certain people. However, this is not a universal undertaking as they develop an idea of how people will generally react to the news and then make a decision whether to reveal information.

It was nice to see the concern from my family, but at the same time it's also stressful for me. If I know that I'm starting a flare-up, I generally don't tell my parents because I still live at home and my room is right next to my parents and my father, I know from experience, will not sleep. He will stay up and he will count how many times I go to the washroom in the night and he comes in the next morning and says "you're not well, you went, five, six, seven, however many times." So I know if they know that I'm sick, that they won't sleep. And if my father's not sleeping then he will wake my mom up every time that I go to the washroom and say "Sue, Sue, Bree's up again. Wake-up she's up again, she's not well she's up." So, neither of my parents will sleep and I won't sleep and then we're all the worst for it. I generally don't tell them, I'll tell my sister and say "don't tell mom and dad, but I'm having a flare-up" or I'll tell my boyfriend, so someone knows I am having a flare-up, "but please don't tell mom and dad because they will be more stressed out because of it."... but it is stressful lying to my parents about it and keeping, I guess, a secret from them. (Bree, Crohn's disease)

In other situations, Bree hides her illness from employers to avoid developing a reputation as the "sick girl."

I'm not the type of person... there have been very few days where I have actually taken time off because of having a flare up. However, I would have been more than within my means to have done so, but I feel guilty when doing so. Which probably even adds to the stress that I have because I'm going to work when I'm probably using the washroom 10, 15, 20 times a day because I don't want to call in sick because I don't want to do that, I don't want to be looked at as the girl who's always sick.

There may be a trade-off though from hiding illness to avoid being known as sick, and being thought of as a poor employee when missing work. For example, Tendra always tells new employers right after she is hired that she has Crohn's disease so that absences from work are explained by her illness rather than her work ethic. She adamantly noted that she does not miss work for anything. Hiding may be quite feasible when symptoms are not severe, and can be fairly successful as Juliet suggests.

Most people when I meet them, I certainly don't tell them that I've got this and it comes out later. And most people say "oh you'd never know, you're so happy" or "you do this or you do that." It's because I don't want this to be the thing that decides what I do with my life. I don't want people judging me by whether or not I am ill. (Juliet, fibromyalgia)

Given the opportunity to re-develop her reputation among new friends when starting university, Regan sought to hide her Crohn's to make the relationships about other things. She said that she "withheld the information when I moved to college last year because I wanted to be me, and then me who had Crohn's. It was such a great opportunity to start over as I was the 'sick' one in high school." Much like Juliet, she was successful and it has worked out well, as she believes that her new friends are her friends because they have common interests and get along well.

In summary, physical and behavioural public appearances and reputations related to illness make it difficult for young people with an illness to feel normal or fit in with others. Although social withdrawal is common enough, people with illness also adjust to the situations in which they find themselves, as do the other people who are participating in these settings surrounding others, increasing the likelihood of achieving a sense of belonging in the world.

ACCOMPLISHING ACTIVITIES

It was May 19th that I got diagnosed but around February two years ago I had gotten into the bath and I couldn't feel my foot. I couldn't feel the temperature of the water, I couldn't feel it when I was touching my foot. So I worked through it for a while and it was hurting my leg while I was walking at work. They tried to diagnosis me with hypoglycemia, thinking that was the problem. I went through a bunch of tests and in May I found out I had it.... I met with a neurologist in Hamilton. I went for a couple of scans. Before I even went for the scans he told me I had it, because they take this little vibrator and they run it up your legs and they do all these cognitive thinking tests, and I failed a lot of them. He pretty much told me I had MS, and they are just going to do the MRIs to confirm it. It's crazy....It was a roller coaster for the first little while. I was still with my fiancé and then I lost my job. I didn't lose it, they took me off of work right away. I was a millwright apprentice. They didn't have a return to work thing or nothing so I was pretty much gone off the bat. .. They noticed something was wrong because I had a really awkward gait in my walk. We used to have to lift up big gear boxes and stuff like that and I couldn't do any of that anymore. You try to get by it and pretend that it's not really what's going on....My fiancé at the time thought it was too stressful, what was going on, so she quit her job. Then [she] had to end up taking an under the table thing at a scrap yard to try and keep our head a float. That didn't work. Then about a month later we found out she was pregnant. I was getting worse. I was having problems with my vision, my balance and my walking and stuff. ... 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. You're 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)

Fatigue. Pain. Physical impairment. Symptoms associated with chronic illness threaten to limit young people's involvement in everyday life. As Mark's quote demonstrates, the ability to accomplish desired activities, such as leisure, school, work, and everyday tasks, contribute to feeling as though one has no place in the world. Further, the preamble also alludes to the process of change that occurs following initial symptoms. Initial periods of chronic illness are often marked by severe symptoms that intrude upon one's daily activities. Early experiences are also

characterized by great uncertainty, trepidation, and hope that illness will depart as quickly as it arrived.

Following initial periods of illness, many people, with the support of others, work towards adjusting their lives and mindsets to minimize or eliminate new intrusions on their ability to accomplish desired activities. In these cases illness becomes an interruption. The quest to make illness a minor interruption stands in opposition to full immersion whereby daily activities are engulfed by the illness. Rather than considering interruption and immersion as two rigid categories, they may be best characterized as ends of a spectrum. In either case, the states of interruption and immersion in illness are characterized by how young people feel physically and the associated mental work required to manage these experiences. This section describes the experience of chronic illness along the interruption-immersion continuum, their connection to young people's pursuits of activities, the mental work invoked in coping and some of the adjustments that influence the extent to which these illness experiences are experienced as interruption or immersion.

Being unable to accomplish desired activities can be a very challenging proposition. Symptoms may 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; I didn't really like sitting there that much and all of a sudden you have to. You come home from school and you're just dead. That's all I remember being is so tired and wiped out and no energy. (Will, Crohn's disease)

Restrictions may be further complicated by expectations around what youth believe they should be doing at their age.

I feel like my life is on pause. I have no money. I have nowhere to go. I'm stuck at my parents' house. I feel like I'm going to be there forever which is horrible. I'm really tired all the time. ... So, I can't get up and do a lot of things. ... Like I said I'm not going to be working. I am really bored. I'd like to think that I'm smart but I'm wasting my potential because I just can't do it. I had all of these dreams and now they're gone. (Emily, multiple sclerosis)

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)

When young people are bound to their homes because of physical restrictions they risk missing out on social leisure opportunities. During these times, chronic illness is not necessarily experienced as immersion. When friends were willing to adjust the ways in which they normally interact with friends, it can help youth with illness feel good about themselves and feel connected to others. Take Juliet's experience for example:

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)

Similarly, Vera talked about friends who would come and visit her at home and “hang out” and co-workers who came to visit her in the hospital to socialize and “share work gossip.”

Importantly, Vera noted that over time she realized that her friends not coming to visit her frequently did not mean that they were moving on without her, but that they were busy with their lives and still cared. So, Vera indicated that she also recognized the need to not always wait for friends to reach out to her, and that she needed to take responsibility and make contact with them. As part of the process of maintaining relationships through social activities, she felt the need to “let her friends in” by being more open about what was happening to her body and how she was feeling.

In pursuing school activities, experiences in high school were characterized by teachers who made accommodations for bad periods of illness by allowing for extensions on assignments, waivers on exams, altered learning environments, and assisted in catching students up on missed class material. As many participants transitioned into university or college their experiences were much more varied, with most young people describing at least one professor who was unhelpful in negotiating bad days. These professors were described as acting as though they were inconvenienced by the prospect of making alternate accommodations. Rules were much more rigid, accommodations less likely, and consequences more significant as some participants dropped out because of poor academic performance or others failed to achieve grades necessary for post-graduate studies. Meeting with some of these participants soon after these academic experiences, it was evident how important these perceived “failings” were to their sense of place in the world and their outlook on the future.

Restrictions experienced in the workplace also featured prominently in discussions of early jobs taken on by youth with illness. Much like Rebecca who missed work days because of the aftermath left by seizures, Tessa and Juliet's uses of sick days were an inconvenience to their employers.

I lost the job I had in the spring because I was sick. They told me that I had taken too many sick days. I hadn't used all of my sick days but I had taken too many close together. They understood that I had an illness but it set a bad example for the other employees. They sat me down, they basically said that there wasn't anything wrong with the work I was doing, they were just concerned that I was taking too many sick days and setting a bad example for the other employees and they didn't like that. It was total B.S., but I took it. I apologized for it. I feel so vulnerable on those. I felt like I had done something wrong. They actually made me cry. ... It's been years of apologizing for being sick. (Tessa, Crohn's disease)

She would say in my reviews ... "you know you do good work, you're personable people like you," and she would give me all these good things, but she would always berate me essentially for not being there all the time. "I'm really busy, I need you here, if you can't do this, this is a problem." And I get it, she was really busy, but at the same time there were certain times when I couldn't do anything about it and it wasn't a choice. You just feel like you're letting down a lot of people over something you can't control and that's disappointing and it makes you feel guilty. (Juliet, fibromyalgia)

Also, when making it to work, the adjustments that need to be made may seem like an inconvenience to some co-workers. Juliet recalled being isolated from co-workers when she had to decline a request to lift boxes or took too many short walks around the office to minimize pain associated with fibromyalgia. Conversely, stories of employers who did not feel inconvenienced were equally prominent amongst young people's experiences. Beth, for example, spoke about her employers being exceptionally accommodating when she was restricted significantly in her duties at work because of her multiple sclerosis. Beth's employer provided her with other tasks to complete, assistance from other part-time staff, and allowed her to complete her work in an alternate manner. Also, Kristin's frequent use of sick time because of diabetes related appointments was met with understanding by her employer. Contrasting her experiences with

those of others she said: “I’m lucky I work in a career where my company and my supervisor are very supportive. ... it’s been fantastic. ...There are lot of people I know who are not nearly as lucky and who when they have that much sick time or when their diabetes affects their work its more of a problem.”

Extended periods of time marked by limitations can contribute to youth feeling disconnected. When the pain in Zach’s hip became unbearable because of his juvenile rheumatoid arthritis, he had to leave university and return home to his parents. As he recalled, “that was really tough because I was leaving university. At that point those were the four best years of my life. Being at university and meeting the people I met... It was a big deal. ... That was tough, that was really tough.” Being disconnected from friends was difficult for Zach as he felt as though he did not have much to do, putting him into what he described as a “depressive state.” Feelings may worsen for a few young people who feel as though the inability to accomplish activities makes it unbearable to continue life. Take Tessa’s case for example:

As of 2008 I was on bed rest and towards the spring of 2009, I was thinking if I wasn’t getting better I was just going to check out. I was ready to kill myself because I couldn’t walk, I couldn’t read, I couldn’t even watch TV, I couldn’t eat. I was living at home. I couldn’t work. I couldn’t attend school anymore. I was just done, if this is going to be my life. (Tessa, Crohn’s disease)

Faced with similar restrictions, Mark reflected on his situation and current inability to accept a future along the same (or worse) lines.

What I’ve gravitated towards now is I have an aunt that had MS and within four years she was in a home. That’s my ultimate fear. My grandfather was in a home, we went and seen him every other month. I don’t want that. I’d rather be given the choice to die and have someone remember me for who I was instead of to keep on going. I remember my grandpa suffering. I don’t remember my grandpa I just remember seeing him in this stupid wheelchair smoking cigarettes and not talking. I’d known him like that for ten years. What kind of prison that must be. What kind of prison that must be. And that’s really where I’m stuck at. I should be allowed to make that choice [to commit suicide] and not be made to feel selfish about it. I haven’t come to the point where I know how to

go on; I just know where I don't want to go. To make decisions for the future and come to terms with it, I never really looked at how to deal with it yet. (Mark, multiple sclerosis)

In addition to physical symptoms that intrude and risk engulfing a person's everyday life, mental work can also do the same. The degree to which this mental work happens varies. In less serious cases, people are momentarily interrupted. For example, people might think about what could happen when they are performing on stage like Mimi or when they make travel plans like Sarah. Also, when people like Rebecca feel their muscles flinch they may be reminded of past seizures and worry that more may be coming. Similarly, Will explained that when he feels tired he wonders "is it because I had a late night last night or is it because I am having a reaction to the Crohn's, or have I not eaten well lately? I think about it in some way or another, probably on a daily basis." In more severe cases, mental work limits leisure activity involvement and enjoyment. As Kristin explained, as one becomes 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 can force an evaluation of whether the benefits of participating exceed 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 young people seek out 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, an inability to accomplish desired activities because of physical constraints or mental work can cause distress for young people. The degree to which young people experience chronic illness as a hindrance to the accomplishment of desired activities operates on a continuum from minor interruption to full immersion. However, adjustments can be made that help young people move towards a state of minor interruption and thereby avoid full immersion. The next sections describe two adjustment processes that were prevalent in the study participants' experiences - developing outlooks and learning to alter routine activities.

Developing Outlooks

People's definitions of how chronic illness impacts their lives are contingent, in part, on the development of particular outlooks, perspectives, and expectations. When physical or mental restrictions develop people may no longer be able to engage in an activity as they once could. When faced with the joint pain and physical limitations imposed by juvenile rheumatoid arthritis, Zach responded by altering performance expectations for the sports in which he was able to participate. Continuing his involvement in cross country running and cross country skiing, he explained his change in expectations:

I would always finish every race and I wasn't good, I wasn't great. I'd finish at the back or I'd finish close to the middle and it'd be a moral victory. Yeah I finished in the top half, that's awesome! There'd be 100 people and I'd finish 50th or something. I'd be like "this is good." I would always think positively. (Zach, juvenile rheumatoid arthritis)

Following long periods of time immersed in illness, young people may also change their perspectives on activities once taken for granted.

It has changed the way I look at life in general. I don't take simple things for granted anymore. Some people will look at things such as walking as a normal every day activity, but I look at it [differently]. For a while I was bedridden, and from being bedridden for so long, and due to the abscess down near my lower back, I was unable to walk. I had no muscles, I had no strength, and generally I had no will to do much. I didn't want to be up walking around [because] I got tired way too fast, and all I wanted to do was lay in bed. Most of the time I didn't have much more of a choice but to lie in bed because it was just too hard to do anything else. However, once I was in the hospital and seeing a physiotherapist, I had no other choice but to get up and learn to walk again. I think that is one of my greatest accomplishments. It was hard, it was rewarding and it forever changed my life. I can remember when I first took the first few steps alone. I remember my mom and dad being in my room when I took about 2 to 3 steps with the aid of a walker. (Melissa, Crohn's disease)

Crohn's has made everything that I am able to do more enjoyable. About a week or so after my discharge after my surgery, I walked to the corner store with my Mom; it was such a big accomplishment and all I did was walk. Being able to sit in the lecture halls at school again was a massive triumph, and I can bet that very few students shared that view! (Regan, Crohn's disease)

Prolonged periods of immersion in illness may also change one's view of what is enjoyable.

When good days emerge for Mark he uses his time to do the basic things he could not do during bad days, and attaches a positive meaning to those pursuits. Asked what he does on good days, he responded:

Well it's not so much entertainment wise anymore. You don't go out to entertain yourself, you go out to live. My good days when I'm feeling good, I'm feeling awesome, I go do my groceries, my laundry, I do housecleaning, stuff like that. It's not about entertainment. It's kind of like an entertainment because you can do it. MS restricts you so much on what you can't do, and when you get those one days where you can do your laundry, you can do your dishes, you can do all that stuff, it makes it all worthwhile for that day. I would have loved to have gone out canoeing but doing my dishes today is great. (Mark, multiple sclerosis)

Similarly, when good days are present some people take the perspective that they need to do as much as they can because of the uncertainty of chronic illness and the arrival of bad days. As Melissa said "I'll just let it push me to do things because I never know when or if I'll ever get as sick as I was again!"

Although changing one's outlook on the pursuit of activities may be an individual undertaking, social influences also play an important part. Three main processes were central to altering outlooks including making comparisons, being influenced by parents, and drawing from past experiences. Most frequently, young people compared themselves to others with an illness who they perceived to be in worse health or had more severe restrictions. Zach recalled having life put into perspective after meeting his girlfriend's mom who had cancer and sister who had a brain aneurism. For him it meant realizing that a lot of other people have difficult life challenges, and dealing with juvenile rheumatoid arthritis was just a challenge like some many others face. Patrick recalled similar experiences while in hospital.

I saw people in there that were [my] age and had basically no quality of life. Or kids that were in there for long stretches of time, and I remember thinking after that I really

appreciated things more after I got out of the hospital. ... It sort of gave me the perspective that when you're back in school, ya maybe this isn't ideal, but then you think of those other kids and you're like man it could be worse, don't feel bad for yourself. So ever since I've had my surgery, things that are stressful in life, aren't really a big deal. Whatever stresses you have in life, it's like man you know what it's not as bad as it could be. I'm not dying. I remember I got close to a guy that had been in there for eight months. He had a [colostomy] bag [because] he had his whole colon taken out. Zero life, zero life. ... He can't even do the easiest things like meeting for coffee. Think of how much that guy would just love to do that. (Patrick, Crohn's disease)

Young people, who think of themselves like anyone else and do not dwell on illness, stand in stark contrast to those who do not. A common theme amongst the experiences of many youth who have adopted a positive outlook is the influence of parents. Youth receive cues from parents such as how they should think of themselves in relation to others. Melissa recalled an early experience following diagnosis: "I still remember driving home from the hospital when my doctor told me that he thought I had Crohn's and saying to my mother 'Is Crohn's disease a disease to be ashamed of?'" Similarly, in the face of trepidation about how his peers would treat him because of his Crohn's disease, Patrick's parents convinced him that other kids his age would not care about him having an illness; a point to which he attributes his confidence in engaging in social leisure activities. Reflecting on extended periods of immersion in illness Zach discussed the role his family played in getting him "out of his funk" by connecting him with a family friend who hired him to help organize a major hockey tournament for charity. This opportunity filled the void of an unfulfilled career path and shaped his enrolment in a post-graduate program in sport and event marketing, an important turning point in his life.

Two important points should be made about the role of parental influence in shaping outlooks. First, influencing youth to take a stoic approach may be beneficial in many respects, but risks limiting the therapeutic benefits of emotional expression. For example, Kerri's parents

sought to influence how she controlled her emotions by comparing her situation to others and emphasizing the need to take action.

One of the things I really liked about my parents and the way that they handled situations in general is “you know you deal with the reality, you don’t feel bad for yourself, other people are going through worse situations.” You can be sad, but you can’t dwell on it because that can lead you to take some bad actions and some bad steps and make some bad decisions. You need to be clear-headed and deal with it; this is the way it is and move-on. (Kerri, type 1 diabetes)

However, as Kerri suggested, “but because of that ... when maybe it would have been appropriate sadness or frustration or whatever, I probably didn’t [express it] and probably still don’t.”

Second, parental advice may not always result in change immediately. Rather, it may be more of a gradual process or one that acts to support other processes as was the case with Rebecca and her adjustment to epilepsy.

Although not as prominent as making comparisons, or being influenced by parents, some young people also drew on past life experiences as a way of developing particular outlooks.

Drawing from her mother’s suicide when she was younger, Mimi always felt as though handling Crohn’s disease was not that big of a deal because of how much grown up she felt already. How she handled the adversity she faced with Crohn’s was often noticed by others, yet she felt as though she just did what she always knew how to do; it just “made sense” to her. In a related sense, Kerri described how her family was used to dealing with adversity because her younger sister has autism, her mother has had breast cancer, and her dad has Parkinson’s and has had cancer. Handling the challenges of diabetes was simply another family task.

Learning to Alter Routine Activities

Another way in which young people adjust their lives to be able to accomplish desired activities is to alter their routine activities. This process can involve learning to take medications,

pursuing activities that minimize symptoms, and dealing with pain. For teenagers this adjustment process typically begins with the help of parents and transitions to being individually managed as youth become older. When young it may be difficult to understand the implications of not taking certain medications or tempting your body with certain conditions. Thus parents are needed to prevent youth from attending birthday parties where the presence of cats or cat dander would threaten an anaphylactic reaction for George, or to force children to take medication, as was the case for many youth.

One parent would physically hold me down on the floor, and the other would give me the needle. ... That had to be really hard on them. Also they both physically needed to be there. For a while, because I wasn't giving my own shots, for sleepovers they would show up at the time I needed a shot and give it to me. ... I imagine that must have been really difficult for them both [in terms of] adjusting their schedules, to be able to allow me to live a life as kids do. With sleepovers and parties and things like that they had to be able to fit that into their schedules. (Kerri, type 1 diabetes)

Following her Crohn's disease diagnosis, Regan felt helpless and withdrew, forcing her parents to take control.

It was very traumatic and it drove me into a deep denial. I wouldn't take my medication unless my parents forced me to. I would lay on the floor in the foyer crying. I would wait by the phone for hours waiting for the doctor to call to say I'd been misdiagnosed, but the phone never rang. My parents would tell me that taking medication would become routine, like brushing your teeth, and for a long time it did not seem so. But all of a sudden, it was like that. And now that I have to take very few medications, it feels like I'm forgetting something. I wasn't able to swallow pills for years, I would put them in apple sauce, and sometimes you can dissolve the pills, so everything was always a bit of a hassle. I think once I understood what they did it made a huge difference in my compliance. I've injected lots of medications and was adamant that I wanted to do that myself instead of the doctors doing it, I learned to place my own NG tube and the like. The more I felt involved, the more I was willing to comply. (Regan, Crohn's disease)

Undertaking medical approaches appeared particularly significant because of their ability to provide the greatest opportunity for a normal life and allow youth to pursue desired activities

they were unable to previously. Notably, though, is the process of determining which medications are suitable particularly in light of often worsening symptoms.

So I was getting a bit healthier and those types of things after those first five or six months. It made it a lot better, it allowed me to get back involved in some of things I was used to doing. Then I was healthy for a while, and had a relapse after. What I kept finding with it was the medication I'd be on, after you're done a steroid treatment or something like that, the medication you'd be on would be ok for a year and then my body would become used to it and I'd have to try and switch onto something else because I'd have a slight relapse. So it'd flare up and you'd have to go see the doctor during that period and struggle through it. That would happen and I would be switching the medication to something else and finally in fourth year I was really sick for about three or four months and I finally went on Remicade just after that, and I've been on it since. I really haven't had a problem, a flare up or anything in the last five years now. With that being said, some of the things I think to deal with having the illness is just learning how to deal with it is the biggest thing. Finding the right medication, finding what food you can eat, what food you can't eat. (Will, Crohn's disease)

As Regan's earlier quotation suggests, over time youth can develop a desire to take care of themselves. In developing such a desire, youth develop a sense of responsibility and alter their activities in a way that may not be congruent with the activities of a "typical" person their age.

You have a whole different set of issues on top of the issues you normally have with being a teenager or a younger person. You already have your stresses of wanting to finish school and having a good job and meeting a person to love and having a home. You already have those pressures. Having pain pressures on top of it sets priorities differently. You can't just go do whatever you feel like when you feel like it. ... a lot of people can afford to do a lot of crazy things and have crazy experiences because their body will handle it. I know my body won't so I don't get into certain situations. I'm not hung-over ever. I'm not having drunken hook-ups or doing anything like that that a lot of people my age had. Not having college experiences because I had to deal with more serious things than that. When you have a constant pain problem, if you're going to be responsible about yourself, you have a lot of different decisions to make. ... You have to be more adult about your decisions; how you're going to eat and taking supplements, and having exercise and doing all those things you're supposed to do. Most twenty year olds aren't going to care about what they're going to eat and the proper amount of exercise, but when you have a pain issue you have to care about that stuff. (Juliet, fibromyalgia)

Sometimes this transition is prompted by parents, particularly as young people reach late adolescence. In Kerri's case her parents wanted her to take responsibility for her diabetes management, and for Myra her lifestyle became such that she was not home on time after school to receive insulin injections from her parents.

A fine balancing act exists for friends and family as they try to remain supportive on one hand while avoiding intrusion on the other. Beyond initial periods of disease diagnosis and initial treatment, many young people described encounters with others that infringed on their sense of autonomy and control of their own disease. Actions once perceived as helpful in the adjustment process become less welcome as young people become familiar with their bodies and develop a sense of how to treat themselves with the support of their doctors. Helping young people remember to take medication, manage diets, or perform insulin injections for type 1 diabetes, are common activities that parents learn to pass control of to their children. When these transitions are not made smoothly, particularly as youth reach their mid-to-late teenage years, youth can feel as though parents are overstepping their boundaries. Myra also felt as though her parents' constant focus on her diabetes made it even harder for her to fit-in and feel normal.

Overall, my relationship with [my parents] isn't that good. But I like the fact that they give me independence now. [Now] with my diabetes they're not always like "did you take blood sugar?" I like that. I don't want someone down my neck saying "did you do this for your illness?" It makes me feel like it is more prominent in my life, and I don't want it to. I want it to be normal. Part of my life, not *my* life. If my parents were like "Did you check your blood sugar right now, an hour ago, whatever?" It's like "oh come on, I'm getting sick of this already, diabetes is not my life." I want to make my life more normal when I have diabetes. If I have diabetes it's going to make my life feel different from everyone else but I don't want to feel that way. So in order for me not to feel that way, it would help if my parents weren't on me all the time telling me if I'm taking care of my diabetes. I like to feel like everyone else, normal. (Myra, type 1 diabetes)

Unwanted involvements in one's disease management also extend to friends and other associates as Kristin experienced when she became friends in university with a nurse in training who was

working with diabetics. This friend became critical of the way that Kristin took insulin to match her food intake, and voiced unwanted opinions about the proper way of approaching diabetes management.

Other forms of adjustment include altering one's daily activities to manage stress and its impact on one's disease and learning how to regulate one's body. For example, following a missed term of university because of symptoms brought on by ulcerative colitis, Chloe who wanted to catch up and graduate with her friends chose the difficult strategy of overloading her semester by taking additional courses. As she recalled, it ended up affecting how she felt causing her to rethink her level of involvement in activities. Chloe described the process of learning to say no to certain volunteer activities and make sure that she had enough time to work on class projects as ways of minimizing stress. Similarly, Vera described how she became very sick after not paying attention to her body and overloading her school and leisure activities. She said being seriously ill in the hospital was a "turning point" that made her slow down and reduce her involvement in activities to the most meaningful ones. Becoming connected with how one's body responds to certain activities was also a way of ensuring that young people could participate in desired activities. Kerri described this process in terms of playing basketball and having Type 1 diabetes.

The first year in high school I didn't try out because I was really shy but also because I didn't know for sure what was going to happen with the diabetes, and having to tell people. ... It was very challenging because the way that my blood sugars reacted to activity was very varied. It used to be that I used to think that different sports had different impacts. I knew that if I swam, I would go low right away and then my blood sugars would drop six hours later. I learned this over time by trial and error. I knew that a basketball game did the complete opposite of a basketball practice. But again only through trial and error. I'd go high in a basketball game and I'd go low in a basketball practice. From the personal research I've done since, a lot of it has to do with my heart rate. Depending on the range that my heart rate is in, is how it impacts my blood sugars,

which is pretty interesting but not the stuff you're thinking about when you're a kid in high school. (Kerri, type 1 diabetes)

Yet, for some youth learning to deal with pain is the best way of ensuring they continue certain activities. As Melissa explained, she will deal with the pain associated with Crohn's disease to do certain things: "I don't change a lot about what I do because I'm used to being in pain ... I've learned how to pretty much go about my every day tasks while being in pain. ... I try not to let the pains stop me." Afterward certain activities she would find a way to handle the pain: "later at night I'll put a movie on, relax and rock, which is my main way of handling my pains." Importantly, dealing with the pain may not be sustainable as Vera experienced with her lupus, without recognizing one's limits.

EXPERIENCING RELATIONSHIPS

As young people attempt to form and maintain relationships with others as a key part of fitting into their social worlds, they may be constrained by a number of factors. Notably, a lack of understanding of illness, and the impact young people have on other people's lives, are prominent for many youth. Subsequently, a number of ongoing adjustments are made as a result of these factors. This section concludes with a description of one adjustment in particular, connecting with similar others.

Understanding Illness

Based on many of the study participants' observations, it is clear they felt that the lack of understanding of their illnesses was often reflected in the fear and unfounded blame sometimes expressed by the people they encountered. This section describes the challenges these perceptions created along with the adjustments and desired solutions expressed by youth with illness.

Regan has experienced a number of situations in which others have misunderstood Crohn's disease, all of which contributed to a feeling of isolation from her social world. Even worse, these occurrences have happened in long established relationships, such as families she used to baby sit for or a dance studio she has attended for years. Now 19, she recalled recent experiences:

Some families that I baby-sat for thought that I was contagious until I explained about the disease. I was systemically discriminated against by my dance school at the time. I was intentionally given awful roles in a ballet, and when I asked why, I was told that it was because of my Crohn's. This severely isolated me from my peers and was a very difficult time. ... I had been dancing since I was 2 years old and it would have been the last place I would have expected it to take place. I felt stupid and unworthy, but I did go ahead and dance because I didn't want them to win. I deeply hated going and it was traumatic each time. (Regan, Crohn's disease)

Similarly, other youth described experiences that evoked negative feelings of self-worth.

Describing her discussions with some university professors about her Crohn's disease, Tessa found that a number of them were unwelcoming and misinformed about related symptoms and limitations.

I remember one professor was like "oh you're not going to throw up during my class are you?" He's like "I don't want that." I remember another one, I had missed class and she had told me that I should just drop out or finish school as soon as I could and get a government job because no one was ever going to want to hire me with a disability. (Tessa, Crohn's disease)

Lacking an understanding of a disease, people may rely on misinformation or equate the disease with some physical state they perceive to be similar. Melissa, for example, found that people mistook her Crohn's symptoms – bloating at times, reduced weight at others – with other more commonly known causes: "I was asked *many* times if I was pregnant, asked if I was anorexic, and if I was bulimic."

Also challenging is the blame that some people may unfairly assign the person with the illness because of a lack of understanding. Upon learning that she had Type 1 diabetes some of Myra's family members blamed her for acquiring the disease.

I remember my parents weren't happy. They were really sad but they were blaming me. Worse off my grandmother: "You're having too much sugar, I told you to cut it down on the sugar." First of all I wasn't even a sugar-aholic if you want to call it that. They were so mad at me. "It's not my fault!" They honestly still think that it's type-2. Who knew about type 1? Kids getting diabetes? (Myra, type 1 diabetes)

Similarly, Tessa recalled her experiences and how being blamed made her feel.

You feel guilty, that's the big thing with a chronic illness. You feel like "what did I do to deserve this? What am I doing to perpetuate all of this bad stuff?" Not only how you feel, and how you handle it, but also how your friends and family handle it. People are really quick to blame you. You know, you're not trying hard enough, or you're doing this to yourself. So then it perpetuates into guilt, and like "what did I do?" People are accusing me that I'm doing something to encourage this. So I just felt totally isolated. (Tessa, Crohn's disease)

One possible response to a lack of understanding is to inform others about a particular disease. However, doing so is not always a straightforward process as young people seek to simultaneously retain the ability to fit-in and increase understanding. Notably, informing others is impacted by the difficulty of explaining illness and one's ability to read a given situation. Recognizing that others are more likely to understand descriptions of illness when they are presented a well-known analogy, Will has described it by saying "well it's ulcers in your stomach, kind of. Well it's not quite what it is but it's the easiest way for somebody to figure it out, or have a good idea." Without such a description it can be challenging, especially since easier approaches may not be considered appropriate. As Will noted "sometimes it's hard to explain exactly what Crohn's is, without telling them to read a book." Similarly, Bree explained:

I get called lame a lot because I don't drink and I would love people to understand that it's something that I have to do to ensure that I can function on a daily basis, so I would love more people to understand that. I would love, while I was in university to be able to

wear a shirt that says I'm not lame, I have a disease. But of course you can't just plaster that stuff and sing it out to people, so. (Bree, ulcerative colitis)

When given an opportunity by her teacher to explain her epilepsy to her peers in high school, Sheila found that the way she was treated by them changed significantly. Previously, she was treated as the "weird kid" by almost all of her classmates because her epilepsy related mannerisms coupled with a unique style marked her as different. Without explanation of the cause of much of this difference, Sheila's peers assumed that she chose to be different or "weird." However, following a description of epilepsy her peers came to view her difference in another light, and respect what she was able to overcome. Although explaining that she had epilepsy and what that meant did not result in the development of strong relationships with her peers, it did facilitate her ability to fit-in.

In addition to finding a way to communicate, young people also need to determine the depth of the information shared. As Bree explained, she is "faced with the difficulty of not only having to explain what I have, but to read the situation to know to what degree I should be explaining." When youth attempt to explain they must continuously read the situation to determine how much they should share.

People obviously notice if I work with them or they see me a lot.... I used to get blood work like every week so I'd always come in with the little gauze and whatever with my arm. And I would be open with the fact, I would tell someone, "well you know I'm not well," or "I had to get a lot of blood work done for medical reasons" and kind of leave it open. ...I say it in a way that people know that I'm open, but I don't want to tell them unless they actually want to know. So I can remember one instance when I used to work with this guy and I probably knew him for three summers. And by the third summer, one time when I mentioned I wasn't well he said, "you know, if you don't mind me asking what exactly is wrong with you?" And I just said "well, my colon is inflamed." And he was like, "oh god no good sentence starts with that." So I kind of left it up to people and, or kind of read the situation. Like if it was with a guy and I was saying, "you know one time when I was not well," and if I could read from their face that they were interested I could just say, "well I have ulcerative colitis which is an inflammatory bowel disease." And then if they ask questions like "well what exactly is that?" then I would explain. But if they didn't ask questions then I would leave it at that. (Bree, ulcerative colitis)

Everyone has different comfort levels and it'd probably be worse if there weren't those people who could handle knowing. And if everyone was like that, like if some people aren't ok with it, I have to respect that. At least they are there for you for certain things. (Chloe, ulcerative colitis)

As Bree and many of the people in the study indicated, it is not so much an unwillingness to explain that keeps them silent, but not knowing what others want to know. For example, Kerri pointed out:

I'm very open if I know people are curious or have questions. So anybody can ask me anything and I will tell them anything they want, but if you don't ask that's when it becomes more difficult because you don't know what somebody may or may not want to know. (Kerri, type 1 diabetes)

In some cases people are pushed to a point where the conversation ends in an uncomfortable manner, particularly when the other person is not willing to minimize the pain for the revealing person.

Other times the person doesn't really have any idea, and then you have to explain and then they kind of delve deeper into, "well so what exactly happens?" You go "well," and you don't want to just come out and say "I have to use the washroom a lot," so you kind of say, "well you know if I eat certain stuff my stomach will get upset, and I get a lot of bloating and inflammation." And they're like "but how does that make you sick?" And you basically at some point you have to end the conversation with, "well you know I have to crap a lot." And then there's the awkward silence in the room, and just kind of, ok I'll see you later type of thing. (Bree, ulcerative colitis)

On the other hand, some youth have friends who make it easy on them by eliminating the awkwardness of a conversation about a disease.

It's hard, it's really hard. The last relationship I was in it was fine, it was completely fine. He responded very well. I think he had a friend who was a physician so he asked a lot of questions from his friend. So he did a lot of research on his own and tried to figure what are long term implications, what does this mean. He responded quite well to it, which I was surprised about it. (Sarah, ulcerative colitis)

I also have friends who have said things like "what's wrong with you?" And I've said, "oh well I have ulcerative colitis" and that's been the end of the conversation. But, I'll

find out at some later point that they went home and researched it ... to kind of understand what I was going through without having to pry too much into my life. That has been kind of nice to show that they've taken the initiative to learn more about it. (Bree, ulcerative colitis)

A number of youth, such as Kristin and Bree, expressed a desire for an increase in public awareness of certain diseases as a way of limiting the awkwardness of social encounters. As Bree explained:

Well you can't really blame it on the person. It's a public misconception I guess, and that just means that people aren't being educated about it, or people who have it aren't talking about it, is I guess where really raising the awareness really comes from. So, it doesn't bother me that people don't necessarily know, or it does but, like I'm not really mad at the person in particular more at the general public for not getting it. ... I don't care if anyone knows what treatment I have but I just would like them to know, "ok she has to use the washroom a lot, her colon's inflamed, and there's nothing really that she can do about it so, whatever." I just don't like having to read the situation and try to guess, does this person really need to know that I'm going to have to crap 20 times a day or should I just stick with the, "oh my colon's inflamed" and see if they want to hear anymore or not. (Bree, ulcerative colitis)

Last, sometimes no information is thought to be better than limited information. Some participants expressed deep frustration over others believing that they understand a person's disease. For Kristin, a lack of understanding of diabetes is not her source of frustration, rather "it's the people who don't understand they don't understand." Reflecting on the challenges of playing basketball in high school, Kerri described a similar experience:

The other thing about playing basketball was the coaches. Sometimes the other players on the team were probably hyper vigilant [too]. ... I definitely found it frustrating at times when people think that they know me better than I know me. ... I was always open to the doctor telling me how the body works and why things go whatever way, and all that is good and great and I'd take that in and I'd learn it. But if you were going to tell me that my blood sugars were going to do something because this is what is supposed to happen, but I knew that's not how my body reacts, I get very annoyed. When people tell me, "no you sit." "I don't need to sit, I'm fine, I can still play." (Kerri, type 1 diabetes)

So, in both Kristin and Kerri's cases, frustration arose because of other people thinking that they knew enough about the disease to be involved. Further, the experience of having one person attempt to control or influence the management of another person's disease seems to be particularly frustrating when adults believe that they know more about a disease than affected youth simply because of their age.

Affecting Others

The ways in which other people respond to illness can have a profound impact on the affected person's ability to fit-in. Developing and maintaining relationships were more difficult for youth when others perceived their illness as an inconvenience or it made them feel uncomfortable. Following years of feeling guilty for having Crohn's, Tessa was sent by her parents to live with an aunt and uncle. She spoke about this as a turning point in her life because they were the first people to make her feel as though she was not an inconvenience or burden.

What really helped me was my parents sent me to stay with my aunt [in Toronto]. Her and her husband, the way that she treated it I loved it because, if I wasn't feeling well she'd say no worries it happens, you have a disease and you don't feel well. It wasn't like "oh my god, you're going to miss this, and what are people going to think." That's what my parents were like. I'm like "I can't eat that," and she's like "no worries. It is what it is, we can't change you, if there's anything we can help you with then great, otherwise don't stress out about it. There's nothing you can change about the situation, if you get sick you get sick. If you feel good, good." That's how I wished most people would treat it. ... So her and her husband really really really helped me in that capacity to rebuild my confidence. Because I'd always be so stressed out, oh my god I'm going to get sick, what are people going to think? (Tessa, Crohn's disease)

Friends who are willing to have conversations that involve talking about a disease without reacting negatively are also highly sought after.

My friend [Trish] really makes me it easier for me because I know that she is one of those people who you can always talk with. No matter what you say, she'll always listen, and I know she won't judge me or cringe away when you give details. I find that is what a lot of people do and you notice that it's making them uncomfortable. She's one of those people that won't get uncomfortable or who I don't feel that I should protect. My mom is

always there but if I see blood I can see her getting really worried about things happening. When I talk with [Trish] it's not like that. (Chloe, ulcerative colitis)

Although some friends may be willing to listen to stories of discomfort, there may be a limit. Victoria and Myra's quotes below allude to what can be called an "emotional economy of relationships." This basically means that over time there is an exchange of emotion that must generally remain in balance. When emotional exchanges become one-sided, people often become impatient.

I also had a friend, who's not a friend anymore, who constantly cracked jokes about how she was sick of hearing about me being sick, and [would say] "stop using it as an excuse." I found that very painful because I try everyday to put on a very strong face and not inconvenience anyone with anything I am going through" (Victoria, Crohn's disease)

Because I'm so aware of my body and how I feel and I always tell everyone "I feel this way, I feel this way right now." I like to communicate the way I feel physically to people. It's just so normal for me now. Sometimes they get sick of it, "Oh you're always complaining." (Myra, type 1 diabetes)

Recognizing this idea of an emotional economy, Melissa talked about how she manages how often she talks about Crohn's: "I think as long as I don't make my life out to be about 'all-IBD-all-the-time', then others don't perceive it that way either."

In addition to feeling inconvenienced by illness, feelings of discomfort also exist. When feelings of discomfort arise it appears as though many people tend to end relationships with their ill friends or family members. Mark's situation provides a clear example of this case. Following the onslaught of symptoms that developed from this multiple sclerosis, Mark described how his family responded:

I lost everybody. Everybody you think. I lost my family. [My younger sister] is the one that comes to see me. But, people got their lives, right? It's like you're dead but alive. People remember you but you're not the same person, so it's not the same anymore. They get on with their lives, and you wait for what's next. You scare a lot of people. I dropped probably about 35 pounds since I was diagnosed so I look a lot different now. A lot of my mannerisms are different now because MS puts big lesions on your brain, so it changes

the way you think, changes the way you act. I never notice it, but [others do]. People can't watch you go through the suffering. A lot of people can't watch you go through the suffering. You're not the same person anymore so it changes everything. Another aspect was my fiancé. I was with her for four years, like I said she was pregnant in August and due to the MS and what it does to you, how it changes you, she left me. She left me for another man. (Mark, multiple sclerosis)

He also described how a close friend responded over time:

I had a friend who lives down at the other end of the hall. I used to be really good friends with him, I used to see him all the time. Slowly over this past year he's been withdrawing because he's been watching what I've been going through and it scares him. Because like I said I was very active and then going to I'm not very active. Nine times out of ten, you call me up, I'm sitting right there [on the couch]. You're not the same person so it's not the same friendship. People get scared of tomorrow, what if, what if, what if. (Mark, multiple sclerosis)

Although it may be undesirable or difficult to fully minimize the discomfort felt by others, some people do make attempts to do so. For example, Patrick will ensure that he never makes others feel guilty for not ordering food that would suit his diet, and Elle discussed situations in which she has ate food that she knew would make her sick to avoid making others feel bad. Similarly, when Kristin is out having a meal with somebody for the first time, she makes sure she asks if others mind that she do her blood tests at the table, even if doing it on her lap.

Connecting with Similar Others

In many cases, young people connect with peers who have the same illness. This connection may happen following social rejection, to receive something they cannot from existing relationships, to learn more about a disease and upcoming challenges, or to help others. When young people have connected with others and developed relationships, they tend to describe the benefits of doing so enthusiastically. Both Will and Patrick talked about being able to open up with somebody in ways that you otherwise would not. In the absence of close friends

where she currently lives, Melissa said that the friends she met by volunteering with the Crohn's and Colitis Foundation have been

that shoulder to cry on, the listening ear, and that helping hand. They know what I'm going through and that just makes things so much easier I can talk to them about everything and not feel the slightest bit embarrassed when it comes to overly personal stuff, because there is a good chance that they have gone through the same thing, [and] if not have heard about it before. I also find it helpful when I'm able to talk them through or help them with something that they are going through. (Melissa, Crohn's disease)

When meeting someone else with the same illness, some people feel that they do not have to negotiate the initial awkwardness associated with revealing and explaining an illness. Rather, as Bree suggested, "there's an instant understanding. If you meet someone and they go, "oh yeah well I have IBD, or I have Crohn's or I have colitis," there's always "ok this person knows exactly what I have to go through." Instant bonding can follow for some people related to similar medications, treatments, surgeries, and embarrassing experiences. Bree equated the experience to meeting a Canadian in a foreign country and instantly having a number of experiences that can be shared.

In some cases, youth feel as though only people with a similar illness are able to understand them and fit with their lifestyle. At a time when other teens are engaging in common teen activities or embroiled with age appropriate concerns, youth with illness are faced with what they perceive to be more pressing issues. Thus, connecting with others who are also faced with similar challenges because of illness seems like an appealing alternative.

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)

This last summer was my most intense flare up and ... through that time it was a least six months that I was at home after the hospital, just really weak and couldn't do anything, I felt the pressure to go out. [My friends] were still into the club scene and I was totally out of that. They just couldn't understand and they were getting upset at me. ... I just had to

stop talking to them. I remember them trying to e-mail me. It's still very hostile kind of e-mails. It was like "How could you do this to us? How can you just not talk to us? What kind of friend are you?" I just had to let it go. There were two other girls who hadn't said anything but they were still part of that group and I had to let them go as well because they all hang out together. I think it was for the best. (Amy, Crohn's disease)

Although some people may take the step of organizing an illness based club and joining another established one like Amy did at university, others may 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, but was constrained because her parents could not afford the fee.

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)

Mark expressed a similar desire when he reflected on early experience with multiple sclerosis.

Referring to a place to go where he could meet people, he said:

It'd be great to see something out there. People are lost when they are told they have MS. Where do you go from there, what do you do? There's no book on it, there's nothing you can learn to prepare you for any aspect of it. It would have been nice to have something like that where I could have went where I could have talked to another 25 year old dude, and have him say "hey dude I understand what you're going through, it'll be alright, you'll sort it out you'll find your way." I didn't have any of that. ...If there's a dude saying "I understand where you're coming from"... It would have been great to have something positive when I was at my lowest lows. It would have been great to know someone who already went through it. I know it's a never ending thing but just to ease some of the confusion. (Mark, multiple sclerosis)

Interactions between people need not always be established relationships to be beneficial. They can also occur in less frequent and informal settings. Zach recalled giving advice to another twenty year old that also had rheumatoid arthritis before a regularly scheduled doctor's appointment.

She was at university and she had to stop playing soccer. She was playing university soccer, and this disease just went right through her and was destroying her joints and she had to stop playing and it was really bothering her. So the two of us kind of chatted for a while and just talked about it. It was set up too, it was an appointment where the two of us would sit together before we saw our doctors and we would just chat about what was going on; what was going on with my arthritis and what was going on with her arthritis. You know, “oh ya I’m on that medication now and oh this feels kind of shitty, I’m not feeling the greatest on it”. Or “I have to stop playing soccer.” I’m like “well you have to stop university but that doesn’t mean you have to stop playing recreational. I never stopped playing.” I think it was good for the two of us because that was the only interaction either of us with someone our own age with this disease. (Zach, juvenile rheumatoid arthritis)

The ways in which people prefer to interact with others may differ as well. For example, Kristin indicated that discussions with followers of her diabetes blog tend to be one sided. When I inquired as to what people asked her when they made contact, with surprise she said that most people don’t ask her anything. Instead, she receives “a long email and its like ‘this is my story, it really made me feel good to read about you, and I’m going to keep reading your blog.’”

Although a desire to meet similar others may be strong, it is tempered by others’ interactional styles and preferences. Referring to his experiences connecting with others online, Mark said:

It’s like people want to talk, but honestly nobody wants to talk back and forth. And when you do get someone who wants to talk back and forth, it’s a lot of whining. ... Obviously it sucks, we both know it sucks, obviously we’re both going through our own things, but tell me about the good stuff in your life that you’re able to do, and where you can go, and what you can do, and the escapes you have found with the restrictions you have now. I don’t know anybody who talks like that. Everybody who seems to have it, are really down on themselves. You don’t get the conversation you need. (Mark, multiple sclerosis)

As Kristin began taking control of her diabetes she was drawn to an online diabetes community to receive ideas on how to best manage the disease. Following her initial entry into the community by asking technical questions of other members, she quickly developed relationships

and received support. Over time though, she ended up leaving the community because of the negative feelings associated with comparisons.

The biggest problem I found for myself was I was doing too much comparison with people who were far more anal about it than I was, and I am pretty anal about my diabetes. It was too hard for me. I was having my diabetes nurse, my doctor, and everybody telling me I was doing a great job and feeling that I was doing so good everywhere else, but then I go on this forum and I'd be like oh my goodness why can't I get it better? I don't even want to tell these people about this because it's not as good as what they are. It was just too discouraging to be on there. (Kristin, type 1 diabetes)

Even when Kristin was online, she found that she controlled the information she shared because of the comparisons and evaluations made by others.

I know times when my blood sugars haven't been well controlled or when my A1C has been bad, then among other diabetics I have hidden how I'm doing. I've been on a few diabetes forums, one in particular online, and a lot of the people who end up on those end up being the micro-managers just because if you don't really care too much about your diabetes, why are you going to spend any time on a diabetes forum. So people on there a lot of the time have just excellent A1Cs. It's ridiculous, I don't even know how they could possibly get that good A1Cs. In those cases, I'm often less likely to talk details about my diabetes because I don't want that comparison. It's funny because when my blood sugars did start to improve, I did still feel weird about it because if I get what I think is a good reading or a good A1C, I know if I post it there is going to be some people going oh that's way too high. And there's other people who are going to be going, "oh that's so discouraging why can't I do that?" So you never really know how people are going to take it. ... There's so much judgment, and it's funny because we talk about judgment from outside the diabetes community but there's so much judgment within in it as well. (Kristin, type 1 diabetes)

Thus, as Kristin identified, the positive benefits many people receive from connecting with others may be reduced when social comparison exists.

Last, in some cases people want to avoid others with a similar illness because they do not want to draw attention to their illness. As Kerri explained:

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 1's. 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, may not be attractive to everyone because of the disruption it causes to feelings of normalcy.

In summary, the level of understanding of illness and the reactions of others to related symptoms can heavily influence how a young person experiences relationships and fits into their social world. A number of ongoing adjustments are often made depending on the situations in which youth find themselves in an attempt to maintain relationships threatened by limited understanding and perceptions of inconvenience and discomfort. One of the major adjustments made is the formation of relationships with others who have the same illness. Although some management may still be required in these relationships, they often provide benefits not found elsewhere.

CHAPTER V: DISCUSSION

This study was guided by the central research question addressed by the dissertation: how and when does chronic illness become a problem for young people in their everyday lives and what types of adjustments are made as a result? As previously noted, in addressing the research question, the analysis was shaped by a symbolic interactionist perspective and the related implications described in the previous section (e.g., Prus, 1996a). As discussed, the findings suggested that chronic illness threatens young people's ability to fit into their social world. In social psychological terms, experiences tied to chronic illness made *achieving identity* potentially problematic. The term "achieving identity" follows Prus's (1996) use of the term and is intended to reflect the idea that identity can have a "here and now" quality as well as a past and future quality, particularly in the experience of the individual. People may indeed have an identity at a given point in their lives even though that identity may also evolve as time passes and personal values and interests change. Further, use of the term in this way is consistent with the theoretical framework employed in this study – symbolic interaction (Fine, 1993; Prus, 1996a). As suggested by the findings and analyses presented in the previous chapter, achieving identity is not purely an individual undertaking as the sub-processes of managing appearances and reputations, accomplishing activities and experiencing relationships occur in relation to interactions with others (Prus, 1996; Sandstrom et al., 2010). For each of these sub-processes, threats to identity were first-hand occurrences or ones anticipated (Goffman, 1963; Mead, 1934). A number of situations and adjustments were also described whereby the individuals in this study sought to minimize potential threats to achieving identity.

The finding that achieving identity is potentially problematic for youth with chronic illness is consistent with previous research (Balfe, 2009; Hilton et al., 2009; Taylor et al., 2008)

but adds a much needed detailed description of the sub-processes involved and further connection to theory to help explain the lived experience of chronic illness in adolescence and emerging adulthood. The findings are also consistent with ethnographic accounts of living with a chronic illness in adulthood (e.g., Charmaz, 1991; Denzin, 1987; Karp, 1996; Schneider & Conrad, 1983), which in various ways highlight chronic illness as being potentially disruptive to identities. However, this study also extends and challenges previous work in a number of ways. First, the findings highlight the importance of accomplishing activities as it relates to achieving identity in chronic illness. The role of accomplishing activities, particularly involvement in leisure, has largely been downplayed in previous research on chronic illness (Kleiber et al., 1995 partially address this issue but much remains underexplored). However, as noted in the introduction, leisure can play an important part in identity formation and maintenance, which is a key component of psychological well-being (Mannell, 2007). Second, although research has indicated that chronic illness disrupts relationships (Taylor et al., 2008), it has not been very descriptive about the sources of discontent, possible exceptions to strained relationships, the types of adjustments people make to develop or maintain relationships, or the importance of relationships to achieving identity (Balfe, 2009). Third, focusing on adolescence and emerging adulthood facilitated a description of experiences with chronic illness that were situated in this period of life, while still highlighting differences in experiences between participants and their peers. The following sections summarize and elaborate upon the contributions made by this study.

APPEARANCES AND REPUTATIONS

Not too thin, not too overweight. No strange movements or untimely expressions of emotions. How young people 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 young people in this study were faced with the threats that chronic illness can bring to looking, acting and being considered normal. Thus, the challenges that chronic illness can create for young people's physical appearance, behaviour patterns, and reputations highlight the importance of the body in social interaction and in achieving identity (Balfe, 2009; Bourdieu, 1984; Goffman, 1963; Kleinman, 1988; Kohler Riessman, 2003; Sanders, 2008; Williams, 2000). These challenges and the efforts and success at being able to form and maintain identity were intimately intertwined with establishing romantic relationships, leisure involvements and self-esteem.

When some young people's bodies were altered during periods of chronic illness they experienced what has been labelled enacted and felt stigma (Goffman, 1963; Jacoby, 1994; Scambler & Hopkins, 1986). Enacted challenges related to participants' bodies were experienced when they encountered negative comments from some friends and family. For example, these enacted challenges were particularly difficult for some to deal with when they were blamed by close family members for their weight gain or loss, as was the case for people like Chloe, Juliet and Tessa. Behaviourally, participants experienced enacted challenges when family and friends (unfairly) accused them of not undertaking the correct course of action in illness management or recovery, family members had (unrealistic) expectations about their ability to present a normal self in public that was not sustainable, organizations sought to shape an ideal image of a person with their illness (i.e., desirable but in need of help), and social settings, particularly those involving food and drink exposed their behaviour as deviating from that of most youth.

Borrowing from Becker's (1963) concept "moral entrepreneurs," people and organizations involved in constructing or sustaining social rules related to physical and behavioural appearances could be called "appearance entrepreneurs." Foucault (1979) called these rules creators and enforcers the "judges of normality," but in his analysis focused much more on institutional practices and roles than the transmission of norms through social interaction with friends and family (e.g., Becker, 1963, 1982; Fine, 1987, 2004b; Prus & Irini, 1980). Friends and family featured prominently in the verbalized experiences of the participants in this study, however, the method and level of analysis likely brought to light the processes of social interaction over institutional practices.

When the existence of a person's illness becomes known to others, through physical or behavioural appearances or revealing, there is a risk that an illness reputation will develop. The development of an illness reputation means that people with illnesses become known primarily as a sick person, an outcome that featured prominently in many of the study participants' experiences. Hughes (1945) referred to this outcome as a "master status" and the idea is also applicable to other social categories such as gender, race, and sexuality (West & Zimmerman, 1987). The existence of a master status or illness reputation tends to dominate the definitions ascribed to people and has a transcontextual quality, unlike roles which are more situational (Goffman, 1959; West & Zimmerman, 1987). When people develop a reputation as being sick, others may draw on cultural scripts (Goffman, 1963; Fine, 2001; Fine & Fields, 2008) to shape their perception about the capabilities of a person who has an illness.

Participants in this study described their displeasure at being thought of as sick above everything else. This labelling process can occur before people (e.g., friends, employers) take the time to get to know the person. The result for many participants was other people's assumptions

that they were incapable of undertaking certain activities or that they were or would be unreliable because of their illness. Goffman (1963) referred to these assumptions as identity imputations, and he suggested that they lead to wide ranging attributions about people's character and competence. Although individuals may undertake steps to alter their reputation by informing others about their capabilities or pushing back against unfounded stereotypes, reputations may persist. Reputations may persist because alternative views of a person that are evident in their behaviours may be ignored by others (Bromberg & Fine, 2002). Referring to political reputations, Fine (1996) argued that reputations persist in part because of an absence of a credible alternative narrative. Thus, the unavailability of more positive illness cultural scripts, preconceptions about people with illness may persist.

As well as encountering this enacted stigma, felt stigma was experienced when participants anticipated being rejected by others because of their illness without encountering any stigma related challenges. For example, 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 behavioural public appearances. In these cases of felt stigma, participants described feeling as though others would not want them to inhabit public 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 nicely 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 behavioural expectations of people with chronic

illnesses. Indeed, research suggests that many young people in general 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, it could be concluded 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).

Sometimes, participants such as Amy acknowledged that their descriptions of felt stigma may be mostly perceived rather than real. Sometimes though, people's felt stigma is confirmed, as was the case when participants' bodies returned to pre-illness and closer to idealized states and other people indicated how much better they now appeared. However, some scholars have argued that felt stigma is much more common than enacted stigma, suggesting that the person with an illness is mostly imagining stigma (e.g., Scambler, 1989; Scambler & Hopkins, 1986). Evaluating the experiences of illness based on the amount and degree of enacted stigma risks downplaying the social influences involved in shaping felt stigma (Blumer, 1971; Nettleton, 2006). Individuals do not simply construct felt stigma on their own. Rather, felt stigma is a social product which is constructed, reproduced and altered through the transmission of prevailing cultural and subcultural values and norms (Becker, 1963; Goffman, 1963; Parker & Aggleton, 2003; Prus & Grills, 2003). Thus, notwithstanding suggestions that people with illness have a responsibility to reduce stigma through their own individual actions or learn to cope with existing stigma (Frank, 1991; Scambler, 1984), any actions aimed at reducing stigma must also treat it as a social problem.

Young people with illness may feel the need to avoid stigmatization generated by physical and behavioural public appearances and reputations by making a number of responses. The study participants' responses ranged along a continuum from social withdrawal to revealing illness, with a number of "covering" approaches in between. Specifically, the techniques employed were (a) withdrawing from social interaction (e.g., not engaging in romantic relationships, avoiding social leisure); (b) covering (e.g., wearing particular clothing, hiding pain); (c) passing-off the changes either directly or by allowing others to make their own assumptions (e.g., increased weight due to inactivity, being sick because of the flu); (d) attempting to change physical appearance through physically active leisure (e.g., exercising to lose weight or gain muscle mass, running to lose weight); (e) ignoring embarrassing situations that may draw attention to the illness (this was particularly possible with the help of friends, see also Goffman, 1959); and (f) revealing illness to stop wonderment about changes. The particular strategy chosen by participants was reflective of their interpretation of the approach that best allowed them to fit in, either immediately or over the near to long term. As Prus and Grills (2003) argued, "to the extent people associate identities with the treatment they receive, they tend to be concerned about maintaining acceptable images (especially avoiding disrespectability)" (p. 152).

Study participants' experiences with managing their appearances and reputations also have implications for how stigmatized identities are categorized. As previously mentioned, 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). Being discreditable means that a person has the ability to cover their illness in the presence of people they encounter but risks being stigmatized if such actions

are not taken. Thus, the central concern is preventing stigmatization 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. In the case of being discredited, people may seek to minimize stigmatization by managing tensions during social interaction (Goffman, 1963).

Prus and Grills (2003) observed that the transition from being discreditable to discredited depends on one or more of “(a) people’s abilities (and willingness) to conceal aspects of their situations; (b) the astuteness of their audiences; (c) inopportune discoveries; and (d) self-disclosures” (p. 82). Although these four processes are consistent with the experiences of the participants in this study, arriving at a description of them using Goffman’s (1963) classification system may involve consideration of additional factors. In this study, four particular issues existed for the young people. First, challenges resulted from substantial weight gain or loss tied to illness symptoms or associated medication altering their appearances. As changes to study participants’ weight rarely went unnoticed and often drew unwelcomed comments from peers and family, they were forced on an immediate basis to respond to the situation. Thus, chronic illness typically described as discreditable may be better described as being somewhere in between discreditable and discredited when bodily changes draw attention but are potentially concealable. Further, it is important to recognize that longer-term adjustments may be made by people with illness to reduce or eliminate the likelihood of future changes to one’s physical appearance.

Second, although it may be tempting to apply fixed categories to particular illnesses, such as people with multiple sclerosis are discredited and people with diabetes are discreditable, this

approach is not necessarily consistent with the ebbs and flows of chronic illness experiences as described in this study (see also Charmaz, 1991, 1995; Kelly, 1992). When participants were experiencing periods of remission, through medication, surgery or good fortune, their physical appearances returned to the way they had been before illness developed or were more consistent with a “normal” state. Thus, in these situations participants might not be considered discreditable as they are not attempting to cover anything but their past. However, when symptoms worsened for those participants who experienced periods of remission and relapse, they once again were faced with being somewhere in between discreditable and discredited. Third, the experiences of young people and adults with chronic illness relative to being discreditable or discredited should be distinguished in certain cases. Although adults with illness cannot be easily categorized in a collective manner, because some illnesses such as Parkinson’s disease or multiple sclerosis may result in one being discredited (e.g., through the use of a wheel chair), younger people with these same illnesses often do not experience the same physical limitations as their illness has not progressed to that stage yet. Thus, it may not be until adulthood that younger people with progressive chronic illnesses that cause a change in physical appearances are faced with the challenges of being discredited.

Fourth, Goffman (1963) appears to have suggested that it is advantageous to avoid being discredited because of the resulting consequences of stigma. Although this may fit with the views held by most people with chronic illness, some noteworthy exceptions also exist. In this study, a few participants described the functional role that physical markers play in eliciting compassion from others. For example, Juliet experienced the compassion she was looking for from her bosses and co-workers in relation to her recent pain caused by fibromyalgia when she was wearing a cast, but as soon as the cast came off they no longer understood how she could be

in pain. Similarly, Emily who has multiple sclerosis found that because she did not have bags under her eyes or other outwardly visible markers, other people could not understand the seriousness of her neurological condition. Further, participants such as Kerri and Bree described experiences in which applying for support for persons with disabilities was made difficult because they lacked the visible aspects commonly associated with disability. Even when people did experience substantial changes to their appearance through changes in weight, the seriousness of chronic illness was not recognized because weight gain or loss is more frequently attributed to other causes, such as inactivity and over- or under-eating. Thus, there are cases in which young people feel as though they would benefit from being discredited.

The main ideas reflected in the theme of managing appearances and reputations are summarized in Figure 1. As shown, many participants experienced some type of physical, behavioural and/or reputation related challenges due to their chronic illness. The perception of these challenges then led to interpretations by the people they encountered in their daily lives. In many cases, these perceptions resulted in other people viewing the person with the chronic illness as not being normal. Others' perception of normality seemed to be influenced by factors such as societal expectations (e.g., what a body should look or act like), encounters with appearances entrepreneurs (i.e., people who have an interest in shaping and enforcing normal appearances), and the presence or absence of alternate stories of what a person with an illness is capable of doing. When participants were not perceived as being normal, they experienced forms of enacted and felt stigma. The ways in which participants were perceived by others was an important factor in their ability to achieve identity. When participants felt as though instances of enacted and felt stigma were a threat to their ability to achieve identity they responded in one of six ways. The particular ways in which they responded, ranging along a continuum of openness,

that is from withdrawal to revealing, was based on their interpretation of what would allow them to best fit into their social world. Responses were not universal, but varied depending upon the situation with which the person was faced.

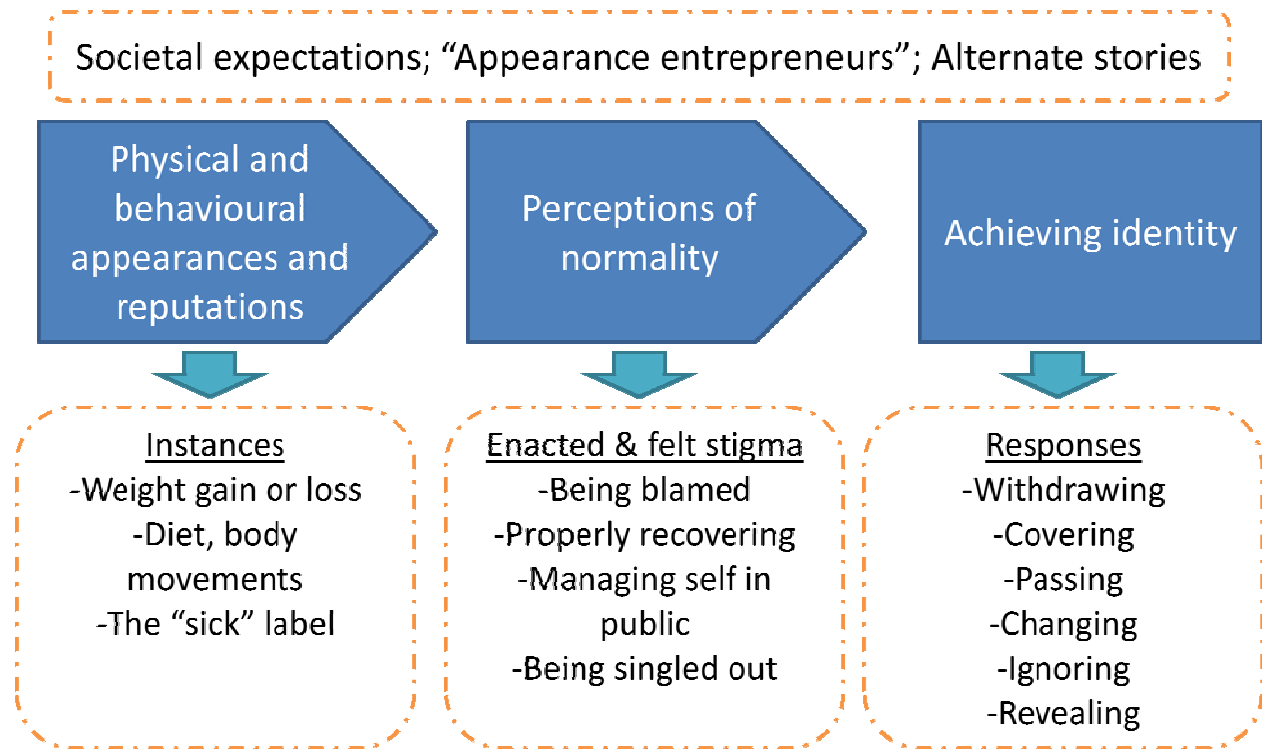


Figure 1. Summary Model of Managing Appearances and Reputations

ACCOMPLISHING ACTIVITIES

Being able to engage in desired activities such as leisure, school and work play an important role in making people feel as though they have a place in their social world (Arnett, 2004; Erikson, 1963; Kroger, 2007; Shaw et al., 1995). Research suggests that engagement in activities plays a role in achieving identity when people connect with others in a particular setting tied to the activity, receive recognition from peers because of engagement in certain activities, and/or compare their involvement in activities to personally or socially desirable

images or life paths (Adler & Adler, 1998; Arnett, 2004; Evans & Eder, 1993; Fine, 1983, 2001; Goffman, 1963; Green & Chalip, 1998; Kivel & Kleiber, 2000; Prus & Grills, 2003). Echoing previous research, participants in this study described in various ways the importance of accomplishing desired activities to their ability to achieve desired identities. The participants also described the challenges of accomplishing desired activities and their effect on their ability to achieve and sustain identities.

Although involvement in leisure was the most prominent type of activity featured in participants' experiences, they also discussed the importance of work and school life to achieving identity. By focusing on young people with chronic illness and identifying the processes involved in achieving identity, this study contributes to the literature addressing the challenges of achieving identity through activities for various population groups (e.g., Henderson, Bedini, & Hecht, 1994; Johnson, 1999; Johnson & Samdahl, 2005; Kivel & Kleiber, 2000; Lewis & Johnson, 2011). Previous research in leisure studies has focused heavily on leisure as a source of identity exploration and achievement because of the relative freedom of choice involved with leisure, and leisure activity as an expression of an underlying identity (Kleiber, 1999; Mannell, 2007).

Comparably, much less attention has been given to the problematic nature of achieving identity through leisure or other activities. Further, although constraints to participation in leisure have been extensively examined in the literature (Godbey, Crawford, & Shen, 2010; Mannell & Loucks-Atkinson, 2005), constraints theory has not typically been extended to understanding the challenges of achieving identity through leisure and the strategies used for overcoming these challenges (Kleiber et al., 2011). An exception was a study of people with spinal cord injuries reported by Kleiber et al. (1995) who suggested it might be worth exploring the idea that leisure

constraints themselves are influential in shaping people's identities. This suggestion still seems to hold promise, and although the present study did not adopt a constraints theory framework, the findings provide some insight into the processes involved.

This study also contributes to research that attempts to examine changes in leisure involvement over time (e.g., Carpenter, 1997; Iwasaki & Smale, 1998; Scott & Willits, 1998). Some researchers have argued that research on leisure and health related issues has not contributed to the description and explanation of patterns of change in behaviours, constraints and experiences during the life course or portions of it (Charmaz, 1983; Carpenter & Robertson, 1999; Mannell & Iwasaki, 2005; Paterson, Thorne, Crawford, & Tarko, 1999; Snelgrove & Havitz, 2010). Thus, this study with its use of interviews that focus on past and recent illness experiences (e.g., Charmaz, 1991; Christian & D'Auria, 1997; Karp, 1996; Schneider & Conrad, 1983), contributes to understanding how initial experiences with chronic illness change over time, including an identification of some of the factors that contribute to those changes. An analysis of the participants' responses indicated that the meanings they attributed to their illness experiences and how these meanings evolved over time were largely consistent with those found in Charmaz's (1991) study on serious chronic illness in adulthood. Thus, to facilitate theory development in this area (Glaser & Strauss, 1967; Prus, 1987, 1996), I have employed terms similar to those used by Charmaz (1991) to describe the experiences of the young people in this study relative to their engagement in activities (i.e., illness as interruption, immersion, and intrusion). More importantly though the use of these terms described well the meanings participants ascribed to their experiences.

Specifically, when illness symptoms were first experienced by the participants in this study, they defined their illness as an intrusion into their daily lives. Illness was viewed with

great uncertainty, trepidation and with the hope that it would not last. As initial symptoms were typically accompanied by fatigue or discomfort, participants were constrained in undertaking daily activities they described as highly meaningful, such as playing sports and music, attending school, hanging out with friends, or going to work. 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; Iso-Ahola, 1986; Kleiber et al., 2011; Wood & Danylchuk, in press). However, among the participants, these substitutions were viewed as less personally meaningful and enjoyable activities, even by those participants self-described as aficionados of the new activities. Importantly, substituted activities were defined in a much more negative light when they were engaged in alone than with friends. Participants could be clearly distinguished on the basis of those who had friends who were accommodating and willing to travel to the person's home compared with friends who were not willing to do so. Thus, even though the leisure activities undertaken with friends in their homes were the same as those undertaken on their own, the connection to friends was an important element. It should be noted though that these types of social activities were still thought of as much less desirable than other activities done outside of the home. Further, participants who had accommodating friends stands in contrast to the picture painted by much of the research on chronic illness among youth that emphasizes overwhelming social challenges (see Taylor et al., 2008).

Following participants' initial illness experiences there was a transition whereby they came to experience their chronic illness along a continuum ranging from minor interruption to full immersion (Charmaz, 1991). Chronic illness as minor interruption means that young people

were able to adjust their lives to meet the demands of illness and engage in desired activities. The additional physical and mental work required in dealing with the illness was more of a nuisance that required minimal adjustment to engage in and enjoy activities. Importantly, this transition from initial intrusion to minor interruption was not only associated with a return to desired activities, but the connection between the activities and their ability to achieve desired identities. That is, through their engagement in activities participants began to feel as though they once again had a place in their social worlds, both in the present moment and looking forward. The amount of time it took for people to progress towards perceiving their illness as minor interruption varied and is likely the product of a number of factors. The factors that coincided with this transition will be discussed in the subsequent section on adjustments and coping.

In contrast to experiencing illness as minor interruption, some participants' experienced a state of immersion whereby their lives were engulfed by the illness (Charmaz, 1991). Following initial intrusion, the transition to immersion involved extended periods of time when young people were not able to engage in desired activities because of physical or mental constraints. Psychological distress was characteristic of extreme states of immersion as some participants viewed their lives as not worth continuing. 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-in-action" (p. 293). Thus, this finding is consistent with Kleiber et al.'s study of adult's experiences with spinal cord injury. Their findings highlighted the relevance of activities in achieving identity. However, the findings of this study contribute to a temporal dimension to understanding the experience of illness by describing the progression from intrusion to interruption or immersion. More broadly, the present study reinforces the relevance of studying constraints to

leisure as being a threat to identity achievement and exploration (Kleiber et al., 1995; Mannell, 2007).

In less extreme cases of immersion, 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 (e.g., Csikszentmihalyi, 1991; Fine, 2001).

In attempting to make their illness a minor interruption to their lives, a number of strategies were undertaken by participants and in some cases these strategies were supported by close friends and family. Two key strategies were developing outlooks and learning to alter routine activities. Both cognitive and behavioural elements are identifiable in the two strategies (Iwasaki & Mannell, 2000; Kleiber et al., 2011). The strategy of developing outlooks itself involved two approaches and are consistent with Kleiber et al.'s (1995) remarks that "the course of recovery, the road to wellness, is shaped through an awareness of what one still can do in making life meaningful and enjoyable" (p. 297). Additionally, selective optimization with

compensation theory (SOC; Baltes & Baltes, 1990) can help explain the participants' use of these strategies. Although this theory is typically utilized as a framework for understanding successful aging, it also seems to apply to the participants in this study. SOC theory holds that one's overall health and well-being can be positively influenced by self-regulation and the adaptation of activities particularly when people are faced with limitations to their involvement. More specifically, individuals select and prioritize goals based on decreased abilities, optimize participation in activities through regulation (e.g., improving skills, increased self-efficacy), and compensate by adapting and modifying activities when faced with restrictions (Janke, Jones, Payne, & Son, in press). For example, Janke, Son and Payne (2009) found that positive health outcomes resulted for adults living with arthritis when they applied SOC strategies to their engagement in leisure.

One approach undertaken by participants that is related to Taylor et al.'s (2008) theme of "getting on with life" included changing expectations of their performance in activities. For example, as a way of facilitating enjoyment that is tied to success in an activity, some participants lowered their expectations relative to their performance in sports. These types of actions are a type of "optimization" strategy. Second, undertaking a "selection" strategy some participants changed perspectives and came to value their ability to perform activities that were once taken for granted - activities such as doing dishes, grocery shopping, going for a walk or sitting through class. Participants' change to valuing their ability to undertake what were previously seen as mundane non-leisure activities has received limited attention in the literature. In fact the present findings contrast with those reported by Shannon and Shaw (2005) in a study of women breast cancer survivors that highlighted a devaluing of non-leisure activities in favour of individual leisure. This finding about the meanings attributed to various activities re-

emphasizes the need to attend to people's own meanings about certain activities instead of presuming that certain activities are better than others or less meaningful when accomplished. The approach of changing outlooks also highlights the call Spinoza made some years ago for a fundamental shift in thinking to focus on what a body can do, rather than what it should do or cannot do (Deleuze & Guattari, 1987).

Changes in outlooks were influenced by three processes. First, participants compared themselves to others with the same illness who they perceived to be in worse shape. This comparison lead them to feel as though life could be worse and that they needed to make the best of their situation. Suls et al. (2002) referred to this process as a downward comparison and it can act as a powerful coping strategy in many contexts other than ones involving chronic illness. Second, participants were able to adopt a positive outlook on life relative to their illness when they had past life experiences to draw on such as family tragedies or other life challenges that taught them how to deal with the challenges of chronic illness. This latter finding is consistent with the findings of research on the coping strategies adopted by young adults dealing with cancer (Kyngas et al., 2001).

Third, parents were influential in shaping participants' thoughts about their selves relative to their peers, promoted opportunities to participate in activities, and encouraged adopting an approach to life that involved a stoic control of emotions. The latter approach, a control of emotions, is an approach that may have positive and negative consequences. Positive outcomes could include adopting behaviours that help young people fit into their social world or develop a psychologically beneficial view of dealing with negative life events. However, a negative outcome could be that a stoic approach may suppress the potential psychological benefits of emotional expression (Frank, 1991; Hochschild, 1983). Thus, promoting the control of emotions

in this context must be approached with care. Moreover, the family unit could be regarded as a social institution that plays a role in shaping participants' use of emotion. In most cases, parents sought to influence their children's emotions as a way of helping them adapt, and therefore their efforts could be viewed as a positive act. However, it seemed as though some parents also had an interest in shaping an image of their children and by extension their family through the use of normalized emotions. Borrowing Trussell's (2009) terms, they sought to "uphold team family." Future research would benefit from delving deeper into the family unit as a source of positive and negative influence on youth's emotion work in the context of chronic illness.

In addition to developing outlooks, participants also learned to alter their routine activities as a way of being able to accomplish desired activities. That is, they engaged in "compensation" strategies (Baltes & Baltes, 1990). The change in routine activities that were most prominent were learning to take medications, pursuing activities that minimize symptoms, and dealing with pain. The process of altering routine activities has been addressed in previous research on young people with illness (Taylor et al., 2008) but it has been typically described in isolation rather than as being a part of a desire to accomplish activities and achieve identity. Notably, learning to take medications typically started with the help of parents and then transitioned to individual care as participants aged. The impetus for this transition with age were (a) parents who pushed for the transition to promote an adoption of responsibility, (b) lifestyles that were incongruent with receiving parental support, and (c) a push for autonomy by participants. These findings are consistent with previous research (e.g., Hilton et al., 2009; Taylor et al., 2008; Zebrack, 2011). The medical model is often, and probably justifiably, the focus of disdain by social scientists for its inattentiveness to other relevant factors that contribute to one's health and well-being, and for over emphasizing the need to "get better" as featured in

Parson's (1951) sick role concept. Importantly, though, medication and surgery played an important role in facilitating participants' ability to engage in desired activities. In turn, involvement in desired activities, as previously discussed, play an important part in helping young people achieve identity. Also important to note is that dealing with pain as a way of accomplishing desired activities was typically experienced as only "successful" in the short term and risked becoming a dangerous approach in the long-term unless accompanied with a reduction in the overall number of activities pursued and/or other stress reduction techniques.

A summary of the theme accomplishing activities is presented in Figure 2. Participants initially experienced illness as an intrusion. As initial symptoms were typically accompanied by fatigue or discomfort, participants were constrained in undertaking daily activities they described as highly meaningful, such as playing sports and music, attending school, hanging out with friends, or going to work. During this time, leisure activities that were easier to engage in were substituted, such as watching television and movies. Following this initial stage, participants could be described as falling somewhere along a continuum ranging from "illness experienced as a minor interruption to the accomplishment of desired activities" to "full illness immersion" whereby their lives were engulfed by the illness. In between these two extremes were the stages of illness as "interruption" and "mental immersion in illness". Two main factors, along with a number of sub-processes, were identified that contributed to understanding participants' placement along the continuum. These factors were participants' ability to develop outlooks and alter their routine activities in ways that facilitated engagement in desired activities.

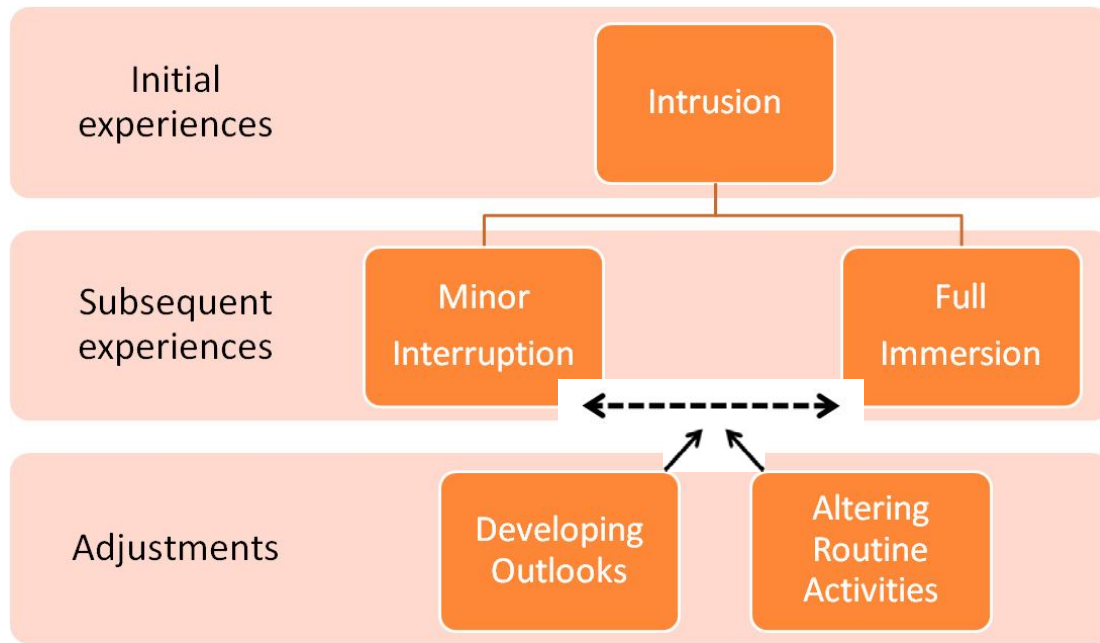


Figure 2. Summary Model of Accomplishing Activities

EXPERIENCING RELATIONSHIPS

The development and maintenance of relationships is characteristic of people's engagement in their social world and are influential in the process of achieving identity through social interaction (Mead, 1934; Prus, 1996a). When existing relationships are disrupted or new ones are made difficult to develop, people can experience a threat to achieving and maintaining identities (Kroger, 2007). Research on stigma and chronic illness highlights the importance of relationships in the identity process for people with illness (e.g., Charmaz, 1991; Goffman, 1963; Hilton et al., 2009; Karp, 1996; Nicholas et al., 2007; Schneider & Conrad, 1983; Sneath et al., 2001; Woodgate, 2005; Zebrack, 2011). However, typically this research does not provide a description of these relationships, including the source of difficulties, and provides little conceptual or theoretical connection to other sociological or psychological research (Notable exceptions are work by Charmaz, 1991 and Goffman, 1963). Thus, this study seeks to contribute

to the literature in addressing how and when chronic illness is implicated in young people's relationships. Specifically, two main factors were found to contribute to how young people with illness experienced relationships: (a) the level of understanding about illness held by the people they encounter and with whom they interact, and (b) how others feel about the impact that people with illness have on their lives.

Understanding Illness and Relationship Management

A lack of understanding of participants' illnesses by the people in existing or potential relationships was a major source of distress. This lack of understanding was manifested in misperceptions about the contagiousness of illness, perceiving limitations to their abilities in leisure and school settings, mistaking symptoms for other causes especially socially undesirable ones, and blaming them for acquiring the illness. All of these misunderstandings contributed to isolation from peers and family and/or reduced feelings of self-worth. Most alarmingly, misunderstanding was most prominent in long established relationships with friends, family, employers or organizations. Although the concepts of misunderstanding illness and blame have been most commonly addressed in the literature in reference to illnesses such as lung cancer, AIDS, depression or anorexia (Chapple & McPherson, 2004; Crandall & Moriarty, 1995), they also play an important role in a number of the chronic illnesses represented in this study.

Participants' experiences suggest that responding to a lack of understanding by informing others about an illness can work to help young people develop and maintain relationships with their peers, but it must be approached strategically. This strategic process identified in the present study has not been reported in previous research that has dealt with chronic illness as being a challenge in relationships (e.g., Taylor et al., 2008). As people respond to openings that allow them to explain their illness they must contend with the difficulty of finding suitable

descriptions or analogies and the challenges of assessing and interpreting others' comfort or interest levels in further explanations. In short, sharing one's "illness story" (Frank, 1995) is a learning process. Everyday interaction is certainly a "dance" in which people continually interpret the actions of others and choose topics and forms of discussion based on its perceived suitability for the audience at-hand (Goffman, 1959). The difficulty of finding the "right" words to describe "what one has" highlights the incommunicability of illness (Karp, 1996). Participants in this study struggled with finding the right analogies to describe their illness in a way that did not require full disclosure of details they perceived to be personally discrediting. The challenge of explaining illness was likely heightened because audiences were typically other young people who, in general, possess less knowledge about illness than adults. In some ways, these challenges of explanation parallel those difficulties faced by other social groups, such as explanations of lived experiences tied to race or sexuality (Karp, 1996).

Although comparatively less common, it should be noted that some explanations of illness, only reduced the negative backlash from peers rather than heightening young people's social status or ability to fit-in and connect with peers. This finding is consistent with previous work on adolescent peer relations that showed young people who had low social status were able to reduce or eliminate negative treatment from peers by challenging held perceptions, yet this negative reduction in treatment did not serve to increase their status to the extent that they became friends with these peers (Brown, 2004; Evans & Eder, 1993; Merten, 1996). In sum, statuses were upgraded from "intentionally isolated" to "tolerated and forgotten."

In addition to determining how to describe illness when the opportunity arises, people are also faced with determining what others want to know and to what degree. As illness conversations began, participants described adjusting their "scripts" (Goffman, 1959) by level of

detail based on their interpretation of the interest of the audience. Sometimes these adjustments worked and “face” was saved, and other times audiences were turned off and turned away from future conversations. As interactions are not one-sided, it should be recognized that non-stigmatized people also experience uncertainty and trepidation, not knowing what to say or how to say it (Cahill & Eggleston, 1995; Goffman, 1963). Thus, both sides play an important role in minimizing potential discomfort arising from illness based conversations. Lacking an understanding of the preferences of others, participants were more likely to remain silent waiting for others to signal their preference. The literature on disclosure typically frames revealing and discussing as a problem of anticipated stigma (Frank, 1991; Goffman, 1963; Hilton et al., 2009), but findings from this study suggest that break downs in interpersonal communication also play an important role.

In contrast to experiences tied to a lack of understanding, many participants described friends and family who compensated for their lack of understanding by seeking out information on their own, asked questions of the person to learn more, already possessed some basic knowledge about the illness, or drew on their life experiences to provide support. Three groups of people emerged, and can be described as “the newly learned,” “the life experienced” and “the wise.” Despite Karp’s (1996) contention that people who have not experienced an illness “can’t get it,” participants in this study discussed a number of situations in which they felt comfortable with the responses of others following their explanations. Although participants’ associates may not have fully grasped what it means to have a particular illness, they were able to develop an acceptable level of knowledge. This group of people who had no previous experience with the illness or comparable life experience can be termed “the newly learned.” This finding is consistent with previous research which found that adolescents and emerging adults with illness

were able to discuss illness experiences with peers who had no previous experience with their illness (Hilton et al., 2009; Woodgate, 2005, 2006). However, as that research did not identify the processes by which youth navigate early and ongoing understandings, this study contributes to the literature by addressing some of the processes involved.

A second group of people termed “the life experienced” consisted of friends of the study participants who possessed a general understanding of dealing with difficult life situations based on past life experiences. Some of the negative life experiences included having a parent who was sick or had passed away, experiencing conditions such as anxiety themselves, or dealing with parents who divorced. Young people with illness were able to relate to these friends despite their lack of specific knowledge of their illness. Participants were particularly drawn to romantic partners who had this type of “insider knowledge” because of the empathy they demonstrated. In addition to the newly learned and the life experienced groups, there are people who possess direct knowledge about illnesses because of certain circumstances such as their jobs in the case of health care workers or educators, and those who have had other family or friends with illness. Goffman (1963) termed these types of people “the wise.” The wise were featured in a number of participants’ lives and were received in mixed ways. When the wise consisted of romantic partners (e.g., in the process of becoming doctors) they were comforting and empathetic towards participants and showed interest in learning more about their symptoms and illness. Alternatively, when the wise were not romantic partners, they were much more a source of discontent as they sought to influence their medically-based behaviours (Foucault, 1979) rather than being a source of meaningful support or connection.

Most often, participants did not know anyone else with the same illness during the initial stages of their illness. Instead, they tended to seek out similar others as part of the coping process

later on (see also Sandstrom, 1990), particularly when they did not have or were unable to develop and maintain relationships with the learned, the experienced, or the wise. Although some connections with similar others happened unintentionally, the majority of relationships formed were as part of an intentional process whereby participants sought out opportunities to meet similar others by joining illness based organizations or volunteering in certain settings. Iwasaki and Mannell (2000) termed this coping strategy “leisure companionship.” This type of leisure initiation by participants, then, was a response in part to a lack of understanding among friends about illness. When connecting with similar others participants described not having to negotiate the awkwardness and embarrassment felt from explaining illness and related symptoms because they perceived there to be an instant understanding. Further, youth with illness are faced with pressures that they perceive to be more serious than the typical concerns faced by their peers. This disconnection can make it difficult to relate to some friends making similar others appealing associates.

Involvement in organized leisure contexts by young people with illnesses is consistent with previous research on leisure coping (Iwasaki & Mannell, 2000) and work focused on youth and adults living with illness (e.g., Evan et al., 2006; Glover & Parry, 2009; Parry, 2008; Snelgrove, Wood, & Havitz, 2010). However, much of the illness-related work has focused on the positive and negative outcomes that result from leisure participation of this nature, and less attention to how these connections address social challenges such as a lack of understanding. So, although leisure companionship can help reduce stress associated with individually focused failure (Iwasaki & Mannell, 2000), it can also address challenges resulting from “societal failures,” such as a lack of understanding of illness. Participants in this study viewed opportunities to connect with similar others as a crucial step towards their ability to fit into their

social worlds (Iwasaki & Mannell, 2000), and when participants were unable to make desired connections with similar others because of a variety of constraints, such as a lack of money or limited awareness of opportunities, they expressed regret and felt as though they were missing out on a valuable experience.

Much like building relationships with non-ill friends by negotiating understandings of illness, the process of connecting with similar others is not without challenges. The finding that connecting with similar others, particularly through leisure companionship, can lead to negative outcomes has been found in previous research (e.g., Glover & Parry, 2008, 2009; Snelgrove et al., 2010). However, limited attention has been given to this issue in research on youth and chronic illness, especially an identification of the processes that make it challenging to connect with similar others. In the context of friendships centered on infertility, Glover and Parry (2008) referred to these processes as “obstructive actions.” Within this study, participants described connections with similar others as a negative experience when (a) negative emotions arise from repeated conversations about negative aspects of illness instead of positive aspects (see also, Glover & Parry, 2009; Goffman, 1963), (b) social comparison makes people feel as though they are not doing as well as their peers who also have illness (see also, Suls et al., 2000, 2002; Glover & Parry, 2008) and (c) being with similar others draws unwanted attention to one’s illness and thereby threatens their desire to present a normal self (see also Snelgrove et al., 2010).

In summary, the sub-theme of understanding illness and relationship management is represented in Figure 3. As participants attempted to form and maintain relationships with others as a key part of fitting into their social worlds, some were limited by a lack of understanding by others of chronic illness. As noted, a lack of understanding was manifested in perceptions by

others of contagiousness, stereotypes about illness limitations, seeing symptoms the result of more onerous causes, and blaming participants for acquiring the illness. All of these instances were unjustified and tied to a lack of understanding. Responding to a lack of understanding by informing others about an illness helped participants develop and maintain relationships with their peers, but it had to be approached strategically. As participants responded to openings that allowed them to explain their illness they contended with the difficulty of finding suitable descriptions or analogies and the challenges of assessing and interpreting others' comfort or interest levels in further explanations. Participants were also faced with determining what others actually wanted to know and to what degree. As illness conversations began, participants described adjusting their "scripts" by level of detail based on their interpretation of the interest of the audience. In contrast to experiences tied to a lack of understanding, many participants described friends and family who already possessed some basic knowledge about the illness, dealt with their lack of understanding by seeking out information on their own, asking questions of the person to learn more, already possessed some basic knowledge about the illness, or drawing on their life experiences. These groups of people could be labelled "the newly learned", "the life experienced" and "the wise" respectively.

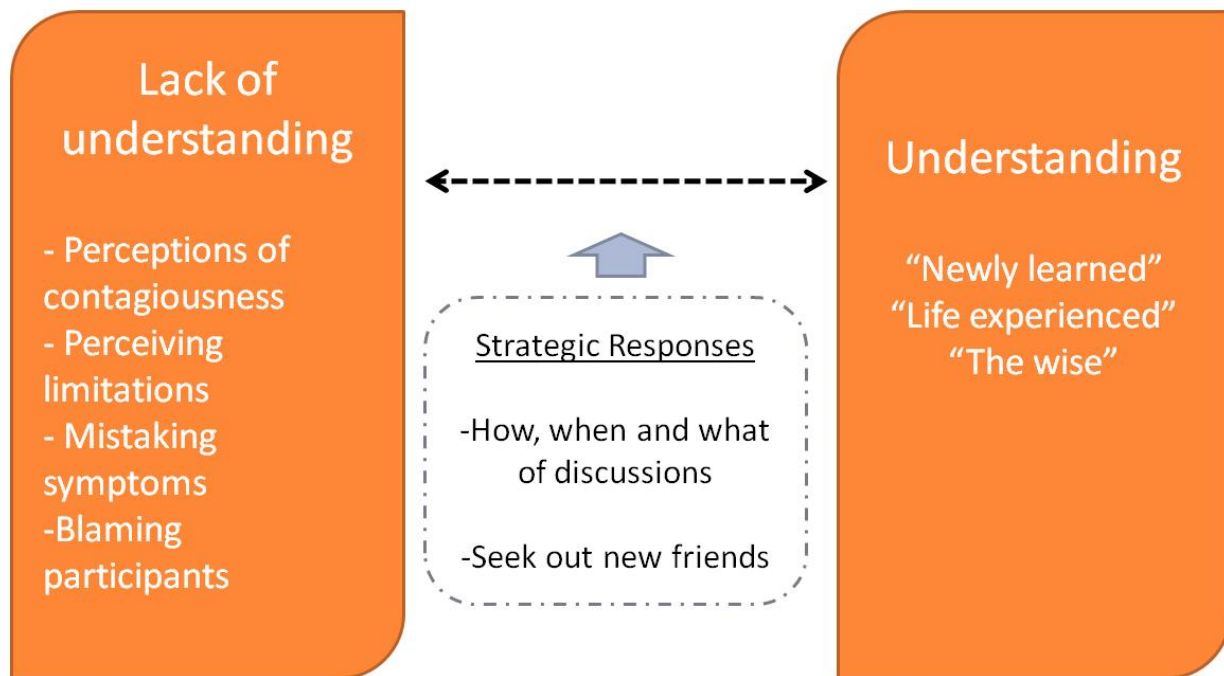


Figure 3. Summary Model of Understanding Illness and Relationship Management

Affecting Others and Emotion Management

The degree to which other people felt affected by participants' chronic illness also impacted relationships. Developing or maintaining relationships were more difficult when others perceived the ill person to be "emotionally draining." As previously discussed, symptoms and social challenges associated with chronic illness can result in behaviours that are not typical of people without illness. For example, people with illness may appear less energetic or they may discuss their feelings more often than others. Responding to these expressions of emotion, friends and family may withdraw or push back suggesting that the person stop complaining or "suck it up." These responses by friends and family were described by participants as occurring over time, indicating a one-sided build up of emotional exchange. Clark (1987, 1997) described this exchange of emotion as part of an "emotional economy" in which sympathy and other forms of expression are employed as currency (see also Hochschild, 1983; Fine, 2001). Thus, if one

person in a relationship feels as though the exchange of emotion is not as desired (not necessarily in balance as people may accept imbalance) they may force change or end relationships.

Experiencing first hand the power of emotional economy or envisioning potential consequences, a number of participants made adjustments to their behaviours. Participants actively managed their expressions of emotions to avoid people perceiving that their lives are about the illness all the time. Ultimately, this emotion work seeks to maintain relationships. Similarly, Charmaz (1983) suggested, “[if] they openly reveal their suffering, show self-pity, guilt, anger or other emotions conventionally believed to be negative, they are likely to further estrange those who still take an interest in them” (p. 191).

An exchange of emotions was not always the result of verbal expressions, as feelings of discomfort also occurred in watching participants go through bodily or behavioural changes or experience symptoms on a sustained basis. Although it is difficult to assess the thoughts of the “others” referred to by the study participants as only people with illness were interviewed, some participants perceived others to be afraid when watching them and others experience illness. Also, as Mark, a study participant, described it, “you’re not the same person, so it’s not the same friendship.” That is, some people cannot adjust their view of the person to sustain the friendship. So, this emotional exchange over time also points to importance of examining the history of relationships and situating definitions of emotions within the context of those relationships (Fine, 1998; Prus, 1996a). Thus, it becomes an “emotional disease” situated in the present and past.

In sum, the potential importance of emotions and emotion management in participants’ experiences with chronic illness was evident in the role they appeared to play in the maintenance of relationships with friends and family and in helping participants fit into their social world and form identities. As previously noted, participants’ control of emotions was shaped by the people

around them and the meanings developed in the various situations in which they found themselves. However, although I originally thought that the concepts of emotions and emotion work would be useful sensitizing concepts (see Chapter 2), they proved to not be as helpful in understanding participants' experiences with chronic illness as anticipated. As previously noted, future research on emotion work could focus on the family unit and emotional exchanges within dyadic relationships to more fully explore the potential role of emotions in the chronic illness experience.

Reflecting on the use of symbolic interactionism as the framework for this study, I believe that it was a useful framework and guided me to be sensitive to and examine aspects of the participants' experiences with chronic illness that had explanatory power and led to important insights. Specifically, participants' experiences highlighted the roles that social interactions, perceptions about others' beliefs and likely actions, and the creation of meaning play in shaping identities, emotions, and experiences with leisure, work and school. Blumer's (1971) suggestion that a "social problem exists primarily in terms of how it is defined and conceived in society" (p. 300) seems consistent with chronic illness being a problem because of how it is conceived and responded to by others, and in turn how others' perceptions and actions take on meanings with real power and influence on the person with an illness. Further, participants' experiences with chronic illness often changed over time as they adjusted to their illness and social environment. Social interaction, socially constructed meanings, and ongoing changes in people's experiences are all key facets of symbolic interactionism (Blumer, 1969; Prus, 1996a). Thus, although the study findings were shaped by the use of a symbolic interactionist perspective as described in chapter three, they are also consistent with the way that participants in this study described their experiences.

CONCLUSIONS

This study sought to provide a description and theoretical analysis of how and when chronic illness can become a challenge for adolescents and emerging adults and the adjustments made as a result. The findings suggested that the main challenge for young people with illness is achieving a desired identity. The ability to develop and maintain desired identities has been identified as an important part of people's psychological well-being (Mannell, 2007) but the chronic illness-identity process had not been addressed in detail by researchers for young people living with a chronic illness. Being able to achieve a desired identity was tied to three processes. These processes included participants' ability to manage their appearances and reputations, accomplish desired activities, and experience positive relationships. As previously noted, most adolescents and emerging adults to some degree face these same challenges in attempting to achieve desired identities. However, experiences associated with chronic illness can intensify these challenges. Although these three processes are common across the experiences of most young people, the factors that contribute to them being a challenge seem to be unique to those living with a chronic illness (e.g., fatigue, lack of understanding of illnesses).

The findings also suggest that participants' experienced chronic illness in varied ways. Many of the adjustments and factors that contributed to these differences, including how people's experiences changed over time, were identified. With respect to the sub-theme, accomplishing activities in particular, these adjustments and factors could be called leisure constraint negotiation strategies, although some of the activities that study participants wished to accomplish were work or school related. Leisure constraint theory has focused primarily on explaining leisure participation although there have been calls for expansion of the theory to explain leisure experience (e.g., Henderson & Ainsworth, 2002). Also, leisure constraint theory,

while recognizing that negotiation strategies can be classified as behavioural or cognitive (Jackson & Rucks, 1993), does not identify the actual nature of the specific strategies that might be adopted or employed by different types of individuals with different life experiences in different social or cultural circumstances (Mannell & Iwasaki, 2005). The present study makes a contribution by identify a number of specific strategies and the processes involve that young people with chronic illness use to help them engage in desired leisure activities. Further, leisure constraints research has been critiqued as being atheoretical (Jun & Kyle, 2011) because it has provided little connection between constraints and underlying concepts or processes that explain behaviours and experiences (e.g., motivation, identity). Thus, this study also makes a contribution by explaining constraints and negotiation strategies in the context of achieving identity.

The identification of these specific adjustments has important implications for the design of programs and leisure spaces for this population group. Indeed programs that teach strategies for adjusting to illness, bring together people with similar illnesses, and create opportunities to participate in desired forms of leisure are needed. However, as the findings demonstrated it should be recognized that some young people with illness will not want to participate in these types of programs because it threatens their ability to achieve identity. Further, at a public policy level there appears to be a need to enhance understandings of illness, and ensure that young people with illness receive opportunities to participate in leisure, work, and school in ways that recognize the personal and social challenges they face.

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 achievement of desired identities in leisure,

work and school contexts for other groups of young people (e.g., Kivel & Kleiber, 2000; Shaw et al., 1995). Second, a particularly interesting avenue for future research stems from the finding that social judgment exists within illness communities. In keeping with a symbolic interactionist approach, this type of social judgment could be examined within a larger study of the activities of illness communities. The types of illness communities identified in this study were those created online, through organized leisure settings such as volunteer organizations or recreation camps, and informally in hospital settings. All of these three settings are underexplored by researchers. Further, within an analysis of these communities, other important areas could be addressed such as the long-term outcomes derived from involvement and the elements of a program or organizations' design that contribute to desired outcomes. Third, as this study did not focus its examination on dyadic or group relationships, future research is needed to address the emotional economy of relationships in the context of young people living with chronic illness on a more detailed basis. Both close friendships and the family unit would be fruitful focal points. The findings from this study, along with other related research (e.g., Ellis, 1995), may serve as a point of departure that sensitizes the researcher to potential issues worth exploring.

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APPENDIX A: STUDY WEBSITE

Study on Teenagers and Young Adults' Experiences with Chronic Illness

Welcome to the website for a study on teens' and young adults' experiences with chronic illness in everyday life. I really appreciate your interest in being a part of this research. Without your involvement this study would not be possible. As someone who has had ulcerative colitis since I was 10 years old, I understand the medical and non-medical challenges associated with illness. While a lot of research continues to be conducted on the medical aspects of illness, very little research has asked teens and young adults about their non-medical experiences.

Developing an understanding of these experiences may help others, such as family and friends, understand the challenges people with illness face and the ways people are able to adjust their lives. Through this study, I am interested in talking to teens and young adults (16 to early 30s), like you, about how your life is impacted by your illness. Following the completion of my PhD, I intend to produce a book based on this research.

If you choose to be involved, and live in Southern Ontario (e.g., Toronto, London, Waterloo) it would be great to chat with you in person. I'd be happy to meet you at a convenient location. If you live outside of these areas and would like to participate we could chat by via phone or e-mail.

All information you provide is considered completely confidential. Your name will not appear in any thesis or book resulting from this study, however, with your permission anonymous quotations may be used. If you have any questions regarding this study, or would like additional information to assist you in reaching a decision about participation, please contact me by email at rsnelgro@uwaterloo.ca. You can also contact my supervisor, Professor Roger Mannell at 519-888-4567 ext. 35404 or email mannell@uwaterloo.ca.

I would like to assure you that this study has been reviewed and received ethics clearance through the Office of Research Ethics at the University of Waterloo. However, the final decision about participation is yours. If you have any comments or concerns resulting from your participation in this study, please contact Dr. Susan Sykes of this office at 519-888-4567 Ext. 36005 or ssykes@uwaterloo.ca.

If you would like to participate please send me an e-mail: rsnelgro@uwaterloo.ca

I look forward to speaking with you!

Ryan Snelgrove
PhD Candidate
University of Waterloo



APPENDIX B: INFORMATION LETTER

Date, 2011

Name

Address

City, Province

Dear (*insert participant's name*):

This letter is an invitation to consider participating in a study I am conducting as part of my PhD in the Department of Recreation and Leisure Studies at the University of Waterloo, under the supervision of Professor Roger Mannell. While a lot of research continues to be conducted on the medical aspects of illness, very little research has asked teens and young adults about their non-medical experiences. Through this study, I am interested in talking to teens and young adults, like you, about how your life is impacted by your illness. To learn more about the study and me, I encourage you to visit the study's website at:

www.ahs.uwaterloo.ca/~rsnelgro/illness

Participation in this study is voluntary. First, it will involve an interview of approximately one hour in length to take place in a mutually agreed upon location. You may decline to answer any of the interview questions if you so wish. Further, you may decide to withdraw from this study at any time without any negative consequences by advising the researcher. With your permission, the interview will be audio recorded to facilitate collection of information, and later transcribed for analysis. Shortly after the interview has been completed, I will send you a copy of the transcript to give you an opportunity to confirm the accuracy of our conversation and to add or clarify any points that you wish. Following the interview, you will be invited to continue an electronic discussion to follow-up on previously discussed topics, and provide you with an opportunity to identify any other points of interest related to this study.

Although, there are no anticipated risks to you as a participant in this study, I suggest that if you do experience any negative feelings, you speak to your family or contact Counselling Services at the university (519-888-4567, ext. 32655, www.adm.uwaterloo.ca/infocs). **[This section will be altered depending on the participant, e.g., K-W Counselling Services: kwcounselling.com]**

All information you provide is considered completely confidential. Your name will not appear in any thesis or report resulting from this study, however, with your permission anonymous quotations may be used. Data collected during this study will be retained for a period of 5 years in a locked office at the University of Waterloo. If you have any questions regarding this study, or would like additional information to assist you in reaching a decision about participation, please contact me by email at rsnelgro@uwaterloo.ca. You can also contact my supervisor, Professor Roger Mannell at 519-888-4567 ext. 35404 or email mannell@uwaterloo.ca.

I would like to assure you that this study has been reviewed and received ethics clearance through the Office of Research Ethics at the University of Waterloo. However, the final decision about participation is yours. If you have any comments or concerns resulting from your participation in this study, please contact Dr. Susan Sykes of this office at 519-888-4567 Ext. 36005 or ssykes@uwaterloo.ca.

I very much look forward to speaking with you and thank you in advance for your assistance in this project.

Sincerely,

Ryan Snelgrove
PhD Candidate
University of Waterloo
rsnelgro@uwaterloo.ca

APPENDIX C: CONSENT FORM

By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

I have read the information presented in the information letter about a study being conducted by Ryan Snelgrove of the Department of Recreation and Leisure Studies at the University of Waterloo. I have had the opportunity to ask questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that I have the option of allowing my interview to be audio recorded to ensure an accurate recording of my responses.

I am also aware that excerpts from the interview may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous.

I was informed that I may withdraw my consent at any time without penalty by advising the researcher.

This project has been reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo. I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact Dr. Susan Sykes, Director, Office of Research Ethics at 519-888-4567 ext. 36005 or ssykes@uwaterloo.ca.

With full knowledge of all the foregoing, I agree, of my own free will, to participate in this study.

YES NO

I agree to have my interview audio recorded.

YES NO

I agree to the use of anonymous quotations in any thesis or publication that comes of this research.

YES NO

Participant Name: _____ (Please print)

Participant Signature: _____

Witness Name: _____ (Please print)

Witness Signature: _____

Date: _____

APPENDIX D: FEEDBACK LETTER

University of Waterloo

Date

Dear *(Insert Name of Participant)*,

I would like to thank you again for your participation in this study. As a reminder, the purpose of this study is to understand teens and young adults' daily experiences with chronic illness.

The information collected during interviews will contribute to a better understanding of the various ways that teens and young adults adjust their lives to meet the challenges associated with illness.

Please remember that any data pertaining to you as an individual participant will be kept confidential. Once all the data are collected and analyzed for this project, I plan on sharing this information with the research community through seminars, conferences, presentations, and research articles. If you are interested in receiving more information regarding the results of this study, or if you have any questions or concerns, please contact me or my supervisor at the email addresses listed at the bottom of the page. The study is expected to be completed by June, 2011.

As with all University of Waterloo projects involving human participants, this project was reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo. Should you have any comments or concerns resulting from your participation in this study, please contact Dr. Susan Sykes in the Office of Research Ethics at 519-888-4567, ext. 36005 or ssykes@uwaterloo.ca.

Best wishes,

Ryan Snelgrove
PhD Candidate
University of Waterloo
Recreation and Leisure Studies
rsnelgro@uwaterloo.ca

Dr. Roger Mannell
Professor
University of Waterloo
Recreation and Leisure Studies
mannell@uwaterloo.ca

APPENDIX E: A DESCRIPTION OF THE CHRONIC ILLNESSES REPRESENTED IN THIS STUDY

Although variation exists within the following illnesses, a general description is presented below to provide the reader with some sense of the characteristics of each illness. These descriptions are not intended to provide a full representation of the physiological aspects of each illness.

Anaphylaxis: a broad term referring to a serious allergic condition that may be life threatening if not treated quickly.

Celiac disease: a condition that is characterized by a damaged lining of the small intestine that prevents the absorption of essential nutrients. The disease is exacerbated by the consumption of gluten.

Crohn's disease: a chronic inflammatory disease of the intestines, most commonly in the small intestine. When not in remission, common symptoms include diarrhea, fatigue and abdominal pain.

Epilepsy: a disorder in which multiple seizures occur and are caused by electrical discharges in the brain.

Fibromyalgia: a condition characterized by long-term widespread body pain in the joints, muscles, and tendons.

Juvenile rheumatoid arthritis: an arthritic condition developed by children and characterized by joint inflammation, joint stiffness, and joint damage.

Lupus: a chronic autoimmune disease characterized by one or more body parts (tissue or organ). Approximately nine times more women are diagnosed with lupus than men.

Multiple sclerosis: an autoimmune disease that affects the brain and spinal cord, and includes relapse-remitting and progressing forms.

Type 1 diabetes: a disease in which the pancreas does not produce enough insulin, which is needed to transfer glucose from the body's blood to the body's cells for energy use.

Ulcerative colitis: a chronic inflammatory disease of the large intestine. When not in remission, common symptoms include diarrhea, fatigue and abdominal pain.