EVERYONE POOPS BUT NO ONE WANTS TO TALK ABOUT IT: THE LIVED EXPERIENCES OF YOUNG PEOPLE WITH INFLAMMATORY BOWEL DISEASE

by

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Abstract

Crohn’s disease and Colitis, the two most common Inflammatory Bowel Diseases (IBD), are on the rise among young people. IBD symptoms include severe abdominal pain and frequent bowel movements, which can result in major dietary restrictions and delays in growth. IBD can also limit people’s physical activity, eating habits, and activities that are distant from a bathroom. Having IBD can be both limiting and embarrassing but little research has investigated the social and emotional implications of these diseases from a qualitative approach. Existing research fails to identify how stigma and dominant IBD discourses affect the lived experiences of people with IBD, young people in particular. IBD can create additional challenges for adolescents because it is perceived to threaten their normal development into healthy adults. The purpose of this project is to investigate how being young complicates the already difficult experience of being ill.

I conducted interviews with three young people and a discursive analysis of official IBD resources for adolescents and found almost no descriptions of the actual experience of illness. Participants who engaged in photo-elicited interviews minimized the physical and emotional repercussions of having IBD. Informational resources designed for youth failed to address the severe physical and emotional pain of Crohn’s and Colitis. Instead, the available resources provided saccharine and arguably unrealistic depictions of IBD that deny young people a forum to express their own struggles. I compare my analysis of the interviews and IBD resources with my own experience and experiences presented in a zine. Analysis of both the interviews and the IBD resources reveals that young people with IBD can experience an embodied disappearance. Their bodies are smaller and weak, they retreat from social situations to avoid embarrassment, and their emotions are denied because they have no forums to be expressive. Finally, young people can experience a compounded disappearance because they are treated not for who they are but for what they should become. I argue that enabling young people the opportunity to speak candidly about the social conditions that contribute to their struggles could help them better understand, negotiate, and express their illness experiences.
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Prologue

I was diagnosed with Crohn’s at the age of thirteen after living with chronic abdominal pain, constipation, fatigue, weight loss, and bouts of unremitting fevers for two years. These symptoms are characteristic of Crohn’s Disease, an inflammation of the intestines that falls under the broader medical category of Inflammatory Bowel Disease (IBD). Since my diagnosis I have been subject to a variety of invasive tests and treatments including an array of potent medications with a host of side effects that are arguably as difficult to cope with as the disease itself. I endured middle school and two years of high school with a feeding tube protruding out of my abdomen, which promised me healing and growth that I am still waiting for. It also resulted in extreme hunger, countless topical infections, and a constant stream of stomach acid that leaked out from around the apparatus to soak my clothes and burn my skin. I have had over six gastroenterologists physically examine the inner workings of my body, three surgeries losing 10 inches of my intestine, and a two month stay at the Children’s Hospital of Eastern Ontario. I understand how difficult and distressing living with inflammatory bowel disease can be.

Three years ago, I wrote my undergraduate thesis, a critical autoethnography that deconstructed the medical field and investigated the power relations that existed between my young self as a Crohn’s patient and the medical and adult authorities that I felt subjugated by. At that point in my life, I was severely ill and receiving little relief from traditional medical therapies. I was losing weight by the day and was living off chocolate soy milk and pretzels because they were the only foods that I tolerated and found even remotely palatable. I suffered from constant abdominal pain and was running to the bathroom upwards of ten times a day with bloody and painful stools. I was frustrated and angry as my doctor kept prescribing increasingly more potent medications with no relief. Since he could not help me, I wondered what I could do for myself. Writing my thesis and changing my diet enabled me to figure that out.
The opportunity to understand the power relations that mediated my illness experience and realize my personal power motivated me to take charge of my health through a change in diet. The book *Breaking the Vicious Cycle* by Elaine Gottschall (2007) outlines a diet that can relieve people of their IBD symptoms. Gottschall asserts that people can enjoy disease relief, if not remission, by removing processed sugars and grains from their diet. Writing my thesis and better understanding the shortcomings of the medical field gave me the desire and motivation to follow through with this limiting and time consuming diet. While my change in diet has not enabled total remission, I have experienced significant improvements in my health and currently rely on no pharmaceutical drugs.

I focused my undergraduate thesis on the subjugation that I had to negotiate as a result of being chronically ill and young but scarcely spoke about how living with Crohn’s disease made me feel emotionally. I failed to acknowledge the times when I felt helpless and dejected from having no control over my body and its erratic functions. I did not speak of the shame that I felt when I could not sit still in my hard school chair because of the hemorrhoids and excruciating anal fissures that I endured as a result of having chronic constipation. I never admitted to crying myself to sleep every night as I pleaded with God to tell me what I what I could have possibly done at the age of 13 to deserve this hell. Those stories were lost in my grand narrative of subjugation by the powerful institution of medicine; those feelings were rarely acknowledged let alone reconciled.

Studying young people was particularly important for me because I have always felt that living with IBD as a child or adolescent was far more complicated than an adult. Being young with little authority over your own body arguably compounds the experience of having little control over your body’s functions and feelings. Receiving little allowance to be a social actor and agential in your own lived experiences would arguably complicate how young people perceive and articulate those experiences.

I knew that I wanted to further research the lived experiences of young people with IBD, not only because of my own insights but because the emotional repercussions
of these illnesses do not seem to be well understood. The research on young IBD patients’ psychosocial functioning is largely quantitative and based in psychology. Statistics and surveys do not capture the narratives or elucidate the struggles of those who are dealing with such difficult issues. Upon reading the existing, albeit scarce, literature on the social and emotional effects of illness, it was apparent that my lack of insight into my own feelings rivals the empirical minimization of others’ emotional experience. There seems to be a pervasive silencing amongst both medical populations and those who live with these illnesses. I knew that I wanted to further investigate this silence.
Chapter 1

Introduction

In the following section, I outline the general and limited empirical understanding of how adolescents are thought to experience IBD. Within the research, both the physical and emotional repercussions of being young and living with Crohn’s or Colitis are addressed but without the detail that effectively captures the severity or the gravity of these illnesses. I address the small body of literature on the psychosocial functioning of adolescents with IBD to expose its shortcomings in effectively illustrating a comprehensive depiction of what it means to be young and live with IBD.

1.1 The IBD Experience?

Inflammatory bowel disease (IBD) is the umbrella term for Crohn’s disease (CD) and ulcerative colitis (UC) which are both chronic and invasive illnesses that compromise the digestive system. Crohn’s disease specifically affects all parts of the digestive tract, causing inflammation anywhere from the mouth to the anus while ulcerative colitis is more localized within the large intestine (Mackner, Wallace & Crandall, 2005). Symptoms generally include abdominal pain and frequent diarrhoea, malnutrition, weight loss, and fatigue (Borgaonkar & Irvine, 2000; Moody, Eaden & Mayberry, 1999). IBD is characterized by periods of remission and relapse which can occur without warning (Engstrom, 1999).

Crohn’s and colitis are on the rise among children and adolescents with 20-30% of diagnoses occurring in patients under the age of 20 (Benchimol, Guttman, Griffiths, Rabeneck, Mack, Brill, Howard, Guan, & To, 2009). There has been a significant increase in juvenile IBD
cases in Ontario, from 42.1 in 100 000 in 1994 to 56.3 in 2005 (Benchimol et al, 2009). Ontario has one of the highest rates of childhood onset IBD, both nationally and globally. There is no known cause of these illnesses but there are a number of speculations, both medical and lay, as to what the cause might be which include genetics, diet, environment, and stress (or some combination thereof).

Children and youth face additional challenges compared to adults when they live with IBD. Due to nutrient malabsorption and a lack of appetite, young IBD patients are affected by inhibited growth and delayed puberty (Mackner, Wallace & Crandall, 2005). Young people with IBD can be smaller in both height and weight than their peers, which can be particularly challenging in adolescence (Mackner, Wallace & Crandall, 2005).

1.1.1 Young People’s Emotional Experiences of IBD

Current scholarship is in agreement that living with IBD as a young person is emotionally troublesome, resulting in poorer psychosocial functioning and increased risk of anxiety and depression. The research is limited by a reliance on quantitative methods that do not enable insight into narratives of young people who live with the disease. Moreover, the majority of the literature seems to pathologize young people’s emotional troubles and behaviours by determining that emotions are in and of themselves medical problems. To the best of my knowledge, there is only one recent study that employed qualitative interviews with young people with IBD to gain a sense of their emotional experiences (Nicholas, Otley, Smith, Avolio, Munk, & Griffiths, 2007). In this section, I review the existing literature showing how little is understood about the emotional experience of IBD among young people and how inadequate and problematic the medical discourse is.
The majority of IBD literature suggests that IBD can result in both social and emotional problems for children and adolescents (Engstrom, 1999). Current research identifies that poor social and emotional functioning as well as lower self esteem are common issues that young people with IBD face (Mackner, Wallace & Crandall, 2005). Being physically smaller than peers, having to use the bathroom frequently, and dealing with the unpredictability of IBD are concerns that are thought to compromise young people’s ability to effectively socialize. Health related quality of life, which includes people’s psychosocial functioning, is also thought to be adversely affected by IBD (De Boer, Grootenhuis, & Derkx, 2005).

Given such social limitations, young people with IBD are apparently more vulnerable to a variety of emotional problems including body image concerns, lower self esteem, and depressive disorders (Engstrom, 1999; Mackner, Wallace & Crandall, 2005). One study found that young people with Crohn’s disease are more at risk of depressive symptoms and psychological problems than other young populations with different chronic illnesses (Rabett, Elbadri, Thwaites, Northover, Dady, Firth, Hillier, Miller, & Thomas, 1996). Children and youth with Crohn’s and colitis are also more likely to experience depression and eating disorders (Mackner, Wallace & Crandall, 2005). Rabett et al (1996) label some young people with Crohn’s disease as neurotic.

There is no doubt that young people with IBD suffer from significant emotional and social challenges due to their illnesses but the aforementioned literature acts to further pathologize their struggles. While the social situations that mediate young people’s emotional struggles with IBD are recognized, the majority of existing research suggests that young people with IBD suffer from subsequent medical problems that warrant more medical intervention. The focus turns to
the psychological problem itself, not the particular emotional struggles of these young people or
the social factors that mediate their experiences.

To the best of my knowledge, only one study interviewed young people to investigate their
particular emotional struggles with IBD. Nicholas, Otley, Smith, Avolio, Munk, and Griffiths’
(2007) qualitative study delved deeper into the lived experiences of young people with IBD.
They used semi-structured interviews with 80 children and adolescents recruited through a
children’s hospital database. The participants discussed having negative self-perceptions and
feeling helpless and vulnerable. Many of the participants shared feelings of social isolation,
embarrassment, and upset due to being physically different from their peers. Nicholas et al
(2007) also found that the participants expressed confidence in their ability to overcome the
struggles of their illness which seems contradictory to the other concerns echoed.

While Nicholas et al (2007) describe the emotional experiences of young people with IBD,
they, like other researchers, neglect the limitations placed on young people and the social stigma
of living with particularly embarrassing illnesses. Dealing with such agonizing diseases is bound
to result in complex and possibly paradoxical emotional reactions that warrant further attention.
Further research should continue to account for young people’s particular narratives and insights
to better understand these tensions. In order to effectively do so, research should also begin to
seriously consider how social factors mediate and complicate young people’s struggles with
IBD.

1.2 Talking Shit

Developing a more comprehensive understanding of young people with inflammatory
bowel disease involves understanding the social factors, in addition to the physical and
emotional, which mediate how they perceive and react to their experiences. Despite the prevalence of Crohn’s and colitis in Canada, these illnesses are not relatively well known or at least they are not talked about. This comes as no surprise given how disgusting and embarrassing the symptoms of these illnesses are. Uncontrollable diarrhea, vomiting, and gas are not alluring topics of everyday conversation.

Dealing with erratic and foul bowel functions and fluids can be particularly challenging not only because of the physical pain that they cause but because of the stigma surrounding bodily fluids, more specifically poo. It seems as if there are no words that effectively describe excrement without making it seem overly medicalized or terribly vulgar. Despite the fact that defecation is a natural and universally shared human process, it is a source of disgust and private shame. Good people don’t air their shit in public.

Such a notion can be particularly troubling for those with Crohn’s and colitis, two chronic illnesses that are defined by erratic and frequent bowel movements. Living with an illness that involves constant attention to the bowels and bottom can result in emotional distress. While research on childhood and adolescent inflammatory bowel disease focuses on such adverse emotions, there is an apparent lack of shit talking. It seems that despite the fact that everyone poops, no one wants to talk about it, not even researchers.

Taft, Keefer, Leonhard, and Nealon-Woods (2009) investigated the effects of stigma on how people make meaning of IBD. They used a perceived stigma scale survey which determined that people with IBD identify that stigma has an effect on their emotional experience with illness. The survey allowed them to identify that stigma was a part of the illness experience but did not elucidate the nature or severity of that stigma. Taft et al (2009) explain the shortcomings of their study and state, “Since the nature of chronic illness stigma is complex and part of a broader
integrated model of biopsychosocial influences on patient outcome, it is not surprising that its
effect is relatively small by definition” (p. 1231).

Another study investigated the gender differences of perceived stigma amongst people
living with irritable bowel syndrome (IBS) (Dancey, Hutton-Young, Moye, & Devins, 2002).
IBS is a condition that is considered to be milder and less pathological than IBD but shares
similar symptoms. Dancey et al (2002) also employed survey methods and could not find any
significant gender disparities. Such findings seem inadequate given that women are often more
prohibited from speaking about foul and vulgar subject matter. Quantitative methods are quite
limited in their capacity to help us understanding the nature or severity of stigma and the process
of making meaning from experience. In-depth qualitative methods are required to understand the
effects of the particular stigmas and social assumptions that mediate the experience of having
IBD as a young person.

1.3 Research Question

The goal of my research is to articulate a more comprehensive understanding of the
adolescent experience of Crohn’s disease and ulcerative colitis. My research seeks to answer the
following questions:

How do young people negotiate dominant discourses of Inflammatory Bowel Disease?

How does being young compound the experience of being ill with IBD?

1.4 My Study, My Voice
The purpose of my thesis is to investigate the experiences of living with inflammatory bowel disease as a young person. I engaged participants in open-ended interviews that I hoped would enable them to speak candidly about their emotions, insights, and experiences. I also analyzed a selection of IBD resources to better understand what discourses are represented in materials targeting young people so that I could compare discourses with participant experiences and my own. Doing so will provide a better understanding of the social forces that mediate individual experiences. My study will contribute to the existing research by providing a more comprehensive and in-depth understanding of young people’s experiences of IBD.

I have included my own voice and perspectives as they relate to the adolescent experience of IBD. It has been my ongoing struggle with Crohn’s disease that prompted me to continue research in this field. As a result, I cannot remove myself from this topic or my perspectives from the research process and I make no efforts to do so. Instead, I have included narratives from my adolescence throughout this paper to substantiate, corroborate, and in some cases challenge the discourses being propagated. To negotiate my position as a Crohn’s patient, a former adolescent, and a researcher, I have engaged in meaningful reflection on my own history to acknowledge not only how I understand the participants’ experiences but also how they helped me realize my own struggles and silencing.
Chapter 2
Theoretical Framework

I examine discourses of childhood & adolescence and health, illness & emotions from both interactionist and poststructuralist perspectives to develop a framework for understanding the embodied illness experience. Discourses, which will be discussed in further detail later in the review, are widely accepted beliefs within a society that are deemed to be truth. Understanding how constructions of health and illness affect both self and society helps us explicate how individual bodies experience chronic illness. Understanding dominant discourses of childhood and adolescence shows how being young complicates the embodied experience of being ill.

2.1 Childhood & Adolescence

In this section I explore the discourses, the widely accepted beliefs of childhood and adolescence, that contribute to what it means to be young. The discourse of the child as “becoming” justifies adult intervention to ensure healthy development while the discourse of the adolescent as “at risk” suggests that young people are disciplined and protected from harmful environments and events that might compromise their healthy development. Consequently, childhood and adolescence are already medicalized periods within the life stage. The following review will elucidate the unique lived experiences of children and youth who not only live with the stigma of chronic illness but also the subjugating status of being young.

2.1.1 Complicating and Conflating Constructs of Childhood and Adolescence

The following review critically deconstructs notions of childhood and adolescent development. Consequently, I have not defined them as distinct developmental stages nor have I
conceptualized them as independent of one another. I reference both populations together as young people. Doing so seemed especially necessary as IBD can result in issues such as delayed growth and difficult emotions, both of which complicate normal expectations of childhood and adolescence.

### 2.1.2 Assumptions of Childhood and Adolescence

Traditional child and youth research emerged from developmental psychological perspectives that pathologized the experience of being young. The development from childhood to adolescence to eventual adulthood became a universal, traceable, and measurable phenomenon. Cognitive progress, physical growth, and emotional maturity became dependent on stages based on one’s age. According to James and Prout (1997), this shared developmental trajectory deems childhood to be a natural phenomenon that, “governs and is governed” by its universality (10). Discourses regarding “natural” and “normal” emerged from the belief in a universal trajectory of development.

The belief that all young people follow a universal developmental trajectory has resulted in a discourse that deems children as “becoming adults” and adolescents as “at risk”. This discourse is unquestioned in the field of medicine. The following explores these discourses as well as their implications for young people.

### 2.1.3 Discourses of the Child as “Becoming” and “At Risk”

The discourse of the child as becoming constructs young people as a work in progress, incomplete, innocent and vulnerable to environmental and social factors that might inhibit sufficient physical and cognitive development. The assumption that children are becoming adults places young people in a position where they are incomplete and inferior to the fully developed adult (Lesko, 2001). Consequently, being young warrants vigilant control and
monitoring to ensure that young people develop into healthy, fully formed, and fully functional adults. When the end goal is a healthy and productive adult member of society, extreme measures are taken to ensure that “normal” development occurs. Consequently, children are seen, not for who they are but for who they will be (Oakley, 1994; Uprichard, 2008).

The importance placed on young people developing into healthy and productive adults highlights their risk of succumbing to developmental threats. There is a pervasive cultural belief that being young means being vulnerable to risk (Jackson & Scott, 1999). Everything from music, early puberty, and excessive independence are framed as dangerous threats to children’s healthy, normal development. Adults are then justified in regulating and controlling their children’s health as doing so will ensure their normal development into adulthood (Lupton, 1994). This is especially apparent when a risk factor such as illness poses a threat on young people’s physical, cognitive, and emotional development.

Adolescence, despite being a later stage in childhood marked by more maturity, is also a constructed period deserving of regulation and control. While they are not perceived to be as vulnerable to outside threats, adolescents are at risk of being a threat to themselves. Their attitudes, behaviours, and subcultures are deemed deviant and warranting regulation.

Adolescence is a medicalized period within the life cycle as it is believed to be a time of hormonal and consequently behavioural imbalance (Skott-Myhre, 2008). The adolescent body is constructed as deviant from the normal body and adolescent behaviour as erratic and devious. Laws that establish the appropriate age to drink and smoke cigarettes, along with various age of consent regulations, suggest that youth are not yet mature enough to engage in adult activities. The adolescent body is strictly disciplined by developmental and behavioural norms enforced by family, educational, and medical authorities.
2.1.4 Biological Capital

Investment in young people’s development is not only done for the benefit of the child. Adults too can derive fulfilment from rearing healthy and productive children. Young people are viewed as a commodity, a stock that increases in value as they mature and progress through developmental life stages. Providing children with the proper conditions to develop is consequently considered essential.

Biological capital is attained when milestones in natural development are met or in some cases surpassed (Bury, 2005). Children’s socialization and development into healthy adults yields biological capital for parents. Lupton (1999) supports this idea as she suggests that parents often live vicariously through their children, investing in them their aspirations so that the adults too can be fulfilled by their children’s accomplishments. As Bury (2005) suggests, there are specific windows of opportunity to meet normal developmental landmarks especially in early life. Consequently, there is often a sense of urgency for parents and medical professionals to ensure that the conditions for healthy development are met at specific periods within development.

Social policies within (but not limited to) educational and medical institutions support and further propagate the need to calculate and regulate child health. Consequently, doctors, nutritionists, teachers, parents, caregivers, and politicians all have varied but vested interests in child health (Oakley, 1994). State interventions such as specialized pediatric medicine, school meal programs, as well as breastfeeding and drug abstinence campaigns reflect and further produce the pervasive notion that young people’s health is a distinct and crucial contributor to their overall development.
Young people are measured against medically determined standards to establish their own normality. Such measures are implemented to ensure that children and adolescents grow both cognitively and physically into normal and productive adult members of society. The importance placed on their future and the inadequacy of their current status objectifies and medicalizes the experience of childhood and adolescence.

2.2 Sociological Study of Childhood and Adolescence

Research in the 1990s began to challenge assumptions that childhood and adolescence are simply periods of development into adulthood. Sociological study began to understand that, “the immaturity of children is a biological fact of life but the ways in which this immaturity is understood and made meaningful is a fact of culture” (James & Prout, 1997, p. 7). The following section critically examines the unique power relations that control and regulate the young body.

Children might be biologically different from adult populations but it is the importance placed on those differences that construct young people as inferior (Mayall, 1996). New sociological paradigms sought to deconstruct and contextualize the power relations imbued in the experiences of childhood and adolescence. Social researchers no longer considered young people as strictly biological objects. The experience of being young was understood as a social construction, “not divorced from class, gender, and ethnicity” (James & Prout, 1997, p. 7).

Periods of childhood and adolescence were understood to be constructs, mediated by the social and cultural contexts in which young people inhabit. Researchers became interested in how adult authority and adult discourse contributed to the creation of child and youth cultures. They focused primarily on the apparent unequal power relations between adult and child worlds.
As an example, the education system, a primary feature of the lives of young people, was created by adults to discipline and regulate the young body. The organization of school timetables that determine when and what children learn, when and what they eat, and when they are allowed to speak are all evidence of this control. The school system even wields control over young people’s physical comportment and bodily functions, regulating posture and determining if and when children are permitted to use the bathroom (Simpson, 2000). The school system is often considered to be an oppressive institution that seeks to control and produce young and compliant bodies, bodies that have been considered powerless as a result of this oppression (Mayall, 1996).

Educational institutions have vested interests in both child cognition and health. As Mayall (1996) states, “At school, children’s bodies and feelings are managed in the interests of delivering the curriculum. Through the health services, norms of bodily achievement are prescribed in the interests of monitoring the nation’s health and assigning children to categories” (p. 111). Promoting and monitoring health within the school system enables adult authority to maintain a constant gaze and control over the health of young bodies which is considered crucial in ensuring future generations of strong and healthy workers (Mayall, 1996; Simpson, 2000).

Young people, how they are conceptualized, and consequently treated in society is largely determined by the assumptions made about their inferiority and inadequacy. Society places a significant emphasis on children’s need to develop into mature, healthy, and valuable adult citizens. Although little study has focused on the power relations that mediate childhood and adolescent chronic illness, the school system as a form of power over the young body exemplifies how young people are subject to particular forms of power that operate to ensure their healthy development.
A critical understanding of the discourses of health and illness will elucidate how both larger society and the individual self are affected by chronic illness. While health is considered something to aspire to and value, illness is depicted quite conversely as something that disrupts both individual as well as societal functioning. Chronic illness can be especially problematic for children and youth to negotiate as it poses a threat to their apparent physical, cognitive, and emotional development. The following provides an outline of discourses of health and illness to elucidate how being ill can complicate the lived experiences of young people. Identifying how health and illness impact both self and society will contribute to an understanding chronic illness as it is embodied by young people.

2.3 Health, Illness & Emotions

Attaining and maintaining health has become a “super value” in our society, “a metaphor for all that is good in life” (Crawford, 1980, p. 365). Conversely, illness is regarded as a disruption to the self and an imposition on societal functioning. The following section outlines dominant discourses of health, illness, and emotions in order to explicate the physical, social and emotional implications of being chronically ill. In order to effectively do so, I address health, illness, and emotions from two sociological perspectives and suggest that an amalgamation of both poststructuralist and interactionist approaches can provide a more comprehensive and embodied understanding of the chronic illness experience.

Sociology of the body, health, and illness scholarship has approached the illness experience from two different but important perspectives. Poststructuralist approaches critically deconstruct the dominant cultural discourses and mechanisms of power that mediate how people understand and produce widely accepted ‘truths’ of health and illness. Interactionist approaches explicate
how illness affects people’s social relations, emotional states, as well as their overall sense of
self, their perceived identity. Contemporary scholars have called for a more comprehensive
approach that identifies how social, emotional, and cultural forces all mediate the physical illness
experience. Embodiment theory acknowledges how cognition, emotions, and physical statehood,
work symbiotically with cultural discourses to shape people’s corporeal experiences, selfhoods,
and surroundings.

2.3.1 Poststructuralist Approach to Health and Illness

Poststructuralism is a subset of postmodernism that seeks to critically examine the widely
accepted truths that are propagated through societal institutions and systems (Mitchell, 1996).
How truth is created and dispersed through dominant discourse and in turn, how individuals are
governed and govern themselves as a result of those truths is further discussed. A
poststructuralist perspective of health and illness helps us understand how the power imbued
within dominant discourse mediates the lived experiences of those with chronic illness.

Dominant social institutions such as the church, the school, and the medical field create
particular forms of knowledge that are deemed as truth. The knowledge dispersed through those
systems largely determines the ways in which both societies and individuals are organized and
organize themselves. Poststructuralism rejects these notions of absolute knowledge and truth and
is critical of the structures that propagate it (Mitchell, 1996). Poststructuralism challenges both
the knowledge and authority of dominant institutions by deconstructing the discourses, the
language, and messaging that they communicate and propagate.

From a Foucauldian perspective, discourse is the organization of words and statements that
produce specific meanings and construct particular realities (Cheek, 2004). Discourses constrain
what is knowable and what is not knowable; what we are able to articulate and what we cannot
articulate. Discourses can control how the body is constructed and how it acts (Mitchell, 1996). Discursive power works on both societal and individual levels to ensure that bodies are disciplined and docile (Foucault, 1976; 1979). The following sections outline pervasive discourses of health and illness and their implications on those who experience chronic illness.

**Health**

Widely accepted definitions of health are not limited to the physical conditions of the biological body. Dominant discourses of health affect how people perceive and produce their overall physical appearance, intellect, actions, emotional states, and behaviours. Health is not simply the absence of illness but is defined by the World Health Organization as, “a state of complete physical, mental and social well-being” (Morris, 1998, p. 241). Health also seems to contribute to societal harmony as it ensures order and productivity (Lupton, 1994). Consequently, health is a source of esteem and capital for those who can attain it.

The pervasive societal imperative to improve and perfect health has resulted in what Robert Crawford (1980) coined as healthism. Healthism is the obsession with the individualized pursuit of health under the assumption that it will result in overall well-being. Consequently, individuals attempt to improve their physical and emotional health through a variety of programs and incentives. These include the neighbourhood gym, self-help media as well as counselling and nutritional resources, which all work to enable and encourage people’s ability to self-control and self-improve in the name of health.

**Illness**

Illness is considered a departure from physical and regulatory health trajectories and is consequently deemed to be socially deviant. As Freund and McGuire (1999) state, illness is considered, “a threat to social order and norms” as it disrupts people’s ability to produce
economic and social capital (p.118). Being ill, weak, and bed-ridden often prohibits individuals from regularly participating in labour practices and social obligations. Such participation is of course integral to the functioning of market economies and normal social functioning. Consequently, those who cannot or do not fulfil their social expectations become subject to moral judgement, stigmatization and marginalization.

Illness is often believed to be an infliction reserved for those who in some way failed to maintain their health. Sexually transmitted diseases are highly stigmatized because they are associated with what is considered to be immoral sexual activity (Lupton, 1994). Chronic illnesses such as heart disease, diabetes, and liver disease are also condemned because these illnesses are thought to result from gluttony and a lack of self-control (Lupton, 1994). The body’s deviation from standard norms of health results in a judgement about the morality of one’s behaviour. Disciplining the body is justified when sickness becomes ‘badness’. Thus, illness is not only a deviation from the physical body but a departure from the social body as well.

Those who are chronically ill are considered morally inferior until they seek medical attention, receive a legitimized medical diagnosis, and adhere to a medically prescribed treatment (Bury, 1997; Lupton, 1994). If the treatment is ineffective, it is often considered the fault of the individual and not of the therapy or medication (Lupton, 1994). Identifying someone as ill or diseased therefore works to not only marginalize individuals, it also acts as correction through medical intervention and disciplining through self-governance.

2.3.2 Poststructuralist Approach to Emotions

The mechanisms of power that construct notions of health and illness also mediate how emotions are expressed and accepted in various cultural contexts. Societies create their own
“emotion cultures” that determine what emotions are socially acceptable, who can or cannot exhibit those emotions, and the extent to which they can be displayed (Turner & Stets, 2005). Socially appropriate emotional displays are associated with moral appropriateness as various events and experiences demand specific reactions. Health-related experiences warrant particular emotional responses, for example how people negotiate illness is regulated by social norms and expectations (Turner & Stets, 2005). Failing to adhere to such norms can result in being judged as emotionally deviant, which has the potential to not only threaten individuals’ immediate social relations but also disrupt overall social order.

People within a culture are permitted to be more or less emotionally expressive based on the amount of power that they possess. Individuals who possess less power are more likely to have their feelings rejected by others (Williams & Bendelow, 1996). Consequently, less powerful people’s emotional expressions are more likely to be ignored or denied. They might also be at risk of experiencing blame, fear, and undue anxiety because their emotions are not taken seriously (Williams & Bendelow, 1996).

Control of self and emotions enables individuals to function within socially normal and acceptable parameters. Turner and Stets (2005) posit that people are socialized in childhood to display acceptable emotions in various situations and to stifle those that are deemed inappropriate. As they state, “Biological emotions such as anger and fear become, shortly after childhood, transformed into cultural meanings that are organized around a relationship to a social object, often another person or group […] as individuals are socialized, they learn the meanings of these sentiments” (p. 8). Young girls in particular are trained to control and suppress their anger to adhere to gendered expectations (Turner & Stets, 2005).

2.3.3 Criticisms of Poststructuralist Perspectives
While a poststructuralist approach can explicate how larger social structures produce the discourses of health, illness, and emotions that govern individual bodies, it fails to focus attention on how the individuals negotiate those forces (Williams & Bendelow, 1998; Shilling, 2003). The individual body is not recognized for having any agency in its actions. In fact, the physical body itself is arguably lost in postructuralist study. Postructuralist perspectives deny that individuals are social actors or agential in their daily lives. An interactionist approach to understanding health, illness, and emotion can remedy this issue as it explores how the physical body experiences and negotiates the world around it.

2.4 Interactionist Approach to Health and Illness

An interactionist approach to understanding health, illness can enhance the poststructuralist as it is concerned with the ways in which individuals negotiate their social worlds. Interactionist research focuses on the notion of the self, one’s individual perceived identity. How illness affects people’s active negotiation of self will be further discussed from an interactionist perspective.

Body and Self

As the name suggests, interactionism focuses on how individuals interact with their environments, which includes the objects and people within those environments. People’s sense of “self”, the identities that they construct and perceive for themselves, is determined based on how they and others make meaning of illness. As Turner and Stets (2005) suggest, “All theorizing within the symbolic interactionist tradition emphasizes the importance of people’s conception of themselves, or self and identity, as a central dynamic of interpersonal behaviour” (p. 102).
Traditionally, the body has been perceived to be the container that houses and restricts the self, a purely biological and fixed entity that is simply a medium for selfhood or identity (Williams & Bendelow, 1998). Consequently, the normal healthy body that performs as expected is generally ignored and its capabilities are taken for granted. That is until the body begins to cause pain, falters, or fails and the body is brought into one’s consciousness and sense of self. A limited body or a body in pain has the capacity to change the ways in which people perceive their identity, their abilities, and their individual worth (Bury, 1982; Charmaz 1991; Williams, 2000).

**Illness**

Individual perceptions and reactions to bodily dysfunction are what compromise the understanding of selfhood (Bury, 1982; Nettleton, 2006). As Bury states, “There is rarely anything in the individual’s biography which provides an immediate basis for recognition of the illness as illness” (p. 171). I will discuss the ongoing process of negotiating illness and self, as well as the social and emotional implications of being chronically ill.

Individuals must negotiate what being chronically ill means, how it will affect their daily lives, and how it will impinge on their sense of self. Chronic illness necessitates a complete reorganization of one’s lived experience (Bury, 1982; Charmaz, 1991). The feelings of shock, despair, and helplessness that result from being unwell and feeling abnormal need to be dealt with, and a new identity and sense of being must be imagined. The reconciliation of altered bodily capacities, the struggle for control over illness, and the renegotiation of social relations are some of the ways in which people with chronic illness attempt to accommodate for their compromised health and new sense of self.
People with chronic illness are forced to redefine their sense of self based on their altered health and bodily capacities. As Charmaz (1991) posits, they most often do so by reconciling themselves to their illness. By acknowledging, accommodating, and adapting to their new physical statuses, individuals can begin to figure out how illness will impose itself on daily life. People most commonly reconcile themselves to illness by altering their physical environments and reworking their own expectations of self. Individuals will attempt to change their physical environments as well as their own expectations for themselves to accommodate for the physical, social, and emotional repercussions of illness (Turner & Stets, 2005).

People’s selfhoods are influenced by their interactions with their family, friends, and colleagues. Sharing illness experiences can change the ways in which ill people are perceived and treated by those who knew them as their former selves. People who have compassionate and accommodating social supports are more likely to feel validated and comforted (Lupton, 1996). Conversely, those who suffer from a lack of support are more susceptible to unfavourable emotions such as guilt, shame, and embarrassment (Turner & Stets, 2005). Living with chronic illness can affect the nature of support that people receive from their social circles. Declaring illness can result in a variety of reactions from others including pity, fear, encouragement, withdrawal or judgment.

Charmaz argues (1991) that in order to avoid such judgement, people with illness are likely to minimize their symptoms and emotions. This can be particularly true for those with invisible illnesses as the less outwardly obvious the illness is, the more difficult it can be to explain to others (Charmaz, 1991). People often try to control their symptoms in public spaces as to avoid reactions from others. Controlling symptoms can enable people to limit the effects of their illness on their daily lives.
When illness becomes apparent and unmanageable however, people’s sense of competence and self-control can be compromised. Feelings of inadequacy, ineptitude, and a devalued sense of self can occur as a result of being powerless over an erratic or painful body (Charmaz, 1991). Miteness, as quoted by Charmaz (1991), states that, “bodily control is a prerequisite to competent adult status”, suggesting that a lack of control means an incomplete or inferior sense of self (p.117). The struggle for control and its effect on the self is especially relevant in the case of people with IBD because both Crohn’s disease and colitis are characterized by uncontrollable bodily functions and unpredictable bouts of active disease. The lack of control over defecation can be particularly stigmatizing and isolating (Kelly, 1992). People might retreat from their social obligations when they feel embarrassed about a body that is out of their control.

The change in people’s perceptions of ability and self-worth often necessitates a change in their social relations. Rather than deny their illness and attempt to lead a normal life, people may restrict social engagements and only go to places where they are comfortable and less likely to experience embarrassment. Bury (1982) suggests that people might experience social withdrawal and isolation if they fail to effectively handle their symptoms and have difficult negotiating a normal sense of self.

People with illness are often concerned that they will become a burden on their friends or loved ones. As a result, they might withhold information about their conditions or withdraw from social situations entirely to avoid feeling that they are imposing on those who are close to them. They might also feel that others might not understand their struggles and will not seek their help or support. Such reactions can result in isolation that alienates ill people from others, their social lives, and former selves.

2.4.1 Interactionist Approach to Emotions
Emotions are indicative of the ways in which individuals perceive and mediate their lived experiences (Williams & Bendelow, 1996). They are the means in which people understand their social relations, their social worlds and their sense of self (Lupton, 1998). Like the self, interactionist approaches identify that emotions are mediated by the meanings that people place on their illness experiences. Those emotions, in turn, signify how the self reacts in its interactions with others.

Guilt, shame, and embarrassment commonly arise from illness (Turner & Stets, 2005). Guilt can arise when socially constructed codes of health are breached. Shame can occur when the self is deemed inferior, when an individual with illness can no longer perform as they could when they were healthy. Embarrassment, an emotion often associated with IBD, occurs when the self is considered to be flawed. Such is the case when bodily functions cannot be controlled or when social obligations cannot be met (Turner & Stets, 2005).

Just as individuals attempt to control the presence of their illness, they must also curb their emotions to maintain a stable sense of self and avoid feeling at odds with themselves. People with illness can employ a number of strategies to remain emotionally secure. Social interactionists who draw from psychoanalysis suggest that when the self is insecure, people will use coping mechanisms to alter adverse emotions (Turner & Stets, 2005). Denial as a coping mechanism enables people to reject any thoughts of difficult emotions while avoidance techniques enable individuals to circumvent them entirely.

People can also attempt to rationalize their emotions or minimize them by changing their frame of reference. They might try to compare their experiences to others who are suffering more and who they deem are worse off (Turner & Stets, 2005). While avoiding emotional disclosure is
possible, it can be quite problematic as it involves a concerted suppression and a denial of personal struggle and self (Charmaz, 1991; Nettleton, 2006).

2.4.2 Criticisms of Interactionist Approaches

People’s daily lives, their emotions, their social relations, and ultimately their sense of self can be significantly compromised when faced with illness. Interactionist approaches to illness and self, however, have neglected to consider how diversity of illness and selfhood can affect the lived experience (Williams, 2000). While it is understood that individuals will experience the symptoms and meanings of illness differently, the specificity of self and illness must also be taken in consideration. Traditional interactionist approaches fail to recognize how variance in age, illness, and self complicates the illness experience.

Williams (2000) critiques Bury’s notion of illness as a biographical disruption as it fails to take the effects of age into account. Both Bury and Charmaz, the pioneering social theorists of chronic illness, focus their research on mostly middle aged people who were diagnosed with chronic illness as adults and presumably lived normal lives prior to their diagnoses. They assume that the adult self is most disrupted by illness because the adult has a more mature and fully developed sense of self to disrupt (Williams, 2000).

Childhood and adolescence are periods where chronic illness is believed to be less significant or disruptive to the self. Charmaz (1991) posits that certain populations including young populations have not yet experienced the demands and responsibilities of real life and consequently may not find illness as intrusive. As previously addressed, developmental approaches to understanding young people frame them less developed, and consequently inferior to the fully formed adult (Oakley, 1994). As Oakley states, young people are often conceptualized not for who they are but for, “what they are not yet” (p. 23). The self is not yet
formed and consequently, the particular experiences of chronic illness for young people are deemed to be less important.

Williams (2000) also suggests that the focus on the self, in itself, can be problematic as it individualizes illness and denies how larger social and cultural contexts construct and mediate the experience of chronic illness. In order to effectively understand the physical, social, and emotional implications of illness, we must understand how social discourse, which includes pervasive assumptions of childhood and adolescence as incomplete and inferior, mediates how one negotiates the self. A combination of both postructuralist and interactionist perspectives is therefore useful to gain a more comprehensive understanding of the illness experience. Embodiment theory, which identifies how body, self, and society are implicated within the illness experience, offers the opportunity to develop such perspectives.

2.5 An Embodied Approach to the Illness Experience

Embodiment theory draws from poststructuralism and interactionism to acknowledge that the body, self, and society all contribute to an understanding of the chronic illness experience. Embodiment is a more holistic approach as it identifies that the body is both socially constructed and agential (Wainwright & Turner, 2003). Approaching chronic illness from an embodiment perspective can elucidate how dominant discourses, notions of selfhood, and the physicality of the illness itself are negotiated by individual bodies.

Social study has often focused on Cartesian notions of a mind/body dualism in which cognition and corporeality were considered to be mutually exclusive. Embodiment theory rejects this dualism and instead offers a shift towards understanding how cognition, emotion, and individual agency work symbiotically to mediate the lived physical experience (Williams &
Bendelow, 1998). In other words, notions of selfhood, social discourse, and the corporeal body all play a role in determining how people negotiate their daily lives (Turner, 2001).

Embodiment theory not only acknowledges the body’s physical experience but also recognizes that the corporeal body is the site in which mechanisms of power and social discourses are mapped out and acted upon. The body is affected by physical sensations including pleasure and pain but it is also subject to social discourse, both of which mediate individual agency. Recognizing how the body responds to physical pain as well as the social conditions that mediate the body’s response is useful when examining the painful and stigmatizing experience of IBD.

As Williams and Bendelow (1998) state, “social institutions as well as micro-social processes cannot be understood apart from the real, lived experiences and actions of bodies” (p. 8). Unlike poststructuralism, embodiment theory recognizes that individuals are social actors (Turner, 2001). While people are subject to discourse, their embodied practices, the ways in which they act and react to those discourses are thought to be agential.

2.6 Metaphors of Illness, Emotions, and IBD

I outline metaphors of the body, illness, and health to further elucidate how people are agential in constructing meanings of the IBD experience. Doing so will further explain how pervasive social assumptions and stigma contribute to an embodied illness experience. To my knowledge, the metaphors of inflammatory bowel disease have never been described. In the following section, I consider how IBD could be taken up in metaphor based on pre-existing depictions of the erratic, leaky body and the militaristic metaphors of illness.
Metaphors are the symbolic interpretations of embodied experience as they emerge from the intersection of cognition, physical experience, emotion, and social discourse (Neisser, 2003). Metaphors explain issues and experiences that are too complex or mysterious to be understood at face value. As Lakoff (1991) suggests, metaphors might help us understand certain abstractions or ambiguity but they in turn construct and propagate specific ‘truths’. Metaphors explain a phenomenon as being something more intriguing than its original form. The meanings derived from metaphors are also more sensationalized and as a result can complicate the ways in which people experience and embody that phenomenon (Neisser, 2003).

2.6.1 Metaphors of the Body

Beginning in the late 19th century, the body came to be understood as a “unified commonwealth” comparing the material body to the nation state (Sontag, 1989). The strong body, much like a strong society, is comprised of smaller organizations that contribute to its overall functioning. Lakoff (1991) posits that both body and state are perceived to share similar characteristics. The individual body, much like an independent nation, can be considered peaceful or aggressive, productive or lazy, strong or defenseless (Lakoff, 1991). Like a unified and independent society, the healthy body demonstrates power and strength.

The body also establishes “defences” and “reserves” of energy and health that fortify its overall well-being or commonwealth (Martin, 1987). The metaphor of the body as a fortress is also in large part the result of modern scientific and medical discourse that urges people to work on their bodies and take precautionary measures to ensure their strength, protection, and resilience. Conceptualizing the body as a singular machine or stronghold stresses its need to be both productive and protective. It is not surprising then that illness is depicted through metaphor as a military violent invasion of the body.
2.6.2 Metaphors of Illness

Illness metaphors are especially prevalent in both medical and popular discourse due to the cultural fear of disease as well as the ambiguity of its causes. Due to deficits in medical knowledge, there are many speculations as to what contributes to or exacerbates illness. Sontag (1989) argues that the more elusive the cause or trajectory of an illness is, the likelier it is to be laden with metaphors. She states that:

The notion that a disease can be explained only by a variety of causes is precisely characteristic of thinking about diseases whose causation is not understood. And it is diseases thought to be multi-determined (that is, mysterious) that have the widest possibilities as metaphors for what is felt to be socially or morally wrong as to the causes and trajectories of many illnesses (p. 61).

When the causes or the progression of illness are difficult to visualize, they become subject to metaphor.

One metaphor specifically, the metaphor of illness as a militaristic attack on the body, significantly impacts how we come to think about disease. Since medical technology has enabled the body to be studied on cellular levels, illness has been likened to a war as viruses and microorganisms invade, attack, and colonize the body (Sontag, 1989). Warlike metaphors are evident in popular cancer discourse as one “has an aggressive case” or “is battling cancer”. Treating illness is also laden with war metaphors as the patient fights back to defend the body fortress. The metaphor of chemotherapy “killing” cancer cells suggests a bodily defence and retaliation.

The use of war-like metaphors to describe disease is problematic because it associates the body and illness with contentious reasoning and potentially rash reactions. Lakoff (1991) explains that under normal circumstances, people are inclined to choose treatment options based on cost-benefit analyses but Sontag argues that the illness as war metaphor complicates this decision making process. According to Sontag, war is considered an urgent crisis where self-
interest and reckless decision-making trumps any ethical or thoughtful consideration of options. Metaphors of illness as combat can also incite over-exaggeration and irrational panic resulting further misconceptions and stereotyping. Consequently, thinking of illness as war can result in individuals making unreasonable and rash judgements in relation to their illness and treatments.

2.6.3 Age/Childhood as Illness Metaphor

Age complicates how illness is depicted as it is considered to be an impediment to normal developmental growth. The perceived helplessness and innocence of children are employed to exaggerate the horror of illness. Havi Carel’s (2008), autoethnography of her experience with a degenerative lung disease uses constructs of age to emphasize her struggles. As she states, “I found myself in an odd position: young but in some ways old; healthy-looking on the outside but gravely ill inside” (p. 7).

Carel also compares her loss of physical capacities to that of developmental regression. She suggests that her lack of bodily control and her inferior ability to function are analogous to the abilities of a child, suggesting that they are incapable and weak. She states that, “Every week I discovered, in a grotesque reversal of childhood development, yet another thing I could no longer do” (p. 5).

Quite conversely, Carel also represents her experience of illness as an accelerated age process suggesting that her body’s destruction as a result of being ill is akin to experiencing rapid aging. She laments, “I imagine this is what it must be like to grow old: to gradually realize that as your body loses capacities your world shrinks too” (Carel, 2008, p. 6). Such sentiments are echoed by other young people who suggest that having IBD causes them to act older than their age (Nicholas et al, 2007).
Young people who are viewed as future entities are also analogized as determinants of pending conditions. Just as illness is a representation of current societal states, adolescents are the thermometers in which the future is measured (Sontag, 1989; Lesko, 2001). This dependency on young people to ensure an adequate future for everyone places adolescents under a state of power and control. Lesko (2001) argues that this social value of adolescents justifies their constant evaluation and monitoring because their health ensures the greater health of society.

2.6.4 Metaphors of Female Bodily Fluids

To my knowledge, no study has focused on the specific metaphors of inflammatory bowel disease. This seems peculiar considering that symptoms of IBD are fluid, messy, and are perceived to be foul and disgusting. The fluidity of breast milk and menstruation have been taken up through metaphor to describe women’s hysteria, their lack of sturdiness, and their inferiority to men. A critical investigation of metaphors associated with female bodily fluids and functions will illustrate how the uncontrollable and erratic fluids associated with IBD can complicate how these diseases are perceived.

The female body has been depicted through metaphor in various ways that suggest its inferiority to the male form. Women’s bodies are considered distinct from men’s as a result of menstrual and birthing processes. The female body is depicted as unstable and unmanageable due to the production and uncontrollable “leakiness” of bodily fluids including menstrual blood and breast milk. As Shildrick (1997) states, “In being somehow more fully embodied than men, women have been characterized simply as less able to rise above uncontrollable natural processes and passions and therefore disqualified from mature personhood” (p. 26). The undisciplined nature of women’s bodily fluids has been used to illustrate women’s apparent inferiority to men (Shildrick, 1997).
Not only does the production of bodily fluids suggest inferiority to men, the fluids themselves, especially menstrual fluid, further stigmatize and marginalize women. Metaphors of menstrual fluid as unclean and as toxic pollution have been constructed to incite disgust and derision for the female body. Martin (1987) suggests that menstruation in the 18th century was depicted as the process by which women manifested and shed their toxins. Menstruation was considered a sordid and disgusting bodily process that warranted medical scrutiny and consequently became a pathological experience (Martin, 1987). While the purpose and function of menstruation is now widely acknowledged, a sense of disgust and hatred of the menstrual cycle still exists. As Sontag (1989) suggests, “a polluting person is always wrong” (p.136). The fluidity of the body and the bodily fluids themselves are both considered threats when they are perceived to be unpredictable, uncontrollable, and even toxic.

2.6.5 Metaphors of IBD

Women’s supposed disorderly bodily fluids compromise their bodies’ integrity much like erratic bowels. Like menstruation, defecation is considered a repulsive and mortifying bodily process. The foulness of fecal matter remains a private matter, one that is not often discussed candidly in society without intent of vulgarity or “sick humour”. Like city sewers, the bowels are hidden deeply within the body and exist out of sight until their noxious fumes or toxic waste uncontrollably burst out of its system.

IBD, characterized by the overproduction and lack of control of bowel movements and other bodily fluids such as bile, vomit, and gas, makes it difficult for the bowels to remain unacknowledged. People with IBD can experience frequent but erratic, and often foul bowel movements. It is something that they often struggle with and try to negotiate in their everyday
functioning, not only dealing with the physical pain but finding the least public and embarrassing times and spaces to relieve themselves.

Dealing with excrement, however, is easier said than done when the urge to defecate often arises suddenly and uncontrollably, occurring in meetings, on the bus, in social situations etc. The disgust and anxiety over bodily fluids is compounded when they can no longer be controlled or hidden, resulting in embarrassment and shame for those who cannot fulfil expectations of bodily control. The offensiveness and stigma surrounding bowel movements arguably makes it very difficult for those with IBD to be able to express their experiences and struggles with illness. Talking about bowel movements with others, including medical professionals becomes difficult due to fear of being judged and shamed.

2.6.6 IBD as Civil War

The label of Inflammatory Bowel Disease itself suggests that the intestinal track is ignited in a burning and fiery attack, evoking metaphors of conflict and war. The difference with IBD and other illnesses is that with IBD the attack occurs from within. While illness has been mythologized as an attack on the body from external forces, autoimmune diseases such as cancer, lupus, rheumatoid arthritis and IBD can be considered a civil war, an assault from within the body.

Autoimmune diseases occur when the immune system overacts and attacks the body’s own organs and functions. It is suggested that, “patients with autoimmune diseases frequently have unusual antibodies circulating in their blood that targets their own body tissues” (Definition of Autoimmune Diseases, www.medterms.com). As a recent article put forth by Science Daily on IBD so illustrates:

Many chronic diseases are the result of the body's immune system mistakenly perceiving that the body is under attack from foreign bodies. A counterattack is then launched -- an
inflammatory response meant to vanquish the intruder. In reality, the immune system has misinterpreted the threat and is actually attacking the body's own cells and tissue (www.sciencedaily.com).

IBD is generated from within the body that is attacking itself. The body is committing treason.

It has been suggested that the immune system itself is a metaphor, a mere fictitious organization of various bodily organs including the lymphatic system, spleen, and thymus perceived to work together to protect the body (Harraway, 1991). Just as the capacities and limits of isolated organs were established in the 18th and 19th centuries, the notion of immunology is the 20th century acted as a means of mediating and regulating the body (Ettore, 1998). According to Haraway (1991) the various organs that are perceived to be allied as the body’s system of defenses are, “located everywhere and nowhere” as a means of reinforcing the boundaries of the body (p. 218). While the immune system itself might be a metaphor, its implications are real, laying blame and responsibility for the body’s malfunctioning on the failures of the individual body.

2.6.7 Psychological and Emotional Metaphors of IBD

The experience of IBD is not only analogized as individual body betrayal but also as a consequence of emotional failure. Cancer has traditionally been regarded as the result of emotional repression and the inability to express and negotiate feelings of rage and other heated emotions (Sontag, 1989). IBD has been viewed quite similarly amongst psychoanalysts as Gerson (2002) states:

Over time, the working psychoanalytic premise regarding ulcerative colitis symptomatology is the following: Individuals with characterological difficulty in expressing rage, when threatened by separation from an important object, implode the rage inward and thereby inflame and damage their intestinal lining (p. 381).
Sontag explains that psychological theories that attribute illness to individual’s emotional states place the blame and responsibility of causing ailments squarely on the ill person. This can result in the ill person feeling additional shame and guilt for having a condition (Sontag, 1989). Moreover, when illness is perceived to be the result of individual failure, it can be implicated in other social failures. As Gerson (2002) suggests, “When it was viewed as a threat, illness appeared to be a metaphor for all the disappointments and losses that had occurred in the family’s history and encompassed the feeling of helplessness and lack of control that generally characterized their lives” (p. 384).

Emotions are often analogized in similar ways to the erratic leaky body. Emotions that flow from within and threaten to erupt or to spill out of the body contribute to the fear of the fluid body. As Lupton (1998) states, “The emotional body is often represented as a grotesque body, a body that is able to contain itself in socially acceptable ways, a body that threatens to burst apart its boundaries” (p. 96). Cultural fears of bodily waste and of emotional disruption are evident in metaphors of emotions and lay perceptions of how emotions should be controlled.

Emotions are commonly described in metaphors that suggest their fluidity and gushiness (Lupton, 1998). Emotions are thought to circulate and current throughout within the body. The body itself stores emotional flow and acts as the container in which emotions are kept and therefore kept in check. As Williams and Bendelow (1996) posit, emotions are considered irrational and private and should consequently be self-contained.

Like bodily fluids, emotions too are at risk of bursting out of body boundaries and endangering the external environment.

Uncontrolled emotions are thought to pour out of the body when individuals “lose it”, that is lose control of their bodies and feelings. As Lupton (1998) states, “Being able to let go of
one’s emotions was described as a fluid or gushy experience, even when it is not directly related to crying” (pp. 89-90). While tears exemplify emotional fluidity, women’s breast milk and menstrual fluids and IBD patients’ excessive defecation also act as cautionary threats of uncontrolled emotion. Women’s erratic bodily fluids, associated with their apparent hysteric emotions, simultaneously devalue women’s bodily processes and emotional expression. Like bodily fluids, emotions warrant regulation and control.

While emotions should be controlled, it is believed that they should not be repressed entirely. People must negotiate and regulate their emotional expressions so that they are not unruly and threatening but also that they are not entirely repressed or subdued. In keeping with the metaphor of emotions as fluid, Lupton (1996, 1998) suggests that inhibited emotions are thought to be “bottled up” within physical bodies. Repressed emotions are perceived to build up internally until individuals can no longer stifle how they are feeling. Turner and Stets (2005) suggest that pent up feelings act like a pressure cooker where emotions intensify until they explode in distorted and irrational fashions. In such cases, people can be considered to be “blowing off steam”, steam being a product of boiled and fiery fluid (Lupton, 1998).

Repressed emotions are also perceived to cause illness. It is commonly believed that when emotions are not dealt with or appropriately expressed they begin to “eat away” at people (Lupton, 1998). Cancer was believed to be the manifestation of repressed emotions that slowly decay the body (Sontag, 1989). While IBD is not characterized as decay, it has been suggested that negative emotions manifest themselves within the gut. Expressions such as “gut-wrenching” and “stomach churning” suggest that adverse emotions can be psychosomatic, as if how people feel emotionally determines how they feel physically.

2.6.8 Implications of Metaphors
While feelings of blame and guilt are evident amongst those who experience illness and its metaphors, symbolizing illness through various representations results in a number of adverse implications. Consider the metaphor of illness as war specifically: it becomes apparent that the ways in which society represents illness can have profound effects on how illness is acted upon. Sontag (1989) posits that imagining illness to be analogous to war is especially problematic as it evokes similar fears and supports similar tactics used in war itself. On individual levels, such sentiments can lead to rash decision making in choosing treatments. It can also result in feelings of self-responsibility, blame, and shame.

Illness as war metaphors can create problematic discourses of illness that marshal societies together in action. Excessive and zealous ideas of illness invoked by war metaphors have the potential to incite extreme sentiments in populations who then might mobilize in efforts to eradicate and destroy the enemy (Sontag, 1989). Mass movements based on metaphorical rhetoric are obviously problematic because they appeal to people’s sense of passion as opposed to logic. Consequently, efforts to incite change are often empty. As Sontag (1989) explains:

Such token appeals for mass mobilization to confront an unprecedented menace appear, at frequent intervals, in every mass society. It is also typical of a modern society that the demand for mobilization be kept very general and the reality of the response fall well short of what seems to be demanded to meet the challenge of the nation-endangering menace (p.173)

It is for these reasons that understanding and critically assessing metaphors and their implications are so important. While both Sontag and Lakoff (1991) argue that metaphors are unavoidable means of understanding the complex world we live in, it does not mean that they should be taken at face value. Recognizing the invention behind metaphors will diminish their
implications. Understanding how illness metaphors work can lessen the stigmatization and individualization that is associated with being young and having IBD.

2.7 Conclusion

Embodiment theory encompasses the study of how both power relations and social relations affect the corporeal body. Understanding chronic illness from an embodied perspective elucidates how social discourse affects both the body and mind. It can also explicate how individuals negotiate those forces. To my knowledge, there is no literature that approaches inflammatory bowel disease from an embodied perspective. Understanding the embodied experience of IBD would elucidate how people deal with living with physically painful and socially stigmatizing symptoms. Embodiment theory would also take into account how discourses of being ill compound the already problematic experience of being young.

Psychological research and medical practice has already pathologized the experience of being young, treating children and youth as medicalized populations. Young people have been subject to discourses that focus on their cultivation and future development which denies their agency and their present lived experiences. Biological capital explains the value placed on raising healthy and active children while illness discourses explicate the implications for failing to do so. What is missing from current research is how young people make sense of these forces and deal with their actual illnesses, and in the process navigate their selfhoods. Embodiment theory provides the opportunity to investigate how social discourses, physical illness, and notions of self are actively negotiated. Such an opportunity seems especially crucial when examining a population whose bodies have been pathologized and whose agency has been denied.
Chapter 3
Research Design and Methods

Having previously written about my struggle with Crohn’s disease strongly influenced my interest in further investigating the lived experiences of young people with IBD. As part of my undergraduate degree, I wrote a creative analytical postmodern autoethnography which enabled me to write a self-reflexive and emotional recollection of my personal narratives of being an adolescent with Crohn’s disease (Ellis & Bochner, 2006). I was able to reflect on the power relations that mediated my struggle by employing a Foucauldian approach that facilitated an understanding of how I was subjected by and resistant to medical and adult power.

I developed the research design for my master’s research project under the assumption that other young people with IBD would want to share with me their insights into their illness experiences. I was confident that they would be willing and able to discuss the power struggles and moments of resistance by which they defined their illness identity. I expected that the participants would all eagerly share their experiences with one another in a focus group, and then come together to act as ongoing reciprocal and empathetic support for one another. I was wrong.

In the following section I explain the challenges that I experienced trying to find participants as well as the difficulties that I encountered trying to hear the voices of young people with IBD. I outline the methods that I employed to better understand why these voices seemed to be silent.

3.1 Recruitment

My initial plan was to recruit and interview 5-7 participants between the ages of 11-16 in the Ottawa area. I assumed that finding young participants through word of mouth and snowballing would be simple because of my involvement in IBD organizations and my connections to others within the local Crohn’s and colitis community. I was wrong. I pursued a number of avenues in search of participants but given the
lack of both physical and emotional space available for young people with IBD, finding participants was a significant challenge.

I began the recruitment process by contacting the Children’s Hospital of Eastern Ontario. I had kept in touch with my paediatric gastroenterologist and hoped that he could inform his patients of my study. Unfortunately this was not possible as policy mandated that all studies endorsed by the hospital must undergo a rigorous ethics process which I would not have been able to complete in time to finish my Master’s project on schedule. I also asked the IBD organization that I was associated with if they could inform their community of my study. They could not as their policy mandated that they were forbidden from soliciting their members.

I began asking young people with IBD with whom I had existing relationships from work that I had done in the past. My contact information was also passed on to other young people with IBD who met the study’s parameters. I spoke with a number of teenagers and parents who, for the most part commended me for my work but said that they or their children would not be able to participate. They offered a number of reasons as to why they would not be suited for my study. A couple of people stated that they were too sick to participate and speaking about their illness experiences would be too difficult at this time. Others said that they were in remission and consequently felt that they would have nothing to talk about.

Three young people, all of whom I had some previous relationship with, agreed to interview with me. Almost immediately, one of the willing participants mentioned that he would not be available the day of the focus group meeting despite the fact that I had yet to schedule the focus group for any particular time or place. I sensed that it would be more difficult for the participants to share their illness experiences with their peers than it would be in an interview with me.

I received approval from the Queen’s University GREB to lengthen the participant age range to 18 years old in search for more participants. I was also approved to extend my research to the Kingston community and to advertise my study in public spaces. I put up posters in the Kingston gastroenterology clinic that served both adult and child patients. I also advertised my study in health food stores in both
Ottawa and Kingston. I hung posters in various public spaces on the Queen’s University campus but became discouraged from advertising in the student residences because it would have been a lengthy process to potentially obtain approval.

All of these efforts yielded one interested young person with whom I met to explain my study. Shortly after our meeting, the young person’s mother contacted me to inform me that her daughter was too sick and consequently too emotionally vulnerable to participate. So then I was back to three participants. I went ahead with the interviews with the three willing young people. I decided to abandon the focus group component of my research process because I sensed that it would not be a comfortable space for the participants. I then decided to supplement the data collected from the interviews with a discourse analysis of available resources as well as my own perspectives.

3.2 Revised Methods

I revised my research design to include other forms of data collection and analysis. In addition to interviewing participants, I decided to critically analyze existing informational resources for young people in hopes that they could elucidate dominant perceptions of IBD. I also decided to include my own voice within my research to supplement the data and emphasize the disjunctions between dominant discourse, the lived experiences that my participants shared with me, and my own lived experience. The following section outlines my revised research plan.

3.2.1 Data Collection

I met with each participant, and the legal guardians of those under the age of 16, prior to their interviews to provide them with information about the project (see appendix A.2). At this point, I explained the consent and assent forms as well as the logistics of the study including the purpose and instructions for photo-taking. The participants of legal age signed consent forms and the participants under the age of 16 signed assent forms while their guardians signed consent forms on their children’s behalf (see appendices A.1 & B.3). I assured the participants that they can participate in as much or as little of the project as they
felt comfortable doing so. The participants understood that they could abstain from any or all parts of the interview and photo-taking processes.

I provided the participants with a disposable camera if they did not have their own camera to use. I also gave them a handout that offered tips and suggestions of objects and situations that they might consider photographing (see appendix C.1). I urged the participants to avoid taking pictures of their own or others’ faces due to ethical concerns. I also advised them to use discretion when taking pictures of bodies.

Only one participant opted to take pictures, none of which were of his body. I discussed his photographs with him during his interview in addition to asking him questions from my interview guide. I relied more heavily on my guide in the other interviews as they had no photos to discuss. Both participants expressed that they could not think of any images that reflected their illness experience.

I engaged the participants in semi-structured interviews that could facilitate open-ended and participant-directed discussion. I began the interview by asking the participants general questions about their age and school grade. I then asked them how having IBD affected them both physically and emotionally. From there I asked the participants to describe their insights on various topics including what it is like to have IBD, how IBD has changed them, and how it might be different to have IBD as an adult as opposed to an adolescent or child (see Appendix D.1 for full interview guide).

3.2.2 Data Analysis

Data analysis began immediately after the first interview. I reflected on how the interview went and the topics addressed in order to prepare for the following interviews. I transcribed each interview verbatim and analyzed them using line by line coding. I used constant comparison methods to identify key categories and themes. I kept memos based on my reflections, interpretations, and questions. All documents including field notes and transcriptions were stored under lock and key. Each participant was assigned a pseudonym to ensure their anonymity.

3.2.3 Discourse Analysis
Discourse analysis involves examining any variety of texts to investigate not only its semantics but its, “situadedness” in larger social contexts (Cheek, 2004, p. 1144). Texts such as informational brochures and educational books can be read critically to unearth the dominant discourses and meanings that underlie what is explicitly stated (Kvale, 1996). A discourse analysis can expose and deconstruct those truths and in doing so can begin to explicate why particular information is presented, why some is ignored, and for what purpose (Cheek, 2004).

Within the last year, I have collected a number of resources for young people living with IBD. I attended educational events held by the Crohn’s and Colitis Foundation of Canada (CCFC) where I received information pamphlets on various topics pertaining to IBD including information specifically created for youth. I was also directed to the CCFC website which features a separate section devoted to Gutsy Youth, a group of young people who claim to be the voice of youth with IBD. I was given a children’s book titled Toilet Paper Flowers created to educate children and young people about IBD. I decided to include Toilet Paper Flowers in my analysis as the book has been distributed to Ottawa public schools as an educational resource. I recognize that there might be other resources available for young people with IBD however the ones that I included seemed to be most available and accessible.

I hoped that these resources would provide some insight into why it was so difficult to speak about these illnesses. It turned out that these resources hardly touched on the emotional and social issues that could make having IBD difficult to talk about. I argue that the failure of these resources to address the difficult and depressing side of illness could facilitate and perpetuate young people’s silence. If the resources available to young people do not address the darker aspects of living with these stigmatizing illnesses, it seemed plausible that young people would perceive it to be socially unacceptable to talk about their illness experience.

I decided to include and analyze a set of zines, titled About My Disappearance, about one man’s struggle with Crohn’s disease as it provided an alternative truth to the dominant discourse. David Roche’s zines, which are independently published magazines, are a candid emotional account of his illness experience. He addresses the stigmas, the isolation, and severe physical and emotional pain that people
with IBD can experience when their disease is active. His account of his experiences echo my own and are similar to what I expected to learn from my interview participants. Unlike the resources put forth by IBD institutions and authorities, Roche’s zines open up space and make it acceptable for others to express their struggles and tell their stories of the more difficult aspects of living with IBD. His zines were a stark juxtaposition to the information provided by the CCFC.

Examining these materials helped me understand the information provided for and withheld from young people by those who are the “official” body representing those with IBD. Analysing the children’s book and the CCFC brochures facilitated an understanding of the dominant discourse about IBD. Conversely, Roche’s zines represented a subversive and marginalized voice that challenged how IBD was packaged and presented in society. It is not important whether the participants were exposed to these particular texts because I believe that they are reflective of the dominant and marginalized discourses about what it means to have IBD.

3.3 Revised Theoretical Orientation

3.3.1 Researching the Unspeakable

While more traditional child and youth research might question the validity of the adolescents’ responses or their developmental ability to comprehend and articulate their difficult emotions, I believe that it was not their age that was responsible for their silencing but the subject matter. I have worked in a variety of settings both related to IBD and otherwise where young people have spoken freely about their struggles with their conditions. They articulated their fears for the future, admitted the self-blame that they carried, and divulged their insecurities. The interviews however did not seem to yield such disclosure.

There are a number of possible explanations that could explain why the participants were not as candid as I imagined that they would be. The three participants stated that they were feeling relatively well around the time of their interviews. The participants’ recollections of their struggles might have been downplayed over time because as Charmaz (1991) posits, when illness occurs in separate periods, it is easily bracketed off and left behind. The physical and emotional experiences of suffering can be difficult
to recall and articulate. I hoped that a discursive analysis of resources available to youth with IBD would shed light on how dominant truths might mediate people’s capacities to speak openly about their experiences.

Arthur Frank (2001) describes the differences between pain and suffering within the illness experience. He explains that pain is the immediate physical experience of discomfort while suffering is the anticipation of that pain. Suffering happens as a result of the enduring fear and concern of knowing that a chronic pain could reoccur. While medical discourse is relatively proficient in identifying and acknowledging pain, Frank argues that suffering is far more difficult to articulate and to understand. Frank (2001) explains:

> Our suffering was what we could not say. We feared saying what we felt, and we feared our words could never convey what we felt but would reduce those feelings to complaints and specific concerns [...] don’t you know it’s what your patients can’t say? (p. 354)

Frank (2001) explains that researchers must instead identify and try to understand the social contexts and conditions that contribute to people’s illness experience. Frank (2001) quotes Smith who states that, “The aim is not to explain people’s behavior but to be able to explain to them/ourselves the socially organized powers in which their/our lives are embedded and to which their/our activities contribute” (p. 360). Understanding the social conditions that influence how people understand IBD would help explain how and why they react to their illness experiences in particular ways.

### 3.3.2 Writing Autoethnographically and Being Reflexive

My ongoing struggle with Crohn’s disease as well as my previous knowledge of, and relationships with the participants enabled me a privileged insight into their IBD experiences. With that privilege however, came a responsibility to be reflexive of how my assumptions affected that knowledge and consequently how that knowledge is used. I had to negotiate how I was going to explore the tensions between what the
participants said and what I thought to be true. I had to understand the logic behind what they had said even though some of my previous experiences with them had led me to believe something different about them. I chose to include my own voice and practice constant reflexivity throughout the research process in order to better understand what the participants did and did not say and why.

My previous knowledge of IBD and of the participants’ histories exposed disjunctions between what they said during the formal interview for this project and what they and their parents have told me in the past. I anticipated that the participants would be more forthcoming and expressive than they were given my previous knowledge of and experiences with the participants. They did not address some of the difficult emotions that they had shared with me in the past nor did they discuss some of the personal issues that I understood them to be grappling with. It was apparent to me that there were absences within the participants’ narratives.

Due to ethical reasons and to protect the participants’ integrity and anonymity, I did not go into detail about these specific tensions and incongruities. Nor did I challenge them directly about their past accounts during the interviews for this project. Instead, I engaged in autoethnographical writing which enabled me to weave my perceptions and voice into the data analyses to not only better understand the illness experience but also difficulties in articulating those experiences (Ellis & Bochner, 2006).

Writing autoethnographically about my difficult experiences with Crohn’s disease as an adolescent provided an alternative and more emotional narrative than those shared by the participants. Juxtaposing my accounts and those within the zines alongside the participants’ interviews elucidated the absences and silences within their narratives. I was able to understand the participants’ stories both in relation to my own perceptions and understandings (Denzin, 2006). In doing so, I was able to better understand why talking about illness was so difficult and uncomfortable. Recalling my experiences of being an adolescent with IBD enabled me to better relate with the discomfort and difficulty of being so emotionally candid and vulnerable.

Writing autoethnographically meant constantly reflecting on my own history; however, I also had to be reflexive about my present status as an adult interviewer and the possibility that I was perceived as
an IBD “authority”. The research participants were not only younger than I was but they also knew me previous to the interviews as either an adult authority or a volunteer with IBD organizations. The pre-existing knowledge that the participants had of me and I of them could have affected what they said and did not say in a variety of ways.

Reflecting on my investment in this project as well as my negotiation of my own illness experience was a necessary component in the research process. I have been reflexive about how my biases have affected my data analyses, not to discredit my partiality but to identify and account for it. Engaging in autoethnographic writing enabled me to be, “self-reflexive but not self-obsessed”, to understand my own position in relation to the participants without letting my perspectives overshadow their stories and experiences (Denzin, 2006, p. 421). In doing so, I was able to recognize the silencing in my own illness narratives.

While the participants were not always forthcoming in their interviews, what they said and did not say revealed three significant themes that are outlined in the next chapter: minimizing the illness experience; negotiating a sense of normalcy; and negotiating being young. I have included my own perspectives throughout the following chapters in a different font to situate myself, my experiences, and my own struggles within the research.
Chapter 4

(Not) Being Ill, Being Normal, Being Young

The participants’ interviews highlighted three key themes which will be discussed in this chapter. A significant portion of the three interviews focused on how the participants grappled with being sick, struggled to achieve a sense of normalcy, and experienced their being young. The participants shared stories of their struggles and daily lived experiences but seemed to do so without much emotional candour. They spoke of particularly difficult and embarrassing situations but their reactions to these situations seemed to suggest that they were unaffected by them. My observations during the interviews as well as my own personal experience led me to believe otherwise.

In this section I outline the following three themes that emerged from the participants’ interviews, being ill, being normal, and being young. These themes represent how the participants negotiate their physical illness as well the social and emotional implications. I have included the participants’ direct quotations, which I transcribed with minimal grammatical editing. I left their pauses and repeated words that highlight their hesitation. I also indicate where the participants laughed, which emphasizes the nervousness in their responses.

I have also included my own narratives within this section. I hope that my interpretations of interactions with the participants and my personal experiences living with Crohn’s disease will substantiate my analyses. I have included my autoethnographical accounts in a different font as is evident below.

Before I started interviewing, I expected that I would have no problems facilitating open and candid discussion. I anticipated that the research participants would be as open and as emotional as other young people with IBD had been with me in the past, in my work as a youth worker or IBD volunteer. The young people I worked with knew that I had Crohn’s disease and often sought me out to talk. We spoke easily about the daily agonies of living with IBD and other difficult topics that exposed our emotional vulnerabilities.
The candour that I expected did not materialize. My illusions that the interviews would be easy quickly dissipated after my first meeting with a participant, who eventually stopped returning my emails and dropped out of the study. My confidence suddenly evaporated, replaced by a sense of nervousness.

Despite my nervousness, I did my best to pay attention to not only what participants said but also to the non-verbal dynamics and messages. I interviewed two of the participants at their family’s houses and one in my office’s conference room. The two homes provided a more comfortable setting for our discussions but it was apparent that none of us felt very comfortable at all. The participants were easily distracted as they played with their pets or cocooned themselves in blankets as we spoke. The other interview, held in a plain conference room, did not offer as many opportunities for distraction or diversion. Instead the participant tapped his fingers on the desk when he spoke about difficult issues. The participants seemed as nervous as I was.

4.1 (Not) Being Ill: Minimizing physical symptoms and emotions

Living with IBD means having to deal with the physical and emotional consequences of an unpredictable, painful, and embarrassing chronic illness. The symptoms of IBD are not easily shared with others because they are isolating and embarrassing. Consequently, sharing emotions that arise from the having IBD are laden with shame and seem difficult to express. The following outlines how participants deal with the physical, social, and emotional repercussions of having IBD. The nature of what the participants say and what it seems they cannot articulate suggests a suppression of both body and mind as symptoms are hidden, personal experiences are trivialized, and emotions are left unexpressed.

4.1.2 Ignoring Symptoms

Participants consistently minimized and hid their symptoms. One participant noted that he ignored the initial onset of symptoms such as fatigue and bloody stools. As he stated, “So uh uh when I first got sick, um I didn’t tell anybody and I sort of ignored it, figured it would go away and when I got like sick to the point well I couldn’t ignore it anymore.” It was unclear what prompted the participant to seek a medical diagnosis. What was evident was that even after diagnosis, participants managed the physical experience of symptoms by paying them as little attention as possible.
Ignoring symptoms commonly involved avoiding social spaces and retreating to private places to both physically and mentally escape their pain. One participant noted that when his symptoms caused discomfort, he would, “get a tv (show) going on my laptop like get out of the get out of my mindset, get lost somewhere else”. Participants commonly used pain management strategies such as resting, watching television, and occasionally spending time with friends because they enabled the participants to divert attention away from their bodies. Overall it seemed that symptoms were usually handled when, as one participant suggested, they are, “pushed to the side” and disregarded. This was most commonly and easily done when the participants were in the privacy and comfort of their own homes, bedrooms, and bathrooms.

4.1.3 Hiding Symptoms

IBD symptoms are not as easily ignored in social or public spaces. In situations where participants could not negotiate their symptoms in isolation, they were managed in ways that cause the least amount of attention to the individual and their illness. Symptoms that could not be ignored were controlled and suppressed. The participants shared stories in which they had experienced the abrupt urge to defecate which required immediate action. While such situations were easily handled at home, the participants noted how difficult it was to find relief when having to use public restrooms, especially at school. One participant recalled an incident where he experienced the sudden urge to defecate while at school. Being wary of using the boy’s room and receiving little sympathy from the school administration, he resorted to calling his mother to pick him up. He recalls, “holding it in, holding it in, holding it in” until he was at home and able to relieve himself.

One participant recalled experiencing the sudden urge to defecate while seeing a movie with friends. Being averse to using public restrooms, he explained how he suppressed the urgency of his physical condition:

But I just had to go to the washroom and it was just like explode out of me and I went down to the washroom and I tried to go but it was like honestly like the washroom was packed if I went it was just like been so noisy it’s like I couldn’t it like I tried and I couldn’t do it. I was in there for
a while and I came back up and my stomach was just going crazy like ‘rawwwr’ and it was just like all that stuff like holding in farts so I could just make it oh my gosh I can’t stand this nananana. And it was just like such a bad situation.

He further explained that to avoid using the public restroom he, “toughed it out till I got home and yeah it’s brutal”.

Hiding and ignoring the erratic, unpredictable, and uncomfortable symptoms of IBD appear to be the most common means of coping. While using such strategies seemed instinctive to the participants, ignoring such symptoms involved a considerable amount of effort. The participants’ narratives elucidate both the mental and physical control they employed in order to handle their illness experiences. Participants felt they must physically contain and control the sudden and embarrassing bouts of gas and bowel movements, as well as detach from the chronic and recurring physical pain of IBD. Hiding and ignoring illness symptoms involved a considerable amount of control over both body and mind.

4.1.4 Divulging Details

Much like the symptoms of IBD are controlled and suppressed, the participants also regulated and limited the details of their illness experience. The participants’ narratives illuminated their reluctance to explain and impart the details of their illness with others. While the participants acknowledged having IBD when people specifically asked, they rarely divulged any explicit information on their own accord. One participant noted, “I tell them as much as I want to tell them” in reference to how he limits the nature and amount of information he shares with enquiring others.

The participants seemed to have pre-scripted anecdotes that they disclosed to those who asked about IBD. Their stories included little personal detail or emotional disclosure. As one participant explained:

my usual answer is oh you know my stomach, I have a stomach thing ah if ah if ah if if or I’ll say I have ulcerative colitis and they’ll say and I’ll say do you know what Crohn’s is and they’ll say yeah and I’ll say um and they usually don’t push that much further if they do you know I’ll just
say oh my stomach’s just a little upset I get cramps or something or I’ll say something that about it that’s confusing but I usually don’t tell people.

While this participant mentioned that he experienced stomach cramps, he noted in his interview that cramping was not one of his most common or cumbersome symptoms. Disclosing stomach aches seems to be more easily explained and less shameful than diarrhoea and bloody stools.

The participants also suggested that their reluctance to speak candidly about their illness experiences resulted because of how ambiguous and convoluted IBD is. A participant explained that articulating the specifics of Crohn’s and Colitis was difficult because the diseases were not well known or understood among the general public. He also noted that the lack of medical knowledge, not knowing the causes or catalysts of IBD, also made it difficult to explain to others. Comparing IBD to diabetes, he explains why he finds it difficult to explain his condition:

It’s one it’s embarrassing and two like I don’t mind saying to like someone I’m really sick like I have to go to the washroom a lot it’s like (laughs) not the best but um it’s hard like. We aren’t real- even know what Crohn’s disease really is like we know it’s autoimmune and inflammatory bowel disease but we don’t know what causes it, we don’t know a lot of stuff so I think that’s what makes it like- there’s no cure for it, stuff like that. And it’s not a well-known disease like cancer, diabetes, like I don’t know how to explain diabetes but I know what it is… hard to explain, not well-known and but yeah.

Another participant more bluntly stated, “yeah but it’s really long to explain so I try to avoid it when possible”, in reference to how she tells her peers that she has missed school because of doctors appointments rather than disclosing that she was at home and sick.

In addition to the disease’s ambiguity, it is apparent that the embarrassing nature of IBD symptoms also makes it challenging to talk about with others. The participants frequently discussed how hesitant they were to discuss gas and bowel movements. Even when talking about diarrhoea and constipation during the interviews, they rarely if ever explicitly used such terms. Instead, they referred to their symptoms in a more round-about and less explicit way, referring to defecation as, “going to the
washroom”. When excrement was discussed in any detail, it was only referred to in neutral terms such as “form” or “frequency”.

“Going to the washroom” seemed to be a particularly contentious issue to talk about. The participants had difficulty divulging any talk of defecation with their peers despite their knowing that they had Crohn’s or colitis. While fecal matter is typically a private matter amongst non-IBD populations, the participants explained numerous occasions where they needed to hastily and immediately remove themselves from social situations, often for long periods of time, to relieve themselves. Being too embarrassed to explain why they abruptly left to use the washroom, the participants would conceal where they had retreated to and why.

One participant recalled an experience where she had to leave class to go to the bathroom. Upon returning to class after a considerable amount of time, she remembered one of her friends questioning why she was in the washroom so long because as her friend said, “that’s crazy, that’s like constipation”. Instead of confirming that she was in fact experiencing poo problems, the participant recalls that she “laughed it off” because if she were to be honest with her friend, her reaction would have been, “too much information”. Joking about their experiences and even lying to friends were ways in which the participants avoided explaining their illness experiences because as one participant noted, “people don’t talk about the bowels”.

4.1.5 Minimizing personal experience

When the participants were asked more specifically about their personal insights and experiences, they seemed to minimize, even trivialize what they have endured. Throughout the interviews, the participants expressed their frustration and in some cases depression but quickly played down those feelings by explaining their conditions as something that, “could be so much worse,” because, as they said, “shit happens”.

One participant discussed how he had to limit his diet and constantly navigate university cafeterias to find foods that would not cause him grief. After acknowledging that he missed the foods that he was no longer able to eat, he followed with statements including, “what are you gonna do?” and, “it’s
not the worst”. The participants rationalized their experiences by comparing them to situations and others less fortunate. When asked how he deals with the frustration of his illness, one participant remarked:

mmm (pause) go on a new medication (laughs). Um, I don’t know just uh tell yourself there’s a lot worse stuff that could happen to you… suck it up. I mean if this is happening right now it’s gonna happen a lot more to you in your life. Get used to it or learn how to deal with it no um.

When asked if such rationalization in itself is frustrating he said, “it is but I mean what else can you do? There is a sense of helplessness amongst the participants but instead of acknowledging that vulnerability, they minimized what they endured and made light of how they felt.

One participant continued by explaining a situation where his illness and small stature, as a result of his illness, prohibited him from participating in competitive sports. Throughout his interview, he repeatedly talked about feeling inferior to his peers because of his size but instead of expressing this upset he states, “I thought I could have done that if I didn’t have UC (colitis) but you know oh well you know it could be so much worse.” He was adamant that having IBD was an insignificant part of his life because it paled in comparison to the suffering and social injustice of others living in far worse conditions. As he stated:

I I remember thinking in the hospital uh yeah how fortunate I I like I guess I got by thinking like how fortunate I was rather than how unfortunate I was because you know out of all the things to have this is you know. Out of all the all the aha ah bad cases in the world, this is it’s so trivial it’s it’s you know, it doesn’t compare to anything significant so uh you know.

Comparing his condition to others in less fortunate situations seemed to comfort this participant.

4.1.6 Denying emotions

The participants seemed resolute in their attitudes towards having IBD but when asked directly about how their illness affected them emotionally, they became elusive and quiet. One participant described what it was like to have IBD as being “interesting” and “confusing”. While she described that her confusion resulted from having to choose treatment options, she did not in explicitly express how that confusion affected her emotionally. This same participant said that she could not remember how being
chronically ill made her feel different while another explained that he had so many frustrating experiences that he could not recall one event in particular. One participant passed completely when asked to describe an embarrassing experience. It was evident that the participants were not accustomed to, or at least not comfortable with, speaking candidly about their emotional experiences related to IBD.

The participants did articulate that they seldom shared their feelings with others. While they cited friends, and sometimes family, as their support systems, the participants seemed to suggest that they did not use friends for emotional support. They stated that friends were often understanding but that they were not needed as emotional support or sounding boards. As one participant suggested when discussing his relationship with close friends:

Um uh uh well like I rely on them for support in that I said you know look my UC’s bothering me today so I can’t do this no questions asked they’d be like ok I understand. ah but you know I’m not gonna call them up and I don’t call them up in tears saying aww you know. It’s more yeah it’s not my no I I don’t do that.

The participants mentioned that they occasionally turn to relatives, some of whom have IBD, if they need to talk. However it seemed that the participants did not seek emotional help, sympathy, or empathy from many people.

Sharing emotions in was not something that the participants generally seemed comfortable with. There was a sense of embarrassment or indignity that the participants felt when sharing their vulnerabilities with others. The participants mentioned that they rarely shared their emotions with others but did recollect specific occasions, when prompted by others or by alcohol, that they ‘broke down’ emotionally and acknowledged their feelings. As one participant recalled:

End of grade 11 and beginning of grade 12 I was on a drug holiday [a reprieve from medication before starting a new treatment] to start Remicade [a commonly prescribed IBD treatment] so I was obviously going through the worst thing ever and that’s like I was just like really really emotional like not so much (laughs) crying to my friends or anything but like I was at a leadership camp and like you try to make kids cry and come out with like what they’re ashamed of and like honestly like I just broke down there just like yeah.
Another participant who generally denied his feelings disclosed that alcohol would bring about emotional disclosure. As he said, “ah ah if I were drunk and I’d get home and I sort of all your emotions come out because of the alcohol and man this really sucks you know but um.” It was evident that the participants were dealing with underlying emotions that they were either unwilling or unable to articulate.

Being chronically ill seemed to mean being reserved and protective of what symptoms, experiences, and emotions are acknowledged and shared. The participants’ repeatedly identified how they physically retreated to handle their symptoms and emotionally withdraw when acknowledging how those symptoms made them feel. Symptoms are ignored or hidden, experiences are minimized and trivialized, and emotions are derided or denied. The participants’ narratives elucidated how difficult it was to explain what they endure and how difficult it was to share that discomfort with others. There is an overall sense of a physical and emotional suppression of the illness experience. There seem to be no words that effectively describe their symptoms and few spaces to safely express how they feel. As a result, both body and mind are actively controlled, suppressed, and denied.

I remember when I was first diagnosed with Crohn’s at age 13 and I was suffering from the most severe abdominal cramping that I had ever felt up to that point in my life (worse was to come when my bowel obstructed but that’s another story). I quickly discovered that crouching into a sort of twisted fetal position enabled some relief from this pain. At any given moment and in any environment, I would literally drop to my knees to lessen my pain. I quickly realized however, that the spectacle of a pail and frail child suddenly collapsing to the ground garnered a lot of unwelcome attention. So I started to pretend to tie my shoelaces.

Pretending to tie my laces gave me a valid reason to abruptly stop what I was doing and fall to the ground. I tied my shoes countless times a day. I tied them when they did not need tying and when my shoes didn’t even have laces. Tying my shoes became my ruse. I was able to suppress my physical pain while evading any sort of explanation or embarrassment.

I did tell my friends of my little deception. I told them that if they ever saw me tying my shoes for a peculiarly long time that it was because I wasn’t feeling well. I also told them that if they were to ever see me in this position that they should just disregard me and keep doing what they were doing. I remember feeling hurt and betrayed when they followed my instructions as I had requested. They kept on walking, left me alone in the playground, and abandoned me on the sidewalk as I huddled in pain, tying my shoes.

I have never before shared this part of my illness experience.

4.2 Not Being Normal: Dealing with Physical & Social difference while Establishing New Norms
As previously mentioned, one participant ignored his symptoms until they became worrisome enough that he felt it necessary to divulge to his parents. He seemed to do so in order to avoid any attention to himself and to his changing body. He mentioned that by ignoring his symptoms he could forget about them and in doing so, his symptoms became, “like such a norm that like I just didn’t think about them as symptoms anymore, I just like I sort of forgot about them which is weird.”

Another participant experienced the onset of her symptoms quite differently. She had been suffering from stomach pains for as long as she could remember and recalled complaining about her symptoms but that nobody believed her. After a while, her symptoms became a regular part of her daily functioning. As she explained, “I, well, before I was diagnosed I thought that the stomach aches were normal… I thought everybody had them.” In both situations the onset of symptoms became a routine and normal part of their regular lives. It was not until they were diagnosed that those symptoms took on new meanings. Being diagnosed with IBD meant never really being normal again, that they would have to change their lifestyles, their attitudes, and their self perceptions in order to negotiate being normal while living with an abnormal chronic illness.

Being diagnosed with Inflammatory Bowel Disease meant being different. The participants spoke of looking abnormal, being smaller in stature and physically weaker than their peers. They also spoke about having to act differently in school and among friends. In order to gain a sense of normalcy, they redefined what it meant to be normal through lifestyle changes or conversely went about being normal by engaging in adolescent activities without consideration of their health. While chronic illness seemed to effect abrupt disruptions in these young people’s lives, they identified that just dealing with IBD became their new norm.

### 4.2.1 Looking Normal

The intestinal inflammation and pain brought on by Crohn’s and colitis can result in malabsorption of nutrients and a diminished appetite. As a result, people with IBD often experience significant weight loss. Children and adolescents can additionally experience delays in physical development or a complete cessation of growth. Young people with IBD are often a lot smaller in stature
than their peers. While not explicitly stated, the participants’ narratives elucidated how being physically deviant from their peers significantly affected how they negotiated their treatments, their school lives, as well as their own self-concepts.

The participants repeatedly spoke about weight gain, growth, and the regimens or treatments that were used to promote healthy development. Diet and exercise were often regarded by the participants as means of weight gain but with questionable efficacy. One participant recalled a period when he was, “thin as bone” and how others who would comment on how skinny he had become. The participant spoke of his struggle to gain weight while feeling unwell. He engaged in regular bodybuilding exercises and a diet supplemented by protein shakes and eventually experienced some weight gain. However, he lost both progress and weight as soon as his medication stopped working and his disease relapsed.

While medication is taken as a means of attaining disease remission, some of the medications prescribed for IBD, steroids specifically, can drastically alter people’s physical appearance. Prednisone, a steroid commonly prescribed to IBD patients, boasts a host of physical side effects that include bloating in the face, facial hair, and acne, as well as other effects on sleep, appetite, and mood. The physical side effects negatively affect how patients are perceived by others, and themselves. One participant could not believe that anyone would be interested in dating him while being on Prednisone. As he recalled, “Also I had a girlfriend that semester, that that summer which I was even surprised about because I was on Prednisone so my face was all puffy I was horribly sickly looking (laughs) I wouldn’t have dated me!”

One participant’s story elucidated the extent to which the fear of looking abnormal affects how people negotiate their treatment options as well as their self-perceptions. This participant spoke about a particularly challenging period when her disease was flaring and she was dangerously underweight. She was not gaining weight on her own and was prescribed feeding through a nasogastric (ng) tube, a tube that is inserted through the nose to allow specialized, nutrient rich liquid formula to be fed directly into the intestinal tract. Rather than go to school with the protruding tube taped to her face, the participant learned to remove and re-insert the tube. The participant explained that she did not feel comfortable being
seen at school with the tube because others would be scared, ask too many questions, and that, “they’d probably think I was retarded or something.”

4.2.2 Being Normal

While looking normal was important to the participants, being physically active and able to keep up with friends socially seemed central to their daily functioning as well as their self-perceptions. The participants were aware of the limits placed on their bodies due to having IBD and all spoke about how difficult it was to be less physically fit and have different needs than their peers. Participants found that having IBD was a significant impediment to their physical abilities, as well as their social and school lives. Experiencing frequent fatigue and a lack of energy made it difficult to engage in competitive or regular physical activity. Trying to keep up with friends was difficult due to missing school and having limits on the nature and amount of social activity that they could comfortably engage in. While not often explicitly stated, these limits seemed to contribute to feelings of inadequacy and inferiority.

The physical demands of school as well as extracurricular sport activities seemed particularly challenging for the participants to negotiate. One participant mentioned that phys. ed. classes were particularly taxing on her. She stated that she was most aware of her illness when she was unable to engage in regular class activity, when she, “can’t like run around and stuff”. Another participant who had to relinquish playing hockey at a competitive level due to his illness stated, “I could get back into it but like it would just be too depressing like aw like I used to be able to play with these guys, I can’t play with them anymore um.” He also mentioned that he used to be a fast runner before having IBD. Despite declaring that he was currently feeling well, he said that he could no longer run at all which, as he stated was, “depressing I guess but it’s one of the things you deal with.” One participant recalled being cut from a competitive basketball team when his disease was flaring. He felt certain that he would have made the team if his disease was not active at the time. He stated that, “I wish I was taller and I feel like the UC may have done something to that so that frustrates me a lot um, for basketball but also like for looks. I wish I was taller.”
While looking and being physically fit was important to the participants for athletic purposes, it became clear that acting and being normal was of major importance in their regular, daily lives. The young people expressed the challenges in keeping up with their daily routines. They addressed how IBD impacted their ability to handle the rigours of school as well as enjoy the sometimes unhealthy social rituals of being a teenager, such as drinking.

Being in high school seemed to create particular challenges for the participants. They noted how having IBD affected their ability to maintain their grades as well as maintain a sense of normalcy among their peers. One participant found that missing class due to regular doctor’s appointments, day long treatments, and sick days was particularly challenging for her. She mentioned that she rarely told her peers why she was away from school when they asked because, “ah yeah having to miss school… it’s not what you normally do.” She noted that it was often safer to be hospitalized than to attend school because being on Remicade made her susceptible to catching colds and infections. She stated, “Well now that I’m in school, I catch every single thing that goes around the school so I still get really tired.” Not only was being at school contentious because the participant’s absence drew unwanted attention to her, being at school also made it more difficult for her to maintain her health.

The majority of discussion about being normal, at school or elsewhere, revolved around socializing with their peers and friends. The participants discussed their attempts to keep up with peers and often evaluated their capabilities in relation to them. Being able to eat the same foods as their friends, to be able to stay up late, and drink alcohol were important teenaged activities for which the participants identified their limits.

Another participant recalled his experience during the first week of university and how he felt when the entire week revolved around partying and alcohol, which is thought to trigger IBD. He stated, “That’s like me like frosh week was like really hard on me (laughs) (inaudible) being you know. It was hard and you take you know when you can drink and when you can’t but um that was hard at first because like my sisters are drinking, all my friends are starting to drink.” The participants were definitely aware of how their conditions affected the ways in which they acted and were reacted to. Moreover, they knew
how having IBD limited the ways in which they could perform and be normal. While the participants generally acknowledged how difficult it was to feel different, they seemed to negotiate those feelings of abnormalcy in a variety of ways.

**4.2.3 Negotiating Normal**

The participants engaged in a variety of strategies in order to achieve a semblance of predictability and normalcy in their daily lives. Two participants had very different ways of handling their illnesses. While one participant spoke of changing his lifestyle to accommodate his illness, another participant discussed how he did not let having IBD get in the way of being a regular teenager.

One participant spoke about how his diagnosis inspired a complete change in how he lived his life. He explained that his diagnosis, “was like boom, lifestyle change […] right away that’s like the hardest thing about it.” This particular participant discussed how his IBD diagnosis provoked multiple changes in his physical, dietary, social, and academic routines. In addition to relinquishing competitive hockey, he spoke about how figuring out what foods he was able to eat. Living in residence and finding foods he could tolerate in the cafeteria was particularly challenging.

This participant also spoke about having to figure out effective medications and treatment regimens. Medication seemed to be a particularly daunting issue for him as well as the other participants, not only because of their side effects but because of the inefficacy of the medications. There is no magic bullet for treating IBD and medications are not effective for everyone. In some cases they may even cause more side effects than the illness itself. This participant discussed his struggle to find treatments that helped him:

I don’t know I think, this really answers your question or not some like hardest part of the whole thing is like trying to figure out what works for you like going on to the medications this one doesn’t work, this one doesn’t work, this one doesn’t work if you could almost just pinpoint right away what medication would work for you or what foods you can’t eat it would be like amazing you’d save years (laughs)
This participant discussed how his experience with one medication offered him a brief reprieve from his symptoms. Unfortunately the medication quickly stopped working and ended up causing him irritation that he struggled with weaning off the drug:

I tried Humira and Humira actually first time I did it you know you do the frontloading and it was amazing it was like of my gosh this is amazing I’m like back to normal then like two days later I was like ah this is so awesome then I used a combination of having bad reaction to the medication and the medication stopped working like (snaps) almost right away.

This participant also discussed the vitamins, allergy pills, and supplements that he took to maintain nutrition as well as reverse some of the illness’ side effects. He explained that he and his mother had looked into how various vitamins and alternative treatments could aid in IBD maintenance and consequently he was taking close to ten different medications or supplements on a regular basis. He discussed how he managed to incorporate taking so many medications into his daily routine and when asked if he thought the process was daunting, he explained:

It’s normal but I find the hardest part is I mean, you wanna get, I’m like a teenager so you wanna get as much sleep as possible so you literally wake up last second probably don’t eat before you go to your first class which isn’t the best and then you come back and you want to take the medication on a full stomach and that’s like one of my top priorities when I take these.

This participant also talked about negotiating his illness in social settings, how he dealt with his symptoms at school and maintained a social life with his peers. He explained that dealing with his illness became easier over time. While he was initially reluctant to use the bathrooms at school, he eventually figured out how to do so while avoiding embarrassment. As he explained, “Yeah and you also like learn like what bathrooms to use, what times they’re usually empty (laughs) stuff like that.” This participant, as well as the others, explained that with time and experience, they were able to hide their symptoms to avoid other people’s reactions and consequently embarrassment.

The participants all spoke about withdrawing from social situations when their diseases were very active. They explained that they felt comfortable telling their friends that they could not be social when
they needed to be close to a bathroom or felt too sick or fatigued to go out. However, the participants actively tried to maintain normal social lives when they could. One participant discussed how he limited how late he stayed out and how much he drank so that he would not trigger his illness. While he assured me that he was not a ‘shut-in’, he explained that he often had to limit his alcohol and avoid drugs. He was not regretful for missing out but rather explained:

I don’t that’s, I like I feel that I don’t (laughs) I mean a lot of people do it and, it’s just like it’s a really good excuse not to. I feel like I wouldn’t do it ever but like it’s a really good excuse not to, and it’s just a good thing to have in my head like, are you stupid? Like why would you ever do that like especially like in your situation. So.

This participant used his illness as an excuse not to get wrapped up in the apparent trappings of late adolescence. He was able to normalize the limits placed on his body by rationalizing excessive drinking and drug use as bad practice anyway.

Conversely, another participant explained how he did not let having IBD affect how he went about living his life and being a normal teenager. Due to his success with Remicade, he felt he could do anything he wanted with little consequence. He explained that his IBD had little effect on his present well-being. Even when his illness was flaring, he did not let it stop him from being social, eating, and certainly not from drinking alcohol when he wanted to. As he explained, “so I wouldn’t be able to go out and do the things that my friends that I usually would want to but for the most part I did it.”

This participant recalled one particular incident where he refused to let his illness stop him from being social and from being normal:

I remember the most extreme case. There were two of them was uh one of them was ah right after ah oh when I was fasting for a colonoscopy/endoscopy ah and I you know I could only have clear liquids and I couldn’t eat anything for so my thing was on a a Monday and I started fasting on Friday and Saturday night my friend had a party so on um what’s uh laxatives so I had to run to the washroom a lot (laughs). I um brought vodka (laughs) and used the washroom frequently but went to the party, got fuckin’ drunk ‘cause ‘cause you know I had no food in me but yeah
This participant often expressed that he was most aware of being different or abnormal when he could not eat, drink, or do what his friends were doing. While he insisted that his illness did not stop him from anything, it seemed as if he was struggling to be normal more than he let on. As he explained:

Ah so lets say um if I’m on a diet people are eating things I can’t eat or playing sports and I can’t keep up because I’m sick, if I’m in the bathroom (laughs) you know obviously it’s not a pleasant experience when you have stomach cramps you’re aware of it yeah. I think when you’re sick you’re constantly aware of it and you’re just you know fighting to to to you know keep up no matter where it is you know

This participant also seemed reluctant to articulate how his illness had changed his life. While he identified being “impaired”, he seemed to deny how that had affected him:

I just always acted regular uh I you know obviously I was impaired because I was very tired and stuff but like I played sports and stuff and I would get really tired and then you know got worse then I got on Prednisone again and then hospitalized and got a blood transfusion so I never really let it interfere with my life.

This participant further explained that he felt most normal, even “jovial” when he was in the hospital because of his treatment but also because it was, “just you know me with my thoughts.” Once again, the participants expressed feeling most comfortable and most normal when they retreated from their normal social spaces, avoiding others’ judgments as well as their own embarrassment.

4.2.4 Establishing a Valued Self

All of the participants explained that having IBD inspired positive changes in their perspectives and behaviours. They explained that having a chronic illness changed their priorities. It seemed as if adopting more positive attitudes and pursuing admirable hobbies helped them rationalize being different. They seemed better able to reconcile feelings of inferiority and negotiate a more valued sense of self when they adopted more enlightened attitudes and took on more respectable initiatives.

As previously addressed, one participant explained that having IBD pushed him to take better care of himself, something that he took pride in. Not only was he proud of how he managed his illness, he
explained that having IBD pushed him to be an overall better person, challenging him to excel in school and extracurricular activities. As he explained:

Take better care of myself (laughs) obviously. Um, listen to my body more, um how else? Almost like challenge myself more. Like I don’t like using Crohn’s disease as an excuse if I said like I like to achieve just as much if not more as I did before

Even the participant who engaged in seemingly reckless behaviour suggested that having IBD inadvertently inspired him to be a more conscious eater, opting for organic and fair trade foods. He explained that having IBD made him more attuned to the world’s injustices and that eating organic was his way of reducing his destructive impact on the planet.

This participant further explained how having IBD not only changed his perspective but his overall character. He recalled that before he was sick, he, “was probably a worse off person. I was meaner I was probably you know a-pathetic apathetic uh you know self-indulgent you know probably a bad bunch of traits. Yeah.” He explained that suffering from IBD had an impact on his decision to pursue social studies in university and, “have an impact on the world.”

Another participant spoke of her hobbies and volunteerism as means of pursuing a valued self. She explained that she plays in the school band and seemed to have a natural talent for her particular instrument. While, this participant did not take pictures for our interview, she suggested that she would have taken a picture of her musical instrument because it was something that she was really good at. She told me that she was too tiny to play the instrument that she originally wanted to as her arms could not reach the end of the instrument. She chose a smaller instrument instead and boasted of her natural talent with it.

This same participant also spoke about her volunteer work with students with developmental disabilities. She spent her lunch hours spending time and tutoring students in her school’s special program. She stated that, “Like, if I never went to the hospital I would have never gotten into volunteering with kids with autism and stuff.” The participant recalled her experience with her diversional therapist when she was admitted to the hospital and explained that she wanted to do that same type of
work for other kids in need. Her lunchtime volunteerism also seemed like a good opportunity to avoid having to eat with the rest of her peers, something that she seemed to grapple with.

Adopting more enlightened perspectives and activities seem to provide the participants with the means to rationalize and compensate for feeling abnormal. When the participants undertook such endeavours it seemed to not only give them a valued sense of self but also a means to rationalize and make meaning out of their illness experiences. It seemed as if they believed that if they were to forever be burdened with an illness that made them abnormal, they were going to spin that difference into something positive.

4.2.5 Conclusion: Being Normal and Establishing New Norms

While one participant expressed a disregard for his condition, not allowing his IBD to affect his lifestyle, another modified his regular routines to accommodate for his illness and his inadequacies. The participants all spoke of how their illness made them feel different from their former selves and from their peers. They discussed to how being smaller, weaker, and less able to keep up with peers socially was difficult and frustrating. Although it was not explicitly expressed, it was apparent that the participants generally felt inferior to others as a result of their physical and social shortcomings.

Despite their efforts to be normal, the effects of IBD seemed to become a normal part of their daily lives. Even when they were feeling relatively well, the participants were aware of being smaller and weaker than their peers and not as free to participate in the regular social activities that teenagers do. It seemed unlikely that these young people ever really felt normal, that they ever felt as healthy, energetic, or unburdened as they did before they were diagnosed but as one participants suggested, IBD had become the new norm:

I’m used to it, that’s the thing, it’s like a new norm. Every time like I’m used to going to the washroom four times a day, I don’t mind it if I get sick, it’s like ah c’mon but like right now I’m healthy and I still go four times but it’s like fine. Good form and all that stuff, and it’s like a new norm, I don’t mind. If I have to get up during class, I don’t mind (laughs) if I have to fart more than usual, I don’t mind (laughs)
A year after my diagnosis I still hadn’t achieved any sort of disease remission. I was still suffering from abdominal pain and consequently a lack of appetite. I was underweight and was significantly below the average height range for a 14 year old girl. My doctor had threatened that if I did not eat, gain weight, and grow that we would have to take drastic measures by way of steroid drugs and tube feeding, both of which I eventually had to endure.

Tube feeding involves having high calorie, high nutrient, and easily digestible formulas pumped directly into the stomach through a tube. I was told that I would be tube fed for two years, months of which I would not be allowed to eat anything but clear fluids to give my bowels a rest. I had to make the decision whether I wanted a nasogastric tube placed in my nose or have a tube surgically implanted into my stomach. I opted to have the surgery as I dreaded the thought of attending middle school with a long skinny hose taped to the side of my face. I was not given the option of removing the tube daily as others were.

After a long recovery I returned to school. I refused to bring the feeding equipment that attaches to the tube with me. I had a portable pump that administered the horrible smelling formula that fed me but could not fathom the thought of carrying it from class to class. The pump often beeped and leaked and I was not going draw more attention to myself. It was bad enough that my cheeks had swollen from the steroids that I was taking. I was already the sickly looking short kid walking around with a moon face; I didn’t need to be more of a freak. So I pumped at night and lived off of Sprite and Jell-O during the day. This was particularly hard because a common side effect of steroids is uncontrollable hunger. I endured this discomfort because I thought it was better than looking abnormal.

The extreme efforts that I took to look and feel normal in my situation quite quickly became fruitless. Shortly after my feeding regimen started, I was weaned off of the steroids which changed my muscle mass and dislodged the gastro-tube. I was rushed to the hospital where they gave me a Tylenol 3 and pulled the anchored tube out through the tiny incision in my abdomen. They implanted a new tube but the incision never healed around it. For the next two years, I lived with a near constant stream of stomach acid that leaked out from around the tube. It stained my shirt and burnt my skin which I would treat with diaper cream in the teacher’s bathroom during lunch recesses.

Achieving a sense of normalcy while negotiating IBD seems virtually impossible. These diseases go far beyond physical pain and can act as a huge impediment to people’s daily functioning. The particular narrative that I chose to share might sound extreme but it happened to me and I know that other people who have had tubes or ostomy bags, devices that collect feces, have suffered similarly. Those two years were a particularly challenging time in my life but my experience with Crohn’s has been
marked by many comparable periods of struggle. Eventually you do learn how to cope with those struggles and handle the pain. It may get easier but it’s never normal.

4.3 Being Young and its impact on the illness experience

The participants minimized the implications of their age much like they did the magnitude of their illness experiences. They denied any particular struggles that they may have endured as a result of being young and instead suggested that it would be more difficult to have IBD as an adult. The participants also spoke of their parents’ involvement in their illness management and shared mixed feelings about parents’ efforts to impose diets and alternative treatments. It was interesting to note that despite the participants’ reactions to their parents’ imposition, they often referred to their own struggles in second person, using ‘we’ to describe their experience. The participants’ experiences seemed to be lost or diffused as a result of their interactions with adult authorities at home and at school.

4.3.1 Being young vs. Being an Adult

I asked the participants if they thought it would be easier or more challenging to have inflammatory bowel disease as a child or an adult. They offered pros and cons to both scenarios, suggesting that children are less emotionally complex and more adaptable making it easier to handle illness. Participants thought that adults were more mature and thus having IBD would not be as embarrassing or emotionally difficult for them but still challenging because adults have to also negotiate their families and careers. When the participants acknowledged how adolescence lent a particular challenge to the illness experience, it was done in self-deprecating ways:

I think it would be hardest for a teenager because um uh they you know they’re very self-absorbed and and uh they don’t grasp what’s really unfortunate, they think you know uh that whatever’s happening to them is the worst thing in the world (laughs) no matter what it is or how trivial it is ah and of course they’re the most emotionally disturbed of the lot (laughs) so uh you know especially high school, you know nothing’s right so uh I think it would be hardest for teenagers ah you know adults they’re mature so they can handle it better and kids they’re so immature that it doesn’t it wouldn’t phase them yeah
In doing so, the participants reinforced their inferiority and denied their own emotional struggles and experiences.

All of the participants agreed that having IBD as an adult would be more challenging because of having adult obligations. They suggested that responsibilities such as maintaining a job and having a family would make negotiating IBD more difficult in adulthood. One participant suggested that despite older people being more aware and acceptant of IBD, it would still be harder to deal with as an adult because:

Everyone knows what it is um but I do think it would be harder just because you have more stress and responsibilities in your life. I think it would be a lot harder being diagnosed with it as an adult. Huh maybe I don’t know, not so much as a teenager and younger than a teenager is definitely I think the worst to be diagnosed but um I think it would be harder as an adult just because you have all those responsibilities you have to actually have a job, you’re supporting your family stuff like that and what the heck’s going on with my body.

The participants did not speak of the difficulties of adulthood with much fear for their own futures. Instead, they seemed to only compare their perceptions of adulthood to their own experiences in ways that once again minimized their current statehoods and experiences.

### 4.3.2. Dealing with Adult Authority

Although the participants did not acknowledge that their own struggles were significant in comparison to their adult counterparts, they did recall stories where they felt mishandled as a result of being underage. The participants recalled a number of incidents when they had to negotiate adult rules. The participants mostly spoke of how being in school complicated their ability to cope with their diseases. Such situations occurred as a result of being young and subject to adult authority.

While the majority of discussion centered around negotiating adult rules, one participant was more candid about feeling angry. She discussed how her parents and doctors disregarded her symptoms and how she struggled for affirmation when they did not believe that she was unwell. As she stated, “‘cause I would always complain of stomach aches and people would stop believing me because I said it
so many times […] Parents, doctors, everybody thought I was lying.” This participant also had difficulty in school, as teachers did not comprehend the severity of her illness. She recalled one particular incident when a substitute teacher either did not understand or believe the participant’s concerns. As the participant stated, “And I’m in music class so say I have stomach ache I ask them if I could skip playing […] They ask why and I tell them I have Crohn’s and they ask, say well shouldn’t you be at home? So it’s like no.”

All of the participants shared stories about having to negotiate their illnesses within the rules and confines of school. One participant discussed how he had to ask his professor for permission to leave his classroom in the likelihood that he would have to frequently and/or urgently leave to use the washroom. The participant explained, “I started new classes last week and one of my professors’ rule was you aren’t allowed to leave the room for any circumstance and I’m thinking ok (laughs) well you’re gonna be getting an email.” The participants identified that teachers and school administrators were most often obliging and helpful once they were aware of the disease constraints. They discussed being given special accommodation such as extensions on work, make-up dates for exams, and the opportunity to miss class. However, the participants seemed reluctant to take advantage of all accommodation and often tried to cope with the demands of school without any special treatment.

Exams seemed to be a particular cause of stress and disease flare-up. One participant discussed how he got a doctor’s note to postpone his exams but rather than explain to his peers that he was unwell, he evaded questioning in order to seem normal. Another participant spoke about cheating on an exam because he was feeling sick, was unable to sleep, and consequently could not study. He remembered feeling ashamed when he was caught cheating and recalled:

‘cause I’m used to getting like good marks and stuff like that and I got in there and just like obviously like it’s no excuse but I told them and they’re like well your mom did call earlier today and eventually they let me rewrite the exam but I mean it was a stupid decision and other than that I’ve never asked for an extension or anything like that

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Rather than acknowledge that he was unwell or risk doing poorly on his exam, this participant decided to cheat, something he had never done before. It was something that he still seemed to feel guilty about. This young man felt compelled to compromise his values in order to negotiate their illness within the normal and expected demands of the school structure.

Being young, being in school, and being subject to adult authority pose specific challenges for young people dealing with chronic illness. The participants seemed to be treated differently and were often not taken seriously. It seemed as if they negotiated the demands of high school and university in order to accommodate for their illness without seeking support in order to avoid additional special treatment. It was also interesting to note how parents’ involvement and support seemed to legitimize the young people’s conditions.

4.3.3 Parental Involvement and being “we”

Parents’ relationships with their children and their involvement in illness management varied significantly. Two of the participants discussed how their parents often took an active role in helping their children maintain their health, finding research and imposing supplementary treatments on their children. The participants’ reactions to their parents’ impositions were mixed, with one participant stating that he appreciated his mothers’ surveillance, while the others’ reactions suggested tension and resentment. Despite such variance, all three participants spoke about their illness management in second person, acknowledging their parents’ involvement in their illness experience. Referring to their own actions and narratives in “we” terms suggests the extensive involvement that parents have in their children’s illness experiences.

All of the participants identified having supportive or at least a sympathetic adult figures in their lives. Parents were often recognized as key support systems, helping the participants with medical appointments and school obligations. Two of the participants mentioned that they spoke to their parents if they needed emotional support but suggested that they do not often do so. One participant said that he checked in with his uncle every so often because he too has IBD. Another participant mentioned that her friends’ parents were often the most sympathetic, if not slightly overbearing as she stated, “mostly their
mothers that are like ‘oh my god you have a stomach ache are you ok?’ yeah fine, just a stomach ache (laughs).”

Some of the participants explained how their parents were devoted to monitoring their children’s illness as they researched new treatments and diets that could improve their health. Even when parents, most notably mothers, were not directly helping the participants, attending their appointments, driving them to school, or cooking their meals, they were ensuring that their children were monitoring themselves. One participant explained his mother’s involvement in his illness management:

she’s just like gung ho with all the research at the very beginning, trying to get me into a bunch of specialists um hmm. Just always asking how I’m feeling. I’ll always get a little text saying like during exams like don’t stress like your health is your number one important thing like stuff like that […] um stuff like that, always ask how I’m feeling and making sure I’m getting my blood work done stuff like that, staying on top of me.

This participant expressed his appreciation for his mother and identified her as his biggest help throughout his entire illness experience.

Another participant was not as thankful for his mother’s involvement and discussed how her concern was often overbearing and unwelcome. Both participants expressed that their mothers had at some point imposed limited diets on them to treat their illnesses. While both participants said that the diets were ineffective, one participant further explained how such treatment became a point of contention between him and his mother:

Ah yeah so gluten free my mom it was it was always my mom’s idea and I I sort of figured that was because she couldn’t I ah sort of handle the disease was incurable besides surgery […] So she’s always looking for cures ah you know she and you always hear these stories about well so and so’s son did it for two years and now they’re fine and you know obviously that’s been wonderful evidence so (laughs) you know […] Uh I didn’t find going off gluten or anything helped me I found it more a nuisance than anything because because I was limited in my eating I ate less which probably made me sicker and angry because my mom kept on trying to push these things which I did not want to do at all
I asked what the participant’s reaction was to his mother’s forcefulness and his answer was, “fuck off.”

He and the other participants admitted that they would often eat foods that were not allowed on the diets their parents imposed because they believed that the diets would be ineffective. Food seemed to give the participants an opportunity to resist their parents’ authority. It was something that they had control over in otherwise powerless situations. While the participants’ resistance through food did suggest that they possessed a sense of their own body knowledge, such acts of resistance did not seem to occur regularly. Instead, the majority of agency that the participants exerted seemed to be done in conjunction with their parents. The participants’ efforts and experiences seemed to be diffused amongst themselves and their adult authorities.

4.3.4 Being “we”

It was interesting that the participants often spoke in plural, using ‘we’ when referencing their insights and experiences. They incorporated their parents into their narratives in ways that suggested that they were as much a part of the illness experience as the young people themselves, for example: “we found I was anaemic”, “we stopped the diets a while ago”, “we didn’t know why (I wasn’t physically fit”), “we got a doctor’s note”, “we thought maybe gluten had something to do with it”, “we didn’t have it (Celiac Disease).” It was apparent that parental authority and involvement had permeated the participants’ experiences. The young people’s own experiences, their agency, and individual body knowledge seemed to be diffused as a result of their parents’ influence.

Around the age of 16, my pediatric gastroenterologist referred me to see a psychologist. He said that it was standard protocol for young IBD patients to speak to someone given how difficult these illnesses can be. I don’t remember my reaction to this referral but I do recall willingly going to the psychologist’s office with my mother. The psychologist asked to speak to my mother first so I dutifully waited outside by reception eating a bag of peanut butter cookies. I remember feeling particularly proud of myself that I was able to eat so many. I would show my mom the empty bag when she came out of the office and she’d be so proud.

My mom eventually returned and it was obvious that she had been crying. Now it was my turn. The psychologist introduced herself and invited me to sit down. Before she even asked me how I was,
she handed me a piece of paper and some crayons and asked me to draw my feelings. Draw my feelings, was I six?! This doctor had belittled me in a way that I had never experienced before. I could feel the sheer anger and frustration stewing in my gut but didn’t dare be disrespectful and actually express those feelings. Instead, I cried. I cried not only because I felt so infantilised but because I was struggling with real issues and desperately needed an outlet. It was quickly apparent that there would be no opportunity for me there.

4.3.5 Conclusion

Being chronically ill, being normal, and being young seemed to determine how the participants defined and embodied their experience with inflammatory bowel disease. Being sick meant having to hide erratic bodily functions and also having to suppress emotions. Being normal was a challenge when the participants looked smaller and felt physically weaker and less capable than their peers. In order to gain a sense of normalcy and hide their abnormalcy, the participants retreated from social situations, relinquished activities, and redefined what normal meant in order to accommodate a very abnormal illness. Being young often meant not being. It seemed as if being young meant having to negotiate particular struggles as a result of their age while forgoing their own sense of self and identity because their experiences were shared and diffused amongst adult authority.

While the participants expressed their daily insights to and struggles and illnesses, a lot of their personal and emotional insights were not explicitly stated. It seemed as if the participants coped by minimizing and trivializing what they endured and suppressing how they felt. However in adopting such coping mechanisms, their emotions were denied and their sense of self compromised. Charmaz (1991) explains that what appears to be denial of chronic illness is often perceived as a refusal to acknowledge experience. It is often assumed that denial occurs in those who are unwilling to deal with their ailments and as a result, they are harshly judged. Charmaz challenges this conception by suggesting that those who are thought to be “in denial” are often just unable to articulate their suffering. It is possible that young people are not denying their emotions but instead are unable to articulate them because of how difficult
the IBD experience can be. While it was not often explicitly stated, there was a sense of shame and embarrassment implied within the participants’ narratives. They were constantly dealing with embarrassing symptoms, feeling different in their regular activities, and feeling shamed and inferiority because of their inabilities to be normal. While it may seem as if participants are denying their feelings, it is possible that there are no words and no means of articulating such emotionally difficult expressions.

I assumed that speaking about IBD would be easy for everyone as it was for me. When it became apparent that the participants were not as forthcoming as I anticipated, I began to wonder what went wrong. I started to question if I was a bad interviewer, if I asked the wrong questions, or did not make the participants feel comfortable. Then I began to think about my own narratives and what exactly I had always been ok divulging to others.

I have always prided myself for being forthcoming about my illness. I often tell people that I have Crohn’s disease and am usually willing to explain the mechanics and not so fine details of IBD to others. I even wrote my undergraduate thesis on the power relations that affected my experience with IBD. However, upon further reflection, it became apparent that my personal narratives, the stories that I have shared with others and even the experiences that I identify with, fail to capture my own emotional struggle. I myself rarely acknowledge the severity of my own physical and emotional suffering. The embarrassing and difficult stories of uncontrolled diarrhoea on the walk home from school or the debilitating pain that kept me awake at night crying have not been included in the narrative of my illness that I have told myself and others. I quickly realized that I too have minimized the effects of my pain and suffering. I too have suffered from the same silencing.

Living with inflammatory bowel disease is an emotional struggle as much as it is physical. It is apparent that expressing those struggles can be particularly challenging. The pain, the messiness, and social stigma that characterize Crohn’s and colitis make these illness experiences very difficult to come to terms with let alone discuss. After interviewing the participants and reflecting on my own experiences, I wanted to further explore why this silencing exists. I turned to educational resources developed by the Crohn’s and Colitis foundation of Canada (CCFC) for young people to better understand how dominant discourse constructs IBD. The following section outlines a discourse analysis of CCFC materials and other resources available to young people. A critical review of these resources elucidates that dominant
understandings of IBD leave little space for young people to talk about the serious issues and emotions that they might be struggling with.
Chapter 5

Discourse Analysis of IBD Resources

In this section, I analyze the dominant and marginalized discourses of IBD that are propagated through a variety of texts. I critically examine some of the relevant informational brochures put forth by the Crohn’s and Colitis Foundation of Canada as well as a children’s book written by a psychologist to reveal the dominant truths being disseminated and the alternative knowledges being concealed. Zines about one man’s experiences with Crohn’s disease provides a contrasting and more subversive perspective to the dominant discourse. This juxtaposition and its implications are further explored.

5.1 CCFC Resources

The Crohn’s and Colitis Foundation of Canada (CFFC) is the largest not-for-profit organization promoting IBD awareness and raising funds for IBD research in Canada. The CCFC was originally developed in 1974 by parents of children with Crohn’s and ulcerative colitis who were concerned about the lack of knowledge and funding for these illnesses. Today, their mission is quite succinctly to “Find the Cure” (www.ccfc.ca, 2011). The CCFC aims to do so by financing scientific and medical research that might shed light on the causes of these illnesses and develop effective treatments and an eventual cure.

In order to finance IBD research, the CCFC relies on sponsorship from corporations including pharmaceutical companies and private donations. The CCFC also relies on people’s membership, volunteerism, as well as their commitment to fundraising. The CCFC website and the informational brochures that they develop encourage individuals with IBD as well as their friends and family to get involved. Volunteers are recruited to assist chapters in organizing their fundraising endeavours and education symposiums. CCFC journals, mailed to their paying members, highlight the volunteers and chapters who raised the most amount of money or experienced the greatest percentage in gross revenue.
While the CCFC does not offer any support work or counselling services for being a member or volunteer, they claim that getting involved with their local chapter enables people to create social and support networks for themselves.

Annual Heal ‘n’ Wheel-a-thon events are organized by regional CCFC chapters across Canada. Fundraising event planning seems to be the chapters’ largest responsibility as chapter councils focus the majority of their attention on organizing events such as the Heal ‘n’ Wheel-a-thon. M&M Meat Shop franchises also hold fundraising barbeques each year in support of the CCFC. Each store is contractually obligated to hold a barbeque, selling hamburgers, hot dogs, chips, and soda to the public with all proceeds going to the CCFC.

_It’s really hard um you walk in first thing to your right is hamburgers, fries and like grilled cheese and it’s just like you shouldn’t be eating that stuff and I never eat that anymore_  
_(Participant discussing the challenges of eating in school cafeterias)_

In addition to fundraising and volunteer recruitment, The CCFC is also dedicated to IBD awareness, educating the public about these diseases and providing individuals with IBD and their families with information on how to treat and cope with these illnesses. While not all of the information put forth by the CCFC will be addressed here, it should be noted how this information is presented because of its overly cheerful messaging that fails to provide a realistic depiction of the challenges that can affect individuals with IBD.

Regardless of the content outlined, the brochures are laden with overly happy and positive pictures of people supposedly suffering from IBD. While IBD is generally not thought to be a positive experience, there is a peculiarly cheerful air to the images and messaging of these brochures. Ehrenreich (2009) has critically examined our society’s overly saccharine breast cancer discourse. She suggests that illness organizations often promote messages of happy attitudes and positive thinking as a means of coping and sometimes treating illness. Such messaging has overshadowed people’s expressions of fear and anger, leaving their concerns unheard in popular discourse. The CFFC has adopted similar methods
of sugar-coating IBD information and images in order to construct these diseases in a more positive and arguably more marketable light.

Issues such as treatment, coping with illness, and risks of cancer are laid out in brochures alongside what I consider to be inappropriately cheerful and unrealistic images. Pictures found in the pamphlets include an elderly man comfortably lying in a hospital bed, apparently either pre or post-op, free from any intravenous tubes or other medical machinery; a family who appear to be laughing hysterically while wrestling on the grass; and a young girl, wearing what appears to be hospital scrubs, happily pouring syrup onto her raspberry pancakes. While these images do not reflect very many IBD experiences that I am aware of, they might be encouraging to people interested in supporting such a positive organization.

The information brochures include titles such as *Prescription for Health*, which outlines medication options and *The Cutting Edge* that discusses surgical procedures. The titles of these pamphlets illustrate the CCFC’s support of dominant biomedical research and knowledge, prevalent throughout all of the information that they disseminate. Even in their brochure titled, *Food for Thought*, they suggest that food and stress do not cause these illnesses because there is no empirical evidence to support those claims. This contradicts my own and others’ experiences. While the CCFC suggests that there are “trigger” foods that can aggravate symptoms and “safe” foods that are more tolerable when a person’s illness is relapsing, they argue that food cannot play a therapeutic or preventative role in disease maintenance.

They caution their readers to not be fooled by “miracle diets” that claim to be curative. While they do acknowledge that diet and stress management can help people’s overall well-being, such claims also reinforce the importance of medications and other empirically supported medical interventions as they are considered the only means of offering disease remission or any real illness relief. Moreover, stating that such lifestyle changes have little impact denies people’s own body knowledge and agency in their own illness management.
I went to the CCFC Education Symposium held for the Kingston community earlier this year. The educational event showcased a variety of health professionals including a gastroenterologist, dietician and a naturopathic doctor. I was particularly excited to hear the naturopath speak because I had recently started pursuing holistic medicine as a means supplementing my efforts to treat my Crohn’s through diet. The doctor spoke about healthy eating and provided the audience with a slide full of tips and resources. I noticed that The Specific Carbohydrate Diet (SCD), the diet I had been following, was listed at the bottom. I was interested to hear what she would say about SCD, especially after the gastroenterologist who spoke prior to her assured the group that there was no miracle diet to treat IBD (despite the fact that he has marketed his own IBD cookbook). I eagerly waited until she reached that final bullet on her slide and then, she skipped right past it. I debated whether or not to ask her to address the SCD in the question period but chose not to. I had already asked so many questions that day and for whatever reason, it didn’t feel right to push my own agenda here.

The information pamphlet titled, *Surviving and Thriving with Crohn’s Disease and Ulcerative Colitis*, provides a guide to living with IBD that very briefly addresses the emotional distress that people with IBD might experience. Within the two paragraphs devoted to “Emotional Overload”, it states that, “On top of the physical symptoms, feelings of uncertainty, embarrassment, aversion to being dependent on others, guilt and self-doubt can weigh you down.” The CCFC also identifies depression as a concern for IBD patients and recommends that medical attention should be sought if such feelings persist. They do also suggest seeking support from loved ones.

While the CCFC identifies the adverse feelings that can result from having IBD, their resources are not sufficient in elucidating the emotional and social struggles of people living with these chronically painful, embarrassing and often physically and socially incapacitating illnesses. Nor are adequate resources or information provided for individuals struggling emotionally with their IBD. For an organization that seeks to inform and educate people and help them cope with their illnesses, they seem to have neglected one of the most difficult and demoralizing aspects of these illnesses.

### 5.1.1 CCFC Resources for Parents and their Children

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The CCFC has also developed specific information pamphlets for children with IBD and pamphlets designed for their parents. While these pamphlets promoted the same biomedical discourses as the resources geared towards adults, the information constructed for parents seemed to be more forthright and detailed about what to expect when dealing with these illnesses. *Smoothing the way: Helping Children Cope with Inflammatory Bowel Disease* is the CCFC’s resource pamphlet for parents of children with Crohn’s and colitis. It provides parents with tips on how to monitor children’s eating to determine their ‘safe’ and ‘trigger’ foods. Parents are assured that children’s physical development will catch up when their disease is brought under control. The pamphlet seems to stress that there is not much that parents can do to aid in gaining remission for their children other than ensure that they are adhering to their medication regimens and getting enough nutrition.

*But um yeah and then uh my parents tried to uh put me on different diets and stuff because they thought that would help so we tried that a bit I was always fighting it and stuff or I’d take different pills from naturopaths and stuff but I I didn’t get it let it get in the way too much but obviously it did impose a little*

*(Participant)*

The emotional repercussions of IBD are once again only briefly addressed. In this context however, they are discussed in relation to how parents can help their child cope. The pamphlet explains that younger children are considered to be more resilient and more adaptable to treatment regimens. Conversely, adolescents are thought to be more emotionally fragile as body image and social status can be compromised when their illness is active. Parents are encouraged to keep their children physically and socially active in order to ensure their overall well-being. Parents are also urged parents to monitor their children for social withdrawal in partnership with teachers and school administration. The brochure includes information about depression, stating that it is normal for young people to feel depressed but if feelings persist once they are in remission, to talk to their children and seek medical intervention if needed.

*It seems disingenuous for the CCFC to recommend that parents foster their children’s independence and agency in their own disease management when they deny that self-management*
initiatives such as diet and stress reduction have little bearing on treating illness. However, parents are encouraged to enable their children some power and agency over their own treatment regimens. It is suggested that doing so would make children active participants in their own illness and also help them avoid parent-child conflict.

They suggest that young people might otherwise resist their treatments and deny their illness in a struggle to gain independence. As the brochure outlines, “In fact, some adolescents rebel against their disease and their treatment unconsciously using denial as a way of dealing with their illness”. It is interesting to note here how the desire to be independent was framed as unconscious and therefore unintentional resistance when in the adult brochure, the desire to remain independent was considered to be a real concern and active struggle for older people.

While the information developed for adult patients at least briefly addresses the specific emotional repercussions of illness, the parents’ brochure only provides information about what they can do for their child. Little attention is focused on what the child is experiencing and instead focuses on how the parent can monitor, assess, and regulate their children’s illness experience. This particular brochure is the only one to display an image of anyone looking depressed or upset. In this case, it was a picture of an upset child, being lovingly held and protected by a concerned looking guardian. The information and images provided within this pamphlet reinforce the notion of the parent as benevolent protector of the helpless child who is vulnerable to an illness that can only be controlled through medical intervention.

5.1.2 Gutsy Youth

While resources for adults, children, and parents at least broach the subject of the emotional struggle of IBD, information developed for youth and apparently by youth misses the mark completely, in my opinion. Gutsy Youth is an offset of the CCFC. The group offers a website with an interactive blog as well as an information pamphlet for adolescents with IBD. The purpose of Gutsy Youth is to advise the CCFC, “on how to better engage youth in the mission- to find a cure for IBD”. Much like its parent organization, Gutsy Youth’s main objective is to recruit volunteers and members under the premise that volunteerism and fundraising for the CCFC can be both therapeutic and empowering.
Like the CCFC, Gutsy Youth provides an information pamphlet promoting IBD awareness and available treatments. The difference with this pamphlet is that it was apparently written for young people by young people. A CCFC Youth Action Council (YAC) is credited for contributing to the Gutsy Youth brochure. The YAC is comprised of youth between the ages of 15-24 who were elected to represent CCFC youth from across the country. The information presented for Gutsy Youth takes more liberty to address restrictive diets and stress reduction strategies because it is advice from young people as opposed to medical authority.

While such a forum for youth voices could provide young people with the opportunity to speak openly and candidly about their emotional experiences, Gutsy Youth fails to raise any issues related to the embarrassment, vulnerability, and loneliness associated with these illnesses. Instead, the brochure’s images are bright and cheerful. The messaging is also quite banal, ineffectively pandering to youth slang and culture. Despite their claim to be interactive, supportive, and the “voice of youth” affected by IBD, there is little discussion or forum to discuss any real emotional or social struggle as a result of IBD.

The Gutsy Youth pamphlet is called, *Tips from the Gutsy Generation: The Basics About Living with IBD* ([http://www.ccfc.ca/site/c.ajIRK4NLLhJ0E/b.6353709/k.F4B5/Brochures.htm](http://www.ccfc.ca/site/c.ajIRK4NLLhJ0E/b.6353709/k.F4B5/Brochures.htm)). Its cover boasts a photo of a group of smiling young people with their thumbs enthusiastically raised up in the air (see Figure 1). The youth all look healthy, none of their faces are bloated from steroids nor are they sporting feeding tubes or IV drips. While the brochure is apparently written by the YAC, its content is remarkably similar to other CCFC resources. The tips echo those provided in other CCFC manuals as Gutsy Youth members encourage their peers to take their medication, be involved in their own illness management, and to be mindful of “safe” and “trigger” foods.

While the Youth’s actual involvement is questionable, it is apparent that this resource was written and developed to pander to youth audiences. Both the layout and messaging within the pamphlet is cheerful and the language is designed to appeal to youth coolness. After the brochure explains who and what the Gutsy Youth are and how others should get involved to also feel empowered, they attempt to explain what IBD is in cheery and cutesy ways. In enlarged font, the pamphlet asks the reader, “Are you
new to the *IBD Crew?*” They explain that IBD, which they also refer to as Icky Belly Disease, is chronic, meaning that “we are in it for life!” The Youth offer further advice such as staying physically active to not get “bummed out” (no pun intended) and to watch all six seasons of Sex and the City when feeling unwell. Such messaging is making very thinly veiled attempts to appeal to a young audience but quite contrarily seems as if it could do the opposite, marginalizing those who seek serious information and support.

Young people who are looking for emotional support and empathy would certainly be hard pressed to find any within the pamphlet or on the Gutsy Youth website. While the Youth state that, “You are not alone!! We understand”, they offer no insight into the daily struggles of living with IBD. Once again there is no talk of the immense pain, embarrassment, shame, or loss of self-esteem that can occur to those suffering from IBD. Nor is there any mention of how symptoms and particular experiences attributed to IBD could cause such feelings. So what is it exactly that they understand? Instead of actually tackling such issues, the Gutsy Youth simply encourages their young readership to, “try to stay positive” and, “try not to worry about being sick”.

The Gutsy Youth website (www.thegutsygeneration.ca) offers a potential space for young people to speak candidly about their illness experiences. It appears however, as if such space is rarely used for anything besides overly positive messaging or narratives that commend young people for raising awareness and raising funds for the CCFC. A *Featured Gut* exposé highlights various young people’s stories. The narratives often elucidate their determination to cope with their illness. While it is important to hear such positive messaging, it seems equally important that the hardships and challenges of IBD are also discussed to open up space for the articulation of suffering. Instead, the majority of narratives end with inspirational analogies or praise for their contribution to CCFC fundraising.

The site also hosts a blog (www.thegutsygeneration.blogspot.com) where Gutsy Youth members can post their own stories and thoughts as well as updates from the CCFC. The blog seems to only be opened for YAC members to post and even then it seems to be dominated by only a few members, whose posts are likely vetted before they are shared on the site. These council members discuss their own
challenging experiences with their illnesses, medications and surgeries but seem to always do so with optimism and heroic bravado. There are also regular postings about CCFC initiatives including the upcoming Heal ‘n’ Wheel-a-thon. It becomes very apparent that the Gutsy Generation is merely another avenue for the Crohn’s and Colitis Foundation to recruit and enlist more volunteers and charitable donations.

The CCFC promotes itself as a leader in IBD awareness and education but it is apparent that their main focus is fundraising in order to find that elusive cure. While scientific and medical research is important, it does not help those who are currently struggling to get by, those who are dealing with the unspoken stigmas of their embarrassing illness, or those who have no supportive and empathetic forums to express their struggles. The CCFC claims to understand and provide such support but it seems as if their overly optimistic and somewhat empty efforts to do so are done with the intention to raise financial support more than they are done for emotional support.

The CCFC is the dominant authority on Crohn’s disease and ulcerative colitis in Canada. These brochures are utilized for advice and guidance by people who are learning about their illness and its implications. Consequently, the lack of attention on the stigmatizing, isolating, and truly painful nature of these illnesses can silence and invalidate those who have no other forum or medium to understand what they are feeling, either physically or emotionally.

The following is an excerpt from a resource put out by the CCFC for young children. It was one of the very few references to feeling emotionally confused and upset about having IBD:

People that have IBD may have all kinds of confusing feelings about the disease and themselves. They may feel sad, mad, guilty or embarrassed. They may wonder “Why me?” It’s okay to feel badly about IBD. People with IBD can help themselves by talking about how they feel. They can talk to their families, doctor and other medical experts, their friends, the people who are important to them. It is important to be able to talk to others and have them listen. Most people are very understanding about IBD. The doctor or nurse can help you explain IBD further. Some people don’t mind talking about their IBD. Other people would rather not talk too much about it. That’s alright too.
If you, or someone you know, has IBD, ask questions so you understand what’s happening (Kids and Inflammatory Bowel Disease, 2011).

Aside from this one excerpt, it has become painfully apparent to me that the CCFC and its subsidiaries are not effective, or at least not interested in providing its volunteers, its members, or the general IBD population with any candid illustration of IBD or any emotional support and guidance to cope with having these illnesses.

5.2 Toilet Paper Flowers

Unfortunately, other authorities who intend on providing resources for young people with IBD are just as misguided. The children’s book, Toilet Paper Flowers, designed to educate young people with Crohn’s disease, also delivers what I see as overly positive and hopeful messaging. Not only does it ignore struggle and suffering, the book seems to patronize young people’s illness experiences. It simplifies and minimizes young people’s emotions, suggesting that their negative feelings can be easily reconciled by making flowers out of toilet paper.

Toilet Paper Flowers was written by Dr. Frank Sileo (2005), an American psychologist and Crohn’s patient. The story begins quite promisingly with a detailed and explicit introduction of what Crohn’s Disease is and its potential social and emotional repercussions. In the book’s forward, Dr. Sileo explains that young people can experience a range of negative emotions as a result of having IBD. He explains that children fight feel guilt and self-blame for bringing on the illness themselves. He further states that young people might be, “frustrated with their bodies. They feel different, inadequate, and embarrassed over frequent bathroom use.”

While it was refreshing to hear such candid discussion about the emotional experience of IBD, I was not surprised that this introduction was written for parents and not for the young reader. Sileo explains to the adult audience that, “It is my hope that the knowledge you achieve can enlighten and empower you. It is important that we acquire as much information as we can about an illness in order to
feel more control of it and to pass this hope onto our children.” Sileo seems to suggest that if informed parents are in control then the children have nothing to worry about.

Sileo recommends that parents allow their children to speak openly about their illness experiences. He states that parents should enable their children to discuss their negative feelings as well as the positive because, “we as a culture put so much emphasis on ‘positive thinking’”. While Sileo identifies that there is a dark side of Inflammatory Bowel Disease that should be acknowledged and discussed, this message is lost if not completely abandoned in the story that he created for the child audience.

Toilet Paper Flowers tells the story of a young girl named Julia, a young Crohn’s patient who has invited her new friend over for a sleepover. Julia is most likely between the ages of 10-12. She is smaller than her friend Nikki and wears a bright pink top underneath a pair of overalls. Her overalls might have been illustrated to hide stomach distension or any number of apparatuses that could be protruding from her abdomen. However, it was most likely coincidental because such topics were not addressed within the book.

Julia is depicted on the front cover, rosy cheeked and smiling while holding onto a toilet paper flower, the craft she makes during her extended stays in the bathroom. The picture of Julia is framed by an ornate gold border much like one would expect Cinderella or Snow White to have on the cover of a Disney movie (see Figure 2). While very few IBD narratives result in anything comparable to a fairytale ending, readers of this book are treated to the following heartwarming tale.

Julia has invited her new friend Nikki to her house for a sleepover and consequently must explain her strange eating habits, her elaborate bedroom set up with a television, and the vase of toilet paper flowers on her desk. When Nikki asks why she spends so much time in the bathroom making toilet paper flowers, “Julia took a deep breath and said, “It’s because I have a disease called Crohn’s disease.” Julia explains her chronic illness using a diagram of the digestive tract. She recalls her colonoscopy and explains her “yucky” symptoms such as diarrhoea. When Nikki applauds Julia for her thorough
understanding of her illness, Julia articulates that, “Knowing and learning about my disease helps me feel more in control of it. Knowledge is power”.

Julia does explain that her illness has made her feel scared, confused, mad, and sad. She tells her new friend that she blamed herself for her illness and grieved being unable to eat the foods that her friends could. She then admits that when she feels down, she hides in her bedroom with her dog. She explains that talking to her friends and family makes her feel better, but that it is the toilet paper flowers that she makes in the bathroom that, “remind me to take good care of myself and to keep hopeful that they will find a cure for this disease.” Julia continues by stating, “No one should go through this, especially kids. I am going to fight this disease and these flowers remind me never to give up the fight and always to have hope.” Nikki then praises her bravery and gives her a big hug. The story concludes as the girls walk towards the kitchen arm in arm to find a snack that they could eat together, Julia smiles because she has, “never felt better.”

While Toilet Paper Flowers does offer a more detailed and realistic account of IBD’s possible adverse physical and emotional symptoms, I argue that it fails to be the source of hope for young people that it claims to be. Julia says that she is a fighter, never giving up hope that she will overcome her condition but her narrative does not resolve or provide constructive advice on how to mediate the concerns and insecurities that young people with IBD share. She retreats to her bedroom when she cannot cope and states, “I don’t like making bathroom noises outside of my house.” In fact, the entire story takes place in her home and rarely addresses how she “fights this disease” at school or in other social environments.

Additionally, while the concept of a toilet paper flower is a catchy gimmick, most people with IBD would not have the time or focus to craft flowers on the toilet as sudden and painful diarrhoea surges out of their body. If anything, the toilet paper roll makes for a better object to clench on than it does a craft project. The young readers are to believe that making these flowers and sharing them with others will make them feel better than ever but it is never explained how or why.
5.3 Knowledge is Power?

Both the CCFC resources as well as Toilet Paper Flowers claim that knowledge is power but one must question what actual knowledge is (and is not) being disseminated. While the resources available for young people with IBD all seem to provide an overview of some of the symptoms and treatments of IBD, very little discussion is being raised around their physical or emotional implications. There is very little discussion devoted to identifying and overcoming embarrassing symptoms, adverse emotions, or their effects in daily life outside of the confines of a bedroom or bathroom. Instead, young people are supposed to be empowered by being marginally involved in their treatment, through fundraising ventures, or by making flowers out of toilet paper.

Nausea, diarrhoea, vomiting, constipation, flatulence, and bloody stools are common IBD symptoms but are rarely talked about because they are apparently too disgusting to be addressed in any detail. The extreme physical pain of stomach cramping, bowel restrictions, and swollen anuses also seem to be too taboo for public consumption. Despite how common and how difficult such experiences are for people with IBD, IBD organizations and authorities have failed to provide resources that discuss such unmentionable content. Such experiences are censored and silenced, left unshared and unspoken behind locked bathroom doors, leaving people with IBD to suffer in silence. As Frank (2001) states, “Suffering is the subversive voice in the biomedical discourse; it is central among all the things that do not fit” (p. 361). It is apparent that discussion of physical and emotional pain has no place in dominant IBD discourse.

It cannot be denied that some emotional aspects of Crohn’s and Colitis were discussed. However, they were most often outlined in detail for the parents as opposed to the young IBD patients. If knowledge is power then the amount of information directed towards parents speaks to the power differential between the benevolent adult protector and the vulnerable child patient. Not only then do young people have no forum to talk about their adverse emotional experiences, they are denied the candid narratives that could provide them with a sense of empathy, shared experience, and community, opening up space to articulate suffering. If knowledge is power, young people are not being afforded either. They do not have
relevant or honest resources available to them that acknowledge that they have any real power over their own bodies and illness experiences.

5.4 About My Disappearance

In stark contrast to the dominant IBD discourse, David Roche, a self-proclaimed punk, musician, vegan, and American early child educator, shares a series of zines about his struggle with Crohn’s disease. Zines are small independently published texts that provided David with the medium to compose and circulate very candid and evocative accounts of his diagnosis, the variety of treatments he struggled to find success with, and his daily lived experience, having to negotiate his illness while fulfilling his obligations and expectations as a teacher, friend, and family member.

Unlike the resources put forth by doctors and IBD organizations, David’s narratives reflect both the triumphs as well as the physical and emotional pain commonly shared by IBD sufferers. David explains his motivation as well as the benefits to writing these zines:

Writing this zine gave me the chance to figure things out, to gain new perspective on some problems that have been nagging at me for a while. It let me give voice to some of my fears and not so much shed them as develop better ways of coping with them. Really, just getting this stuff out of my head has been immensely helpful. Everyone should do it. And then everyone should trade me their zines (About my Disappearance 2, p.2).

David explains that writing these zines has been integral in his own illness reconciliation. His evocative writing also opens up a space for others to reflect and speak about their experiences. His honest and courageous narratives can inspire others to reject the shame and stigma of IBD and come to terms with what they have endured. I argue that this is something that has not been enabled through dominant IBD discourse or practice.

David’s zines titled About My Disappearance (AMD, chapters 1, 2 & 3) recount the period of his diagnosis as well as the years following where he struggled with the unpredictability and pain of frequent
relapses. The zines are printed in black and white alongside various pictures which includes a stencil of eerie hospital buildings, a man with his internal organs exposed, and most poignant, a picture of his own colon that was likely taken during a colonoscopy. The zines are small, probably equivalent to 10-12 pages each in length, but his narratives are powerful, describing feelings of body betrayal, frustration, humiliation, and periods of severe depression when he retreated from his friends and social life.

David recalls the onset of his symptoms when the pain from stomach cramping and frequent diarrhoea kept him bed ridden and barely able to eat a cup of clear broth a day. Despite feeling exhausted and lethargic, his pain would keep him awake at night. He feared that if he did fall asleep, he might never wake up again. David described his existence by stating, “I always felt half asleep if not half dead” (AMD 1, p.15). He recalls feeling and looking sickly, losing almost a pound a day. In reaction to his appearance, he states:

One morning I made the mistake of looking at myself naked in the mirror before I showered. My emaciated body looked like a morbid caricature of someone about to die; every rib visible, my stomach concave; a thin veneer of skin wrapped around a trembling skeleton. I wanted to cry. When you find your own body repulsive, you don’t rebound so easily (AMD 1, p. 16).

In addition to his own physical statehood, David was incredibly candid about the frequency, odour, consistency, and agony of his bowel movements, its effects on his body as well as his sense of self. He jokes that, “If Eskimos [sic] have 40 words for snow, I think we with Crohn’s should have at least 20 words for our excrement” (AMD 1, 39). While our culture barely has one word to describe poo that is not either overly medical or overly grotesque and inappropriate, David manages to effectively describe his shit, the pain it brings about, and the embarrassment it causes. He describes running to the bathroom more than six times a day and recalls, “My asshole was so tender from a month and a half of constant diarrhea that it hurt to cough.” He bluntly states, “I shit myself three times over four days. Do you know what that does to your confidence, to yourself self esteem?” (AMD 1, 15).
Equally embarrassing was his stool collection for diagnostic testing. David describes the mortifying and humiliating experience of collecting his excrement and storing his stool in the refrigerator all while feeling so ashamed that he hides the entire process from his flatmates:

Here’s how it goes: I was given a plastic bedpan with wings so I could hang it between the rim of the toilet and the seat. I’d shit into that and then scoop it out into the vials. Unfortunately, it wasn’t as easy as that. I wouldn’t say it was an arduous task, but there were complications. After I squirted my diarrhea into the bedpan I had to wipe, but I couldn’t drop the used toilet paper into the bedpan. So I had to take it out of the toilet and, not knowing what else to do with it, set it on the floor in front of me. It’s hard to describe the potpourri of emotions you feel when staring at a bucket of your pudding-consistency excreta, knowing you’re about to dig into it with a wooden tongue depressor… a little embarrassment, a little confusion, a touch of “why me?” (AMD 1, pp. 7-8).

In an effort to hide the evidence from his roommates, he attempts to throw the plastic bag filled with his soiled bedpan and tools out the window into the dumpster on the street. He recalls being too weak to throw the bag far enough and it winds up landing in the street. David notes the irony in the experience with an air of self-deprecation.

David was just as candid about his pain. He described the severe abdominal and anal agony that he endures in addition to the overall body ache from being rundown and lethargic. He explains, “Every trip to the bathroom and every meal, no matter how small, was followed by debilitating abdominal pains, forcing me to lie curled up in bed until they subsided into a manageable dull ache” (AMD 1, 15). He speaks of a very disturbing experience that many IBD sufferers understand: the near torturous experience of being examined by a doctor:

I told the doctor about my problems and told her I thought I had Crohn’s Disease. She said I have the symptoms of Crohn’s, but didn’t want to say anything definitively. Then came something I hadn’t counted on: the doctor wanted to check my stool for blood. She put on a rubber glove and had me drop my pants. Had I known then what I know now, I would have fought back like a cornered mongoose. I mean, I knew where that rubber-gloved finger was going, I just didn’t expect it to be so painful. Between my asshole being tender from the month and a half of constant diarrhea, the hemorrhoids (which I had just found out I had), and the ulcerations (which I
wouldn’t find out about for another week), it hurt so much I thought I was going to vomit. Plus I felt kind of humiliated (AMD 1, pp. 23-24).

David then questions the purpose of the doctor’s actions as he had already explained his symptoms. The doctor instructed him to take warm baths and use baby wipes to soothe his, “poor anus”. She also asked that he collect his stool again. When the lab did not seem to have the proper vials to do so, the technicians instead instructed him to scoop his shit into denture cups. With insult added to injury, this experience was not only excruciating but humiliating.

David seems to write these zines with a twisted humour and an appreciation for the unfortunate irony of his circumstances. He speaks candidly about his body betrayal and resulting emotional struggle. He speaks openly about feeling insecure and unsure that someone could ever find him attractive after experiencing drastic weight loss and from the side effects of steroids. He describes the frustration, anger, and depression that results from being burdened with his unpredictable and erratic condition. As he states:

On top of that there was the feeling that I couldn’t count on my body anymore. Watching my body spiral out of control and not being able to do anything about it—the weight loss I couldn’t stop, the nearly uncontrollable shitting—took a heavy emotional toll on me. I lost faith in my body. What can I count on it to do? When will it abandon me again? (AMD 2, p. 9)

He is very forthcoming and brave as he speaks about breaking down in tears, withdrawing from friends, and questioning his own identity and self-worth.

Although the narratives that David shares in his zines deal predominantly with the physical and emotional experiences that he has endured, he assures his readers that there have been good times among the bad. He states that, “There’s more excitement and joy in my life than pain and depression. But joy is much easier to cope with. It doesn’t take processing. The depressed and lonely times are the ones you need to figure out and get beyond” (AMD 2, 1). David’s last zine ends when he finally finds relief with the help of a new medication. While he provides his readers with a happy ending, it is not laden with unrealistic and overly cheerful messaging or false hope for the future.
Instead, *About My Disappearance* identifies that living with IBD means constantly reconciling the bad times and renegotiating lessons learned in order to cope with the shitty hand that he was dealt. While David is not an adolescent, his narratives broach many of the same issues and concerns that both young people and adults with IBD share. His narratives elucidate that having Crohn’s disease, despite age and despite being in remission or not, becomes a permanent fixture in one’s daily life and an ongoing factor that mediates one’s sense of self. David explains that he shares such difficult and explicit narratives in order to create a space where people can discuss such tough subject matter because otherwise, “when you spend enough time not really talking about your illness you begin to think it’s unspeakable.”

He makes it ok to talk shit, to not only talk about defecation and other disgusting IBD symptoms, but also about the social and emotional struggles, even if they involve feeling angry and frustrated. *About My Disappearance* provides people with an alternative discourse to the overly saccharine mainstream positivity that silences and marginalizes those who are suffering. These zines have the power to begin candid and meaningful discussion around the everyday lived experiences, struggles, and small triumphs of people, both young and old, who are living with otherwise stigmatizing and isolating illnesses. And as David Roche suggests, doing so can be a significant step in reconciling the illness experience.
June 24, 2011

I was scheduled in to see my gastroenterologist yesterday after begging his receptionist to squeeze me in. Evidently the stress from writing my thesis and veering off my diet had resulted in a flare up that seems to be less manageable than the others that I so often experience. After over two years I finally succumbed to my doctor’s insistence that I go back on medication. I requested a round of steroids, which would at least buy me three months of illness relief. This relief however comes at a cost. Taking steroids means the risk of side effects which include acne, facial hair, puffy face, restlessness, and severe mood swings, to name only a few. Given how I was feeling, it seemed as if the trade off would be worth it even if it meant spending my summer off looking and feeling like a grotesque facsimile of myself. I had been through it all before and lived to tell about it, so I suppose I can do it again.

While my doctor agreed to write the prescription, he urged me to seriously consider taking a more potent and more permanent (permanent, hah) maintenance drug. The treatment, Humira, involves bi-monthly Epi-pen like injections of biologic drugs that apparently feel like you are shooting battery acid into your body. He has been pushing this medication on me for years now and took advantage of my current vulnerability and willingness to consider a medication by telling me that given my age and gender I was at risk. He explained that because I was a young female and the location of my active disease, I am more vulnerable to chronic intestinal inflammation that could result in more surgery to remove crucial parts of the bowel.

While I was composed at this point in the appointment, I should note that I had already broken down in tears when the resident came in to ask me a couple of questions prior to even seeing the gastro doc. My composition did not last long however. The gastro asked me why I was so reluctant to try this drug and I lost it and began to bawl. I tried to explain that I was concerned about the increased risk of eventual cancer, the immediate possibility of developing lupus and other adverse side effects, as well as the fact that I hate needles all while my eyes and nose dripped down my face.

At this point my doctor was halfway out the door. He always seemed to have little patience for me when I cried but managed before he left the room to tell me that I should stop being so negative and start being more hopeful. I mustered up the audacity to say, “you try going through what I’ve been
through and still be optimistic”. I quickly apologized and blamed my outburst on thesis-related 

exhaustion.

After the appointment, I went downstairs to the lab to have my blood taken for testing. The 
technician, who was likely only a few years older than me, noticed my reddened and tear-stained face 
and asked me what was wrong. I said that I had Crohn’s disease and just had a bad appointment. She 
turned to me and with immense sympathy said, “that’s so tragic at your age”.

In my literature review, I outlined poststructuralist and interactionist approaches to understanding health 
and illness. I proposed that a combination of both perspectives could provide a more comprehensive 
understanding of the illness experience. An embodied perspective compels us to understand how 
dominant discourses affect the individual body and consequently how that body acts within its social 
worlds. To my knowledge, no study has focused on an embodied understanding of inflammatory bowel 
disease, let alone an embodied understanding of adolescent IBD. Within this study, I sought to explore 
how discourses of age complicate the already elaborate network of power relations and social relations 
that mediate the illness experience. Interviews with young people, a discursive analysis of dominant texts, 
and a reflection of my own lived experiences provided the means to explore how body, self, and society 
mediate how young people make meaning of and negotiate their illnesses. Exploring these different but 
connected facets of the illness experience contribute to an understanding of embodied illness, and as I will 
further discuss, an embodied disappearance.

The first results chapter outlines how three young people with Crohn’s or colitis perceive and 
express their illness experiences. Their narratives elucidate not only how difficult it is to negotiate IBD 
but also how difficult it is to discuss these issues. The interviews illuminated the participants’ reluctance 
to articulate both the physical pain and emotional struggle that I understand to be synonymous with IBD. 
The second chapter, an analysis of popular IBD texts, explicates how IBD organizations contribute to this 
silencing. IBD authorities including the Crohn’s and Colitis Foundation of Canada fail to address the 
severity of these illnesses as well as the often troubling emotional implications. Moreover, their resources 
reproduce an overly positive and saccharine illness discourse that denies people a forum where they can
be angry, cynical, or saddened by what they have endured. David Roche’s personal narratives captured in the zines titled, *About My Disappearance*, effectively illustrates the possibilities and promise that such a space could provide. Unfortunately, David’s candour seems to be rare and consequently many people with these illnesses suffer from loss, despair, and as I argue, an embodied disappearance.

6.1 An Embodied Disappearance

In *About My Disappearance*, David uses the concept of disappearance to explain his lack of appetite, his dwindling energy levels, as well as his retreat from his social life. The idea of disappearing, of vanishing from his social obligations and of fading farther from his former self, captures his emotional and physical struggle with Crohn’s disease. The notion of disappearance seems like a particularly poignant way to understanding how young people embody inflammatory bowel disease. In this section, I expand on David’s utilization of the concept of disappearance to elucidate how body, self, and, society are all implicated in how young people with IBD can experience an embodied disappearance.

6.1.1 A Corporeal Disappearance

People with IBD can experience a variety of adverse and extreme changes to their corporeal body, all of which can contribute to a sense of loss or disappearance. The agonizing and often debilitating pain that manifests itself in the abdomen and anus can prohibit individuals from identifying with their bodily statehoods. Their pain forces them to relinquish former expectations of their physical capacities and negotiate an inferior and obscured sense of being, being smaller and less capable than their peers.

The physical body can also disappear when the intestinal tract is inflamed and deemed ineffective. Pieces of the bowel or the bowel in its entirety are at risk of surgical removal. The intestines are then replaced with medical apparatuses that take charge of nourishing the body, carrying and absorbing food, and storing and eliminating bodily waste.

A lack of appetite and inability to absorb nutrients can result in extreme weight loss and consequently a multifaceted bodily reduction. Not only is the physical body smaller and less substantial,
its colour vanishes and its energy is depleted. The failure to not only be healthy but to look healthy and strong can result in feelings of inadequacy and inferiority.

Such feelings are most poignant amongst young bodies as IBD threatens their overall physical development. Children and youth with IBD can experience delayed physical growth, belated puberty, and in some cases permanent underdevelopment. Young people are not only subject to feeling inadequate but their lack of physical development can also result in vigilant control and disciplining at the hands of medical and adult authority, which results in a lack of control and authority over that already diminished body.

6.1.2 A Social Disappearance

The deterioration of the actual flesh and substance of the physical body rivals the physical absence of the body in normal environments and social situations. Symptoms of chronic pain, diarrhoea, and constipation force the body to retreat to private and isolating spaces. The body is forced to retreat to the bathroom for long periods of time. The weary body, exhausted from pain, must withdraw to the bedroom, couch, or other secluded locations so that it can “zone out” and divert itself from its hurting.

The physical body is subject to minimized expressions of that hurting. The lack of words as well as a societal denial of the physical pain of illness prohibits people from expressing their pain. The ill body must also deny its physical statehood to avoid judgment and further stigma. The body retreats from social interactions and obligations in order to avoid uncomfortable and embarrassing situations where their disease might make them feel abnormal and ashamed.

6.1.3 Emotional Disappearance

The same forces that contribute to the physical isolation of the body can also mediate an emotional disappearance. Just as there are no words that effectively express the physical symptoms of IBD, there seems to be no words and no public forums that enable one to be candid about their emotional struggles. Dominant and pervasive IBD discourses deny the severity of the emotional difficulties that these illnesses can bring about. Consequently, people who are enduring negative feelings have little space to articulate their suffering. People’s emotions are censored and silenced.
While dominant societal understandings of IBD ignore the emotional pain that IBD can cause, biomedical discourse pathologizes those emotions. People’s emotional distress can be viewed as problematic and characterized as a depressive disorder. The body is not only denied the opportunity to articulate its feelings in social forums, the emotions that they do possess are medicalized. Their behaviours become further subsumed in medical discourse and their bodies are subject to additional medical intervention. The emotional body disappears.

6.2 A Compounded Disappearance

The notion that IBD can result in an embodied disappearance is compounded when the bodies that are chronically ill are also young. Discourses of children and youth as “becoming adults” and as “at risk” justify the added subjugation that they face. Being incomplete reinforces the importance of young people’s physical, cognitive, and emotional development while their inferior status subjects them to control and monitoring. The implications for young people can include a denial of their current statehoods and a diffused sense of self.

Inflammatory Bowel Disease complicates the pre-existing child-adult power relations as both Crohn’s and colitis pose risks to young people’s healthy development. IBD threatens young people’s normal physical growth and their development into healthy adults. Consequently, urgent and sometimes drastic medical interventions and measures are taken for the child, without any obligation to seek their consent. Such measures neglect to consider that young people possess the ability to be agential in their own lives. Parents speak for their children and assume authority over their bodies and behaviours resulting in a “we” identity. The child’s sense of self, her thoughts, and behaviours, are not her own but determined by and diffused through the adults who have authority over them.

The emphasis placed on the young body’s future health can also deny their current selfhoods. The physical, social, and emotional experiences in their present statehoods are considered secondary to what they must become in the future. Young bodies are not acknowledged for what they are, but rather for what they must become. Consequently, their current self, their needs, desires, and experiences all disappear.
6.3 Making a Reappearance

I hope that this research will inform future endeavours that seek to provide young people with the opportunities to openly discuss illness issues, articulate their suffering, and find support among others who have experienced similarly. Children and youth have faced a pervasive silencing that has prohibited them from having any official space to do so. In order to facilitate such a space, young people should first be recognized for possessing agency and insight into their bodies and personal experiences. Secondly, young people should be provided with the forum to not only discuss their lived experiences but to also critically examine the stigmas and discourses that mediate those experiences. Facilitating such opportunities could break down the barriers that are contributing to the young body’s disappearance.

While the majority of what the participants discussed reinforces notions of silencing and disappearance, the participants did display moments of agency and resistance that should be recognized and further researched. My analysis of the participants’ interviews predominantly focused on the silences and apparent absences within their narratives however it should be acknowledged that their narratives also elucidated their agency. The young people interviewed were not passive actors within their lived experiences but instead displayed concerted efforts to control both their bodies and emotions. The young people physically contained their defecation, they purposefully retreated to their bedrooms, and they deliberately reserved their emotions. Further investigation should consider how young people’s actions explicate their embodied experiences with IBD.

The participants also exhibited individual body knowledge in which they identified having insight into their own bodily experiences. They knew when the diets that were forced upon them were not effective, they knew when they were misdiagnosed, and knew that they were unwell when nobody else believed them. Consequently, the young people interviewed demonstrated not only their agency but their resistance as well. They ate the forbidden glutinous bread, they refused to adhere to treatments that they did not agree with, and they told their parents to back off when they were being too overbearing. Such
agency, while challenging parental authority, should be encouraged to enable young people to exercise their body knowledge and have authority over their illness experiences.

The participants spoke about pursuing endeavours that enabled them to feel purposeful and valued. They sought opportunities and adopted attitudes that helped them rationalize living with a chronic illness and find a sense of reason in their struggle. They volunteered with students who had developmental impediments, pursued studies in social justice, and explained how they wanted to achieve greater things for themselves in spite of having IBD. The participants demonstrated an ongoing desire to achieve a valued sense of self. I believe that facilitating opportunities to understand the complexities of their illnesses and express their emotional struggles will also help young people find purpose and meaning in their illness experiences.

I strongly believe that young people could achieve that sense of value and purpose if they had a space where they could be candid about their illness experiences. Young people would greatly benefit from having a forum where they could speak openly about the physical and emotional repercussions of IBD without judgment or a silencing air of inflated optimism. They would no longer have to minimize what they felt or hide what they were struggling with.

However, it has become apparent that speaking about the physical and emotional effects of inflammatory bowel disease can be difficult. They might not be ready or willing to speak openly. Instead, interventions should focus on engaging young people in conversations about the pervasive stigmas and discourses that mediate their experiences. Doing so could provide young people with the means to critically understand, negotiate, and reconcile living with IBD.

Frank (2001) explains that the purpose of research should not be to understand the individual’s suffering but instead should identify and examine the social conditions that cause that suffering. Young people too, should be afforded the opportunity be aware and be critical of the discourses of illness and age that complicate having IBD. Understanding the social forces that compound their illness experiences could be vindicating as responsibility can be displaced from the individual self to larger society.
Identifying such social conditions could also elucidate the shared experience and community that is so obviously missing in dominant discourse.

6.4 Conclusion

Writing both theses and being able to critically reflect on my own struggle with Crohn’s disease has enabled me to identify the forces outside of myself that have affected how I perceive and negotiate my condition. Such negotiation however, is an ongoing and difficult process. Living with IBD means living with a disease that is stigmatizing and painful, unpredictable and erratic. At any point and without warning, IBD can bring about a whole new set of problems that warrant new ways of approaching and handling the illness experience. For that reason, looking towards the future does not seem as necessary as focusing on the present struggle and the immediate self. Instead of focusing on how and what young people are becoming, the emphasis should be placed on their current state of being.

This study focused on how young people negotiate being ill, being normal, and being young when faced with the physically and emotionally painful experience of living with inflammatory bowel disease. Critically examining the dominant discourses and stigmas surrounding IBD elucidated the pervasive silencing that prohibits young people from being candid about their struggles. Creating a space where young people can articulate their experiences, express their emotions and suffering, and develop a critical understanding of the social conditions that mediate those experiences and emotions, could provide the opportunity for illness reconciliation and communal support. It could provide young people with the forum to understand and negotiate the illness experiences that are too difficult to articulate. Such a space could also challenge the discourses that currently enable young people to suffer in silence.
References


Wainwright, S.P., & Turner, B.S. Reflections on embodiment and vulnerability. *Med Humanities*, 29, 4-7. doi:10.1136/mh.29.1.4


Appendix A1: Letter of Information for Parent

Title of Research Project: Everyone poops: How young people negotiate living with inflammatory bowel disease

Investigator(s):

Principal Investigator: Jessica Diener  
MA Student, School of Kinesiology and Health Studies  
Queen’s University  
(613) 449-9050

MA Supervisor: Dr. Elaine Power  
School of Kinesiology and Health Studies  
Queen’s University  
(613) 533-6000 ext. 74690

Introduction:

I am a Master’s student at Queen’s University inviting your child to participate in my study. Before you give consent for your child to be part of the study, please take the time to carefully read and consider the following information.

Purpose of the Project:

In this project, we will explore the social and emotional experiences of children and youth living with Inflammatory Bowel Diseases (IBD) (i.e. Crohn’s and Colitis)

Description of the Project:

This project has three parts. In the first part, I will meet with you and your child at a time and place that is convenient for you for a 15-20 meeting. The purpose of this meeting will be to discuss the project, sign consent and assent forms, and to ask me any questions that you or your child might have about the project. I will also give your child a disposable camera (if needed) and the guidelines for taking pictures. Over the next 1-2 weeks your child will have the opportunity to take pictures of the tangible objects and
physical surroundings that he or she feels best represent his or her stories and lived experiences resulting from having IBD.

At the next meeting, your child and I will meet at a place and time that is most convenient for her or him, for a one-on-one interview. This meeting will take about 1 – 1.5 hours during which I will ask your child to discuss the photos that he or she chooses to share. I will also ask your child a variety of interview questions including, “Tell me about what it’s like to have IBD” and “What is the most frustrating part of having IBD?” If your child chooses to continue on with the project, he or she will be invited to take part in two focus groups with the other youth participants (total 5-7 participants). The focus group will involve revisiting some of the pictures that the participants choose to share. The group interviews will also be a forum for the participants to discuss emerging themes from the initial individual interviews. Such themes will be discussed amongst the group without divulging specific or personal details from the participants’ individual interviews. With your consent, these interview sessions will be audio taped so that I have an accurate record of the stories and experiences that your child shares with me (see consent form). The audio recordings will be kept in a locked cabinet or in password protected digital files (see section on confidentiality). If you do not feel comfortable with your child being audio taped, I will be able to take written notes throughout the interview process.

Potential Risks:

This research project does not intend to cause harm in any way. Your child does not have to answer any questions that he or she feels uncomfortable with. However, it is possible that talking about personal experiences of illness will be emotional for your child. If the interview process causes your child any stress that they might want to talk about, I will have resources available to direct your child to for free youth counseling. I have contacted Kids Help Phone (1-800-668-6868) along with the Youth Services Bureau of Ottawa Crisis Line (613 260-2360) to ensure that their services are appropriate and available. Your child can also see a school counselor or a private counselor. For more information on these services, please see the attached form.

Potential Benefits:
I hope that your child benefits from having a safe and supportive forum to share their stories of illness with others who have experienced similarly. The young participants might also benefit from learning self-management and coping strategies from the other involved in the focus groups.

Very little study delves into the experiences of being young and having IBD. Gaining an understanding of the social and emotional repercussions of being a child with such illnesses may help doctors, nurses, nutritionists and counselors provide the best care possible for these populations.

If you wish, the results of this project will be made available to you.

**Confidentiality:**

Your child’s information will remain confidential (private) to the extent permitted by law. I will be the only one who transcribes the taped sessions. Your child’s name will not appear on the transcribed notes or in any final reports. Your child’s information will be assigned a code or a pseudonym (false name) to protect his or her identity and I will keep all information in a password protected computer file. Paper copies of transcripts and notes will also be kept in a locked filing cabinet. Your child’s name will be recorded only on the consent form and on a master list that links his or her name to the code or false name assigned to your child. These will be securely stored separately from transcripts and notes.

Your child’s identity will be kept strictly confidential throughout the project. My supervisor, Elaine Power, and I are the only ones who will have access to the information collected in this project. I will not include any identifying information when reporting findings, such as in my thesis dissertation or other publications that might come out of this project. Summaries of these reports will be made available to you if you wish (see consent form).

**Honorarium:**

To thank your child for taking the time to participate in my research study, I will give him or her the choice of a $10 gift certificate from iTunes, Chapters, Shoppers Drug Mart or the movies. I will cover all costs related to the cameras and photo finishing. If your child would like to get an extra set of photos, I
will cover that cost as well. I will also provide bus vouchers if your child needs to take transit to get to the interview location.

**Participation:**

Your child’s participation in this project is voluntary, meaning your child is not being forced to participate. Your child does not need to answer any questions that cause discomfort or that he or she simply does not want to answer. Should he or she wish, your child can leave the project at any time. If this is the case, I will ask you and your child if you would like any information you or child have provided up to that point to be included or omitted from the project.

Thank you for taking the time to read this letter. Please let me know if you have any questions or comments about participating in this project. I can be reached at (613) 449-9050 or at 8jad6@queensu.ca. Should you have questions, concerns or complaints about this project you may also contact Dr. Elaine Power at (613)533-6000 ext. 74690 or at power@queensu.ca, or the Queen’s University General Research Ethics Board at (613) 533-6081 or at chair.GREB@queensu.ca.

Sincerely,

Jessica Diener
8jad6@queensu.ca
(613) 449-9050
Appendix A2: Letter of Information for Youth Participant

**Title of Research Project:** Everyone poops: How young people negotiate living with inflammatory bowel disease

**Investigator(s):**

Principal Investigator: Jessica Diener  
MA Student, School of Kinesiology and Health Studies  
Queen’s University  
(613) 449-9050

MA Supervisor: Dr. Elaine Power  
School of Kinesiology and Health Studies  
Queen’s University  
(613) 533-6000 ext. 74690

**Introduction:**

I am a Master’s student at Queen’s University inviting your child to participate in my study. Before you give consent for your child to be part of the study, please take the time to carefully read and consider the following information.

**Purpose of the Project:**

In this project, we will explore the social and emotional experiences of children and youth living with Inflammatory Bowel Diseases (IBD) (i.e. Crohn’s and Colitis)

**Description of the Project:**

This project has three parts. In the first part, I will meet with you and your guardian(s) at a time and place that is convenient for you for a 15-20 meeting. The purpose of this meeting will be to discuss the project, sign consent and assent forms, and to ask me any questions that you or your guardians might have about the project. I will also give you a disposable camera (if needed) and the guidelines for taking
pictures. Over the next 1-2 weeks you will have the opportunity to take pictures of the tangible objects and physical surroundings that you feel best represent your experiences living with IBD.

At the next meeting, you and I will have the opportunity to meet at a place and time that is most convenient for you, for a one-on-one interview. This meeting will take about 1 – 1.5 hours during which I will ask you to talk about the photos that you choose to share. I will also ask you a variety of interview questions including, “Tell me about what it’s like to have IBD” and “What is the most frustrating part of having IBD?” If you choose to continue on with the project, you will be invited to take part in two focus groups with the other youth participants (total 5-7 participants). The focus group will involve revisiting some of the pictures that the participants choose to share. The group interviews will also be a forum for you and the other participants to talk about some of the topics that came up in your first one-on-one interviews.

Such topics will be discussed without revealing any specific or personal information from the one-on-one interviews. With your permission, these interview sessions will be audio taped so that I have an accurate record of the stories and experiences that you share with me (see consent form). The audio recordings will be kept in a locked cabinet or in password protected digital files (see section on confidentiality). If you do not feel comfortable with being audio taped, I will be able to take written notes throughout the interview process.

Potential Risks:

This research project does not intend to cause harm in any way. You do not have to answer any questions that you feel uncomfortable with or simply do not want to answer. However, it is possible that talking about personal experiences of illness can get emotional. If the interview process causes you to feel any stress or upset, I will have resources available free youth counseling. I have contacted Kids Help Phone (1-800-668-6868) along with the Youth Services Bureau of Ottawa Crisis Line (613 260-2360) to ensure that their services are appropriate and available. You can also see your school counselor or a private counselor. For more information on these services, please see the attached form.

Potential Benefits:
I hope that you find it helpful to talk to other young people your age who might have similar experiences living with IBD. I also hope that you have the opportunity to learn from each other and support each other when you share your stories.

Very little research currently exists on the experiences of being young and having IBD. Gaining an understanding of the social and emotional repercussions of being a child with such illnesses may help doctors, nurses, nutritionists and counselors provide the best care possible for these populations.

If you wish, the results of this project will be made available to you.

Confidentiality:

All information that you share with me will remain confidential (private) to the extent permitted by law. I will be the only one who transcribes the taped sessions. Your name will not appear on the transcribed notes or in any final reports. Your information will be assigned a code or a pseudonym (false name) to protect your identity and I will keep all information in a password protected computer file. Paper copies of transcripts and notes will also be kept in a locked filing cabinet. Your name will be recorded only on the consent form and on a master list that links your name to the code or false name assigned to you. These will be securely stored separately from transcripts and notes.

Your identity will be kept strictly confidential throughout the project. My supervisor, Elaine Power, and I are the only ones who will have access to the information collected in this project. I will not include any identifying information when reporting findings, such as in my thesis dissertation or other publications that might come out of this project. Summaries of these reports will be made available to you if you wish (see consent form).

Honorarium:

To thank you for taking the time to participate in my research study, I will give you the choice of a $10 gift certificate from iTunes, Chapters, Shoppers Drug Mart or the movies. I will cover all costs related to the cameras and photo finishing. If you would like to get an extra set of photos, I will cover that cost as well. I will also provide bus vouchers if you need to take transit to get to the interview location.
**Participation:**

Your participation in this project is voluntary, meaning that you are not being forced to participate. You do not need to answer any questions that cause discomfort or that you simply choose not want to answer. Should you wish, you can leave the project at any time. If this is the case, I will ask you and your guardians if you would like any information that you or your guardians have provided up to that point to be included or omitted from the project.

Thank you for taking the time to read this letter. Please let me know if you have any questions or comments about participating in this project. I can be reached at (613) 449-9050 or at 8jad6@queensu.ca. Should you have questions, concerns or complaints about this project you may also contact Dr. Elaine Power at (613)533-6000 ext. 74690 or at power@queensu.ca, or the Queen’s University General Research Ethics Board at (613) 533-6081 or at chair.GREB@queensu.ca.

Sincerely,

Jessica Diener
8jad6@queensu.ca
(613) 449-9050
Appendix B.1: Parent Consent Form

Everyone poops: How young people negotiate living with inflammatory bowel disease

Researcher: Jessica Diener, 8jad6@queensu.ca, 613-449-9050

I, ________________________________, the parent/guardian of _________________________ have read and kept a copy of the letter of information for the *Everyone poops: How young people negotiate living with inflammatory bowel disease* study and my questions about my child participating in this project have been answered.

I understand that the purpose of this project is to explore the social and emotional experiences of young people living with inflammatory bowel disease. In participating in this project, my child will be taking pictures of his or her surroundings and objects that your child feels depicts those experiences. Your child will be discussing the photographs and their stories about their illness with Jessica Diener along with the other participants during the focus group interviews. These discussions will be recorded with an audio recorder.

I understand that my child’s pictures will not be used for other purposes without my, and his/her written consent, and that my child’s identity will be kept confidential in any reports or papers that are written about this project.

I also understand that my child’s participation in this project is voluntary and that he/she can withdraw from the project at any time without any negative effects. He/she does not need to answer any questions that he/she does not want to answer. I am aware that I may contact Dr. Elaine Power or the Queen’s University General Research Ethics Board with any questions, complaints or concerns that I have about this project.

I hereby consent for my child to participate.

____________________________________
Name of Participant

____________________________________

Name of Parent

____________________________________

Signature of Parent

____________________________________

Date

____________________________________

Name of person who obtained consent

____________________________________

Signature

____________________________________

Date
Appendix B.1 continued…

___ By initialing this statement, I am granting permission for Jessica Diener to use a tape recorder or audio recorder.

___ By initialing this statement, I agree to be contacted again by Jessica Diener if she has follow-up, or clarification questions after our meetings

I wish to receive a summary of the findings of this project:  
Yes  No

Please send the project summary to the following email or postal mail address:
Appendix B.2: Youth Assent Form

Everyone poops: How young people negotiate living with inflammatory bowel disease

Researcher: Jessica Diener, 8jad6@queensu.ca, 613-449-9050

I, ________________________________, have read and kept a copy of the letter of information for the Everyone poops: How young people negotiate living with inflammatory bowel disease study and my questions about participating in this project have been answered.

I understand that the purpose of this project is to explore the social and emotional experiences of young people living with inflammatory bowel disease. In participating in this project, I will be taking pictures of my surroundings and objects that your child I feel best depict those experiences. I will be discussing the photographs and their stories about their illness with Jessica Diener along with the other participants during the focus group interviews. These discussions will be recorded with an audio recorder.

I understand that my pictures will not be used for other purposes without my written consent, and that my identity will be kept confidential in any reports or papers that are written about this project.

I also understand that my participation in this project is voluntary and that I can withdraw from the project at any time without any negative effects. I do not need to answer any questions that I do not want to answer. I am aware that I may contact Dr. Elaine Power or the Queen’s University General Research Ethics Board with any questions, complaints or concerns that I have about this project.

I hereby assent to participate.

____________________________________  __________________________________
Name of Participant                  Signature of Participant
Date

Name of person who obtained assent

Signature

Date
Appendix B.2 continued…

___ By initialing this statement, I am granting permission for Jessica Diener to use a tape recorder or audio recorder.

___ By initialing this statement, I agree to be contacted again by Jessica Diener if she has follow-up, or clarification questions after our meetings.

I wish to receive a copy of my interview transcripts:  Yes  No
I wish to receive a summary of the findings of this project:  Yes  No
Please send the transcripts and the project summary to the following email or postal mail address:
Appendix B.3 Consent for use of Photos

Everyone poops: How young people negotiate living with inflammatory bowel disease

Researcher: Jessica Diener, 8jad6@queensu.ca, 613-449-9050

In addition to allowing Jessica Diener to view my photographs during our one-on-one sharing session, by initialing the following statements, I also give her permission to use my photographs for:

___ the focus group interviews (photos shared to be determined by myself)
___ her Master’s thesis
___ papers published based on this project
___ presentations based on this project

OR ___ DO NOT use my photographs for anything other than the sharing sessions

AND ___ I give Jessica Diener permission to use my all my photographs EXCEPT for:

1. ____________________________ 4. ____________________________
2. ____________________________ 5. ____________________________
3. ____________________________ 6. ____________________________

By signing this form, I acknowledge that I am free to withdraw my permission for other uses of my pictures at any time, and that Jessica Diener will take steps to protect my privacy at all times.

__________________________________________
Name of participant

__________________________________________
Name of person who observed consent

__________________________________________
Signature of participant

__________________________________________
Signature

__________________________________________
Date

__________________________________________
Date

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Appendix C.1 Instructions for taking photos

Everyone poops: How young people negotiate living with inflammatory bowel disease

Researcher: Jessica Diener, 8jad6@queensu.ca, 613-449-9050

This is your chance to have fun and be creative if you like. The aim for this part of the project is for you to take about 10-20 photos of the objects, physical spaces, and settings that capture your feelings and experiences living with IBD. These photographs can be spontaneous or arranged (i.e. a picture of your medications all lined up). Try not to take too many pictures of people or yourself unless they are taken with yours/their faces covered; this is to keep the photos as confidential (private) as possible. If you do include photos of people and do not want these to be shared, you can write them down on the Consent for use of Photos form and I will be the only person to see the photos.

Here are a few ideas to help get you started; it is up to you to decide what photos to take. The photos should be meaningful to you:

- Objects/places/activities that comfort you when you’re not feeling well
- Foods you eat when you’re not feeling well
- Foods that you cannot eat but wish you could
- Places you spend a lot of time because of having IBD
- Objects/places/activities that you cannot participate in because of having IBD
- Objects/places/activities that represent parts of your health management routines
- Objects/places/activities that are frustrating as a result of having IBD
- Objects/places/activities that have changed since being diagnosed
- Objects/places/activities that represent specific stories or experiences with having IBD
- Objects/places/activities that represent accomplishments as a result of having IBD
- Objects/places/activities that represent your feelings about illness
- Any objects/places/activities that you feel represent what it means to live with IBD

General Directions for Using the Camera (if using a disposable camera)
1. To take a picture, look through the viewfinder, press the button on the top of the camera on the right side.
2. Before you take the next picture, wind the dial until it stops. The counter on the top of the camera should have decreased by one. The number on the counter at the top of the camera tells you how many photos are left to be taken.
3. This type of camera does not take close-up photographs. Make sure the object you are photographing is at least 1 meter (3 feet) away.
   If using the camera indoors, turn on the flash first. After you take the picture, turn the flash off until you take the next picture.
D.1 Draft Interview Guide

Everyone poops: How young people negotiate living with inflammatory bowel disease

Researcher: Jessica Diener, 8jad6@queensu.ca, 613-449-9050

General questions about the participants:
1. How old are you?
2. What grade are you in?
3. Do you have any brothers or sisters?
4. How old were you when you were diagnosed with IBD?
5. Rate how you’ve been feeling lately on a scale of 1-5, 1 being feeling really bad, 5 being really good, and 3 being average. What do you think affects how you feel?
6. How do you manage your illness?
7. Does anyone help you manage your illness? How?
8. Rate how you’ve been feeling emotionally lately, 1 being really bad, 5 being really good, and 3 being average. What do you think affects how you feel?

Questions about the participants’ photos:
1. Tell me about this picture.
   a. Where was it taken?
   b. What does it mean to you?
2. How did you find taking the pictures?
3. Are there any photos that you would have liked to take but didn’t?

Interview Questions:
1. How do you take care of yourself when you’re not feeling well?
2. How has your daily routine changed because of your illness?
3. Tell me about how you reacted when the doctor told you that you’ve been diagnosed with IBD.
4. How do you think it would be different to have IBD as a kid than it would be to have it as an adult?
5. Describe how your family and friends have been there to support you.
6. How do your family and friends treat you when you are not feeling well?
7. How has being sick changed the way that people in general treat you?
8. Do your siblings treat you differently?
9. Describe a situation where you’ve felt embarrassed about having IBD.
10. Describe a situation where you’ve felt proud despite your illness.
11. Describe a situation where having IBD has made you feel different from your friends.
12. How much of your experience with IBD do you share with your friends?

D.1 Draft Interview Guide continued

13. Describe for me the (physical/emotional) feelings do you associate with having IBD.
14. In what situations are you most likely to be aware of/think about your illness?
15. Tell me about when you’ve felt uncomfortable or different because of your illness.
16. Tell me about what it’s like to have IBD.
17. How has having IBD changed you?
18. What do you think is the hardest thing about having IBD?
19. What is the most frustrating part of having IBD?
20. How has having IBD made you more hopeful or fearful of the future?
21. How has having IBD changed your perspective/outlook on life?
E.1 E-mail Invitation to Participate

My name is Jessica Diener and I am a second year master’s student in the School of Kinesiology and Health Studies. I am currently recruiting youth participants for my study titled, *Everyone poops: How young people negotiate living with inflammatory bowel disease.* The study will be investigating the lived experiences of children and youth who have Crohn’s Disease, Ulcerative Colitis, or another form of IBD.

I would appreciate it if you could share this information with anyone who meets the following criteria and may be interested in participating in this study.

**Criteria to participate in the study:**

- Youth between the ages of 13-17 who have been formally diagnosed with IBD
- Has been diagnosed with IBD for more than three months
- Lives in Ottawa or surrounding areas
- Speaks English
- Is available for one individual, 1 – 1.5 hour interview session and two subsequent 1-1.5 hour focus group interviews (to be scheduled at the participants’ convenience), to discuss their social and emotional experiences as a result of having IBD

For more information about the study, please see that attached information sheet.

If you have any questions or if you know of individuals who would like to participate in this study, please contact me at 8jad6@queensu.ca or 613-449-9050.

Thank you for your assistance.

Sincerely,

Jessica Diener
M.A. Candidate
E.2 Invitation to Participate E-mail Attachment

Everyone poops: How young people negotiate living with inflammatory bowel disease

Researcher: Jessica Diener, 8jad6@queensu.ca, 613-449-9050

Study Details

Participation Criteria:
I am recruiting youth, between the ages of 13 – 17, who have been formally diagnosed with inflammatory bowel disease (IBD) for at least three months. The youth must live in Ottawa and should have access to a central meeting space (exact location to be determined based on participants’ convenience).

Project Description and Time Commitment:
This project has three parts. The first part will be a short meeting of about 15-20 minutes. During this meeting we will talk about the project, sign the consent and assent forms and I can answer any questions that the participants or their guardians might have. I will give the participant a disposable camera (if needed) and instructions for taking pictures. Over the next 1-2 weeks the participants will take pictures of the objects, settings, and activities that they feel best depict their experiences with having IBD.

The next meeting will take about 1 – 1.5 hours. During the meeting I will ask the participant to talk about their photos and I will ask some questions. The questions will be about the social and emotional experiences that they have endured as a result of having IBD.

The third part of this project involves the participants coming together to partake in two focus group interviews. The willing participants will have the opportunity to discuss relevant themes
that emerged from the initial individual interviews. They will also have the opportunity to share whichever photographs they choose with their peers. As is the case with all aspects of this study, the participants can abstain from answering any questions or participating in specific activities that they choose not to.

**Location:**
The meetings will take place at a location that is convenient for the participants. The first meeting, to make introductions and sign appropriate forms, will most likely happen at a coffee shop or library. The second meeting for the individual interviews will take place in a private setting such as a room at a community centre or at a public library. The location for our focus groups will be determined based on what it most convenient for all of the participants involved.

**Honorarium:**
I will give the participant the choice of a $10 gift certificate from iTunes, Chapters, Shoppers Drug Mart or the movies.

If you are interested in participating in the study or if you would like more information, please contact Jessica Diener at 8jad6@queensu.ca or 613-449-9050.
Appendix F.1 Free Counseling Resources

If after participating in this project you feel you would like to talk to someone about your feelings and experiences, there are people you can call. The services listed here are free and confidential.

**Youth Services Bureau of Ottawa Crisis Line** - is a crisis line available to youth ages 12-15 that offers immediate counseling, supportive listening, along with information on other resources available in the Ottawa area. For more information, you can find their website at [http://www.ysb.on.ca/](http://www.ysb.on.ca/) or call them at 613-260-2360 or 1-877-377-7775.

**Kids Help Phone** – is a free telephone or online counseling service available 24 hours a day to children and youth up to age 20. You can get help from a counselor or they can help you find services in your area to meet your needs. To find out more you can go to their website at [www.kidshelpphone.ca](http://www.kidshelpphone.ca) or to speak to someone you can call them free at 1-800-668-6868.

**School Counselor** - You can make an appointment with the counselor at your school.
Figure 1
Figure 2

Toilet Paper Flowers
A Story for Children About Crohn's Disease

By Frank J. Sileo, PhD
Illustrated by Martha Gradisher