

Running Head: CIBD AND IDENTITY

Identity Concerns for Young Adults with Chronic Inflammatory
Bowel Disease: Identity Structuring and Discordance

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Abstract

Hundreds of young adults in Canada are diagnosed with Chronic Inflammatory Bowel Disease (CIBD) each year. Identity development often becomes intertwined with the diagnoses of this chronic, incurable illness, resulting in a necessity for ill individuals to, in some form or another, assimilate this illness into their identity. In this study, twenty-one young adults with CIBD were interviewed in an effort to better understand the experiences they have had with the illness. To this end, a semi-structured interview was utilized. An initial focus of the interviews was the framework of Identity Status proposed by James Marcia (1966, 1988). Based on the responses of the participants to this interview, two main themes were delineated through a Grounded Theory methodology (Strauss & Corbin, 1990). These themes, Identity Structuring and Discordance, are discussed in terms of the individual and social ramifications present for young adults with CIBD.

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worth having.

while I can hear her laughing out loud at such a statement, I believe that such a goal is one

TABLE OF CONTENTS

	Page
Approval	2
Abstract	3
Acknowledgments	4
Table of Contents	7
List of Tables	9
List of Appendixes	10
Introduction	11
Review of the Literature	13
a) Epidemiology of CIBD.....	13
b) CIBD and Stress.....	16
c) CIBD and Psychopathology.....	18
d) Chronic Illness and Psychological Development.....	21
e) CIBD in the Social Milieu.....	23
f) Identity and CIBD.....	24
g) Concerns with the Medical Model.....	29
h) Narrative Psychology and Chronic Illness.....	30
Research Goals	32
Method	33
Participants.....	33
Interviews.....	34
Results	35
Theoretical Sampling and Analysis.....	35
Development of Thematic Categories.....	36
Establishing Reliability.....	36
Content Analysis.....	37
Interview Themes	39
Identity Structuring	40
Life Before CIBD.....	41
Life With CIBD.....	44
Identity Negotiation and Re-negotiation.....	52
Life After CIBD.....	55
Overview of Identity Structuring.....	58
Discordance	59
<i>Cry Wolf</i> Paradox.....	61
Stigma.....	67

Social Expectations.....	71
Overview of Discordance.....	77
General Discussion.....	78
References.....	81
Tables.....	88
Appendices.....	103

List of Tables

		Page
Table 1	Marcia's Identity Statuses.....	88
Table 2	Participant Summary.....	89
Table 3	Characteristics of Individual Participants.....	90
Table 4	Kappa Coefficients.....	91
Table 5	Content Analysis.....	92
Table 6	Content Analysis by Gender.....	98

List of Appendices

	Page
Appendix A Semi-Structured Interview Schedule.....	103
Appendix B Advertisement for Participants.....	105
Appendix C Public Relations Letter.....	106
Appendix D Informed Consent Form.....	107
Appendix E Letter of Thanks for Participants and Study Summary.....	108
Appendix F Coding Sheets.....	109
Appendix G Coding Manual.....	112
Appendix H Grounded Theory Progression.....	120

**Identity Concerns for Young Adults with Chronic Inflammatory Bowel Disease:
Identity Structuring and Discordance**

Chronic Inflammatory Bowel Disease (CIBD; specifically, Crohn's disease and ulcerative colitis) is frequently diagnosed in young adults. CIBD can be seriously limiting in numerous personal, social, and academic functions due to the unpredictable and severe nature of the illness. Often, missed time from school for medical reasons is a relatively minor concern for young adults who suffer from CIBD as they also have to deal with exhaustion due to poor nutritional intake, severe abdominal pain and a variety of other physical and social problems that often coexist with the illness itself (Wood et al., 1987). Treatments for CIBD are often as invasive as is the illness itself. The biophysical and aesthetic effects of many treatments can be, in many cases, of greater social concern to the adolescent than malnutrition or even the unpredictable intense pain that is typical of CIBD.

Given that the usual age of onset of such an invasive disease is during adolescence (Whitehead & Schuster, 1985), it is understandable that young adults' perceptions of themselves as being healthy, normal youths can become altered, thus interfering with the normal development of their understanding of who they are now and who they feel they will be in the future. Concerns regarding the development of the adolescent's personal and

social identity during the progression of chronic illnesses such as CIBD have also been raised (Falvo, 1991).

The effects of any chronic illness, including CIBD, often entail a number of stigmatizing social ramifications which can play a major role in the formation of individual identity at various stages in individual development. Acute illnesses and psychosomatic conditions, as differentiated from chronic illnesses, generally lack the long term effects that are inherent in chronic illnesses and are thus less of a developmental concern for those who suffer from them. Some of the more well-documented research into chronic illness has focused on separating the psychosocial ramifications of chronic illness from those of acute illness and psychosomatic conditions (Mayo, 1956). Chronic illnesses are incurable conditions of long duration and, in the specific case of CIBD, very unpredictable in activity and trajectory.

Chronic illness, broadly conceptualized, can have a profound impact on an individual's identity. However, the impact extends beyond just the individual with the illness. The lives of those around the ill individual, including family, friends, colleagues, and those with whom they share intimate relationships also share to various degrees the experience of chronic illness (Falvo, 1991). Upon initial diagnosis, the lives of individuals with CIBD change to various extents depending on a variety of factors, including the nature and severity of the disease, the quality of social relationships they have, and their psychological state at the time. Individuals become involved with the illness process and,

as a result, must examine how the disease will fit into their understanding of who they have been to that point, who they are now, and who they will be in the future. It also becomes important for chronically ill individuals to examine how others in society perceive them. It is how these individuals perceive such changes and developments and how the illness becomes intertwined with their identity that is of interest in this study.

Review of the Literature

Epidemiology of CIBD. CIBD, first described in 1932, is of two primary varieties (Donaldson, 1989). The first, ulcerative colitis, is the more common of the two, with a prevalence rate estimated at between one and two percent of the population of industrialized countries. The second CIBD, Crohn's disease, has been found to be somewhat less prevalent, at an estimated prevalence of less than one percent of the industrialized nations' population (Whitehead & Schuster, 1985). The primary difference between Crohn's disease and ulcerative colitis is the specificity of the infected sites. Crohn's disease can occur anywhere in the gastrointestinal tract, from the mouth to the rectum, while ulcerative colitis is specific to the colon and generally occurs in longer segments of the intestinal tract than does Crohn's disease (Donaldson, 1989).

Crohn's disease has been found to be almost twice as common in Whites as it is in Blacks and three to eight times more prevalent in Jewish individuals of European descent than it is in other White populations (Donaldson, 1989). Few explanations have been

forthcoming which could explain this demographic pattern. The most common rationale is that CIBD has a genetic component that is somehow related to environmental factors. However, little research has been conducted to substantiate this suggestion. Males are typically affected at the same rate as females and the age of diagnosis is lower than 22 years of age in more than 50% of all reported cases (Whitehead & Schuster, 1985). The age of onset of CIBD is crucial since it specifically affects adolescents. This gives researchers sufficient cause to focus on the developmental concerns of the illness.

CIBD has no known cause or cure. CIBD and complications arising from the illness are the fifteenth leading cause of death in the United States, although remissions of up to 20 years occur as frequently as do deaths caused by the disease. Both long-term remissions and deaths occur in approximately 20-40% of all reported cases in CIBD populations, with the remaining 60-80% of CIBD sufferers experiencing a wide range of disease activity (Donaldson, 1989). The direct symptomology of CIBD includes frequent diarrhea, severe abdominal pain, anorexia, nutritional deficiencies, weakness, fatigue, and muscle wasting. Of particular concern for adolescents and young adults are the additional related symptoms, which include growth retardation due to poor nutritional intake, arthritis, and missed menstrual periods, each of which are quite common in patients with CIBD (National Foundation for Ileitis and Colitis, 1983). In a review of literature regarding the epidemiology of CIBD, Lemire (1992) cited skin problems such as Erythema nodosum and Pyoderma gangrenosum as frequent physiological concomitants of the

illness. Other extra-intestinal complications Lemire found to be reported with increased frequency in CIBD patients included eye problems (Iritis and Uveitis), anemia, gallstones, kidney stones, and liver abnormalities. Colon cancer is perhaps the most feared of possible illnesses related to CIBD and has been found to occur significantly more in long-term CIBD patients than in control groups (Whitehead & Schuster, 1985).

Treatments for CIBD range from elemental diet therapy to pharmaceutical treatments to surgical interventions, among others. Generally, surgery for CIBD is considered to be a last resort simply because removal of the diseased portion of the intestinal tract does not necessarily prevent the recurrence of the inflammation in another part of the gastrointestinal tract (Donaldson, 1989). Each of the treatments commonly utilized in controlling CIBD, in concert with the illness itself, can have a variety of sequelae that can profoundly affect the psychological condition of the individual involved. For example, it is common for adolescents with CIBD to be expected to forgo solid food of any kind for extended periods of time, often even for years. All of their nutritional intake is in the form of a high calorie liquid that is pumped into the youth via a nasogastric (Ng) tube inserted in the nose. In many cases, youths are expected to wear the Ng tube in addition to a vest that supports the bags of milky liquid and a small pump for up to twenty hours each day, necessitating that they wear the vest and Ng tube to school and other social arenas. The stigmatizing nature of such a device will be discussed later in this study.

Other stigmatizing conditions related to CIBD include excessive flatulence and poor bowel control, which is often accompanied by frequent diarrhea. In many cases, ostomies are surgically implanted in CIBD patients as a means of controlling the illness. Pollution (the loss of bowel control) is the major concern with each of these conditions and, particularly for the young adult, can be a source of extreme humiliation and shame. Loss of control over basic body functions, particularly those related to elimination, often intensifies feelings of isolation and indignity, leading the youth with CIBD to be reluctant to report such symptoms to family, friends, or even to medical professionals (Vallis, 1994). This reluctance to report symptoms has frequently led to CIBD being compared to and misdiagnosed as Anorexia Nervosa. Misdiagnoses of this sort are relatively frequent not only because of the obvious common denominators of loss of appetite and malnutrition, but also because of the similarities in the psychological functioning of those with the illnesses, including reluctance to seek out external assistance (Taylor, 1990). Such associations have led to numerous studies on the relationship between CIBD and psychological functioning (see Clouse & Alpers, 1986, for a partial review of some of these studies).

CIBD and Stress. There is a small body of research that looks specifically at the importance of stress in the lives of CIBD patients. Rahe's (1974) research indicated that increased presence of stressors in individual's lives was highly correlated to an increase in

reports of illness. Hotaling, Atwell, and Linsky (1978) noted that such connections between stress and illness reports could be based on one of three main models: 1) a Direct Relationship Model, in which stress events interfere with normal biological functioning; 2) the Sick Role Model, in which perceptions of certain events being stressful actually lead to perceptions of illness; and 3) the Mental Health Model, which states that illness reports are indicative of underlying psychological problems. While no attempt is presumed to be made in the present study to differentiate between these models, they have been included to provide an example of a framework within which stress and illness relationships can be examined in a broader individual identity framework. These models also suggest that illness can be looked at from perspectives other than the traditional medical framework.

The manner with which chronically ill populations deal with stress has been investigated often with the goal of determining a causal relationship between the two. Duffy, Zielczny, Marshall, and Byers (1991) reported that subjects with either Crohn's disease or ulcerative colitis who had been exposed to stressful episodes in their lives had a significantly higher rate of relapse into active disease than did subjects whose lives had been relatively stress-free over the same six month period. These results were substantiated, at least in regards to Crohn's disease, in a study conducted by Garrett, Brantley, Jones, and McKnight (1991). However, since the former study focused primarily on long-term stressors and the latter focused mainly on daily stressors, the

research conducted by Garret et al. cannot be seen as a replication of the Duffy et al. study.

How individuals deal with stressors and how they assimilate them into their normal daily functioning is of concern when looking at the broader picture of identity development. Von Wietersheim, Kohler, and Feieresis (1992) indicated that although CIBD subjects did not necessarily have more stress in their lives, their methods of coping with these stressors were inadequate and thus they experienced greater feelings of stress. Other research has indicated that CIBD patients often feel an incongruous degree of guilt for their problems which, in the traditional medical literature, could be seen as another indicator of the internalizing psychological style mentioned by Wood et al. (1987), or possibly an indicator of poor coping techniques (Eisendrath, Way, Ostroff, & Johanson, 1986).

Studies of patients with Crohn's disease have indicated a relationship between psychological functioning and biological repercussions (Wood et al., 1987). These findings would suggest that while the severity of the disease may not directly predict the severity of psychological dysfunction, there may be a relationship between illness activity and the style of psychological functioning employed by the individual.

CIBD and Psychopathology. Whitehead and Schuster (1985) reported on a variety of psychological traits found to be common in CIBD patients, including

depression, obsessive-compulsive disorders, hypochondria, hysteria, an inability to form and maintain interpersonal relationships and an unhealthy attachment to their parents, especially their mothers. In a related study, Szajnberg, Krall, Davis, Treem, and Hyams (1993) found high rates of psychopathology as measured in the 3rd Revised edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III-R) among CIBD populations and their parents. Other research has supported the assumption that there are significant correlations between CIBD and psychopathological problems (Clouse & Alpers, 1986) such as depression (both bipolar and unipolar), anxiety, and obsessive-compulsive disorders (Kunsenbeck, Korber, & Freyberger, 1990). However, such diagnoses are becoming less frequent in the research literature as most investigators move toward a broader method of diagnosing psychological problems in chronically ill populations. These methods attempt to achieve a broader understanding of the experiences of chronic illnesses.

Schwarz and Blanchard (1990) completed a review on available research on CIBD as it relates to traditional psychopathological treatments. They reported that although some previous research had indicated that psychological treatments had a positive and significant effect when applied to CIBD subjects, their evidence was not strong enough to conclude that implementing certain psychological treatments for CIBD patients would be of any significant benefit to them. Meadows and Treasure (1989) found that psychotherapeutic techniques used for treating bulimia were helpful in treating

Crohn's disease in patients in which the two conditions co-existed. However, their study is the exception to the rule and is very limited practically since the population that could benefit from such treatments is very specific and quite small.

Tarter, Switala, Carra, and Edwards (1987) suggested that there is a small but significant number of CIBD patients with psychological disorders when compared with control groups. This study also indicated that a significant number of patients with CIBD have psychological disorders that predate the age of onset of the CIBD. However, they are reluctant to state a causal relationship between the preexisting psychopathology and CIBD diagnosis due to their rather limited sample size. Another link between Crohn's disease and bipolar depression is the age of onset, which was significantly correlated between Crohn's disease, bipolar depression, mania, and other affective disorders (Holroyd & DePaulo, 1990). In other words, each of these affective disorders has an age of onset consistent with that of Crohn's disease. A variety of other studies indicate an apparent relationship between CIBD and certain forms of psychological difficulties (Cavanaugh, 1986; Donaldson, 1989; Theinmann & Stiener, 1992; and Wood et al., 1987), but none can definitely support a causal link between the two.

Affective disorders are clearly disproportionately diagnosed in CIBD populations compared to healthy populations. What is it about this particular group that makes them so vulnerable to depression, obsessive-compulsive disorders, or any number of psychopathological disorders? An alternative way to re-conceptualize these disorders, in

addition to the traditional psychiatric framework, is to see them all as being related to the individual's concept of self or identity. This would suggest that while these disorders can be genuine psychiatric conditions, they could also be symptomatic of the individuals' need to re-evaluate and re-negotiate their identity in light of their illness and all of the concomitant problems arising from it. For example, the behaviors related to bipolar depression may be related to the individual's struggle with their identity as a chronically ill person as well as to the more commonly seen conditions that are associated with depression. In this light, various psychological disorders are related to the larger issue of identity development. As a result, the psychopathology model might not be the only way to conceptualize illness. Psychopathological considerations are only a part of the framework of the CIBD sufferer's perception of self. They may be a part of the much larger construct of identity development.

Chronic Illness and Psychological Development. There are a number of developmental concerns that have been identified in reference to children and young adults who experience different chronic illnesses. Bibace and Walsh (1980) examined children's explanatory style in reference to their chronic illnesses within the framework of Piaget's model of cognitive developmental stages (Piaget, 1972). They found that children aged between 2-6 years (Piaget's Preoperational Stage) generally didn't understand the realities of their illness. They tended to believe that they were sick because of fate ("God made

me sick”) or simply because they had “caught” the illness. Some older subjects (aged 7-10 years, coinciding with Piaget’s Concrete/Logical Stage) also stated that they had ‘caught’ their illness, but tended to have a greater understanding of contagion and the actual medical basis for becoming ill by a transmittable illness.

Children who had reached the Formal Operations/Logical Stage (aged 11 years and up) generally had a better understanding of their illness. They understood, for example, that there were some purely physiological aspects of their illnesses that they had little or no control over. This research makes it clear that the age of diagnosis of chronic illness is crucial to a developmental understanding of the illness. A seven- year- old diagnosed with CIBD, for example, would have a very different understanding of the illness than would a newly diagnosed twelve- year- old, who would have a different understanding again than an eighteen- year- old.

It is important to note that Piaget’s model of cognitive development is only one way of examining psychological development in young people. It is presented here simply as a means of examining how young people understand their experiences with chronic illnesses. Other perspectives are required when looking at the broader issues of identity development, both personal and social, which are also concerns that arise when looking at this type of population.

CIBD in the Social Milieu. The undercurrent of chronic illness is a constant presence in the lives of young individuals with CIBD when even such common tasks as going for a drive or sitting in a classroom for a period of time can become major dilemmas (Kleinman, 1988). Scambler (1984) noted the stigma associated with diarrhea and other socially undesirable symptoms of CIBD that often result in the individual's withdrawal from social situations to avoid embarrassment. The stigma associated with chronic illnesses such as CIBD often extends beyond the individuals and into their relationships with families and friends, especially in that there are often special accommodations that must be made by others to integrate the chronically ill individual into "normal" social life.

Given that chronic illnesses are long term, uncertain, and intrusive in the lives of those afflicted with them, it is not surprising that many individuals with CIBD isolate themselves from others (Strauss et al., 1984) and often engage in a futile search for various causes that might be responsible for their condition (Kleinman, 1988). The pressures that these individuals place on themselves are often coupled with the specific demands of society, which expects an ill person to get well and to stop being sick. These demands place chronically ill individuals in a very difficult position. They have to deal with the vigorous demands of society, the common pressures associated with normal daily living, and also with the chronic illness itself.

Identity and CIBD. The concepts related to personal and social identity are somewhat difficult to define. Various definitions have been suggested that typically include some sort of developmental progress toward achievement of a predetermined goal. Perhaps the most immediately recognizable of the numerous definitions of identity is Eric Erikson's progressive stages of identity development (Erikson, 1959). In Eriksonian terms, the identity of the individual permeates the entire individual and thus, everything about the individual should be considered a function of the individual's identity (Waterman, 1982).

For the purpose of the present study, Erikson's psychosocial stages will be used as a theoretical framework from which to expand the knowledge of identity in chronically ill populations.¹ From an Eriksonian perspective, the development of the individual's identity is a paramount consideration given the fact that the age of onset (diagnosis age) of CIBD often coincides with the adolescent stage of development. This is a vital stage of psychosocial development in many ways. The Eriksonian stage of Identity versus Role Confusion typically occurs in adolescence (Erikson, 1959), assuming that the preceding developmental stages have been encountered and successfully negotiated (Bourne, 1978a). As Josselson (1980) noted, these Eriksonian stages do not have distinct starting points, middles, or endings and as a result, some overlap can occur between stages. Identity

¹ The primary point of reference and source of information, however, will be gleaned from the texts of the interviews with participants. The methodology for acquiring these participants and the interview process will be discussed later in this thesis.

formation, as such, cannot be seen as an absolute stage but should rather be viewed as a single circle in a series of overlapping circles.

This stage of identity formation coincides with the Piagetian cognitive developmental stage of formal operations, in which the adolescent begins to be more concerned with the future as well as with hypothetical possibilities. This allows individuals to make reasoned decisions when faced with various contingencies (Piaget, 1972). However, as Rowe and Marcia (1980) note, the achievement of formal operations, while necessary to identity formation, is not sufficient for achieving an identity. Individuals must choose to utilize these abilities to question their place in reality. In the case of chronically ill individuals, questions surrounding their illness would be seen as being crucial to their concept of who they are at this stage of development.

The issues at this stage of identity formation focus around the central question "Who am I?" The manner in which the individual goes about answering this question and the personal and social issues surrounding it lead the individual into a variety of styles of identity formation (Marcia, 1966). James Marcia (1988) has conducted extensive research into identity development and functioning based on the Eriksonian model. He found that within the stage of Identity vs. Role Confusion there are certain styles, or statuses, which individuals utilize to face the particular stage. The determination of an individual's identity status is contingent upon the levels of exploration and commitment the youth makes toward several goals, including vocation, political beliefs, theological orientation,

interpersonal relationships, and sexual beliefs (Table 1). Individuals engage in different levels of exploration of each of these goals and subsequently make various levels of commitment to them. Often, the level of commitment is based on the freedom an individual has to engage in the exploration of each area in the first place (Bosma, 1985).

Marcia (1980) has noted that limits placed on individuals during the adolescent years can hinder progress toward the ultimate goal of full Identity Achievement. These individuals simply stop exploring the options that are open to them as individuals and become "stuck" in what they feel is meant to be their role. Marcia referred to this type of "stuckness" as Foreclosure, which is not deficient identity development, but is instead a less than optimal achievement based on the fact that the individual has made a commitment to some form of ideological and interpersonal constructs without truly examining them.

Foreclosed individuals typically make these commitments based on beliefs given to them or adapted from their parents or care-givers. Individuals in Foreclosure can function as individuals and as a part of society, but they are not aware of all of the options open to them because of their lack of exploration into such options. In the case of CIBD, we can conceptualize the role as that of the chronically ill person. As will be discussed later, individuals with CIBD often find that the number of options that had previously been available to them to be reduced.

Individuals who attain Identity Achievement, on the other hand, have fully explored their options through the process of undergoing an identity crisis, which has been called the "essence of adolescence" (Adams, Ryan, Hoffman, Dobson, & Nielson, 1985) although identity achievement is the goal of all identity development which occurs throughout the life span (Josselson, 1980). This crisis basically challenges youths to consider their beliefs and make commitments based on the results of their experiences with these crises. To achieve this goal, individuals must be able to compare and contrast their personal views with those of others and of society (Adams, 1976). Individuals who successfully achieve identity are generally seen as functioning optimally in society. Individuals with CIBD, in general, would be expected to have experienced a crisis of health. However, the degree of crisis is frequently contingent upon the individual's perception and depth of understanding of the disease and its many concomitants.

Individuals who are in the process of experiencing an identity crisis are referred to as Moratoriums. These individuals have made no commitments, primarily because they have not completed their exploration into the options available to them. Marcia's final identity status is known as Identity Diffusion. Individuals in this particular status have not experienced a crisis situation, yet at the same time have made no commitment to any particular interpersonal or ideological construct. These individuals basically drift through their lives on a day to day basis, making limited long-term commitments and generally forfeiting the control of their lives to external environmental factors.

Marcia's framework has been criticized as being designed primarily around male populations. Specifically, the focus of Marcia's statuses had been the levels of exploration and commitment to domains which were perceived as being either more male specific (political and religious ideologies, vocational choices) or female specific (interpersonal relationships, sexual beliefs) (Archer, 1992). While the identity status framework has been revised to include sexual beliefs and interpersonal relationships (Bourne, 1978b; Rogow, Marcia, & Slugowski, 1983), Archer argues that the identity domains are not gender specific at all. Another criticism is that the interrelationships between the domains are often overlooked (Archer, 1992). While a response to each of these criticisms is beyond the scope of this thesis, they are noted here as valid concerns in identity status research.

Marcia's identity statuses, despite the aforementioned criticisms, can provide a very helpful framework in which CIBD patients can be examined. No research based on Marcia's work has been conducted on CIBD populations specifically, although Gavaghan and Roach (1987) conducted identity status research on young cancer patients and suggested that follow-up on chronically ill populations other than cancer patients was needed to further validate the field of chronic illness and identity status research. Stern, Norman, and Zevon (1991) conducted a study on the levels of exploration and commitment in regard to career choices made by adolescent cancer patients and found that while their subjects were generally optimistic about their vocational future, they tended to foreclose on career choices at an earlier age than healthy adolescents. Although the

present study does cite the Gavaghan and Roach (1987) and the Stern, Norman, and Zevon (1991) studies as conceptual catalysts, the methodologies used in this study will be of a significantly different nature.

Concerns with the Medical Model. Research conducted on chronic illnesses such as CIBD has typically been embedded in the biomedical model. The studies focusing on the psychopathology relating to CIBD primarily concern themselves with the classic symptomology of psychological disorders (see for example Clouse & Alpers, 1986; Holroyd & DePaulo, 1990; and Schwarz & Blanchard, 1990). Such research is very often used to as a means of arriving at possible treatments for the psychological symptoms displayed by CIBD patients. Generally, the focus of these studies has been to delineate a model of psychological functioning of patients with CIBD by comparing them to control groups or samples of other chronically ill populations. This can be conceptualized as a typical methodology utilized by many researchers working within the psychiatric framework. While a wealth of valuable information can be, and has been, collected and reported in this manner, the present study does not follow the traditional medical research model. The nature of the present research problem cannot be restricted to simply determining whether or not psychopathology is exhibited by chronically ill individuals.

An alternative method of understanding chronic illness that takes into account the individual stories of the sufferers can be used to understand the nature of the psychosocial

effects of the illness. Goertzel and Goertzel (1991), for example, included a qualitative component in their study of pediatric cancer patients to achieve a better understanding of the experiences of chronically ill children. This allowed the children themselves to voice their experiences, an option that is generally not available within the framework of the medical model. Such stories, relayed by ill individuals, can provide a deeper comprehension of how the illness has affected their lives, thus expanding our understanding of the effects of the illness.

Narrative Psychology and Chronic Illness. Individual stories, or narratives, allow chronically ill individuals the opportunity to explore their experiences of illness and how these experiences have had an impact on their lives. Further, the person is given the opportunity to articulate their understanding of their illness. Narratives give individuals a means of making sense of who they are within a given context. Churchill and Churchill (1982) suggest that the best way for individuals to gain an understanding of themselves is through their own personal narratives, which allow them to make sense of their experiences while at the same time maintaining distance between themselves and their histories. While the narrator has a personal stake in the narrative, he/she does not have to become enmeshed in the whole experience all over again, primarily due to the passage of time between the events and the telling of their story.

For chronically ill populations, there have been suggestions that the telling of personal narratives can be very beneficial in that they feel better in knowing that someone has heard their story and has, in some way, shared their experiences (Brody, 1987). These narratives are, however, more than simply one-sided synopses of past events. They allow the listener the opportunity to assist the narrator in articulating the illness experience. The listener accomplishes this through the act of listening to their stories and also by hearing the individuals construct their identity both in the stories as well as through them. Yardley (1987) stated that the measurement of abstract psychological constructs such as identity status must be both subject driven and context embedded. To this end, participants will be the source of all information gathered within the context of a semi-structured interview.

The use of Marcia's framework in studying chronically ill populations in general and CIBD populations specifically has not been considered in the literature before. To facilitate the development of this field of research, a theoretical framework must be developed. This can be achieved in part by engaging in field research which, optimally, strengthens the theoretical framework (Lincoln & Guba, 1985). Thus, a qualitative approach can be seen to have far more applicability in studying the identity concerns of young adults with CIBD than the more traditional research designs which might be used to test hypotheses. The specific design employed in the proposed study involved utilizing a semi-structured interviews with focused probing to elicit responses from the participants who have been systematically, rather than randomly, selected.

Research Goals

Based on this survey of some of the available literature, it can be proposed that the original diagnosis of CIBD can involve many problems for the ill individual involved, especially in regard to identity formation. Further, since CIBD is often diagnosed in adolescence, it can be assumed that individuals with CIBD are also at a stage of development at which they have a lot of choices to make ideologically, vocationally, interpersonally, and sexually. The presence of CIBD can have an impact on these choices in any number of ways.

Based on these conclusions, it was the goal of this study to examine the way in which young adults with CIBD construct their identities. In other words, the participants in this study shared their answers to the generic question "Who am I at this point in time?" To this end, a semi-structured interview (Appendix A) was utilized to elicit responses from participants regarding their individual development in light of their illness. Rather than attempting to formulate specific research hypotheses to be investigated through statistical data analysis, the goal of this study was to discern major thematic responses from the interviews.

Method

Participants. Twenty-one young adults who had been diagnosed with some form of CIBD and were between the ages of 17 and 28 were interviewed for this study. More specific demographic information, including frequencies of CIBD type, are included in Table 2. Information regarding the individual participants is located in Table 3. Participants were recruited utilizing a variety of means. The first three interviews were conducted with personal acquaintances of the author. Additional participants were recruited at two separate meetings of the Crohn's and Colitis Foundation of Canada (CCFC) in Halifax, Nova Scotia, Canada. The author approached the meeting coordinators to ask permission to appeal to those in attendance during these meetings. Prospective participants were informed of the authors credentials and research goals and were then asked to place their names and phone numbers on a sign-up sheet which was then circulated throughout the room. Contact with these participants was made within four weeks of the meetings.

In an effort to recruit more participants, advertisements were posted at three universities in the Halifax area (Appendix B). The advertisements contained the home phone number of the author which individuals with CIBD who were interested in the study could call at their convenience. Additional advertisements were posted at the Halifax Infirmary, a division of the Camp Hill Medical Centre, also in Halifax (Appendix C).

Interviews. Each participant was asked to read and sign an informed consent form (Appendix D) prior to starting the interview. All participants agreed to have their interviews recorded on audio cassette. They also permitted the author to use excerpts from their interviews in future presentations and/or publications. Each interview generally followed the semi-structured interview (Appendix A), which was devised by the author based on interview schedules used previously in comparable research (i.e., Marcia, 1966; Mathieson, 1992). The nature of the interview allowed for a considerable amount of freedom for the participants to discuss what they felt was relevant in regard to their experience with CIBD. However, the central information requested in the interview schedule was obtained in all interviews.

At the conclusion of each interview, participants were given a copy of the informed consent form and were also thanked for their participation in the research. A follow-up thank you letter containing a brief summary of the research findings was sent to each participant at the conclusion of the study (Appendix E). Temporary copies of the interviews were made for use by two student coders. These copies were all destroyed at the conclusion of the coding process. The original cassettes were used in the typing of manuscripts. Upon completion, all manuscripts and original cassettes were returned to the author for further analysis.

Results

Theoretical Sampling. In accordance with grounded theory, theoretical sampling was employed in the present study. This implies that rather than attempting to collect a large sample of the population in hopes that the information they provided would be representative of the population in general, a smaller sample was directly interviewed until the information that they were providing began to overlap across interviews. Interviewing was concluded when each category of information was saturated with information provided by the participants in the interviews. The requirement of saturation of information is consistent with the approach used in this study, based on Glaser and Strauss (1967) and Strauss and Corbin's (1990) description of Grounded Theory.

In reference to the present study, the criteria for saturation of information was considered to be satisfied when the information provided in an interview was not strikingly different from the information provided in previous interviews, most variation within categories was accounted for, and each of the main types of themes raised within an interview could be viewed as having a discernible relationship to other themes from previous interviews.

Development of Thematic Categories. Open coding was employed in the early stages of the interviews in an effort to derive themes in regards to the participant's

responses to the semi-structured interview. In its simplest form, open coding is the “...breaking down, examining, comparing, conceptualizing, and categorizing...” of data (Strauss & Corbin, 1990). Many themes began to evolve during the process of open coding and as more interviews were analyzed and it became apparent that many of the themes raised by individual participants were common across many interviews. At this point, axial codes were formed on the basis of these themes arising from the open coding stage. Axial coding involves restructuring the open codes into new paradigms, resulting in the establishment of main categories and sub-categories. These new main categories, which have been called Identity Structuring and Discordance based on the nature of the thematic responses from the interviews, will be discussed later in this paper.

The main categories of Identity Structuring and Discordance were also compared through selective coding. This process involved explicating the core themes from the various narratives for the purpose of relating them to one another. The relationship between the two main categories is also examined in detail later in this thesis.

Establishing Reliability. In an effort to ensure the reliability of the information provided in the interviews, two undergraduate psychology students were trained to act as coders for each of the interviews. These coders were expected to listen to each interview and code the information provided by the participants on a coding sheet (Appendix F). The codes were based on a detailed coding manual devised by the author. This manual

(Appendix G) describes the types of responses participants might give as well as the criteria for coding various responses. The coders, who were instructed to maintain the absolute confidentiality of the participants if any identifying information was given on the cassettes, were given three interviews to train with before the coding of the actual interviews began. After they coded these training interviews, they met with the author to discuss each interview and to ensure a high level of agreement between all three parties. When it was determined that the coders had a firm understanding of their requirements in terms of coding, they were given the rest of the interviews to code. After the coders completed the rest of the interviews, they met again with the author to discuss the interviews and the codes they had assigned to each response. The reliability of the codes provided by these coders was established by calculating kappa coefficients, which measure inter-rater reliability (Fliess, 1971). The kappa coefficient for each interview response can be found in Table 4.

Content Analysis. At the conclusion of the interviews, the cassettes were reviewed to ensure accuracy between what the participants said and what was recorded by the author, both on field notes and on the coding sheets derived from the coding manual that had been used by the independent coders. The frequency of the participant's responses to the various questions on the semi-structured interviews was also recorded. The frequency

of the participant's responses as well as the percentage of responses to different aspects of each question are located in Table 5.

Each question was broken down into smaller components, initially to provide the independent coders with a framework from which they could base their judgments for coding purposes. The manner in which these questions were broken down typically represented most types of responses provided by the participants. In a few cases, no responses could be recorded for various reasons. In a few interviews, certain questions were not asked because they simply did not apply to the participant. For example, a number of participants indicated that they were not involved in intimate relationships of any kind, including very close friendships. In such cases, the participant was not asked any of the questions regarding intimate relationships. In other cases, the participants were students who had not yet entered the workplace, even on a part-time basis. Such participants were not asked any questions regarding changes and support at the workplace since for them, such a place did not yet exist.

Deleted after the fourteenth interview, the question regarding participant's perceptions of which sex dealt with the illness more effectively tended to do little more than confuse the participants. Many said that the question seemed incongruous with the rest of the interview, which generally dealt with their personal experiences with CIBD. The gender question was originally added as a means of having the participants think about the relationship of gender to CIBD. Obviously, this question was not appropriate

for this purpose. According to one participant, the gender question "...stuck out..." from the rest of the interview. Upon discussion with some participants, the independent coders, and other colleagues, the author determined that the gender question did not belong in the interview schedule. Differences in gender, then, is seen simply as a function of the frequency of response types between male and female participants (Table 6).

In general terms, there tended to be little difference in the types of responses given by male and female participants. This would tend to indicate that experiences with CIBD are not necessarily gender-embedded but rather are of a generalized nature. Males and females with CIBD tend to share common experiences that are not necessarily contingent upon their gender. More males, three in total, spontaneously mentioned areas to which they were committed (friends, self, staying positive) than did females (one mentioned a commitment to religion). However, since only a total of four participants spontaneously mentioned commitments other than the ones probed for by the interviewer, their appearance would seem to be related more individual concerns rather than to gender specific domains.

Interview Themes

Based on the information provided by the participants in their interviews, two main categories were determined to be the most salient issues for the participants. The themes are broken down into their component parts in Appendix H through the Grounded

Theoretical progression, leading from open categories to axial categories and finally to the main categories. The first theme was named Identity Structuring because the process that participants seemed to undergo as they assimilated the illness into their lives was a process of structuring around the constant changes that had occurred, were occurring, and would occur in the future as a result of their illness. The second category, Discordance, was so named because of the feelings of mis-fit and discordance participants felt as chronically ill young people.

Identity Structuring

As noted in the previous section, identity structuring was one of the two major themes drawn from the interviews. This concept of structuring was clearly seen in a number of interviews as being a crucial issue in assimilating CIBD into the participants' sense of who they felt they were. Given the relative complexity of a concept such as identity structuring, it is perhaps best explained in terms of the component parts from which it is derived. These component parts were delineated from the interviews and tend to follow a more-or-less progressive format, leading from life before CIBD to life with CIBD and the subsequent re-negotiation of identity that occurs in many cases, particularly when CIBD becomes a part of the participant's life at a relatively older age. The final

category deals with the participants expectations of what the future holds for them, especially in terms of their illness.

Participants often created these segments themselves, moving clearly from life before CIBD to life with CIBD and the expectations of what life would be like in the future with CIBD. However, this progression was usually not cleanly divided by any sort of shift in the interview itself and in many interviews, there tended not to be a chronological framework to the story being told. Participants would move from one part of their story to another in what appeared to be an order framed not only by the semi-structured interview but also by the priorities they placed on their experiences. As such, the categories of life before CIBD, life with CIBD, and life after CIBD will be discussed here in chronological order given the understanding that this is not always how it occurred in the interviews.

Life Before CIBD. The first category, life before CIBD, was raised by many participants, particularly in reference to their search for the cause of their illness. In many cases, individuals tried to make sense of their having CIBD in terms of their previous behaviors. Such attempts at rationalization tended to revolve around health care, especially diet. Generally, participants either felt that CIBD was essentially a “punishment” for previous eating and health habits, while others stated that despite their eating everything that they thought were supposed to, they still got CIBD. This creates a

dichotomy between those who thought that they got what they deserved and those who felt unjustly punished for crimes they did not commit. Such a dichotomy extended beyond issues of health care and into more general belief systems. One participant wondered why “God cursed [him] with this [CIBD],” voicing a concern that individuals with CIBD have in terms of finding a reason for their being ill with such a humiliating disease. Regardless of the level of sophistication of the participant’s understanding of the physiology of CIBD, such searching for a cause was relatively common in the interviews. While they might understand that no one knows what causes CIBD, they would attempt to rationalize their own experiences with the illness as being contingent upon their actions and behaviors.

Attempts at various rationalizations are not limited only to the individuals who have CIBD. In fact, many participants noted that they did not really understand why they had CIBD but others who were involved with them, including family and friends, often tried to explain the reasons for their illness. Frequently, such attempts at rationalization would occur before an initial diagnosis could be made. The non-specificity of the symptoms, accompanied by the fact that flare-ups frequently occur during times of high stress, often led people around the participants in this study to attribute the illness to poor coping skills and “nerves.” One participant, a seventeen year old male high school student, remembered having symptoms on the first day of junior high school, prior to his initial diagnosis with Crohn’s disease. He recalled his mother saying “‘It’s just your nerves’” The participant agreed, “So I said ‘Alright’ and I went to school and I had pains

in my stomach all day and I just thought it was nerves, 'cause that's what Mom said. I came home and I still wasn't feeling good and I realized that it wasn't my nerves." In this case, the ill individual recalled acquiescing to his mother, despite his knowing that his sickness was more than simply a case of first-day-at-a-new-school butterflies. Such stories were common throughout the interviews, often with more ultimately negative results.

Participants who looked back over their experiences in their lives before they began to exhibit symptoms of CIBD generally felt that their lives had become significantly different in a number of ways. These changes, however, could not always be easily classified in a 'then-and-now' type of comparison because their lives had progressed, in many cases, regardless of their illness. In other words, being diagnosed with (or at least having symptoms of) CIBD did not always immediately change their lives to any great extent. The changes necessitated by having CIBD often tended to be more gradual and less overt than the changes that would be associated with more acute health concerns such as broken bones or than those changes associated with more invasive problems such as the loss of limbs or terminal illnesses. However, many participants looked back at their lives before CIBD as being very positive times which, had the illness not become a factor, would have continued in some form or another to the present day.

Life With CIBD. Participants would frequently move from the area of their lives before CIBD into talking about their daily experiences with CIBD, emphasizing particularly the differences between their lives “then” and their lives “now.” As noted previously, this distinction was not always readily apparent in the structure of the interviews, although most participants did describe their experiences within some sort of framework that contained information regarding their lives before CIBD and their lives with CIBD. This framework was not necessarily ordered chronologically and in fact, occasionally contained information presented in a reverse chronology, that is, from descriptions of current conditions leading back to the time before the initial diagnosis. This is important when considering the participant’s conceptualization of where they stood in reference to their illness. Those who described it in a chronological progression leading cleanly from life before CIBD to current health status could be seen as having some sense of distance from the disease. The illness was not seen as being as central as it was to those who were experiencing active symptoms and who were less likely to distinguish between then and now. Those in states of active disease had more of a stake in their illness simply because it was something they were experiencing even during the interview itself.

One such participant, a twenty-five year old female graduate student, noted that she had to “radically” alter her lifestyle when her symptoms were active. These alterations included her diet and, more importantly to this participant, her activity level. Her particular illness seemed to get much worse when she was under stress and as a graduate

student in a professional program, the stress level was very high. This participant, while able to give a fairly coherent story of her illness, did not easily make the distinction between her history of illness and her current experiences. Rather, she told her story in small vignettes, each relating to her current experiences. For example, at one point she told of one fellow student back in junior high school who, when she saw the participant's Ng tube and apparatus, exclaimed in surprise "What the fuck is that?" This vignette appeared as the participant was relating her story of having few problems with being socially accepted despite having CIBD. The participant then went on to discuss how much she missed eating when she was sick and again went back to her high school years to cull an example of the social significance of eating. In this interview, the participant would start with her current feelings and experiences and would then go back to her history with the illness to draw upon for an example to make her point.

Other interviews followed a very distinct chronology, as was the case with one twenty-five year old mature student with Crohn's disease, which was in remission at the time of her interview. Her story followed a very distinct trajectory, leading succinctly from her life before CIBD, to her initial diagnosis, to the various degrees of effectiveness she experienced with different treatments, to her current status. Her story, while sharing many similar characteristics with other participant's, followed the clearest chronological path. Her illness, while in remission, appears to be a very different entity than does the active illness of the previous participant in that the former views the CIBD as something

that had happened and might happen again while the latter viewed the illness as something that was happening to her right now. These two examples are perhaps extreme points on the continuum which participants use to distance themselves from the illness. In some cases, for example, the participants did not view the illness as invasive as did others. Perhaps this could be explained in terms of the present activity of the illness itself. The more active the illness, the more invasive it would appear to the participants.

Disease activity is only one component of the broader picture of living with CIBD. Participants raised issues revolving around the daily requirements of assimilating CIBD into their lives, issues that involved not only health adaptations such as diet and exercise but also the more pragmatic issues of awareness of washrooms and dealing with self-pollution. These latter issues will be discussed later in terms of the stigma associated with CIBD. The basic question participants asked at this stage is “Who am I now,” as compared to the “Who was I” question they would ask themselves when looking at their lives before they experienced symptoms of CIBD. Responses to the former question, as noted, ranged from health concerns to the basics of life with CIBD.

In terms of health issues, participant’s responses ranged from having limited daily problems with CIBD to having significant symptomology and treatment regimens that had serious impact upon their daily lives. Participants who had little daily difficulty with CIBD on a daily basis typically noted this in their responses to the question regarding their normal week. A few participants noted that CIBD did not play any significant role in their

normal week and would describe daily activities associated with their work or family, often in great detail. One twenty year old male student, who was not experiencing active symptoms of his ulcerative colitis at the time of his interview, described his normal week in terms of what he does on each day of the week. CIBD did not fit into his daily life at all.

On the other hand, for those whom CIBD was a major player in daily living, a very different picture of their normal week would be presented. Their descriptions often centered around diet, pain, diarrhea, and treatment regimens. One twenty-five year old teacher with Crohn's disease likened the effects of frequent pain on his health to "...bending a coat hanger..." His story involved frequent episodes of high disease activity that would necessitate his dropping out of his usual activities, including school and work. Another seventeen year old male student with Crohn's disease, who was at the time of the interview being treated with elemental diet, described his typical day as centering around his "hook-up" times (times at which he had to pump the elemental diet fluid into his stomach). His daily activities were strictly governed by the requirements of his treatment schedule.

Other participants cited dietary concerns as one of the major factors in their daily living activities. A twenty-five year old female participant with both Crohn's disease and ulcerative colitis and whose position required a significant amount of travel and stress stated that one of the most difficult situations in dealing with CIBD was knowing when to

eat. For example, a meal a half-hour before participating in an activity could have disastrous results, not only because of the possibility of the occurrence of pain, but also the possibility of diarrhea or the loss of bowel control. As a result, her daily activities were strictly a function of when she ate, which in turn was a function of her work schedule. This made many activities very difficult to coordinate, particularly if they were of a more spontaneous nature. Many other participants also noted the limits imposed by having to deal with the requirements of the illness.

Other areas of daily life were also seen as being limited or governed by CIBD included social activities and working situations. Many participants noted a distinct drop in their social activities despite the continued support of their friends and peers. Most participants noted positive support from their friends and in fact, frequently stated that their relationships with their friends had actually improved, usually because of the crisis that accompanied the illness which would often result in strengthened relationships. Those around the individuals with CIBD would change their activities in order to accommodate the ill person, for example, by staying home and watching a movie as opposed to going out for dinner. Support such as this was seen as invaluable by many participants who saw such accommodations as a means of re-joining the social world from which they had feared to be excluded.

However, not all individuals necessarily encouraged their friends to make any sort of accommodations on their behalf. One participant, a nineteen year old female student

with Crohn's disease, stated emphatically that she did not want her friends, or anyone else for that matter, making any sort of accommodations for her because of her illness because after all, "It's not *their* disease" [italics added]. Her point was emphasized by a twenty year old male participant who said that he did not like it when he saw people who were sick with any illness who would "make(s) more of it than it is" in order to get some sort of preferential treatment, either from peers, employers, family members, or teachers. Such behavior, he felt, was not helpful, particularly in reference to people with CIBD who are frequently viewed as being complainers and malingerers.

Others who come into contact with individuals with CIBD on a daily basis, such as employers, family members, and educators, had different forms of impact upon the participant's daily lives. Most participants reported difficulties at work and school, most relating to time missed due to illness and to the chronic fatigue that often occurs when individuals with CIBD are in states of active disease and do not absorb the necessary nutrition required for healthy functioning. A twenty-five year unemployed former graduate student had a very hopeful perspective when she started her graduate work. However, shortly after she started, her ulcerative colitis flared-up, ultimately resulting in her having to quit the program. Her frustration was echoed by another twenty-five year old female student who recalled that her career in secondary school was less than optimal because of the time she missed due to her illness. As a result, she had significant difficulty in coping in the university environment, difficulties which were compounded by her

sporadically active Crohn's disease. In such cases, individuals experienced failure despite the efforts not only of themselves but also of their superiors such as teachers and program coordinators. Although similar themes of failure were quite common in the stories of the participants, some felt that the failures due to their CIBD had ultimately made them stronger people.

There are, of course, a number of factors that can intervene in the lives of individuals with CIBD that can affect how the individual deals with the illness on a daily basis. These factors, including the trajectory of the illness, the levels of support that was available to them from external sources such as family, friends, and employers, and so on, all become intertwined with the individual's sense of who they are and where they fit in within the framework of society. Their experiences with CIBD often necessitates a re-negotiation of who they perceive they are, particularly as chronically ill young people. They have to re-structure their identity to fit not only their own perceptions but also society's perceptions of what a chronically ill young person is.

To many of the participants in this study, the role of the sick person seems to be well defined if the disease itself is well known. For example, many participants compared CIBD to other illnesses such as AIDS or cancer in order to gain an understanding of what they, as ill people, were supposed to be. A twenty-six year old male participant recalled his experiences when he was initially diagnosed with Crohn's disease by comparing CIBD to other diseases he had heard of: "It's [being diagnosed with CIBD] as bad as someone

saying to you that you've got cancer, I think, 'cause you're so scared." Cancer is seen in this case as the archetypal disease against which all others are to be compared and feared accordingly. Within this comparison base, however, there are few examples of experiences had by chronically ill *young* people that the participants could draw upon.

Most of the common imagery of chronically ill individuals includes images of the older cancer patient or the terminally ill AIDS patient, neither of which fit the CIBD participant's expectations of what was required of them. The difficulty in developing an identity as a chronically ill young person appeared to be that they had no common frame of reference upon which they could compare themselves. They would compare themselves to other healthy young people, but usually such comparisons were framed in terms of being either better or worse than them. Most participants felt that they were somehow not as good as healthy young people, as evidenced in a comment made by a twenty-five year old participant with Crohn's disease, who stated that she was "...very jealous of people who are not sick." Her frame of reference was other young people who did not have a chronic illness. This comparison naturally led her to feel inferior in some ways, particularly in terms of the activities in which she could no longer participate. As a previously active person, the appearance of the illness made it necessary for her to analyze her status and to re-negotiate her perceptions of her individual identity. As young adults, the participants had been developing their individual sense of who they were, usually as healthy individuals. The onset of symptoms and initial diagnosis of CIBD forced them to

re-examine their sense of who they were. Was the individual with CIBD the same person as he/she was before with the added condition of a chronic illness or was the individual now, because of the illness, a distinctly different person?

Identity Negotiation and Re-Negotiation. The re-negotiation of identity has been noted as being a very critical concern for chronically ill individuals (Mathieson, 1992). While Mathieson's research centered around cancer patients, the premise of the necessary re-negotiation of the individual sense of self can be seen as being applicable to many chronic illnesses, CIBD being no exception. Re-negotiation is a very complex construct, particularly when looking at young adults who do not have the firmly established sense of identity that older individuals have. They are often in the process of negotiating their identity when they are diagnosed with CIBD. This makes re-negotiation a somewhat different entity because there is no firmly established identity upon which the young adult can build or change. Thus, the re-negotiation occurs simultaneously with negotiation.

The process of identity negotiation involves the explorations that young adults make in an effort to determine who they are and where they fit in within society. Through the course of these explorations, the youth makes choices that ultimately have some bearing on their future roles. The intrusion of CIBD into the lives of young adults makes the availability of various options rather limited. Physical limitations and social concerns prevent these young adults from exploring all of the options available to them and as a

result, they are forced to make commitments based on incomplete or non-existent experiences. Ultimately, this exclusion from different experiences can lead to a significant amount of frustration for young adults with CIBD. A twenty-five year old female participant with ulcerative colitis related her experience with the inability to fully explore her options, regardless of their relative importance: “When it’s really [CIBD symptoms] bad, I don’t feel that I can go out anywhere. I feel like a prisoner in my home, y’know, in my body...because it’s very uncomfortable to be at a grocery store and have to zero in on a bathroom. It’s just not worth it to go anywhere.” In this case, the participant felt that rather than undergo the humiliation and exhaustion that accompanied even a short shopping trip, she would stay home. Similar concerns were commonly related throughout the interviews, indicating that individuals with CIBD often experience difficulty in even the smallest of explorations. Their inability to fully explore the options available to them and the premature commitments they are subsequently forced to make can result in an incomplete negotiation of identity.

It should be noted that incomplete negotiation of identity is not synonymous with deficient identity negotiation. Incomplete implies that given the opportunity, the individual would have completed the exploration required to make well-reasoned commitments to various domains, resulting in a fully developed individual identity. In the case of the individual with CIBD, the opportunity to explore is often seriously curtailed, resulting in this sort of incomplete negotiation. Incomplete identity negotiation would be

seen as being comparable to Marcia's (1966) conceptualization of the Foreclosed identity status. In contrast would be deficient negotiation, which implies that despite having the opportunity to explore the options available, the individual chooses not to make the explorations and commitments necessary to develop a fully developed sense of identity. This is comparable to the identity status of identity diffusion, described by Marcia as an inability to explore the options available and to make any sort of commitments to any number of domains.

There were numerous examples of incomplete negotiation within the interviews. More than one participant noted that they picked their university major based on a cursory search of what courses were being offered. One participant, upon completing his Bachelor of Arts degree decided that he was feeling healthy enough to work on a teaching degree. His decision to enter into teaching was something that he had been interested in for some time. However, his actual enrollment in a teaching program was contingent upon his health. His previous university experience had involved a lot of "...jumping around the university calendar..." to take various unrelated courses. While he eventually did settle on a major, his decision was significantly delayed by his concerns for his health. Another nineteen year old participant stated that she selected her major because of pressure from her parents and teachers. Her illness prevented her from exploring other options beyond the ones set before her by others and as a result, she ended up preparing for a career in an area in which she was not truly interested. In both of these cases, the

individuals had to re-negotiate their identity to fit their illness in relation to their vocational choices.

Within the process of negotiation of identity, individuals have to explore the options available to them in terms of what they expect from the future. Educational courses are selected within criteria necessary for future plans, particularly vocation. Social interactions provide the individual with a means of further exploring the various options available. Most young adults make commitments to various domains such as vocation, education, family, religion, and so on by examining the options available to them and then making the commitment based on the results of their explorations and on their expectation on how their choices will influence their future identity (Marcia, 1966). For young adults with CIBD, the unpredictability of the future often becomes a central concern that limits their ability to fully explore the options available to them.

Life After CIBD. For the chronically ill individual, the future has a very different meaning than it does for the healthy person. Participants frequently noted that the course of the illness has a very unclear trajectory, making it was difficult to plan ahead to any extent. The uncertain frequency of pain, diarrhea, exhaustion, and other symptoms caused many participants to remove themselves from society to some extent. While most participants mentioned CIBD in positive terms when they were asked about their view of their future, the illness was always mentioned as a significant consideration. The

participants could not frame their future without considering the effects of the illness. Of course, since CIBD is not yet curable, the title “Life After CIBD” does not mean to imply the vision of a future without CIBD. Rather, the title simply implies the vision the participants had of their future with CIBD.

For individuals with CIBD, the uncertainty of the illness makes daily living very problematic and the ability to make plans for the future is seriously compromised. Without a realistic view of the future, these young adults have little to hope for beyond a very short-term view of the future which may itself turn out to be inaccurate because of a sudden flare-up. As a twenty-six year old participant said in response to the question about his view of the future, “My future is tomorrow...with a problem like this, you don’t know what you’re future is.” For many participants, the future is not worth even considering to any great extent because of the lack of stability they encounter with their CIBD.

Concerns about the future extended beyond individual health concerns and vocational choices. Many female participants, for example, expressed various concerns in regard to their ability to reproduce. While none of the participants in this study were parents themselves, the issues of having children while experiencing symptoms of active disease or while on medication that might have adverse effects on the pregnancy were quite prevalent. Other participants expressed concerns about issues ranging from fears of developing colon cancer to the availability of health insurance. These concerns about the

future indicate that while having CIBD does not preclude individuals from thinking about their future, they tend to be concerned with the specifics of the ramifications that the illness will have on them personally, professionally, and socially. Some participants were apparently wholly optimistic in their, as in the case of a seventeen year old high school student who noted that "...it [CIBD] hasn't affected my life so far, so I really don't see why it would affect me in the future." This participant's view, however, could be seen as being perhaps a bit unrealistic in that he had been on and off elemental diet tube feeds for over three years. CIBD had in fact become a very large part of his life and had been very disruptive in his and his family's life since he first started to exhibit CIBD symptoms.

As noted earlier, most participants had high expectations of their futures despite their CIBD. Not all participants looked to the future with such optimism. Statements such as "'Cause, y'know, when I'm depressed I start thinking well, what value is there in this sort of life when you're always in pain, in various forms of discomfort and, uh, in some ways, it's a very humiliating disease..." indicate a less-than-hopeful view of life with CIBD. While statements such as these were relatively rare in the interviews, they did occur, indicating a concern that these individuals had about what they could expect in the future with their illness.

Given the unclear nature of the trajectory of CIBD, concerns regarding topics such as future employment, family status, and daily living, among others, could be seen as being particularly valid. Individuals with CIBD have to find some methods of assimilating their

illness into their expectations of the future, regardless of the fact that with CIBD being a part of them, their future could not follow any sort of predictable path. While it is true that the future is never a constant for anyone, the frequency and severity of flare-ups related to CIBD make accurate planning a most difficult task for those who have the illness.

Overview of Identity Structuring. Identity structuring could be defined simply as the method in which chronically ill young people develop their sense of individual identity. Identity structuring tends to follow a path leading from their life before they became ill to their experiences with the illness and the negotiation and re-negotiation that occurs as they attempt to assimilate their illness into their conceptualization of who they are. It also encompasses the young adult's expectations of what the future holds for them.

Identity structuring, while encompassing a wide range of experiences, cannot be viewed as a sufficient framework in and of itself when looking at the effects of CIBD in the lives of young adults. There are a number of considerations that are not accounted for within identity structuring. These identity concerns can, to some extent, be encompassed within the other major category derived from the interviews. This category, which will be discussed in detail in the next section, is called Discordance.

Discordance

Discordance was the second of the two major themes derived from the interviews in this study. In its simplest form, the category of discordance includes the stories that participants would tell that did not easily fit within the parameters of identity structuring. These stories tend to revolve around the role of the chronically ill individual within society and the effects that having a chronic illness can have on young adults. In the interviews for this thesis, themes of discordance were, of course, specific to young adults with CIBD. However, discordance does not necessarily have to be limited to individuals with CIBD. It is, rather, a general term used to describe the feelings of mis-fit that young adults feel when there is something about them that is not necessarily “in tune” with those around them.

Discordance was described by a number of participants in terms of not only having a chronic illness such as CIBD but also in terms of being a chronically ill young person. The discriminating factor between being ill and being young and ill is basically that adolescents often deal from a position of little power when dealing with the adult world. Having CIBD forces them into the adult world in many ways, particularly into the medical world. Participants frequently noted that while the support they received from medical professionals was good, they had a difficult time in making their voice be heard. Even if their voice was heard, many participants felt the real difficulty was going beyond being heard and being taken seriously. The first sub-category of discordance is called the “Cry

Wolf' Paradox because of the various situations participants described in which they were not taken seriously by those around them.

The second sub-category within the larger framework of discordance is that of Stigma. The stigmatizing effects of many diseases have been well discussed in the literature (Scambler, 1984), although not in terms of young adults with CIBD. For this group, there appears to be a very specific concern about stigma first because of their age and second because of the nature of a chronic, inflammatory bowel disease. Participants noted that there is a difference between an ill older person and an ill adolescent or young adult, the differences including the level of activity expected of young adults in comparison to older adults as well as the devastating effects that social limitations can have on young adults. CIBD is also of concern in relation to stigma because it is, after all, a bowel disease that has many uncomfortable and socially repelling symptoms. These include frequent diarrhea, loss of bowel control, flatulence, inability to eat, exhaustion, and severe and unpredictable pain, among others. The stigmatizing effects of these conditions will be discussed in reference to the participants' experiences with them.

The final sub-category described under the heading of discordance is that of social expectations. Social expectations are the expectations that people in general have of chronically ill individuals. These expectations are described by the participants in this study in terms of their applicability to individuals with CIBD. However, upon close examination, the concerns raised by the participants do not appear to be limited to one

single experience with one illness. People in general have expectations of sick people, regardless of the specific condition. The difficulties noted by participants in this study tended to involve the lack of visibility that is common with CIBD. Their concern that unless it was a visible disease, no one would know they were ill and would have the same expectations of them as they would for a healthy person, even though they were incapable of meeting these expectations. Participants also noted the types of behaviors expected of them, especially in regard to their attitude toward the illness itself. Two main characteristic attributions, that of the “heroic sufferer” and that of the “constant complainer,” will be discussed in terms of the expectations required of each.

Cry Wolf Paradox. Perhaps one of the most salient themes that occurred through the course of the interviews in this study was that of the difficulty participants experienced in trying to be heard and believed by adults, especially family members and medical professionals. For many participants, stories of vain efforts to be taken seriously were common, particularly during the early stages of the illness before the initial diagnosis was made. This sub-category was named the Cry Wolf Paradox because of the similarity in the stories of the participants to the popular fable. In each case, the story is of a child who is not believed by those who are in authority. The difference, of course, is that in the fable, the mischievous and ill-fated little boy who cried wolf did so to attract attention to himself so that he would have some companionship. In the case of the participants in this study,

the cry was simply an effort to find some sort of reason for their pain. The paradox exists in that while the participants felt truly ill, they had difficulty in making others believe them, and when they finally did find someone who would listen, they were dismissed as malingerers and complainers. Participants recalled having feelings of powerlessness in the face of adult authority, feelings that ultimately made them feel like liars and whiners. These feelings carried on into their later experiences as young adults with CIBD, making them examine the validity of their disease.

The most common problem youths faced in the time between the onset of symptoms and the initial diagnosis was the non-specificity of their symptoms. Stomach pain before school was commonly noted by participants as one of the early symptoms they experienced. Of course, with such a non-specific symptom, it was difficult to get anyone to believe their story and they would be sent to school regardless of their pain, which adults and siblings would disregard as malingering. One participant, a twenty-five year old university student, recalled having a particularly difficult time with her family and physicians, all of whom, she recalled, dismissed her symptoms as simply "...adolescence." Obviously, this was not actually the case, but despite continued symptoms and a decline in her general health, those around her, including school staff, continued to disregard her. Eventually, after months of trying different physicians, she was diagnosed through a process of elimination as various medications were tried and disregarded and replaced with different medications. The participant noted the frustration and stress she felt as a

relatively helpless player in her own health care. Another twenty-three year old male participant recalled being told by his physician that he would "...grow out of it." These participant's poor health was devalued as adolescent angst, ultimately resulting in a worsening of their conditions.

The primary difficulty in diagnosing CIBD, as previously noted, lies in the non-specific nature of the symptoms. There is also the added difficulty in that the symptoms are similar to those often associated with psychological dysfunction. For example, loss of appetite, weight loss, exhaustion and fatigue are symptoms both of CIBD and of different eating disorders according to the criteria described in the Diagnostic and Statistical Manual of Mental Disorders (Fourth Edition) (DSM-IV) (American Psychiatric Association, 1994). Non-specific stomach pain, diarrhea, nausea and vomiting are all symptoms of CIBD and are also indicators of factitious disorders, also according to DSM-IV classifications. The difficulty in making a diagnosis is compounded by the transitory inflammatory nature of the illness. While it might be active at one point, by the time the individual with the symptoms undergoes objective biophysical testing, the disease activity could be so low as to be undetectable by most commonly used diagnostic tests. Thus, physicians cannot be held accountable for the lack of quick diagnoses in most individual cases. However, the participants in this study tended to feel that psychiatric labels were too quickly applied to them, often before any type of diagnostic test, biophysical or psychological, had been attempted.

One male participant, a nineteen year old high school student with Crohn's disease, also had a very difficult time in obtaining verification from others that his symptoms were real and not just an adolescent means of getting out of school. The response that he and his parents received from his pediatrician was that since there did not appear to be any indications of disease from the few tests they had performed, the participant should see a psychiatrist. For this effort in relative futility, the participant remarked that he would "...never [be] able to forgive the doctors... 'cause they thought it was in my head." This participant recalled the humiliation he felt in having to see a psychiatrist when he knew that the pain he felt was real.

This participant went on to indicate that this experience with the psychiatrist led him to believe that maybe his illness was in his head. As a result, he tried to stop complaining of pain and tried to live with the pain under the assumption that he was somehow creating it himself. As the pain continued and his dietary intake decreased, the participant recalled becoming very depressed to the point of becoming suicidal. Eventually, he and his parents forced the issue and demanded a diagnosis, which was then quick in arriving. The participant looked back at this whole experience during the course of the interview and stated: "I felt very hurt. I don't like to cry 'Poor Me' but as I said, I felt very hurt [because] of what they did to me."

This participant's story was not unique among the interviews. Other participants had experienced similar situations along their paths to initial diagnosis as well as

throughout their experiences with CIBD. Participants told of being sent to see psychiatrists and psychologists to get to the bottom of their problems while others were offered medical advice ranging from cutting down on caffeine intake to increasing the amount of bran in the diet. While no-doubt there was some validity to some of these suggestions, the off-hand manner in which the participants recalled such advice being delivered emphasizes the difficulty these individuals with CIBD had in getting support from those around them.

Many participants recalled having significant difficulty being believed by teachers and school administrators. Given that school is a central area in a young adult's life, the implications of not being taken seriously, even in the presence of a physicians certificate, are numerous. The added concern of missed time due to the illness appeared to be the primary issue that caused participants difficulties at school. One participant, a twenty-five year old male, noted some very difficult experiences at the post-secondary vocational institution he attended. In his case, no accommodations were made for the time he missed due to his illness, despite the fact that he completed most of the work necessary for the courses. Eventually, he dropped out of that program and enrolled in another at a different institution that made allowances for his illness, including a freedom to miss time from class as long as he could do the work and write tests. The participant, who suffered a fairly severe flare-up during his tenure in the first program, recalled the high levels of stress caused not only by the demands of the program itself but also by the reluctance of the

administration to make any accommodations for him: “It was all this stress, all this stuff going on that really set me back...”

Again, stories such as this one were not uncommon in the other interviews.

Another participant, a twenty-three year old male university student, recalled his experiences throughout high school as being “...horrible...” He remembered having to ask for permission to use the washroom and on one occasion, having to run out of class due to the urgency of his need to get to the washroom. He was punished for leaving the room despite his teacher’s order not to and as a result did not return to the class for the rest of the semester. This participant stated that he was not in control over this situation. He felt like he was at the mercy of not only the teacher and the school administration, but also of his illness. He summarized his feelings of powerlessness in this comment from his interview: “Crohn’s does run your life. You run your life around a bathroom.”

The issue of powerlessness, enhanced by the young age of the individuals involved and the non-specificity of the symptoms of CIBD, is further complicated by relative anonymity of CIBD itself. Many participants felt that even after an initial diagnosis, they had a difficult time in convincing others that they were indeed ill because no one seemed to know what Crohn’s disease or ulcerative colitis were. People who the participants tried to tell about their illness frequently responded by asking if CIBD was like an eating disorder or like Irritable Bowel Syndrome (IBS), a non-inflammatory, non-chronic syndrome that also affects the bowel. Many participants responded to the open-ended

question regarding the most important topic they felt that was discussed throughout the interview and the question asking them if there was anything else that they would like to add to the interview by stating the need for public awareness and education about CIBD. Their frustration of not being believed by not only those around them but also by society in general is indicated in their desire for more people to become aware of CIBD. However, many participants also stated outside of the context of the interviews that they felt that the promotional campaigns initiated by the CCFC were helpful in this regard, particularly the television advertisements and the affiliation of the CCFC with one of Canada's professional baseball teams.

The lack of visibility and understanding of what exactly CIBD is made it difficult for participants to make others understand their specific cases. Others would look at the participants as different and as "sick people." As a result, the participants would often feel as though they did not fit in with those around them, including peers and family. These feelings of mis-fit, coupled with the actual physical differences that were often concomitant with the disease, are the underlying concepts that define the next sub-category, Stigma.

Stigma. Stigma has been noted to be a concern for individuals who suffer from chronic illnesses (Scambler, 1984). As noted earlier in this discussion, the stigmatizing nature of an illness such as CIBD can be amplified by the age of the individual and by the

socially undesirable symptoms of the illness itself. Stigma, in terms of the present study, refers to the stories participants told of their feelings of not fitting in and seeming somehow different from others who do not have chronic illnesses. These stories were quite common throughout the interviews and indicated that individuals with CIBD frequently feel stigmatized even though their illness is neither obvious or contagious, two of the conditions that are typical of stigmatizing behaviors.

Participants related their CIBD to stigma in two primary ways. The first was through the disease and its undesirable symptomology, such as diarrhea, weight loss, flatulence, loss of bowel control, among others. The second relationship existed between people's perceptions of the various effects of CIBD treatments such as steroid treatment and elemental diet feedings. In both situations, the participants felt that they stood out from others in some way, usually in a negative context. And in most cases, the same participants did not want to feel different. The stigma associated with CIBD was related to how the participants viewed themselves and their identity. One nineteen year old participant summarized the perceptions of many participants by saying "I wish I was like other people - Why do I have this [CIBD]?"

In terms of the typical symptomology of CIBD, many participants felt that while their symptoms could be hidden, they sometimes could not keep them hidden from their peers. A twenty-five year old female participant, whose stronger symptoms included frequent and urgent bouts of diarrhea, indicated the fear inherent in having such a

condition. When asked if she ever compared herself to others who do not have CIBD, she responded “Sure, all the time. Even before, I mean I was only diagnosed two years ago, but I look back now and say ‘God, I never ever had to worry about where the next bathroom was.’ I never had to worry about ‘Oh God, am I going to mess myself if I do this?’ or, y’know, it just...I guess the whole thing is you base your whole life around where the next bathroom is right now. I never had to do that before.” Such comments regarding the uncontrollability of the occurrence of pollution and other distressing symptoms added to the participant’s impression that they are in some ways markedly different from everyone else.

These feelings of being different leads to feelings of anger and jealousy. One participants said that she was “...very jealous of people who are not sick,” sentiments echoed by other participants who, upon comparing themselves to healthy people, found themselves to be lacking in many respects. These feelings of inferiority can be seen as being related to the stigma of being sick and in the case of CIBD, being sick with a bowel disease. The stories the participants told indicated that such a stigma had a powerful effect on their identity in that they felt devalued by others and as a result, they were forced to examine their sense of who they were and who others perceived they were. The stigma, however, typically went beyond the effects of the disease itself.

More distressing to many of the participants than the undesirable symptoms of the CIBD were the invasive treatments that are so frequently prescribed for the disease.

While the individuals were fully aware of the necessity and efficacy of the treatments, they nonetheless felt that the very visible treatments led to increased stigmatization of them and their illness. The two most frequently mentioned stigmatizing treatments were steroid treatment and elemental diet. The most visible side effects of steroid treatments include facial mooning (a “fattening” of the facial area), acne, sweating, facial and body hair increases, and weight gain. Elemental diet is delivered via a small pump linking a pouch of fluid to an Ng tube that is taped to the individual’s face. Both of these treatments, then, can be seen as being quite invasive on the individual’s personal appearance.

The visible signals of steroids and elemental diet treatment were noted by some participants as being the most problematic concerns of their experiences with CIBD. Public reaction to these treatments was frequently noted as being quite negative. A twenty-three year old participant put it this way: “The Crohn’s created a very bad self-image of myself because I got big from the steroids and I didn’t like what I looked like and I still don’t like what I look like.” While many participants were in junior high school when they were starting to undergo these treatments, participants felt that comments such as being called a “...tube-nosed freak...” went beyond simple adolescent name-calling. Individuals recalled being unwilling to attend or being completely left out of various social and athletic events, leading to feelings of isolation. Such situations, of course, increased the participant’s sense of being stigmatized because of their illness.

The issues surrounding the stigma associated with CIBD tend to revolve around the physical symptoms and treatments that are commonly affiliated with the illness. A few participants, however, noted the stigmatization of the psychosocial aspects of the illness. The common perception of the individual with CIBD, according to some participants, is that of a “cry baby” who use their “pseudo-illness” to get what they want. However, this stigma is somewhat different from the two previously discussed in that it is a preconceived notion of what the sick person should be like whereas the other two are generally a “knee-jerk” reaction to someone who looks or acts in an unconventional manner. Stigma associated with perceptions of the behavior of an individual with CIBD is related more to social expectations than it is to an instant reaction to something unfamiliar. Stigma and social expectations, while intertwined with one another, are conceived of separately in this study because the stories the participants told tended to separate the two into distinct categories, specifically, their experiences with stigma were not made less salient if the theme of social expectations was missing from their story or vice-versa. The sub-category of social expectations will be discussed in the following section.

Social Expectations. There are numerous expectations that are placed upon people with any number of health problems and those who have chronic conditions are, of course, no different. Young adults who have CIBD frequently have a fairly healthy appearance and are difficult to recognize as having a chronic illness. As such, the

demands of society on individuals who suffer from CIBD can vary considerably. In the interview group, the stories concerned with social expectations ranged from none at all to very positive and/or very negative experiences.

Social expectations could best be defined as the roles society expects of individuals in different situations. For example, the social expectations of a religious leader include such demands as high moral character, honesty, and wisdom. Of course, these types of expectations are not and cannot always be met. The participants in the present study identified two main expectations that they had encountered in their experiences with CIBD. The first was that of the “constant complainer,” or the expectation that individuals with CIBD are difficult people to deal with because they never stop whining about their pain and fatigue. The other type of expectation was that of the “heroic sufferer,” a “Movie-of-the-Week” -type role that identifies the person with CIBD as someone who “keeps a stiff upper lip” and triumphs over the illness through sheer force of will. Participants discussed the difficulty they experienced in attempting to live up to these expectations that, justly or not, had been placed on them.

The role of the constant complainer was described by participants as a very difficult expectation to deal with. The perceptions of the participants indicated that this idea of the whining person with CIBD is common and, unfortunately, validated by many individuals who take advantage of others by using their CIBD as an instrument of manipulation. One participant who admitted to using CIBD to get out of various

responsibilities stated that while using CIBD in such a way, he was quite aware of the perceptions that people have of individuals with CIBD. He explained that he used CIBD only when necessary and admitted that his use of his illness was "...awful, in a way, 'cause it stereotypes others who have it." Other participants who used their illness to get attention or to escape responsibility were generally aware of the stereotype they were contributing to, but felt that they were owed some benefits from having to live with a chronic illness.

In the case of the expectation of the constant complainer, participants felt that their role was to not live up to this expectation but rather to live it down. Frustration was commonly expressed by participants who felt that having this role forced upon them did little for their health. The conundrum associated with this type of expectation is that regardless of the validity of the existence of disease activity, any mention of pain or requirements for accommodations will be perceived as being complaints and as griping. There is little the ill individual can do short of not mentioning his/her distress and suffering quietly.

The issues surrounding the expectation of the constant complainer include the individual's perception of self. Participants commented on the fact that the more they were told to stop complaining because it was all in their head, the more they felt like they were perhaps making more of the illness than there was. One twenty year old male participant who had Crohn's disease recalled thinking that he might be "crazy" because

he was being told that the pains he felt in his stomach were actually in his head. Other participants noted similar situations in which they were told to stop complaining about their pain. Another twenty-five year old female participant, for example, recalled being chastised by her siblings for “faking” her symptoms in order to get parental attention when she was in junior high school. She recalled being particularly upset when her parents began agreeing with the siblings, leaving her with no option but to lie about the reasons she was unwilling or unable to participate in various tasks. Eventually, she stopped complaining about her Crohn’s symptoms altogether and began to make up excuses for her inability to participate, ranging from allergies to simple fatigue. As this participant grew older, however, she recalled that more people began to believe her as and eventually, she began to feel more comfortable about talking about her pain and other symptoms.

The role of the constant complainer was typified by many of the participants as one of the most difficult aspects of dealing with CIBD in social environments. They felt uncomfortable talking about their illness and, as was the case with the stigma associated with CIBD, the lack of public awareness of the disease made it difficult to explain to others. Participants also felt that the role of the constant complainer was one that would be very difficult to live down without increased public education regarding CIBD, especially in the schools where those who deal with students who have CIBD tended to be unaware of the nature of the disease. Participants felt that this lack of awareness was one of the primary reasons for the problems they faced in school. Participants who noted few

problems in school tended to have went to schools in which the staff and other students were briefed about CIBD and the treatments for the illness. One participant recalled that before she returned to her school, her teacher and classmates had been told exactly what to expect in regards to the illness and the Ng tube and apparatus that the participant would be wearing when she returned to school. This information made her return to the school environment a relatively easy transition, not only for her but also for her peers and teachers.

In the case of this participant, explanations of missed time and unwillingness to participate in various activities were accepted without the negative response that other participants noted. This would appear to be primarily due to the level of information that was available at the school. However, this amount of information is uncommon in the general public and thus, the stereotypical view of the individual with CIBD as the constant complainer tends to linger.

The other expectation of the individual with CIBD, that of the heroic sufferer, was also noted by participants to be somewhat problematic for different reasons. Foremost among these is the relative impossibility of achieving such a lofty expectation. While the role of the constant complainer was one participants appeared to have difficulty living down, the heroic sufferer was one that they had difficulty living up to. The perception underlying the expectation of the heroic sufferer appears to be that a silent chronically ill person is a good chronically ill person. While not raised as frequently in the interviews as

was the expectation of the constant complainer, this theme of the heroic sufferer was considered to be worth mentioning because of the dichotomy it creates for people with CIBD in particular and those with chronic illnesses in general.

Participants recalled situations in which they were expected to live up to this expectation despite, as one participant put it, the “...various forms of agony...” they were in. Regardless of their situation, they would be expected to fit into one of the two major form of expectations. If they said anything about their illness, they were complaining. If they kept silent, then they were seen as dealing well with their illness. The dichotomy created makes it difficult, if not impossible, for individuals with CIBD to find a forum in which they can talk about their experiences with their illness without having to fall within one of these two categories. Without such a forum, their choices are limited. In most cases, participants noted that such a forum could be found in close friends or in family members who, knowing the participant well and also having a knowledge of the disease, would be willing to listen to the participant without enclosing them into one of these expectation types. In these relationships, as in the interview setting provided in this study, participants would be encouraged to feel free to discuss their experiences in their own terms without having to worry about being classified according to these expectations.

Overview of Discordance. Discordance was one of the two major categories drawn from the interviews in this study, the underlying concepts of which were the Cry Wolf Paradox, Stigma, and Social Expectations. Discordance included the stories that did not fit within the defined parameters of the other major theme, that of Identity Structuring. The stories that fell under the discordance category tended to involve the role of the ill individual in society, including the perceptions that others have of ill people. Two of the sub-categories (Cry Wolf Paradox and Stigma) dealt with perceptions that others had of sick people and the effects of their perceptions on individuals' behavior. The expectations that society has of sick people were discussed under the sub-category of Social Expectations. Discordance, in general, can best be described as a means of identifying the feelings that young adults feel when they do not, for one reason or another, appear to fit in with those around them.

General Discussion

In this thesis, an attempt has been made to look at an invasive chronic illness in terms of the ramifications such an illness has on the concept of identity in young adults. CIBD has been described as a painful, unpredictable disease that can have any number of complications and undesirable side-effects. Treatments that presently exist for this illness are often perceived as being as problematic as the illness itself. The implications of such an illness on the lives of young adults have been discussed, primarily in terms of the effects that CIBD can have on an individual's sense of who he/she is, who he/she has been, who he/she will be in the future, and where he/she fits into society.

In terms of identity, the main category of Identity Structuring was derived from the interviews with twenty-one young adults, all of whom have some form of CIBD. The issues they raised within the framework of this category included a progression leading from their perceptions of who they had been, who they were at the time of the interview, and who they felt they would be in the future. The conceptualization of identity status provided by Marcia (1966) can be seen as being very useful in framing the stories related by the participants in terms of their perceptions of identity, particularly in reference to their exploration and commitment to different domains such as vocation, education, family, and so on.

The second major theme derived from the interviews was that of Discordance. Discordance was based on the participant's stories of where they felt they fit in society.

Their feelings of not quite being a full part of society, of mis-fit, can be described in relation to the sub-categories that were elicited from the interviews. These sub-categories, including the “Cry Wolf” Paradox, Stigma, and Social Expectations, allowed participants to describe the reactions that others have had to their illness, as well as their own perceptions of what society expects of them as chronically ill individuals.

These themes, when looked at in tandem, attempt to describe the experiences of young adults with CIBD. While the information gleaned from the interviews cannot be expected to be generalized to all young adults with CIBD, the themes evoked can be seen as a framework into which experiences with similar illnesses can be discussed. Young adults with chronic illnesses other than CIBD, while unique in their own right, are subject to the similar stages of identity development as were the participants in the present study. While the effects of different illnesses are of course unlike those related to CIBD, the process of developing a sense of who one is and dealing with public perceptions of the chronically ill individual can be seen as being common among illness types.

The primary goal of this study has been to define some sort of mechanism which young adults could use to talk about their experiences with their illness. In terms of identity structuring and discordance, a framework was devised that accommodated the stories of individuals with CIBD. The two main categories appear to allow for a comprehensive amount of information that can be seen as being relevant to the illness experience for young adults with CIBD. The identity concerns that face young adults with

CIBD are numerous and complex. However, with such a framework in place, it can be hoped that these young adults will at least have a means of conceptualizing their concerns.

Ultimately, it is their stories that are the foundation of this framework and ultimately, it is they who can benefit most from it. --

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Table 1

Marcia's Identity Statuses

Identity Status	Exploration	Commitment
Identity Achievement	<i>YES</i>	<i>YES</i>
Moratorium	<i>YES</i>	<i>NO</i>
Foreclosure	<i>NO</i>	<i>YES</i>
Identity Diffusion	<i>NO</i>	<i>NO</i>

Table 2**Participant Summary**

Total N	21
Mean Age	22.9
Age Range	17-27
Mean Age at Diagnosis	16.5
Range of Age at Diagnosis	11-18
Mean Length of Time with CIBD (Years)	6.4
Mean Years of Education	15.0
Range of Years of Education	11-18
Males	12
Females	9

Types of CIBD

Frequency of Crohn's Disease (CD)	14
Frequency of Ulcerative Colitis (UC)	3
Frequency of Coexisting CD and UC	3
Frequency of Undifferentiated CIBD	1

Types of Treatments

Frequency of Medication Only	9
Frequency of Surgery Only	0
Frequency of Diet Only	0
Frequency of Combination of Medication, Surgery, and/or Diet	11
Other	1

Table 3

Characteristics of Individual Participants

CIBD Types	Age	Diagnosis Age	Years of Education	Male	Female
CD	22	21	16		X
CD	26	24	16	X	
CD	27	20	17		X
CD	19	17	13		X
CD	27	24	15		X
CD	23	15	16	X	
CD	19	14	12	X	
CD	25	18	14		X
CD	17	12	11	X	
CD	26	12	15	X	
CD	25	13	17	X	
CD	18	9	13		X
CD	25	18	18	X	
UC	19	11	14	X	
UC	22	17	17		X
UC	25	22	16		X
UC	27	22	16	X	
BOTH	25	23	14		X
BOTH	19	12	13		X
BOTH	20	15	14		X
UNDIFF	25	9	17		X

Table 4

Kappa Coefficients*

<u>Category</u>	<u>Kappa Coefficients</u>
Treat	1.0
Diet	1.0
Normal Week	0.78
Compare	1.0
Diff: Family	0.85
Diff: Friends	1.0
Diff: Intimate Relationships	1.0
Diff: Others	1.0
Fun	1.0
Work	0.91
Gender (Interviews 1-13)	1.0
Support: School	0.92
Support: Professional	0.86
Support: Family	1.0
Support: Peers	0.81
Support: Intimate Relationships	1.0
Support: Medical Professionals	0.90
Commit: Career	0.65
Commit: Family	0.75
Commit: Health	0.65
Commit: Education	0.68
Future	0.64

** Kappa coefficients of 0.75 or greater reflect excellent agreement beyond chance, while those between 0.40 and 0.75 represent fair to good agreement beyond chance, with those below 0.40 representing poor agreement beyond chance (Fliess, 1971)*

Table 5

CONTENT ANALYSIS

		(N=21)	
		<u>Frequency</u> <u>Percent</u>	
1.	Treatments for Illness		
	1) Medication only	9	42.9
	2) Elemental diet only	0	0
	3) Surgical interventions only	0	0
	4) Combination	11	52.4
	9) Response unclear/ Not Applicable	1	4.8
2.	Specific diet		
	1) Physician regimented diet	7	33.3
	2) Self regimented diet	11	52.4
	3) No specific diet	3	14.3
	9) Response unclear/ Not Applicable	0	0
3.	Describing a normal week		
	1) CIBD is a significant factor	15	71.4
	2) CIBD is not a significant factor	6	28.6
	9) Response unclear/ Not Applicable	0	0
4.	Compare self to others who do not have CIBD		
	1) In a positive way	3	14.3
	2) In a negative way	13	61.9
	3) Do not compare	5	23.8
	9) Response unclear/ Not Applicable	0	0
5.	A.D) Difference in relationships with family		
	1) Positive changes	10	47.6
	2) Negative changes	6	28.6
	3) No change noted	4	19.0
	9) Response unclear/ Not Applicable	1	4.8

	<u>f</u>	<u>%</u>
A.II) Difference in relationships with friends		
1) Positive changes	9	42.9
2) Negative changes	5	23.8
3) No change noted	6	28.6
9) Response unclear/ Not Applicable	1	4.8
A.III) Difference in intimate relationships		
1) Positive changes	9	42.9
2) Negative changes	1	4.8
3) No change noted	4	19.0
9) Response unclear/ Not Applicable	7	33.3
B) Difference in the way others look at you		
1) Positive changes	4	19.0
2) Negative changes	9	42.9
3) Mixed responses from others	7	33.3
4) No changes noted	1	4.8
9) Response unclear/ Not Applicable	0	0
C) Impact on fun and recreation activities		
1) CIBD has limited recreational activities	15	66.7
2) CIBD has not limited recreational activities	7	33.3
9) Response unclear/ Not Applicable	0	0
D) Impact on work at school/place of employment		
1) Negative impact	13	61.9
2) Positive impact	6	29.6
3) No changes noted	2	9.5
9) Response unclear/ Not Applicable	0	0

	f	%
6. Men and women's reactions to CIBD²		
1) Men handle it better	2	9.5
2) Women handle it better	3	14.3
3) No difference	6	28.6
9) Response unclear/ Not Applicable	10	47.6
7. A) Supports at school		
1) Positive supports noted	10	47.6
2) No support/ negative support noted	10	47.6
3) Not applicable	1	4.8
9) Response unclear	0	0
B) Supports at the workplace		
1) Positive supports noted	9	42.9
2) No support/ negative support noted	4	19.0
3) Not applicable	7	33.3
9) Response unclear	1	4.8
C) Supports from family		
1) Positive supports noted	17	81.0
2) No support/ negative support noted	1	4.8
3) Not applicable	3	14.3
9) Response unclear	0	0
D) Supports from peers		
1) Positive supports noted	18	85.7
2) No support/ negative support noted	0	0
3) Not applicable	3	14.3
9) Response unclear	0	0
E) Supports from intimate relationships		
1) Positive supports noted	10	47.6
2) No support/ negative support noted	0	0
3) Not applicable	10	47.6
9) Response unclear	1	4.8

² This question was deleted from the interview schedule after the fourteenth interview.

F) Supports from medical professionals		f	%
1) Positive supports noted		11	52.4
2) No support/ negative support noted		10	47.6
3) Not applicable		0	0
9) Response unclear		0	0
8) Committed to areas			
1) Career			
high commitment/high thought		14	66.7
high commitment/low thought		4	19.0
low commitment/high thought		2	9.5
low commitment/low thought		1	4.8
no response		0	0
2) Family			
high commitment/high thought		14	66.7
high commitment/low thought		3	14.3
low commitment/high thought		0	0
low commitment/low thought		3	14.3
no response		1	4.8
3) Health Concerns			
high commitment/high thought		15	71.4
high commitment/low thought		0	0
low commitment/high thought		1	4.8
low commitment/low thought		4	19.0
no response		1	4.8
4) Education			
high commitment/high thought		16	76.2
high commitment/low thought		0	0
low commitment/high thought		3	14.3
low commitment and thought		1	4.8
no response		1	4.8

5) Other areas		
Religion	f	%
high commitment/high thought	1	4.8
high commitment/low thought	0	0
low commitment/high thought	0	0
low commitment/low thought	0	0
no response	20	95.2
Self		
high commitment/high thought	1	4.8
high commitment/low thought	0	0
low commitment/high thought	0	0
low commitment/low thought	0	0
no response	20	95.2
Staying Positive		
high commitment/high thought	1	4.8
high commitment/low thought	0	0
low commitment/high thought	0	0
low commitment and thought	0	0
no response	20	95.2
Friends		
high commitment/high thought	1	4.8
high commitment/low thought	0	0
low commitment/high thought	0	0
low commitment/low thought	0	0
no response	20	95.2
9) Vision of the future		
1) CIBD is mentioned in a positive light	19	90.5
2) CIBD is mentioned in a negative light	1	4.8
9) Response unclear/ Not Applicable	1	4.8
10) Anything Else		
Public awareness	6	28.6
Fear of eating	1	4.8
Family history of CIBD	1	4.8
Family support	2	9.5
Frustration with medical professionals	1	4.8
Stress	1	4.8
Support at school	1	4.8
Insurance availability	1	4.8
No response	7	33.3

11) Most important topic in interview	f	%
Need for public education	5	23.8
Reactions of others to CIBD	2	9.5
Need for relaxation	1	4.8
Need for sense of humor	1	4.8
Need for alternative treatments	2	9.5
Necessity of coping skills	1	4.8
Stress	2	9.5
No response	7	33.3

Table 6

CONTENT ANALYSIS BY GENDER

	<u>Females (N=12)</u>		<u>Males (N=9)</u>	
	<u>F</u>	<u>Percent</u>	<u>F</u>	<u>Percent</u>
1. Treatments for Illness				
1) Medication only	5	41.7	5	55.6
2) Elemental diet only	0	0	0	0
3) Surgical interventions only	0	0	0	0
4) Combination	6	50.0	4	44.4
9) Response unclear/ Not Applicable	1	8.3	0	0
2. Specific diet				
1) Physician regimented diet	5	41.7	2	22.2
2) Self regimented diet	5	41.7	6	66.7
3) No specific diet	2	16.7	1	11.1
9) Response unclear/ Not Applicable	0	0	0	0
3. Describing a normal week				
1) CIBD is a significant factor	7	75	6	66.7
2) CIBD is not a significant factor	3	25	3	33.3
9) Response unclear/ Not Applicable	0	0	0	0
4. Compare self to others who do not have CIBD				
1) In a positive way	2	16.7	1	11.1
2) In a negative way	7	58.3	6	66.7
3) Do not compare	3	25	2	22.2
9) Response unclear/ Not Applicable	0	0	0	0
5. A.I) Difference in relationships with family				
1) Positive changes	4	33.3	6	66.7
2) Negative changes	4	33.3	2	22.2
3) No change noted	3	25.0	1	11.1
9) Response unclear/ Not Applicable	1	8.3	0	0

	Females		Males	
	f	%	f	%
A.II) Difference in relationships with friends				
1) Positive changes	5	41.7	4	44.4
2) Negative changes	3	25	2	22.2
3) No change noted	3	25	3	33.3
9) Response unclear/ Not Applicable	1	8.3	0	0
A.III) Difference in intimate relationships				
1) Positive changes	6	50	3	33.3
2) Negative changes	1	8.3	0	0
3) No change noted	2	16.7	2	22.2
9) Response unclear/ Not Applicable	3	25	4	44.4
B) Difference in the way others look at you				
1) Positive changes	0	0	0	0
2) Negative changes	1	8.3	3	33.3
3) Mixed responses from others	6	50	3	33.3
4) No changes noted	4	33.3	3	33.3
9) Response unclear/ Not Applicable	1	8.3	0	0
C) Impact on fun and recreation activities				
1) Recreational activities limited	9	75	5	55.6
2) Recreational activities not limited	3	25	4	44.4
9) Response unclear/ Not Applicable	0	0	0	0
D) Impact on work at school/place of employment				
1) Negative impact	8	66.7	5	55.6
2) Positive impact	3	25.0	4	44.4
3) No changes noted	1	8.3	1	11.1
9) Response unclear/ Not Applicable	0	0	0	0
6. Men and women's reactions to CIBD³				
1) Men handle it better	1	8.3	1	11.1
2) Women handle it better	2	16.7	1	11.1
3) No difference	4	33.3	2	22.2
9) Response unclear/ Not Applicable	5	41.7	5	55.6

	Females		Males	
	f	%	f	%
7. A) Supports at school				
1) Positive supports noted	7	58.3	3	33.3
2) No support/ negative support noted	4	33.3	6	66.7
3) Not applicable	1	8.3	0	0
9) Response unclear	0	0	0	0
B) Supports at the workplace				
1) Positive supports noted	4	33.3	5	55.5
2) No support/ negative support noted	4	33.3	0	0
3) Not applicable	3	25.0	4	44.4
9) Response unclear	1	8.3	0	0
C) Supports from family				
1) Positive supports noted	10	83.3	7	77.8
2) No support/ negative support noted	0	0	0	0
3) Not applicable	2	16.7	1	11.1
9) Response unclear	0	0	0	0
D) Supports from peers				
1) Positive supports noted	10	83.3	8	88.9
2) No support/ negative support noted	0	0	0	0
3) Not applicable	2	16.7	1	11.1
9) Response unclear	0	0	0	0
E) Supports from intimate relationships				
1) Positive supports noted	6	50.0	4	44.4
2) No support/ negative support noted	0	0	0	0
3) Not applicable	6	50.0	3	33.3
9) Response unclear	0	0	1	11.1
F) Supports from medical professionals				
1) Positive supports noted	5	41.7	6	66.7
2) No support/ negative support noted	7	58.3	3	33.3
3) Not applicable	0	0	0	0
9) Response unclear	0	0	0	0

8) Committed to areas	Females		Males	
	f	%	f	%
1) Career				
high commitment/low thought	4	33.3	0	0
high commitment/high thought	7	58.3	7	77.8
low commitment/high thought	1	8.3	1	11.1
no response	0	0	0	0
low commitment/low thought	0	0	1	11.1
2) Family				
high commitment/high thought	9	75.0	4	44.4
high commitment/low thought	1	8.3	3	33.3
low commitment/high thought	1	8.3	0	0
low commitment/low thought	1	8.3	2	22.2
no response	0	0	0	0
3) Health Concerns				
high commitment/high thought	9	75.0	6	66.7
high commitment/low thought	0	0	0	0
low commitment/high thought	0	0	1	11.1
low commitment/low thought	2	16.7	2	22.2
no response	1	8.3	0	0
4) Education				
high commitment/high thought	9	75.0	7	77.8
high commitment/low thought	0	0	0	0
low commitment/high thought	2	16.7	1	11.1
low commitment and thought	0	0	1	11.1
no response	1	8.3	0	0
5) Other areas				
Religion				
high commitment/high thought	1	8.3	0	0
high commitment/low thought	0	0	0	0
low commitment/high thought	0	0	0	0
low commitment/low thought	0	0	0	0
no response	11	91.7	9	100
Self				
high commitment/high thought	0	0	1	11.1
high commitment/low thought	0	0	0	0
low commitment/high thought	0	0	0	0
low commitment/low thought	0	0	0	0

no response	12	100	8	88.9
Staying Positive	f	%	f	%
high commitment/high thought	0	0	1	11.1
high commitment/low thought	0	0	0	0
low commitment/high thought	0	0	0	0
low commitment and thought	0	0	0	0
no response	12	100	8	88.9
Friends				
high commitment/high thought	0	0	1	11.1
high commitment/low thought	0	0	0	0
low commitment/high thought	0	0	0	0
low commitment/low thought	0	0	0	0
no response	12	100	8	88.9
9) Vision of the future				
1) CIBD is mentioned in a positive light	10	83.3	9	100
2) CIBD is mentioned in a negative light	1	8.3	0	0
9) Response unclear/ Not Applicable	1	8.3	0	0

Appendix A. Semi-Structured Interview

1) Could you tell me a bit about yourself?

Prompts How old are you?

Where do you live?

Are you in school?

If yes, what level? If no, what do you do?

What is the highest level you have completed so far?

Who do you consider to be your immediate family?

Who are they?

What do they do?

How old are they?

Where do they live (i.e. Live with you or elsewhere?)?

How long have you had your illness?

What sort of treatments have you had for it?

How often do you have symptoms of CIBD?

Are you on any sort of treatment regimen now?

How well does it work?

Does your disease require hospitalization at times?

Is there anything else that you would like to tell me?

2) How would you describe your normal week?

3) I'm wondering if you ever compare yourself to a person who does not have CIBD (for example, someone who is healthy all the time)?

When do you make these comparisons?

How do you feel about the results of these comparisons?

4) What things about your life are different now from before you were diagnosed with your illness?

Prompts How did your relationships change with your friends, if they did at all?

Did your relationships with your family change?

If yes, in what ways were they different?

Have you found any difference in the way people in general look at you now?

How about the people with whom you were closest?

Has your illness had an impact on your more intimate relationships?

Has your illness affected the things you do for fun and recreation?

How has your illness affected your work at school/place of employment?
Do you think that men and women with CIBD react differently to it?

5) What sort of supports have you found to be available to you at school, at home, with your peers, or with medical professionals?

6) What do you feel that you are committed to at this point in your life?

7) Where do you see yourself in the future, for example, five years from now?

Prompts Where does your illness fit in?

How do you (will you) go about making these decisions about the future?

8) We have talked about a number of things in this interview. What stands out to you as being the most important issue we have discussed? (Suggest identification of illness, changes in relationships, treatments, and so on if the participant cannot name any particular issue).

9) Is there anything else you feel is important that we did not yet discuss? Have you any questions for me?

Appendix B. Advertisement for Participants

**Needed:
Individuals with
Inflammatory Bowel
Disease**

Graduate Psychology Student is conducting interviews with individuals who have IBD (i.e. Crohn's Disease or Colitis).

If you are between the ages of 16-28 and have an IBD and would like to share some of your experiences with the illness, I would like to interview you at your convenience. Please call **Brent Macdonald** at **457-0676** to obtain further information.

This study has met with Ethics Approval from the Mount Saint Vincent University Graduate Education Department

Appendix C. Public Relations Letter

This letter is to inquire about the possibility of placing posters in and around the Camp Hill Medical Centre. These posters are designed to elicit participants for a study on Inflammatory Bowel Disease that I am conducting as part of my Master's thesis in Psychology at Mount Saint Vincent University. My thesis, entitled "Identity concerns for young adults with Chronic Inflammatory Bowel Disease," is being conducted under the supervision of Dr. Cynthia Mathieson, an Assistant Professor at MSVU.

I have included in this package approximately thirty copies of the poster, which has been stamped and approved for posting at MSVU. I have also included a copy of the informed consent form I am using in this study for your own information.

Should you have any questions or concerns about this research, please feel free to contact either myself at 457-0676 or Dr. Mathieson at 457-6599. I thank you again for your time and hope to be in contact with you in the future.

With Thanks,

Brent P. Macdonald

Appendix D. Informed Consent Form

This study is designed to look at the effects of chronic inflammatory bowel disease and how it affects individuals. Participants in this study will be interviewed by Brent P. Macdonald, a graduate student at Mount Saint Vincent University in Halifax, Nova Scotia, under the supervision of his thesis supervisor, Dr. Cynthia Mathieson (Psychology Department, MSVU).

Interviews will be recorded on audio cassette for later transcription into written text. Access to these cassettes and the written texts will be limited to Mr. Macdonald, Dr. Mathieson, and two research assistants who will not be made aware of the identity of the participants. Cassettes will be held by Dr. Mathieson and again, no identifying marks will be made on the cassettes or transcripts themselves. Participants who desire a copy of their taped interview may receive one upon request.

All participants have the option to refuse to answer any question or to discontinue their involvement in this study at any time. If you have any questions or concerns regarding this study, please feel free to contact Brent Macdonald (work - 457-6513; home - 457-0676) or Dr. Mathieson (c/o MSVU Psychology Department, 457-6399). Should you have any concerns or questions at the conclusion of the interview, again feel free to contact Dr. Mathieson. You will be given a copy of this consent form for your records. Should you wish for a summarized form of the results of this study, please provide your address in the space provided below. Thank you very much for participating in this research.

Brent Macdonald

By signing below, I acknowledge that I have read the above statement and agree to participate in the study on chronic inflammatory bowel disease conducted by Brent Macdonald. I understand that I may discontinue my participation at any time I desire and that all confidentiality will be protected.

Signed: _____
 Date: _____
 Researcher's Signature: _____
 Participant's Mailing Address: _____

Portions of various interviews might be used in either written form or in audio form for academic and training purposes. If you are willing to have portions of your interview used for either of these purposes, please indicate by circling one of the choices below:

Written Form Only
 Audio Form Only
 Both Written and Audio Form
 Neither Written nor Audio Form

Participant's Signature: _____
 Researcher's Signature: _____
 Date: _____

Appendix E. Letter of Thanks to Participants and Study Summary

Dear

I just thought that I'd drop you a note (better late than never!) to again thank you for helping me out with my research. Your interview was very helpful and valuable to me and hopefully it was of some value to you as well.

I have concluded my interviews with other young adults who have Inflammatory Bowel Disease. Twenty-one people in all participated and I hope that it was a valuable experience for all. Enclosed is a summarized copy of the results of the study, which was presented at the Annual Convention of the Canadian Psychological Association in June, 1995. As I mentioned during your interview, the study was also part of my thesis at MSVU. Your help was invaluable in helping me complete the thesis.

I hope all is going well for you and that you are in good health. Again, thank you very much for being an active participant in this research. None of it would have been possible without your help.

With Thanks,
Brent Macdonald

Summary of CIBD Study

Hundreds of young adults in Canada are diagnosed with Chronic Inflammatory Bowel Disease (CIBD) each year. Often, diagnoses of CIBD coincide with critical stages of identity development, ranging from late childhood (roughly 7-12 years of age) and adolescence (13-17 years) to young adulthood (18 - mid-20's). Identity development often becomes intertwined with the diagnoses of this chronic, incurable illness, resulting in a necessity for ill individuals to, in some form or another, assimilate this illness into their identity. Through this process of identity development, individuals attempt some sort of reconciliation between the perceptions of who they had been before their diagnoses, who they will be in the future, and the experience of being a chronically ill person as well as society's perceptions of them as chronically ill individuals. Interviews with twenty-one young adults (17-27 years of age) were conducted to examine these issues as well as the feelings of discordance they felt as chronically ill individuals. These semi-structured interviews were designed to allow participants to fully discuss their experiences of living with CIBD. An initial focus of the interviews was the framework of Identity Status proposed by James Marcia (1966, 1988). Narratives provided by the participants delineated numerous themes, primary among which are feelings of discordance inherent in living with CIBD and experiences with identity development.

Appendix F. Coding Sheets

Participant Number _____
Coded By _____
Date of Coding _____
Time to Code _____

For each item, circle the applicable code.

Code 9 if information is MISSING

Code 8 if tape is UNCLEAR

1) TREATMENTS

Code 1 = Medication
 2 = Elemental Diet
 3 = Surgical Interventions
 4 = Combination

2) DIET

Code 1 = Yes, Physician
 2 = Yes, self
 3 = No

3) NORMAL WEEK

Code 1 = CIBD
 2 = No CIBD

4) COMPARE

Code 1 = Yes, Positively
 2 = Yes, Negatively
 3 = No

5) a.i) DIFFERENT: FAMILY

Code 1 = Positive Change
 2 = Negative Change
 3 = No Change

a.ii) DIFFERENT: FRIENDS

Code 1 = Positive Change
 2 = Negative Change
 3 = No Change

a.iii) DIFFERENT: INTIMATE RELATIONSHIPS

Code 1 = Positive Change
 2 = Negative Change
 3 = No Change

5) b) **DIFFERENT: OTHERS**

- Code 1 = Yes, Positively
2 = Yes, Negatively
3 = Yes, Qualified/ Combination
4 = No Difference

5) c) **FUN**

- Code 1 = Limited Activities
2 = No Limits

5) d) **WORK**

- Code 1 = Negative Changes
2 = Positive Changes
3 = No Changes

6) **GENDER**

- Code 1 = Men Handle CIBD Better
2 = Women Handle CIBD Better
3 = No Difference

7) a) **SUPPORT: SCHOOL**

- Code 1 = Positive Support
2 = Negative Support
3 = Not Applicable

b) **SUPPORT: PROFESSIONAL**

- Code 1 = Positive Support
2 = Negative Support
3 = Not Applicable

c) **SUPPORT: FAMILY**

- Code 1 = Positive Support
2 = Negative Support
3 = Not Applicable

d) **SUPPORT: PEERS**

- Code 1 = Positive Support
2 = Negative Support
3 = Not Applicable

e) **SUPPORT: INTIMATE RELATIONSHIPS**

- Code 1 = Positive Support
2 = Negative Support
3 = Not Applicable

f) SUPPORT: MEDICAL PROFESSIONALS

- Code 1 = Positive Support
 2 = Negative Support
 3 = Not Applicable

8) COMMITTED

For this section, score each area with the applicable code. For example, if the participant has thought a lot about health concerns but does not appear to be committed to them, score it as 3 - 2.

AREAS

- 1 = Career
 2 = Family
 3 = Health Concerns
 4 = Education
 5 = Other (Specify)

CODES

- 1 = High thought and commitment
 2 = High thought but low commitment
 3 = Low thought but high commitment
 4 = Low thought and low commitment

Scores:

9) FUTURE

- Code 1 = Positive
 2 = Negative

10) ANYTHING ELSE

11) IMPORTANT

Appendix G. Coding Manual

Code 9 if information is missing

Code 8 if tape is unclear

1) What sort of TREATMENTS have you had for your illness?

Code 1 = Medication

Generally, pharmacological treatments will include steroids (Prednisone, Cortisone), 5-ASA Derivatives (Asacol), Sulphasalazine (Salazopyrine), and others such as Flagyl.

Code 2 = Elemental Diet

This type of treatment is typically delivered via a nasogastric (Ng) tube inserted in the nose and extending into the individual's stomach. Some people also drink high nutrient drinks such as Ensure.

Code 3 = Surgical Interventions

Most common surgeries are resections and ostomies. Any surgical procedure related directly to CIBD activity should be coded.

Code 4 = Combination

This code includes any combination of the first three areas, any treatment not described here, or if no interventions have been attempted at all.

2) Are you, or have you been, on a specific DIET?

Code 1 = Yes, by Physician

Diet is regimented by a physician or a nutritionist. Code this even if only a portion of the participant's entire diet is regimented (i.e. Low salt/sugar diets/ no milk products/ High fiber diets).

Code 2 = Yes, by Self

Most participants in this area will state that they are on a diet that they found to be good for them. Typically, a 'hit-and-miss' approach is utilized in establishing this type of a diet.

Code 3 = No

If the participant says that he/she eats basically the same things as he/she did before becoming ill, use Code 3. If any specific changes are noted (i.e. 'I can't eat chocolate anymore'), use Code 2.

3) How would you describe your NORMAL WEEK?**Code 1 = CIBD**

CIBD is a significant factor in the participant's normal week. This could be a general statement which either includes CIBD or starts with a mention of CIBD and how it fits into a participant's daily life. Participants might start by describing a normal week without CIBD and then compare it to a normal week with CIBD. In such cases, the week with the most description or with the most emphasis will be coded accordingly.

Code 2 = No CIBD

CIBD is not described as being a significant factor in the Participant's normal week.

4) Do you ever COMPARE yourself to a person who does not have CIBD?**Code 1 = Yes, Positively**

This code applies to participants who do compare themselves to others in a favorable light. For example, "In a way, I guess I'm better than them because I've experienced a lot," or "I'm more aware of my health."

Code 2 = Yes, Negatively

Participants compare themselves to healthy individuals with a sense of envy or feelings of inferiority. For example, "I wish I could be like them," or "My body is not as good as other people's."

Code 3 = No

Often, participants might say "No, not really" when asked this question, only to go on and compare themselves anyway. This should be coded 1 or 2 depending on the quality of their comparison. Code 3 implies that they have not and do not compare themselves to healthy individuals.

***** Some participants might respond both positively and negatively to this question. In such cases, code the response that seems to you to be the more overriding or salient theme for the participant.

5) *What things about your life are different now from when before you were diagnosed with your illness?*

a.i) RELATIONSHIPS WITH FAMILY

Code 1 = Positive Change

Participant feels that CIBD has improved relationships within his/her family - OR - any improvement in familial relationships are a direct result of the CIBD.

Code 2 = Negative Change

Participant feels that CIBD has caused problems in his/her family. Responses will vary, but should include problems in communicating about the illness, feelings of isolation, fear, and so on.

Code 3 = No Change

Participant notes that his/her diagnoses with CIBD has had no impact on familial relationships. If the participant notes any change, it should be coded as 1 or 2.

a.ii) Same as a.i, but substituting **FRIENDS** for **FAMILY**.

a.iii) Same as a.i, but substituting **INTIMATE RELATIONSHIPS** for **FAMILY**.

5) b) *Have you found any DIFFERENCE in the way that other people look at you?*

Code 1 = Yes, Positive

Participants note that other people look at them in a more positive light . For example, "People tend to respect me because I've done so well in spite of my illness," or "They see me as being more understanding and compassionate."

Code 2 = Yes, Negative

Participants in this category will generally note some sort of feelings of stigma or negative reactions to their illness. For example, "I think

that they see me as being diseased or sickly," "The illness has made me undesirable," or "Other people tend to shy away from me because I look so sick."

Code 3 = Yes, Qualified or Combined

General responses in this category will include such phrases as "Well, I get different responses," or "It depends on the person." However, if the participant goes on to describe these further, Code 1 or 2 depending on the quality of the response (positive or negative).

Code 4 = No Change

This category will have responses that suggest that the participant feels that CIBD does not influence how others look at them.

5) c) Has your illness had an impact on the things you do for FUN and recreation?

Code 1 = Limited Activities

CIBD has caused the participant to alter fun/recreational activities. For example, "I can't do all the things I used to," "I don't have the energy to play sports anymore," or "It's difficult to be active when you can't wander more than fifty meters from a washroom."

Code 2 = No Limits

CIBD has not limited the participant from engaging in his/her average activities at the usual level. This category should include people who were not active in the first place, before they became ill. No limits implies no change. Examples: "It hasn't stopped me from doing anything I'd done before" or "It didn't really do much anyway."

5) d) Has your illness affected your WORK at school or place of employment?

Code 1 = Negative Changes

Participant notes problems at school/work that are directly related to CIBD. This includes lost time due to illness, lack of motivation/energy,

lack of understanding from teachers/employers/staff, decreased productivity, and so on.

Code 2 = Positive Changes

Participant feels that CIBD has resulted in a better working atmosphere, increased quality of work, more motivation, improved relationships with teachers/employers/staff, and other positive changes.

Code 3 = No Change

CIBD has not had an impact on the participant's vocational/academic progress.

6) Do you think that men and women with CIBD react differently to it? (GENDER)

Code 1 = Men handle it better than women

Participant feels that men tend to have better coping techniques or tend to be more communicative about CIBD, resulting in their being able to deal with the illness in a healthier, more efficient manner than females.

Code 2 = Women handle it better than men

Same as Code 1, but with women being better able to deal with CIBD than men.

Code 3 = No difference

Participant feels that neither sex handles CIBD significantly better than the other. If the participant suggests that one sex might handle it a bit better than the other, code it as 1 or 2. If they say they don't know or that they hadn't really thought about it, code 3.

7) What sort of SUPPORTS, if any, have you found to be available and useful to you?

a) SCHOOL - includes accommodations from staff, guidance counselors, administration, general understanding of the illness, other social supports.

b) PROFESSIONAL - support at the workplace, including part time and summer jobs. Employer accommodations, time off without repercussions, and so on would be positive supports.

c) FAMILY - Family actively engaged in information seeking or advocacy on participant's behalf, ease of communication about the illness, and so on.

d) PEERS - (Fellow employees or students) Adaptations made to accommodate participants into social activities, general understanding of the participant's needs and limits and so on).

e) INTIMATE RELATIONSHIPS - Basically the same as 7)d) but in respect to much closer relationships and more significant adaptations and understanding.

f) MEDICAL PROFESSIONALS - Includes all medical professionals, from family physicians and nurses to Gastroenterologists and nutritionists. Information will likely be seen as the major source of support from this group, although understanding, physical supports, emotional support, and so on will likely become apparent through the interviews.

Codes

Code 1 = Positive Support

Easily accessed supports of the types outlined above.

Code 2 = Negative Support

No support available or very difficult to access.

Code 3 = Not Applicable

Participant did not search for such supports.

8) What do you feel you are COMMITTED to at this point in your life?

Basically, this question is designed to gauge how much thought an individual has put into certain areas such as vocation, education, family, and so on. Look for the amount/quality of thought put into each of these areas by the participant as well as the areas which the participant mentions.

Codes**AREAS**

- 1 = Career
- 2 = Family
- 3 = Health Concerns
- 4 = Education
- 5 = Other (Specify)

Code 1 = High level of thought and commitment to these areas

Code 2 = High level of thought, but relatively low commitment to the areas.

Code 3 = Low level of thought put into the areas, but the participant is nonetheless committed to them.

Code 4 = Low level of thought put into each of the areas and little indication of a commitment to them.

***** Generally, levels of thought and commitment will be fairly self-evident. If not, code according to your impressions resulting from the rest of the interview. You must code this section.

9) *Where do you see yourself in the FUTURE, for example, five years from now?*

Code 1 - Positive

CIBD is mentioned in a positive/hopeful light. For example, "I don't think that it will be very important for me," "There might be a cure by then," or "I hope to be in remission."

Code 2 - Negative

CIBD is mentioned in a negative light. Participants might feel that their illness will hold them back in many ways. Participants might also mention that their view of the future is limited to daily living. Examples: "I just take it day-to-day," "My future is tomorrow," or "I'll have a hard time, especially if I want a family."

10) Is there ANYTHING ELSE that I didn't mention that you would like to talk about?

No codes, simply enumerate the participant's responses in the order they are mentioned.

11) What stands out to you as being the most IMPORTANT thing we have talked about in this interview?

No codes, simply enumerate the participant's responses in the order in which they appear.

Appendix H. Grounded Theory Progression

Open Categories

- Previous illness experiences
- Initial diagnosis
- Reasons for “getting” CIBD
- Examining previous lifestyle

- Assimilation of CIBD into lifestyle
- Understanding of the illness
- Making lifestyle accommodations
- Daily coping with CIBD

- Frustration of inability to attain goals determined before CIBD

- Future framed by illness trajectory
- Trajectory unclear

- Adolescent’s role in medical realm
- Power issues
- Malingering
- Identification of psychopathology

- Feelings of mis-fit
- Physical differences
- Invasiveness of treatments

- Living up to other’s expectations
- The “Heroic Sufferer
- The “Constant Complainer”
- Role Expectations

Axial Categories

- Life Before CIBD*
- “Who was I?”

- Life With CIBD*
- “Who am I now?”

- Re-Negotiation*
- “How does CIBD change who I am?”

- Life After CIBD*
- “Who will I be in the future?”

- Cry Wolf Paradox* “Can my voice be heard?”

- Stigma* “Why can’t I fit in?”

- Social Expectations* “What is expected of me now?”

Main Categories

IDENTITY STRUCTURING

IDENTITY STRUCTURING

IDENTITY STRUCTURING

IDENTITY STRUCTURING

DISCORDANCE

DISCORDANCE

DISCORDANCE