

LIFE EXPERIENCES OF YOUNG ADULTS WITH A CHRONIC ILLNESS: AN
ANALYSES OF CROHN'S DISEASE AND COLITIS

by

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ABSTRACT

What is the experience like for young adults living with Crohn's disease or colitis? This question provided the focus for interviews and written narratives of 10 participants in a study exploring the perceptions of, responses to, and management of the life experience of living with an illness. Qualitative approaches to research, involving phenomenological principles, guided the study. A synopsis of each individual participant's interview and written narrative comprise a large part of the body of the thesis. Eight themes, established from the interviews and written narratives of all participants, describe the essence of the phenomenon.

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CHAPTER ONE

Introduction

The purpose of this study was to examine how young adults make sense of the influences Crohn's disease or colitis have had on their lives. This project investigated young adults' perceptions of, responses to, and management of the life experience of living with an illness. The value of this study is in understanding the experience of young adults coping with chronic illness from their own perspective. The main thrust of this study was to contribute to the understanding of chronic illness variables, in particular those involved with having Crohn's disease or colitis, and how these variables are experienced by young adults.

Crohn's disease and colitis are grouped under the heading of Inflammatory Bowel Disease. They are both chronic illnesses that affect the intestines. Colitis attacks the inner lining of the large bowel while Crohn's disease (also known as Ileitis) is characterized by inflammation which penetrates the entire thickness of the bowel wall, usually in the small intestinal area. It may attack at any point of the gastrointestinal system from mouth to anus (Steinhausen & Kies, 1982).

The signs and symptoms of Inflammatory Bowel Disease are as follows: a) bloody diarrhea; b) abdominal pain; c) weight loss; d) fever; e) fatigue; and f) malnutrition.

Onset often occurs during adolescence, a time when the physical and emotional impact can be devastating as sexual and physical growth are often delayed (Steinhausen & Kies, 1982). The cause of these illnesses is, at the present time, unknown and no specific treatment is effective for all people who suffer from them (Steinhausen & Kies, 1982). The primary treatments involve several different types of drugs (Salazopyrin, a sulpha drug; Imuran, an immunosuppressive; 5-Aminosalicylic acid, and various types of steroid based drugs) and different types of surgeries (bowel resections, where a piece of intestine is surgically removed; ileostomies, where the body's fluid wastes from the smaller intestine are emptied through a surgically prepared opening in the skin on the front of the abdomen, and the material collects into a bag which is attached to the skin by means of special adhesives; or colostomies, which is similar to an ileostomy but the surgical procedure involves the large bowel). Persons with Crohn's disease or colitis may also face frequent hospitalization because of the consequences of inflammation (i.e. fistulas).

Colitis was first discovered and diagnosed in 1905 and Crohn's disease in 1932. Prevalence figures for Canada are estimated at 110,000. Two-thousand new cases are diagnosed each year (Asakura, Tsuchiya, Aiso, Watanabe, Kobayashi, Hire, Ando, Takata, & Sekiguchi, 1982).

Persons with Crohn's disease or colitis have approximately one chance in ten of having other cases of

these illnesses among their blood relatives. The conditions may skip generations or may appear in successive generations (Asakura et al., 1982). Past research (Ben-Sira, 1982) has found a negative correlation between age and chronic disease indicating that young adults have fewer chances than older adults of being chronically ill. However, this finding does not appear to hold true for Crohn's disease or colitis. These illnesses strike most frequently between the ages of 15 and 29 (Asakura et al., 1982). Thirty percent of all people visiting their doctors suffer from a digestive tract related disease. People with gastrointestinal diseases occupy more hospital beds than all people with cardiovascular and respiratory diseases (Asakura et al., 1982).

Inflammatory Bowel Disease is believed not to be an emotional disorder. Crohn's disease and colitis have not been found to be caused by stress or anxiety and are not restricted to certain personality types (Asakura et al., 1982). In the past, Crohn's disease and colitis have been investigated largely from the perspective that these two illnesses were caused by emotional and psychological disturbances (Arapakis, Lyketsos, Gerolymatos, Richardson, & Lyketsos, 1986; Castelnova-Tedesco, 1966; Freyberger, Kunsebeck, Lempa, Wellmann, & Avenarius, 1985). However, in the last two decades it has been realized that there is no stereotypical personality which is disposed to the development of Crohn's disease or colitis (Arapakis et al.,

1986; Mendeloff, Monk, Siegal, & Lilienfeld, 1970; Monk, Mendeloff, Siegel, & Lilienfeld, 1969). Previous psychological research on Crohn's disease and colitis has centered around attempting to find psychogenic causes for the illnesses (Arapakis et al., 1986; Castelnova-Tedesco, 1966; Freyberger et al., 1985). With very mixed results and many assumptions and over-generalizations along with recent advances in medical research in the area of these chronic illnesses, the psychogenic label has been discredited.

Though many attempts were made, links between psychogenic factors as a cause of Crohn's disease and colitis have never been established. Arapakis et al. (1986) in comparing people with colitis and irritable bowel syndrome, found individuals in both groups to be less dominant than the control group, have more tendencies to react to frustration by directing anger and blame toward themselves, be more anxious and more depressed than the control group. However, no characteristic modes of behaviour and thought predisposing people with colitis to the development of their illness were found. The finding that people with colitis scored higher on anxiety and depression is of limited usefulness because it does not take into account how illness symptoms interact in creating an individual with higher anxiety and depression. Therefore, a more holistic picture of how chronic illness symptoms interact with a person's psychosocial development is very important. Arapakis et al. (1986) over-generalized their

findings by implying that the finding of low dominance in people with colitis may reflect the activation of a psychosomatic factor which led to the symptoms of the illness. They also found a high level of intropunitiveness, characterized by the tendency to react to frustration by directing anger and blame toward oneself, the internally focused emotions often being experienced as guilt or shame, which they thought predicted the presence of neurotic symptoms confirmed by their findings of elevated anxiety and depression of these groups. However, they admit that their data do not clarify whether it is associated with the same dynamics underlying the primary disease process, or if it is reactive to the psychosocial impact of the primary disease (Arapakis et al., 1986).

Freyberger et al. (1985), commenting on some previous psycho-therapeutic findings with regards to people with Crohn's disease, suggested that people with the disease show a disruption in both affective and cognitive processes. They also refer to four people with the illness who have been treated within one of their research projects. They found that the people with Crohn's disease had relatively undifferentiated emotions and their thinking tended to dwell on the mundane. The authors concluded that these personality traits caused the disease. No research was conducted to see whether these traits were prevalent before the chronic illness onset or if they only appeared after.

Monk et al. (1969), in an epidemiological study, found no important personality differences between people with colitis and a control group. Individuals hospitalized with colitis were interviewed and compared with a sample of the general population and with a group of people with "irritable colon," who were interviewed in the same way. Individuals with colitis did not differ from the comparison groups. The large proportion of Jewish people in the colitis group was the most distinctive characteristic of this group. The higher number of Jewish people might be accounted for by genetic factors. Mendeloff et al. (1970) replicated these findings. Esler and Goulston (1973) also found that people with colitis did not differ along personality dimensions from a control group of people with general medical problems.

Daniels, O'Connor, Karush, Moses, Flood, and Lepore (1962) treated 57 people with Colitis with psychotherapy. They compared them with 138 people with colitis not receiving psychotherapy. When compared on life adjustment in family and career, those who received psychotherapy were generally higher in adjustment scores. However, the number of sessions did not correlate with the improvement or worsening of actual bodily symptoms. The changes were found to be psychological in nature, not physical. In another study, evaluations of the effectiveness of psychotherapy in the treatment of people with colitis showed that counselling had demonstrated favourable effects emotionally, but once

again, not physically, in contrast to a control group which changed hardly at all in any respect (O'Connor, Daniels, Flood, Karush, Moses, & Stern, 1964). Those who underwent ileostomy for relief of colitis symptoms showed an improved change in their body image as a result of psychotherapy (Druss, O'Connor, & Stern, 1972).

Although results were mixed on whether Crohn's disease and colitis were psychosomatic illnesses, some studies automatically assumed that these chronic illnesses fell under this label when selecting their participants. Taylor and Doody (1985) studied monodic speech samples obtained from 20 psycho-neurotic and 20 so-called psychosomatic persons, using selected Thematic Apperception Test cards, and different methods of content analysis. The individuals assumed to be psychosomatic were 10 people with Crohn's disease and 10 people with colitis. It appears important to recognize that generalizations were made to a psychosomatic population from a sample that has been shown to not be psychosomatic. Other aspects of Crohn's disease and colitis have been studied: Fishler and Fogel (1973) studied 25 children who had ulcerative colitis, and matched controls. Scores on the Bell Adjustment and Maslow Security-Insecurity Inventories revealed no difference between these groups.

A recognition of the need for different research approaches to understand these illnesses resulted in Alberts and Lyons (1988) study on colitis. These researchers implemented research practices with a framework of trying to

find helpful coping strategies for individuals with this disease. The relationship of illness variables (demographic, illness quality, treatment, lifestyle and interpersonal) to the eight coping styles as measured by the Millon Behavioural Health Inventory were investigated in 38 adults with colitis for the purpose of identifying coping styles important in managing the condition. Another inference drawn from the results is the support given findings of Monk, et al. (1970) and Mendeloff, et al. (1970), that no characteristic personality is representative of people with colitis. The participants did not demonstrate a particular character profile. The possibility that psychological treatment could result in a more adaptive coping style was discussed.

Psychological Aspects of Crohn's Disease and Colitis

Any severe illness in a young adult represents a crisis (Pless & Pinkerton, 1975). The nature and extent of disruption accompanying an illness will often vary according to the age at which it occurs. Either the illness itself or restrictions imposed by its management may interfere with functioning and disrupt development and normal living. Chronic illness is frequently associated with ongoing problems. The young adult's adjustment will be affected by a number of factors that, separately or together, may occur during the course of an illness.

Some illnesses require periods of restricted mobility or isolation from familiar people and surroundings.

Steinhauer, Mushin, and Rae-Grant (1982) commenting on some findings with regards to people with a variety of chronic illnesses, suggested that a young adult with a chronic illness may withdraw into fantasy as a means of coping, this tendency being enhanced by isolation. This may lead to an escalation of unrealistic expectations regarding the illness and management (Steinhauer et al., 1982).

Recent writers suggest that it is during the initial period that the stress is high and psychological assistance may be required (Geist, 1979). Generally speaking, the more debilitating the illness and the poorer the prognosis, the greater the stress on the person. A serious chronic illness, especially if the clinical course is one of relentless progression, is bound to produce terrible stress for the person. If the illness is active in young adulthood the person will experience a great sense of depression when they are forced by the illness to scale down their hopes and expectations. If the illness is clearly visible and frequently elicits reactions of disgust or aversion from others (e.g., scarring from surgeries), the continued confrontation with the discomfort of others may prove a serious blow to the person (Steinhauer et al., 1982). Some illnesses require a program of management and restrictions, such as Crohn's disease and colitis with its frequent medications, dietary restrictions, and regular testing (Steinhauer et al., 1982). These programs of management and restrictions can cause anger and frustration.

Upward mobility in work can be seriously limited by a chronic illness (Steinhauer et al., 1982). A person is often faced with having to take time off of work when their illness acts up. Also their performance at work may be hindered by their illness.

In estimating the costs of an illness, the hidden dollars-and-cents cost must be considered (e.g., medications, special diets, etc.) (Kalnins, Churchill, & Terry, 1980). For people with limited income, these expenses may be a major source of additional pressure. To relieve some of this pressure, people may make the dangerous decision of denying that they need the medications.

To some extent, all people react with denial to the shock of their illness. Denial is probably never completely abandoned, certainly not at any single time. Persistent denial in the face of illness interferes with the person's ability to deal with their illness, thus perpetuating the crisis precipitated by the illness.

Depression is a stage in their coming to terms with the implications of their disease. Some people learn to accept the illness and its consequences for their life. Others never do so, and their life may be dominated by their unresolved depression (Steinhauer et al., 1982). Perhaps half of the grief suffered from painful illnesses is psychological (Pawl, 1979).

Persistent abdominal pain is a symptom often experienced by those with Crohn's disease or colitis. When

faced with continual pain, even the most hearty and stable mind can falter. Those afflicted lose some of their ability to respond to their environment. They may concentrate less on interpersonal relationships than on the pain itself. Relationships then become irritating rather than joyful. Routine activities become harder and may be neglected (Pawl, 1979).

In a chronic illness, where a painful process becomes overwhelming for whatever reason, the person so afflicted may initially lose her or his enthusiasm for life. As the grief is drawn-out over days, weeks or months, the sufferer may become withdrawn, moody, irritable and eventually depressed to the point where life's goals and responsibilities may be deserted. The psychological components of the person's pain problem need as much attention therapeutically as the organic portion (Pawl, 1979). A young adult's response to pain varies with how that pain is perceived (Nover, 1973).

Pain caused by the young adult's illness may produce irritability. This trait may present additional pressures and may result in feelings of guilt, and inadequacy in the person. If pain is bad enough and lasts long enough it ultimately wears people down (Steinhauer et al., 1982).

Persons with Crohn's disease or colitis are likely to be anemic and protein deficient. This can make them tired and listless. They may find dealing with life tasks a huge burden.

These illnesses often cause a person to restrict their diet to the point of avoiding solid foods. Prolonged periods on liquid diets or on intravenous feeding can be associated with depression. Depression can be another emotional symptom commonly found among those with a chronic illness (Steinhauer et al., 1982).

Diarrhea is a common symptom of these diseases. When diarrhea is severe it often continues through the night and hinders proper sleep patterns. Without sufficient sleep a person's alertness and behaviour can be affected (Steinhauer et al., 1982).

Certain forms of medication may affect the young adult's alertness and behaviour (e.g. steroids). Occasionally headaches occur with certain drug treatments and irritability may result (Steinhauer et al., 1982). Persons affected by steroids can become depressed.

Along with various drug treatments, Crohn's disease and colitis can require frequent hospitalization, painful procedures, and repeated surgery, which can present particular difficulties for young adults. Hospitalization requires the individual to be away from family and friends for prolonged periods of time. For the person who has to have surgery it can be devastating (Steinhauer et al., 1982).

Factors Mediating Psychological Adjustment

A strong network of family and friends may ease the physical and emotional burden of day-to-day living for the

chronically ill person (Steinhauer et al., 1982). Successful management of the emotional aspects of chronic illness is based on a recognition that illness in a person will have major implications on mental health and relationships. The more people have resolved their emotional issues, the better they will be able to meet their physical and needs and to deal successfully with the additional strains imposed by illness with minimal damage and disruption to their lives. Only when people have received a clear and definitive diagnosis can they begin to deal first with the necessary practical planning and later with the arduous but no less important task of emotionally accepting the inevitable (Steinhauer et al., 1982).

The professional who recognizes the potential for disruption that a chronic illness can produce can do much to minimize the destructive effects and to aid in the reintegration and adaption of the person (Steinhauer et al., 1982). People may need honest and repeated explanations of their diagnosis, progress, and prognosis, and time to digest this information. It may prove helpful for professionals to be simple and direct, avoiding unwarranted optimism or excessive pessimism. Timing may also be important.

Ongoing contact with the person allows various professionals to explore the person's understanding of the illness and help deal with emotional reactions to it. By asking how the person sees her or himself and the illness, the person can be encouraged to raise concerns. Those people

who understand and can perceive accurately the nature of the disease, its symptoms and prognosis, and who can discuss these directly will greatly safeguard their adjustment. An increasing number of authors support discussion of even the most painful feelings related to illness (Geist, 1979). One study involving people with cancer showed that those who talked most about their illness were the ones who were least depressed (Geist, 1979). What is openly acknowledged is generally less threatening than that which is known but not discussed (Steinhauer et al., 1982). Some people may need active encouragement to express feelings that have been held in but are tearing them apart.

Throughout hospitalization, the person should be encouraged to keep in contact with friends, either through visits or by mail. Embarrassment or shame because of the illness may contribute to an alienation from peers who, given proper encouragement, could be a major source of support for the person (Steinhauer et al., 1982). Alienation from others can slow the ability of that person to adjust emotionally to their illness situation.

In making important decisions, some people need help to recognize and weigh the facts of the situation, and reassurance and encouragement once a decision has been made (Steinhauer et al., 1982). A counsellor can be extremely helpful to the person (Steinhauer et al., 1982). If a person must continue with steroid therapy and psychological

distress is a problem, it may be necessary to seek professional counselling.

In circumstances involving surgery it is important to try and find a balance between not alarming the person unduly and yet still offering some psychological preparation. Support and encouragement should be offered to people, if possible. The psychological preparation for surgery should begin well ahead of the event in order to better cope.

The term coping has often been used to describe the processes by which people attempt to adjust to stress. Coping is seen as having two main components, intrapsychic mechanisms, and behaviour (Ray, Lindop, & Gibson, 1982). More current theories of stress and coping describe coping behaviour as goal directed and responsive to stress. Coping is presumably elicited when the individual cognitively appraises a situation as posing threat, harm, loss or challenge. Appropriately selected coping strategies may help to buffer the individual under stress from emotional breakdown or maladjustment (Felton, Revenson, & Hinrichsen, 1987). Lazarus (1981) proposes that the particular kinds of coping behaviours which people use are determined by both personal characteristics and those of their social environment, and, most importantly, by the nature of the stress with which they are dealing and which they have dealt with in the past. Health-related stressors, particularly those seen as requiring acceptance (i.e., chronic

illnesses), were found by Lazarus to have a significantly higher likelihood to prompt emotion-focused coping (i.e. strategies directed at reducing the emotional distress prompted by the problematic situation), rather than strategies directed at altering the source of the stress itself. Depending on the definition of coping used and on the nature of the illness studied, research has found typical coping strategies of individuals suffering from chronic disease to include: denial, selective ignoring, information seeking, taking refuge in activity, avoidance, reminiscence about former good times, learning specific illness-related procedures, blaming others and seeking comfort from others (Cohen & Lazarus, 1979; Weisman & Worden, 1976). These studies have provided valuable descriptions of the types of coping strategies employed by individuals when faced with illness.

Although contemporary developmental psychology has highlighted the importance of age as a dynamic interaction variable, differences attributable to age with regards to Crohn's disease and colitis have not been the target of research. During the life span, a person is faced with many developmental tasks and life transitions. The change from high school into post-secondary education or the work force is one major life transition. Young adults must leave behind adolescent roles and status often along with the physical, social, and emotional support of home. In exchange, they take on new academic or work pressures, personal

responsibilities, and social networks (Astin, 1968; Newcomb, 1964) as well as relationships of intimacy (Erikson, 1963).

Bronfenbrenner (1979) viewed the transitions during development as involving the adaption to progressively broadening spheres of influence. The individual brings her or his own strength and style to each transition and thus individuality has an active impact on the nature of the adjustment that is made. Individuals actively mediate stress to achieve their own adaption. The factor of concern in the present research was that of young adults' life experiences adapting to a chronic illness.

The present research was concerned with these young adult experiences. Young adulthood is an especially interesting and potentially significant period of development for the investigation of life experiences with a chronic illness. Young adulthood involves a number of transitions, including those from high school to college, university, or work, and from living with parents to living independently (Compas, Davis, and Forsyth, 1985).

Young adulthood is frequently described as a period of development during which dramatic life changes and transitions occur. A chronic illness may make demands that exceed a young adult's resources. Having to deal with a chronic illness may by far exceed the bounds of a normal course of life - it may be a factor which imposes upon an individual, demands which are perceived as overwhelming (Ben-Sira, 1982).

The potentially damaging characteristics of chronic illness - and particularly the uncertainty of its prognosis, namely, the continually accompanying hazard of the unpredictable development of more occurrences impose new demands upon the chronically ill person. The individual has to cope with burdens, which are often accompanied by stigma and the continuing fear of further episodes. These burdens have the capacity of depriving individuals of some of the control over their lives (Ben-Sira, 1982). The impact of chronic illness on psychological adjustment can be profound (Felton et al., 1987).

The value of the proposed study is in learning to understand the experience of young adults coping with chronic illness. With 2,000 new cases being diagnosed each year, it is quite probable that professionals within the health field and related occupations will come across an individual attempting to live with one of these chronic illnesses. To understand how one can be more helpful in aiding individuals with a chronic illness, health professionals need to first understand how people experience their lives in relation to their disease.

Qualitative methods were the design of choice for this research. If we are to support and help young adults' in their efforts to deal with chronic illness, then there is a need to understand more fully the unfolding effects of illness. However, looking at chronic illness in a vacuum may result in irrelevant findings.

The purpose of this study was to understand more fully the experiences identified by young adults dealing with a chronic illness, to uncover more of the processes in living with an illness as meaningfully experienced by them. To achieve these purposes, qualitative methodology and procedures were chosen for this study. Qualitative methodologies are indispensable when attempting to understand a person's world - meanings, feelings, motivations - which must be brought forth through the participant's subjective point of view (Schwartz & Jacobs, 1979).

To understand the experience of a young adult living life with a chronic illness, it is especially necessary to explore their reality. Such exploration requires a specific kind of qualitative research methodology: the phenomenological inquiry. This kind of examination leads to an understanding of an individual's experiences. My rationale for choosing phenomenology as the approach for my inquiry was its appropriateness to address my research question. Merleau-Ponty's (1956) definition of phenomenology as the study of essences, and my core issue, to understand the elements of a particular real-life experience, are in accord with one another.

Outline of study

This study chose a phenomenological method to explore lived-experiences of young adults dealing with Crohn's disease and colitis. My presentation of the information from this inquiry is in the form of descriptions of the underlying themes of the experience. To this end I formulated one core research question. This question, "What is the experience of living with Crohn's disease or colitis?", was designed to elicit a body of transcribed interviews and written narratives from young adults from which I could systematically uncover the basic themes of the phenomenon.

In Chapter II, a description of the nature of this study is presented, including references to literature concerning the methodology selected, some history regarding the conception of this study and the procedures utilized to complete the research. Summaries of each individual participant's lived-experience, referred to as "situated structures" (Karlsson, 1993), are presented as Chapter III. These summaries, while shortened from the original transcribed interviews and written narratives, remain, in large part, verbatim accounts. Chapter IV contains the common underlying themes delineated from all the participant's transcribed interviews and written narratives that describe the experiences of living with Crohn's disease or colitis. These themes are referred to as the "general

structure" (Karlsson, 1993). Finally, in Chapter V, a discussion of the themes is presented. Relevant literature is incorporated in this discussion. Ways that counsellors may contribute to the emotional health of young adults with Crohn's disease or colitis is also offered.

CHAPTER TWO

Research Methods

In this chapter, a description of the nature of this study is given. Along with this description, references to writings connected with the methodology chosen will be supplied. Some accounts of the formation of this investigation, the limitations of the method, my own presuppositions prior to the research, a description of the participants, and the procedures used to complete the study will be presented. Included in the presentation of the procedures will be a description of the way the written narratives and interviews were used. Procedures used in the data analysis and the construction of the presentations of individual participants' experiences will also be explained. Examples from the data will be provided in order to show the steps involved in the particular methodology used.

Gerhardt (1990) points out that as more people are living with chronic illnesses, it becomes increasingly important to understand the social and psychological aspects of chronic illness. She suggests that because the quality of life of people with chronic illnesses is very central to health care, psychosocial research in the area has grown in importance. There has been increasing recognition on the part of physicians and others involved in the welfare of individuals with a chronic illness, such as epilepsy, that the illness may be less disabling than their psychosocial

outcomes (Scambler & Hopkins, 1989). Some researchers (e.g. Armstrong, 1990) note that a qualitative method is necessary to explore the very personal life experienced outcomes of living with a chronic illness. I also believe that qualitative research was best suited for studying and understanding a person's perceptions of their illness. Qualitative accounts of illness provide incredible depth and insight into the experience of illness not readily available through other means (Murphy, 1987). For a researcher to study the experience of chronic illness, she or he needs to focus on the experience of people with illness. Study of illness must consider people's everyday lives living with and in spite of illness. A methodological analysis undertaken by Shontz (1982) showed that improvement in knowledge, gained from research, requires investigators to be more careful about considering and including the experiences of chronically ill participants. The lack of this type of consideration is one of the primary reasons why so little knowledge gained from research in psychology is directly applicable in counselling practice (Shontz, 1982).

One way that may help to improve research is to include the chronically ill participants in the investigative process wherever possible. A way to do this is to treat such persons not as subjects but as equal participants in the research enterprise or as consultants who are experts regarding their own conditions and experiences (Shontz, 1982). Inquiry that involves a mutual cooperative

relationship between researcher and participant is the preferred method of study. Based on the belief that research involving a mutually cooperative relationship would be important for this study, participants were seen as equals in the investigation and as authorities on their life experiences. The participants were included in the research as much as possible. A thorough explanation of the nature of the study was provided as an orientation to the research. The decision to make this in-depth description of the proposed study was based on my view that in collaborative inquiry, participants need to be aware of the researcher's thinking. None of the research agenda was kept hidden from the participant.

In this line of research that deals with an individual's experience with chronic illness, my view is consistent with the perspective taken within phenomenology that it is important that I saw my participants as partners as opposed to patients (passive recipients of care). This view is important because people who are sick spend only a fraction of time in their patient role. While being a patient may be an important aspect of being ill, it is by no means the only one nor necessarily the most important. One needs to study how people manage their illness in their everyday lives. The intent of this study of chronic illness was to transcribe interviews and written narratives of young adults with Crohn's disease or colitis, and then analyze them, in order to understand their experience.

The primary aim of phenomenological inquiry is illumination and understanding (Sandelowski, 1986). The value of a phenomenological investigation lies in the discovery of human experiences as they are lived and perceived by participants, rather than in supporting preconceived ideas regarding those experiences. The value of this research method is participant-oriented rather than researcher-defined (Sandelowski, 1986). Such methodology is useful in providing information with respect to phenomena about which little is really known (Polkinghorne, 1983; Sandelowski, 1986).

Phenomenological research emphasizes the individual and subjective experience. Phenomenology studies what the experience of being in one's life is like (Tesch, 1990). It is the systematic investigation of subjectivity (Bullington & Karlson, 1984). The aim of phenomenology is to study the world as it appears to the participants (Tesch, 1990). The value of a phenomenological study is measured in terms of its power to let us come to an understanding of the participant's experience (Langeveld, 1983). Phenomenological research illuminates human experiences by describing the essence of the subjective experience (Tesch, 1990). According to van Manen (1984), the method of phenomenology can be reduced to four key interrelated procedures:

- 1) turning to a phenomenon which seriously interests us;
- 2) investigating experience;

- 3) reflecting on themes which characterize the phenomenon; and
- 4) describing the phenomenon through the art of writing and rewriting. (p. 18)

Limitations and Evaluation of the Method

The limitations of qualitative design need to be considered when looking at this study. The external validity of qualitative research, that is, the degree to which the findings can be generalized to the population from which the participants were drawn, may be considered a limitation. Qualitative research depends on human participants with clear stories to tell, but the validity of its findings can be threatened by overgeneralizing those stories or not placing them in their proper perspective. Guba and Lincoln (1981) suggest that fittingness be the criterion against which the applicability or transferability of a qualitative research project be evaluated. Transferability may be thought of as parallel to external validity or generalizability. A study meets the criterion of fittingness or transferability when its findings can adapt to contexts outside the study situation and when its audience views its findings as meaningful in terms of their own experiences (Guba & Lincoln, 1989). In addition, it is important that the findings of the study "fit" the data from which they are derived (Sandelowski, 1986). One of the major criteria for establishing the degree of transferability or "fit" involves the presence of thick description. What the researcher does

is to supply comprehensive data in order to facilitate transferability judgements on the part of others who may want to apply the study to their own situations, or situations in which they have an interest (Guba & Lincoln, 1989).

The value of this qualitative research resided in the discovery of human phenomena or experiences as they were lived and perceived by the participants. Therefore the value is participant-oriented rather than researcher defined. Guba and Lincoln (1981) suggest that credibility be the criteria against which the value of qualitative research be evaluated. A qualitative study is credible when it presents descriptions of a lived experience that the people having the experience would immediately recognize as their own. A study is also credible when other people (other researchers or readers) can recognize the experience when they encounter it after having only read about it in a study (Psathas, 1973).

The retrospective approach predominates in this investigation of Crohn's disease and colitis. This approach relied on interviews and written narratives. How accurately people remember the past event and its relative significance to them at the time it occurred may be considered a limitation (Jenkins, Hurst, & Rose, 1979). Another limitation stems from the nature of the interview process. The flexibility, adaptability, and close human interaction acknowledge subjectivity and possible bias.

This qualitative research emphasized the meaningfulness of findings achieved by reducing the distance between investigator and participant. The interview was regarded as a way of giving the subjective situation greater clarity. Interviewing was used as a strategy for documenting accounts of lived experiences. Oakley (1981) suggests that the formulation of the interviewer's job is more useful when it becomes a data-collecting instrument for those whose lives are being researched rather than a data-collecting instrument for researchers. Such a reformulation is enhanced where the interviewer allows for close human interaction (Oakley, 1981).

Dexter (1956) looked at the pretense of neutrality on the interviewer's part and found it to be counterproductive and felt that participation requires alliance. Selltiz, Yahoo, Deutsch, and Cook (1965) suggest that much of what we call interviewer bias can more accurately be described as interviewer differences, which are inherent in the fact that interviewers are human beings creating some form of personal connection with participants, and not machines that work identically. Oakley (1981) proposes that personal connection is more than interviewer bias - it is the condition under which people come to know each other and to admit others into their lives and is fundamental in creating meaningful research.

Guba and Lincoln (1981) suggest that confirmability be one the criteria for meaningfulness of findings in

qualitative research. Confirmability is achieved when value and applicability is established (Sandelowski, 1986). A specific strategy used for ensuring the value and applicability, as well as the fittingness or transferability, and credibility of this qualitative study was that of using two different data collection procedures to determine the congruence of the findings.

One strong recommendation made more and more often in studies, whether quantitative or qualitative, is that more than one way of gathering data be used whenever possible (Gorden, 1980). This use of more than one information gathering technique, to cross-check or supplement the other, is often referred to as triangulation. Lather (1986) states that triangulation is critical in establishing data credibility. With the belief that triangulation is essential if data are to be deemed credible, this study employed interviews, and written narratives, authored by the young adults, as two different information gathering techniques. The transcriptions of interviews and written narratives were initially analyzed separately. The beginning stage involved reading them until I had a satisfactory comprehension in order to proceed with the next level of the analysis. The analysis continued by dividing the interview protocol and written narrative into smaller units. At this point they were still treated as separate data. Each unit was then analyzed and transformed in relation to the entire interview protocol or written narrative. It was after this point that

they were cross-checked with one another in order to establish that the reports were reliable. Once the interview and written narrative data were judged as dependable they were combined.

Guba and Lincoln (1981) propose that auditability be another one of the criterion of rigor or merit for qualitative findings. A study and its findings are auditable when another researcher can clearly follow the path used by the investigator in the study (Sandelowski, 1986).

Auditability is achieved when the researcher leaves a clear path concerning the study from its beginnings to its end.

Auditability was specifically achieved in this study by describing, explaining, or justifying: 1) how the participants were included in the study and how they were approached, 2) how the data were collected, 3) the setting in which the data were collected, 4) how the data were reduced or transformed for analysis, and presentation, and 5) the specific technique used to determine the value and applicability of the data. Despite some possible limitations, I think that the present study may be considered as an important contribution to the understanding of the factors that are involved in the life experiences of young adults with Crohn's disease or colitis.

My Own Assumptions: Presuppositions Prior to the Research

My own experience of chronic illness, in retrospect and in the present, seems to have moved through several turning points, which usually have included some shedding of old feelings, thoughts, and behaviours and a taking on of different perceptions. A variety of change, in my life, in my relationships, and within myself has been one of my ongoing experiences. These changes generally created a new awareness of life. During these changes, having at least one nurturing relationship has been crucial. Discovering a sense of intimacy has been critical, because I have at times experienced feelings of alienation due to various aspects of having Crohn's disease. Each change caused wholly or in part by my chronic illness brings new meaning to life through my own integration of the event and support and affirmation by a significant other.

That this experience is one that young adults with a chronic illness live through has been confirmed through encountering a growing number of persons with Crohn's disease and colitis who relate many of the same type of stories. Meetings with these young adults have consistently been experiences for me of great learning. While each story I listened to was rich in its uniqueness, I wondered if there might be a number of common threads that would emerge clearly if such stories were explored in a more systematic way.

One experience of which I had become aware related to a lowering of self-esteem. Some people with Crohn's disease or colitis, including myself, seemed to experience dramatic shifts in feelings about self. I wondered if a lowering of self-esteem was one of the common experiences of living with these illnesses.

The key assumption underlying my research is that, regardless of the unique factors that shape the experience of individual young adults with a chronic illness, some invariant themes will ultimately characterize the essence of the experience. It is this assumption that serves largely as a foundation for my commitment to pursue a phenomenological study of young adults with chronic illness.

Participants

Participants were selected because they could illuminate the phenomenon being studied. A volunteer sample was made up of 20 to 25-year-old young adult females and males who had been diagnosed with Crohn's disease or colitis at least six months prior to participation in the study. Participants were able to converse and write in English. A final sample size of ten participants was determined by an interplay between theme saturation (when no significantly new patterns in interview responses, and written narratives emerged), and the time that was available to run the study.

I initially planned to study the experience of adolescents, made up of 17, 18, and 19-year-olds. However, I

had difficulty in obtaining participants. I do not think this was due to a lesser prevalence of Crohn's disease or colitis in this age group, but rather, to the possible discomfort adolescents may experience in talking about their illness.

Procedures

Participants were recruited through notices posted in several gastroenterology clinics throughout the lower mainland (see Appendix A). The participants were the only source of data for my study and were seen as partners in the investigative process. Two different data collection techniques were used, unstructured in-depth interviews, and written narratives. The recruitment and assessment of suitability occurred first, over the phone, then appointments were arranged.

Written narratives. Before the interview, participants were sent a booklet of blank paper to write a narrative involving their experience regarding Crohn's disease or colitis. The participant was asked to bring the completed written narrative to the interview appointment. It dealt with the individual's experience by focusing on a written life history. In this analysis written narratives as life stories-autobiographies-of young adults with Crohn's disease or colitis were considered as purposely constructed accounts of life experiences affected by their illness. Narratives are a construction of an individual's social world (Rafoth &

Rubin, 1988). Written narratives can be defined as writing in which words are sequentially organized, as the summary of experiences in the order in which they are believed to have occurred (Labov, 1972).

Writing a narrative can shift one's attitude to life from their movement in it towards their reflection on it. To write a narrative is to unfold one's life (Young, 1987). The sequential and summary character of narrative fosters a view of life as informed by significant incidents (Natanson, 1970).

Ricoeur (1980) suggested that every narrative combines two dimensions in various amounts, one chronological and the other non-chronological. The chronological characterizes the story as made out of events. The non-chronological is the creation of patterned significant wholes out of scattered events.

Alexander (1988) believes that the richest sources of data are those which deal with the recollection from memory of various aspects of life already lived, as in a written narrative. People generally find it easier and less threatening to describe recollections of incidents and events involving the critical times in their lives than to respond to evaluative questions concerning those same events. Therefore, to develop a deeper understanding of a participant's life it is preferable to work from data in which the individual is describing people, places, and incidents that seem to be the significant memories of that

experience. In this study I was particularly interested in the use of written narrative as a means of understanding how young adults make sense of the influence Crohn's disease or colitis has had on their lives by incorporating it as part of the larger story of their lives. Influence implies a connection between past events and present or future events.

Interviews. Interviewing is most valuable when the main objective is to understand a person's beliefs, attitudes, values, knowledge, or any other subjective aspects of an individual (Gorden, 1980). There are several distinct advantages to the interview, some which have been outlined by Orlich (1978): the respondent's feelings can be revealed; the respondent is given an opportunity for free expression and; the respondent may express personal information, attitudes, beliefs, and perceptions that might not have been obtained by any other administered instrument. The interviews were conducted individually in one of the rooms of the Counselling Psychology Department at the University of British Columbia. Before the actual interview began, the study was described and volunteers were asked to complete a consent form (see Appendix D). Then they were asked to complete a brief demographic questionnaire which provided me with descriptive information about them (see Appendix E). Once the questionnaire was completed, the interview began. I started the interview with a general orienting statement (see Appendix C). Research interviews should begin with a clear introduction to the participants

(Tolor, 1985). This important process provides information for respondents. Although this type of interview is referred to as unstructured, it is not meant to be a completely unplanned activity. The topic of research that is being explored or measured should be as clearly defined as possible whether a structured or unstructured approach to interviewing is being used.

After the orienting statement the actual interview began. I did not employ a detailed interview guide but had a very general plan. I asked an initial open-ended question i.e., "To begin, perhaps you could tell me a bit about when you were diagnosed as having ____ [participants specific disease (ie. Crohn's or colitis)] ____." This open-ended question was intended partially to focus the participants thoughts toward giving data to meet the primary objectives of the study, but I made sure I allowed them freedom of expression. Open-ended questions encouraged the respondents to compose their own answers (see Appendix F) and allowed respondents to speak freely and at length on the subjects in question (Tolor, 1985). They are valuable to understanding issues and topics. Therefore, the substance and direction of interviews varied with the participant's responses. Body language skills such as eye contact, nodding of head, and open posture was used to help the ongoing development of rapport. The interview lasted between one and two hours, with the total time of all interviews equalling 17.1 hours. The interview was audiotaped.

Phenomenological research emphasizes the meaningfulness of findings achieved by reducing the distance between investigator and participant and by eliminating artificial lines between subjective and objective reality (van Manen, 1984). From the perspective of phenomenological inquiry, scientific objectivity is itself a socially constructed phenomenon that produces the illusion of objectivity. No rules can change the fact that there is no way to study a thing without changing it. However, a possible threat to the value of a phenomenological study lies in the investigator-participant relationship (van Manen, 1984). The credibility of phenomenological research is enhanced when investigators describe and interpret their own behaviour and experiences as researchers in relation to the behaviour and experiences of participants. The possible threat of becoming so enmeshed with participants that investigators have difficulty separating their own experiences from their participants' can be monitored by deliberately focusing on how the researcher influenced and was influenced by a participant (Sandelowski, 1986).

I maintained a process-type diary throughout the project. This diary contained my notations of my ongoing efforts to interpret the data. The process diary did not specifically enter in to the results but rather contained my notations describing my observations about my interactions with participants and decision making regarding the conduct of the study.

Data Analysis

The interviews were audio-taped and subsequently transcribed. The written narratives were collected in booklets. Data collection, analysis, and verification occurred simultaneously throughout the life of this qualitative research project. Analyses emphasized the participant's descriptions of important life events that they feel have been effected by their chronic illness. Data analysis began with the transcription of the interview and the reading of the written narrative. The interviews and written narratives produced 320 transcribed pages. Any reference to the name of the participant was substituted by a pseudonym. Other people's names were substituted by a descriptive word referring to the relationship to the participant.

The analysis of data began in this phenomenological research as soon as the first data were collected. I suspended as much as possible my meanings and interpretations and entered into the world of the unique individual who was interviewed. Some researchers list their own presuppositions in writing, so that it becomes easier to hold them at bay (Tesch, 1990). I also did this, but I remained aware that even then biases cannot be controlled completely. Close attention was paid to the texts, and written narratives, and the details of words in each. I began by analyzing each person's data, and then identified

common themes in all the material until a significant vivid richness occurred.

The method for data analysis used in this study was based on the Empirical Phenomenological Psychological Method (EPP) developed by Karlsson (1993). The results of the EPP-method consist of psychological phenomenological structures. A structure that involves one individual's experiences of the phenomenon is called a "situated structure." A structure that encompasses all the participants' protocols of the phenomenon, included in a study, is called a "general structure."

First I read the entire data set consisting of the participant's transcribed interview and written narrative. Phenomenological reading is more than a casual taking note of the content. The researcher immerses her/himself in the data, reads and rereads, and dwells with the data, so s/he may achieve closeness to them and a sense of the whole (Tesch, 1990). The researcher is open to the text and refrains from imposing any theoretical explanatory model upon it (Karlsson, 1993). It was expected that recurrent themes would begin to emerge that illuminate the central features of the phenomenon. Uncovering a theme (ie. life experiences include feeling a great deal of anger) provided the guiding framework for my interpretation. Within this framework, a process of perceiving themes was ongoing. I remained receptive to this process, so as to be open to the

creation of new meanings that were expected to emerge through the course of the study.

To begin to uncover themes that reveal the core of experience, I read and studied the transcripts and written narratives a number of times. This step contained the discrimination of smaller units. The participants' transcribed interviews and written narratives were divided into units. The transcripts were divided where a shift in meaning was determined. The unit was marked directly on the transcript. A unit division occurs in the following example from a female participant's transcribed interview:

Others around me, in my life, did not quite like my plans to continue on with university and studying again in the fall because of my colitis, and that made me angry because I wanted to and was going to continue in the fall. (34)/But when I started back I realized that I was not going to be able to do it. (35)/

In this example, unit 34 is considered to be describing the situation before this participant started back to university. After unit 34, there occurs a temporal change in the description which is then divided into a new unit. The division is, first and foremost, a practical aid (Karlsson, 1993). Sometimes I divided a very short sentence, if a few words contained important significance to be further analyzed. Although sentences were divided into separate units, the analysis of each unit, which occurs in the next

step, was always done in light of the whole interview or written narrative.

In the next step of analysis, the point was to trace out the psychological meaning that the participant has lived through and described in the interview and written narrative. The analysis of each unit was always interpreted and transformed in relation to the complete interview and written narrative. To provide an example of this transformation process, unit 34, previously shown above, is presented below together with a methodological comment. First the unit is presented followed by an explanation of the unit. The explanation is presented in an indented paragraph. Finally, a methodological comment is presented.

Unit 34. Others around me, in my life, did not quite like my plans to continue on with university and studying again in the fall because of my colitis, and that made me angry because I wanted to and was going to continue in the fall.

This participant, perceives that others do "not quite like" her plan, and she experiences feelings of anger because she wants to continue, despite others' concerns regarding her colitis and the effects continuing may have on it.

Comment: The impression is given that this participant's plans (to continue university) involves a conflict that

causes anger. As the analysis of this unit is understood in the light of her entire transcribed interview and is transformed in relation to her complete interview, this concept of anger is supported in many other units. The angry conflict is between the participant and others' that do not agree with her decisions and would prefer to have her follow their advice.

In the next step the interview and written narrative data were compared in detail. This is essential if data are to be deemed credible. The interview and written narrative data agreed with one another and were combined and integrated as one whole set of data. Then a synthesizing of the transformed data of each participant separately into what Karlsson (1993) terms a "situated structure," presented in the form of a synopsis, took place. When writing the situated structure it is important to check the original transcribed interview and written narrative. It is in this step that I freed myself, somewhat, from the participant's structuring and arranged the units in a phenomenologically significant way. I attempted to find the most suitable form of presentation for each phenomenon. The "situated structure" describes the experiences of each particular participant living with their illness. Here follows an example from the "situated structure" of the female

participant presented earlier. In this example, a comment follows the excerpt:

Janet has decided to still try and do certain things that she really wants to, although many people tell her that she has to live a different lifestyle now that she has colitis. She gets angry when people say that she looks sick and that she's under too much stress. She gets angry when people argue that she needs to stop going to school and working. Janet wants to continue going to university and working. "I am going to no matter what they say. Unfortunately, I don't think I am going to be able to successfully." She gets angry when she hears that others think she is incapable of continuing her activities. However, she too questions her ability to continue in all her life activities.

(Comment: This part deals with the participant's angry conflicts because of her still trying to do certain things that she really wants to, although others tell her that she has to live a different lifestyle now that she has colitis. This segment concerns her strong will to continue in all her life activities, and her feelings of anger towards other people that argue with her and advise her to consider quitting work and school. However, there appears to be a part of her that thinks the others may be partially right).

The final step is a move from the situated structure to what Karlsson (1993) terms the "general structure" (many examples of the same phenomena), which incorporates the themes of a phenomenon which run across several if not all of the situated structures of each participant. I also in this step returned to the raw data. An issue particular to this step, when dealing with themes, is the chance that I may have left out applicable elements from the transcribed interviews and written narratives of all the participants, which could prevent a proper explication of the themes. I made a serious effort to compare the different interviews and written narratives with one another. The analysis that will be presented in the general structure is based on all the data from the 10 participants. The analysis of all the participants together in this last step was presented in terms of different themes representative of the life experiences of young adults with a chronic illness. My goal was to summarize the original stories with sufficient elaboration to review the understanding within the statements of the participants and my interpretation. Here follows an example from the "general structure" involving the theme of anger. The excerpt will be followed by methodological considerations:

Several of the participants experienced angry conflicts because of still trying to do certain things that they really wanted to, although others tell them that they have

to live a different lifestyle now that they have Crohn's disease or colitis. Many of them wanted to continue in all their life activities and had feelings of anger towards other people that argued with them and told them to restrict their activities. Although angry because of being told to limit activity, several participants appeared to think that this was probably necessary "I am going to no matter what they say about having to restrict my activities. Unfortunately, part of me thinks that they're likely right."

When looking at the example from the female participant's "situated structure", presented earlier, the decision about continuing university and work, was understood as involving an angry conflict. Such a translation was felt to be appropriate for this particular participant's transcribed interview and written narrative. When looking at all the other transcripts from this study, nine out of ten of them refer to feeling a great deal of anger. In other words, from the data the theme of "feeling anger" is experienced by young adults living with Crohn's disease and colitis.

Here follows a summary of the different steps of analysis from a methodological point of view. The raw data are transcribed interviews and written narratives describing certain experiences, thoughts, and feelings. Unit 34 from a female participant's transcribed interview, presented

earlier, was explained to mean "that others do 'not quite like' her plan, and she experiences feelings of anger because she wants to continue". The analysis then moved from the description of an experience to an explanation of what this experience meant in light of both this particular female participant's transcribed interview and written narrative.

In the final step, the theme (life experiences include feeling a great deal of anger) is explored. A shift of reflection on each separate participant's transcribed interview and written narrative to all transcripts together is carried out. The theme is considered to see if and how it pertains to all the participants' experiences. This final step of the analysis involves finding out if, in general, for these young adults, the experiences of living with Crohn's disease or colitis includes "feeling a great deal of anger."

Thus, this theme of anger is established at a general level, compared to just one participant's situation. This theme was experienced by nine of the ten participants while the other seven themes were experienced by all ten participants. With this theme of anger, the different steps of analysis have been shown; first tracing out the meaning of experiences, then the generalization of experiences from each individual participant's transcribed interview and written narrative to all the participants' transcribed interviews and written narratives.

CHAPTER THREE

Analysis and Results

The results obtained from the descriptive data are presented in the present chapter. All ten participants' transcribed interviews and written narratives were used in the data. There were 7 women and 3 men. The mean age of participants was 24.2 years.

The first section of this chapter provides what Karlsson (1993) terms a "situated structure," depicted in the framework of a summary of each participant separately. A "situated structure" contains a particular participant's experiences. When working with the situated structure I consistently checked back to the initial transcribed interview and written narrative. It is in this presentation of the results that I released myself, partly, from the participant's arrangement and structured the pieces in a phenomenologically meaningful fashion. I tried to find the most useful method of presentation for each phenomenon. On the following pages are the complete "situated structures" of each participant's combined interview and written narrative. Reflections from the process diary are presented at the end of the chapter.

Janet

Janet is a 23-year-old female with colitis. She was diagnosed at the age of 18. She was receiving anti-inflammatory drug treatment at the time of her participation in this study and had not as yet had surgery for her illness. Janet appraised her own health as poor. She described herself as feeling "sick and weak".

Janet's situation began when she started noticing some symptoms at the age of 16, while attending grade 11. She went to go see her doctor and her doctor told her "to just put a hot water bottle on it and it should go away." So she just lived with it until she began really being affected by symptoms a year later. One of the primary symptoms she suffered from was having to vomit every time she ate. This quickly diminished any desire for food. With Janet's lack of food intake came a severe decrease in energy, and an inability to continue with many of her life tasks.

Janet rapidly lost weight, and with it her energy to participate in enjoyable activities as well as her ability to keep up with everyday responsibilities. "I could no longer do anything, work and especially not play." One of the enjoyable activities that she found she had to say "no" to was socializing with friends, and particularly when it involved food.

With each food that made Janet sick, her diet became more and more restricted, "It was to the point of living off apple juice and crackers." She was feeling extremely sick and so resolved to go see her doctor again. When her doctor saw how thin she had become he decided to send her to a specialist, and this specialist immediately diagnosed her with colitis.

Janet lost weight and along with her weight her "muscle mass vanished." She was no longer able to be as active as she was before, "I lost so much muscle mass, I lost my ability to do anything physical, I couldn't exercise, so that made me feel really, really bad all over, general yucky feeling." During this time she was not feeling good about herself as she was weak, thin, and had no energy for anything.

Janet grieves the "loss" of many of things she can no longer do. She has had to give up many of the activities that she enjoys, "Somebody might phone up, 'let's go skiing' and if I'm not feeling that great I have to say 'no,' I don't really feel like going skiing." She says "no" to these activities because she is afraid of getting sick. "I never know when I'm going to get sick, like really sick, like the time I ended up in the hospital because I was just ridiculously low on blood." At the age of 22 while attending her fourth year of university Janet became anemic, and she was given her first blood transfusion. Having a blood transfusion was "very different" for her and it scared her.

"The transfusions were another thing that was new and scary for me." The transfusions made her realize just how sick she was, and at this point she realized that she "no longer knew what it meant to feel healthy. I was just sick, feeling lousy, and having no energy all the time."

All through Janet's first three years of university she took a full course load although she "was feeling lousy and low on energy." Then she came to a decision for her fourth year to drop down to a lesser load. She thought she could no longer handle the full course load.

"This was a big thing" for Janet because she was no longer going to graduate with her peers. She became close with some of the other students, and now she was giving up graduating with them. She was angry that she had lost the chance to graduate with all her friends, "I was so pissed off at my disease because I wasn't going to graduate when I really wanted to and I was scared that I may never graduate."

Janet is "afraid" of things that she "never felt afraid of before." She "felt very anxious and nervous going to school." "Would I feel okay enough to get to school." She "would get nervous about getting sick" before she made it to class and she remembers "getting anxious at work as well." "I was scared at school and I was scared at work. I'm scared all the time now, in the present, and I'm scared about what my life is to bring me."

Janet becomes scared when she thinks about her future living with colitis, and knows it's going to be different because she has a chronic illness, "You're not going to be young forever, it's going to effect you differently when you get older, your health is no longer the same." She grieves the loss of this good health that she once had before her body was invaded by this chronic illness. "My illness has just taken over and has stopped me from living my regular life, and I really miss my regular life."

It scares Janet when she thinks about her future and how her illness will effect having children, "It worries me. I think when I get older and if I do have kids am I going to get sick ? I don't want to be sick all the time, all my life."

Janet continues to worry about many things that could become a part of her experience living with this sickness. She is troubled by her increased chances of getting cancer from her colitis. Plus being on medicine all the time scares her, and she uncertain whether she is ever going to spend a day without medication. Janet's future is full of uncertainties, "It's scary because I don't know what's going to happen."

Although work was difficult for Janet, as she never knew when she was going to get sick, she did not want to tell anybody there about her illness. She has a hard time telling people about her chronic illness. She doesn't like anyone to know about her disease because she doesn't want

them to think that she's "any different or not capable of doing something." Janet finds that "some people are uncomfortable" finding out that she has colitis and then treat her "differently." Having people "feel anxious" around her makes her "uncomfortable" with herself. She is generally uneasy with talking about her illness. Her discomfort with some people knowing about her disease has stopped her from accepting invitations to various social gatherings. She fears being with people that are uncomfortable knowing about her illness.

Janet points to how her illness frequently elicits discomfort from others, and how this causes a decrease in her self-esteem:

I try so hard to avoid having people find out that I have this illness because it's such a conversation stopper, and it makes people uncomfortable. It also makes me feel real lousy about myself because they're uncomfortable with me and who I am as a person, my disease is part of me, that's just the way it is unfortunately.

She emphasizes how having colitis commonly evokes uneasiness from others, and how this has a huge impact on her self-image.

Janet becomes "angry with people that feel nervous" around her just because she has a chronic illness, and she wonders about the reasons they feel uncomfortable with her. However, she knows the reasons she feels uncomfortable with

them, "One of the reasons I don't like to talk about my disease is because I feel like I become a different person in their eyes. It makes me feel very uncomfortable." She loses her old self in their eyes because they now see her as someone different, and they're not sure how to act around her.

Along with feeling angry about people treating her differently, Janet also becomes angry when people suggest that she somehow brought on her illness. She does not think that she did cause her colitis, "I do not think my personality or emotions caused this, I look back and think 'how could that have been'." She states that she has read that doctors are close to finding a medical cause for Colitis. So, she wonders why others are still trying to make her feel guilty. She gets angry when other people "blame" her for causing her chronic illness. Janet becomes angry when it feels like people are suggesting that she caused her disease, "People say to me "you're under too much stress", and I become defensive because I feel that a bunch of people that I don't even really know are blaming me for causing my disease."

Janet gets angry when people ask her if she's under too much stress at school, and suggest that maybe this is the reason for her having colitis. She states that school hadn't even started when she was feeling sick. She believes strongly that she did not cause her colitis, "I didn't cause my disease, nothing I did could have caused the hell that I

have to go through now." Janet then looks at her life before colitis to see if anything in her past family history could have made her more susceptible to contracting colitis.

However, she feels that "it couldn't have been better, I was basically free of any real stress."

Janet feels safe with the people who don't blame her for causing her disease, and who don't treat her any differently. She feels safe with the people that know all about it and accept it. The people she does feel comfortable with are the people that don't make her feel different.

Janet has decided to still try and do certain things that she really wants to, although many people tell her that she has to live a different lifestyle now that she has colitis. She gets angry when people say that she looks sick and that she's under too much stress. She gets angry when people argue that she needs to stop going to school and working. Janet wants to continue going to university and working. "I am going to no matter what they say.

Unfortunately, I don't think I am going to be able to successfully." She gets angry when she hears that others think she is incapable of continuing her activities.

However, she too questions her ability to continue in all her life activities.

Janet doesn't like a lot of different people knowing about her colitis. "I hate that so many people know about it because then there going to be looking at me differently all the time." She gets angry when one person passes on

information about her condition to others without her consent, and this is one of the main reasons she doesn't like certain people knowing about her chronic illness, "I hate when it seems everyone is talking about my disease with one another without me knowing about it, and then these people come to me with all their inquiring questions."

Janet gets angry when people ask her personal questions about her illness because talking about her colitis causes her "to become very emotional." She doesn't like people to come to visit her in the hospital because then they expect her to tell them all about her illness. She doesn't like getting many visitors at the hospital because she doesn't want people asking her personal questions about her disease. Janet does not like explaining her illness and then be asked why she developed it, "It's just such a hard thing defining it for visitors, and then I don't want them to ask 'why did you get sick, what happened'." "It's like they feel they can encroach on my privacy, and I don't want them to because I've already been invaded too much because of this disease." She associates people's questions about her disease with the violations she has already experienced at the hands of her illness as she indicates:

I've already been through hell because of this disease, and the last thing I need is a bunch of people asking me questions like "are you too stressed out maybe?" I wasn't before this but I sure the hell am now.

Janet continues to discuss the concept of stress and emphasizes that she knows many "people that are stressed out." She questions "why nothing happens to them if stress is a causal factor in colitis." However, she admits that she feels more stress now, since developing colitis and finds this "scary." "I certainly do feel more stress now, to the point of feeling like I am losing control at times."

Janet emphasizes the experience of losing some of the control over one's life when living with colitis. "This damn disease has so much control over my future life." "I am pissed off at the amount of control I feel I've lost to my illness." She ends by stating that she feels a great deal of anger towards her illness because of all the fear, uncertainty, and lack of control it has created in her life.

Anita

Anita is a 25-year-old female with colitis. She was diagnosed at the age of 14. She was receiving steroid treatment at the time of her participation in this study and had bowel resection surgery once for her illness prior to participating. Anita appraised her health at the time of the interview as not good. She described herself as being "sick".

Anita's situation had its beginnings when she was on vacation with her relatives. She was 14-years-old and began having a lot of pain in her stomach area. Her relatives took her to a doctor, and it was determined that she had colitis.

After being diagnosed with colitis Anita found herself spending a great deal of time in the hospital. She was put through many tests and observed for long periods of time. She was also prescribed various medications.

Anita states that it is a different lifestyle growing up and spending so much time in the hospital. She feels like she has never "fully developed as a young adult" because of spending so much of her life "institutionalized". She feels that her life has taken a completely different path than most because of all the time she has spent in hospitals. She states that she is treated differently by others because of having colitis.

When Anita wasn't in the hospital she was in school, and she states that her experiences in school were horrifying. She remembers feeling "very ugly and being hated" by other students because of the visible side effects of her illness and medications. She remembers being treated horribly by others at school because she had a chronic illness. Because of Anita's illness she had to take frequent trips to the bathroom, and this was noticed by other students. They would follow her to the bathroom and then make fun of her.

Anita states that she was treated like a "freak" by other teenagers because of being sick, and they made her feel like "there was definitely something wrong" with her. She felt "attacked" by others her own age and very different in comparison to others her own age. She states that her illness experience set her apart from "normal" children. Anita feels that she is not "normal" because she has this disease.

Anita states that the disease causes "real inhumane and abnormal treatment." She feels that in her experience it isn't so much the illness that is miserable but the situations that she is placed in because of her illness, and the way she is treated in those situations. Although she also states that the colitis itself is miserable and inhumane.

Anita's illness and the treatment of her illness made her feel like an "ugly, sick, girl" that could be treated in any way that others chose. "I never knew when I was going to be sick, rushed off to hospital and put through hell by the medical world." She puts emphasis on these feelings as being very important in her experience.

Anita remembers many horrible images in her experiences living with colitis. She recalls "lots of blood" in her experience of her illness, and she remembers lots of her hair coming out in handfuls. She also remembers her nails coming out of her hands. All of these incidents are caused

either by the disease itself or by the medications given to Anita to control the symptoms of the disease.

This illness causes Anita to feel "very unhappy and very angry" over all the things she is put through because of it. She finds it difficult because she is angry about her colitis but doesn't know who she can be angry at. However, she then goes on to admit that some of her anger is focussed at the doctors for all the tests they put her through.

Anita also feels anger towards herself and her body for having this chronic illness. She is just now realizing that it isn't her fault but still has difficulty erasing the emotional content of this self-blame. She has difficulty with her anger regarding her disease because she still doesn't really know who to be angry at, "But I can't blame anyone, because they were all trying to help me when they put me through those degrading procedures." So at times Anita turns her hostility on herself, and then feels guilty. Guilt is another emotion that she experiences frequently because of this illness. She is angry at the doctors who treat her and then feels guilty because they are only trying to help her, "I hated them and I still do, and then I feel guilty and angry at myself for that hate."

Anita experiences feeling a great deal of anger. She is angry for being hurt by her colitis and she is angry for being humiliated. She is enraged by all the things that her colitis and her doctors put her through and all the medications she has to take to try and control it, "A lot of

the medications they put me on and a lot of the tests they did were pretty unpleasant. I've resented all of them ever since for infringing on my body that way."

Anita emphasizes the violation that she felt while being put through many "degrading tests and procedures." "When I was 15, there were too many incidents to count of how many times doctors shoved things up my rectum. I felt completely stripped of any dignity." For her the disease is inseparable from the "extreme abuse" that she felt from the beginning of her diagnosis, and the control she had to give up over her body.

Anita feels a "total lack of control" over her body and her subsequent body image since being diagnosed with colitis. "Somehow when you're in the hospital your rights to your own body are taken away, and this effects the way you see yourself from then on in." She finds it very hard to talk to anyone about this aspect of her experience as she feels very alone with this part of her illness experience, "I find nothing that matches my experience regarding the destruction of my self-esteem, and how it is so tied in with the violations upon your body that this illness seems to bring about."

Anita also feels a great deal of fear as part of her illness experience. Going out in public is one of the things she, at times, is fearful of and she expresses:

I know it's a bit weird but when I'm not feeling well
I'm scared to go out anywhere because I never know

what's going to happen, and I prefer to just avoid having anything happen. I think it's sad that I have this new fear.

She characterizes her life as being full of fear and full of grieving. "I'm always afraid and I'm always sad for having to be so afraid of lots of situations now. I know I've missed out on a lot because of being afraid." Anita ends by looking back on how much of the excitement of teenage years she lost because of her colitis, and displays a great deal of grief as she does this. "I yearn for my previous world without fear and my healthy body rather than this one that has been taken over by colitis."

William

William is a 25-year-old male with Crohn's disease. He was diagnosed at the age of 14. He was receiving anti-inflammatory drug treatment at the time of his participation in this study and had not had surgery for his illness. William appraised his health at the time of the interview as poor. He described feeling "a pain" in his abdominal region that had been there "consistently for months."

William's situation began when he first felt "exorbitant amounts of stomach discomfort." "Perfectly afraid I was when all these weird things were happening in

my body." "Because of all the pain I was experiencing in my stomach I was unable to continue regularly in school, normal existence was gone." He felt like his life had changed overnight. "This thing had taken over my body, I was sent to the hospital, and nothing was ever going to be the same again."

William's doctor immediately sent him to the hospital. A stomach specialist told his mother that he had Crohn's disease, and then his mother told him. What followed was a series of "painful, scary, and evil tests."

William felt like it wasn't right for him to be living his life in a hospital and undergoing all these procedures.. He was scared of never knowing what was going to happen next or who was going to come and wheel him away for another test. He felt alone in the hospital especially at night time when no one was there to keep him company. When people did come to visit him, he felt like he was "someone for them to feel sorry for." "I was scared and everyone felt sorry for me."

William was "fearful" of his "situation". "I was scared of everything that was happening." He remembers his mother also being very scared. His mother reacted to him differently after he was diagnosed with Crohn's disease, "I got special treatment." "A lot of extra pampering that then turned into overprotection."

William's mother told him not to get angry and to stay calm at all times. "I was supposed to not get upset because

it might bother my stomach." He was unsure how to deal with his feelings when he wasn't supposed to somehow acknowledge them.

After William was diagnosed with Crohn's disease, he remembers being able to get away with "various types of bad behaviour." He recalls breaking his mother's living room window once because he was mad at her for not allowing a friend to stay overnight on a school day. He "faked" that he was really upset about it. His mother comforted him and then apologized. "In the end I got my way." William states that this situation would have never occurred before he had Crohn's disease.

William points to the "many abusive tests" that he had to go through as one of the most difficult experiences with having Crohn's disease. He remembers having to drink "liquid chalk" as part of one of his x-ray examinations. The liquid made William feel nauseous, so he dumped as much as he could down a sink when no one was looking. He felt "invaded by these tests" but at the same time he felt "guilty" because he wasn't fully cooperating with the medical staff. He remembers being left alone in hospital corridors for long periods of time while waiting for more tests. William initially felt "lonely" but then came to wish that people would leave him alone so he wouldn't have to go through anymore.

William's mother would take him out for his favourite breakfast after the tests and he felt appreciative but

didn't really take pleasure from it, "Thank-you, but I just could never full heartily enjoy them anymore." "The enjoyment of eating was lost" because of his diseased stomach. He misses "being able to enjoy food."

William saw a counsellor at the hospital who helped him talk about his illness and all he had lost because of it. He feels this was very beneficial in helping him cope with the Crohn's disease, as he states:

One of the things that I discovered through talking with this counsellor is that I carry around a lot of fear because I never know when I am going to get sick, feel pain and have to take time off of work. I never know when my illness is going to throw a wrench into my life.

He feels that counselling has helped him to deal with some of these fears. William also remembers having a male nurse who played a major role in helping make his hospital stay "bearable." "The whole hospital experience was very scary" for him but the counsellor along with this particular nurse acted as a friend and helped him to feel "safer." "They also helped me to quit feeling sorry for myself like everyone else was."

William "hated" having people feel sorry for him. He made a decision then to hide his disease from others, "Don't talk about it, then people won't feel sorry for you." "Having people feel sorry for me all the time, caused me to

feel sorry for myself." "You don't feel very good about yourself with all these people feeling sorry for you."

Although William doesn't discuss his illness very much, to prevent people from feeling sorry for him, he believes that his Crohn's disease still controls his life and his relationships with others and he reflects further on this:

Even though I try to keep it under lock and key, it doesn't prevent it from coming into my life and taking over some social situation. It really affects me in a big way and has really shaped my person.

He states that his disease controls him and has made him who he is today. "This disease has taken over and is controlling a huge portion of my life. I am who I am because of Crohn's disease."

William likes who he is but he hates some of the difficult times he experiences with having Crohn's disease. He despises the pain that's associated with his illness and he hates the hours spent in the bathroom. He hates not enjoying good food, "Food is now just something I have to consume in order to survive. My whole perspective on food and so many other things in my life have severely changed."

Since being diagnosed with Crohn's disease numerous changes have occurred in William's life. He has experienced many losses and is just now coming to terms with some of them. He is slowly facing the fact that he has lost his healthy body and will now live with Crohn's disease for the rest of his life. However, William ends by stating that, "I

cry alot and I'm scared stiff but I must deal with the changes and the losses as they come, stay as active as I can, and hope that my life turns out okay." He attempts to live one day at a time although he still feels a great deal of fear about his future and all the changes he is to face.

Elaine

Elaine is a 23-year-old female with colitis. She was diagnosed at the age of 22. She was receiving steroid treatment at the time of her participation in this study and had bowel resection surgery twice for her illness up to the time of the interview. Elaine's health at the time was not good as she described how she has "never gone into remission" and feels "sick most of the time."

Elaine's situation began after her 22nd birthday as she began to feel very sick. She became "genuinely anxious" because she knew of someone who had colitis and her symptoms were very similar. Elaine's "worst fears came true" as her doctor told her that she did indeed have colitis, "I was frightfully scared."

Along with fear, Elaine lives with many other emotions caused by her colitis. However, the primary one she mentions is fear. She states that, "it's been a year of fear never

knowing when I'm going to feel symptoms, and it scares me because I still haven't gone into remission."

Although Elaine is not in remission and feels sick, she forces herself to continue life tasks including work. She has continued working although it may not be the best choice for her health, but she finds that accepting her illness and the limitations it puts upon her is difficult. "I know I probably shouldn't be working as much as I do but I find it hard just to stop because of my stupid disease. I don't want it to limit everything I do in my life."

Elaine lives with "constant worry" regarding the limitations colitis may place upon her, especially at her job. She worries about whether she will make it through the day without getting sick, "There is the constant worry of if I will be okay to make it to work, through work, the day etc." She states that, "the constant not knowing is the worst aspect of having colitis." "The not knowing is the main cause of the fear and anxiety." "Will I make it through the day without getting sick, will I make it through the day without causing a scene, will I make it through the day without everyone finding out that I have a chronic illness." She states that all the worry uses up what little energy colitis leaves and then hardly any energy is left for life tasks, such as work. This causes a great deal of frustration for her as she tells of having one concern after another. Elaine finds all this worrying very tiring and very hard.

Elaine found life so much easier before having colitis. She could use her energies on life and not on worrying about an illness. She saw herself as much happier before having colitis and everything in life was easier. Elaine grieves the "damage done" to the easier life she once had. She now finds everything harder and this makes her "angry and very sad."

Having colitis has brought about an assortment of losses in which Elaine grieves over. Loss of activities that brought her personal satisfaction is one of those losses she points to:

I constantly feel unhappy when I contemplate my life that I had and all the fun activities that I did and how it is now dead. Existence was so much easier and gratifying before I got this depleting illness and it really infuriates me.

Elaine's performance at work makes her angry as it is greatly hindered by colitis, "As a consequence of my condition my work suffers quite a bit." Along with anger she also feels sad when she thinks about the loss of her normally good job performance, "I feel depressed about my work." She finds work long and hard. "I don't know how much longer I can do as much working as I am doing now."

"Constant uncertainty" are two common words in Elaine's life, "not what to do now but more what will I be able to do." "Now I feel dazed and scared because I don't know what to do with my life now that I have colitis." She is

uncertain how one is supposed to live life with colitis. This question causes feelings of "fear and anxiety". "I'm scared because I don't know what I am supposed to be about since living with colitis, heck I don't even know how this disease got in my body."

Elaine then goes on to talk about possible causes of her illness. She wonders if maybe she worried too much as a child and perhaps that brought about her illness. However, she doubts this as remembers having a very healthy and happy childhood. Elaine is confused about the cause of her illness. She recognizes that her worrying was not any more exaggerated than anybody else's she knew and this is confusing. She wonders why she should get colitis from the normal amount of worrying that she did.

Elaine spends time thinking about other possible causes of her illness. She ponders her past habit of procrastinating and questions whether that may have caused stress, and in turn caused her disease. However, in the same breath she doubts that the stress she had in her life before having colitis could have caused this major illness, and the symptoms that she now has to deal with. Elaine continues to wonder about cause and ponders her diet. However, that too is a "dead end" because she was very careful with her health and her eating habits.

Elaine remembers being very health conscious. She recalls eating healthy and exercising regularly before being diagnosed with colitis. She feels a great deal of

frustration in not knowing the cause of her illness. Elaine participated in many sports before having colitis and was very physically active. However, ". . . because there has, as of yet, been no medical cause fully found I still wonder if I, in some way as a child, caused myself to get colitis and this makes me feel guilty."

Along with feeling guilty, Elaine is angry that she has developed colitis. She feels angry at herself. She states that her "self-worth has diminished greatly since being diagnosed with colitis and this is probably partly due to being angry at myself a lot of the time." Elaine's diminishing self-worth is partly due to her "guilt and anger" at self for possibly causing her illness. She does not like the thought that she may have caused her colitis because she then has to see herself as somehow emotionally or psychologically unstable. Along with getting angry at herself she also gets angry when other people allude to the idea that she might have caused her disease, "When anyone seems to mention that I probably got sick because I put too much stress on myself, I get defensive and angry." Elaine continues:

I sometimes feel like I am somehow to blame for having colitis because there really is nobody else to blame and I become uneasy around people that suggest that I am to blame for having it. This makes me feel like I am a real dud.

Anger directed towards oneself, self-blame, and feeling blamed by others are contributing factors to a lowering of Elaine's self-esteem.

Elaine has difficulty talking with other people about her illness. Talking about her illness brings up feelings of fear that she does not want to show or experience. "I know I have a real hard time talking about my condition without getting emotional, especially scared."

Elaine emphasizes the part that fear plays in her life. "I am scared of my own body because it has been assaulted by some foreign disease." She speaks of the violation that she feels from her disease and how this is a huge contributing factor to her feelings of fear, "It has taken over my body, filled me with fear and changed my life forever."

The "changes" to Elaine's life since being diagnosed with colitis have been "scary and overwhelming." She has had to go through many "new and different experiences." She is uncertain whether she has fully accepted that she has to make changes in her life in order to live with colitis. However, Elaine states that more and more she is taking her illness into account when making life decisions. At the moment she is faced with a decision around career and is considering what limitations her illness may place upon her in this area.

Elaine experiences changes that have been caused by her disease as being very much out of her control. Elaine states that her colitis takes away some of the power she has over

the path she wants her life to take. She talks of the many aspects of decision-making that she now feels are out of her control. Her colitis seems to limit many parts of her life and she feels that she has to adapt to this control in some way, "It seems like there is so little command over your own body and pretty much over your life."

Colitis limits Elaine's ability to partake in many enjoyable activities, and she often has to say "no" to activities that she takes pleasure from. She grieves over the loss of these enjoyable activities and finds that this loss is one of the primary negative effects of having this chronic illness. Along with these gratifying activities being more difficult to participate in, she states that another negative effect of her illness is that life tasks are also so much harder. Elaine's responsibilities in life have become much more laborious and stressful. One of the life tasks that she finds now finds more difficult is work. Elaine finds working very hard with having colitis, "Going to work isn't an easy task." She then states that, "colitis causes me to feel high levels of anxiety at work", "I get very anxious when I'm at work and that's the main thing that makes working difficult." Elaine ends with stating that the two most serious side effects of colitis, thus far, have been her limited ability to do the things she enjoys and her lack of accomplishments at work because of the adverse effects it will have on the rest of her life options.

Amy

Amy is a 25-year-old female with Crohn's disease. She was diagnosed at the age of 16. She was receiving anti-inflammatory drug treatment at the time of her participation in this study and had not had surgery for her illness. Amy appraised her health at the time of the interview as not good. She described how she lacked energy and generally didn't feel well.

Amy was "devastated" when she was told that she would have to live with Crohn's disease for the rest of her life, "This was no simple sickness, this was a chronic illness which involves lifetime treatment." After she was diagnosed, she was faced with the decision of whether to go on steroids or not, "Did I want to live with the agonizing symptoms of the disease, the constant fear of a possible occurrence or risk the endless list of severe side effects of steroids." She chose to refuse the steroids her doctor had offered and seek out other forms of treatment.

Amy had a lot of difficulty searching out relevant information on her condition and other possible methods of treatment. No one seemed to be able to answer her questions about how this disease was going to effect her life and if there were any other treatment options apart from taking steroids. She points to the importance of having information on her Crohn's disease, "Without the knowledge of my disease

I have no control and I have so little control over what happens."

Amy mentions loss of energy and general good health as one of the things she now has little control over, "I have lost so much control since Crohn's disease has taken over my life, and I really am angry and sad about this." She states that:

I am only now beginning to understand how little is truly known about my condition and the numerous changes that I am to face in my life that are basically going to happen to me without my ability to regulate them. The lack of control she now feels over her life has caused her to become more reclusive and escape somewhat from her life. Amy feels that she has become very introverted since being diagnosed with Crohn's disease, "The switch to introversion I know, has a lot to do with all the anxiety I have inside of me, I never know when I'm going to get sick and I have no power over when and where it will happen."

Amy discusses other possible reasons for her more reclusive lifestyle, "Also I think the introversion has a lot to do with the way I feel about myself as a person, I'm sick and it's hard to like myself so I go into this shell and hide." One of the ways she avoids going in to this shell is to get angry. Amy feels rage towards her illness because of what it has done to her world, "I am so pissed off about the way this disease has forced itself into my body and into my life." "I've become actually desperate and at the same

time genuinely enraged." She targets her disease and its side effects as the reasons for her anger. Amy ends at this point by perceiving that the one objective that she has is to put effort into trying to express her anger and other feelings she has towards her Crohn's disease in healthy ways, "I want to stay healthy emotionally and the way I can do that is by trying to express as many of the emotions that are inside me in a healthy way, including rage."

Teresa

Teresa is a 25-year-old female with colitis. She was diagnosed at the age of 15. She was not receiving any type of drug treatment at the time of her participation in this study. Teresa had two different surgeries for her illness. The first one was an ileostomy with an external bag. With the second one she was given an internal bag. Teresa appraised her health at the time of the interview as good. She described her surgeries as relieving most of her physical symptoms.

Teresa's situation began when she started feeling sick at the age of 15, while attending grade 10, however, "My doctor told me that, "it's just in your head". So what was I supposed to do? I tried to ignore it and continued on with

starting grade 11 the following fall." She then began feeling really unhealthy during the first month of grade 11.

"Feeling sick was scary" for Teresa, especially when she didn't know why she was feeling so sick. She was getting worried about feeling so sick so she went to seek a second opinion. After many visits and several different tests, the second doctor diagnosed her with colitis. The whole experience of going to the hospital to see a doctor and have all these tests was new for Teresa. She was never really sick before so "all this was a big thing" to her.

Teresa has an "ongoing struggle" in regards to the origins of her disease and she finds this struggle difficult, "The fight for me, within myself, to decide on the origins of the disease, has been tough because you can't even get medical people to agree on its cause." The medical profession makes the search for a cause difficult for her because they themselves cannot agree on the origins. She remembers when she first received her diagnosis from the second doctor and how much of a "huge shock" it was, "then he couldn't even really tell me what caused it." "One day, all of a sudden, I was diagnosed with colitis and no one knew how or why."

Teresa remembers "desperation" over the pain she was feeling in her stomach caused by her colitis. "Being 15-years-old and still crying and screaming for hours waiting for the pain to stop." "It felt like my world was crumbling inside me."

Teresa's illness was severe from the outset and it stayed severe all the way through until she was 19-years-of age. At 16 she was given an ileostomy and an external bag. She had this bag throughout her 16th and 17th year. Teresa remembers how important outward appearances were at that age and how she was considered very different because of her bag. At 18-years-of-age she was given an internal bag and by 19 most of her symptoms had subsided.

Teresa states that she is still very highly affected from her illness, the hospital, and those operations. One experience caused by her colitis that has really had a lasting effect on her was the times that she spent in a hospital for chronic patients. She spent anywhere from 1/3 to 2/3's of the year, every other year, between 15 1/2 years-of-age and 19, in that hospital. Teresa states that she spent an average of 2/3's of a 4 year period of her life in the hospital because of having colitis. Her experience in that hospital has left a lasting impression on her.

Teresa states that some of the most "intense" experiences of her colitis took place in the hospital. She again emphasizes the importance of this in her experience. She remembers there being very restricted visiting hours in the hospital and she recalls being "incredibly lonely and sad" because her family was only allowed to visit during certain hours. Teresa grieves over the lost time at home with her family. "It was like I wasn't really part of my

family's home because I was basically living in the hospital."

Along with grieving over the lost time with family, Teresa states that she also grieves a lot over the loss of her body that she had before colitis, "When I think about my body I just curl up and rock and cry for long periods of time. I just want to escape from all that pain and fear and have my old body and self back." She longs for the self that did not feel all this grief and anxiety.

Teresa emphasizes the large amount of dread she carries around with her because of never knowing when she was going to feel some sort of illness symptom, "I still feel it, all that fear of never knowing when I was going to get sick, and it's hard to get rid of it. That feeling of fear was so intense." She feels that along with uncertainty about symptom relapses the violations upon her that her illness caused has also created a lot of the fear she holds inside, "another portion of this apprehension and anxiety is my body reverberating from the violations."

Teresa also feels violated by all the pills that had to enter her body in order to treat her chronic illness. She was on new pill programs every year. She feels shame because of the way her and others have had to treat her body, "Rolling through life is characterized by a fair amount of humiliation, disgust about myself, my body, and all the drugs I had to pump into it, and I'm only now getting over it." Teresa feels her body is "manifesting a distressed

person" and a person that feels violated, scared and unsafe. She had a hard time feeling safe with her colitis, "People had a difficult time understanding that I never felt secure especially after my surgery. I had been violated and I was scared."

When Teresa woke up from her surgery and she saw the long scar down her entire stomach she remembers feeling in shock. She sees her scar as playing a large part in her life experiences. She feels "maimed" and is still "partly in shock about it." Teresa states that she is no longer "intact." She feels that a lot of her experiences have to do with the surgeries, her scar, and how these things have affected her relationship to her body.

When Teresa was seventeen she quit high school because of her illness. She was in grade 12 at that time. She remembers doing well in English 12 and failing everything else. Teresa states that she couldn't care about doing well in school. She did not believe she had any sort of future ahead of her, "I felt that I wasn't really strong enough to have much control over my future so why even care about school." She states that she is intelligent but because of her colitis she has been unable to pursue higher education in a consistent fashion. "I couldn't deal with school. It was only making apparent how worthless I already felt."

Teresa's disease has made her feel "devalued" and has greatly diminished her sense of self-worth. She remembers always feeling like an "outsider." "I felt like a loser and

how hard that made my life." She stated that she was stunned that anybody would want to hear stories about her experiences in living with colitis. Teresa ends by remembering how much easier life was before developing colitis. She longs for her previous world and her healthy body and healthy view of self before colitis.

Helen

Helen is a 23-year-old female with colitis. She was diagnosed at the age of 19. She was receiving steroid treatment at the time of her participation in this study. Helen had not had surgery for her illness. Helen appraised her health at the time of the interview as not good. She described herself as "very low on energy" and feeling "sick."

Helen's situation started when she was on holidays with her family. She was 19-years-old and began having a lot of "blood in her bowel movements." Her family took her to a doctor and he diagnosed her with colitis. Helen states that her life became a lot more difficult from that moment on.

Helen had never heard of colitis prior to her own diagnosis, "I didn't know what it was and that was a big thing." "It was an entirely unknown illness" to her, "and then came all the unknown tests." The test experience for

her was "really scary" because she "had never gone through anything like that before." Helen talked to some other people that had colitis and been through many of the same procedures and they scared her because they were telling her "about a lot of horrible things" that she was going to be going through. It was "scary" for her to hear all that information as she indicates:

I was in a room with two others that had colitis and been through it all and they scared me because they were saying "this is what's going to happen to you, you're going to have surgeries and be on steroids for the rest of your life" and all this other stuff.

Helen's first treatment was through the use of steroids. Her initial experience with the steroids was positive because they made her feel better. However, she "began to feel anxious" as the length of time she was on steroids increased, "I was on steroids for a long time, so that didn't make me feel very good. It felt like they were making me really weak."

Helen's "energy levels began to decrease rapidly." She "was tired all the time and getting to school was a difficult task." She would avoid eating at school and at her part-time job, in order to prevent any illness symptoms, so she was not providing her body with the nutrition she needed to keep her strength up. "I did not want to get sick at school or at work and cause an uncomfortable scene so that's

why I never ate." Helen was low on energy because she generally didn't eat at all during the day.

Helen "found the regular winter school term difficult" because she didn't have much energy to put into it. She was always having to ask for assignments and exams to be deferred through out the term. She then had a difficult summer because she had to take summer school courses to keep up with her program of studies. Along with summer school, Helen was also trying to work so she could make enough money to pay for her next fall's tuition. She then started university full time again in September. She was still not eating very much throughout this time. However, Helen did eat at home because she "felt safe." "It was okay to get sick at home, but it was not okay to get sick at school."

Looking back now Helen thinks she should have taken a break from school but she didn't because it was a competitive program and she didn't want to lose her chances of staying in it, "At that time, I was in a competitive program, so I thought if I get out now it would be harder to get in, because I got in right after high school, so it would be more difficult." She "began to hate school" because it was so difficult to continue with it while dealing with her colitis. The medication she was taking at that time did not seem to be helping.

Helen's doctor then switched steroid medications. However, she "became sick of taking so many different drugs." She stated that the steroids were not good for her

and she "was fearful of the side effects of them", "I was on steroids, I felt really bad because I knew this is not good for me and I would read up on it and it was scary." The medicine Helen took for her illness felt "wrong," so she attempted to seek out other means of controlling her colitis.

Helen tried a naturopathic doctor. However, the diet he put her on did not seem to help. She found it "frustrating" because she could "barely eat anything as it was" and then there were more restrictions put on her diet. The naturopathic way just wasn't going to work for Helen so she made the decision to go back to using the new steroid medication.

Helen doesn't know if she is going to stay on medication all her life. "The future scares me." She is scared that she "will consistently not feel well and always have to be on major medications." It scares her because she has been on several different drugs and hasn't gone into remission through the whole period of time that she has had colitis.

Helen states that the hardest thing about living with colitis is not being able to function during the day without thinking about it. She feels anxious about where the bathrooms are and always has to be thinking about that, "The worry about where is there a washroom, that is a big thing." It "hinders" her life and her ability to be spontaneous. Her illness "disrupts" her day and any routine schedule she

attempts to set up. "It causes a big problem throughout my whole day at school. It has changed the way I look at each day."

Helen states that colitis has changed her life. Her illness is "directing" her life, "Dealing with this disease is a huge hassle and sometimes it pisses me off the way it can just step in and take control of any plans that I may have arranged in my day." Helen expresses a great deal of anger towards her disease for all the changes it has forced her to deal with, both physical and emotional.

Physically Helen's disease has been "horrendous." Emotionally, her illness has been "overwhelming", "Emotionally it can get you." "It just screws you up, never knowing when you are going to be sick."

Everything in Helen's life now is a hard task. "Everything is more difficult and I just get tired of it sometimes. Actually I'm tired most of the time because I can't really do any of the active things that I used to." Having to give up her love of being active in sports because it was so difficult to continue with was a huge loss to her. She grieves the loss of her body's ability to perform. "I just can't do it anymore. My body won't let me."

Helen speaks of the affects of having a body with a chronic illness, "Having a sick body makes you feel bad about your whole self." Having colitis negatively influences the way she views herself, "How I see myself has changed so much for the worst, since I've had colitis." She has "felt

huge changes" in her body and the way she sees her body and her self. "I've changed so much, I'm weaker and that makes me scared and that scared feeling seems to weasel its way into all areas of my life."

Helen experiences fear with meeting new people and prefers to stay with all the people that she knows and feels safe with. "This anxiety is a hard thing to deal with." Her "fear of new social situations" was not there before she developed her disease. She remembers not even thinking about being afraid in unknown situations. But now Helen finds that she is often frightened of new situations, especially when she is feeling sick.

Helen continues talking about how when she is feeling sick she wants to be around people she feels safe with. She states that when she was healthy this need was never there. However, when she's feeling symptoms and she is in a new situation, it makes her anxious and scared, "When I'm not feeling well and I'm around people I don't know very well I feel uncomfortable."

Helen proceeds to tell of the way she searches out "more comfortable, less anxiety producing environments." She wants to be with people she feels at ease with. She states that she thinks this is her way of trying to find methods of gaining some control when she is feeling illness symptoms, "When I'm not feeling well I need to have a very controlled, safe, familiar environment because the disease takes away a lot of your feelings of power when you are sick." Helen

feels more in control when surrounded with people she knows well.

Helen feels less anxious when she is with people she knows. She states that, at times, since she has had colitis, she gets "scared and anxious about different situations for no reason." She believes that her illness has caused her to feel all this new fear, "This thing has caused you to become like that, that's how I see it." Helen ends by stating that, "I feel a great deal of anger about all this anxiety that colitis causes me to have to deal with in my life."

Michael

Michael is a 25-year-old male with Crohn's disease. He was diagnosed at the age of 17. He was receiving anti-inflammatory drug treatment at the time of his participation in this study. Michael had three bowel resection surgeries for his illness. He appraised his health at the time of the interviews as not good. He described himself as "suffering with abdominal pain" and feeling "very low on energy."

Michael's situation began when he first felt "extreme abdominal pains." He felt "very scared about all these pains." He was unable to explain to others how bad he felt, "I was alone in my pain and suffering."

Michael wondered why this was happening to him, "Why was I being given all this pain?" He has never been able to find the answer to that question. When he first began having symptoms, no one knew what was wrong and his life began to "change drastically."

One of the aspects of Michael's life that changed was his participation in enjoyable activities as he was "very much involved in sports, especially basketball." He evaluated himself as a pretty good basketball player but he began to have difficulty participating, "I'll admit I saw basketball as a huge part of who I was because I was pretty good at it, and then all of a sudden I was robbed of my energy and my ability to do it anymore."

As the symptoms grew Michael's energy decreased. He was no longer able to participate in the sports that he enjoyed, I guess because of having to deal with all the pain I was feeling in my stomach, I had no energy to do anything else especially basketball and I became a forgotten team member." Dealing with pain consumed much of his energy and his ability to participate in enjoyable activities.

Michael felt very alone in his pain. "I was a lost member of society because I couldn't belong on these teams anymore." "I was no longer a basketball player and I didn't know what my identity was anymore besides being a sick person." He was "no longer outgoing, social, and popular." Michael "retreated" into his "own world", "I was alone." "I

felt sad and was suffering a great deal because I didn't know what to do."

After suffering with pain and various other symptoms (ie. loss of appetite, weight, and energy) for several months, Michael's family doctor sent him to a gastroenterologist. "My doctor sent me to a stomach specialist. I was sort of afraid because he put me through quite the barrage of tests." This was a "scary" thing for him as he had never spent so much time with doctors and so much time in the hospital. The gastroenterologist diagnosed him with Crohn's disease. "He actually made quite a quick diagnosis I suppose and so there I was. At least I could put a name to all these various symptoms I was experiencing."

Michael never knows when he is going to have an "attack" of symptoms and be rushed to the hospital, "They truly are attacks. They happen so quickly. I feel completely attacked and violated by my illness. It has destroyed my body and keeps me from living a regular life." Michael longs for more control over his body, his illness and his life but thus far nothing has been successful for him:

My illness controls my life, I watch what I eat, I take my medication, but it still monopolizes my life. It's amazing I've kept one job for so long because I never know when it's going to take over and I am going to have to phone in sick.

The fact that Michael feels ill a lot of the time and has little control over his symptoms makes it difficult for him

to feel good about himself, "Crohn's disease makes me feel inferior, my dignity has been lost. I'm just a sick person with no control over their bodies or their life" Along with his illness specifically causing a decrease in his self-esteem he also points to his experiences in the hospital as having a major effect on his self-regard. Michael never knows when he is going to end up in the hospital as he indicates:

I never know when I am going to feel the symptoms of my disease. I could end up in the hospital tomorrow and they treat you in such a degrading way in the hospital you feel like a helpless little kid.

Michael hates the lengthy stays in the hospital and the effects of this. "I think one of the worst things about having this chronic illness is being in the hospital and away from the woman that I love." He hates the pain that his wife has to go through with having a partner with Crohn's disease and having to spend so many nights away from him while he is in the hospital.

Michael hates "hearing pathetic stories from other people with Crohn's disease." Others have told him that their partners couldn't cope with them having a chronic illness, "I hear that 'my wife left me because of my disease'." He hears that they couldn't be proper parents because of Crohn's disease. If Michael was to believe all these stories he states that he would be left incapable of doing anything with his life. However, he does not give

credence to all these stories, "That's not true." He believes that even living with a chronic illness, one can enjoy life and have healthy relationships. Michael is trying to have fulfilling relationships and live his life to the fullest. However, he still feels angry about his life often and at times is "debilitated by these feelings." Along with being angry Michael also feels scared. However, he states that he feels less alone then what he did when he first was diagnosed because he shares more about his illness with others that he trusts.

Michael is beginning to share more with others about his illness. He tells friends now why he can't eat certain foods or why he can't participate in various activities, "It feels good being honest about my health". He believes that he must "accept" himself and his illness before others can accept him and one of the ways he can do this is by being more open with friends about his disease.

Michael states that he is slowly becoming more accepting of the fact he will live with Crohn's disease for the rest of his life:

It's a chronic illness, a scary word that chronic thing, so I guess that means pretty much for my entire life and I am starting to accept that. Acceptance is one thing but all the emotions that come up when I think about that, especially fear, it can be overwhelming sometimes.

Michael ends by stating that he still feels a great deal of fear about having to live with Crohn's disease forever but he attempts to live one day at a time. "Scared about the future but just have to live life."

Ted

Ted is a 25-year-old male with colitis. He was diagnosed at the age of 18. He was receiving steroid treatment at the time of his participation in this study. Ted had not had surgery for his illness. He appraised his health at the time of the interview as not good. He described himself as feeling a "great deal of pain."

Ted believes that his situation actually began when he was told that he would have to live with colitis for the rest of his life, "This was no innocent affliction, this was an incurable condition." "My body had been violated by some foreign sickness that was going to be with me for the remainder of my life." "I was put through so much right from the word chronic." "When it was determined that I had a chronic illness that was affecting my intestinal tract I was immediately put on steroids and put through a continuous barrage of degrading tests that seemed to never stop."

Ted was "appalled" by the lack of compassion doctors had for his condition as he was so "scared of this unknown

illness and these demeaning examinations." Fear was an emotion that he felt had taken over his life but no one helped to calm these fears, "Fear of this disease, fear of every test room that I was wheeled into, but no one ever explained to me what was actually going to be going on." He states that all that anxiety just piled up inside him and made dealing with everyday life very difficult, "This illness makes me feel scared, weak and unable to deal with this world", "At times I hate myself for feeling so frightened and fragile and I figure I'll never make it, and nobody seems to understand these feelings."

Ted questions his ability to deal with this fear and the difficult experiences that he now faces in his life:

When faced with a future of having to confront pain, social inhibitions, and the continuous abuse of my body from drug therapy, it makes me wonder if I have the strength to cope. I feel I have come very close to facing death.

He felt he has faced his own mortality at a very young age and is forced to make major alterations in the way he lives his life. He speaks of these alterations as ones that were not of his choosing:

I felt like I had lost complete control of my life, something foreign had taken over and I was scared and all I can do is try to change some things in my life to see if I can cope better. The changes I have had to

make have cost me a great deal. I have lost a lot in my life since being diagnosed with colitis.

Ted points out the huge losses he has faced. "My whole existence as I knew it was gone and I was very down and very scared of what I was about to be confronted with."

Along with an increase in feelings of anxiety over all the unknown changes Ted is faced with, he also states that, "I've become very depressed and at the same time feeling very angry." He focuses on the illness and its side effects as the target for his anger. At this point Ted ends by emphasizing that the only thing he can do is to try to deal with his angry feelings in appropriate ways and "cope on a day to day basis."

Nancy

Nancy is a 23-year-old female with colitis. She was diagnosed at the age of 18. She was receiving steroid treatment at the time of her participation in this study. Nancy had not had surgery for her illness. She appraised her health at the time of the interview as poor. She described herself as "suffering from a fair bit of sick feelings."

Nancy's situation began at the beginning of her first year of university. This is when she initially started to feel sick. She remembers being "very scared" because she did

not know what was wrong with her. Her regular doctor told her that there was nothing wrong with her, so she decided to seek a second opinion and the doctor who supplied the second opinion diagnosed her with colitis. Nancy was sick for close to a full year before being diagnosed, and with an illness she had never heard of.

Nancy had never heard of colitis and this lack of knowledge concerning her diagnosis added to her "already all consuming fear." However, there was some sense of relief with finding out that there was something medically wrong with her. Although she was scared she was also comforted to find out that she "was not just going crazy", and she was relieved to know that there were other people out there who had the same disease who she could talk to about her feelings.

Nancy's hospital experiences included a great deal of emotions, primarily fear, "I remember being quite emotional, especially scared, and it had to do with being in the hospital and having to undergo all these different tests." She experienced many "strange and violating" procedures during her first hospital stay. These violating tests caused her to experience feeling "out of control" of her body and her life while in the hospital, "Everything was very new to me and out of my control." While in the hospital Nancy heard stories from older women who had been living with colitis for some time and these stories added to her already increasing feelings of being out of control. Along with

increased feelings of being out of control, their stories increased her feelings of fear. She also saw concern in her parents caused by what was going on, which again elevated her own anxiety, "Also, seeing the look of alarm on my parents' faces didn't help my own feelings of being scared."

Nancy went on a quest to find all the information she could about colitis in hopes to alleviate some of her fears through knowledge. She read many pamphlets and she was surprised to find that the information the older women were giving about what was going to happen to her was contradicted in these medical brochures. The symptoms the women were talking about only happened in rare instances. This did help to alleviate some of her fear. However, many of Nancy's fears were not lessened.

Nancy realizes now that she will have colitis for the rest of her life and this realization also causes a great deal of fear in her along with feelings of deep despair. Things were happening so fast during the first phases of her illness that she did not think about it as being a lifetime affliction. "It's always going to be a part of me. I'm never really going to be truly healthy again and that really depresses me."

Although Nancy recognizes that colitis is a chronic illness, she hangs onto the hope that she will at least go into remission. Her parents have lifted her hopes with stories of people they know who are better now. They tell her that, if only she took better care of herself she would

be in remission. "Although this provides hope it also causes a great deal of guilt and pressure." She has spent a great deal of effort in researching ways in which she might be able to take better care of herself. However, nothing has been able to help Nancy into remission.

Although the knowledge Nancy has gained has not helped her into remission, she feels that the information she has gathered is allowing her to slowly take more control over her decisions in her life. She states that this knowledge regarding her colitis is very important to her because it allows her this increased control. Medication and diet also allow her to have more control over some of the symptoms of her illness. She states that this feeling of increased control is important to her because "there is generally, so little control over the affects of colitis." Nancy points to her weight and her body image as two of the things she feels little control over. She tried to convince herself that the fact that she lost a lot of weight might be a positive side effect of colitis. However, she was unsuccessful in convincing herself of this as she knew that the lack of control over her weight-loss was a sign of ill-health.

Nancy states that good health is so important to her and she may never have it again. She longs for the healthy body she had before colitis "invaded" it. She feels her healthy body has been "raped" by her disease and then "devastated by the tests" she is put through because of her

disease. Nancy also feels "violation from all the drugs" she has to take into her body to try and stabilize her disease.

Nancy grieves over the loss of her body before colitis. She has had "a complete body image change." She can no longer see herself as a "healthy, vibrant 23-year-old young woman." Nancy sees herself as "puffy faced and unhealthy." She states that, "this view of her body and her self is one of the hardest aspects of having colitis" because of the way it lowers her self-worth. "I see myself as weak and lazy and this makes me very depressed."

Nancy misses her lost "body strength." She wants to be a good athlete again. She misses being able to exercise regularly. Nancy sees all these losses as "a big blow" to her identity and image of self.

Scholastic accomplishment, usually an important source of self-esteem for Nancy, was greatly restricted after developing colitis, I just haven't been able to do my best at university, and this makes me feel like a loser because I can't get anywhere. It's hard for me to get good grades when I have to miss so much." She frequently encounters having to take time off of school when her illness acts up and in turn this alters her chances of attaining a high standard. With this then comes a lowering of her self-esteem.

Nancy states that she may look okay to people from the outside, but inside she feels "ugly, dirty and sick." "I know that even though I may look fine my insides are not fine." She states that these feelings about herself have

changed her life "drastically." When there are the rare times when she feels healthier, her whole self-esteem positively changes.

Nancy states that she has "definitely changed, as a person, since being diagnosed with colitis." She tries to look for some positives in some of these changes. Some of the positives that she has found include more empathy and understanding for people that are suffering from some kind of difficult situation. Nancy also states that she no longer takes things for granted. She states that her priorities in life have changed. She tries harder to enjoy the things she has in her life.

Nancy is trying to have a more easygoing attitude to life. However, she does worry, but she now worries about the symptoms of colitis and how they are going to make each moment harder as opposed to worrying about the moment itself. Discussing all the new anxieties she is faced with leads her into talking about how life is now so much harder. "Nothing is easy anymore and it makes me so angry." "Life is much more stressful because you never know when you might be sick. So many things are now harder, school, work, play, you name it." Nancy finds working very hard with having colitis, "Going to work isn't an easy task. You never know when you are going to get sick and that makes you worry." She states that, "colitis causes high levels of anxiety no matter where you are", "I get very anxious when I'm at work. What if I was to get sick. This also causes me to avoid anything,

including fun things." Colitis also causes her to have to say "no" to more activities that she enjoys and she grieves over the loss of these enjoyable activities.

Nancy ends with talking about how hard university is for her, "I try to laugh and take things in stride but it is really hard. I find university really hard." She continues:

I think that the most difficult side effect of colitis, thus far, and that I just can't laugh about, has been my low performance in university because of the deleterious effects it will have on the rest of my life choices.

Reflections from the Process Diary

I had conversations with young adults with Crohn's disease and colitis within as equal relationship as possible. As they disclosed their experiences to me, I often heard the statement: "I have never talked about that with anyone else". They seemed to regard my interest in their lives as an indication of understanding that they stated had rarely been shown to them. I attempted to never pose as somebody superior to them, or as a judge of their actions, but as one of them.

Overall, the interviewing experience and written narratives worked well, and followed the guidelines I had established. There was an ease about the process that seemed to be aided by the introduction to the participants, and by

the meaning that this particular lived-experience held for each participant. During my relating to the participants, it appeared that a level of trust was developed that helped in the telling of their stories. When words or groups of words had not been fully understood by me during the interviews, participants were able to quickly clarify the nature of their actual statements.

Feedback about the value of the process for participants was shared during the research interview. One participant commented on how important it was to have the opportunity to talk about his last few years. Another participant described the process of writing a narrative as an activity that was particularly valuable in helping her to reflect and become more aware of who she was in relation to her illness. All of the participants found the interview and writing a narrative very meaningful in terms of sharing what was of central importance in their life experiences with a chronic illness.

I felt very strongly about transcribing each tape, word for word, and doing the entire job myself. I found that listening to these tapes and reading the written narratives, over and over, was an important step in the data analysis. This kind of in-depth concentration with each transcript was a significant part of the process of identifying themes. I feel I know the ten histories almost as well as I know my own story. This kind of familiarity aided me in a process of

reflecting on the fundamental nature of the experience that was invariant across stories.

CHAPTER FOUR

General Structure

This chapter consists of the prevalent underlying themes involved in living with Crohn's disease and colitis. These are defined by all the participant's transcribed interviews and written narratives. These themes are referred to as the "general structure" (Karlsson, 1993).

My role as researcher is to illuminate the data of all the participants, to describe it in a way that makes it visible to others. After studying the descriptions of the phenomenon, I explicated themes which were deemed to constitute the primary features of the phenomenon. Each theme is illustrated by a number of examples from individual transcripts, and written narratives, that verify its selection. This discussion of themes is seen by van Manen (1984) as the core of the phenomenological description. Data from all the participants together is presented in a full form, including extended quotations.

This final step is a move from the situated structure to what Karlsson (1993) terms the "general structure". I also in this step returned to the raw data. A problem specific to this step, when dealing with themes, is the possibility that I may have overlooked relevant units in interview protocols and written narratives, which would hinder an adequate analysis of the themes. I made a great effort to compare the different transcribed interviews and

written narratives with one another. The results obtained from the analysis of all the participants together in this last step is presented in terms of different themes. The analysis is presented in terms of characteristics of the life experiences of young adults with a chronic illness. My attempt was to report the original accounts with enough elaboration to assess the agreement between the communications of the participants and my interpretation.

Summary of the Themes

1. The life experiences of young adults with Crohn's disease or colitis include the constantly accompanying threat of the unpredictable occurrence of symptoms.

2. The life experiences of young adults with Crohn's disease or colitis include grief and loss.

2.1 Performance abilities

2.2 Body and positive body image

2.3 Enjoyable activities

3. Life experiences of young adults with Crohn's disease or colitis include a significant lowering of self-esteem.

4. The experiences entailed in the lives of young adults with Crohn's disease or colitis include a marked increase in feelings of uncertainty accompanied by fear or anxiety.

4.1 Unknown illness

4.2 Unknown hospital

4.3 Tests

4.4 Seeing significant others worry

4.5 Feelings caused by illness

5. The experiences of young adults with Crohn's disease or colitis involve a great deal of change and adjustment in many dimensions.

5.1 Self

6. The experiences of young adults with Crohn's disease or colitis include deprivation of some of their control over their lives.

6.1 Weight

7. Types of experiences include feeling violated.

7.1 Drugs

7.2 Medical procedures

8. The life experiences include feeling a great deal of anger.

Discussion of General Structure

1. The life experiences of young adults with Crohn's disease or colitis include the constantly accompanying threat of the unpredictable occurrence of symptoms

One of the most apparent element experienced by young adults with this chronic illness is the threat of unpredictable symptoms and "constant worry" as to whether they will make it through various life tasks without getting sick. "There

was the constant worry of if I would be able to make it to school, my classes, the day etc." "I never know what kind of day I am going to have, and whether I am going to make it through it without getting sick. It's really, really awful having to live that way." The "endless uncertainty" as to whether they will get sick has been noted by many as one of the worst aspects of living with Crohn's disease or colitis, "Everyday I would wake up, usually feeling awful, and not knowing what kind of day lies ahead for me." "You just never know, you never know, and this can drive you nuts and really frustrate you. You're always faced with this constant worry." Frustration and worry are the common feelings that accompany this threat of unpredictable occurring symptoms, "It would be quite frustrating because most of my energy went into worrying if I would make it to and through the work day rather than on the work itself." "School was real hard because you're always having to think about your damn disease and whether it's going to cause you to rearrange your day. I always have to worry about it." All the participants have felt some form of uneasiness about getting sick:

It was like, will I make it to school, will I feel okay, because I remember I'd be fine, but nearing school I'd think, well I'm just about there, but I'd get nervous cause I'd think, am I going to be okay. Another participant states that, "Your life is one big question mark, am I going to get sick today?" These young

adults worry about whether they will make it through "the day, the week, the year," without getting sick, "A day doesn't go by without having to think about your illness, and at night it's even worse. I just hate that constant uncertainty you are faced with." They never know when a symptom is going to appear and how it is going to effect the moment, "One minute I could be enjoying a conversation with friends and the next I could be bedridden with huge pains in my stomach. It's a constant worry." They worry about when they are going to feel symptoms of their disease. "My disease, and it really is a disease because you can never feel at ease with it. You never know when it is going to pop up and totally wreck your day." When looking at all the stories that were used in this study, it was found that all of the participants included statements concerning "unpredictable occurrences of symptoms."

2. The life experiences of young adults with Crohn's disease or colitis include grief and loss

The participants' experiences include grief and loss. One of the things that these young adults "grieved" over was their less than perfect performances at life tasks, "My marks in school have dropped considerably since dealing with this disease, and I sometimes can't help crying about this. School is important to me, but it has had to take a back seat to my health." In the stories we can see the emphasis

placed upon the "loss" of their performance abilities in various important activities because of Crohn's disease or colitis, "My illness makes my job very hard, and now I just do enough to complete whatever it is I have to do. My body is no longer able to do that little bit extra that it used to." The participants also emphasize the "grief" they experience over the loss of their healthy bodies. "My once healthy body has been taken over, and it will never be the same. I'm no longer a so-called strong person." These young adults point out that their bodies suffer especially from feelings of weakness. "A slug, that's how I feel, a slug and even a weak slug sometimes. My body can barely get up in the mornings anymore." In the stories they "grieve the loss" of their healthy bodies before Crohn's disease or colitis "took over." "I've lost so much. My life feels so much more devoid of anything important to me since I've had this illness. I've lost so much. It's even hard to find meaning now."

Another element of the life experiences of young adults with Crohn's disease or colitis is that these illnesses cause them to have to say "no" to activities that bring their lives enjoyment and meaning. They recognize that their "involvement in enjoyable activities has to greatly decline." As this participant emphasizes:

I know I have to give up some of the sports I do, but it is so very hard to do that when you love them so much, and they help to bring joy into your life.

"Sorry, no," is a line I have had to repeat to friends

too many times now.

An example of this theme from a male participant goes as follows:

I have to look for other hobbies in my life because at the moment I can't do any of the ones that I used to, and I guess they have to be less physical. I've had to give up so much of the physical part of who I am.

Another participant states that, "I know I have to say 'no' to doing some things if I'm not feeling well, especially sports and travelling." "I can barely leave my home now, and if I do, it's generally with the car, no walking anymore.

Having to give up taking walks has been a huge thing to me."

The participants are "forced to grieve over the loss" of many things they can no longer do or do as often, "I still do it but not as often, and I guess I'll just have to accept that. But accepting it is hard, I still really miss doing it." Having Crohn's disease or colitis causes an assortment of losses of enjoyable activities in which these young adults grieve over. "I feel real sad, sure, no doubt, and over a lot of things. If I thought about it I'd probably fall into some type of deep depression." Another participant's experience indicates:

I constantly feel unhappy when I contemplate my life that I had, and all the fun activities that I did, and how it is now dead. It almost makes me feel like I am dead sometimes, and that's not a nice feeling. I dream so often about the way my life was. Existence was so

much easier and gratifying before I got this depleting illness.

Another participant states that, "This illness has taken so much and left so little. Oh, how I long for my life before this thing." The present study supplies clear support for how having a chronic illness can cause reminiscence about former good times and lead to grief over the loss of these more enjoyable times.

2.1 Performance abilities

Performance abilities are abilities which allow the individual to be competent at various life tasks they face. The stories provide examples of grieving over the "loss of performance abilities" after developing Crohn's disease or colitis:

This disease has degraded my performance in everything, I mean this fully, and I can't help but emphasize this. It's a low point in a person's life when they realize they can't meet the standards that they used to be able to.

The participants' performance abilities in various activities are greatly hindered by having Crohn's disease or colitis and this creates feelings of "sadness" over the loss of these abilities, "As a consequence of my condition, my grades suffered quite a bit." Another illustration of this theme is told as follows:

Everything takes a turn for the worst, including my job performance, but I can't help it, what am I supposed to do, I am doing my best, and I just have to keep with it. I have to accept that I can't do as well, at least not at the moment.

These young adults feel that without Crohn's disease or colitis they could do much better, "Mostly I feel that I haven't done as well as I could have in my job because of my illness." "That's just the way it is. Some of these things, such as my less than perfect school record, are the worst." Some of them stated that the effects of Crohn's disease or colitis on their performance abilities cause them their most "critical life problems."

2.2 Body and positive body image

Grieving "over the loss" of their healthy bodies pervades the participants' experiences. For some of these young adults the loss of their healthy bodies and the negative body image that they are faced with appears to have a "deeper significance than any of the other losses" that they experience. "Talk about losing yourself. When your body goes, you go, and that's the worst." They recognize that the image of their bodies as "weak, sick and tired" is something that troubles them, "Feeling weak, was something that bothered me, because I didn't have the strength I used to."

Another example of this theme is expressed by a participant with Crohn's disease:

I have to give up the dream of the past life when I had a healthy strong body and could do anything. But it's hard, because for me I think it's one of the hardest things to accept is that my body is no longer well.

The participants "emphasize the loss" of their healthy bodies and positive body image as one of the most difficult aspects of having this illness, "I think one of the hardest things to deal with in terms of my body was that it was never going to be healthy again." "Never again, those are two hard words, and they're the truth of my existence, and I'll always, always miss my health." Their bodies before having Crohn's disease or colitis are "greatly missed."

2.3 Enjoyable activities

Enjoyable activities include playing sports, exercising, and travelling. The participants recognize that their "involvement in enjoyable activities has to decrease." A participant with colitis expresses one of the effects of her chronic illness thus:

There's another thing, I can't play racquetball anymore, one of my main true loves, and I may be able to again sometime, at least I certainly hope so, but for now I have to give it up. I have to give it up, that's all there is to it.

Another participant states that, "I know I have to give up some things if I'm not feeling well, especially sports and travelling." "Here we go again on the topic of having to give up stuff, and right now I'm the king of having to give up stuff. I just can't play sports right now." These young adults experienced a negative difference in their ability to participate in enjoyable activities, "I was a good basketball player, but then I had no energy, and I just couldn't do it anymore." In the following statement this theme is clearly present:

I can do a little bit at a time, but I sure have to pay attention to what my body is telling me, and often it's saying "sorry you just can't go cycling today". It's depressing getting those messages from a body that used to say "yes let's do it".

Having to give up their love of being active in various activities is a huge loss to them:

I was involved with a lot of sports. I'd do anything from aerobics to wall climbing. So, that was a hard loss, a lot of those things I just physically couldn't do them anymore. So now I'm just climbing the walls in a totally different way.

They have all had to give up some activity:

I know it's stopped me from doing some things. Actually I guess it's stopped me from doing a lot of things, it's hard. Somebody might phone up, "let's go skiing"

and if I'm not feeling that great, "no I don't really feel like going skiing".

Another participant states that, "I want to do it because I love doing it, it's a part of me, but I just can't anymore. I have to take it more easy." The participants are no longer able to be as active as they were before:

I couldn't do anything physical. Basically I can only just lie around and watch T.V. I can watch the exercise shows, but while sitting on my behind. I couldn't exercise. I can't just hop up and join in. So, that made me feel really, felt really bad.

Another participant states that, "You just feel blah because you can barely do anything fun anymore, and that's really lousy feeling." Along with losing the ability to enjoy more physical type activities, many of these young adults can no longer fully enjoy many other things such as eating, "Sad that I couldn't even enjoy my favourite breakfast anymore." The following statement echoes this theme:

One of biggest things was going out to different restaurants with friends and sampling different types of foods, but I certainly can't do that anymore, unless they're serving exotic flavours of jello.

Another participant states that, "You just eat because you have to. You don't eat out of enjoyment anymore." This experience was both sad and frustrating:

I was sad because so many of the aspects of my life

that made it full, I could no longer participate, and angry, boy does it make you angry because you have to adjust your life so much, and you have to miss out on so much. I watch other people live my life for me in a way, and that makes me angry, I guess at them, and at me. I can watch hockey, but I can't play it anymore.

It's harder to enjoy life as much now that I have this disease.

Another participant states that, "It's so hard to find things that you can still do that you enjoy, and be able to do them half decently. It's very sad actually." They express that they are "forced to grieve over the loss of many things" that they used to enjoy. "I still enjoy life, but I've certainly have had to give up a lot, and I've cried a lot. It's like a funeral for your past life." "I cry inside as I have to sit on the sidelines of my old life and watch others enjoy the activities that I used to. I don't enjoy always being an observer instead of a full participant."

Having Crohn's disease or colitis causes an assortment of losses of enjoyable activities in which the participants grieve over:

I always feel so sad when I think about the life that I had, and all the fun activities that I did, and how it is now gone. Life was so much easier and enjoyable before I got this draining disease.

Another participant states, "Past life versus present life, well I'm sorry to say the past life wins out, and that is

disturbing. Sometimes I think I spend more time thinking about the good old days then living here in the present." This present research supplies clear support for how having a chronic illness can cause reminiscence about former good times and lead to grief over the loss of these more enjoyable times.

3. Life experiences of young adults with Crohn's disease or colitis include a significant lowering of self-esteem

A decrease in self-esteem has been included, by the participants, as one of the critical experiences of living with Crohn's disease or colitis. Many of these young adults state that one of the hardest things about having their illness is how there self-esteem has been lowered:

It's like I have to find out who I am all over again, because right now I don't really like who I am, and I know it's because I see myself through the looking glass of my illness. This is not a good idea, because it makes you see yourself as being pretty useless as a human being.

Many emphasize how having Crohn's disease or colitis causes a "huge blow" to their self-image:

I prefer not to think about myself because the picture isn't very nice right now, and it's better to try to just live life without thinking about yourself very

much. This disease has made me feel real lousy about who I am as a person.

The participants feel some lowering of their self-esteem, "Whirling through existence is defined by some shame and disgust about myself." "It's hard to look at yourself in the mirror because you see this scarred person for life, and I don't know how to get around that view. I know it's no good to think about yourself that way." Their disease has made these young adults feel a great diminishment in their sense of self-worth, "I always felt so much like a loser, schmo." "You can't help but feel a little less of a person then what you were before they cut you open and took parts of your body out. It's like being Frankenstein, no I'm only kidding, I guess." Another participant states that, "You sometimes feel like a freak." An example of this theme from a male participant goes as follows:

I think others look at you differently, especially when you have your shirt off and they see your stomach has been cut open for some reason. So, I guess others' reactions have caused me too, to look at myself as not quite right.

Living with a chronic illness has caused all of these young adults, at one time or another, to not feel good about themselves, "made me feel really bad all over. I felt, I don't know, dirty or something. Real bad. General yucky feeling." Another participant's experience indicates:

Sick, you just feel like a sick person, because on the

surface that's who you are, and you have to dig deep to save any sense of your self-worth. You have to dig deep for this or else you're not going to care about taking care of yourself.

Another illustration of this theme is told as follows, "You just don't care about yourself so much. If you're sick, you're sick, and that's the way it is. What can you do anyway, really. You don't even have the motivation to care about yourself really." Another example of this theme is expressed by a participant with Crohn's disease:

I don't think about me, I guess cause I don't like what I might see, and then I'd feel even worse, and it would be a vicious cycle. If you don't care for who you are at the moment, and you look closer, then it's only going to make it worse.

Life experiences of young adults with Crohn's disease or colitis involve a considerable lessening of self-regard, "When you're an ugly, sick little girl, you're just too foreign." A participant with colitis expresses one of the effects of her chronic illness thus:

You're different than who you were before getting this disease, and you're different inside. It can't be helped. You no longer have the healthy normal body that you once had. You can't help but see yourself as somewhat abnormal now.

Throughout the stories there are clear expressions of how one of the effects of this chronic illness is that there are

feelings of being "ugly and abnormal." These feelings then greatly affect the view the participants take of themselves.

The participants point to how the illness frequently elicits discomfort from others and how this causes a critical blow to their self-esteem:

I try so hard to avoid having people find out that I have this illness because it's such a conversation stopper, and it makes people uncomfortable. When they feel uncomfortable then I feel uncomfortable, and so on, and so on. I basically become uncomfortable with myself. It also makes me feel real lousy about myself because they're uncomfortable with me and who I am as a person, my disease is part of me, that's just the way it is unfortunately.

In the following statement this theme is clearly present:

My disease is a part of me, and I have to accept it, and hopefully the people around me can accept it, and the changes it may cause in my life, and in relation to them. But so far a lot of people around me have been uneasy in their reactions to me now, since they know I have this chronic thing inside me.

Many of these young adults emphasize how having Crohn's disease or colitis commonly evokes uneasiness from others and how this has a huge impact on their self-image.

Academic success and upward movement at work, regularly a significant source of self-esteem, can be severely restricted when having to deal with these illnesses:

I just haven't been able to do my best at work, and this makes me feel lousy about myself because I can't get anywhere. I can only do what my health allows me to do, and sometimes that's not very much. Sometimes it's not very much at all, and that's hard to face up to.

I'm surprised I even still have a job.

The following statement echoes this theme, "I have to miss so many unplanned days, and so finishing something seems to take a lot longer. How am I supposed to move up the ladder of success here, I can barely make it to the first rung." Participants repeatedly experience having to take time off of school or work when their illness acts up and in turn this affects their likelihood of achieving high standards:

I've had every second exam deferred, I've had extension after extension. I'm just lucky I have an understanding department. I guess the next thing is to give myself a break, because I don't, and sometimes don't treat myself well enough, and then this destroys really who I am as a person.

With their inability, at times, to achieve high standards, comes a lowering of their self-esteem.

Participants also described feelings of uneasiness and blame because of having Crohn's disease or colitis. This in turn negatively affected the way these young adults regarded themselves:

I sometimes feel like I am somehow to blame for having Crohn's disease, because there really is nobody else to

blame, and, and I become uncomfortable around people that suggest that I am to blame for having it. If I am to blame for having it, where does that leave me, and how am I to feel about myself and my ability to heal myself. I'll tell you, it leaves me in a really low place. This makes me feel like I am a real loser.

The following statement continues elaborating on this theme:

Really, really awful. I don't know how to do deal with this blame that some people put upon me, and then I put it on myself at low points. If I am to put this blame upon myself it only serves to exacerbate my already declining feelings of worthwhileness.

Feeling blamed was another noted contributing agent to a lowering of some of the participants self-esteem.

4. The experiences entailed in the lives of young adults with Crohn's disease or colitis include a marked increase in feelings of fear or anxiety.

Fear and anxiety are common experiences for young adults with Crohn's disease or colitis. The participants felt scared when they first began feeling sick. "I was terrified. What was going on inside me?" They do not know what is wrong with them, "Throughout my first year of university I was sick, and progressively getting worse without knowing what was wrong, and this was very scary." "Oh sure, real anxious. You feel completely incapacitated, and no one can tell you

what's wrong." In the stories we can see how they experienced living in "constant fear" with Crohn's disease or colitis. "Crohn's disease has filled my entire existence with fear and I just don't know. I feel this fear so often." These young adults emphasized feeling "very scared" with having this illness. "This illness does that to you, and I don't think it's something that's going to end. I think I'll always have this fear as long as I have this illness." "One situation to another, there all new now really, and they all cause attacks of anxiety, because you're entering into them with this illness. Even old everyday responsibilities take on new fear with this illness." In the stories there are many incidents in which the participants express how they live with a lot of anxiety especially while they are involved in a life task such as school or work, "There was the constant worry of if I would be okay to make it to work, and through the day etc." "Fear of everything involved in your day and fear of how you will handle it if you were to feel sick. So much of living with this illness is an unknown." So much is unknown about Crohn's disease and colitis and the fear and anxiety appear to be primarily related to this uncertainty:

Living with this illness, I guess in a way it's natural to feel scared. If you thought about it, I think it would be more unhealthy to kid yourself into thinking everything is alright, because so much is like the big unknown, and you're living with it inside of you.

Not knowing anything about the illness causes a lot of fear.

Fear of the hospital is a fundamental one that pervades the participants' experience, "I remember being quite scared and anxious about my illness and it had to do with being in the hospital. The hospital is the worst part of it all."

Another participant emphasizes, "The hospital, now there is one scary place. You never when there going to poke you with a needle or do some other horrible thing." A distinction can also be made between fear of the hospital and fear of medical tests and procedures experienced while in the hospital, "My time spent in the hospital are some of the worst in my life, and all those terrifyingly disgusting tests that you're put through while you're there. The hospital and the tests are the worst things I've ever experienced." There are a variety of tests administered to those with Crohn's disease or colitis (ie. Barium swallow X-rays, Colonoscopies, various blood tests, etc.):

It was all so new for me and I didn't understand, you're weak and low on blood to begin with, and then they're poking every day for more to see if you have enough. It just doesn't make sense sometimes.

Many of these young adults expressed how they had never experienced being in the hospital and going through these types of procedures, and found it "very anxiety provoking."

Seeing significant others worry about what the participants are going through can increase the already present fear and anxiety that living with Crohn's disease or

colitis causes. "Everything was very new and scary to me, seeing the looks on my parents' faces didn't help either, and only caused me to be more fearful." This participant reflects on a past memory:

I looked in the mirror and I saw terror, and then I looked to my family for comfort but they couldn't help being terrified for their child either. The bad thing was though, that seeing them scared only made me more scared.

These young adults stated that they experience fear regularly and to see others worrying about them only enhances their own feelings of "intense fear."

Feelings caused by Crohn's disease or colitis include: "anxiety," "fear," "despair," "guilt," "worry," "nervousness," "frustration," "anger," and "guilt." These overwhelming emotions can, at times, become too much to deal with and also cause the participants to feel afraid of their own overpowering feelings, "Sometimes I just get a flood of emotions come up and it's extremely scary, because it feels like they're just going to take over. I've become afraid of my own feelings." An element of their situations include experiencing "one fear after another." Another participant states that:

I don't think I've ever felt at peace since having Crohn's disease because I'm scared of it most of the time, and there's so much to be scared of. It seems a

lot of your life is, is spent worrying about your health.

All these young adults remembered how their feelings of fear used up what little energy they had for actual life tasks, "It would be quite frustrating because most of my energy went into worrying if I would make it to and through my exam rather than on the exam itself." "No wonder work was so hard, I spent so much time having to worry about my illness and how it might affect my work. Meanwhile it was already affecting my work." Another component of the participants' experiences was related to additional numbers of worries. "My Crohn's has given me so much more to worry about and I hate it. I never know how and when it will affect my life." They experience anxiety over how the illness symptoms will effect "each moment" of their lives, "I find I worry a lot about my condition." "It's a chronic illness, that means it's not going to go away, and it will continually cause some form of distress in my life. The problem is I don't know when the worst of it will happen." The young adults worry about whether, "if at some time during the day," they will "start feeling sick." "I feel sick most of the time, so it's just become a regular thing. But I do still worry about it." The future scares the participants, "it's scary because I don't know what's going to happen." "Unknown, that's a big word, but it's the definition of life now and in the future. This is what makes me truly scared." They are all afraid of things that they never felt afraid of before:

I felt very anxious and nervous. Nervous about silly things, and things you'd think a person wouldn't feel nervous about. I never used to be scared of these things. Things that I would never feel anxious and nervous about, like getting to school.

An example of this theme from a male participant goes as follows:

At work I started feeling scared because I never know what's going to happen with my health that particular day, and who knows, I never know if I'm going to have to, maybe have to leave. Who knows, I may have to leave this interview because of some symptom taking over.

Another participant states that, "I remember getting anxious, a lot more anxious than I normally would be." "I was a risk taker, and I mean that in a positive way. But now I've just become a bunch of scared bones."

A more clear distinction will now be made between the following sub-themes of fear and anxiety: a) over unknown illness b) over hospital experiences c) medical tests and procedures d) seeing others worry, and e) overwhelming emotions:

4.1 Unknown illness

So much is unknown about Crohn's disease and colitis which causes a great deal of fear and anxiety for those living with it. Many of the participants had never heard of Crohn's

disease or colitis when they were first diagnosed, "I had never even heard about Inflammatory Bowel Disease and I remember feeling very scared about this." "Of course you're scared, you're diagnosed with some chronic illness and no one in your family has ever heard of it. First your in pain and then you're just scared stiff." All these young adults have experienced feeling frightened, "Once upon a time I began to get incredible abdominal pains and I was scared." "I was scared of the symptoms themselves and how they were making me feel. All this pain and discomfort." Many of them point to fear as being one of the primary experiences in having their illness, "I'm scared about the future and how this illness is going to affect it and that's just the worst of it." Another example of this theme is expressed by a participant with Crohn's disease:

The future is totally unknown, I guess for everyone it generally is, but I think with having a chronic illness it makes it even more unpredictable, and that's one of the hardest things to live with. Will I always be feeling this lousy?

Another participant states that, "It's scary because I haven't, through this whole time period, gone into remission." "I'm sick on and off, and more on than off. If I'm always going to be this way, how will I reach any of my goals for my future?" It scares many of the participants when they think about their future and how their illness will effect it:

It worries me. Yeah, I'm sometimes overwhelmed with worry, and I think what's going to happen. How will I develop with a normal life. I think, when I get older, and I do have kids, am I going to get sick? I don't want to be sick all the time, all my life, and cancer is another thing, if you've had it for then ten years. That really scares me, and it's a big possibility. Sometimes I don't know how to deal with all of it. So, things like that are worrying me now.

A participant with colitis expresses one the effects of her chronic illness thus:

All these worries now, there's probably numerous I could mention, but I guess the biggest one is worry about my future, because there is so much unknown about Crohn's. I don't really know what it holds in store for me.

Not knowing very much about the illness and how it will effect their future lives causes a lot of fear.

4.2 Unknown hospital

Fear of the hospital is a central one that pervades the participants' experience and appears, for many, to have a deeper meaning than some of the other fears, "I remember being quite scared and anxious, and this had to do with being in the hospital. The hospital is one of the scariest places I have ever been." These young adults stated that

their hospital experiences caused an "overwhelming sense of fear." "The hospital is like a house of horrors, and there is always something scary lurking around the next corner. I've never felt so scared in my life as when I was in the hospital." The situations entailed in the lives of young adults with Crohn's disease or colitis involve a prominent increase in feelings of fear and anxiety caused by their hospital experiences, "I didn't belong in the hospital. I belonged at home with my wife and I belonged at work. She was scared. I was scared." A distinction can also be made between fear of the hospital and fear of medical tests and procedures experienced while in the hospital.

4.3 Tests

There are a variety of tests administered to those with Crohn's disease or colitis. The participants' experiences of medical tests caused an "overwhelming sense of fear", "I remember being quite scared about having to undergo all these different tests." In the following statement this theme is clearly present:

They wheel you into some room and then the hell begins, and it's unbelievably scary. I've never seen instruments like that before. All these procedures were very new to me. When I was diagnosed with the illness it was just one new scary thing after another.

The following statement echoes this theme, "Crohn's disease has made me experience a totally different reality, and in a way, it's unreal. It certainly was never part of my experience before having Crohn's." The test experiences for many of these young adults were frightening because they had never gone through anything like them before:

The tests, yeah, that was really scary too because I'd never done anything like that before. Wow, did they hurt, and were they scary. It seems so unbelievable when you have a little distance away from it, and to be talking about it now in a matter of fact manner. So, when they did like a scope, so that was strange for me, because it was like all really different. The barium tests, now there were some really awful ones, and the taste of that stuff. If the disease didn't make you nauseous then those tests certainly would. It was scary.

Another participant states, "Fear, major fear. I never have gone through the stuff I have to now." Many of them express how they had never experienced going through these types of procedures before and found them "very anxiety provoking."

4.4 Seeing significant others worry

Seeing significant others worry can increase the already present fear and anxiety that living with Crohn's disease or colitis causes. The participants state that they experience

fear regularly and to see others worrying about them only enhances their own feelings of "intense fear." "You look to people to calm your nerves but they can't help you because their nerves are shot too, and they almost need reassuring from you. It's funny how you almost begin to play that role a little." Another participant states that, "Everything was very new and scary to me, seeing the looks on my parents' faces didn't help either, and only caused me to be more fearful." "It must have been horrible for my parents to have a sick son in the hospital, and I knew they were scared for me. So I guess I knew I should be scared too." "Not only my parents, but anyone who visited and saw me hooked up to all these intravenous gadgets. I was scared, they were scared, and it kind of went around like that." All of them remember significant others being very scared:

My mom was scared. Her only child has an illness and he's going through so much. Boy did she spoil me after that. She treated me differently and in a way that made me think that there was really something to be afraid of.

4.5 Feelings caused by illness

The stories provide examples of situations where various strong emotions cause fear and anxiety for these young adults living with this illness. Sometimes these emotions cause the participants to have difficulty talking about

their illness, "I have real trouble discussing my illness because, as you can tell, there are many unresolved feelings attached to it, and there's just so many of them. So when I talk about it, naturally the feelings come up to." Talking about their disease brings up "uncontrollable feelings" which they do not want to experience:

I know I have a real hard time talking about my condition without getting overwhelmingly emotional. I don't want to have to always be getting emotional, and so I try not to talk about it. I get scared sometimes, of all these feelings inside me. All these feelings are such a new and different aspect of my life to deal with, and they make me very fearful.

Another participant states that, "There's all this stuff down there and I think it all started building from the moment I started feeling pain in my stomach. So there's lots of scary stuff down there." These young adults feel scared of all these feelings, "I'm scared of my anger and all the other emotions that having Crohn's has caused in me." "Even just saying I have Crohn's disease creates scary feelings and tons of other stuff that's scary. My body is carrying this disease and then all these feelings along with it." All the participants feel that their body is carrying around a person that feels scared and unsafe with itself:

Rolling through life is characterized by a fair amount of fear. Fear of the disease and fear of all the

feelings the disease causes. I think it's almost like having panic attacks in an informal sense. I still wake up scared, and feeling all this stuff, and not knowing what to do.

An example of this theme from a male participant goes as follows, "Not knowing what to do with all these feelings but actually talking about them is helping somewhat. You just carry this stuff around from so many things." All of them believe that their illness has caused them to feel a lot of fear in different types of areas:

You can get nervous about things for no reason. Well I don't know if it's actually for no reason, I mean you've got this disease, so I'm sure that helps to really screw you up. I certainly wasn't this way before. Everything's fine, but this illness has caused you to become like that. Feeling so much fear, and then feeling fear because of feeling fear. If that makes sense, cause you see, I have feelings of fear, and then just feeling that fear and knowing it's there causes even more fear, and it kind of goes around in a vicious circle I suppose. That's how I see it.

Another illustration of this theme is told as follows:

I'm trying to become more aware of what I'm feeling, and try to get rid of it some healthy way. There's all this scary stuff and if I don't get rid of it it's just going to build on top of each other and cause me even more unbelievable fear.

These overwhelming emotions can, at times, become too much to deal with and cause these young adults to feel afraid.

5. The experiences of young adults with Crohn's disease or colitis involve a great deal of change and adjustment in many dimensions

Change and adjustment is another important aspect of living with Crohn's disease or colitis. These changes are very much focussed upon in the interviews and written narratives.

"I've had to adapt to much new and it's just an ongoing thing. It's like living a totally different life sometimes." The changes to the participants' lives and the "new and different things" they have had to go through since developing their illness have been "overwhelming" for them, "I sometimes don't think I can handle all the changes, changes in health, changes in how others see me, changes in how I see myself. It's strange when you start to see yourself as a patient." Frequent visits to medical professionals was something new for these young adults:

I rarely saw my doctor and then all of a sudden I'm in his office just about every week. I have to rely on his ability to take care of me, and so you feel like you can never be truly independent. I have to rely on the medical world. The only times I was ever in the hospital was when I was visiting someone else, and now I'm a regular face in the halls. It's really different

when nurses recognize you, or you begin to feel like you have your own surgeon. It's definitely new for me, but an experience I could live without. It's a huge new thing in my life and I hate it.

Another participant states, "It has caused huge changes in my day to day living and have to somehow adapt. I have to find different coping skills for life." "It is such a new and different aspect of my life to deal with." "Dealing with change is an ongoing struggle with Crohn's disease and a struggle it is. I don't even know what I can eat anymore, something as simple as that." Significant changes in eating habits is also something different for them:

I used to eat anything I wanted, when I wanted, and it's not like I didn't eat healthy, it's just that I didn't have to spend every minute of the day thinking about it. Now I do, and it's weird. You almost have to become obsessed with your food intake. Now my whole life revolves around foods I can and can't eat, and when I can and can't eat them.

Another example of this theme is expressed by a participant with Crohn's disease, "Having to pay attention to my diet is something totally new for me, and I sometimes forget to, which isn't a good thing. So it's a huge change to have to think about it so much." Crohn's disease or colitis has changed the participants' lives "drastically." As this participant emphasizes:

In every area of my life this disease has created huge

changes and I'm only now realizing how they have affected me. Actually I still don't really know what the long term affects of all these changes are going to be.

Another participant states that, "I have experienced out of this world change since being diagnosed with this illness, and it's probably going to be a life long adjustment." In the following statement this theme is clearly present:

I've always been a person that could adapt to most situations, and it's a good thing because there is lots to adapt to with Crohn's. I'm sure it's affected me in a big way to the point of changing me as who I am.

The participants' personality is another thing that has changed and adjusted since developing Crohn's disease or colitis:

I think it's impossible to have this disease and not have it affect who you are in some way. People have told me that I have changed as a person and I agree with them. I guess the biggest change is I probably live more for the moment and don't plan as much for the future. That isn't necessarily a bad thing either, but I've also become more timid, which I do judge as a negative thing.

All these young adults stated adamantly, "without a doubt," that they have "changed in many ways."

Going through everything involved in having Crohn's disease or colitis is "overwhelmingly new" to these young

adults and has created change in many dimensions of their lives. Having to start living with a chronic disease has caused different routines in the participants' lives:

You get up in the morning, you have to make sure you get plenty of sleep, you have to make sure to eat certain foods, and then you take your medication. You have to be really conscious of all this stuff.

It is a "big change" for them to go through:

Spontaneity kind of goes out the window, generally, everything seems like it has to be so planned out, just in case you get sick or something, and you need to have some way of getting out or something. This is all stuff I never thought of before, so Crohn's certainly has changed the way I deal with my life.

All these young adults state that having Crohn's disease or colitis has altered their life, "it's basically changed my life." "My life is barely a reflection of the one I had before Crohn's, and that is the truth. The truth in life now has changed, and it is much more painful than what it was." "I am faced with something very new and unpleasant to deal with and it has changed my life."

5.1 Self

"My personality is another thing that has changed since developing Crohn's disease." These changes and adjustments in personality are clearly spelled out in the stories:

I've changed as a person, and some good and some bad. I try to enjoy the things I have to their fullest, and that's good. But there's so much bad, like being more socially scared, being less of an active participant in life and more of an observer. These are all core changes to who I was as a person.

These young adults state that they "definitely have changed" as people since developing Crohn's disease or colitis, "I'm a completely different person because of my disease, I know I have changed." A participant with colitis expresses the effects of these changes in self thus:

I think it takes me longer to trust people now because I need to know that they can handle all the gross stuff about me which is involved with my disease, and I know it's kind of weird, but that's the way I've become now. I need to feel comfortable with a person if I'm going to spend time with them.

Another participant states that:

I'm scared of so many things now, and I don't really know why. Well know that's not entirely true. I do know some of the reasons why, such as I'm living with an illness that could rear its ugly head at any time. I've gone through so much and I don't really want to go through anymore.

Another example of this theme is given by a female participant who told of her experiences as follows:

So maybe I've also become more of an avoider of things,

especially unknown things, because there is already so much unknown in my life, and this is definitely a change in way of being for me. So this disease doesn't just change your physical being but I think it changes you right down to the core of who you are.

They state that they are "definitely changed" people "inside." "I'm not the same person I was, and I sometimes long for the person I was. I could just live life without all this anxiety inside." An example of this theme from a male participant goes as follows:

I know I've become more of an escapist, and what I mean by that is not taking drugs or alcohol, but going inside myself more. I probably could easily become an alcoholic or something but I still do care enough about myself to avoid having that happen, and so being an extreme introvert when I was once an extrovert is bad enough. I spend more time on my own.

The following statement echoes this theme, "I think I'm more lonely now because it's harder to be out there as a person, and you don't have as much confidence because you're sick. When you're sick you stay inside yourself more." They emphasize that the cause of these changes is their illness. "I was way more outgoing before I developed Crohn's, and I was completely comfortable with myself. Now it's a struggle to get to that place again." The following statement continues elaborating on this theme:

My disease has altered my personality because I can

never really feel safe with it, and I only feel comfortable around certain people. Security and comfort are two big words in my life. Especially when I'm sick. It's amazing how when I'm feeling better that my way of being becomes more similar to the way I was before developing my disease.

Another illustration of this theme is told as follows, "I can be two different people, sometimes the sick, quiet, blah person or the well, outgoing, energetic person, and this can be confusing. I think these changes are definitely hard for the people around me." The participants state that one of the experiences involved in having Crohn's disease or colitis is some change in their personality, "I've become very introverted and somewhat depressive since developing Crohn's disease." "I suppose more depressed is a way of putting it and lack of motivation for life. You know, that vigor or something for life, that's really changed." All of these young adults adamantly assert, "without a doubt," that they have "changed in many ways."

6. The experiences of young adults with Crohn's disease or colitis include deprivation of some of their control over their lives

The participants state that there is "little control" over their lives with having their illness. These young adults related stories involving the feeling of being "deprived of

some of the control" over various aspects of their lives since developing Crohn's disease or colitis:

Crohn's has taken so much from me, including my ability to direct the own play of my life, and this is so rampant in my experience. Like for my body, it just does its own thing now, well not its own thing but its disease thing.

They all long for more control over their body and their illness:

I do search out as many ways as possible to add more control to my life, and sometimes it's good, and sometimes it's not very successful. Actually, generally I just fool myself into thinking I've gained control of my disease.

For many of the participants nothing seems to have been successful, so far, in helping to gain more control over their bodies and their illness, "I try, but it controls your life." "You end up just giving up, and letting it do whatever it does, because you realize that you don't have control anyway. It's not very good, I know." Their illnesses have deprived them of some of their control over their lives, "it's directing my life." "Where I want to go and where colitis will allow me to go may be two different things. It seems to have much more control over my life path than I do at the moment." By reading their stories it is easy to discern the "decrease in control" they experience.

6.1 Weight

As stated above, the participants have related several stories involving the feeling of being "deprived of some of the control" over various aspects of their lives since developing Crohn's disease or colitis. These feelings emerge in different ways, one of which is the "loss of control" over their weight. "One month I'm close to my ideal weight and the next I could have lost ten pounds. For me that's not a good thing." These young adults state that there is such a "minute amount of command" over one's weight, "This illness has caused my weight to fluctuate quite a bit." Another participant indicates:

If I don't eat meals every three hours, and I sometimes have to force myself to do this, I could lose weight just like that. You don't really have much control over it I suppose, especially if you've had operations to remove some of your small intestine, because that's where most of what you eat is taken into your body.

The experiences of young adults with Crohn's disease or colitis contain difficulty in the management of their weight, "I lost weight. Sort of like on a roller coaster. If you're feeling well you gain weight, if you're not it just peels off you. I was losing weight before I knew it." "I don't even care about my weight anymore, really. You come to realization that you can't do much about it, so why obsess about it"? They believe an affect of having Crohn's disease

or colitis is that it causes their weight to change often and they experience this as something they don't have very much control over.

7. Types of experiences include feeling violated

Feeling "violated" from some situation involved in having their illness, is another experience the participants encounter. All these young adults experienced some form of "assault" from different aspects of having their illness. "Having colitis has caused me to experience a lot of degrading things in my time, and I still don't know their true effects. But I sure know they have affected me." Many of them point to this violation as "one of the hardest things to deal with."

I will now here continue to sketch more clearly two further sub-themes of "violation.":

7.1 Drugs

All participants experienced some form of "violation" from different aspects of having their illness. One type of "violation" mentioned is from the drug plans they are put on, "You pop all these pills, and some of them are so big you scratch the back of your throat with them. Some are even sharp-like, and I don't understand the reason for that." These young adults tell many stories of "all the strange

medications" they are put on, "I think one of the hardest things to deal with in terms of my illness was being on various different medications, especially steroids." In the following statement this theme is clearly present:

So you're put on drugs to help but then there are all the side effects that you have to take different drugs for to counteract. I don't know how to feel about my body anymore when I have to put all these foreign substances into it.

The participants emphasize being on various medications as "a very difficult aspect" of having Crohn's disease or colitis:

Sometimes I just want to stop taking the pills, but I know in the end that would be the wrong decision. I still worry though of the long-term affects of taking all these drugs, and I don't think anybody really knows, because a lot of them are pretty new.

They see these drug treatments as having a "large effect" on their bodies, "I was taking steroids and my face puffed up, my muscles got weak, I even experienced bizarre mood swings. That stuff is hard on you, and the people around you." These young adults point to this violation as "a hard thing to deal with."

7.2 Medical procedures

As stated above, all participants experienced some type of "violation" from various aspects of having their illness. Another form of "violation" mentioned is from the medical procedures they are put through:

This is really difficult to talk about because I sometimes still have nightmares related to some of the tests that I went through in the hospital, and I don't know how to live with it really. I find this really, really difficult. It's hard to explain because it was all done in the name of healing.

"Desecration" from the medical procedures is something the participants experience:

I don't know what it's like for a male, but for a woman it's horrible because generally the doctors are male, and I know to them it's just a job, but maybe that makes it even worse, I don't know. I do know that I felt completely ripped apart by some of those experiences.

Another participant states that, "I feel it's all about shame, and agony, and humiliation." Another example of this sub-theme is given by a female participant who told of her experiences as follows:

You go through these things in order to find ways to help, but then you're left with having to deal with the affects of these things, and they're all pretty

horrible. The disease itself is bad enough, but wow, those tests are something else.

These young adults point to the violating medical procedures that they had to go through as a difficult experience in having Crohn's disease or colitis, "Gross test after gross test." "I never ever talk about what happens behind those closed hospital doors, and what it's like. I think people would squirm." They emphasize the violation that they felt, "They saw a body that could be turned upside down, and shove things up and down it, lights poked up it." "It takes a while to be able to connect with your body again. It's like it was somebody else's body for a while."

8. The life experiences include feeling anger

I would like to end this "General Structure" section by discussing anger. The life experiences of young adults with Crohn's disease or colitis include feeling a great deal of anger. "Of course you feel angry. You've been ripped off big time." The participants "feel rage", "I remember feeling angry." "It's taken so much away from you, so you can either be depressed or you get angry, and I think getting angry sometimes is the better choice. Life is hard, so get angry." They "feel angry" because, since developing Crohn's disease or colitis, "life is very hard." "I'm mad because my old life was taken from me and replaced with a life that is ten fold harder. I'm real angry that I have this damn disease."

These young adults "feel angry" when they think about how "easy things were" before they had Crohn's disease or colitis, "Sure things were easier when you have a healthy body, but Crohn's has taken that away from me, and now I have an illness that I'll have for the rest of life. Yeah, I'm angry."

Several of the participants experienced angry conflicts because of still trying to do certain things that they really wanted to, although others tell them that they have to live a different lifestyle now that they have Crohn's disease or colitis. Many of them wanted to continue in all their life activities and had feelings of anger towards other people that argued with them and told them to restrict their activities:

Others around me, in my life, did not quite like my plans to continue on with university and studying again in the fall because of my colitis, and that made me angry because I wanted to and was going to continue in the fall.

Although angry because of being told to limit activity, several participants appeared to think that this was probably necessary "I am going to no matter what they say about having to restrict my activities. Unfortunately, part of me thinks that they're likely right."

Dealing with their disease causes feelings of irritation:

Dealing with this whole thing is a hassle. It's

frustrating because it takes you out of your life, just like that. You can be living, doing your thing, get sick, and end up in the hospital. Being angry sounds to mild. I hate it, hate it, hate it, hate it.

The following statement continues elaborating on this theme, "I don't like being angry, but sometimes I can't help it, and I have to deal with it. Oh great, another thing I have to deal with, and that makes me even more angry." The participants "feel angry" when they think about "how difficult life is now."

CHAPTER FIVE

Discussion

The present chapter will include a restatement of the important question in this study. Along with this restatement, a summary and discussion of the results obtained from the investigation will also be covered. Finally, the research and counselling implications, as well as the personal meaning of this study will be discussed.

The issue of central importance in this study was that of the life experiences of young adults with Crohn's disease or colitis. Several invariant threads ran through the types of life experiences described by respondents. The life experiences of young adults with Crohn's disease or colitis, as described in this study, has been conceptualized as being made up of common themes. Unpredictable activation of symptoms occurred for the participants of this study. Grief and loss was another component reported in the process of living with Crohn's disease or colitis, either of performance abilities, body and positive body image, or enjoyable activities. The experiences of these young adults involved a notable lowering of self-esteem. In this inquiry participants emphasized feeling fear or anxiety - over their illness, of the hospital, over tests, of seeing significant others worry, and of overwhelming feelings caused by their illness. Change and adjustment was described as a common experience for these young adults, including changes in

certain aspects of their personality. Participants' experiences involved major changes: academic, social, and personal which they had to attempt to adjust to. Deprivation of some of their control over their lives was frequently reported as an ever present ordeal, including loss of control over their weight. Another common experience for these young adults came in the form of feeling violated, including violation from many of the medications they took into their bodies, and many of the medical procedures they were put through. Anger was a prevalent feeling for the persons in this study and has been listed as the eighth and final main general theme.

It is important to note that only one of the general structure themes, feeling a great deal of anger, was not mentioned by all 10 participants. Also, all themes for these particular participants have a propensity for being negative experiences. For example, the constantly accompanying threat of the unpredictable occurrence of symptoms causes worry and stress in the participant's lives. While the experience of grief and loss creates sadness and "depression". The serious lowering of self-esteem causes damage to the way they view themselves.

There were no representative differences found between the experiences of female participants and male participants. However, there were two minor differences noted. The first involves female participants, in general, placing more emphasis on the experience of feeling violated.

Although all these young adults mentioned the feeling of being violated, the female participants expanded on this theme much more frequently than the males. The second recorded difference concerns comments made by one female participant regarding feelings of fear over how her illness may affect having children.

These results provide basic information which helps to understand some of the specific components of living with Crohn's disease or colitis. This in turn allows us to see which particular variable might be the focus of intervention for those involved in the lives of people with these diseases. These findings can assist in increasing awareness of the influences Crohn's disease or colitis has on the life of a young adult.

The participants in this study described the constant accommodations that they must make in their lives and the social and psychological costs accrued by those adjustments. It points out that the work of managing Crohn's disease and colitis is more than just a matter of "illness management." The work takes place within the context of everyday living. Through this study of life stories of people with Crohn's disease or colitis the negative effects that many people with these diseases experience is well demonstrated in all of the stories considered here.

It is important to consider the participants' life stories within the context of their particular developmental stage. Young adulthood is frequently described as a period

of development during which dramatic life changes and transitions occur. Young adults are generally faced with taking on new scholastic or employment demands, personal obligations, and social networks. The participants talked about many changes and adjustments in their lives. They described numerous negative experiences involving such things as a decrease in their performance abilities at work and school, and a decrease in their social activities.

All themes for these particular participants having a propensity for being negative experiences may be due to the relative homogeneity of the sample. Nine of the ten participants appraised their health, at the time of the interview, as poor. Most described themselves as feeling sick and in pain. Many of the participants had never experienced any periods of remission.

Comparisons to Other Literature

In general, these young adults reported that they were plagued by aversive intrusions in everyday activities and regular existence. They indicated that they found their recent past, since being diagnosed with Crohn's disease or colitis, characterized by negative limitations on the experience of enjoyable activities. In light of research reviewed on Crohn's disease and colitis these findings show how the notion that either the illness itself or restrictions imposed by its management may interfere with functioning and disrupt normal living (see Steinhauer et al., 1982). The greater frequency of disturbance in normal

activity of young adults with a chronic illness is worthy of further attention.

The experiences described regarding feelings of anger established that this was a very prominent emotion for the participants. The results on anger are consistent with work done on psychological aspects of chronic illness in which the demands of a disease caused frustration and resentment (Steinhauer et al., 1982). Many of the young adults in the present study accented how having Crohn's disease or colitis frequently conjured up feelings of anger.

The current findings fit with research that has shown that upward mobility in work, often a major source of self-esteem, can be seriously limited (i.e. Steinhauer et al., 1982). An individual regularly encounters having to take time off of work when their illness acts up. The participants in the current study spoke often of how their work performance was substantially affected by their illness.

Prior research has indicated that if an illness frequently elicits discomfort from others, it may prove a serious blow to the person (Steinhauer et al., 1982). The present data depict this indication. Many participants emphasized how having Crohn's disease or colitis commonly evoked uneasiness from others and how this had an enormous impact on their self-image.

The young adults in this present study talked about issues involving feelings of uneasiness around people and

how this was one of the contributing factors to a lowering of some of their self-esteem. This is parallel to reports made by Steinhauer et al. (1982) that suggest that embarrassment or humiliation because of the disease may contribute to an alienation from peers who, offered appropriate assistance, could be a significant source of help for the chronically ill person.

The diminishment of self-esteem experienced by the participants appears to have an effect on several of their social relationships. Many of them speak of feeling uncomfortable in social situations. Wills (1985), in looking at supportive functions of interpersonal relationships, suggests that social relationships that are supportive and comfortable can increase feelings of self-esteem. Social integration can provide a source of general positive affect, a sense of stability in one's life, and a recognition of self-worth. However, relationships that cause discomfort can have the opposite effects (Wills, 1985). Previous research that examined social relationships from the perspective of young adults with cancer, indicated that the impact of cancer and its management, and the negative effects it has on self-esteem, influences negatively a young adult's capability of interacting in social settings, especially new ones (Lynam, 1990). The participants in Lynam's (1990) research felt a lack of confidence in approaching new social situations, they felt "vulnerable" and "exposed". Many of

the young adults in the present study also found social interactions difficult.

This connection between social competence and self-worth appears to be affected, in part, by the stigmatizing nature of Crohn's disease and colitis. Several of the participants experienced embarrassment which is perhaps tied to feeling stigmatized. For the young adults in Lynam's (1990) research, establishing new relationships was hindered by their embarrassment of their own appearances. Some of the young adults in the present study told of how having one of these chronic illnesses often causes others to look at them differently which brings about embarrassment and feelings of stigmatization. Many of the participants point to how their chronic illness frequently evokes uneasiness in others and how this causes a negative impact on their self-esteem. Some of them tell of how they try hard to avoid having people find out that they have one of these diseases in order to prevent any uncomfortable reactions, because these reactions cause feelings of stigmatization and create a diminishment in their sense of self-worth. Norbeck (1981), in his writings on social support, presents the view that diseases can create the potential for alienation of individuals from persons in their social system. Discomfort from others appears to make the young adults in the present study feel bad about themselves and influences their decisions regarding decreasing social activities. Occasionally the participants have also experienced the stigma of blame by

others for having their illness which was another noted contributing ingredient to a lowering of some of their self-esteem. Despite statements made related to the concept of stigmatization, there were not enough accounts given by the participants connected with this notion, to be able to include it as a sub-theme on its own. Although all the young adults reported being concerned about their reduced self-esteem, problems resulting from the possible stigmatizing effects of Crohn's disease or colitis were reported by only some of them. Perhaps the participants in this inquiry did not mention experiencing stigmatization as often as those with other illnesses, such as cancer, because the physical effects of Crohn's disease and colitis are not as readily noticeable as those related to having cancer. Clearly, more research is needed to establish the conditions under which those with Crohn's disease and colitis feel more or less stigmatized.

The young adults in this current investigation experienced overwhelming change, including change in how they saw themselves as people. Some of the participants talked about how they had become "escapists and avoiders". They saw themselves as lonely and isolated. This experience of being isolated can be seen to be related to some of the consequences of feeling stigmatized. As mentioned earlier, when discussing the self-esteem category, some of the young adults tried hard to prevent having people discover that they have Crohn's disease or colitis because they feel it is

inevitable that it will make others feel uneasy. These uneasy reactions then bring about feelings of stigmatization for the participants. Lynam's (1990) research suggests that many young adults with cancer experience feelings of isolation because of the inability of people in their lives to provide support comfortably. The situations of some of the young adults in the present study involved feeling isolated and appears to be related to experience of stigmatization involved in people reacting in uncomfortable ways towards them.

The participants in this inquiry talked about how their illness has led to extreme changes that burden many areas of their lives. Riegel (1975), in researching adult life crises, spoke of critical events as forming a focal point for change. Being diagnosed with Crohn's disease or colitis has created major life-changes for the young adults in the present study. The participants shared their experiences of change and described many of these changes as unwanted.

The theme of change and adjustment can be seen to be related to another of the primary themes in this analysis, that of grief and loss. Brammer (1991) states that change can be experienced as loss, as regular life is disrupted, and loss precipitates feelings of grief. The young adults in the present study experienced both a great deal of change in many dimensions of their lives and grief over the loss incurred by many of these changes. The experience of loss causes feelings of grief. Adjusting to the loss of past

capacity to fulfill one's life, or the loss of specific physical abilities, takes time, and possibly expert assistance. The difficult tasks for a person dealing with change and loss caused by an illness are both physical and psychological in nature with the psychological tasks often proving to be the more difficult (Brammer, 1991). The situations of the participants in the present study involved a great deal of change, loss, and grief.

When the young adults in this current inquiry were diagnosed with Crohn's disease or colitis they were forced to give up many things - performance abilities, body and body image, and enjoyable activities - and were compelled to make adaptations. The relation between grief and loss is apparent in this case of severe loss. Illness causes a change that involves crises and is laden with intense feelings of loss (Brammer, 1991). In considering the changes that the participants in the present study experienced in living with their illnesses, this grieving response is understandable. They went through a process of giving up the familiar for the unknown and scary.

The young adults in this investigation appraised their illness as something to which they needed to adjust to. Brammer (1991) suggests that adjustment is an automatic adaptational response to some form of change that is causing an additional burden in one's life. He proposes that adjusting to a situation may be the sensible thing to do

when it is futile to struggle against the changed circumstance (Brammer, 1991).

Ben-Sira (1982), in examining chronic illness, stress, and coping, found that change is an especially important aspect of living with a chronic illness. He states undoubtedly, that a chronic illness by far transcends the bounds of a reasonable course of life. He emphasizes how a chronic illness calls for a person to make modifications and adaptations which may be perceived insurmountable (Ben-Sira, 1982). The participants in the present study experienced overwhelming changes in numerous areas of their lives.

Relationships with others appeared to go through change and adjustment for these young adults. Although there was not enough mention of this change in relationships to include it as a sub-theme, adjustment to the way the participants behave in social situations exist in their experiences. Additional investigations would be useful to more fully explore the theme of change in relationship environments of those with Crohn's disease and colitis

Ben-Sira (1982) found that the chronically ill person has to cope with new demands which have the potential of stripping a person of control over their life. A powerful theme established in the present findings concerned the deprivation of some of the young adults' control over their lives. The young adults in this study live much of their lives feeling little control over the path their situations are to take.

A strong primary theme found in this research involved the constantly accompanying threat of the unpredictable occurrence of further episodes. A frequently mentioned concept, that is strongly related to this theme of unpredictability, was the notion of uncertainty. Ben-Sira (1982), established that the uncertainty of a chronic disease's prognosis, particularly, the constantly accompanying danger of the unforeseen incidence of other bad episodes is a particularly important aspect of living with a chronic illness. Uncertainty, as defined by McIntosh (1976), involves the inability to accurately predict outcomes. According to Mishel (1984), uncertainty is generated by events characterized as unpredictable, unfamiliar, or lacking information. Mishel (1981) suggests that in the illness experience, uncertainty has four forms: ambiguity in respect to the state of the illness, complexity regarding the treatment and the method of care, lack of information about the diagnosis and seriousness of the illness, and unpredictability as to the course of the disease and prognosis, including how often and for how long hospitalization will occur.

Two sub-categories of the fear and anxiety theme established in this investigation concerned the unknown aspects of Crohn's disease and colitis, and the unknown aspects of the hospital. These sub-categories of fear and anxiety can be seen to be related to the overriding feeling of uncertainty found in Theme 1. However, Theme 1 deals

specifically with the unpredictability of symptoms, while the present theme deals specifically with fear and anxiety. These young adults felt scared when they first began feeling sick and also feel anxious because not much is really known about these illnesses. In addition, the participants become fearful when faced with all the new experiences involved in being hospitalized. Mishel (1981) found that limited prior experience with hospital events may intensify uncertainty. Many of the young adults in the present study expressed how they had never really experienced being in the hospital and were uncertain as to what was going to occur. These uncertainties impose huge demands on the chronically ill person. Along with uncertainties specific to the illness, the timing of onset of Crohn's disease and colitis is at a time when developmentally there are many uncertainties about one's future. There are also uncertainties about the changes in one's body during this time. Therefore, the primary theme involving the constantly accompanying threat of the unpredictable occurrence of further episodes and the two sub-categories of the fear theme warrant further investigation in relation to the larger concept of uncertainty.

The results obtained involving unpredictability and uncertainty share similarities to those collected in Wiener's (1975) study on the burden of rheumatoid arthritis in persons 28-30 years of age. She reported that people with rheumatoid arthritis learn, over time, that its flare-ups

and specific manifestations are unpredictable. It imposes the burden of total absence of predictability. There is uncertainty about such things as: (1) whether there will be any pain or swelling; (2) the area of involvement; (3) how long it will last; and (4) how frequently flare-ups will occur. Under this condition of variable uncertainty, one of the critical affects is psychological, involving having to monitor pain every day, or even every hour. The results obtained in the present study also included the theme of constantly accompanying threats of unpredictable occurrences of symptoms.

Wiener (1975) also found that a reduction of performance skills may occur for those with arthritis, attributable to factors that included loss of body strength. A weakening and then wasting of muscle may occur above and below the affected joint, causing a loss of strength. Having Crohn's disease or colitis caused a variety of losses for the participants in the present study, including loss of performance abilities, and bodily strength.

The present research provides clear indications of how having a chronic illness can prompt reminiscence about former good times and lead to grief over the loss of these easier times. These findings illustrate those reported by Cohen and Lazarus (1979), and Weisman and Worden (1976). Their studies of peoples' experiences with serious illnesses, identified coping behaviours. These studies found

typical coping strategies to include reminiscences about former good times.

In general, this sample of young adults reported that they experienced loss over not being able to do more physical-type activities since developing Crohn's disease or colitis. In light of phenomenological research on other chronic illnesses, these findings are consistent with the notion that an important characteristic of chronic illness is that there is a noticeable loss in physical ability. Haase's (1987) study showed that chronically ill adolescents diagnosed with either leukemia, chronic renal failure, cystic fibrosis, recto-vaginal fistula, pulmonary stenosis, or scoliosis experienced extreme loss of physical ability. Difficulty with physical changes and the effect they have on daily living and quality of life was a prominent theme for the participants in her study. Physical changes, at times, caused more concern than the actual disease (Haase, 1987). The themes of feeling a great deal of anger, and lack of control, present in the current study, delineate another finding of Haase, that anger, and feeling a lack of control is a common response to many situations involved in having an illness. Also, in her investigation, she found that experiences of uncertainty over the outcomes of the various illnesses was a prevalent theme. The concept of uncertainty is also present in the current study and, as discussed above, can be found within the primary theme of

unpredictability and within two of the five sub-categories of the fear and anxiety theme.

The present study found a marked increase in feelings of fear or anxiety over the unknown aspects of chronic illness, and of medical tests. Hasse (1987) found that fear of changes in physical status, disease reoccurrence, and the intrusiveness of procedures were three common themes. Experiencing unpleasant but necessary medications was another theme found in her study. The participants in the present study experienced feeling violated by the drugs that were prescribed for their illnesses. Thus, the young adults in the current study share some of the same experiences of those with leukemia, chronic renal failure, cystic fibrosis, recto-vaginal fistula, pulmonary stenosis, and scoliosis studied by Hasse (1987).

In addition to the findings that concur with previous research, two notable sub-themes emerged from this investigation that were not clearly illustrated in the literature reviewed. Participants in the present study showed that one of the types of important experiences involved in living with these chronic illnesses was that of feeling anxiety, specifically caused by overwhelming emotions brought about by having to deal with their illness. A marked increase in feelings of fear and anxiety over the unknown aspects of chronic illness, and of medical tests were themes found in Hasse's study (1987), however, the young adults in this current study also felt anxiety caused

by experiencing overpowering emotions they encountered because of having Crohn's disease or colitis. An examination of this theme indicates that many of the participants feel frightened and unsafe carrying around all these strong emotions. One may assume then, that some form of counselling, although perhaps not necessarily helpful for the treatment of the physical symptoms of these chronic illnesses, may be conducive to the emotional health of those living with these illnesses.

The primary theme of change and adjustment in many dimensions, included the sub-category of perceived changes in self. It was found that these young adults experienced a change in their "personalities" since developing their illness. An examination of this theme indicates that being less of an active participator in life is one of the changes in self experienced by these participants. Many reported feeling like a entirely changed human being because of their disease and yearning for the person they once were. It appears possible that experiences involved in having Crohn's disease or colitis may actually cause notable changes in that persons representation of self. While this element has not clearly surfaced in the literature reviewed, this theme is strongly noted in the present study.

Some previous research suggests that Crohn's disease and colitis may have been caused by emotional and psychological disturbances (Arapakis et al., 1986; Castelnovo-Tedesco, 1966; Freyberger et al., 1985).

Although, three young adults talked about cause, the other seven made no mention of this issue. Therefore, this topic appeared as a non-salient theme in the current study. The lack of importance placed upon this topic by most of the participants in the present study, in general, may suggest that their experiences of living with Crohn's disease or colitis, did not highly involve the question of whether their illnesses were caused by some type of emotional disorder or not. Perhaps, because of this idea, today, being generally discounted, this was no longer a prominent issue for them.

Implications for Research

Through this study a whole host of questions in connection with the life experiences of young adults with Crohn's disease or colitis have presented themselves. Many of these new inquiries are specifically related to the general themes. These include such questions as: Would some form of counselling benefit these young adults in dealing with grief and loss, self-esteem issues, overwhelming feelings caused by illness, including anger? Does the marked increase in fear and anxiety over the illness, hospital, and tests, affect other domains of life? Would providing more information regarding tests alleviate some of the fear surrounding them? What are the positive changes involved in adapting to Crohn's disease or colitis? What are some healthy ways for a young adult with a chronic illness to gain more control over their life? Could the experience of

persons with an illness be made less violating? In addition to questions specifically related to the general themes, related arenas for inquiry could involve the exploration of the nature of change in key relationships of persons with Crohn's disease or colitis. For example, how might friendships or family relationships be transformed when one has a chronic illness?

Another group of questions that arise from this study include speculations concerning the nature of changes in the world of work or school. Does having Crohn's disease or colitis tend to precipitate, or involve, a process of career change? Are there particular kinds of work that tend to attract persons who have a chronic illness? Are there certain fields of employment that are more supportive of persons with an illness? This study, as a preliminary attempt to understand what people with Crohn's disease or colitis experience in their lives, raises another pertinent question. Are the results applicable to other chronic illnesses? In every sphere of life, questions addressing the impact of having Crohn's disease or colitis could be explored.

Implications for Counselling

With 2,000 new cases of Crohn's disease and colitis being diagnosed each year, it is quite probable that persons within the counselling field will come across an individual attempting to live with one of these chronic illnesses. The results of the present study suggest that there are several

common themes among the experiences of young adults living with Crohn's disease or colitis. The qualitative data from this current study provides an understanding of the experiences of living with these chronic illnesses, which in turn could provide an increased awareness of how a counsellor could be more effective in supporting a person that has one of these illnesses.

One of the themes present in the data indicates a need for help around grief issues. Along with experiencing grief, a marked increase in feelings of anxiety was another common theme found in the present study. Counselling may help in dealing with these emotional reactions involved in having Crohn's disease or colitis. Counsellors who understand and perceive accurately the experiences of living with these illnesses may help the individual in dealing with these feelings.

Counselling, involving the emotional aspects of Crohn's disease or colitis (ie. grief, anxiety, and anger), may be improved if it is recognized that these illnesses will have major implications in many areas of an individual's life, including such domains as the loss of performance abilities at school and/or work, and participation in enjoyable activities. The more the individual deals with their anxiety, grief, and anger stirred up by having Crohn's disease or colitis, the better they may be able to deal with the physical demands of their illness and the additional strains imposed by their illness. On the other hand, failure

to deal with the emotional responses to having Crohn's disease or colitis may decrease the individual's ability to deal with the demands of their illness, thus increasing the likelihood of severe ongoing emotional distress over the losses experienced.

Participants in the present study lost a great deal as their past performance abilities became severely limited. Along with loss of performance abilities, restrictions on activities of the participants in the present study appeared to be inevitable. By emphasizing areas of satisfactory functioning and potential strengths, counsellors may do much to help the individual living with Crohn's disease or colitis achieve a balanced acceptance of their strengths and limitations.

Helping individuals deal with their anxieties so that they can deal with the demands of their illness may play a crucial part in minimizing more serious and long-lasting emotional distress. What is openly acknowledged is on the whole less ominous than that which is known but not discussed. Openly acknowledging feelings of anger may be another important process for young adults with Crohn's disease or colitis to go through. One of the common emotions found in the present study involved feeling a great deal of anger as a result of having to deal with Crohn's disease or colitis. Some individuals need a chance to express their anger in a healthy way in order to better deal with the management of their illness. Counsellors who continue to

approach the individual with empathy may be able to help them deal with their anger and other strong emotions in an appropriate way.

Given the wide range of limitations put upon career and/or education, when counselling a person with one of these illnesses, specific attention may need to be paid to supporting them through the great deal of changes they will likely go through. Adjustments to transitions was a common theme for the young adults in this study. With an increased understanding of the many adjustments those with Crohn's disease or colitis must make, the potential for providing better therapeutic intervention during these transitions increases.

The diagnosis of Crohn's disease or colitis precipitated many changes in the lives of the participants in the present study. The counsellor who recognizes the potential for negative affects that, according to the results in this current study, are inevitably produced, may do much to minimize the destructive effects and aid the individual in adapting to life with an illness. The participants in the present study were seen as having to constantly adapt to situations that they felt were out of their control. They have the day-to-day struggle of trying to keep some sense of balance and control within all the changes and give meaning to their lives as they attempt to manage their chronic illness.

It appeared to be quite difficult for the young adults in the present study to have a sense of control with having Crohn's disease or colitis. Perhaps in this case what a counsellor might do is provide some form of confirming the areas in the young adult's life where they can have a sense of control. The counsellor can help the young adult with Crohn's disease or colitis focus around the areas where a sense of control is possible.

For young adults dealing with these illnesses, counsellors might help by working with them using a more Client Centred approach so as to allow the person a sense of control, a feeling they are not often allowed within their lives. Client Centred Therapy can be seen as a useful style of counselling for allowing a client to have more of a sense of control over the therapeutic process and their lives. Client Centred Therapy attends to what is regarded as intrinsic processes of adaption. Client-centred therapy implies that people seeking psychological assistance are treated as responsible clients with the power to direct their own lives. It is assumed that the person can be trusted and does not need to be controlled by others who are in a superior and expert situation.

Counsellors may also consider group therapy for individuals with Crohn's disease or colitis. Discussing their feelings and concerns about how their illness has affected their lives with others who may have common experiences could provide needed support. The counsellor may

be helpful in this respect by assisting the young adult with Crohn's disease or colitis in finding people that may also be dealing with one of these chronic illnesses.

The evidence accumulated in the present study demonstrates that feelings of grief, anxiety, and anger can be a consequence of having Crohn's disease or colitis. Along with these various feelings, experiences of loss regarding performance abilities and participation in enjoyable activities, a great deal of change and adjustment, and a deprivation of control over one's life all appeared as resulting from having Crohn's disease or colitis. Counselling could be an important area where an individual would be provided with important psychological support in dealing with these many issues.

Personal Meaning

In the beginning of this study, I was motivated by the hope of providing more illumination of what living with a chronic illness was like, as it was being experienced by young adults. My interest arose out of my own experience with Crohn's disease and my role as a counsellor in supporting people dealing with various life issues. As I became immersed in the study - with reading, with the interview dialogues and written narratives, with transcribing tapes of the sessions, with constructing the stories - I gradually became aware of how I too have lived

or am living through many, if not all of the experiences that the participants have had. These experiences have been transformed for me, over the duration of this study, into a deeper sense of what living with a chronic illness has meant in my life. This transformation is difficult to communicate in words, but the different feelings surrounding this new awareness has had an effect on how I see myself and my reactions to the world. It was as if reading the transcripts, over and over, created a richer intimacy with my own life. The themes repeated throughout the interviews and written narratives, flooded my thoughts with memories of my own experiences. As I explored these memories, I experienced an increased awareness of how living with a chronic illness has had a profound impact on who I am as a person.

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APPENDICES

APPENDIX A
RECRUITMENT NOTICE

RECRUITMENT NOTICE

PARTICIPANT RECRUITMENT NOTICE FOR YOUNG ADULTS WITH CROHN'S
DISEASE OR COLITIS

Young adults are needed for a research project on the nature
of life experiences of young adults with Crohn's disease or
colitis.

Participation involves two interviews of up to one hour and
a half.

If you are interested in volunteering and/or would like
further information please phone:

Glenn Matthes at 879-7790

Department of Counselling Psychology

University of British Columbia

Supervised by: Dr. Richard Young

APPENDIX B

Orientation to the Written Narrative

Orientation to the Written Narrative

The orientation to the narrative will now be described in general form:

As a follow up to our conversation over the phone here is a short orientation to the written story part of your participation in this study. This part involves writing a composition about your experiences with having Crohn's disease (colitis). This composition is like your life story or autobiography. This story is like a summary of your experiences in the order in which they occurred. It involves describing incidents and events which you feel were important or critical in your life.

All information from the story will be treated confidentially and be used for research purposes only. You only have to write as much as you feel you want to. If there are any questions or concerns you have regarding the written narrative please feel free to phone me. Here is a booklet of blank paper you can write your story in. Please bring your completed story to our interview appointment.

Once again, thank-you for your participation.

APPENDIX C

Introduction to the Interview

The introduction at the very start of the interview will now be described in general form:

Thank you ____ (name of participant) ____ for volunteering to participate in this study. I know I spoke to you a bit before about the nature of this study and its purpose, but I would like to briefly go over some of that information again to help make it clearer. If you have any questions about the research please feel free to ask them. This study is being conducted as part of the requirements for my masters degree in Counselling Psychology. Dr. Richard Young from the Counselling department is my supervisor.

I am trying to find out what it is like for a person in your age group to have to deal with Crohn's disease or colitis. Because we all live in different ways, one person's way of dealing with living with a disease can often be quite different than another person's way and I'd like to know how you've been able to live with your disease. The information from these interviews will help me understand how people in your age group experience dealing with Crohn's disease or colitis which in turn may lead to better ways of assisting young adults in their struggle to adapt to their disease. With your permission, I would like to use a tape-recorder to tape your story so that I can concentrate on listening to you now without having to interrupt you to repeat something that I would like to write down. The tape will be transcribed but any information that may identify who you

are, such as your name, will not be used. All information that you give me will be treated confidentially and be used only for research purposes. You may stop your participation in this interview at any time. At this time I would like you to take a look at this permission form (hand to participant). Please read it completely and feel free to ask any questions before signing it. Before we begin, are there any questions or concerns that I haven't addressed? (pause) To begin, perhaps you could tell me a bit about when you were diagnosed as having ____ [participants specific disease (ie. Crohn's or colitis)] ____.

APPENDIX D
CONSENT FORM

UNIVERSITY OF BRITISH COLUMBIA

The Life Experiences of People With a Chronic Illness:
Analyses of Crohn's Disease and Colitis

Consent Form

I, _____, consent to my participation in a research project regarding my experiences dealing with a chronic illness. This project is being conducted by Glenn Matthes (Ph. #. 879-7790) a graduate student of the University of British Columbia's Counselling Psychology program for his Masters thesis. He is being advised by Richard A. Young Ed.D, whom I may contact at 822-6380.

The purpose of this study is to examine how people make sense of the influences Crohn's disease or colitis has had on their lives. In this study the researcher plans to investigate individuals' perceptions of, responses to, and management of the life experience of living with an illness. The value of this study will be in understanding my experience of coping with chronic illness from my own perspective. I am aware that my participation will involve participating in an audiotaped interview. The interview will last up to two hours.

None of the data including the audiotape will be available to any persons other than the researcher and the researcher's supervisor. I understand that my participation in this research is voluntary and may be terminated at any time. I may refuse to answer any particular questions. Should I have any questions about the procedures, I may ask them at any time.

I also acknowledge receipt of a copy of this consent form.

Date: _____

Signed: _____
Address: _____

Ph. #: _____

APPENDIX E
DEMOGRAPHIC QUESTIONNAIRE

The Life Experiences of Young Adults With a Chronic Illness:
 An Analyses of Crohn's Disease and Colitis
 Demographic Questionnaire

Principal Investigator: Glenn Matthes
 University of British Columbia
 879-7790

Note: This form is to be completed by the participant
 in the presence of the researcher at the
 beginning of the research procedures.

Project No. _____

Sex: Male _____ Female _____

Age: _____

What specific illness do you have?: Crohn's Disease ____
 Colitis ____

Year and month disease was diagnosed: _____

Are you receiving any type of treatment for your
 illness at the present time?: Yes _____ No _____

If yes, what type of treatment are you receiving?:

Have you ever had surgery for your illness?: Yes _____
 No _____

If yes, what type of surgery did you have done?:

How would you describe your health at the present time?:
 Very Good I _____ I Bad
 1 2 3 4 5

Is there any other information you feel the researcher
 should be aware of before the procedures begin? If yes,
 please provide it here:

APPENDIX F
Sample Interview Questions

I'm wondering if Crohn's disease (or colitis) has had any influence on your life.

- What is it really like having a chronic illness?

- Do certain people in your life play a part in your dealing with the disease?

- Do certain places play a part in your dealing with the disease?

- Are there any other things that play a part in your dealing with the disease?

I'm wondering how you have responded to having an illness.

- How have you dealt living with a chronic illness?

What do you think causes Crohn's disease or (colitis)?

When was your chronic illness diagnosed?

- I'm wondering if you think your emotions or personality caused your illness in any way.

- Do you think counselling would be of any benefit in helping you to deal with your disease?

- Do you think counselling would have any effect on the bodily symptoms of your disease?

I'm wondering how you have attempted to deal with your illness.

- Have you had to change your behaviour in any way since developing your illness?

- Did you have any future plans that you felt you had to alter because of your illness?

- I'm wondering if you have ever had to alter your activities because of your disease.

- Has your life changed in anyway because of your illness?

Have you ever sought help from others (apart from your doctor) in dealing with your illness?

I'm wondering if you think your age effects how you deal with your disease.

- Has having a chronic illness changed your social life in any way?

- Has having your illness changed the way you view your body?