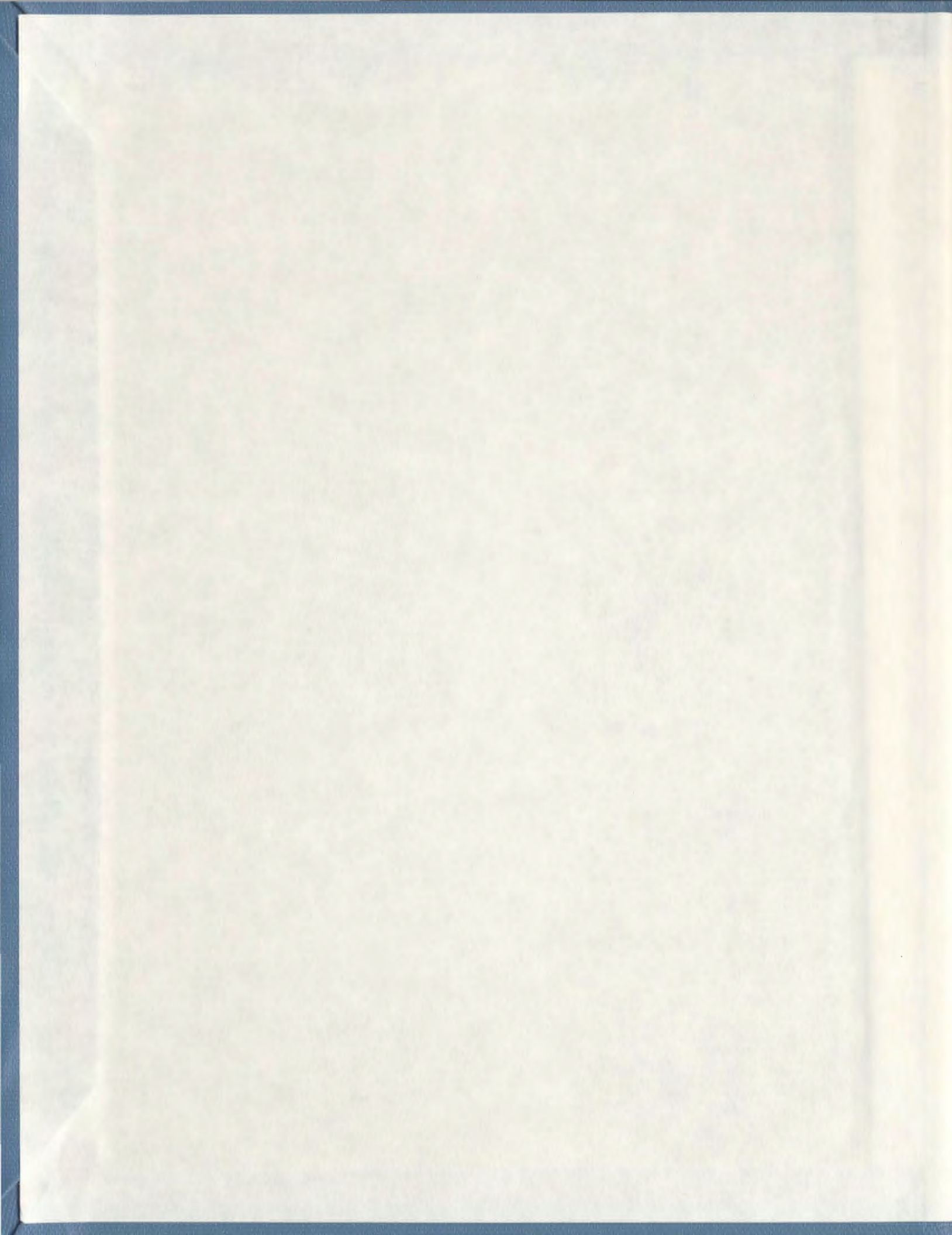


YOUNG ADULTS LIVING WITH INFLAMMATORY
BOWEL DISEASE:
A PHENOMENOLOGICAL STUDY

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by

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Abstract

Inflammatory bowel disease (IBD) is a chronic condition affecting the digestive system. It is characterized by periods of exacerbation and remission and often poses many difficulties for those living with the disease. Young adulthood is a period with many life transitions. These transitions coupled with living with inflammatory bowel disease present unique challenges for young adults. The purpose of this study was to explore the experiences of young adults living with inflammatory bowel disease. There was little qualitative research available on the topic of living with inflammatory bowel disease. It was decided that a phenomenological research approach would provide rich, in-depth description, and understanding of the experience. Three young adult women who met specific criteria participated in the research study. Collection of data occurred through un-structured interviews. Colaizzi's (1978) method of data analysis, including bracketing of assumptions, was used to identify seven essential themes, which when combined best describe the women's experience. The seven themes identified were: (1) dealing with symptoms: a constant struggle, (2) embarrassment: trying to hide the condition, (3) uncertainty: it could flare up at anytime, (4) lost time: interfering with normal life, (5) the double edged sword: treatment can be as difficult as the disease, (6) needing to maintain a supportive environment and (7) accepting the challenge of living with IBD. Through phenomenological inquiry into the lived experience of these young adults with inflammatory bowel disease, a greater understanding of their experience was gained. This understanding helps to enhance nursing's knowledge base on the phenomenon.

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TABLE OF CONTENTS

ABSTRACT	ii
ACKNOWLEDGEMENTS	iii
CHAPTER 1	
INTRODUCTION	1
Background	2
Ulcerative Colitis	3
Crohn`s Disease	4
Extra-intestinal Manifestations	4
Rationale	5
Research Question	8
Research Purpose & Objectives	8
CHAPTER 2	
LITERATURE REVIEW	9
Qualitative Research	10
Living with IBD	11
Food as a Coping Strategy	16
Experiences with Medical Treatment	17
Quantitative Research	19
Disease Impact	20
Coping	22
Psychosocial Functioning	23
Summary	24
CHAPTER 3	
RESEARCH METHODOLOGY	26
Participants	28
Recruitment of Participants	30
Setting	31
Data Collection	31
Data Analysis	33
Validation	34
Ethical Considerations	36
Summary	38

CHAPTER 4	
FINDINGS	40
The Women	40
The Experience of Living with IBD	41
Dealing with Symptoms: A Constant Struggle	41
Embarrassment: Trying to Hide the Condition	44
Uncertainty: It Could Flare up at Anytime	47
Lost Time: Interfering with a Normal Life	50
The Double Edged Sword: Treatment can be as Difficult as the Disease	54
Needing to maintain a Supportive Environment	56
Accepting the Challenge of Living with IBD	60
Summary	62
CHAPTER 5	
DISCUSSION	63
Living with IBD	63
Living with a Chronic Illness	67
The Shifting Perspectives Model of Chronic Illness	71
Summary	73
CHAPTER 6	
LIMITATIONS AND IMPLICATIONS	74
Limitations	74
Implications for Nursing Practice	75
Implications for Nursing Education	79
Implications for Nursing Research	79
Conclusion	81
REFERENCES	82
APPENDICES	
APPENDIX A: LETTER TO LOCAL GASTROENTEROLOGISTS/ NURSES	91
APPENDIX B: FORM PROVIDED TO PHYSICIANS/NURSES TO RECRUIT PARTICIPANTS	93
APPENDIX C: CONSENT FORM	96
APPENDIX D: INTERVIEW QUESTIONS	102
APPENDIX E: TABLE 1	104
APPENDIX F: HIC APPROVAL	106

Chapter 1

Introduction

Inflammatory bowel disease (IBD) is a chronic condition that affects the digestive system, and includes both Crohn's disease (CD) and ulcerative colitis (UC). IBD is characterized by periods of remission and exacerbation; the latter often poses a number of challenges for those who live with the disease (Mussell, Böcker, Nagel, & Singer, 2004). Living with IBD frequently requires long-term medication, hospitalization, and/or surgery as well as changes to lifestyle (Crohn's and Colitis Foundation of Canada (CCFC), 2007). Many factors have an impact on how a particular individual may be affected by IBD (Casati, Toner, deRooy, Drossman, & Maunder, 2000; Sainsbury & Heatley, 2005; Searle & Bennett, 2001). Age is one such factor, and although IBD can occur at any age, many of those living with the disease are diagnosed between the ages of 15 and 25 years (CCFC), and as a consequence often experience many of the challenges of living with the disease during their young adult years, when they are facing a number of developmental issues (Ruchala & Clauson, 2006).

Despite the many difficulties associated with IBD, qualitative research into the "lived" experiences of IBD is somewhat limited, particularly in the case of young adults, with quantitative research predominating (Vanderheyden, Verhoef, & Hilsden, 2006). Yet developmentally, young adults are experiencing challenging life transitions and these transitions, coupled with living with a chronic condition such as IBD, can create unique experiences, which need to be explored through rigorous inquiry. There is a growing literature on children's and adolescents' experiences with IBD (Nicholas

et al., 2007), but less research that focuses specifically on the young adult. Young adulthood usually covers the period from late teens to late or mid 30s, (Ruchala & Clauson, 2006). For this research I have identified it as from 19 to 29 years of age as that is the period when many individuals are establishing their adult roles. This is a study of young adults' experiences with IBD, using a qualitative, descriptive phenomenological approach that provides an in-depth description and understanding of the experience. This study was guided by the approach outlined by Colaizzi (1978) as this approach allows the researcher to "remain with the human experience as it is experienced" (p. 53).

Background

In order to gain an understanding of a person's lived experience with any chronic illness, a brief general overview of the scope of the problem and the etiology, as well as, disease manifestations is useful background in appreciating some of the challenges these individuals face. Since IBD is a chronic inflammatory disease of the bowel characterized by periods of exacerbation and remission, chronic recurrent destruction of tissues, as in the case of IBD, often leads to permanent scarring, which can impair gastrointestinal function (Thoreson & Cullen, 2007).

IBD affects approximately 170,000 Canadians (CCFC, 2007). Most commonly, IBD first appears in persons between the ages of 15 and 25 years, but can first appear between the ages of 45 and 55 years (CCFC). It can also have an earlier onset; occurring in the pediatric population (Hugot & Bellaiche, 2007). According to epidemiological research being conducted at the University of Manitoba and funded

by the CCFC, Canada is leading the world with the highest rate of CD and one of the highest of UC. Many factors have been identified as being associated with the disease, and different explanatory theories have been developed, but the cause of IBD remains unknown. Causative factors of IBD may include a genetic predisposition, as patterns of the disease tend to be of familial origin (Baumgart, 2008; Gomez, 2000; Lewis et al., 2007). While the exact cause is unknown, autoimmune dysfunction may also be implicated (Johnson, 2007). Although CD and UC are both classified under the term IBD and both result in inflammation, each condition has unique features and so I will present a brief overview of each condition.

Ulcerative colitis. Ulcerative colitis (UC) occurs only in the colon (the large intestine) and always affects the rectum, with disease continuing along the bowel from the rectum, and depending on the extent of disease can continue to the cecum (Thoreson & Cullen, 2007). UC is characterized by inflammation of the inner mucosa of the intestine, which results in ulceration that may cause abscesses and bleeding (Johnson, 2007). UC is also characterized by bloody diarrhea or sometimes constipation, depending on which part of the colon is affected (Thoreson & Cullen). False urges to defecate and tenemus (persistent pressure in the anus) can also be present, especially with rectal disease (Sabil, 2003). Abdominal pain, often felt in the left lower quadrant, is squeezing in nature and can radiate across the lower abdomen (Thoreson & Cullen). During an exacerbation an individual with UC may experience changes in appetite and weight, fever, chills, and sweats, along with the risk of

megacolon (non obstructive colon dilation and necrosis leading to potential perforation).

Crohn's disease. Crohn's disease (CD) is similar to UC but can occur anywhere from the mouth to the anus. It occurs most commonly in the terminal ileum extending to the cecum and ascending colon (Gomez, 2000). Like UC, CD is characterized by inflammation. Inflammation in CD can be patchy and frequently affects all layers of the intestinal mucosa, thus causing fistulas to develop (Johnson, 2007). CD is also characterized by abdominal pain, especially around the navel and in the lower right quadrant (Gomez). Pain is sometimes described as a steady, dull ache. It can be associated with a swollen abdominal mass and worsens with eating and during certain activity (Sabil, 2003). Discomfort can be accompanied by frequent diarrhea, fatigue, changes in weight and appetite, nutrient malabsorption, anemia, fistulas, abscesses, perianal disease, and even bowel obstructions.

Extra-intestinal manifestations. Both CD and UC can have extra-intestinal manifestations (Baumgart & Sandborn, 2007). These include painful joints, osteoporosis (especially with steroid use), skin disease (erythema nodosum and pyoderma gangrenosum), fatty liver, primary sclerosing cholangitis, gallstones, kidney stones (especially with resection of the ileum), eye problems, blood clotting abnormalities, pancreatitis, and malnutrition. It is possible for some or all of these symptoms to occur during exacerbation or treatment.

Understanding the pathophysiology of IBD is important in providing insight into the potentially devastating effects living with IBD can have for an individual.

Given the wide range of symptoms that a person who has IBD may experience, living with IBD would affect many aspects of daily living.

Rationale

Given the scope of the problem and the physical manifestations of IBD, understanding the effect on individuals with this condition is important. As IBD is often diagnosed during adolescence and young adulthood, and results in a wide range of physical and psychological challenges, describing and understanding the experiences of young adults who live with IBD is of utmost importance (CCFC, 2007; De Boer, Grootenhuis, Derkx, & Last, 2005; Mackner, Sisson, & Crandall, 2004; Nicholas et al., 2007).

One important reason that an increased understanding of the experiences of young adults who live with IBD is needed, is the number of children who are now being diagnosed with IBD (Hugot & Bellaiche, 2007). Anywhere from seven to fifteen percent of those diagnosed with IBD in western countries are diagnosed in childhood. Given the chronic nature of IBD, this means that these children will experience their young adulthood while living with IBD, thus reaffirming the importance of understanding what it is like to be a young adult living with IBD.

A second reason that this research is important is that chronic diseases are increasingly given greater attention because of the costs and burdens of chronic diseases to individuals and society in terms of health care costs, and lost time at work, as well as the decreased quality of life for the individuals who are affected (World Health Organization (WHO), 2005). Most of the discussion of chronic disease focuses

on cancers, cardiovascular and respiratory diseases, and diabetes with not much reference to IBD (WHO). Yet IBD is an important health problem and we need to understand more of the impact of this chronic disease on individuals. IBD and irritable bowel syndrome are the most common causes of chronic intestinal diseases and use anywhere between 30 to 50% of gastrointestinal services in the world (McFarland, 2008).

Living with a chronic disease such as IBD requires adherence to long-term treatments (CCFC, 2007). These treatments are critical in order to obtain and maintain remission of disease symptoms. Despite the necessity of long-term treatment, there are a number of barriers that have been identified and that result in individuals not adhering to treatment (Tumbough & Wilson, 2006). These barriers include the experience of side effects, fear of side effects, and the person's inability to understand the need for the medication when the disease symptoms are in remission. Poor medication adherence is particularly problematic during disease remission (D'Inca et al., 2008) and can lead to exacerbations of the disease. Exacerbations of IBD can have a huge impact on a young person's life, so prolonging and promoting periods of remission are essential. Gaining a better understanding of what it is like to be a young adult living with IBD may assist nurses and other health care professionals in their efforts to support and promote adherence to treatment and thus deal with some of the burden related to chronic disease.

Finally, young adulthood is characterized by major periods of life transitions, some of which may include attending post-secondary institutions and starting a career or getting a job, dating, and getting married, or developing a long term relationship, and beginning a family (Lenz, 2001; Ruchala & Clauson, 2006). It is also a period in life

when individuals find themselves more independent from their parents and take on greater responsibility. Independence, responsibilities, choices, changes, and stressors are elements of the transition experienced in young adulthood and present significant developmental challenges. These challenges, coupled with a chronic disease that revolves around the socially taboo and embarrassing subject of 'bowels' can impact significantly on all aspects of a young adult's life (Norton, 2004; Schneider & Fletcher, 2008).

My interest in the phenomenon of living with IBD also comes from my experience as a nurse. During my nursing career while meeting and working with individuals living with IBD, the desire to understand this multidimensional phenomenon emerged. I subsequently explored the research literature on IBD and found limited qualitative research on the experience of young adults living with this condition, despite the number of individuals who are affected. No research of this kind has yet been conducted in the province of Newfoundland and Labrador, Canada where I work and live. Most of the research that I found in the area of IBD had been completed from a quantitative or medical perspective and included individuals with wide age ranges. While these studies have provided important information about the disease activity and measures of quality of life, they have provided little insight into what it is like to live with this condition on a daily basis (Daniel, 2001). Gaining an understanding of the experience of IBD as "lived", is a necessary step in filling the knowledge gaps presently noted in the current research on IBD. Based on this perceived knowledge gap, the potential impact of IBD on the lives of young adults, and

my nursing observations, I decided that a deeper insight into young adults' lived experiences of IBD would be beneficial to nursing and other health professions.

Research Question

The specific research question was: What is the experience of living with inflammatory bowel disease for the young adult?

Research Purpose and Objectives

The purpose of the research was to explore the experiences of young adults with IBD using a phenomenological approach developed by Colaizzi (1978) and specifically my objectives were to:

- 1) describe their experiences; and
- 2) gain a greater understanding of this experience.

Chapter 2

Literature Review

A primary review of the literature on inflammatory bowel disease (IBD), Crohn's disease (CD), and ulcerative colitis (UC) was conducted using CINAHL, EMBASE, and PUBMED data bases, to get an overview of the research completed on IBD, that I felt was most closely related to my proposed research. Since the focus of the research was on young adults living with IBD, the search terms "inflammatory bowel disease", "Crohn's disease", and "ulcerative colitis" were each paired with "lived experience", "young adults" and "qualitative research". Thirteen qualitative research studies were located on living with IBD and all of these are included in the review of the literature. An additional study (Finfgeld, 2000) was located in a textbook on chronic illness (Miller, 2000) and I included that as well. When I began my research only three of the qualitative studies had been published.

A secondary review of the literature was conducted also using CINAHL, EMBASE, and PUBMED using the search terms "inflammatory bowel disease", "Crohn's disease", and "ulcerative colitis" combined with "chronic illness" and "concerns" or "psychological factors". These searches yielded a large number of quantitative articles, mainly related to quality of life, and those selected were based on the relevance of the findings to my study. For this particular section of the literature review I did not include those studies that were specific to young children, adolescents, or elderly. Much recent literature is on children and adolescents with IBD. I did include the article though if young adults were included in the study. In this

chapter I will first present a detailed review of those qualitative studies and a summary of relevant quantitative studies.

Qualitative Research

Fourteen qualitative studies were located that addressed either living with inflammatory bowel disease (IBD), (Brydolf & Segesten, 1996; Daniel 2001; Dudley-Brown, 1996; Hall, Rubin, Dougall, Hungin, & Neely, 2005; Nicholas et al., 2007; Schneider & Fletcher, 2008), living with aspects of IBD or treatment approaches (Fletcher & Schneider, 2006; Hall, Rubin, Hungin, & Dougall, 2007; Jamieson, Fletcher, Schneider, 2007; Rogers, Kennedy, Nelson, & Robinson, 2004; Rogers, Kennedy, Nelson, & Robinson, 2005), or living with a chronic disease that included IBD (Delmar et al., 2005; Delmar et al., 2006; Finfgeld, 2000). Some of the reports combined experiences with IBD and irritable bowel syndrome (IBS) as these two conditions share similar symptom experience and have some of the same dietary restrictions (Fletcher & Schneider; Jamieson et al.; Schneider & Fletcher), two were limited to individuals with UC (Brydolf & Segesten; Dudley-Brown), and the remaining studies included individuals who were diagnosed with IBD and included both CD and UC. Three of the phenomenological studies located were based on the same data set (Fletcher & Schneider; Jamieson et al.; Schneider & Fletcher), but had a slightly different focus. Two of the grounded theory studies were also based on common data, but each had a different focus (Hall et al., 2005, 2007). Both studies on UC and medical appointment type preference came from the same data (Rogers et al.,

2004, 2005), and the two studies on chronic disease that included UC, also came from the same data (Delmar et al., 2005, 2006).

The age groups of the participants in the studies varied somewhat. Five studies focused on young adults (Daniel, 2001; Finfgeld, 2000; Fletcher & Schneider, 2006; Jamieson et al., 2007; Schneider & Fletcher, 2008), one on children and adolescents (Nicholas et al., 2007), another on both adolescents and young adults (Brydolf & Segesten, 1996), while the remaining studies had a wider age range (Delmar et al., 2005; 2006; Dudley-Brown, 1996; Hall et al., 2005, 2007; Rogers et al., 2004, 2005). The methodological approach by the researchers also varied. Seven were based on phenomenology (Daniel; Delmar et al., 2005, 2006; Dudley-Brown; Fletcher & Schneider; Jamieson et al.; Schneider & Fletcher), four used grounded theory (Brydolf & Segesten; Finfgeld; Hall et al., 2005, 2007), one was based on an interpretive ethnographic approach (Nicholas et al.), and the remaining two studies were based on qualitative interviews with a subset of participants from a larger quantitative study on medical appointment preference for UC follow-up (Rogers et al., 2004, 2005). Despite these differences, they nevertheless provide important insight into what it is like to live with IBD.

Living with IBD

One of the earliest studies located on living with IBD was by Dudley-Brown (1996), who conducted a pilot study using phenomenology. She included three participants aged 30-58 years (2 men and 1 woman) who had UC. This researcher wanted to find out what it was like for these participants to live with this condition.

Themes identified were related to the uncertainty of the course of the disease because of the remissions and exacerbations, how emotionally difficult fecal incontinence was, the importance of finding a successful treatment and having a normal life, how much the disease affected all aspects of their lives, and how they felt controlled by UC. Her participants did vary as to how helpful they found health professionals in dealing with their condition and some of the concerns that they had identified. The number of participants was too small to identify variation within some of the other themes.

Also in 1996, a study by Brydolf and Segesten was published using grounded theory. It was a study of 28 adolescents and young adults aged between 11 and 28 years and based on the self-concept mode of the Roy Adaptation Model. The researchers wanted to explore how these individuals felt living with UC had affected their concept of self. Eleven of these individuals had an ileostomy; a condition that would have an effect on self-concept. The participants all identified how the disease created a “sense of alienation” both from themselves and their peers. The sense of alienation led to some restrictions in their lives that were influenced by how supported they felt, their level of self-confidence, and how mature they felt in dealing with the consequences of the disease. Support from parents and positive coping strategies made the disease process more manageable.

Finfgeld (2000) used grounded theory to develop a theory of courage as a management strategy for chronic illness. She focused on young adults aged 20 to 39 years and had some individuals with CD among the 21 participants (12 women and nine men); although the exact number with CD were not identified. All the participants had

some type of long-term health problem. The core variable identified was termed “becoming and being courageous” and in this process individuals learned how to struggle with their health problems and concerns, understand how to handle these concerns, engage in behaviour that enabled them to move beyond their concerns and even help others, leading to the final outcome of being able to thrive and maintain personal integrity, i.e., become courageous. These phases were influenced by both intrapersonal (e.g., hope and self-confidence) and interpersonal factors (e.g., role models, social sanctions, and health professionals). These findings suggest that courageousness in the face of a chronic illness is a learned behaviour.

Daniel (2001) used King’s Theory of Goal Attainment to study young adult’s perspective of what it was like to live with IBD. She used a “qualitative phenomenological descriptive method” (p. 85) as a means of learning about this perspective from five participants (2 women and 3 men) between the ages of 18-24 years. Some of the concerns all participants had in common were those related to their body image. They attributed these body image concerns to the side effects of treatment and embarrassment from bowel incontinence, the need for support, and being understood. The second most frequent concerns were grouped under growth and development issues and highlighted the participants’ desires of wanting to have a normal life and the concern over the effect the disease had on interpersonal relationships. Uncertainty about the disease and finding treatments that worked were also important; but not to all participants.

Hall and colleagues (2005) used grounded theory to understand the process by which individuals with a low quality of life come to understand and cope with IBD. They selected 31 participants (19 women and 12 men) who had scored the lowest on quality of life scores in a larger study on IBD. The participants varied greatly in age; being from 26 to 99 years of age. The core concept identified was “health-related normality” and this represented the social psychological process of the participants in their efforts to maintain normality despite the restrictions in terms of freedom, health, and normality that the disease imposed on them. The participants also identified a number of strategies that they employed in their efforts to maintain the normality they sought. These strategies were grouped under psychological, behavioural, social, and biomedical categories. Some of the strategies included learning to adapt and cope, making changes in lifestyle, planning trips around how available a toilet would be, seeking social support of both an informal and formal nature, and adhering to medication use. Embarrassment, the taboo associated with IBD, and lack of understanding surrounding the condition were definite barriers to the participant’s sense of normality.

Delmar et al. (2005, 2006) published two studies from a larger study on living and coping with chronic illness. They used a phenomenological approach and interviewed 18 individuals; six had “type 1” diabetes, six were diagnosed with UC, and six had coronary occlusion. The participants were equally divided by gender in each of the three diagnostic categories and their ages ranged from 18 to 75 years. The first study focused on achieving self-harmony despite having a chronic illness. Self-

harmony was related to the ability to accept their health status and maintain hope for improvement in their life situation. Hope centered around expectations of treatment and being able to lead a “normal life”. The second publication focused on how participants viewed their chronic conditions and self-management of these conditions. Important to the participants’ experiences were living with the contradictory relationship between both independence and dependence when they had a chronic condition and the importance of choice in order to participate in self-management. The participants also recognized the role that guilt could play in self-responsibility and self-control when it comes to living with their chronic illness. The authors believed there were no differences in the findings related to the type of chronic illness the individuals experienced.

As part of a larger quantitative study on quality of life in children and adolescents with IBD, Nicholas et al. (2007) used an interpretive ethnographic approach to understand how these young individuals experienced this condition. They interviewed 80 children or adolescents between 7 and 19 years of age. Included in the group were 44 men and 36 women; 61 had CD and 19 UC. These participants’ experiences were grouped under three broad categories of challenges; 1) concerns around symptoms and treatments, 2) a sense of vulnerability and lack of control over the disease process, and 3) negative self-concept and difference from peer group. Strategies that helped these young people cope with their condition were grouped under social support and personal resources such as having a positive outlook and identifying other individual strengths.

Schneider and Fletcher, (2008) used the same data set as in the publication by Fletcher and Schneider (2006) and Jamieson et al. (2007), but with one less participant, to identify some of the negative impacts IBS or IBD had on the participants' lives. Seven women between 18 and 22 years of age participated in the study. Phenomenological analysis was used for this data. Schneider and Fletcher focused on the physical and emotional domains of these women's lives. The women identified symptom experience and limitations in both food consumption and physical activity as the main physical effects of the disease. They identified helplessness because of the lack of control over symptoms, embarrassment around "bowel" symptoms, and guilt over cancelled social events because of symptom experience as the main negative emotional outcomes of having IBS and/or IBD. The findings illustrate how pervasive these conditions can be on a person's life.

Food as a Coping Strategy

Food consumption has an impact on IBD and watching or omitting certain foods is one strategy used to manage this condition. Using phenomenology, Fletcher and Schneider, (2006) studied eight women between the ages of 18 and 22 years who had been diagnosed with either IBD or IBS, to understand the strategies that they used to cope with these conditions. Food and beverage consumption strategies, and in particular understanding the particular foods and beverages that acted as "triggers" for a flare-up, were identified as the most common strategies used. As a consequence these women learned to avoid these foodstuffs. The need to employ these strategies was especially important when the women were away from their homes for meals. As

a consequence they also learned healthier eating patterns and learned a great deal about the relationship between food and IBD or IBS. The women acknowledged that stress was also a factor in their exacerbations and that the controlled use of food did not always prevent a flare-up.

A second publication exploring diet change necessitated by a diagnosis of IBD or IBS used the data from the same eight female participants as above (Jamieson et al., 2007). Information from a 14-day food diary enhanced the data from the interviews conducted with the participants. The researchers identified three main themes that illustrated how diet was related to the women's condition; control of disease, support from family and friends, and adverse or negative behaviours. The focus in the article was on how the women determined their diet and the important factors impinging on this determination. They also examined what role the physician played in giving dietary advice, what they learned from experimenting with food, the quality and type of information they sought, and actual modifications they made to the food that they consumed. Modification of diet did play a big role in helping these women deal with their condition and symptom experience affected the modifications they made. Use of diet helped the women feel more in control of their lives. They also felt that many physicians did not do much beyond prescribe medication and knew little about the role of diet in these conditions.

Experiences with Medical Treatment

Individuals with IBD are required to take long-term medication. Non-adherence to medication is a frequent problem among individuals with IBD. Non-adherence to

medication was a prominent theme in the study by Hall et al. (2005). As a consequence the same researchers used grounded theory to further explore problems around medication use and identify some of the concerns around non-adherence (Hall et al., 2007). The same data set as used in the previous study (i.e., Hall et al., 2005) reported above was used. Use of medication was related to health behaviours, such as, accepting the illness and a need for medication, concerns about side effects and being on long-term medication, and the impact of symptoms on their lives. Most of the participants engaged in self-management strategies and reported that the quality of relationships with their physicians varied a great deal.

Two of the qualitative studies located on IBD were part of a larger study that evaluated the change from a fixed appointment system to an open access follow-up with physicians (Rogers et al., 2004; 2005). The change in type of physician follow-up was initiated in order to be more responsive to individuals with chronic illnesses. The qualitative part of the study used a phenomenological approach. The aim of the first publication was to describe the patients' experiences with the new arrangement, i.e., open-access follow-up. Twenty-eight individuals with IBD (CD = 11 and UC = 17) and between the ages of 22 and 68 years took part in unstructured interviews. There were 16 women and 12 men. Most of the participants liked the change in follow-up and felt it was more responsive to their needs for medical follow-up with a disease that has an uncertain course. Some of the reasons reported for liking the new system were they could get medical attention when they felt they needed consultation and they felt it gave them more autonomy in managing their disease. Participants,

who were less likely to experience the change as positive, were those who felt less secure about the new arrangement or not wanting the responsibility for follow-up.

A second publication on the evaluation from a fixed-appointment to an open-access follow-up focused on changes in patient behaviour following the initiation of the new appointment system (Rogers et al., 2005). The same participants as the previously described study (Rogers et al., 2004) were included in this part of the study. In general the participants liked the new system as they felt it was more responsive to their needs and that it was more “patient-centered” and promoted a more equal relationship with the attending physician, than was present in the old system. Those participants that did not like the new system as well as the previous system of fixed-appointment approach, felt that their concerns were more marginalized than in the previous system where follow-up tended to be more inclusive. Recently diagnosed patients generally like the newer system better than patients who had been in long-term follow-up. Some of the problems seem to stem from how well the physician was prepared for the new system of follow-up and physician willingness to let patients be more involved in self-management.

Quantitative Research

Besides the qualitative studies just described in some detail, a number of quantitative studies were located that help with understanding some of the factors associated with living with IBD, and that would have an impact on an individual’s “lived experience” with this condition. This section of the literature review includes some of these studies that seemed most pertinent. Many of the articles located in the search,

covered research on IBD pathophysiology, etiology, treatment and treatment outcomes, or surgery. Given the scope of my research I felt it was not relevant to include this research in the review of the literature.

The majority of the quantitative studies or reviews addressed quality of life (QoL) and associated factors identified as important in living with IBD. QoL is characterized as “an elusive concept approachable at varying levels of generality from the assessment of societal or community wellbeing to the specific evaluation of the situations of individuals or groups” (Felce & Perry, 1995, p. 51). With specific clinical populations it is an equally complex concept, because it is multidimensional and usually examines well being and functioning in the physical, psychological, and social areas of a person’s life (Spilker, 1990). Many studies use generic QoL measures such as the SF-36 and some the more specific Inflammatory Bowel Disease Questionnaire (IBDQ) that is disease specific.

While most of the quantitative research included in this section addressed QoL, the literature can be divided into three categories. These three categories are: 1) disease impact (Bernklev et al., 2005; Casellas, Lopez-Vivancos, Badia, Vilaseca, & Malagelada, 2001; Kinash, Fischer, Lukie, & Carr, 1993a; Zutshi, Hull, & Hanmel, 2007); 2) coping (Kinash, Fischer, Lukie, & Carr, 1993b; Larsson, Lööf, Rönnblom, & Nordin, 2008; Mussell et al., 2004; Petrak et al., 2001; Smolen & Topp, 1998;); and 3) psychosocial functioning (Drossman, Patrick, Mitchell, Zagami, & Appelbaum, 1989; Guthrie et al., 2002; Tumbull & Vallis, 1995).

Disease Impact

The disease impact of IBD is multidimensional and affects many areas of patient's lives. A study by Kinash et al. (1993a) described the impact of IBD on daily life. Using a descriptive survey design, data that related to disease impact and patient characteristics were analyzed. In addition structured interviews were also used to elicit data. These respondents did not report that the disease had a high impact on their daily lives. They did have some concerns around their bowel symptoms. Two areas of their lives where there was some impact were social activities and sleep. Those participants who reported greater disease impact also reported lower levels of life satisfaction. Both age and gender were important in that individuals under 35 years of age and women reported lower satisfaction with their lives.

The impact on quality of life may vary, depending on if the person is experiencing an exacerbation or a remission. In their 2001 research to determine the impact IBD has on various dimensions of QoL, Casellas et al. used a survey design to elicit responses from 289 participants with IBD between the ages of 25 and 42 years. During periods of exacerbation the QoL of these participants was decreased, with digestive and systemic symptoms having the highest impact, and social impairment as having the lowest impact. For those participants in remission, systemic symptoms and emotional functioning continued to be present and had the greatest impact on QoL.

In another cross-sectional design study the QoL of 497 participants with IBD was assessed (Bemklev et al., 2005). Participants had a mean age of 43.3 years and almost half were women. In this study participants who recounted medication related

side effects from the prescribed steroids and/or immunosuppressive drugs they were prescribed reported a lower QoL. As well, having extra-intestinal manifestations, increased number of exacerbations, and being women were three factors associated with having a greater disease impact on QoL.

Zutshi et al. (2007) conducted a quantitative cross-sectional study using questionnaires to determine what factors affected CD and what made symptoms worse. They surveyed a patient population (N = 1220) with CD who ranged in age from 17 years to greater than 70 years. A small percentage of the participants (10%) were between 17 and 25 years of age, but findings were not reported by age group. Results suggested that disease symptoms negatively impacted employment and that factors such as food, lifestyle change, and alcohol were some of the factors that made symptoms worse. In general when participants experienced major changes in their lifestyle, such as job change or family changes, they reported that symptoms worsened.

Some research has been conducted to examine how school and leisure activities or labour market participation is affected by IBD (Calsbeek, Rijken, Bekkers, Dekker, & vanBerge, Henegouwen, 2006; Calsbeek, Rijken, Dekker, & van Berge Henegouwen, 2006). In the study on school and leisure activities, the researchers compared 5 groups with different diagnoses (IBD, chronic liver disease, congenital digestive disorders, celiac disease, food allergy) and a “normal” control group of 758 individuals in total who ranged in age between 12 to 25 years (Calsbeek, Rijken, Bekkers, et al.). Respondents with IBD had a greater number of physical complaints and more fatigue than other clinical groups or normal participants, with

the exception of those with chronic liver disease, who were similar to IBD. For those with IBD other differences noted were the need for more frequent hospitalizations and greater use of prescribed drugs. School and leisure activities did not seem to be greatly affected, but these young people may have made the necessary adaptations. There was no reporting of differences, if any, between the younger (adolescents) and older participants (young adults).

In the second study on the same population as in the previous study but excluding individuals 12 to 14 years of age, the researchers examined how characteristics associated with the disease, such as type of diagnosis, and burden of the disease, defined as physical complaints, anxiety and depression, disability, hospitalization, medications use, diet adherence, and toilet use, affected employment (Calsbeek, Rijken, & Dekker et al., 2006). The authors reported that individuals that had IBD had more limited opportunities to work than the normal comparison group. The finding was attributed to the frequent hospitalizations, use of daily medications, and frequent use of the toilet. This finding held when student and non-student groups were compared. The last two studies did not use QoL measures

Coping

Coping or how one manages various demands that taxes or threatens an individual has the ability to mediate the effects of a disease (Miller, 2000). Studies were located that examined the coping patterns of those living with IBD. The earliest study located was by Kinash et al. (1993b) and used the same participants and data as the study reviewed previously (i.e., Kinash et al., 1993a). The researchers examined the

coping patterns of 150 participants diagnosed with IBD. The participants with IBD reported that they used problem-oriented coping methods more often versus affective-oriented methods. Problem-oriented coping is directed towards an action, e.g., modifying a diet, while affective-oriented coping is directed towards feeling, e.g., not being angry. The participants that used problem-oriented coping reported increased levels of life satisfaction and the converse was true for participants using the affective-oriented coping method. Coping methods may be a modifiable factor for those with IBD as these methods can be learned.

Smolen and Topp (1998) used a descriptive design to study coping methods and how these methods affected perceived health, functioning, and well-being. Data from 46 participants with IBD was obtained. Participants were between the ages of 16 and 95 years, mainly diagnosed with CD ($n = 37$), and were mainly female ($n = 34$). Participants who used more emotion-focused coping methods (i.e., responded emotionally to a situation) had lower scores on perception of health, functioning, and well-being. In contrast to the previous findings by Kinash et al. (1993b), those participants who used problem-focused coping methods did not report an increased level of health, functioning, or well-being. Optimistic coping (i.e., positive thinking) though was predictive of better perceptions of health and well-being.

In a survey design study of 1322 participants with IBD, data were analyzed to determine disease specific and generic QoFL and coping methods (Pettrak et al., 2001). They compared QoFL scores of patients with IBD with QoFL scores of people in the general population. Results indicated that when compared to the general population,

participants with IBD have a decreased QoL. As well, depressive coping was strongly associated with decreased QoL. In contrast to other studies this research found that active coping during exacerbation was also associated with decreased QoL. QoL during an exacerbation may be lower than while in remission regardless of the type coping strategy used.

A 2004 study to assess the concerns of patients with IBD and the impact of psychological and disease factors on QoL, examined disease related concerns of 72 participants between the ages of 18 and 65 years who were living with IBD; CD = 47 and UC = 25 (Mussell et al.). They found that such things as medication side effects, having an ostomy, disease uncertainty, being a burden to others, energy level, and loss of bowel control were all high ranking disease concerns. Concerns did not vary greatly by disease category, but it did by gender with women having greater concerns. Types of coping strategies were also studied. The concerns identified were all significantly increased in participants that used depressive coping methods and these participants had lower scores on QoL measures. Depressive coping included such factors as self-pity, feeling helpless, being resigned to the situation, and withdrawing from social interactions and events.

In the most recent study located, Larsson et al. (2008) examined QoL in participants with IBD and how they coped with disease activity. Seven hundred and forty-two participants between the ages of 18 and 65 years with IBD completed questionnaires. Participants with active disease reported lower QoL and higher emotional distress. This is congruent with the findings of Petrak et al., 2001.

Participants most frequently used optimistic (e.g., thinking positively), self-reliant (e.g., depends on self rather than others), and confrontive (e.g., facing the situation) coping strategies, but use of these strategies was not found to be a significant predictor of QoFL.

Psychosocial Functioning

Psychosocial functioning is not always well defined but usually refers to a range of psychological conditions, but mainly depression and anxiety or self-esteem and body image, as well as how restricted a person is in terms of the social or leisure activities he/she is involved in or participation in school and/or work (Mackner, Crandall, & Szigethy, 2006). A number of the quantitative studies examined psychosocial functioning in participants with IBD. In an early study by Drossman et al. (1989), the researchers evaluated 150 participant questionnaires to measure QoFL. The findings indicated that participants with IBD experienced a decreased psychosocial functioning and this was further decreased in participants with CD versus UC. The participants in the study reported concerns surrounding having surgery, degree of energy, and body image issues as factors that affected their psychosocial functioning.

Not unlike Drossman et al. (1989), Tumbull and Vallis (1995) studied disease specific and psychological factors that influenced QoFL. In their study 22 participants with a mean age of 32 years completed questionnaires. The research findings indicated that disease activity did not predict QoFL, but those participants with enhanced psychosocial functioning experienced greater QoFL. The converse was true for those participants who reported more psychological distress.

In a cross-sectional study, results from the 116 participants who had a mean age of 45.9 years and living with IBD (UC = 37, CD = 75, and unspecified = 4) were analyzed to determine the impact of disease and psychological status on health QoL (Guthrie et al., 2002). Similar to previous research their findings indicate that both psychological symptoms (depression) and disease activity (severity of symptoms) contributed to decreased QoL. While no significant difference in severity of symptoms were reported by diagnostic category, participants with CD had higher scores for depression. When the researchers controlled for disease severity in their data analysis, they found no significant differences in the influence of depression on QoL.

Casati and Toner (2000) reviewed the literature on psychosocial aspects of IBD. They included 71 articles in their review. It was not a systematic review of the literature. Their intent was to present what was known about psychosocial aspects of IBD. Some of the main areas they identified were the extent to which disease symptoms such as decreased energy, poor body image or feeling dirty, isolation and being a burden on others, and a lack of information from physicians negatively affected individuals with IBD. Effective treatment of IBD is suggested as one of the important factors in increasing life satisfaction and thus QoL (Janke, Klump, Gregor, Meisner, & Haeuser, 2005).

Summary

In this chapter I have presented and reviewed research of both a qualitative and a quantitative nature. The qualitative studies I have reviewed covered research around living with IBD, food as a coping strategy, and experiences with medical treatment. The research on living with IBD presented several commonalities in disease concerns, especially those around elimination worries, and body image, along with concerns about normality when living with IBD. Social support, including support from health professionals, was identified as an important aspect that helped when living with this disease and several of the studies explored adaptation to living with IBD.

The lives of those with IBD are affected by their disease symptoms, especially with respect to social activities, and they experience a great deal of uncertainty in relation to this disease. It also causes such feelings as being controlled by the disease or a sense of alienation because of the nature of the disease.

Food as a coping strategy was a topic of research and explored people with IBD and IBS using food or diet changes to aid in controlling their disease. The remainder of the qualitative research covered medication use and adherence, along with exploration of the usefulness of moving to an open-access follow-up style of medical appointments for those living with IBD.

In addition to the qualitative research I reviewed many quantitative research studies in this chapter. While all the quantitative research reviewed examined QoL in some form, more specifically the quantitative research covered the categories of disease impact, coping, and psychosocial functioning. Research on disease impact again shared

many commonalities and with some of the qualitative research reviewed in terms of identifying disease related concerns. Some disease related concerns common in the quantitative studies were around elimination worries, medication side effects, and extra intestinal symptoms as impacting QoL for those living with IBD.

While the studies on coping when living with IBD uncovered some differences, overall those using depressive or emotional type coping strategies experience a decreased QoL versus those using problem-oriented or optimistic coping strategies. Finally, results from the quantitative research that explored the impact of psychosocial functioning found that those living with IBD who had a decreased psychosocial functioning experienced a decreased QoL compared with those who had enhanced psychosocial functioning. Overall the review of the literature on IBD, both qualitative and quantitative, contributes to an increased understanding of what it is like to live with IBD.

Chapter 3

Research Methodology

The descriptive phenomenological methodology of Colaizzi (1978) was selected to investigate the experiences of living with inflammatory bowel disease (IBD), either Crohn's disease (CD) or ulcerative colitis (UC) as a young adult. Phenomenology is suited to investigating lived experience from a holistic perspective (Streubert-Speziale & Carpenter, 2007). Colaizzi describes his approach as "an understanding-descriptive methodology" (p. 58) and since my research objectives were to describe and understand the experiences of young adults living with IBD, I felt this was an appropriate research methodology.

Nurse researchers have used Colaizzi's (1978) method to study the meaning of lived experiences of particular phenomenon, including the experience of chronic illness (Michael, 1996). According to Colaizzi, in order to psychologically investigate human experience one must choose a method which "neither denies experience nor denigrates it or transforms it into operationally defined behavior; it must be a method that remains with human experience as it is experienced, one which tries to sustain contact with experience as it is given" (p. 53). He further stated that this could best be achieved by using the phenomenological approach of description.

In phenomenology, the subjective experience of the individual is valued and respected and the existence of multiple realities is acknowledged (Streubert-Speziale &

Carpenter, 2007). Knowledge about the experience is constructed through collaboration and interaction between the participant and the researcher. It is the meaning of an individual experience that becomes important, not merely the experience itself (Colaizzi, 1978).

A phenomenologist must initiate inquiry with an examination of his/her presuppositions about the investigated phenomenon (Colaizzi, 1978). This helps the researcher uncover certain beliefs and attitudes that they hold regarding the particular phenomenon. To do this and in keeping with the psychological approach of Colaizzi, I continuously examined my personal beliefs and assumptions regarding the research phenomenon of living with IBD. My self-reflection aided in minimizing the influence of my personal beliefs during the data collection and analysis, and helped to accurately reflect the data gathered (Streubert-Speziale & Carpenter, 2007).

Bracketing is a term used to describe the process by which a researcher sets aside presuppositions on a particular phenomenon (Gearing, 2004). In research practice, what the researcher means by the term is not always clear and as Gearing indicates, there are a number of different approaches or typologies of what bracketing is. In this research the type of bracketing I used most closely approximates that of “existential bracketing” as described by Gearing, i.e., “hold in abeyance suppositions and theories of phenomenon’s lived experience” (p. 1440). I did not review theories of chronic illness until after I had completed my data analysis. As well I worked with my supervisory committee to compare and discuss my data analysis throughout the study and we discussed how my understanding of what I had read, may have influenced my

data analysis. Systematically using the data analysis procedure as outlined by Colaizzi (1978) also helped in not letting presuppositions have undue influence.

Participants

The participants for this study included three young adults between the ages of 21 and 31 years. In qualitative research the number of participants can include anyone who has experience with the phenomenon of interest and can communicate it (Colaizzi, 1978). I had originally planned to recruit eight to ten participants for the study, but due to difficulties in recruitment that are discussed later in the limitations section of the study, I was only able to obtain three participants.

Criteria for participant selection included young adults who were: 1) diagnosed and living with IBD (either CD or UC) for a minimum of one year and did not have an ostomy; 2) between the ages of 19 and 29 years; and 4) able to speak, read and write English, as language is important to the data collection and analysis.

Participants with either CD or UC were targeted for the research study. Although I recognized these were different conditions, one could expect similarities in their lived experience. Both conditions often require the same treatments and share many of the same symptoms and complications. I recognize that most literature suggested CD affects a person's life more profoundly than UC, due to greater symptom severity for those with CD (Drossman et al., 1989; Dudley-Brown, 2002), however, research and self-help books investigate and combine both conditions more often than not (Sabil, 2003; Smolen & Topp, 1998).

When I was in the design phase of the study and examining the feasibility of recruitment, I discussed my proposed study with a local gastroenterologist, and he suggested that I interview participants who had a confirmed diagnosis and some time to get used to the idea of having the condition. I agreed with this suggestion as I felt that individuals who were newly diagnosed with IBD would have very different experiences from individuals who had been living with the condition for some time, so I had as a criterion that participants have been living with this condition for a minimum of one year. Using the same reasoning I did not include individuals with an ostomy. Individuals with an ostomy have greater problems with body image and concerns about clothing than those who have not had an ostomy (Simmons, Smith, Bobb, & Liles, 2007). My recruitment strategy was not to negate the experiences of those newly diagnosed, nor of those who had an ostomy. I also felt that because I had consulted the gastroenterologist and would be somewhat dependent on his office for recruitment that I would take into account his advice. Both research ethics boards and physicians can act as powerful gatekeepers for “clinical populations” such as individuals diagnosed with IBD and collaboration is suggested as one strategy for recruitment (Bond Sutton, Erien, Glad, & Siminoff, 2003).

In an attempt to capture what it was like to be a young adult living with IBD, I decided that the ages from 19 to 29 years most accurately reflected the young adult population. During the study due to difficulties in acquiring participants I reevaluated this criterion and included anyone who volunteered up to the age of 31 years as long as

the participant had experienced this condition as a younger adult and met the other inclusion criteria.

Recruitment of Participants

Participants for the study were recruited with the help of either local gastroenterologists or nurses who conduct clinics or work in endoscopy units operated through Eastern Health, Newfoundland and Labrador, Canada. I contacted these physicians and nurses with information regarding the study and a request to assist me in acquiring participants (see Appendix A). If they agreed to help with recruitment, physicians and/or nurses would present potential participants who met the inclusion criteria with a brief one-page information sheet (see Appendix B) about the study, at which time potential participants could agree to provide their name and contact information to me. The initial information sheet given to potential participants by their physician/nurse included general information about the study as well as information on the participant selection criteria and measures used to maintain a participant's confidentiality. Those young adults who were interested in receiving more information on the study had the opportunity to provide their name and contact information, which was then passed onto me by the physician/nurse. Upon receiving any contact information, I called the potential participant to provide them with further information about the study, answered questions they may have had, ensured they met eligibility criteria, and determined whether they were interested in participating in the study. At the beginning of the first interview, the participants formally consented to participate in

the study and have their interview audio-taped by signing the consent form (see Appendix C).

Setting

In determining the appropriate setting for the interview I allowed each participant to choose a place where she would feel most comfortable for data collection. I offered the option of going to the person's home or arranging a private office in the Health Sciences Centre. Two of the participants chose a private seminar room in the Health Sciences, and one because of the nature of her job and the necessity of frequent travel, asked to have her interview conducted by telephone. Both participants who chose to come to the Health Sciences Centre were familiar with the hospital and clinic part of this building so locating and accessing the centre was not problematic. The main reason given for the choice of setting was the privacy that it afforded, and that the participant would be away from family members, when she talked about her condition.

I ensured that the setting for all three interviews was both comfortable and private, and validated that this was so with each participant, prior to beginning the interview. I also checked with each participant throughout the interview to ensure she continued to feel comfortable and that her privacy was being maintained. This was particularly important for the participant being interviewed by telephone because I was unable to see any cues that might indicate discomfort.

Data Collection

Colaizzi (1978) described different "methods", i.e., written sources, dialogal interviews, and observations as all means of gathering descriptive data to understand

the phenomenon of interest. I selected an interview as the method best suited to my research study and a means of capturing the young adult's experiences with IBD. In particular Colaizzi suggested an un-structured interview. This type of interview that often takes the form of a dialogue between a participant and the researcher is more likely than a question and answer approach, to help the persons engaged in the conversation to be on an equal level and to establish trust (Colaizzi). I facilitated the participants' descriptions of their lived experience by using open-ended, clarifying questions if needed (see Appendix D). In most instances this was not required as participants talked freely about their experiences. Using an open-ended approach for my interviews allowed me to follow the participant's leads but gave me some needed guidance if the participant required a prompt. I began the interview by asking the participant "to tell me what it was like to live with IBD" and ended when the participant felt she had fully described her lived experience. Each initial interview lasted approximately one hour.

Although participants were informed in their consent forms that two interviews would be required, only one interview was tape-recorded with each participant. The intent of the second interview was to obtain any clarification from the first interview and of the theme clusters and initial interpretation I had made. When I contacted the participants by telephone and described to them my initial analysis of the data, none of them said that they had any new information to add so a second interview was not needed.

The interviews, in keeping with what Colaizzi (1978) suggested, were audio-taped and then transcribed verbatim. In addition, I made some written notes immediately following the interview, as well as engaging in journaling of thoughts and changing assumptions. These thoughts and notes were included in the data analysis.

Data Analysis

Colaizzi (1978) outlined a set of procedural steps to assist with data analysis and interpretation and suggested that these steps “are by no means definitive” and that the steps “be viewed flexibly and freely by each researcher” (p. 59). As a new researcher I used these steps as closely as possible as my guide for data analysis and interpretation. These steps summarized from Colaizzi’s description (pp. 59-62) [where italicized it is because italics are used in the original] are:

1. Carefully read each transcribed interview to both develop a feeling for and a sense of the data;
2. Extract *significant statements* from the data based on the phenomenon investigated;
3. *Formulate meaning* for each of the significant statements identified;
4. Take the formulated meanings and put into *clusters of themes*; and
5. Integrate the significant statements, formulated meanings, and themes into an *exhaustive description* of the phenomenon.

In keeping with phenomenology as described by Colaizzi (1978) following data collection and transcription, I began the analysis of the data by reading the interview texts to identify significant statements of what it was like to live with IBD. Next I tried

to identify the meaning of each significant statement. Meanings were formulated for each statement identified. I then organized similar formalized meanings into clusters of themes. Table I (see Appendix E) is an example of how I took significant statements about treatment, formulated meanings from these statements, and clustered these meanings into a theme. My written interpretation of each description was validated by multiple re-readings of the data and was supported by the use of direct quotations. This interpretation was further validated by review of the descriptions with my supervisory committee members. I then returned to the participants for validation of the descriptions and of my interpretations. While there was no new data during the validation phase, some clarification and affirmation of the themes was obtained, and incorporated into the exhaustive description of each of the identified themes.

During the data analysis process I reviewed previous journal notations, thoughts, and emerging themes and continued to engage in these activities. I continued to identify any presuppositions I had about the phenomenon being studied and in the final analysis my description of themes was directly supported through the use of direct quotes from the participants.

Validation

When considering the quality of phenomenological research it is important to note that this methodology should be measured against itself and whether it has accomplished its goal of describing the experience (Colaizzi, 1978). To accomplish this Colaizzi suggested a number of steps that he incorporated into his procedural steps associated with data analysis and that he termed “validation”.

The first attempt at validation occurs when the formulated meanings are clustered into themes. It is crucial at this time to take the themes and check them against the original data to see if any important information in the original data is not accounted for in the themes or if the themes go beyond what is represented in the data. This step was carried out in conjunction with meetings held with my supervisory committee members. We independently worked through the steps of data analysis and discussed our conclusions.

A second means of validation suggested by Colaizzi (1978) is to take the findings, once you have validated them in the step just described, and return to the participants in order to establish if your descriptions compare with their experiences. This can occur through a second interview or if needed a series of interviews and any new information must be incorporated into the final description. Following thematic analysis I provided each participant with a brief description of my themes via a follow-up telephone call. At this stage no new information was added and participants felt it had captured their experiences. Thus the women who took part in this study validated my findings.

This process of validation I used is similar to one of the means of establishing credibility that was suggested by Lincoln and Guba (1985). They identified this process as “member checks”, and further described it as a means “whereby data, analytic categories, interpretations, and conclusions are tested with members of those stake holding groups from whom the data was [sic] originally collected” (p. 314). Of the means of establishing credibility outlined by Lincoln and Guba, they suggested member

checks were the most important.

Ethical Considerations

For research to be accepted by other scholars, practitioners, and the general public, it must not only be rigorous but must also meet the appropriate ethical standards. These ethical standards are specified and monitored through institutional research ethics boards (REBs), and these REBs in Canadian institutions adhere to the Tri-Council Policy Statement Regarding Ethical Conduct for Research Involving Humans (2005) generally referred to as the *Tri Council Policy Statement*. Prior to beginning my research, my proposal was submitted to, reviewed by, and approved by Memorial University's REB, the *Human Investigation Committee (HIC)* and continued approval was obtained throughout the research (see Appendix F). HIC monitors research on an annual basis to ensure the researcher adheres to the recruitment strategies and data collection as approved. It also requires the researcher to report any adverse effects of the research.

The HIC approved my planned recruitment of participants. The plan approved was asking local gastroenterologists or nurses who conduct clinics or work in endoscopy units operated through Eastern Health, Newfoundland and Labrador, Canada to distribute letters to patients who met the inclusion criteria. Eastern Health gave permission for me to approach these employees to assist with recruitment. These steps were necessary to protect confidentiality of patient information, i.e., not disclosing patient names and contact information to me without the patient's permission, as well

as to ensure I did not put any pressure on patients to participate in my research by approaching them directly.

Prior to my data collection I obtained informed consent and informed participants of their rights and any potential risks. When conducting research involving humans it is important that participants are fully aware of their rights and any risks to them in participating in the research. During an initial meeting with each participant, I discussed the purpose of the study, how confidentiality would be maintained, the right of each participant to refuse to answer any question, and the right to withdraw from the study at any time without influencing current or future care. The interview process was explained to the participant, and permission to be interviewed took place with the signing of the consent form (see Appendix C).

Although participation in the research may not benefit the participant directly, the participants had the unique experience of sharing their lived experience with IBD. When considering risks to the participants I discussed with them that participation in the research could result in their experiencing emotional distress, during or following the interview, as a consequence of sharing this experience. The potential risk of experiencing emotional distress during and following the interview was also identified in the consent form. I had agreed to help identify if support would be beneficial, and if necessary, would have provided the participant with a name and telephone number of a prearranged support person. No participant expressed that she experienced distress nor did any request or require the need of a support person. All participants were receiving

ongoing care and support from physicians and other health care professionals so they would have access to care when needed.

Maintenance of confidentiality was also part of my ethical approval. Each participant was told that personal identifying information would not be shared with others and that interview tapes would be returned to participants (if desired) or destroyed 10 years following completion of the study. Real names of participants did not appear on any transcriptions, on audiotape labels, on computer disks labels, computer storage devices, on any written notes, or in presentations of the study in order to keep the information provided confidential. Tapes, transcriptions, and notes were kept under lock and key at my home and were accessible only by me. I was the only person who knew the identity of the participants. The participants were informed that a transcriber would be used and it may be possible that participants' voices may be recognized. Transcribers were asked to take a verbal oath of confidentiality. Members of my supervisory committee were given transcribed interviews, but not given any identifying data relating to the participants.

Summary

A descriptive phenomenological approach as outlined by Colaizzi (1978) was used to guide the study. Three young adult women who were diagnosed and living with IBD were recruited for this study. These participants met set criteria and selection procedures. Data collection involved conducting and transcribing unstructured, open-ended interviews. Colaizzi's steps of data analysis were used to identify clusters of themes and to develop a description of the phenomenon. Validation and ethical

considerations were continually addressed throughout the research process.

Chapter 4

Findings

What is it like to live with Inflammatory Bowel Disease (IBD)? How did the women in the study experience living with IBD? This chapter presents an overview of the findings of what it was like for these three women to live with IBD. While each woman's experience was unique, all three had similar experiences and feelings regarding what it was like to be a young adult living with IBD. Seven common clusters of themes were identified from the data, and the themes, together with a description of these themes, is presented in this chapter. While the overall theme was true for each of the women, there were both similarities and differences in their perceptions and lived experiences.

The seven themes that came from the women's experiences were as follows: (1) dealing with symptoms: a constant struggle; (2) embarrassment: trying to hide this condition; (3) uncertainty: it could flare up at anytime; (4) lost time: interfering with normal life; (5) the double edged sword: treatment can be as difficult as the disease; (6) needing to maintain a supportive environment; and (7) accepting the challenge of living with IBD. While these themes are presented separately, in combination they best describe the experience of these women.

The Women

The participants consisted of three women; two were diagnosed with Crohn's disease (CD) and one with ulcerative colitis (UC). The first woman was 22 years of age and had been living with CD for approximately two years. She had several

exacerbation/remission cycles since her diagnosis and was currently experiencing an exacerbation of symptoms and taking the medication Prednisone. The second woman was 28 years old and had been diagnosed with CD at age 20. She too had experienced many up and downs in gaining successful control of her symptoms, and was currently maintaining a remission of symptoms by taking the medication Imuran. The third woman was 31 years old and had been diagnosed with UC as a teenager. Like the others, she had experienced many ups and downs in the course of her disease experience and at the time of the interview was maintaining a remission by taking the medication Methotrexate. Each of the women was employed, and was either married or in a committed relationship. None of the women interviewed had children. Each was followed long term by a local gastroenterologist and all were recent patients of one of two endoscopy units within Eastern Health, Newfoundland and Labrador, Canada.

The Experience of living with IBD

Dealing with Symptoms: A Constant Struggle

Symptom experience was a large part of what it was like to live with IBD. In fact having experiences around symptoms, like not being able to eat because “*of pain in my stomach and diarrhea*” and having no energy because “*I was just losing blood every day*”, largely defined many periods of these women’s lives. This theme was predominant because of just how much the physical symptoms of IBD dominated much of their lives. There were a number of significant statements from the interviews that were clustered under this theme. Dealing with the struggle of managing disease symptoms had a big impact on daily life. All three participants described the struggle

they had with what they considered devastating symptoms when their disease was exacerbated:

When you're in the middle of a flare-up, you're not sick all day long, you're fine for like five hours, and [then] you could have a three hour stretch kneeling over in pain with cramps and using the washroom twenty times.

I was so young, then I'd come home then and I'd be up all night going to the bathroom. I was eating but, I couldn't eat, every time I'd eat I'd go to the bathroom. I lost a lot of weight when I got sick.

By this point my eyes were full of big red blotches - comes with Crohn's - my mouth was coated with sores. I was pale, I was underweight and I couldn't stand up by myself for very long periods of time at all.

The experience of symptoms was pretty well a constant, because whether they had an exacerbation or were in remission, they still had some symptoms they had to face. The only thing that distinguished the symptoms of exacerbation and remission was that they were of a different nature. An exacerbation meant that it was a symptom of the disease while during remission the symptom was as a result of being on long-term medication. These differing symptoms both presented a number of physical difficulties and challenges for each of the women. During an exacerbation they were physically exhausted and weak from the pain, diarrhea, and not eating; each a characteristic of the disease. These disease symptoms were at times quite debilitating and always an intrusion in their lives:

So every time you eat something you are going to the bathroom and you're dying in pain right? You can't go anywhere. It's definitely not nice.

I had no energy because I was just losing blood everyday. I was kneeling over with pain on the couch because I had such bad cramps.

Diarrhea and a constant feeling of urgency to have a bowel movement meant that the women always had to be near a bathroom. Dealing with frequent bathroom trips was bad enough, but the diarrhea was associated with severe pain, “*it was like labour.*” and dealing with the pain took a real toll. For some the urgency and need to have a bowel movement was one of the most unpleasant of all the symptoms they had:

Anything, everything about using the bathroom was not normal and [was] painful and frequent, like five or six times a day.

I mean I had times where I've been fine the whole day and I woke up in the middle of the night... I've actually woke [sic] up out of my sleep to go to the washroom numerous times.

Having a remission did give them some respite from the actual symptoms of IBD and this respite was welcome, but because of the nature of the medications it did not mean that they were symptom free. It just meant they had different symptoms to deal with, because during periods of remission, they had to deal with the side effects of their long-term medications as a daily struggle. These side effects produced a wide array of physical symptoms such as fluid retention and bloating, joint soreness, and headaches. In addition to the unpleasant bodily feelings associated with the physical symptoms, they felt self-conscious about these highly visible physical symptoms.

Like one was Prednisone and I gained twenty pounds from all the fluid and stuff on the drugs. I found that quite bad, like I didn't want to go anywhere. All my face was covered in acne; all side effects from the drug. So I found that really hard. It pretty much changed your -you know, changed your appearance, and you are also physically in pain.

For the women, life while taking corticosteroids (the hallmark of treatment for an acute exacerbation of IBD) was often just as challenging as dealing with the disease symptoms:

When you're on high doses of Prednisone your face looks like it gained thirty pounds and nobody understands. "Oh she's gained weight you know". Nobody understands why you look so big. That's really hard to deal with.

Embarrassment: Trying to Hide the Condition

Feelings of embarrassment permeated much of these women's experiences and began when they first started having disease symptoms. When they talked about IBD they either prefaced some of their comments by saying some incident was embarrassing, or after they related a particular event they told me it was embarrassing, or they were embarrassed. Much of this embarrassment stemmed from uncontrollable bowel symptoms that left them in socially abnormal or awkward situations.

I can remember walking into my university class and all of a sudden, with no warning, I used the bathroom right there in my pants. I mean extreme embarrassment and not knowing what to do and not knowing why this is happening.

One of the strategies they used to cope with their embarrassment was to try and hide any manifestation of their disease, such as diarrhea and incontinence, because

these symptoms were the most embarrassing of all their symptoms. In relating some of their more embarrassing situations with IBD, the women described their frequent trips to the bathroom as something they felt they just had to hide, because they did not want their friends to know about “*always having to go to the bathroom*”. It was particularly bad when they were growing up:

When you're growing up all your friends - oh that's [diarrhea] gross you know - and you're younger you know, and it's just that you have to hide everything. You still have to hide some stuff from people, you know.

These feelings of embarrassment when they were growing up also prevented at least one woman to try and hide her disease. She told me about the first time she noticed her symptoms, and how it was really the embarrassment that prevented her from telling her mother about what she was noticing:

I was having a bit of blood. I just thought that could be a broken blood vessel or fissure and I didn't think much of it. Obviously being that age you don't run to your mom right away and say I have blood, it's kind of embarrassing.

When the women were traveling, or out, or in public places, they were often worried about what would happen. While all of the participants experienced urgency and occasional fecal incontinence, one woman in particular described feeling extremely embarrassed over a situation of incontinence. This woman described how terrible it was to experience this fecal incontinence in a public situation:

[when] I've got to go[to the bathroom], I'll just panic and we'll try to rush to the nearest bathroom. I've had accidents before and that part is really bad. - [Once] there was no bathroom and I just couldn't hold it so I went in my clothes. I had to get out and

go into the bathroom and wash my clothes. It was just very embarrassing.

Part of the embarrassment stemmed from others knowing about their situation, or just talking about bodily functions, especially bowel movements, which they considered as “*socially taboo*”. These women did not consider it acceptable to discuss their disease symptoms, other than in health care interactions and used words in their interviews such as “*too graphic*” or “*gross,*” as to why it was not acceptable for discussion. It was because of their feelings on this topic, that it was a constant battle to hide the nature of their bowel movements and frequent trips to the bathroom. When further expressing the “*socially taboo*” nature of the disease, participants described not only hiding the physical manifestations, but also not wanting to talk about their disease with others:

I'm kind of thinking it's because of the type of disease it is and people don't want [you] to describe it.

Just as they felt the need to hide their symptoms and not let others know, they also felt a need to hide the associated treatments. Using such treatments as medication, enemas increased feelings of embarrassment:

I take enemas every night as well, I mean that's pretty hard to you know hide. You know I stick something up my ass you know - it's kind of you know - I don't mean to be vulgar about it but, how do you explain that to somebody. I mean you can't explain that to somebody who's immature that's for sure. You have to you know - I mean you're constantly hiding things right and it's just embarrassing sometimes.

The “bowel” symptoms of the disease and associated treatments made it different from other chronic diseases and less acceptable to share any aspects of their disease with others. As IBD is a bowel disease that causes such things as gas, abdominal cramps, and diarrhea, it was difficult to share this information with others. It is often a hidden disease in that unless the women shared their symptoms with others, nobody knew. The women felt that IBD is not talked about regularly nor publicized as much as other chronic diseases. They said they felt that IBD is both less acceptable to talk about and not easy to discuss because of the embarrassment it causes:

Like I can picture them saying “oh I’m a diabetic”, but I can’t picture them saying that they have this [UC].

Crohn’s can be an embarrassing disease, it’s a bowel disease. I didn’t want everybody and their brother knowing that I’m there with diarrhea and all this different stuff.

It is one thing to discuss fluctuations in blood sugars, but another thing to discuss diarrhea. The latter was much less socially acceptable. All women in the study expressed many feelings of embarrassment when it came to living with IBD. The physical aspects of the disease contributed to their feelings of needing to hide their disease from others and feelings of embarrassment in social situations.

Uncertainty: It Could Flare up at Anytime

The fact that IBD is characterized by exacerbations and remissions and that these events are marked by an element of unpredictability contributed to a feeling of a lack of control, and this lack of control resulted in feelings of uncertainty. The women described how the uncertainty surrounding their illness affected both their day-to-day

coping as well as any plans for the future. It was the feelings of uncertainty around what may occur in either the course of their disease or their lives that marked many of the significant statements in the interviews and that are included under this theme. One woman described the uncertainty and unpredictability of her disease exacerbations as being both irritating and emotionally draining:

You know, just basically trying to maintain [disease remission] is the hardest part, it kind of creeps up on you. It's like a cold, you're fine for a year and you almost forget you have it, and then you look in the toilet one day and you go "oh great". It's just irritating at some point, and it gets you down emotionally that's for sure.

This same woman, who was dealing with a recent exacerbation at the time of the interview, expressed frustration and illustrated the impact that seeing the symptoms return again engendered. It is that “one day” when you notice the signs that the disease has returned that you feel let down, even though you are aware of the chronic nature of the condition:

It was so disappointing when I started again a couple of weeks ago. Oh my God I was devastated. I was devastated. It's like a flu that you can't get rid of you know, it's just devastating when you - everything is going fine you know - everything in my life was perfect you know - and I mean I just went to the washroom one day and I saw blood again, and like I hadn't seen this in ages and you know it really startles you, and upsets you at first.

The return of symptoms after a period of remission could come as a shock and certainly a disappointment. It was the suddenness of the symptoms returning that bothered the women. One day they were free of disease symptoms, but then the symptoms appeared again, and once more their lives were disrupted in so many ways. It

really changed any plans they had made and often left them feeling helpless. One woman further expressed frustration surrounding the chronic exacerbation/remission associated with the disease as well as the changing nature:

It's like you're a normal person you know, until boom one day - Its funny it's just one day it comes on you -it's not so much gradual, you know. It was when I first got diagnosed, but now it comes on with a vengeance.

This uncertainty influenced how the women monitored their bodies for the return of symptoms, or thoughts of how they would meet expectations of work and social life. Often at the backs of the women's minds and pre-occupying many of their thoughts, either upon waking or going to sleep at night, was the uncertainty of if they would once again have symptoms. This uncertainty could mark going to bed or getting up in the morning:

I'm constantly thinking am I going to wake up and not be able to go to work today because I have such bad cramps.

Exacerbation of symptoms was unpredictable and uncertain. How this uncertainty could affect employment, school, and other responsibilities was something they thought about often. The same woman just quoted when discussing her disease and employment, further expressed the frustration of the unpredictability of her disease and how difficult it is to deal with when it comes to work:

Every time I use the washroom and have cramps, I can't give you a doctor's note. It's a symptom of my medical condition, you know what I'm saying, it's not like I have strep throat and I can go to the doctor and get a doctor's note. And like they're employers, it's a big thing to explain to your employers if it's a problem. Some people don't understand. I don't think there's

enough awareness out there because some people don't even know what it is - a lot of people.

She felt it was important for her employer to understand her disease and the uncertainties she faced. She furthered felt that her chronic illness was different from an acute illness and needed to be considered as such. This woman felt that if her employer had a better understanding it would translate into greater feelings of support when it came to dealing with her disease and her employment situation.

The feelings of uncertainty and frustration that the women felt, often led to expressions of anger and resentment. One participant described the uncertainty of her disease in a statement that expressed her emotional fluctuations between it's the worst disease and it could be a lot worse:

Yeah your just on edge you know, you're just, so mad but yet you have to think okay at least I don't have diabetes or something you know, you almost feel selfish, but at the same time you're like it's not fair, you know.

Lost time: Interfering with a Normal Life

Having IBD placed a number of restrictions on these women's lives, because of their symptoms and the unpredictability of the course of the disease, as well as uncertainty of when it would flare-up again. It was both the unpredictability and uncertainty that interfered with a sense of normalcy and interfered with leading a normal life. This theme centered on losing time with friends, educational opportunities, or more recently work and starting a family.

I got diagnosed in the summer and I was starting college in the fall, so I start, but by December I was so sick that I had to quit. So I had to give up school. I found that really bad.

The women described a number of examples of how living with IBD interfered with what they would consider a normal life. This theme was particularly prominent and was much more difficult when they were younger. They missed out on many experiences and activities with their friends; experiences they considered part of normal activities and growing up. Participants described how living with IBD and its restrictions had changed their lives:

I guess I'm always on guard a bit. I found getting ulcerative colitis took away my youth a bit. I definitely found that. You know how when you're nineteen or early twenties it's suppose to be the best time of your life. I didn't have that. I definitely didn't have that. That was the worse time in my life.

It's changed my life because there's a lot of things I can't do. I was only young when I got it so like, there's different things I still won't do. I won't go camping or stuff like that like, you know, I always want to be near a bathroom.

Youth is usually a time filled with many social activities and a time that most adults look back on and remember feeling fairly carefree. Youth had been different for these women. They didn't feel carefree; instead IBD disrupted and restricted their lives. It caused them to miss out on many adventures and opportunities that youth offered; a sense of lost time. They noted that usually teens do not have to worry about being near a washroom or turn down activities for fear of not having washroom facilities, but these worries were a reality and they felt a need to be near a bathroom almost all the time:

If we're going away, I have to know where the bathroom is, and I always prefer my own bathroom because it makes me nervous when there's no bathroom around because when you got to go, you got to go.

All three of the women described this same reliance on being near a washroom, and one participant said how this interference in her life was one of the most difficult things for her to deal with:

You are not comfortable unless you know where the washroom is in a building, and high school, going to cabin parties, I'd never go you know. Just because sometimes you don't have a washroom that's working you know. There's little things like that I find the hardest part to deal with.

Another participant described her reliance on a being near a toilet as an absolute necessity, even though she knew this reliance limited where she could go and what she could do. In fact, when she had a flare up of symptoms, a toilet for her was a safe haven. Being near a bathroom was reassuring and made her feel safe. It offered protection, a sense of feeling better just because she knew she had a safety net nearby:

Going on road trips with your friends and stuff like that, I mean you can't go because you know you're sick. You can't be not near a toilet. It's like sometimes you have cramps, you don't need to use the washroom, you sit on the toilet and it makes you feel better. It's weird. It's like a sanctuary.

Living with IBD interfered with how they actually lived their lives; imposing a number of restrictions on them. These restrictions could at times lead to social isolation. One woman in particular voiced this isolation and the huge emotional toll it took on her.

Sometimes you just break down, like cry, because you're so frustrated you know. You can't go out on a Friday night and drink until 4:30am like everyone else because you can't get sick, you know, you just feel left out sometimes. You can't do things with other people or you just get frustrated because you're on this medication. And you wake up after you just finished your trial of medication and there's blood again. You know, you cry. You break down. For someone to say, and hug you and tell you it's fine and understand you know, "Are you okay?", it's nice for someone to ask if you're okay. You know it's nice like that.

For the two married women in the study the desire to become pregnant and start a family was prominent, but due to limitations their disease and its treatments placed on the possibility of motherhood they had to deal with this perceived loss. It was another form of "lost time" in that their childbearing years were affected. Not only did these women have to deal with the disease and treatment symptoms, they also had to cope with the loss of not being able to get pregnant as a result of their disease and its treatments.

That's a really big thing like that because I have this disease. They told me that when I got ulcerative colitis, actually that was one of the first things that they said that it might affect the ability to have kids. They did tell me that.

Actually I did mention it because of the other thing. I'll tell you one thing that's really changed my life from it, is that I can't have kids.

IBD actually interfered with their ability to start a family or even to entertain the possibility of a pregnancy. As young adults this was one of the major influences that the disease had on their lives. For these women this was a devastating loss.

You can't get pregnant on Methotrexate. Right? So that's one very devastating thing for me.

Every time I come off it [medication] I get sick and they just really don't recommend me trying to carry a baby. That's probably the biggest thing

in my life that is bothering me about it. So all the decisions around pregnancy, like we've always kind of felt cheated because young people in a new relationship, if they want to, if they feel they are in a permanent relationship and they want to be you know have sex and not be protected then that's okay if they get pregnant. We can't do that. We don't have that option of being unprotected.

Although they experienced not having a baby as a loss, they also described how they had come to terms with it as a couple, but frequently they found themselves in situations where they were reminded of the fact that they could not have a baby.

You know what I mean like there's so many questions? We are okay with that, we are in our own place, we're looking at different aspects of adoption, how that would work. We still have that pressure every day and from people who don't know us, people at work. I was sick a couple of mornings, my Crohn's kind of acted up a little bit and I was dizzy, nauseous and that kind of stuff and I had to take two days off of work. Everybody was like, "Oh it sounds like morning sickness; you're pregnant aren't you?" It's a daily reminder. There's three people pregnant in my office right now and they're like, "Oh it's soon you're turn." I'm like yes but it's so complicated.

The Double Edged Sword: Treatment can be as Difficult as the Disease

Effective treatment is absolutely necessary to control symptoms of IBD and effect remission of the symptoms of this disease condition. The women certainly recognized this fact and talked about their treatment as they discussed living with IBD. This theme addresses both the acknowledgement of the need for medication and the concern over taking the medication. Benefit and risk was usually contained in all the statements on medication:

Well he [physician] put me on steroids. First of all, Prednisone, obviously it's a pretty risky drug. So he put me on I think probably the highest available dose for somebody of my age and weight or tolerance. But I remember after the first

pill it was like a miracle drug. Like I probably cut down using the washroom probably five times that day, you know, because it worked so well.

The women took their prescribed medication because they felt they did not have much choice in the matter. They recognized that you either take medication or you have to suffer the consequences of an exacerbation. So while they clearly understood the need for medication, they also understood the risks associated with taking these and this could create a serious concern. Being on some of the medications prescribed also meant some invasive monitoring to see what effects it had on other body organs:

I still have a lot of worries with the Methotrexate because I have my blood checked regularly. I have to have liver biopsies done. There are a lot of side effects with the Methotrexate. They told me like in ten years I've got an increase chance of getting cancer from the drug, right? I don't have any life, like as long as I stay on that drug I'm stabilized but as soon as I start weaning myself off, I start getting sick. I really don't have much of a choice right? I do worry about that because it's such a strong drug and I've been on it so long and I was so young when I went on it. I do worry about that, everyday I worry about that.

Even though the women experienced a number of side effects, particularly in the case of steroids, with weight gain and retention of fluids, all the women admitted that it was the treatment that made their IBD symptoms bearable. After recalling a time when she received an intravenous treatment of steroids one woman described the drug as amazing:

The next morning my eyes were cleared up and my mouth was cleared up. I couldn't believe it. It was amazing.

In an attempt to control disease symptoms, after numerous drugs failed to aid in maintaining disease remissions two of the women were taking drugs that altered their immune systems. They were worried about some of the serious side effects, but it was a trade off between having effective treatment that would control symptoms and having a more normal life, yet they were concerned about other health effects in the future. Sometimes too, the drugs were often a case of trial and error. One woman discussed a trial with Imuran and the impact it has on her health:

I tried one drug Imuran and I wasn't really getting any better, but they told me that drugs take about three months to work. It suppresses your immune system. I had to be hospitalized and I found out that it actually inflamed my pancreas. So I had to stop taking that one, they are very potent drugs. They are not nice drugs at all.

Even though the various medications that were used to treat their disease produced worry and altered their body image, they also recognized that taking these were necessary adaptations they had to make in order to live with IBD – the use of medications truly was a double-edged sword. One of the desires that the women expressed was for some medication that would work and not have some of the serious side effects associated with most of the current treatment:

The Prednisone is so serious you can't just take it, you know. That's the last resort usually they [physicians] usually hesitate- I hate it when I go in, when I'm sick and they just say "let's try this for another little awhile". I need to be better now, you know. I wish there was a drug out there that would fix it.

Needing to Maintain a Supportive Environment

This theme arose from the participants sharing their experiences with disclosing their illness to others and the supportive or non-supportive reactions they received. It also captures how important supportive people and environments were to them. All of the women were currently in supportive relationships with a partner and they discussed how IBD had either affected their relationship with the partner or one of the hardest things was how do you tell your boyfriend about this disease. One woman because of a previous negative reaction when dating decided an indirect approach was better:

I went on the Internet and all I did was basically print off, basically an idiot explanation for colitis. So what is colitis, what happens when you have it, what are the options? He just read it and then he said, "ok, I understand", you know, and he thought back, I remember you talking about that or I remember symptoms or whatever you know.

For this particular woman it was easier to use written material then trying to explain or talk about her disease. Once her boyfriend had read the material the lines of communication were open and it enabled them to discuss her specific experience in a more open manner. Another woman found telling people about her disease was easier if they shared a similar experience to hers:

Anyway, I have told a few people, because there's a co-worker who has colitis, she was off work for a long time really sick. She's got issues with pregnancy and she's on Imuran and she shared that, so I shared it [my experience] back with her.

While the women described being more comfortable telling others about their disease and experiences now that they had developed more comfort around the topic, they also realized that others could possibly not feel this comfort. As a result some expressed ambivalence towards sharing with others because of the nature of the disease and how some people may react:

So sometimes I feel like oh it's just Crohn's no big deal, right, don't worry about it, if they ask. You know I'm much more comfortable with it now but I know that other people might not be, so I try and minimize as much as I can.

At times they did feel that others just would not, or maybe, could not understand their disease. These women often felt that volunteering information about their disease was not always desirable. For one woman telling others about her disease was something she did very little of and only then when she felt she had to tell them. It was usually a response to a question or perhaps a needed explanation rather than volunteering any information.

It's not something that I talk about a whole lot, right? Unless I got to or whatever - if someone asked me I would tell them.

While the women had mixed feelings around their desire to share with others their experience of living with IBD, in certain situations they felt it was sometimes necessary, regardless of the fact that it was often difficult to share this information with others. The women often felt that others could never understand what it was truly like to live with IBD and the impact it had on their lives.

The women did discuss the impact that having support had on their lives. The support for all came mostly from family and significant others. Not all of the women experienced positive support and one woman even described the loss of a relationship that she feels occurred as a result of IBD:

I was only young and he was young and we just, it was just too hard to handle. I can see that happen especially when you're young right. No I didn't find that he was supportive when I first got it.

Most of the women felt that their partner was the most supportive person in their lives at this time. For one woman it was her husband to whom she vented all her negativity regarding her disease. She described maintaining a positive outlook on the exterior, but being able to truly be angry when she was with him:

All my aggression on him, every bit of stress I felt went on him. He was wonderful. I was always mean to him the whole time. I think it was like a coping mechanism. You kind of play on that positive part of my personality and you put a positive outlook there so nobody really knows how upset I really was, and then it all kind of went to him and he took it. He bore the burden which wow when you think about that's pretty amazing.

While not all of the women described venting their anger with their partners, another woman confirmed that it was her boyfriend who was the basis of her supportive relationship:

My family and my boyfriend and stuff, I mean I've been with him for two years and he's done everything, like he's you know, been there for everything pretty much, and he always asks me, you know, "how's your bum."

Even though the women were able to develop a supportive relationship with their partners, the same was not always true for friends:

I didn't really talk about it a lot to my friends, right? Actually, I even found I lost a few friends because I couldn't go out anymore and stuff.

Another big impact on me was my friends, you know the old saying; you know who your friends are when bad things happen, right? I mean I had no contact, basically, with the majority of my friends that I had before I was sick. Nobody wanted to talk to me because my whole life centered around being sick and trying to be healthy. I used to talk about it a lot. It was a major thing that I talked about. I think that kind of scared people off.

Accepting the Challenge of Living with IBD

Living with IBD had presented a number of interrelated challenges for these women, but accepting the challenge and facing the future while living with IBD, allowed the women to move on and see other sides of the disease. The women described a personal growth and a learning that had occurred as a result of living with these challenges.

You learn as you go along, your still learning, there are still things you know, that surprise me.

At the same time, after going through such a traumatic experience and adjusting to it, I've grown from that. I think that other than having to live with Crohn's for the rest of my life, it was a positive experience in the end because I've learned from it.

Over time, like I said, I find it's more common now and stuff and people are more aware of it then back then so I'm finding it easier now, right?

They described the many positives that living with IBD had on not just their lives, but also those of their families, and even on work life. In addition it gave them a better understanding of others and what they might be experiencing in their lives. One of the outcomes they noticed was that it had increased their sensitivities towards others.

There's so many things that impact young adults no matter what the health concern is. but in my particular situation my life changed completely. It was positive in my education wise, my parent's relationship and my husband's relationship with me blossomed.

So I find it really helps me with my work and it helps me understand other people. There are a lot of positives. I'm still figuring it out everyday.

As well, the woman felt that the longer they lived with the disease the more empowered they have become. They had learned to handle their disease better and develop a degree of comfort that previously they did not have. As a consequence it is now easier to handle the challenges, to share with others, and to live successfully with IBD:

But, you know it's good like that, but I don't really care if they are uncomfortable with it because I mean you know, I'm open now, so more mature about it. So it doesn't bother me, if it bothers them it's their problem.

Yes, and things like; there's always something they can do if it's not drugs then they can remove it all I've heard and I've heard a lot of stories about that but then I heard that sometimes when you get that done, the complete removal that you can still live a normal life with that done.

The longer they lived with the disease the more comfortable they were with various aspects of the disease. There was an adaption or an acceptance over time. They learned to live with it. Their disease was a part of their life and a part of them.

Probably like the longer you have it the more you just start to realize different things that you shouldn't eat and you become more experienced with it, you know what I mean? It's not so new to you; you're not so scared as you are first when you're diagnosed.

Yes, but I think that definitely the longer you've had it the better it will get like you know. It's definitely a lot better than when I was first diagnosed. You just get used to it and, you know, you learn how to deal with it better.

For these women living with IBD presented its share of struggles in their lives, yet they were also able to find significance in their IBD experience and live successful and fulfilling lives.

Summary

Three women described what it was like to live with IBD. The themes and a description of the themes that emerged from these personal accounts have been presented in this chapter. These themes were supported by direct quotes from the women that illustrated how IBD had affected them and was continuing to affect their lives. In keeping with phenomenology as described by Colaizzi (1978) and valuing

individual experiences, this chapter helps to portray what it is like to live with IBD and the impact it has on the lives of the women who participated in the research.

Chapter 5

Discussion

Being a young adult, and in particular a young woman, living with Inflammatory Bowel Disease (IBD) is a complex experience. IBD such as ulcerative colitis (UC) and Crohn's disease (CD) does have a profound effect on the lives of young adults who are affected. This research describes the many ways that the lives of individuals with IBD may be affected. This chapter is divided into two main sections; the first section compares this research with other research on IBD and highlights some of the similarities and differences. In the second section I situate my research within the context of research and theoretical work that has been done on chronic illness.

Living with IBD

The findings from my study support a number of the findings from other studies that have been conducted with those who are affected by IBD, either CD or UC. While there are a number of similarities there are also differences. The women in my study repeatedly expressed concern, worry, and feelings of embarrassment about elimination and incontinence. This is a common concern that has been identified in previous research on IBD (Daniel 2001; Dudley-Brown, 1996; Hall et al., 2005; Kinash et al. 1993a). There was also a general struggle when dealing with disease symptoms that was evident in the women's stories. It was apparent that the physical symptoms of IBD and its treatments were constant, and had a major impact on daily life. In research by Dudley-Brown (1996), participants described their disease as affecting all aspects of their lives. They also expressed that UC controlled them. Given that symptom

experience plays such a prominent role in these women's lives it is not surprising that like Dudley-Brown's participants they often seemed to feel controlled by their disease.

The uncertainty surrounding the nature of disease exacerbation and remission was another reoccurring theme in the women's experience. Living with IBD creates a sense of vulnerability and a sense of lack of control over the disease process (Nicholas et al., 2007). For the young adults in this study the uncertainty and unpredictability associated with living with IBD was emotionally trying. Even though they were aware and understood the chronic nature of IBD, the women experienced a great frustration when their symptoms returned or worsened. The worry over the return of symptoms or the actual return of symptoms essentially had a negative impact on their quality of life. These findings are supported by previous research that demonstrated that increased numbers of exacerbations and an uncertain disease course are associated with a decreased sense of life satisfaction (Bernklev et al., 2005; Casellas et al., 2001; Daniel, 2001; Dudley-Brown, 1996).

For young adults IBD interferes with their sense of normalcy and their ability to lead a normal life. In previous research involving participants living with IBD, having a normal life was important, and often IBD interfered with this ability (Brydolf & Segesten, 1996; Daniel, 2001; Dudley-Brown, 1996; Hall et al., 2005; Nicholas et al., 2007). The young adults in this study often felt they missed out on experiences that other young adults were having. They felt that losing out on these experiences was directly related to being a young adult living with IBD. Participants in the study by Brydolf and Segesten described a "sense of alienation" from themselves and their peers that resulted from having IBD. Young adults are typically involved in many social

activities, but for these women, young adulthood was marred with missed activities and restrictions on social connections. They felt they lost friends as a result of having IBD. The young adults in Daniel's study expressed a similar concern over the effect their disease had on their relationships with others.

Also impacting the young adult's sense of normalcy was their need to be near a washroom and/or always know where a washroom was located. While findings in previous research identified elimination worries as a major concern for those living with IBD, specific concerns around the location of a washroom were not as prominent as they were for these young adults. Findings by Hall et al. (2005) indicated that participants with IBD often planned trips around how available a washroom would be, and this was similar to the women in this study.

Embarrassment about bowel symptoms and especially if fecal incontinence occurred, was another prominent factor that interfered with the women's sense of normalcy. Thus a sense of stigma associated with anything related to the bowels was part of their experience. Socialization in many cultures makes the area of "bowel control" a taboo topic (Norton, 2004). Wilson (2007) studied the experience of fecal incontinence with 22 participants who for a variety of reasons had this symptom. She found that her participants were generally reluctant or unwilling to discuss this problem with others and that reluctance extended to health professionals. Johanson and Laffery (1996) identified fecal incontinence as the "silent affliction" because of the taboo nature of talking about bowel functioning. Likewise, Collings and Norton (2004) in their study with women who had fecal incontinence noted how socially isolating this

symptom can be, and how the negative repercussions it had on women's self-image had caused feelings of shame and embarrassment for some of the women.

One aspect of living with IBD for the married women in my study that was felt to have an impact on their ability to lead a normal life, was the limitations their disease and treatments placed on their ability to get pregnant. For these women this was a great loss that they had to cope with. It appears that this has not been explored in previous research on living with IBD, but is a major impact that living with IBD potentially has on a young adult's life.

Dealing with the treatments of IBD was identified as an important part of living with IBD for these young adults. Side effects of treatment have been associated with a decreased quality of life (Bernklev et al., 2005; Casellas et al., 2001; Hall et al., 2007). The women were very conscious of the many physical side effects of the medications used to treat their disease, in particular those caused by steroids and immunosuppressive medications. While there was much despair related to these side effects and the impact on their lives, there was also a realization that these medications kept their disease symptoms in check. These young adults, like Dudley-Brown's (1996) participants expressed the importance of finding a successful treatment. There were also many commonalities in the research findings of Hall et al. (2007) in that the young adults accepted the need for medication, but experienced a constant concern about side effects and the impact of being on medications long term.

Previous research on IBD has identified the importance of social support in successfully living with IBD (Brydolf & Segesten, 1996; Daniel, 2001; Fletcher & Schneider, 2006; Jamieson et al., 2007). For the young women in my study having a

significant other to provide support was important. Although support was identified as also coming from their families, it was their partners who provided the basis for their supportive relationships. The women also described a sense of feeling more comfortable sharing about their disease to those who shared a similar experience. While participants in Hall et al.'s (2005) study described the taboo nature associated with IBD as a barrier to normality, little research exists regarding disclosing about IBD to others. These young adults felt that it was often difficult and at times even unacceptable to talk about IBD. For the most part they simply didn't talk about their disease to others.

Living with IBD as a young adult is not without its challenges. Living successfully and transcending the disease was a process that these women experienced. Each woman went through a process of learning to live with her disease and there was a sense of personal growth and acceptance. Finfgeld (2000) who studied courage in managing chronic illness found that in becoming courageous one learns how to work through dealing with the disease and its concerns, and moving beyond them. Many positives were described by the women when considering their life with IBD. Living with IBD had somewhat of a positive impact on things like their families, their education, their careers, their personal relationships, and their disease acceptance.

The experience of living with IBD for the young adults in my study is complex and multidimensional. Previous research on IBD supports many of the findings of this study. There are some themes that were described in this study that have not been explored in past research that contribute to understanding what it is like to be a young adult living with IBD.

Living With a Chronic Illness

The findings of this study add to and expand previous research on living with a chronic illness. For those living with IBD, day-to-day coping and functioning are affected, and a number of restrictions are placed on their ability to experience life in a way that is meaningful to them and as a consequence affects their psychological wellbeing. While many people with chronic illnesses must deal with the challenges that affect their psychological health (Thorne & Paterson, 2000), it is important to know how different chronic illnesses with particular signs and symptoms affect individuals with the disease.

IBD and the associated symptoms created feelings of embarrassment, uncertainty, a decreased sense of control, and threatened normalcy. These feelings were congruent with Price's (1996) suggestion that with any chronic illness, uncertainty about how to manage the body or treatment, a frustration with bodily functions, and an apprehension with how to maintain a "normal" social image. Managing the body, especially managing bowel function, was both a source of embarrassment and a restriction in what my participants felt they could do.

Michael (1996) specifically examined how individuals with chronic illness integrated this illness in their lives. Although her participants differed from those in my study in terms of age range (greater range), gender (males and females), and diseases (diabetes, cardiovascular and respiratory disease, and arthritis), some of her larger themes, but more particularly her sub-themes, were similar to my findings. As with her participants, the women in my study confronted loss especially the loss of connectedness. My participants felt somewhat isolated from others because of their

symptoms and need to be near a toilet during exacerbations. Another similarity with at least some of her participants was that the women in my study could view their illness in a positive manner.

Living with IBD involved a definite amount of uncertainty for the young adults in my study. Lundman and Jansson (2007) who studied meaning when living with long term disease also found participants, none of whom had IBD, experienced a great deal of uncertainty. This uncertainty was mainly a result of the disease impact in everyday life rather than the disease itself. While narratives from my participants demonstrate that there is uncertainty with the disease itself, similar to Lundman and Jansson's participants, there was uncertainty because of the impact of the disease on daily life. This was evidenced from worries about elimination and incontinence, social acceptance, and missing out on activities. For both my participants and Lundman and Jansson's it was quite a challenge to live life while surrounded by this uncertainty.

The participants in my study described both the emotional impact of dealing with the unpredictable nature of IBD. This finding is commonplace in research on living with other chronic diseases. Cunningham and Jillings (2006) in their research of individuals living with fibromyalgia revealed how their participants described the emotional and psychological impact living with the disease had on their lives. The very nature of the variability and unpredictability of the symptoms of fibromyalgia was a contributor to this. Like these participants with fibromyalgia, the young adults living with IBD in my study felt the unpredictability of disease symptoms affected their emotional and psychosocial functioning. They described instances when the symptoms of IBD were so unpredictable they were afraid to make plans, travel, or socialize. Not

knowing which symptoms they would have when or when the disease might flare again at times played havoc on their emotions and sense of well-being.

Unlike the participants with fibromyalgia in Cunningham and Jillings (2006) study that talked about the challenges because of the difficulties surrounding getting a diagnosis, IBD has specific diagnostic criteria. So this was not a particular challenge that my participants faced. Regardless of any difficulty surrounding getting a diagnosis, participants in both studies expressed a desire for a cure or improvements in medical treatments. The benefit/risk nature of medications used to treat their disease was a real concern for both groups and finding a livable balance between side effects of medication and symptom control was an important aspect of living with chronic illness. Finally while both groups lived almost daily with the challenges presented by their diseases, they described the importance of trying to stay positive.

Conrad, Garrett, Cooksley, Dunne and Macdonald (2006) studied individuals living with hepatitis C. Like IBD the symptoms of hepatitis C were often unpredictable and caused much disruption in the life of a person living with either of these chronic diseases. Participants living with hepatitis C described occasions when they felt like they had to remove themselves from the world until they got better. The young adults with IBD in my study described occasions where they just didn't feel well enough to carry out their normal lives and activities.

Lempp, Scott and Kingsley (2006) completed research on the impact of rheumatoid arthritis on patient's identities. The key themes that arose from their participants were similar to some of those that were identified for the young adults living with IBD who participated in my study. Themes surrounding the emotional

impact of the disease, worries about the future, concerns about pregnancy, positive and negative work experiences, changes in physical appearance, changes in social activities and changes in self image were all themes identified by those living with rheumatoid arthritis that showed similarities for the participants of my study.

Young adults living with IBD share many of the same experiences as those living with other chronic diseases. Comparison to several different chronic diseases was made in the preceding discussion, and demonstrates that living with chronic illness shares many of the same experiences. While the experiences of the young adults in my study share many similarities to those living with other chronic illnesses, the lived experience of being a young adult with IBD identify some of the specific challenges faced.

The Shifting Perspectives Model of Chronic Illness

In considering theoretical work that has been completed on living with chronic illness I choose to look at Paterson's (2001) shifting perspectives model of chronic illness. According to Paterson's model the chronic illness experience "contains elements of illness and wellness" (p. 23). Both the perspectives of illness and wellness are present but depending on the situation one will take precedence. When illness is in the foreground the focus is on aspects of illness such as sickness, suffering, loss, and burden. When wellness is in the foreground the person living with chronic illness is engrossed in wellness experience. This perspective commonly occurs with diagnosis or onset of new symptoms which forces a person to concentrate on their illness, which in turn aids in reflection and acceptance of the disease.

The second perspective in the shifting perspectives model is that of wellness in the foreground (Paterson, 2001). When this perspective is in the foreground the focus is on an evaluation of the illness as an “opportunity for meaningful change in relationships with the environment and others” (p. 23). The focus is on the self and not the disease as shaping the person’s identity. There is a separation from the body and the mind. Wellness can become the foreground when people living with chronic disease learn as much as they can about their disease, develop supportive environments, and acquire skills such as negotiating, understanding the body’s responses, and sharing knowledge about their disease. There is often a positive move to a focus on the spiritual, emotional, and social areas of life, without the body being the main focus.

A “threat to control” is a major factor in a shift from wellness in the foreground to illness in the foreground (Paterson, 2001, p. 24). If this threat goes beyond the person’s coping a shift from wellness to illness in the foreground can occur. Once a person realizes that they have shifted perspectives, they can identify the need for change and produce change or accommodation to the situation that has caused an illness focus. This may be a sudden or gradual process.

According to Paterson (2001) there are several paradoxes evident in this model. First, is that a person living with a chronic disease, even though wellness may be in the foreground, needs to pay attention to the disease in order for wellness to remain in the foreground. The person must also acknowledge and deal with change and loss as part of the perspective of wellness in the foreground. Second, those living with wellness in the foreground often have to shift to an illness in the foreground perspective when receiving health care or receiving help from others.

Neither perspective in the model is right or wrong (Paterson, 2001). While a person may more commonly have wellness in the foreground the perspective is not fixed and a person will change between the two perspectives in order to meet their needs or situations. This model allows for a constantly shifting change between the two perspectives as a normal occurrence.

In the narratives provided by the young adults in my study one can see by means of sharing their experience they were focusing on an illness in the foreground perspective, and as they shared difficult situations in living with their disease they were focused on their body as diseased. There were times sharing their experiences when they seemed to realize this focus and were quick to point out situations or experiences where one could see that wellness was in the foreground. When sharing their stories as an overall experience there seemed to be a wellness in the foreground perspective present and a sense of disease acceptance and hope for the future.

Summary

Living with IBD for the young adults in this study shared many similarities to other research completed on living with IBD. The experience of these young adults adds to and validates previous research on IBD. It is important to note that there were some differences identified in my study that do not appear to be present in previous research. The experience of living with IBD while diverse, shares many of the same themes that those living with other chronic illnesses experience. Finally living with IBD is situated in the shifting perspectives model of chronic illness.

Chapter 6

Limitations and Implications

Limitations

There are potentially some limitations to the current study. The limited number of participants affected my ability to describe as fully as I would like the experiences of young adults with inflammatory bowel disease (IBD). I experienced a great deal of difficulty in finding eligible participants. Participants were recruited with the help of physicians and nurses and this was in keeping with the approval of the ethical review board that reviewed the research. I do not know to what extent these individuals were active in participant recruitment, or how many individuals they approached, or how many did not want to be part of the study. Participant volunteers were few in number and spaced over a long time frame.

My initial contact with physicians to aid in recruiting participants was unsuccessful. When I made follow-up with the physicians via their secretaries to check on recruitment, I often found that my participant letters were often misplaced or sitting in their original envelopes with none given to potential participants. One physician, when contacted a second time, reconsidered my request for assistance, and requested I contact his secretary to arrange an appointment with him to discuss the research in further detail. When I met with him I was told that he was no longer able to assist me as he had ongoing research and was recruiting participants. In an area with a small population base and a number of researchers actively recruiting participants, the competing demands for research participants are great. The three volunteers who

participated in the research were recruited with the help of nurses in the endoscopy units.

A further potential limitation of the study was that because data collection occurred solely through interviews, my developing ability to conduct the interviews may have influenced the quality of the participants' descriptions. While I tried to maintain a good dialogue in my approach to interviewing, at times I needed to rely on questions. Using interview questions to elicit a description of the participant's experiences, in contrast to their theoretical knowledge of the topic, depends on the skill of the researcher (Colaizzi, 1978). One of my interviews was conducted via telephone and although this participant requested this method because of the nature of her job and the amount of travel involved, it did restrict my ability to see how she presented herself during the interview and may have affected how I interacted with her.

A third limitation is although I had provision for a second interview with each of the participants, when I telephoned them to get validation of the themes, that I had identified none of the participants had any new information to add, thus the findings are based primarily on one interview. The women did confirm what I presented to them and reiterated some of what was contained in the first interviews. Data collection was not through prolonged engagement with participants as is sometimes the case in phenomenology.

Implications for Nursing Practice

There are implications for nursing practice that are apparent in the findings from this study and that support what has been found in other studies of individuals with IBD, although these implications need to be considered with caution and in light of the

limitations I have identified. First, understanding and being familiar with the chronic illness experience, as well as the effects that a particular disease can have on daily living, is very important for nurses to consider when interacting with individuals affected. Nurses have the opportunity to encourage people with IBD to actively participate in decisions regarding their health. The women in my study illustrated the importance for individuals with IBD to be able to take control of their health and actively search for ways to manage their disease. A partnership role with the nurse can provide clients with access to such things as support through therapeutic communication, teaching, referrals, resources, and alternatives or adjuncts to medication and surgery. Mishel (1999) indicated that although there are few studies that examine the role of health care professionals in the chronic illness experience, it has been identified that health care professionals are important. In particular, health care professionals have a vital role in such things as assessment and establishing a diagnosis, assisting with self-management of the disease or illness, and promoting wellness and a sense of normalcy for clients.

During the transitions and challenges throughout the course of the disease, nurses can provide much needed support for the client. Letting the client know that it is normal to experience fear, uncertainty, and frustration can be very important. Active listening on the part of the nurse can communicate a nurse's interest and understanding to the client. Active listening in order to gain an understanding of the illness experience is no doubt challenging and time consuming. Yet, at the same time, active listening provides the nurse the opportunity to consider more than the physical problems and to help identify the influence and effects that the disease has on a client's life, as well as

the coping strategies utilized by the client. Gaining a better sense of what the client is dealing with will enable the nurse to develop a more inclusive plan of care and support for the client. This more inclusive framework will help foster client empowerment and encourage the client to participate in the management of his or her individual health and wellness process.

Nurses need to recognize the importance of recognizing the “individuality” of a client’s experiences in living with IBD. The effects that IBD can have on a person’s life, while at times encompass many commonalities, may also vary based on the person’s social support network, self-awareness, confidence, and self-management strategies. According to Sharoff (1997), in her research on people’s experiences of disease within chronic illness, interventions and support must reflect the client’s present state and incorporate the individual’s perception of their needs. Thus, a thorough assessment of functioning, sense of well-being, and goals is necessary.

Promotion of independence and self-care during the illness experience may heighten autonomy and promote support seeking (Delmar et al., 2006). As well, continuous interactions and reassessment of the client can help the nurse identify the client’s needs more accurately. Accurate assessment can help the nurse develop an individualized plan of care incorporating the client needs, strengths, and challenges.

The nurse also has the opportunity to increase her/his awareness of IBD from the client’s perspective in order to help establish helpful resources and supports that will reinforce or provide new options for clients living with IBD. The findings demonstrate that there is a need for a multidisciplinary role in caring for the client with IBD, which would include ensuring continuity of care, promoting a positive self image,

and identifying and minimizing treatment side effects when possible. Helping the client access additional resources and information on such things as diet, alternative treatments, and coping strategies would be useful. As the nurse assumes a partnership role with the client who is living with IBD, she/he may help in creating a much more meaningful and fulfilling experience, thus promoting health and wellness within disease.

Education of the public regarding IBD and how it affects a person's life may enhance public understanding and alleviate feelings of embarrassment on the part of the person with IBD. Education and increasing awareness of the public may also provide persons with IBD a more supportive and accepting environment in which to live. Increasing support on the part of the public, and the nurse, may help alleviate some of the frustration experienced by people with IBD when attempting to overcome some of the many challenges that can be experienced, such as body image alterations, managing symptoms, and maintaining normalcy.

Some of the nursing literature on fecal incontinence and the stigma associated with this symptom could be helpful to the nurse in addressing that particular problem (Garcia, Crocker, & Wyman, 2005; Mason, 2007). There are some ways of addressing the problem of fecal incontinence and helping patients explore their feelings about the symptom. On a broader level, public education can help to make the problem of fecal incontinence, not such a stigmatizing condition.

An understanding of the influence of IBD on a person's life, and also the effects of treatments, can enhance the nurse's ability to provide support and care for the client with IBD. Promotion of a positive self-image and self-concept for the person dealing

with body image disturbances can subsequently encourage more social interaction and sharing. Increased social interaction can enable the client with IBD to deal with the changes in body image and can help increase her/his sense of acceptance by others, and overall sense of normalcy.

My findings indicate that persons with IBD experience feelings of uncertainty when living with IBD and this finding has been noted in other studies. Facilitating and promoting health within illness can enable acceptance of IBD as well as increase a person's desire to achieve a quality of life that is acceptable to them. Promotion of optimism as well as actively listening to fears and uncertainties can aid individuals in transcending IBD.

Implications for Nursing Education

Along with nursing education on the etiology, treatments, and side effects of treatments for IBD, promotion of a framework in nursing education that examines broader factors can enhance the nurse's ability to care for the client with IBD. Consideration of the mind-body-spirit connection for the individual living with IBD can provide nurses with an enhanced ability to care for the whole person. Incorporation of a wellness model in nursing education allows nurses to support a person with IBD who may be struggling to achieve a sense of wellness while living with the disease. Integration of the present research findings, along with other qualitative research on the experiences of living with IBD, can provide student nurses with the knowledge necessary to care for the whole person.

One area the nurse-educator can address is teaching students about the area of stigma and fecal incontinence. By having this as a discussion topic with students, the

nurse educator can help students learn to deal with some of the more difficult areas of nurse-patient interaction, as well as teaching students about how to employ “problem-solving” around how to deal with the symptom (Mason, 2007). If nurses learn to be more comfortable with certain topics they may be more likely to explore them with their patients.

As well, nursing education that promotes critical thinking can produce nurses who are able to consider more than the physical effects of IBD. Critical thinking can challenge student nurses to become active listeners and interpreters of the needs of clients with IBD. Perhaps, nurses who have acquired the skill of critical thinking can, in the future, develop enhanced nursing interventions in the care of the client with IBD.

Implications for Nursing Research

As a result of the findings from this study, there are several implications for nursing research. Further research is needed on the experiences of young adults living with IBD in order to determine what it is like to live with IBD during the young adult years and to expand on how being a young adult can have an impact on life with IBD. My research is a beginning effort in this work.

Other areas of research on living with IBD could also be explored, such as the experience of males, or persons of varying cultures living with the disease. Further research could examine partners/spouse and family members experiences as well. This type of research could determine if different types of supports and care are necessary for these particular groups and individuals as they live with or support someone with IBD.

One of the themes, *Accepting the Challenge of Living with IBD*, suggests a psychosocial process has occurred in which some resolution with this condition has occurred. It is not known if this is a usual outcome, or something particular to the women who volunteered to take part in my study. Further research could occur, using grounded theory, to examine that process. This would allow for identification of what conditions enhance or act as barriers to acceptance, what are the stages of acceptance, and what variations occur in the process.

Finally, a longitudinal study could look at different times in the illness experience of living with IBD to determine if disease experience and perceptions change over time. This may provide nursing with better knowledge and tools needed to identify the supports and care needed at various stages of the disease and life, thereby, enhancing the persons abilities to live with the exacerbation-remission cycles of the disease.

Conclusion

A phenomenological approach was chosen to investigate the experiences of young adult's lived experience with inflammatory bowel disease. Three participants living with inflammatory bowel disease and meeting the sample criteria were recruited to provide rich descriptions of the experience. Each participant's lived experience with inflammatory bowel disease was shared through an interview. Colaizzi's (1978) method of data analysis was used to identify pertinent statements of experiences with IBD, cluster these statements into themes, and to write a rich description of the themes. Findings were presented through these themes and supported by direct quotes from the

participants. A number of implications for nursing practice, education, and research, were evident from the findings. The experience of living with inflammatory bowel disease touches all aspects of a person's life. Inflammatory bowel disease impacts the whole person - impacting not only the physical, but also the social, emotional, and spiritual aspects of a person's life. Nurses have many opportunities to share in the lives of those living with inflammatory bowel disease and through a more inclusive broad approach, can help clients to live with and transcend their many challenges.

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Appendix A: Letter to Local Gastroenterologists/Nurses

63 Chanterelle Drive
Con. Bay South, NL
A1W 4E4
709-834-2149
ronandtracy@nl.rogers.com

September 11, 2004

Dear [Dr./Ms.] :

My name is Tracy-Lee Faulkner and I am a graduate nursing student at Memorial University of Newfoundland. I am conducting research on the experiences of young adults living with inflammatory bowel disease. I feel that results of this study could enhance nursing understanding of what it is like to be a young adult living with inflammatory bowel disease.

I am looking for potential participants for this study. Participants for this research should be between the ages of 19-29; be able to speak, read and write English; are followed by a local Gastroenterologists conducting clinics in locations run by Eastern Health, Newfoundland, Canada; have been diagnosed and living with inflammatory bowel disease (either Crohn's disease or ulcerative colitis) for a minimum of one year; and do not have an ostomy.

I am requesting your help in accruing participants for this study. If you have patients who fit the criteria could you please provide them with the potential participant letter and if they are agreeable, have them consent to providing me with their name and contact information.

If you are interested in finding out more information about this research or have any further questions please do not hesitate to contact me at 834-2149. Once your patients have consented to having me contact them, I will pick up the forms. I will contact your office on (date) to see if any completed forms are ready. This research will be confidential and is approved by Memorial University's Human Investigation Committee.

Thank you for considering this request and I will be in touch.

Sincerely,

Tracy-Lee Faulkner, B.Sc.N, R.N

Appendix B: Form Provided to Physicians/Nurses to Recruit Participants

63 Chanterelle Drive
Con. Bay South, NL
AIW 4E4
709-834-2149
ronandtracy@nl.rogers.com

June 5, 2004

Dear Young Adult Living with Inflammatory Bowel Disease;

My name is Tracy-Lee Faulkner and I am a graduate nursing student at Memorial University of Newfoundland. I am conducting research on the experiences of young adults living with inflammatory bowel disease. I feel that results of this study could enhance nursing understanding of what it is like to be a young adult living with inflammatory bowel disease.

I am looking for potential participants for this study. Participants for this research should be between the ages of 19-29; be able to speak, read and write English; are followed by a local Gastroenterologists conducting clinics in locations run by Eastern Health, Newfoundland, Canada; have been diagnosed and living with inflammatory bowel disease (either Crohn's disease or ulcerative colitis) for a minimum of one year; and do not have an ostomy. If you are unsure if you meet these criteria, your Doctor can help you determine your potential eligibility.

If you are interested in finding out more information about this research and your potential participation I would like to contact you. If you are willing, I am requesting that you provide your name and contact information on the next page. Once you have provided this information, I will pick this form up from your doctor and call you. This research will be confidential. It will not affect your current health care. Although your Doctor will know you provided your contact information to me, he/she will not know whether you have decided to participate or not.

Thank you for considering this request and I hope that you will allow me to contact you and provide more information about the research.

Sincerely,

Tracy-Lee Faulkner, B.Sc.N, R.N

As a potential participant, please retain this letter for your records

Young Adult's Living with Inflammatory Bowel Disease

I _____ would like to learn more information

about the research study looking at the experiences of young adult living with inflammatory bowel disease. I give permission for the researcher to contact me at the phone number provided below. After learning more about the research, I am under no obligation to participate in the research.

Date: _____

Name: _____

City/Town: _____

Phone Number: _____

Completed form to be returned to researcher by physician

Appendix C: Consent Form

October 2003

Faculty of Medicine, Schools of Nursing and Pharmacy of Memorial
University of Newfoundland; Health Care Corporation, St. John's; Newfoundland
Cancer Treatment and Research Foundation

Consent to Take Part in Health Research

**TITLE: Young Adults Living with Inflammatory Bowel Disease: A
Phenomenological Study**

INVESTIGATOR(S): Tracy- Lee Faulkner

You have been asked to take part in a research study. It is up to you to decide whether to be in the study or not. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

The researchers will:

- **discuss the study with you**
- **answer your questions**
- **keep confidential any information which could identify you personally**
- **be available during the study to deal with problems and answer questions**

If you decide not to take part or to leave the study this will not affect your usual health care

1. *Introduction/Background:*

Young adults face many challenging transitions in their lives. These transitions may be even greater when you also live with inflammatory bowel disease (IBD). There is not a great deal of research that informs nurses and other healthcare professionals about what it is like for a young adult to have IBD, how it affects their lives, and some of the adaptations they have to make. This study will provide a greater understanding of young adults who live with IBD.

2. **Purpose of study:**

I am conducting this study for two reasons. The first reason is to describe the experience of living with inflammatory bowel disease as a young adult. The second reason is to gain a greater understanding of the experience of living with inflammatory bowel disease as a young adult. I hope this will help nurses and other health care professionals who work with young adults that have Inflammatory Bowel Disease.

3. Description of the study procedures and tests:

During the first interview, you will be asked to share your experiences as a young adult living with inflammatory bowel disease. You will be asked questions to help you share your experience. During the second interview with you I will share my interpretations of your experience. I will ask you whether or not you feel these findings accurately reflect your experience. You can share any other information about your experience at this time. With your permission, I will audio record both interviews. Upon completion of the study I will keep the audio-tapes of your interview. All information you provide including your identity will be kept confidential.

4. Length of time:

You will be expected to participate in two interviews. Each interview will last approximately one hour. The interviews will take place at a location that is comfortable and private to you and at your convenience. Following the interview a transcription of the interview will be made.

5. Possible risks and discomforts:

You may experience emotional distress during and following the interviews as a result of sharing your experience. I will call you the day after each interview, to see if you are experiencing any distress, and if so provide you with the name and number of a support person.

6. Benefits:

This study will have no direct benefit for you. You may benefit from sharing your experience.

7. Liability statement:

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

8. Questions:

If you have any questions about taking part in this study, you can meet with the investigator who is in charge of the study at this institution. That person is:

Tracy-Lee Faulkner (709) 834-2149

Or you can talk to someone who is not involved with the study at all, but can advise you on your rights as a participant in a research study. This person can be reached through:

Office of the Human Investigation Committee (HIC) at ~~709~~-777-6974

Email: hic@mun.ca

Signature Page

Study title: Young Adults Living with Inflammatory Bowel Disease: A Phenomenological Study

Name of principal investigator: Tracy-Lee Faulkner

To be filled out and signed by the participant:

Please check as appropriate:

I have read the consent	Yes { }	No { }
I have had the opportunity to ask questions/to discuss this study.	Yes { }	No { }
I have received satisfactory answers to all of my questions.	Yes { }	No { }
I have received enough information about the study.	Yes { }	No { }
I understand that I am free to withdraw from the study	Yes { }	No { }
<ul style="list-style-type: none"> • at any time • without having to give a reason • without affecting my future care health care 		
I understand that it is my choice to be in the study and that I may not benefit	Yes { }	No { }
I agree to take part in this study.	Yes { }	No { }
I agree to have my interviews audio-recorded	Yes { }	No { }

Signature of participant

Date

Signature of witness

Date

To be signed by the investigator:

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

Signature of investigator

Date

Telephone number: _____

Appendix D: Interview Questions

Interview Guide

Thank-you for agreeing to take part in my research about young adults who live with inflammatory bowel disease. Please tell me about being a young adult living with inflammatory bowel disease.

The following questions may be used as a guide by the researcher in exploring the young adults' lived experiences with inflammatory bowel disease.

- 1) When did you first experience inflammatory bowel disease?
- 2) When was the diagnosis of IBD made?
- 3) How did you feel about this diagnosis?
- 4) What has your life been like since your diagnosis?
- 5) Describe those things that make your condition worse or better?
- 6) Who are the people who have provided you with help?
- 7) Who do you turn to or draw on for support?
- 8) Who do you think could provide you with help?
- 9) What are the things you do that help you deal with this disease?
- 10) Describe some specific times when IBD has affected your life?

Appendix E: Table 1

Table 1
Significant Statements, Formulated Meanings, and Cluster of Themes

<u>Significant Statements</u>	<u>Formulated Meanings</u>	<u>Cluster of Themes</u>
I found out it [Imuran] actually inflamed my pancreas, so I had to stop taking that one.	Because of the side effect she had to stop taking the drug even though it helped	Double edge sword: Treatment can be as difficult as the disease
They [drugs] are not nice at all.	Concern about effects of drugs	
He [physician] put me on steroids, first of all, Prednisone, obviously it's a pretty risky drug	Concern about effects of drugs – understands aspects of risk	
They have to wean you off it because it's such a risky drug	Understands risk with drugs	
Pretty much got me back to normal. I mean I had side effects – a swollen face – joint soreness	Drug worked but also had side effects	
I got to the point, I don't care [about side effects] whatever, it takes to get this pain taken away	Realizes that even though she has side effects, the drug works	
I don't care if I was on Prednisone right now and looked as big as a whale	Willing to put up with risks of drug as long as it helps	
When you're on high doses of Prednisone your face looks like it gained 30 lbs. and nobody understands	Others lack of understanding of Drug and side effects	

Appendix F: HIC Approval



Memorial
University of Newfoundland

Human Investigation
Committee Research and
Graduate Studies Faculty of
Medicine The Health
Sciences Centre

November 10,

2004

Reference

#04.190

Mrs. Tracy-Lee Faulker
C/o Dr. Shirley Solberg
School of Nursing
Memorial University of Newfoundland
2nd Floor, H.S.C.

Dear Mrs. Faulkner:

This will acknowledge your correspondence dated October 21, 2004, wherein you clarified issues and provide a revised consent form for your research study entitled "**Young adults living with inflammatory bowel disease: A phenomenological study**".

At the meeting held on **September 30, 2004**, the initial review date of this study, the Human Investigation Committee (HIC) agreed that the response and revised consent form could be reviewed by the Co-Chairs and, if found acceptable, full approval of the study be granted.

The Co-Chairs of the HIC reviewed your correspondence, approved the revised consent form and, under the direction of the Committee, granted *full approval* of your research study. This will be reported to the full Human Investigation Committee, for their information at the meeting scheduled for **November 18, 2004**.

Full approval has been granted for one year. You will be contacted for annual update in September 2005.

Modifications of the protocol/consent are not permitted without prior approval from the Human Investigation Committee. Implementing changes in the protocol/consent without HIC approval may result in the approval of your research study being revoked, necessitating cessation of all related research activity. Request for modification to the protocol/consent must be outlined on an amendment form (available on the HIC website) and submitted to the HIC for review.

For a hospital-based study, it is your responsibility to seek the necessary approval from the Health Care Corporation of St. John's and/or other hospital boards as appropriate.

This Research Ethics Board (the HIC) has reviewed and approved the application and consent form for the study which is to be conducted by you as the qualified investigator named above at the specified study site. This approval and the views of this Research Ethics Board have been documented in writing. In addition, please be advised that the Human Investigation Committee currently operates according to the Tri-Council Policy Statement and applicable laws and regulations. The membership of this research ethics board complies with the membership requirements for research ethics boards defined in Division 5 of the Food and Drug Regulations. Notwithstanding the approval of the HIC, the primary responsibility for the ethical conduct of the investigation remains with you.

We wish you every success your study.

Sincerely,

John D. Hamett, MD, FRCPC
Co-Chair
Human Investigation Committee

Richard S. Neuman, PhD
Co-Chair
Human Investigation Committee

JDH;RSN\jd

C Dr. C. Loomis, Vice-President (Research), MUN
Mr. W. Miller, Director of Planning & Research, HCCSJ

