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A STUDY OF THE EFFECTS OF A FORMALIZED EDUCATION PROGRAM FOR PATIENTS WITH INFLAMMATORY BOWEL DISEASE

by

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled A STUDY OF THE EFFECTS OF A FORMALIZED EDUCATION PROGRAM FOR PATIENTS WITH INFLAMMATORY BOWEL DISEASE submitted by Barbara Maureen Waters in partial fulfillment of the requirements for the degree of MASTER OF NURSING.

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ABSTRACT

Inflammatory bowel disease (IBD) patients lack disease knowledge, suffer physical dysfunction, have impaired quality of life (QOL), and need frequent healthcare. Using a pretest-posttest design, this study evaluated the effects of an education program on 69 patients randomized to standard care or education and standard care. Knowledge increased for both groups ($\underline{p} = .000$), with the education group having higher scores ($\underline{p} = .000$). Perceived knowledge also increased ($\underline{p} = .000$), with the education group having higher ratings ($\underline{p} = .001$). Perceived health increased ($\underline{p} = .001$), but not between groups. No difference was found for medication adherence, QOL, or healthcare utilization. Patient satisfaction was higher in the education group ($\underline{p} = .001$). Increased healthcare utilization correlated with higher medication non-adherence ($\underline{p} = .01$) and lower perceived health ($\underline{p} = .05$). Formal IBD patient education confers significant benefits of improved knowledge, perceived knowledge, and patient satisfaction. The short study duration may not have permitted appreciation of potential long-term benefits on QOL, medication adherence, or healthcare utilization.

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DEDICATION

I dedicate this work to my husband Frank, whose encouragement, support, and unwavering faith in my ability helped make my dreams possible, to my children, Christina, Allan, Jonathan, and Kimberly whose unconditional love, hugs, and understanding gave me the strength to continue the challenge, and in memory of my loving mother, who was my inspiration to become a nurse.

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CHAPTER ONE

Introduction

Inflammatory bowel disease (IBD) is a chronic illness that has significant effects on the physical, psychological, and social well being of the individual. The symptoms and complications of the disease can impair physical health considerably. Quality of life (QOL) suffers, particularly when the disease is active (Drossman et al., 1991b; Mitchell, 1988). The disease may impact employment, education, and childbearing (Mayberry, 1999; Rubin, 1996). Disease symptoms, impaired emotional and social functioning, severe disease, and complications can lead to frequent health care utilization (De Boer, Sprangers, Bartelsman, & De Haes, 1998; Drossman et al., 1991b).

The multifaceted impact of the disease on the individual requires an integrated approach to disease management that incorporates biological and psychosocial aspects (Corazziari, 2000; Drossman, 1998, 2000; Talal & Drossman, 1995). Essential to an integrated biopsychosocial approach, is the provision of appropriate medical therapy, education about the disease and symptom management, identification of stressors and behaviours that may contribute to illness, and support of the individual in development of effective coping methods (Drossman, 2000; Talal & Drossman, 1995).

Review of the literature revealed that patients have knowledge deficits about IBD (Eaden, Abrams, & Mayberry, 1999; Jones, Gallacher, Lobo, & Axon, 1993; Marshall, 1979). Patients who perceive that they lack adequate information about IBD report poorer health (Moser et al., 1995). Surveys have consistently demonstrated patients' desire for more information about IBD, outcomes, risk of cancer, and new developments in disease management (Martin, Leone, Castagliuolo, Di Mario, & Naccarato, 1992; Rees, Mayberry, & Calcraft, 1983). Studies have revealed that patients are concerned about the impact of the disease, sexual intimacy, complications, and body stigmata, and that those who are experiencing greater symptoms report a lower level of health (Drossman et al., 1991).

Currently, there are no published studies in the English literature assessing the effectiveness of structured educational interventions for patients with IBD. Review of the literature regarding structured psychoeducational interventions in other chronic illnesses reveals improved knowledge, improved psychosocial parameters, increased adherence to medical regimens, improved outcomes, and decreased health care utilization (Devine & Westlake, 1995; Gibson et al., 2000; Mazzuca, 1982). Although these findings support the importance of patient education, research is required to assess the benefits of education in the IBD population.

Identification of knowledge deficits and patient concerns in the IBD population would provide valuable insight for educational interventions by nurses working with these patients. Demonstrated positive outcomes as a result of a structured education program would validate the importance of formal patient education in this population and provide further supporting evidence for the biopsychosocial approach to disease management of IBD.

Purpose of the Study

The purpose of the study was to evaluate the effects of a formalized education program on patients with IBD. Specifically, the study assessed the effects on: (a) knowledge scores, (b) perceived knowledge level, and (c) medication regimen adherence. Secondary outcomes assessed included: (a) QOL indices, (b) perceived health status, (c) patient satisfaction and (g) health care utilization.

The hypotheses tested were:

1. Patients in the education program group will demonstrate higher knowledge scores, and increased perceived knowledge levels at immediately post-education and at 8 weeks post-education than those in the group receiving the current standard of education.
2. Patients in the education program group will demonstrate increased medication adherence behaviour at 8 weeks post-education than those in the group receiving the current standard of education.
3. Patients in the education program group will demonstrate higher QOL indices, improved perceived health status, immediately post-education and at 8 weeks post-education; and less frequent health care utilization at 8 weeks post-education than those in the group receiving the current standard of education.

4. Patients in the education program group will demonstrate greater satisfaction with care at 8 weeks post-education than those in the group receiving the current standard of education.

The effects of gender, age, level of education, occupation, type of disease, disease duration, severity of disease, co-morbid illness, previous IBD education, participation in previous IBD studies, Internet use, attendance at the Crohn's and Colitis Foundation of Canada Support Group (CCFCSG), and membership in the Crohn's and Colitis Foundation of Canada (CCFC), previous studies on the outcome variables were assessed statistically. The effect of reading the provided IBD pamphlets on Control Group IBD knowledge was assessed. Additionally, a statistical description of the recruitment process and attrition from the education program was undertaken.

Definition of Terms

1. Knowledge Level: Level of knowledge about IBD as measured by the scores obtained from the Knowledge Questionnaire (KQ) (Appendix A) and Crohn's and Colitis Knowledge Questionnaire (CCKNOW) (Appendix B).
2. Perceived Knowledge Level: Perception of one's personal knowledge level about IBD, rated on a 10-point scale of a little to a lot, as measured by the Visual Analogue Scale for Perceived IBD Knowledge (Appendix C).
3. Medication Regimen Adherence: The extent to which the patient takes medications, as prescribed, as measured by the number of times medications are recorded as missed in the Patient Diary (Appendix D).
4. Quality of Life: The physical, psychological, and social well being of the patient and the interaction of these aspects of self on the ability to reach personal potential as measured by the Inflammatory Bowel Disease Questionnaire (IBDQ) (Appendix E) and Rating Form of IBD Patient Concerns (RFIPC) (Appendix F).
5. Perceived Health Status: Personal perception of one's global level of health, rated from poor to excellent, as measured by the 10 point Visual Analogue Scale for Perceived Health Status (Appendix G).

6. Patient Satisfaction: The degree of overall satisfaction with the care and information provided by health professionals based on a four point Likert Scale on the Patient Satisfaction Questionnaire (Appendix H).
7. Health Care Utilization: Access to physician services via outpatient clinic visits, attendance at emergency, or admission to hospital for reasons related to IBD, as measured by the number of recorded visits in the Patient Diary.
8. Disease Severity: Degree of illness severity as measured by the Crohn's Disease Activity Index (CDAI) (Appendix I) or Activity Index (AI) for ulcerative colitis (Appendix J).

Significance of the Study

Patient education is recognized as essential to comprehensive disease management in chronic disease populations. Patient education has been demonstrated to improve disease knowledge, self-management, medication adherence, and QOL while decreasing health care utilization. Identification of knowledge deficits and patient concerns in the IBD population would provide valuable insight for educational interventions by nurses working with these patients. Demonstration of positive benefits from a formal education program for patients with IBD will provide evidence to change current practices of relying on informal teaching during IBD Outpatient Clinics and reliance on written materials for education.

CHAPTER TWO

Literature Review

Inflammatory Bowel Disease

Inflammatory bowel disease (IBD) includes two disease etiologies, Crohn's disease (CD) and ulcerative colitis (UC). The diseases share similar symptomatic, epidemiologic, and demographic features, but differ in clinical course, etiology, and therapeutic response. UC is characterized by acute and chronic mucosal inflammation of the large bowel that is continuous and originates in the rectum. The inflammation of CD is transmural, patchy, and manifests anywhere in the digestive tract but predominantly in the small and large bowel (Lim, 2000; Marion, Rubin & Present, 2000; Rowlinson, 1999). Relapse rates within the first year of the initial episode of both CD and UC are approximately 50%, with 66% of CD sufferers experiencing two or more acute episodes, and 10% of those with UC developing long-term remission (Ballinger, 2000).

The incidence rates for CD and UC range from approximately 0.5 to 15 cases per 100,000 population world wide, with the highest rates found in the countries of the northern hemisphere and in urban areas. In northern Alberta, the incidence rate for CD and UC was 6.0 per 100,000 population during the period of 1977 to1981 (Sandler & Eisen, 2000). Epidemiologic studies indicate that the incidence of IBD is bimodal with a peak occurring in the 20 to 29 year old age group and a lower peak in the 60 to 79 year old age group (Ballinger, 2000; Lashner, 1995; Sandler & Eisen, 2000). Women have a greater risk of having CD than men; conversely, there is a trend for an increased risk of developing UC in men (Lashner, 1995; Sandler & Eisen, 2000). The disease is uncommon in non-Caucasians in undeveloped areas, but the incidence among other racial groups is increasing in Westernized urban regions (Sandler & Eisen, 2000). Smokers have two times the risk of developing CD and half the risk of developing UC than do non-smokers (Lashner, 1995). There is an increased risk of developing IBD in individuals who have a first degree relative with the disease.

There is conflicting evidence regarding the overall mortality of IBD, but it has been suggested increased mortality occurs in those with severe CD and from acute toxic megacolon as a complication of UC (Ballinger, 2000; Sandler & Eisen, 2000). Studies of morbidity demonstrate that IBD resulted in an average of 11,700 hospitalizations annually in England from 1982 to 1985, and approximately 80,000 hospitalizations annually in the United States from 1984 to 1987 (Sandler & Eisen, 2000). Drossman, Li, Leseman, & Patrick (1992) reported an average of 3.18 physician visits over 6 months for symptoms of IBD, a mean of 0.85 hospitalizations over 2 years, and a lifetime rate of 1.46 surgeries in a large, national sample of individuals with IBD.

Individuals with IBD experience a constellation of symptoms that includes mild to severe diarrhea, abdominal pain, fever, fatigue, anorexia, nausea, and weight loss. Hematochezia may be prominent with UC and in cases of significant large bowel CD (Ballinger, 2000; Lashner, 2000; Miner, 2000). Complications for both diseases include anemia, osteoporosis, bowel perforation, obstruction, and stricture (Bellanger, 2000; Marion, Rubin, & Present, 2000; Miner, 2000; Philips, 2000). Systemic complications are more common in CD as are nutritional deficiencies, fistulas, cholelithiasis, and nephrolithiasis. There is an increased risk of colorectal cancer in both diseases, but the risk is significantly higher in UC. Primary sclerosing cholangitis is strongly associated with UC (Miner, 2000). Afflicted individuals may also suffer from extra-intestinal manifestations such as peripheral arthritis, ankylosing spondylitis, uveitis, scleritis, episcleritis, erythema nodosum, pyoderma gangrenosum, and apthous stomatitis (Lamers, 2000; Levine, 2000). Severe disease and complications often result in surgical intervention (Ballinger, 2000).

The psychosocial effects of IBD can be significant. Active disease can have a negative effect on health perception, psychological indicators, and functional capacity. Those diagnosed with IBD not only have to cope with the physical symptoms of disease, but also experience stress related to worries about sexual intimacy, complications, and body stigma (Drossman et al., 1991b). Individuals with IBD may experience extended absences from school and work as a result of hospitalizations (Mayberry, Probert, Srivastava, Rhodes, & Mayberry, 1992). Long periods of unemployment appear to be higher for individuals with IBD (Mayberry et al., 1992; Mayberry, 1999). Impaired fertility, teratogenic immunosuppressive therapy, and active disease pose difficulties for childbearing (Burakoff, 2000; Hanan, 1998; Clearfield & Herrero, 1998; Rubin & Korelitz, 1996). Symptoms of the disease can also lead to sexual dysfunction (Moody, Probert, Rhodes, & Mayberry, 1992; Moody & Mayberry, 1993). Additionally, families of individuals with IBD also experience impairment of their QOL in relation to their loved one's illness (Cheung, Garratt, Russell, & Williams, 2000).

Inflammatory Bowel Disease Patient Education

The importance of patient education in the management of chronic illnesses such as diabetes and asthma is well established (Brown, 1990; Gibson et al., 2000). To date, only descriptive studies of IBD education that address patient knowledge levels, desired information, preferred methods of education, effects of disease-related knowledge on QOL, and two abstracts describing an educational intervention have been published in the English language literature. The most prominent and consistent finding in the studies is that patients with IBD want more information about their illness (Jones, Gallacher, Lobo, & Axon, 1993; Kennedy et al., 1998; Mansfield, Tanner, & Bramble, 1997; Marshall, 1979; Martin, et al., 1992; Mayberry, Morris, Calcraft, & Rhodes, 1985; Probert & Mayberry, 1991; Rees, Mayberry, & Calcraft, 1983; Scholmerich, Sedlak, Hoppe-Seyler & Gerok, 1987; Ward, Shah, Eaden, & Mayberry, 1998).

Patients place significant value on having information about IBD (Marshall, 1979; Mayberry, 1985; Smart, Mayberry, Calcraft, Morris, & Rhodes, 1986). Topics of interest identified by patients include the cause of the disease, symptoms, prognosis, therapy, complications, risks to family, side effects of medication, diet, current research, self-management of medications, and cancer risk (Martin et al. 1992; Mayberry et al., 1985; Rees et al., 1983). The importance of topics varies between groups. Rees found CD patients rated cause of the disease, treatment, and side effects of treatment as the three most important topics. Martin found CD patients rated information on the cause of the disease, diet, symptoms, long-term evolution, new treatments and drugs, and therapy as the most important. UC patients were less concerned with long-term evolution and therapy and wanted more information on cancer risk. Martin concluded that educational material developed for a particular population does not necessarily fit the needs of another group.

Hawkey and Hawkey (1989) studied the effect education leaflets have on patient knowledge for gastrointestinal diseases. Leaflets were developed by expert gastroenterologists and then edited to obtain a Flesh reading ease score of 60 to 65 (understandable to those with an intelligence quotient of ≥ 90, approximately 75% of the population). Questionnaires were sent to 1150 patients, of whom 50% had received leaflets. Replies were received from 751 patients, 398 of whom had received leaflets. Most patients found the leaflets helpful and few had increased anxiety as a result of the information. Patients felt the leaflets were more helpful than specialists, particularly regarding the symptoms of the illness and treatment (81%, 71% respectively, $p \leq .05$). The patients who received the leaflets scored significantly higher on the knowledge tests than those who did not ($p < .01$). Disease specific questions revealed that the IBD patients in the non-leaflet population had several misconceptions about the disease.

Preferred educational sources and mediums have also been studied. Rees et al. (1983), in a survey of 73 CD patients, found the preferred mediums for take home information in order of priority to be booklets, cassettes, and videos. Fifty-eight percent of patients expressed a willingness to pay for the information. Martin et al. (1992) surveyed 50 CD patients and 50 UC patients regarding preferred educational media. A book written specifically for patients about their disease was the highest rated medium followed by a videocassette that could be taken home. Probert and Mayberry (1991) found that trained advisors, videos, and booklets were selected about equally as sources of information in a group of 59 IBD patients. Seventy-six percent specified specialists as the preferred advisor, but 50% would accept information from specially trained nurses. Another important source that has been identified for information are patients themselves. Lay organizations of sufferers of the disease and booklets prepared by patients are valuable resources that are often not considered (Mansfield et al., 1997; Probert, Godber, Calcraft, & Mayberry, 1991).

A lack of understanding of IBD is another significant finding in the studies of IBD education. Three studies have tested the knowledge levels of patients with IBD. Marshall (1979) tested the knowledge of basic facts about IBD, anatomy, symptoms, tests, and medications in 37 CD patients who attended an Inflammatory Bowel Clinic. Total scores ranged from 17 to 88% with a mean of 57%. Factors that increased scores were youth and higher education. Rate of disease recurrence increased scores, particularly after the first episode. Unfortunately, the author did not include the statistical data in the article for independent verification of the conclusions.

Jones et al. (1993) developed a knowledge questionnaire (KQ) that assessed knowledge of anatomy and function of the bowel, extraintestinal complications, risks of family members, IBD diagnosis and therapy, and self-management of the disease. The mean score of the 56 IBD patients tested was 13/36 (36%) with a range of 2 to 29. CD patients scored higher than UC patients did, but this finding must be interpreted with caution due to the small number of participants in the study. Professional occupation, membership in the National Association of Crohn's and Colitis (NACC), and younger age correlated with higher scores. Disease duration did not correlate with knowledge scores. Additionally, analysis of the responses demonstrated some confusion about drug therapy and misconceptions about disease management.

Eaden, Abrams, and Mayberry (1999) developed the Crohn's and Colitis Knowledge Score (CCKNOW score), a tool for testing knowledge of IBD and treatment in patients. Two hundred UC and 154 CD patients completed the questionnaire. The median score was 10/24 (42%). Similar to the findings of Jones et al., professional occupation and NACC membership had a positive influence on scores, however there was no statistical difference in scores between the patients with CD and UC. Patient confusion about drug therapy was found in this study also.

In a letter to the editor of the American Journal of Gastroenterology, O'Sullivan and Morain (2000) detailed the results of a questionnaire they administered to 34 patients in a pilot study. Their findings were similar to Eaden et al. (1999) and Jones et al. (1993) regarding patient confusion about drug therapy and the influences of age and duration of disease on knowledge scores. O'Sullivan and Morain also found no difference in the scores between CD patients and those with UC. All three authors emphasized the importance of knowledge questionnaires for determining specific areas of information deficit, identifying confusion and misconceptions, and as a tool for assessment of education programs.

Verma, Tsai, and Giaffer (2001) examined the relationship of disease knowledge to QOL. A random sample of 250 patients was mailed a questionnaire to assess the level of disease knowledge. Responders to the questionnaire subsequently received a validated

QOL instrument for IBD for completion. Disease knowledge was assessed with 12 questions that asked for information regarding disease type and location, surgical history, medical treatment, awareness of lay support agencies, the effect of disease on travel, insurance, pregnancy, and employment. A patient information score (PIS) was calculated from the responses, with a score of >7 considered a satisfactory level of knowledge. Sixty-four percent had PIS scores greater than seven. CD patients had higher mean PIS than those with UC ($p = .001$). Poor scores were attained for the questions addressing disease interaction with self-management. Of the 178 patients, only 12 had a normal QOL score and 99 had scores indicating significant impairment in QOL. No relationship was found between QOL and PIS. The authors note that the lack of correlation may be attributable to the inherent difficulty in objective assessment of QOL and that increased awareness of the disease may contribute to greater anxiety and lower QOL. This study is significantly limited by the assessment of disease knowledge. The questionnaire was only 12 questions, many of them addressing knowledge of personal disease history. The high scores may be related to accurate recall of personal medical history and not understanding of the disease process, treatment, and self-management.

Two studies have specifically addressed patient knowledge of specific risk factors. Shields and Low-Beer (1995) surveyed 102 patients with CD about their smoking. Only 13 patients (12.7%), 11 smokers and 2 non-smokers were aware of the increased risk of disease recurrence from smoking. Forty percent of these patients were smokers and 19% were former smokers, none who quit smoking because of CD. Robinson, Hart, and Hayberry (1996) surveyed 43 patients with UC on maintenance therapy, which had intact colons about the risk of colorectal cancer. Although 86% knew of the risk of cancer, only 44% were aware of screening procedures for the disease. In their study of the relationship between disease knowledge and QOL, Verma, Tsai, and Giaffer (2001) found that 82% of patients did not understand the effects of smoking on IBD. Significantly more CD patients smoked (59%) than those with UC (19%) ($p < .000$). The authors of all three studies expressed concern that lack of knowledge could result in increased morbidity for patients.

Several factors have been identified that may contribute to patients' lack of knowledge; lack of understanding of explanations, failing to remember information provided, poor access to information, physicians neglecting to educate patients, and lack of knowledge among health practitioners about IBD (Marshall, 1979; Shields & Low-Beer, 1996; Rees et al., 1983). Risk of causing anxiety in patients has been raised as a concern in providing patients information about their disease. Smart et al. (1986) did a follow-up survey of 125 patients regarding their anxiety levels after receiving an information booklet about IBD. Only 13% experienced any increase in anxiety as a result of learning more about their disease and 90% felt the booklets should be readily available to patients.

Scholmerich et al. (1987) surveyed 80 patients regarding information needs and fear factors. The most commonly identified fear factor among all patient groups was cancer (52%). Patients with CD feared surgery most, women expressed concern about diagnostic tests, and men identified drug side effects as a fear factor. In spite of the identified fears, most patients (90%) wanted complete information about IBD. The authors suggested that education could help dispel some of the fear patients have about their disease.

Patient comprehension of written gastroenterology material was identified as a potential barrier in assisting patients to understand diagnostic tests and discharge care. Watkins (1995) tested thirty patients with the Wide Range Achievement Test to determine their reading level grade and then performed a Cloze test on one of two regularly used pamphlets. Most patients' reading level was rated at post-high school level, but only 7% could understand the discharge pamphlet and just 13% could understand the diet pamphlet without assistance. Although the sample size was small and only two pamphlets were used, the author noted the significance of the lack of comprehension for patients and the need to reinforce the information provided. The author made no comment about the readability level of the materials as a possible contributor to poor comprehension.

Although no studies regarding educational interventions for patients with IBD have been published, Schreiber et al. (1999) published an abstract describing a study of 87 consecutive patients recruited from three centres, of which 30 received a minimum of 12 hours per month of education with an interactive CD-ROM. The remaining patients were the control. The education intervention decreased medication non-adherence as measured by self-report from 67% to 20% of patients. There was no change in quality of life (QOL) indices or disease activity over the 3 months of the study. There was a significant improvement in a disease-time-trade-off test where patients exchange disease free years for years of life, with the education group decreasing from 3.3 to 1.4 years. As compared to controls, trends toward lower health care utilization and relapse rates over six months were noted for the education group, but did not reach statistical significance. Robinson, Thompson, and Wilkin (1999) published an abstract describing a study that compared 101 participants educated in disease self-management to102 controls. Mean clinic visits were 0.87 per patient for the education group, versus 2.91 per patient for the control group. The authors did not specify the timeframe of the study.

Quality of Life in Patients with Inflammatory Bowel Disease

Patients with IBD must cope with physical symptoms, psychological stressors, and interference in social function as a result of their disease. In a review of QOL studies by Casati, Toner, De Rooy, Drossman, and Maunder (2000), major issues that were identified for patients with IBD were fatigue, loss of control, body image, isolation and fear, not reaching full potential, feeling dirty, lack of information, and feeling a burden to others. Consideration of these issues is essential to comprehensive care and education of IBD patients.

Mitchell et al. (1988) undertook the first quantitative study investigating QOL issues in patients with IBD. Ninety-seven patients responded to an IBD Symptom Questionnaire (ISQ), listed all physical, emotional, and social problems they had experienced as a result of their disease, and then were provided with a prepared problem list to further assist them in identifying difficulties. Regression analyses were undertaken to identify correlations between physical symptoms and psychosocial experience. Five major dimensions were identified: primary bowel symptoms, systemic symptoms, emotional dysfunction, personal functional impairment, and social impairment. Systemic symptoms were found to increase disturbances in other dimensions ($\underline{p} < .001$). Patients cited frequency of bowel movements, abdominal pain, fatigue and malaise as major physical stressors. Emotional disturbances, particularly frustration, irritability, disappointment, and depression were prominent concerns. Interference with social function was the least problematic.

The ISQ was further refined into the Inflammatory Bowel Disease Questionnaire (IBDQ) (Guyatt et al., 1989). The tool was subsequently validated in a multi-centre clinical trial of 305 CD patients (Irvine et al., 1994). Statistically significant psychosocial disturbances were found in IBD patients as compared to normal controls, particularly in the physical and emotional dimensions. Even relatively well IBD patients demonstrated a difference from controls ($\underline{p} < .001$).

A study to assess disease activity in relation to psychosocial function of 30 IBD patients found a strong relationship between disease activity and psychological distress (Turnbull & Vallis, 1995). Utilizing the already validated instruments IBDQ, Symptom Checklist-90-R, and Sickness Impact Profile (SIP), the authors were able to demonstrate combined biopsychosocial factors were predictive of total QOL ($\underline{p} < .07$). Turnbull and Vallis also tested coping ability with the Rosenbaum Self-Control Schedule as part of the psychosocial assessment. Patients' ability to cope was not predictive of QOL, however post-hoc analysis revealed a strong correlation with increased psychological distress and poorer coping ability ($\underline{p} < .02$). Although the study sample was small, strong statistical consistency between the results of the IBDQ, Symptom Checklist-90-R and SIP validate the findings.

Martin et al. (1995) compared the QOL of 72 healthy controls, 57 patients with UC, and 55 patients with CD. Utilizing a tool modeled after the IBDQ, the authors found significant disturbances in the areas of physical and emotional function, as well as mild social impairment, particularly in patients with moderate to severe disease ($\underline{p} \leq .05$). Normal controls had low scores in all categories indicating minimal biopsychosocial disturbance. Patients in remission had scores almost twice that of normal controls in the areas of systemic symptoms and emotional function ($\underline{p} < .01$). The authors postulated that the chronic nature of the disease causes psychosocial disturbances that persist in the absence of biological activity.

Drossman et al. (1991a) undertook a national survey of 997 randomly selected IBD patients in an effort to characterize the experience and health perceptions in relation to the disease. Overall, patients' perceived level of health was good (3.76/5) and they had low physical dysfunction (2.8, with zero being no dysfunction). The mean disease activity was fair to good, mean pain index was mild, and most were having four bowel movements daily. CD patients had poorer perceived well being, greater psychological distress, and more social dysfunction ($p \leq .06$). These findings were reflective of the more severe disease symptoms, abdominal pain, disease activity, and greater number of complications reported by this group. The authors assessed patient coping and found that, on the whole, IBD patients adopted effective coping strategies. Evaluation of coping styles revealed that self-blame and avoidance behaviour correlated strongly with poorer psychological functioning and greater physiological distress ($p < .0001$). The cross-sectional design of the study limits the ability to predict the impact of IBD on patients over time. Nevertheless, the findings emphasize the importance of assessment of psychosocial issues in disease management.

Drossman et al. (1991) utilized data collected in the national survey to develop the Rating Form of IBD Concerns (RFIPC). Patient responses were broken down into four indices: impact of disease, sexual intimacy, complications, and body stigma. The five greatest concerns among all patients in order of importance were the uncertainty resulting from having IBD, the effects of medications, energy level, having surgery, and having an ostomy. Comparison of UC and CD responses revealed statistically significant differences in rankings. UC patients were more concerned about developing cancer, while CD patients worried about their energy level, social achievement, burdening others, pain, finances, and risks to family ($p < .002$). UC patients had significantly greater worry about complications than CD patients. Demographic analysis revealed females had significantly higher ratings for the impact of disease and body stigma indices ($p = .000$, $p = .001$, respectively). Younger patients reported significantly greater concern about body stigma and intimacy. Lower educational preparation and increased disease severity were associated with higher scores across all indices. Patient concerns were concordant with scores on the SCL-90 and the SIP that the participants also completed.

The RFIPC has subsequently been used as an instrument to examine the relationship of patient concerns to a number of variables. Moser et al. (1995) studied the relationship between IBD disease worries and concerns, socio-demographic variables, and the perceived IBD knowledge level in a group of 102 IBD patients. In addition to the

RFIPC, patients were provided with a visual analogue scale to evaluate their perceived knowledge levels of IBD, socio-demographic data was collected by survey, and physicians utilized the Crohn's Disease Activity Index (CDAI) to quantify disease activity. The top five concerns identified were needing an ostomy, medication side effects, having surgery, the uncertain nature of the disease, and energy level. The study did not show a relationship between patient concerns and disease severity as assessed by physicians. Aside from gender, no socio-demographic variables produced statistically significant differences on RFIPC index scores. Females had significantly greater concern about being a burden to others, passing the disease to others, and being treated differently. There was a significant correlation between perceived knowledge levels and patient concerns ($p < .004$). Those patients who felt least informed about IBD had greater concerns. The only variable affecting knowledge perception was duration of disease, a positive effect. The authors concluded that there was a relationship between patient concerns about their disease and the level of knowledge. Although the authors established a link between the perceived level of knowledge and patient concerns, there was no measure of actual disease knowledge that supported the conclusion. Further study that assesses perceived knowledge, actual knowledge levels, and patient concerns needs to be undertaken.

Maunder et al. (1997) utilized the RFIPC to identify differences in disease concerns in a group of patients who underwent counseling or psychiatric care. A total of 253 patients completed the RFIPC, from which a group of 50 patients were identified as having received counseling or psychiatric care. The counseling patients reported more severe symptoms, greater health care utilization, more chronic illness, lower weight, and poorer health status than controls ($p \leq .04$). Analysis of the concerns of this group of patients revealed greater concern about self-image, pain, and finances after controlling for illness severity and gender. The authors noted that increased illness severity in itself could create the need for professional support. Women had higher RFIPC scores than men and had the greater representation in the counseling group, suggesting they had gender based psychological issues.

Maunder, Toner, De Rooy, and Moskovitz (1999) assessed the influence of gender and disease on patient concerns in a group of 343 IBD patients. In addition to completing the RFIPC, patients were asked to report the degree of 13 IBD symptoms for evaluation of disease severity. There was no difference between men and women in the identification of the top three concerns, energy level, medications side effects, and the uncertainty of IBD. Women reported greater symptom severity than men ($\underline{p} = .04$). There were no significant socio-demographic variables or differences in disease ratio in the gender groups. After adjustment for greater disease symptoms, gender comparisons demonstrated that women had greater concern over body feelings, attractiveness, feeling alone, and having children ($\underline{p} < .001$). Men with CD reported a lower level of concern regarding sexual performance and intimacy than men with UC ($\underline{p} < .001$). The authors postulated that the lower than normal reporting could have been due to reluctance to address the issue, or that disease severity and subsequent interference with sexual performance had resulted in a sense of resignation, therefore lower concern.

The degree of health care use has been strongly correlated with psychosocial factors. In the comprehensive survey conducted by Drossman et al. (1991a) cited earlier, physician visits and hospitalizations were analyzed in relation to biopsychosocial factors. Physical symptoms, psychological distress, and poorer physical function correlated with greater health care utilization ($\underline{p} \leq .02$). With the exception of female gender, socio-demographic factors had minimal or no effect on utilization ($\underline{p} \leq .017$). Hospitalizations were related to physical dysfunction. Drossman, Li, Leserman, and Patrick (1992) found the greatest predictor of physician visit frequency was perceived well being. Maunder et al. (1997) also noted increased health care utilization in patients who required counseling. De Boer et al. (1998) reported similar findings in a longitudinal study of 222 IBD patients. Disease activity, poor emotional functioning, impaired social function, and disease burden were predictive of increased health care utilization ($\underline{p} < .01$). Limitations of the De Boer study included reliance on recall for quantifying health care utilization and lack of clarification about the reasons for the physician visits.

Sexual intimacy is an identified index of the RFIPC and an important factor in QOL. Moody, Probert, Rhodes, and Mayberry (1992) studied sexual dysfunction in women with CD. A female investigator interviewed 50 women with CD and their buddy controls. There were no significant sociodemographic differences between the groups. Twenty-seven percent of women in stable relationships with CD had infrequent or no sexual intercourse as compared to only 4% in matched controls ($\underline{p} < .005$). Of the sexually active women, there was no difference in frequency of intercourse between groups. Reasons specified for sexual inactivity included abdominal pain, diarrhea, and fear of incontinence. Dyspareunia was almost twice as common in women with CD than in controls ($\underline{p} < .01$). Women with perianal disease and fistulae were at greater risk of dyspareunia ($\underline{p} < .05$).

In a follow up study by Moody and Mayberry (1993), 50 female UC patients, 54 male UC patients, 46 male CD patients, and 122 controls were surveyed about their sexual function. There was no difference in socio-demographic variables and frequency of sexual activity. Although dyspareunia was more common in UC females that were sexually active (38%), it was not a statistically significant difference when compared to normal controls (18%) ($\underline{z} = 2.6$). The partners of men with UC and CD took significantly longer to conceive than controls ($\underline{p} < .001$, $\underline{p} = .02$ respectively). Patients cited fear of incontinence, fatigue, abdominal pain, and proximity of toilet facilities as factors that interfere with sexual activity. Although there were no significant differences in sexual activity between the groups, IBD patients have unique concerns that affect sexual intimacy.

Although social impairment is the area of least concern to patients with IBD, the disease can have an impact on the ability to fulfill personal potential, particularly when symptoms are severe. Sonnenberg (1992) demonstrated in a prospective epidemiologic study of the German national database that 9.2 to 11.4% of employees with IBD require rehabilitation and up to 3.3% of IBD employees are granted disability pensions. This is a significant finding in a group of chronic patients who are in their prime working years.

Mayberry, Probert, Srivastava, Rhodes, and Mayberry (1992) compared educational and career achievement in 58 CD patients, 23 buddy controls, and 27 community controls under the age of 40. Of the patients who were diagnosed while students, 42% had missed more than 2 weeks of school due to hospitalization compared to 4% of controls ($\underline{p} < .001$). However total time lost from school due to illness was higher in the buddy and control groups. Seventeen percent of the CD patients missed exams and 14% felt they were unable to meet educational goals due to their illness.

Twenty-four percent indicated their disease had prevented them from progressing in their career. Significantly more long-term unemployment was found in IBD patients ($p < .01$).

In a subsequent study of IBD patients and their employers using the same sampling technique, Mayberry (1999) found that 43% of patients felt their illness had prevented advancement. In both studies, twice as many CD patients as control group participants had experienced long periods of unemployment, 37% of patients felt employers should not know of the diagnosis and 30% were prepared to actively conceal the information. In the second study, 35 companies were surveyed about IBD in the workplace. Unfortunately, IBD patients' fears about the impact of disease on employment were substantiated by a minority group of employer responses. Two companies would reject applications from IBD patients outright and the rest would await a medical report. Eight percent of companies admitted that IBD could negatively affect opportunity for promotion and 30% would not give patients paid leave to attend medical appointments, however 60% would adjust workload and 16% would pay for private care.

Childbearing is an issue that has been identified as a concern, particularly for women. Studies show that women with IBD who are in remission have the same risks and outcomes as normal controls with the exception of an increased risk of preterm delivery. Active CD can decrease fertility and significantly increase risk to the fetus (Burakoff, 2000). As noted previously, Moody and Mayberry (1993) documented a significantly longer time period for conception in the partners of men with IBD. Studies show that pregnancy does not increase the risk of disease recurrence, however active disease may be worsened, particularly in the first trimester (Burakoff, 2000; Clearfield & Herrero, 1998; Rubin & Korelitz, 1996). Sulfasalazine has a documented effect on male sperm counts and morphology, which is reversible with withdrawal of the drug (Burakoff, 2000; Clearfield & Herrero, 1998; Rubin & Korelitz, 1996). Other drugs that impact childbearing are methotrexate, which causes fetal chromosomal abnormalities and cyclosporine, which is nephrotoxic, hepatotoxic, and causes hypertension. Women on these medications are advised to practice birth control during therapy (Burakoff, 2000; Hanan, 1998). Most IBD patients can achieve a successful, healthy pregnancy, but for the woman on toxic medications or with chronically active IBD, particularly CD, childbearing may be delayed, difficult, and emotionally stressful.

Patient Education for Chronic Disease

Patient education is recognized as an essential component to the provision of comprehensive, safe, and appropriate health care. Although formal patient and public health education can be traced back to the 1800's, it was not until the 1970's that education was studied formally as an intervention (Bartlett, 1986). Since that time, thousands of studies investigating patient education have been published. Studies have addressed education in various diseases, a variety of settings, and utilizing a multiplicity of methods. The studies vary significantly in sample size, design, quality, and outcome measures thus there are conflicting reports about the efficacy of patient education and methods. To address the difficulty in evaluating patient education literature, researchers have developed meta-analysis, a process of methodical, rigorous review and statistical analysis of published and unpublished studies to answer research questions (Brown, 1991). Although meta-analysis minimizes bias, results must be interpreted critically due to the inherent problems that arise from combining data of mixed validity (Cooper, Booth, Fear, & Gill, 2001).

In a meta-analysis to evaluate the therapeutic value of patient education in chronic disease, Mazzuca (1982) reviewed 320 studies, of which 30 met the criteria: an experimental design, participants that had a chronic illness, an education program provided by a health care professional, and a dependent variable that included either a measure of adherence or long-term health outcome. Significantly positive effects sizes were found for adherence (0.67, $p < .01$) and therapeutic progress (0.49, $p < .01$). A small positive effect size of 0.20 ($p < .05$) was found for long-term health outcomes. Time since the intervention was noted to diminish the calculated effect size. Mazzuca also compared the methods of education and found that behavioural approaches had significantly larger effect sizes than didactic teaching alone (0.77 and 0.17, respectively, $p < .01$).

Brown (1990) undertook a review of 82 studies that utilized either an affective, cognitive, or psychomotor educational intervention in diabetic adults. Significant effect sizes were calculated for composite knowledge (1.05), dietary compliance as measured by self-report (0.57), and metabolic control as measured by glycosylated Hb (0.41) at the 95% confidence interval. Psychological outcomes had a small, but positive effect size of

0.27. Brown also assessed the relationship between study characteristics and effect sizes. The only statistically significant relationship found was a converse association of age to composite knowledge with greater age having lower knowledge scores.

Devine has undertaken several meta-analyses to evaluate the effectiveness of psychoeducational care in chronic disease patient groups. Psychoeducational care is described as provision of information, behavioural skill development, cognitive therapy, or psychosocial support (Devine, 1992; 1995). Devine and Refschneider (1995) found a change for blood pressure (d = .44), knowledge (d = 1.03), and medication adherence (d = .74) in 88 studies of hypertensive adults (CI = 95%). The effect on knowledge was noted to diminish with time. Knowledge results measured at two weeks were significantly higher than those at four weeks and beyond (d = .98, d = .46, respectively).

A meta-analysis of 116 studies of adults with cancer by Devine and Westlake (1996) revealed statistically significant effect sizes for decreased anxiety (d = .56), depression (d = .54), mood, (d = .45) nausea (d = .69), vomiting (d = .34), pain (d = .43), and improved knowledge (d = .90) (CI = 95%). Only depression and vomiting had homogeneous results. The heterogeneity of the other outcomes led to further analysis to determine possible interactions that were affecting the magnitude of effect size. Analysis of individual educational approaches yielded a homogeneous positive effect size for the reduction of anxiety for muscle relaxation (d = .60) or muscle relaxation/guided imagery (d = .62), and for pain with relaxation type interventions (d = .91)(CI = 95%). Nausea was found to have a homogeneous effect size when only studies that identified nausea as a pre-existing problem were analyzed (d = .91)(CI = 95%). Analysis of treatment characteristics for patient knowledge revealed that provision of printed material was associated with significantly larger effect sizes.

In a meta-analysis of 65 studies of adults with chronic obstructive pulmonary disease, Devine and Pearcy (1996) found evidence of improved psychological well being (d = .58), endurance (d = .77), functional status (d = .63), VO$_2$ Max outcomes (d = .56), dyspnea (d = .71), and adherence (d = 1.76) (CI = 95%). The author noted significant methodological weaknesses in the studies, particularly the lack of control group study design, therefore interpretation of the data should be with caution.

In Devine's (1996) meta-analysis of 31 studies of adults with asthma, moderate to large effect sizes at the 95% confidence interval were found for decreased incidence or severity of asthma attacks ($\underline{d} = .56$), improved adherence to therapy ($\underline{d} = .78$), decreased use of PRN medications ($\underline{d} = .62$), increased psychomotor knowledge ($\underline{d} = 1.02$), more positive psychological well being, and better functional status ($\underline{d} = .46$) ($\underline{p} < .05$). Although functional status had a moderate positive effect size, the calculated fail-safe N was less than five.

Gibson et al. (2000a) examined 11 studies of information only education for adults with asthma. There was no effect on hospital admissions, physician visits, lung function or medication use (CI = 95%). Variable effects were seen for symptoms. Gibson et al. (2000b) also examined 25 studies that included asthma self-management education with regular practitioner review. Odds ratios for health care utilization were significantly lower at the 95% confidence interval: hospitalizations (57), emergency room visits (0.71), and unscheduled physician visits (0.57). Patients with written self-management plans showed a greater reduction in hospitalizations. Overall, nocturnal asthma decreased (0.53). Although there was little change in lung function for the studies, programs with patient medication self-adjustment had better lung function than those that relied on physician adjustment.

Not all meta-analyses have had such positive results. Pakkala and Merinder (2000) evaluated 10 studies of psychoeducational interventions for adults with schizophrenia. Of the studied outcomes, only relapse and/or hospital admissions rates demonstrated statistically significant improvement (relative risk = .8, CI = 95%). Knowledge gains, mental state, and global function had positive trends, and there was no notable change in medication attitudes, insight, or patient satisfaction. Although the study was severely limited by a scarcity of primary studies with adequate data for meta-analysis, the results had findings that were suggestive of some patient benefit.

Mullen, Mains, and Velex (1992) undertook a meta-analysis of 38 random controlled trials of cardiac rehabilitation to assess the overall effect of patient education on adherence, morbidity, mortality, and to determine the relative effects of education. The authors' also assessed educational methods and identified problems in patient education design. Blood pressure had a moderate weighted average effect size (WAES) of 0.51 and mortality had a small effect size of .24 (CI = 95%). Exercise, diet, return to work, morbidity, and smoking had minimal positive effect sizes (WAES P .19) and drug adherence had a negative effect size (WAES = -.09). The authors' limited the analysis to control group studies only because pretest-posttest designs had consistently higher effect sizes, significantly limiting the total number of studies. All of the effect sizes were calculated on less than 10 studies with systematic exclusion of outliers thereby potentially biasing the results and significantly reducing the data set for sub-group analysis. Interpretation of the data must be with caution.

Researchers have also assessed barriers to patient education and the effectiveness of educational strategies. Barriers to education include gate keeping by health care providers and poor readability of educational material. Effectiveness of educational strategies has been assessed by comparison and on the basis of specific outcome.

Rotor et al. (1998) evaluated the effectiveness of education strategies on patient adherence in a meta-analysis of 153 studies. Overall, no single strategy was more effective in improving adherence, although combined approaches were more effective than a single intervention. Knowledge outcomes were moderate (*r* = .31, *p* < .0001). Statistically significant positive effect sizes for all interventions were calculated demonstrating benefit of educational interventions on adherence.

Theis and Johnson (1995) undertook a meta-analysis of 73 studies to determine the effect of selected teaching outcomes. Structured education (*d* = .54), independent study (*d* = .52), and reinforcement of instruction (*d* = .46) yielded the best results (CI = 95%). Multi-method (*d* = .44) and audio-visual instruction (d = .44) also yielded moderate results (CI = 95%). Provision of written material (*d* = .37), group teaching (*d* = .27), and individualized instruction had small positive effects (CI = 95%).

Zernike and Henderson (1998) evaluated the effectiveness of a structured patient-centered education program versus the practice of ad hoc teaching in the clinical setting. Using a control group pretest-posttest design, the authors randomly assigned 40 patients with hypertension who met study criteria to the control group or intervention group. All subjects met with the researchers for a conversational style interview. Those who were in the intervention group were assessed for learning needs and received education. The control group was simply interviewed for information. There was no difference between the groups on the pre-test. There was a statistically significant increase in knowledge on the post-tests of the intervention group at discharge (p = .0035) and eight weeks post discharge (p = .0013). There was no statistically significant difference in the control group scores over time (p = .2924, p = .9977, respectively). At one year, the intervention group still scored significantly higher on the post-test than on the pre-test (p = .04). The study clearly demonstrated the benefits of structured education over ad hoc teaching.

The use of leaflets in patient education is common practice. Barlow, Bishop, and Pennington (1996) evaluated the availability of leaflets for rheumatology patients. Results of the study showed that leaflets were often not stored within reach of patients and that health care providers attitudes determined use. Physicians felt pamphlets gave too much information and increased anxiety, whereas nurses, physiotherapists, and occupational therapist wanted more comprehensive information for patients. Utilization of leaflets by health care providers was generally in conjunction with consultation to clarify, review, information provided. Leaflets were also seen as a reminder and resource for patients. Some leaflets were felt to be poorly presented and too technical for patient understanding. Dixon-Woods (1998) had similar findings in a study assessing printed information dissemination in general practice. Additionally, she noted that health care provider's pre-formed opinions of their clientele in relation to intelligence and social class may also determine whether patients were offered printed materials.

Readability of patient education materials has been found to be a significant factor in comprehension. Assessment of readability of patient education materials in several studies has demonstrated that the information was written at grade levels that were high school or higher (Duffy & Snyder, 1999; Meade, Diekmann, & Thornhill, 1992; Merritt, Gates, & Skiba, 1993; Reed-Pierce & Cardinal, 1996; Wilson, 2000). In a study by Estey, Musseau, and Keehn (1994), only 30% of subjects were able to comprehend reading material written at the grade nine level. Of the remaining subjects, 31% required assistance for comprehension, and 39% were unable to comprehend the material at all. Information written at the level of grade five had a significantly higher comprehension level of 77%. Quality of production, lack of information, and failure to keep information up-to-date have also been identified as barriers to information in patient education materials (Meade, Diekmann, & Thornhill, 1992; Scriven & Tucker, 1997).

In reviewing the aforementioned meta-analyses, the authors consistently identified five key problems in the available literature: lack of detailed comprehensive description of interventions, inadequate description of participants, incomplete statistical data, lack of random controlled trials, and need for research on long term effects of educational interventions. Mullen, Mains, and Velez (1992) noted the importance of basing education programs on theoretical models. In a review of 12 meta-analyses that identified behaviour modification in chronic disease as an outcome, Cooper, Booth, Fear, and Gill (2001) identified these same problems. They noted the need for validated instruments, inclusion of psychosocial outcomes, and qualitative trials to evaluate educational processes, stronger quantitative study design with a focus on random controlled trials, and more comprehensive reporting of interventions, participant descriptors, and participation/attrition rates.

Although there are identified weaknesses in the design and reporting of patient education trials, review of the literature consistently demonstrates benefits to the patient. Increased knowledge, improved psychological indicators, greater adherence to therapy, better outcomes, improved functional status, and reduction in health care utilization have been demonstrated to varying degrees. Educational strategies that are comprehensive and interactive appear to be superior in effecting outcomes. Furthermore, barriers to learning must be a consideration for health care providers in the provision of patient education.

CHAPTER THREE

Method

Descriptive studies of patients with inflammatory bowel disease (IBD) have identified a lack of knowledge about the disease, medications used for treatment, and symptom management. The disease has negative affects on quality of life (QOL) and increases health care utilization. The benefits of education in chronic disease populations have been clearly established. In addition to improved knowledge level, education programs have demonstrated positive effects on medication adherence, psychosocial function, outcomes, and health care utilization. This study was designed to identify the effects of a structured education program for adults with IBD on knowledge levels, perceived knowledge levels, quality of life indicators, perceived health status, medication regimen adherence, health care utilization and patient satisfaction..

Design

A pretest-posttest, control group design was used. Participants were randomly assigned to the education group or control group. Both groups received the education literature currently provided to patients. In addition, the education group attended a 12-hour, structured education program provided in three-hour blocks over four consecutive weeks. The education program provided general information about IBD, therapy, and disease management and was tailored to address the knowledge deficits and worries and concerns of the subjects identified from pretest data (Appendix K). Applying the principles of adult teaching and learning, the researcher used a variety of teaching strategies designed to enhance learning and improve critical thinking skills. Remedial teaching was offered in the event of a missed class. Those participants who missed more than one class were removed from the data set, but were welcome to continue to attend the education program. They were also offered the opportunity to attend the missed classes during the control group education program offered after the study was completed. Data was collected at three time points in the study: baseline (T 1), immediately post-education (T 2), and 8 weeks post-education (T 3)(Figure 3.1).

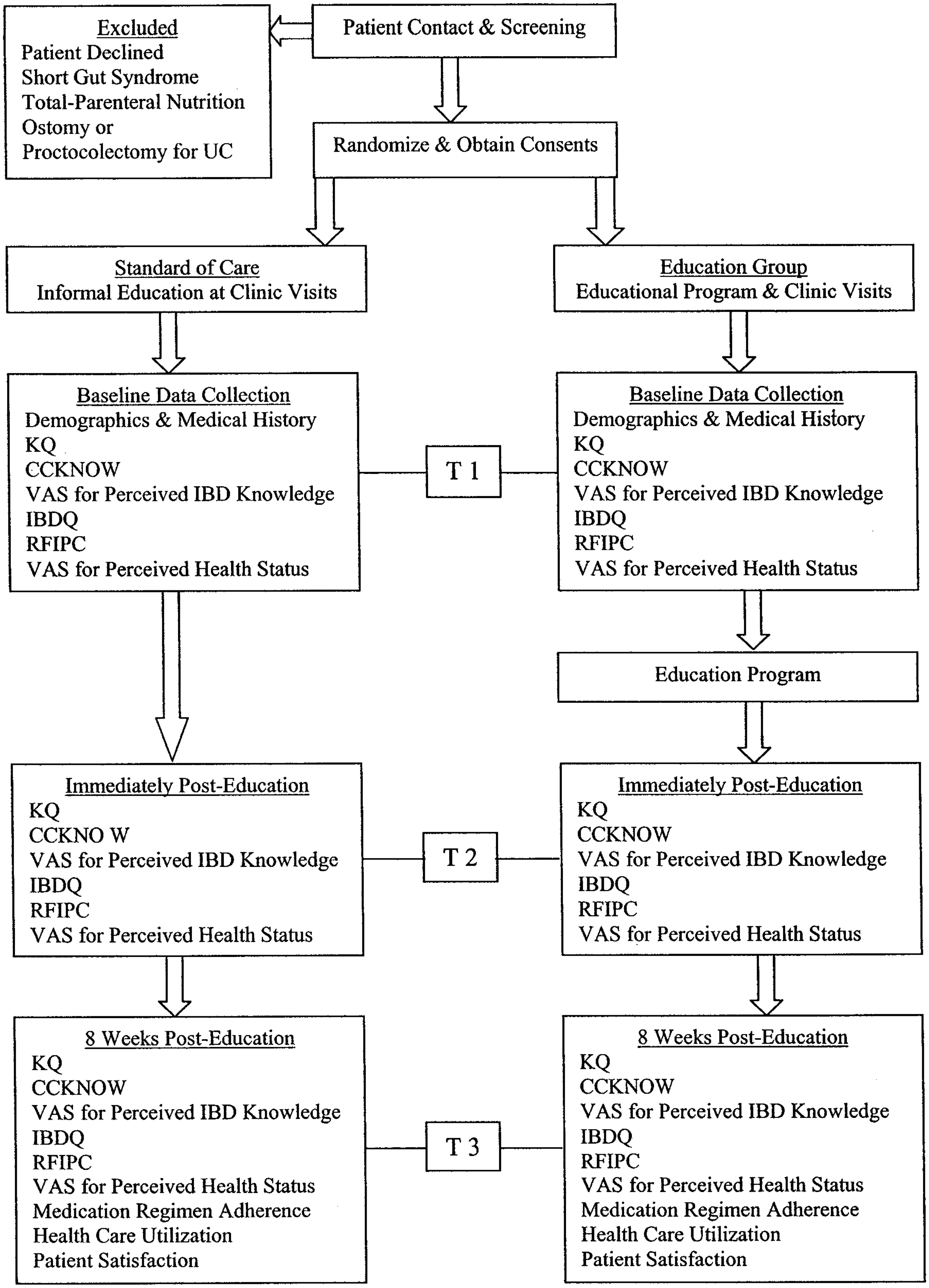

Figure 3.1. Study design with data collection time points.

Participants were recruited by mail-out or direct approach during routine clinic visits. At the time of first personal contact, potential participants were screened for inclusion/exclusion criteria and received information about the study and confidentiality procedures. The researcher discussed the study with them, ensuring they understood the commitment to the study, that their medical records regarding IBD may be audited, and that all participants would have an opportunity to attend the education program.

Mail-out recruitment was from the practices of three of the participating gastroenterologists. Based on chart review, 259 patients who had been seen in the previous two years and resided within a two-hour commuting distance from the hospital were selected for the mail-out. The letter and enclosed study pamphlet explained the study and invited the patient to participate (Appendix L). Each patient received one follow up telephone call to answer any questions and discuss participation in the study. Patients that indicated an interest in the study were screened for eligibility during the telephone call and if qualified, arrangements were made for enrolment. Anyone who had a previously scheduled appointment during the four-week recruitment period was enrolled during the clinic visit. Participants not scheduled for an appointment with their gastroenterologist during the recruitment period were given an appointment in a study enrolment clinic. The patients of the fourth participating gastroenterologists were screened and recruited during regularly scheduled clinic appointments at the University of Alberta Hospital.

At the time of enrolment, participants received a previously prepared, sealed envelope, labeled with the assigned study number. The contents of the envelope included: a letter advising the patient of group assignment, the baseline data collection instruments, a Patient Diary, current IBD literature in use by the participating gastroenterologists, a Study Consent Form and a Release of Medical Information form (Appendix M). Those who were randomized to the education program group also received information about the time and place of classes. Patient names and study numbers were recorded on a confidential roster for the permanent study record. All data was collected under the assigned study number to ensure patient confidentiality. Patients also underwent a routine medical examination, blood tests, and were instructed on how to complete the symptom reports for classification of disease activity during the clinic visit. Participants completed the first set of questionnaires and visual analogue scales to measure IBD knowledge, perceived IBD knowledge level, quality of life, and perceived health status. Demographic data collected included gender, age, level of education, and occupation on the Patient Profile questionnaire (Appendix N). Participants' IBD diagnosis, disease duration, co-morbid illnesses and data for calculation of disease severity were recorded. Prior IBD education opportunities were identified and included; Internet use, participation in previous IBD studies, prior IBD education programs, attendance at the Crohn's and Colitis Foundation Support Group (CCFCSG), and membership in the Crohn's and Colitis Foundation (CCFC). Additionally, participants were asked to provide a yes/no response to the question "Do you ever miss taking your medications?"

The immediate post-education data was collected by mail-out of the questionnaires or during regularly scheduled appointments. The mailed data collection instruments included a self-addressed, stamped envelope for return of the package. Reminder telephone calls (maximum of two) were made to participants to return the completed documents. Participants were advised to complete the documentation without referring to any literature they may have and to return the documents by a specific date. Data for the following variables was collected at the immediate post-education time point (T 2): knowledge scores, perceived knowledge level, quality of life indicators, and perceived health status. The education group also completed a patient satisfaction questionnaire about the education program (Appendix O). The control group was asked if they had read the provided educational pamphlets.

The third data collection point, 8 weeks post-education (T 3), was also collected as described previously. The Patient Diaries were returned with the questionnaires. Data collected included; knowledge scores, perceived knowledge level, medication regimen adherence, quality of life indicators, perceived health status, patient satisfaction, and health care utilization. Letters were mailed to the physicians of fifteen randomly selected active participants requesting information about any healthcare visits related to IBD, medication changes, and who initiated the appointment (Appendix P). The responses were compared to participants' self-reports as an audit of the accuracy of patient diaries.

Sample

Eighty-nine adults (17 years and older) with a diagnosis of IBD confirmed by radiographic/endoscopic examination and/or histology/surgical pathology were enrolled. Participants were recruited by convenience sampling during a four-week period from the aforementioned mail-out (82 patients) or during regularly scheduled appointments with their gastroenterologist (7 patients). Inclusion criteria included the ability to attend the education program and be fluent in written and spoken English. Participants with short gut syndrome, on total-parenteral nutrition, disease limited to ulcerative proctitis, a proctocolectomy for ulcerative colitis, an ostomy, or who underwent surgery during the study that required an ostomy, were excluded as these populations have unique health management issues.

Instruments

Knowledge Scores

Knowledge Questionnaire. Jones, Gallacher, Lobo, and Axon (1993) developed a true/false/don't know knowledge questionnaire to evaluate patient education programs (Appendix A). Utilizing data obtained in a study by Rees et al. (1983) that assessed what Crohn's disease patients wanted to know, forty-four questions were generated. Topics covered included: (a) general knowledge about the disease (anatomy and function of the bowel, extraintestinal symptoms, risk of the disease for relatives), (b) medical management (tests, medications and side effects, surgery), and (c) personal disease management (diet, physician consultation).

The KQ was piloted with 20 consecutive patients in a colitis clinic, 16 of whom completed the questionnaire in full. An analysis of difficulty and discrimination was undertaken. Those questions that had a high index of difficulty or were deemed to have poor discrimination were deleted or reworded. Thirty new patients took the test and 16 of them repeated the test four weeks later for retest reliability.

Reliability testing on the results revealed a high internal consistency with a Cronbach's coefficient alpha of .84. Correlation of the test-retest scores was also high ($r_s = .92$, $p = .002$). Finally, the test was administered to another group of 60 patients. Additional data regarding age, duration of full time education, and membership in

National Association of Crohn's Disease and Colitis (NACC) was also included. Correlations between these factors and knowledge scores were consistent with findings in other published studies.

The authors note that the language must be adjusted to what is used locally to ensure clear understanding for test subjects and that less ambiguous wording of some questions could improve the reliability of the KQ. Additionally, they identified that the KQ may not fully reveal the misunderstandings or beliefs about the disease that a patient has thus opportunity for education may be missed. Nevertheless, the KQ is a validated instrument for testing patient knowledge of Crohn's disease (CD) and ulcerative colitis (UC).

Crohn's and Colitis Knowledge Questionnaire. Eaden, Abrams, and Mayberry (1999) developed the CCKNOW questionnaire to assess patient knowledge of inflammatory bowel disease (Appendix B). Thirty multiple-choice questions regarding general IBD knowledge, medication, diet, and complications of IBD were drafted and reviewed by physicians. Utilizing a contrasted-groups approach, the resulting questionnaire was piloted with randomly selected groups of junior doctors, nurses, and ward clerks. A factor analysis of questions for discrimination resulted in deletion of six questions. The revised version was re-tested on the doctors, nurses, and ward clerks. The questionnaire, with added demographic questions, was then mailed to 647 randomly selected IBD patients from a database that included the practices of seven gastroenterologists. There was a 55% response rate with the single mailing with no follow-up reminders.

Reliability and validity were confirmed by variance testing of the group scores, correlation analysis of the questions, and readability testing. As expected, the scores for each group were appropriate for the anticipated knowledge level with the physicians scoring highest and ward clerks lowest, confirming construct validity. The Kruskal-Wallis test demonstrated a statistically significant difference in the scores across the three groups ($p < .0001$). Internal consistency was established with a Cronbach's alpha of .95. The Flesh Kinkaid readability score was grade level 4.4.

The results of the survey mailed to patients revealed a median score of 10/24 (confidence interval 9-10). Members of NACC scored significantly higher than non-members and only a few points lower than nurses. The higher score for the NACC members reflects the greater access to information that these patients have. Patients who were not members of NACC scored only slightly higher than the ward clerk group. The patient scores as compared to the group results were in keeping with anticipated knowledge levels, further demonstrating the construct validity of the questionnaire. Additionally, the overall results for the IBD patients are consistent with previously published findings. The authors note the questionnaire is a valid tool for evaluation of patient knowledge, identification of topics for education, stimulation of discussion, or evaluation of an education program.

The KQ and CCKNOW are valid instruments for the measurement of patient knowledge in IBD. Although either questionnaire could have been used to evaluate patient knowledge independently, each addresses the knowledge of IBD with a different style of question. The areas of knowledge tested are similar, but many of the questions are different thus providing a broader base of information testing. Response rates for individual questions were evaluated for the questionnaires using the baseline and immediate post-education responses. No questions were discarded, as the total correct response rates were greater than 50% for every question.

In the test-retest study design, using the same instrument increases the risk of sensitization of the participants to the questions, an issue of particular importance in tests of performance. Utilizing two instruments with different formats and a large variety of questions provided a pool of 61 questions and thus helped minimize sensitizing subjects. Answers were marked directly on the exams for clarity and to avoid retention of questionnaires. After marking, answers were transcribed on score sheets for calculation of topic section (diet, anatomy and physiology, general IBD knowledge, medications, complications of IBD) and total scores.

Perceived IBD Knowledge

Visual Analogue Scale for Percevied IBD Knowledge. The VAS is a simple measure of a subjective response that can be quantified for statistical analysis.

Participants rated how much they thought they knew about IBD, from a little to a lot, by marking on a graded color scale. Using the color scale helped nullify the numeric influence on patient grading (e.g. selecting the middle number on the scale as a non-committal response). A scale was subsequently applied to the patient marks and a numerical value assigned for statistical analysis (Appendix C).

Medication Regimen Adherence

Medication adherence data was collected by self-report in the supplied Patient Diaries. Participants recorded each missed medication and the reason in the Medication Management section of the Patient Diary (Appendix D). Participants selected the reason from a provided list or recorded one of their own. Participants returned their diaries with the 8-week post-education questionnaires. The number of incidents of missed medication was tabulated for each month for descriptive statistical analysis. Reasons for missed medications were also tabulated for reporting.

Reliance on self-disclosure for following prescribed medication regimens is an accepted method of evaluating adherence, although it is recognized that patient reporting may not be entirely accurate. Alternative investigations such as pill counting or review of prescription renewal would have significantly increased the demands on the participants and researchers, so were not included. To help verify the veracity of the self-reporting, participants were surveyed at baseline (Patient Profile) and again at the end of the study (Patient Satisfaction Survey) about whether they ever missed taking medications.

Quality of Life Indicators

Inflammatory Bowel Disease Questionnaire.

The questionnaire was developed to assess the effect of IBD on quality of life (Guyatt et al., 1989) (Appendix E). Mitchell et al. (1988) developed an IBD Symptom Questionnaire (ISQ) to identify the areas and extent of dysfunction in patients with IBD. Medical professionals involved in the care of patients with IBD and 77 patients with the disease were interviewed with an open-ended questionnaire developed from a literature review of the issues related to IBD and other quality of life instruments. The interviews resulted in a 150-item problem list that was divided into five dimensions: bowel symptoms, systemic symptoms, functional impairment, social impairment, and emotional disturbances.

A convenience sample of 97 IBD patients (excluding proctitis and ileostomy patients) were interviewed and asked to identify all physical, emotional, and social difficulties they experienced in relation to their disease. When they had completed identifying problems voluntarily, they were provided with the prepared problem list to further elicit information. The participants were then asked to rate the severity of each identified problem they had identified with a 4-point Likert scale.

Guyatt et al. (1989) utilized the data from the ISQ to develop the IBDQ. The 30 most frequent and highest rated problems were formulated into questions that were tested for poor wording and presentation, and then edited. Expert clinicians in IBD reviewed the IBDQ and two additional items were included based on their feedback. The questions were categorized into four dimensions: bowel symptoms, systemic symptoms, emotional function, and social function. Sixty-one IBD patients were interviewed twice, one month apart, using the IBDQ and an instrument for measurement of physical and emotional well being developed by the Rand Corporation. Thirty of the 61 patients had serial examinations by physicians and ratings of their disease activity utilizing the Van Hees Index for Crohn's disease or the St. Mark's index for ulcerative colitis.

The reliability and responsiveness of the IBDQ was tested utilizing paired t-tests from the two interviews. Using the differences in standard deviation compared to mean scores, a coefficient of variation was then calculated. For stable patients, there was a demonstrated low variation (0.06 to 0.15) suggesting strong reproducibility. In patients with clinical change, there were statistically significant differences in the IBDQ scores across all four dimensions (bowel symptoms, $\underline{p} < .001$; systemic symptoms, $\underline{p} < .001$; emotional function, $\underline{p} < .001$; social function, $\underline{p} = .013$). Comparison of the t-test standard deviations of stable patients and those with a change in disease status reveals ratios greater than one across all dimensions (1.4 - 3.0), further supporting the responsiveness of the IBDQ. The questionnaire was found to be responsive for both Crohn's disease and ulcerative colitis when the data were analyzed separately for each group. The differences in Rand scores for physical and emotional function were lower than those of the IBDQ demonstrating the strength of the instrument for the IBD population.

The authors' utilization of current literature, clinical experts in the field, and patient input to develop the questionnaire supports content validity. Construct validity is demonstrated by correlation with other measures. The change in the disease activity index compared to the IBDQ bowel symptoms and systemic symptoms resulted in correlation coefficients of .33 and .36 respectively. Correlation with the Rand questionnaire for emotional function was .76. Comparison of patients' global ratings of change in disease to bowel symptoms, tiredness to systemic symptoms, and emotional function to IBDQ emotional function resulted in correlation coefficients of .42, .36, and .52 respectively. The correlation coefficient comparing physician global rating of change in IBD activity and the dimension of bowel symptoms was .30.

The IBDQ was subsequently tested in a large multicenter trial, the Canadian Crohn's Relapse Prevention Trial (CCRPT) (Irvine et al., 1994). Three hundred five patients with CD participated in a study of low-dose cyclosporine versus placebo for long-term maintenance therapy. The subjects were reviewed at least every two months for 18 months. Responsiveness of the instrument was again demonstrated by significant differences in the IBDQ scores of those patients who had relapses or required surgery. Cyclosporine therapy failed to alter the disease course and this was reflected by no measured improvement of QOL as assessed by the IBDQ. The IBDQ scores correlated highly with the CDAI ($\underline{r} = -1.67$, $\underline{p} < .0001$) and Harvey-Bradshaw index ($\underline{r} = -0.56$, $\underline{p} < .0001$), reaffirming the validity of the instrument. The test-retest coefficients ranged from .64 to .70 demonstrating a high degree of reliability. A comparison of IBDQ mean scores of CCRPT study patients (168), IBD patients in the community (164), and normal controls (211) revealed similar results for the study and community IBD patients and a significantly higher score for non-IBD controls.

The IBDQ has since been validated in numerous studies (Cheung, Garratt, Russell, & Williams, 2000; De Boer, Wijker, Bartelsman, & De Haes, 1995; Han, McColl, Steen, Barton, & Welfare, 1998; Russel et al., 1997). A self-administered version of the questionnaire has since been developed and validated (Han, Gregory, Nylander, Tanner, Trewby, Baron, & Welfare, 2000; Irvine, Feagan & Wong, 1996). Additionally, a short version of the IBDQ (SIBDQ) has been developed for clinical practice to help differentiate inactive versus active disease (Irvine, 1999; Irvine, Zhou, & Thompson, 1996; Lopez-Viancos, Casellas, Badia, Vilaseca, & Malagelada, 1999).

Rating Form for Inflammatory Bowel Disease Patient Concerns. Drossman et al. (1989) sought to develop an instrument that would measure the worries and concerns of IBD patients that affected health related quality of life (Appendix F). Items for the RFIPC were derived from concerns identified to Dr. Drossman by patients (12) and from elicited responses during 45-minute videotaped interviews with eight IBD patients (9). Utilizing the identified concerns, a rating form was constructed with 21 questions worded as "Because of your condition, how concerned are you with ....?" Response was by VAS ratings from 0-100. Zero rated as "Not at all" and 100 as "A great deal" (p.1380).

The questionnaires were given to a pilot group of 62 IBD patients referred from a variety of settings. The patients were also asked to provide (a) demographic data (age, sex, race, occupation, work status, education, height, weight); (b) disease history (diagnosis, area of bowel disease, date of onset, months free of symptoms, current symptoms, current complications, and co-morbid illnesses); (c) health care utilization data (number of hospitalization in the last two years, number of surgeries, type of surgeries, number of physician visits in the past six months; (d) a rating of their health on a Likert scale from poor to excellent. They also answered the Sickness Impact Profile (SIP) questionnaire and underwent a physical exam by the referring physician. The physicians completed a one-page checklist that confirmed the disease information provided by the patient, rated the disease activity, and provided an assessment of overall health status.

The RFIPC proved to be a reliable and valid instrument. The test-retest reliability coefficient calculated on data collected from 90% of the subjects was .87 overall and ranged from .47 to .79 for the individual items. Validity was tested by comparing the RFIPC to the physician assessment of disease severity and to the SIP, a validated instrument for measuring health related QOL (test-retest reliability .92, internal consistency .94). Those patients with greater worries and concerns had a higher SIP score indicating poorer function (UC: $r = .46$, $p < .0003$; CD: $r = .48$, $p < .0001$). Comparison of all three measures demonstrated a correlation of higher disease activity, poorer function, and greater concerns in UC patients only ($r = .48$, $p < .002$). The RFIPC demonstrated sensitivity to different patient groups similar to the SIP. CD and hospitalized patients had more concerns and greater dysfunction than UC patients and outpatients/ respectively. Those patients with poorer overall function and greater worries also had a higher level of health care utilization.

Drossman et al. (1991b) further refined the RFIPC by adding three additional items derived from comments written on the questionnaires by subjects in the pilot study. The revised RFIPC was analyzed in a study that surveyed 991 randomly selected members of the Crohn's and Colitis Foundation of America (CCFA). A self-administered booklet that included the SIP questionnaire, SCL-90-R symptom checklist, Ways of Coping-Revised questionnaire, RFIPC was mailed to the subjects. The booklet also included a questionnaire to collect demographic, disease history, symptom experience, and health care use information. The response rate to the questionnaire was 74%.

The authors undertook a factor analysis of the individual items to create four indices of concern: (a) impact of disease, (b) sexual intimacy, (c) complications, and (d) body stigma. The item correlation to the indices was high ($r = .95$ to $.99$), as was internal consistency ($\alpha = .79$-$.91$). Construct validity was tested by group comparison of the items and indices. A t-test comparison of UC and CD patients' response to items using the Bonferroni method to adjust for multiple comparisons demonstrated statistically significant differences on a number of factors ($p < .002$). Statistically significant differences were found between the disease groups and genders when the mean index scores of the indices were compared. Analysis with ANCOVA controlling for disease type, gender, age, education, and disease severity explained most of the differences. Nevertheless, the RFIPC demonstrated a statistically significant difference in the higher degree of concern about disease complications in UC patients ($p = .0001$). There was also a statistically significant difference demonstrating greater concern in women regarding impact of the disease and body stigma that was not explainable by demographics, disease, or illness severity ($p = .0001$ and $.0013$, respectively).

Criterion validity was assessed with multiple regression analysis comparing the indices to patient self-reports of well being and health status, the SLC-90, and the SIP while controlling for age, gender, education disease type, and disease severity. A strong relationship was demonstrated between patients' self-report of well being and all RFIPC indices except sexual intimacy ($p \leq .0513$). The indices, impact of disease, and body stigma positively correlated with self-report of health status ($p = .0001$, $p = .0248$, respectively). Impact of the disease correlated significantly with the scores of the Global Symptom Index of the SCL-90 ($p = .0001$). The SIP has eight functional scales that the RFIPC was compared to: physical, psychosocial, recreation and pastimes, home management, communication, eating, sleep and rest, and work. The impact of disease correlated significantly with all of the functional scales of the SIP ($p \leq .0325$). Sexual intimacy correlated with the physical and psychosocial scales ($p = .0286$ and $p = .0091$, respectively). Complications of disease correlated with all of the function scales except communication, eating, and work ($p \leq .0464$). Body stigma only correlated with the work scale ($p = .0071$).

The RFIPC has been utilized and analyzed in other studies (Bergquist & Babic, 1999; Hjortswang et al. 1997; Moser et al., 1995) Moser et al. studied the relationship between IBD patient disease worries, disease aspects, sociodemographic variables, and the perceived level of knowledge about IBD. UC patients had significantly greater concern regarding loss of bowel control and feeling dirty or smelly ($p = .032$, $p = .048$, respectively). Women were significantly more concerned about being a burden on others, passing the disease to others, and being treated as different than men ($p < .024$). There was no correlation between the RFIPC sum score and disease or sociodemographic variables. Disease duration correlated with perceived IBD information level ($p = .05$). There was a significant correlation between lower perceived IBD information level and higher RFIPC sumscore ($p = .003$).

Hjortswang et al. (1997) specifically assessed the validity, reliability, and responsiveness of the RFIPC in 203 Swedish patients with UC. Construct validity was confirmed by testing three theoretically based hypotheses that the RFIPC (a) should correlate well with the patients' global score of well being, (b) have a greater association with QOL measures (SIP) than disease activity indices (Modified Clamp-Softley and Seo), and (c) should demonstrate a difference in concerns between remission and relapse patients. The RFIPC had a fair correlation to patients' global well being scores ($r_s = .69$) and demonstrated that relapse patients had more concerns than remission patients

(p = .001). The correlation with the SIP score (r_s = .43) was higher than the disease activity indices (Modified Clamp-Softley: r_s = .31 and Seo: r_s = .23). Test-retest reliability was acceptable in a group of remission patients who were followed up at months three and six (r_s = .73). The RFIPC was not found to be responsive to symptoms of disease activity. Comparison of intra-individual responses in the relapse group did not demonstrate significant change (p = .9999) when there was significant change in the disease activity indices (Modified Clamp-Softley: p = .0005 and Seo: p = .0004).

Bergquist and Babic (1999) undertook an analysis of the RFIPC in a group of 109 patients over one year. Subjects completed the questionnaire on four occasions, each three months apart. During the course of the study, 436 questionnaires were completed, 29 during a relapse, 365 during remission, and 42 were invalid due to missing data. Correlation analysis between the RFIPC and general well being had a high correlation (p = .001). The authors undertook a factor analysis of the items, but could not find supporting data for classification into the established RFIPC indices. The RFIPC was predictive of relapse or remission in adjusted group sizes (remission group size decreased to be comparable to relapse group) utilizing multivariate linear discrimination. Classification was successful in 78.1% of cases. The RFIPC showed a lack of sensitivity to changes of disease activity over time.

The RFIPC is a valuable tool in determining psychosocial concerns in the IBD population, differentiates the concerns between groups, and is more sensitive for IBD than general QOL tools. Development of the RFIPC included classification of concerns into indices with a data set of 991 patient questionnaires. Bergquist and Babic's (1999) study did not support this finding, however, their data set was of 394 questionnaires completed by 109 patients. Since the RFIPC tends to reflect a more global experience of the patient and is not sensitive to disease activity, there may have been little variability in the responses by patients over time, thus the true data set would be reduced to 109 responses, which may have been an insufficient number for classification into indices. The RFIPC is a validated instrument that captures information about health-related QOL issues in patients with IBD.

The IBDQ and RFIPC are both QOL measures, however each instrument assesses health status from a different perspective. Utilization of both instruments provided a comprehensive evaluation of QOL. At each data collection point, patients received a new questionnaire to mark their answers on. The IBDQ scores were calculated for each dimension of health and as a total. Scores for the RFIPC were calculated for each index and as a sum.

Perceived Health Status

Visual Analogue Scale for Perceived Health Status. Patients rated their personal perception of global health from poor to excellent by marking a non-numeric graded coloured scale. A 10-point scale was later applied to assign a numerical grade for statistical analysis (Appendix G).

Health Care Utilization

Assessment of health care utilization assessment was by patient self-report. Subjects recorded any IBD related visit to their family doctor and/or gastroenterologist and admissions to emergency or hospital in the Health Care Visit section of the Patient Diary. Information collected included the date of the event, reason for seeking medical attention, whether the visit was patient or physician initiated, tests ordered, and medication changes. For admissions to hospital, patients also reported the length of stay and procedures.

To confirm accuracy of reporting, an audit of 15 of the diaries was undertaken by random selection. The hospital records and IBD Outpatient Clinic charts were correlated with the self-report data. Additionally, a letter was sent to the selected patients' family physician requesting documentation of IBD related visits. This information was also correlated with the patient diaries.

Patient Satisfaction

The Patient Satisfaction Questionnaire used a Likert Scale format to assess the level of satisfaction with provision of IBD medical care in relation to: (a) information sharing (b) meeting information needs (c) medication education and (d) understanding provided information (Appendix H). Three items were included that assessed medication adherence. Those who participated in the psychoeducational program also completed a questionnaire to assess the level of satisfaction with the psychoeducational program. The question assessed (a) satisfaction with program content and whether the participant's learning needs were met and (b) the program format and presentation. Responses were recorded directly on the questionnaire and a space for comments was provided for each question for both surveys.

Demographic Data and Medical History

Demographic data was obtained by self-report using the Patient Profile questionnaire (Appendix N) and review of the patient health record. Data collected included gender, age, level of education, occupation, participation in previous IBD studies, prior IBD education programs, Internet use, attendance at the CCFCSG, membership in CCFC, and participation in previous studies. Personal information for contact and data tracking included the participant's address, telephone number, personal health care number (PHN), hospital identification number, and the name of the family doctor. The medical history included the type of IBD, year of diagnosis, current medications, previous surgery, and co-morbid illnesses. A record of study progress for each participant was maintained.

Disease Severity Determination

Crohn's Disease Activity Index. The CDAI was the first instrument developed and validated for quantitative assessment of disease activity (Yoshida, 1999) (Appendix I). The National Cooperative Crohn's Disease Study, comprised of gastroenterologists from 13 centers, developed the instrument for quantification of disease activity in trials. Eighteen variables were generated by the participating gastroenterologists and evaluated in a total of 186 clinic visits, 16 of which were repeat visits. Patients kept a seven-day diary of symptoms that they brought to clinic. The physician completed a data sheet, examined the patient, and rated the patient condition as very well, fair to good, poor, or very poor (Best, Becktel, & Singleton, 1976).

Best et al. (1976) used multiple regression analysis to determine which items correlated best with the physician scores of patient condition. Step-wise multiple regression analysis was also completed to assess which variables had the greatest effect on the model. Eight variables were identified: (a) the number of liquid or soft stools per week, (b) the sum of daily pain ratings over seven days, (c) the sum of daily well being ratings over seven days, (d) extra-intestinal manifestations of the disease, (e) medications used for diarrhea control, (f) presence/absence of an abdominal mass, and (g) body weight. The eight variables were assigned a weighted index by dividing the item coefficient by the smallest coefficient. Finally, ratings of disease activity were assigned on the calculated scores of the cohort. Those with a score of <150 were considered to have quiescent disease and those with a score of ≥ 450 were categorized as having severe disease (Best, Becktel, Singleton, & Kern, 1976).

The CDAI was subsequently validated in a large multicenter trial of more than 500 patients as well as other large studies (Best, Becktel, & Singleton, 1979). The CDAI was re-evaluated utilizing a database of 1058 patient visits. When the eight variables were reassessed utilizing the same multiple regression formulas as the original study, the results were consistent with the first study. The other 10 variables that were dropped in the first study were not evaluated, as the data had not been consistently collected.

Yoshida (1999) reviewed the CDAI and other instruments for the measurement of Crohn's disease. The instrument was found to be reliable with a strong correlation coefficient between the CDAI scores and physician assessments of .7 (< .70 considered reliable). Test-retest reliability was demonstrated by correlation coefficients of .969 to .994 between the re-derived variables and those of the original studies. Inter-rater reliability has been found to have a wide variance in a prospective study of experienced clinicians, however after further education, the variance narrowed. Yoshida notes that the CDAI is an operator-dependent diagnostic tool that requires experience in its use for consistency.

Yoshida describes the construct validity as good, citing the use of experts to generate the variables as a standard in development of instruments. Content validity, the degree that the instrument reflects the disease, is supported by the demonstrated responsiveness of the CDAI to disease activity and the strong correlation with physician assessment (Yoshida, 1999). The CDAI was designed to measure clinical indicators and has been demonstrated to be a poor tool for assessing quality of life issues in IBD (Garrett, & Drossman, 1990; Martin, Leone, Fires, & Naccarato, 1995; Mitchell et al., 1988). Criterion validity relates to the degree that an instrument correlates with the gold standard. Yoshida notes that the CDAI has become the gold standard for quantifying disease activity and has been used in studies for 25 years.

Activity Index. The AI for ulcerative colitis is a quantitative measure of disease activity (Appendix J). Seo et al. (1992) compared endoscopic, laboratory, and clinical variables to the traditional classifications of Truelove and Witts'. The classification system of Truelove and Witts' is a quantitative system of evaluating disease severity in ulcerative colitis that was developed in 1955 and has become the gold standard for clinical use. Disease severity is classified as mild, moderate, or severe based on stool frequency, blood in the stool, body temperature, pulse, hemoglobin, the erythrocyte sedimentation rate (ESR), abdominal tenderness, and radiographic findings (Truelove & Witts', 1955).

Seo et al. (1992) examined 18 variables in 85 clinical courses of ulcerative colitis in 72 patients. To reduce the subjectivity of clinical findings, careful recording and confirmation was undertaken. Patients recorded their symptoms in a daily diary and were interviewed every day by a physician. The physician also macroscopically evaluated the form of stool and quantity of blood several times each day. Three gastroenterologists independently confirmed the physician evaluations. Inter-rater agreement was high at 92.9%, 89.4%, and 97.6%.

For the purposes of statistical analysis all subjective variables were assigned a numeric value. Spearman's rank correlation coefficient was used to study the relationship of clinical variables to disease severity. The clinical parameters that demonstrated a significant correlation were stool frequency, bloody stool, body temperature, pulse rate, and abdominal pain ($p < .001$). Laboratory data highly correlated with disease severity included the white blood cell count (WBC), platelet count, ESR, α_1-globulin, α_2-globulin, β-globulin, γ-globulin, and C-reactive protein (CRP) ($p \leq .05$). Converse correlations included the red blood cell count (RBC), hemoglobin (Hb), hematocrit, serum total protein, albumin, and total cholesterol ($p \leq .05$). Endoscopic scoring of disease activity also correlated strongly with disease severity ($p < .001$).

The activity index was developed by multiple stepwise regression analysis of the identified significant independent variables using disease severity as the dependent variable. The regression analysis identified bloody stool, frequency of stool, ESR, Hb, and albumin as statistically significant factors that influenced disease severity ($p \leq .02$). A formula was developed using the regression coefficients and constants: $\text{AI} = 60 \times \text{blood in stool} + 13 \times \text{bowel movements} + 0.5 \times \text{ESR} - 4 \times \text{Hb} - 15 \times \text{albumin} = 200$. Criterion validity was confirmed with comparison of the formulated AI to Truelove and Witts' classification ($r = .8382$, $p < .001$). AI values of <150 correspond with mild disease, 150 to 220 to moderate disease, and >220 to severe disease. Responsiveness of the AI was demonstrated by comparing the admission and discharge values in the remission and non-remission groups. There was significant change in the AI in response to disease activity ($p \leq .05$). Finally, the activity index was compared to disease extent by one-way analysis of variance and Tukey's test. The AI of pancolitis was higher than distal forms ($p < .05$).

The AI was found to be more sensitive in detecting change in disease activity than Truelove and Witts' index for patients with moderate colitis (Seo et al., 1995). Although these patients received two weeks of steroid therapy, no change was noted using Truelove and Witts' criteria. AI values dropped significantly during the course of therapy for patients who did not require surgery ($p \leq .01$). The patients who required surgical intervention had no change in the AI.

Hjortswang, Strom, Almeida and Alber (1997) provided further confirmation of the responsiveness of the AI. The authors utilized the AI in a study evaluating the RFIPC in 232 patients with UC. The authors compared the RFIPC to a Modified Clamp-Softley Activity Index and the AI. The median AI between remission and relapse groups was 98.5 and 179.0, respectively ($p = .0000$). Significant change was noted in the AI in remission patients that relapsed ($p = .0005$), whereas no significant change was detected in AI scores over time in the patients who remained in remission ($p = .0004$).

Although the AI is a relatively new instrument for evaluating UC disease activity with limited use in clinical trials, development of the tool utilized strict clinical criteria, strong statistical methodology, and comparison to the gold standard. The AI has been demonstrated to correlate strongly with the gold standard and disease severity, has excellent responsiveness and test-retest reliability, and utilizes assessment tools that are standard of care. The quantitative values generated facilitate accurate statistical analysis.

The CDAI and AI are based on laboratory work and a seven-day report of symptoms. Patients were provided with a symptom report to complete and laboratory requisitions at the time of enrollment. The symptom records were returned by mail or during the first education class. Laboratory results were directed to the participating gastroenterologists for review and were subsequently recorded on the CDAI or AI tool. Symptom Records and laboratory requisitions were included in the Patient Diary to complete the week prior to scheduled physician visits for IBD and at the end of the study. Subjects were evaluated for disease activity at each appointment with their gastroenterologist during the course of the study and at the 8-weeks post-education (T3) to determine change in disease activity. The CDAI requires an abdominal examination for masses associated with severe disease. Subjects with CD had an abdominal examination at the time of enrolment and during any scheduled gastroenterologist appointments. At the end of the study, if there had been no change in disease activity according to the symptom record and no prior abdominal mass, the participant was assumed to have no abdominal mass and received a score of 0 for this parameter. After review of the symptom records at 8 weeks post-education, several subjects were identified as being at risk for increased disease severity and all had received follow up with their gastroenterologists.

Data Analysis

Descriptive statistics were used to describe participants' characteristics for knowledge scores, perceived knowledge level, medication regimen adherence, quality of life indicators, perceived health status, patient satisfaction, and health care utilization. Comparisons between the education and control groups using repeated measures analysis of variance (ANOVA), independent samples t-tests, and Chi-square as appropriate at the .05 level of significance were made. Relationships between perceived health status, knowledge scores, perceived IBD knowledge, QOL indices, patient satisfaction, and health care utilization were examine using Pearson's r. Participants' demographic characteristics (gender, age, level of education, occupation), disease profile (type of IBD, disease duration, severity of disease, co-morbid illness), and prior IBD Education (participation in previous IBD studies, Internet use, prior IBD education programs, attendance at the CCFCSG, membership in the CCFC) were assessed using t-tests and ANOVA to discriminate possible factors that could affect outcome variables and to determine predictors of knowledge and adherence behavior.

Ethical Considerations

The study received approval from the Health Research Ethics Board, Capital Health and Regional Research Administration, Capital Health. Participants were fully informed about the expectations of the study (Appendix L) and written consent was obtained (Appendix M). Potential participants were advised that declining to participate in the study would not affect the care they would normally receive. Additionally, participants were advised that they could withdraw from the study at any time without concern that their care would be affected. Participants signed a release of medical information form. The design of the study ensured that participants continued to receive standard care regardless of how they were randomized. To ensure equal opportunity for all participants, the control group was offered the opportunity to attend the full education program conducted after the study was completed.

Confidentiality was maintained through assignment of study numbers at the time of enrolment. Information that could specifically identify the individual was blocked and the assigned study number placed on the documents. The personal identification information about participants is kept under lock and key. All study records are secured in a locked environment for a minimum period of five years.

CHAPTER FOUR

Findings

Using a pretest-posttest design, the effects of a formalized education program for patients with inflammatory bowel disease (IBD) were evaluated. Participants were recruited and randomized to the control (ad hoc patient education during clinic visits) or education group (12-hour education program). Data were collected at baseline (T1), immediately post-education (T2), and 8 weeks post-education (T3). The primary outcomes evaluated were IBD knowledge, perceived IBD knowledge level, and medication adherence. Secondary outcomes included quality of life (QOL) indices, perceived level of health, health care utilization, and patient satisfaction.

The outcomes were assessed in relation to demographic, disease related, and prior IBD education variables. Demographic variables examined were age, gender, level of education, and occupation. Duration, severity, disease type, and co-morbid illness were included in the disease related variables. Opportunities for IBD education included participation in IBD studies, prior formal IBD education, Internet use, membership in the Crohn's and Colitis Foundation of Canada (CCFC), and attendance at the Crohn's and Colitis Foundation of Canada Support Group (CCFCSG).

Descriptive statistics were used to depict participant characteristics, recruitment results, education program attrition, and study completion. Statistical comparison between groups and over time were undertaken to test the hypotheses and assess relationships between the variables. Baseline group comparisons were made on all variables to determine any potential effects on outcomes. Nominal and ordinal data were analyzed using Pearson Chi-square and Fischer's exact test; t-test and repeated measures ANOVA were used for interval data. Relationships between variables were assessed with Pearson's r.

Recruitment

Following a health record review for selection of potential participants, 259 patients were sent an information letter about the study. Successful personal contact by telephone was made with 167 (64%) of the mail recipients. Nine (6%) were excluded according to the study criteria and 82 (49%) were enrolled. Personal contact was not made with 13 patients whose letters were returned with no forwarding address and the telephone number listed in the health record was out of service. Of 12 patients approached while attending their gastroenterologist's clinic, 7 (58%) were enrolled. Reasons for declining participation included other commitments, not interested, felt they did not need further education, too far to travel, too ill with co-morbid disease, the classes were too late in the day, and lack of transportation. Other commitments included employment, other evening activities, childcare issues, and demands of post-secondary studies. Of the 76 (46%) that declined participation, 63 (83%) indicated that they would like to participate in an education program if offered again in the future. A summary of recruitment results is included in Table 4.1.

Table 4.1
Summary of Participant Recruitment

Response to Recruitment	Clinic Total (N= 12)		Mail Out Total (N = 259)		Contacted & Eligible from Mail Out (N = 158)
	n	%	n	%	%
Mail Returned			13	5	
Unable to Contact			79	31	
Excluded	0	0	9	3	
Enrolled	7	58	82	31	52
Declined	5	42	76	29	48

Reasons for Declining	Clinic Total (N = 5)		Mail Out Total (N = 76)		Clinic & Mail Out Total (N = 81)
	n	%	n	%	%
Other commitments	4	33	39	51	53
Not interested	0	0	10	13	12
Education not needed	0	0	5	7	6
Too far to travel	1	8	15	20	20
Co-morbid illness	0	0	3	4	4
Classes too late	0	0	2	3	2
No transportation	0	0	2	3	2

Study and Education Program Attrition

Of the 89 enrolled participants, 69 (78%) completed the study. Eleven education program participants were withdrawn from the data analysis when they missed more than one class. Reasons for missing classes included poor driving conditions (n = 2), conflicts with employment/post-secondary education (n = 6), and IBD exacerbation/complications (n = 3). Of the remaining 34 education group participants, 3 did not complete their questionnaires at T2 or T3. Six control group participants did not complete both T2 and T3 questionnaires. Those who did not complete all questionnaires were not included in the repeated measures ANOVA outcome analysis. Reasons for incomplete questionnaires included illness (n = 2), death in the family (n = 1), lost in the mail (n = 3), and lost to follow up (n = 3).

Description of Participants

Of the 89 participants enrolled, 38 (43%) were male and 51 (57%) were female. Ages ranged from 17 to 74 years, of which 71% were aged 25 to 54 years. Completed education ranged from junior high (7%) to some form of post-secondary training (54%). Employment history reflected a variety of occupations from student to professional. Thirty-two of the Crohn's Disease (CD) participants had undergone surgery for their disease; ulcerative colitis (UC) participants with resection were excluded from the study. Missed medications were reported by 48 (54%) of the participants (Table 4.2).

Physicians were a source of information about IBD for 80 (90%) participants. Forty-two (47%) participants received information from a nurse, 16 (18%) had benefited from dietary counseling, and 4 had seen a psychologist regarding their IBD. Pharmacists were a source of information for 12 (13%) participants. Fourteen participants (16%), six from the control group and eight from the education group, stated they had received some formal education about their disease outside of clinic visits.

Thirty-two (36%) participants had UC and 57 (64%) had CD. The length of time participants had IBD ranged from < 1 year to > 35 years, with the 50% of participants having the disease for 5 to 15 years. Current medication therapy for the participants included steroids, azathiaprine/6-MP, methotrexate, 5-ASA, antibiotics, and monoclonal antibodies. Twenty-five percent of participants were on some form of osteoporosis therapy and ten percent were taking oral alternative therapy preparations (Table 4.3). Mean disease severity scores were moderate (150 to 450) for CD ($M = 160.35$, $SD = 110.19$; $M = 153.82$, $SD = 132.31$) participants and mild (<150) for those with UC ($M = 113.14$, $SD = 32.71$; $M = 110.50$, $SD = 36.10$) throughout the course of the study (Table 4.4). Co-morbid disease was reported by 47 (53%) of the participants. Extra-intestinal diseases associated with IBD included osteoporosis, nephrolithiasis, ankylosing spondilitis, vitamin B12 deficiency, and chronic anemia (Table 4.5).

Ten participants (11%) were currently enrolled in an IBD related study and 28 (31%) had been in a study previously. Twenty participants (22%) had attended the CCFCSG and 23 (26%) had been members of the CCFC. The Internet was an information source for 48 (54%) participants and 14 (16%) had been in some form of formal IBD education program (Table 4.6).

Comparison of total participants by gender revealed no differences for age, education level, or missed medications, but a statistically significant difference was noted for occupations. Males had a higher rate of employment in the skilled trade/technician category ($n = 12$, 32%) as compared to females ($n = 2$, 4%) ($\chi^2 = 28.14$, $p = .000$). Females had a higher rate of employment in the clerical/service/sales category ($n = 14$, 27%) as compared to males ($n = 2$, 5%) (Table 4.7). Analysis of disease variables demonstrated no gender difference for disease type, surgery, co-morbid illness, or medication therapy. Significantly more females ($n = 14$, 28%) had a diagnosis of less than five years than did males ($n = 3$, 8%) ($\chi^2 = 16.03$, $p = .042$) (Table 4.8). No gender difference was found for education variables (Table 4.9).

Total participant comparison by disease revealed no differences for age, occupation, or missed medications (Table 4.10). No differences were found for years of disease or co-morbid illness (Table 4.11). Nor were there differences for CCFCSG attendance, CCFC membership, or Internet use (Table 4.12). A greater proportion of UC participants (76%) had some form of post-secondary education as compared to those with CD (42%)($\chi^2 = 10.92$, $p = .012$). There was also a statistically significant difference in study participation between CD participants ($n = 31$, 54%) and those with UC (n = 7, 22%) (χ^2 = 9.27, p = .010). Comparison of medication therapy was not undertaken as the diseases are managed differently.

Forty-four participants were randomized to the control group and 45 to the education group. Comparison of the control and education groups revealed no statistically significant differences for demographic (Table 4.2) or disease variables (Table 4.3). Nor was there a difference between groups for IBD study participation, prior IBD education, Internet use, or CCFCSG attendance. Significantly more participants in the education group (n = 17, 38%) than in the control group (n = 6, 13%) had active and former membership in the CCFC (χ^2 = 6.77, p = .009) (Table 4.6).

Table 4.2
Demographic Characteristics of Participants

Characteristic	Total (n =89)		Control Group (n =44)		Education Group (n =45)		Comparison		
	n	(%)	n	(%)	n	(%)	χ^2	df	p
Gender							1.90	1	.122
Male	38	(43)	22	(50)	29	(64)			
Female	51	(57)	22	(50)	16	(36)			
Age Range							4.73	5	.450
17 - 24	9	(10)	3	(7)	6	(13)			
25 – 34	16	(18)	6	(14)	10	(22)			
35 – 44	26	(29)	15	(34)	11	(24)			
45 – 54	21	(24)	9	(20)	12	(27)			
55 – 64	13	(15)	8	(18)	5	(11)			
65 – 74	4	(6)	3	(7)	1	(2)			
Level of Education							3.03	3	.387
Junior High	6	(7)	4	(5)	2	(2)			
High School	35	(39)	16	(18)	19	(21)			
College/Trade/Technical School	27	(30)	11	(12)	16	(18)			
University	21	(24)	13	(15)	8	(9)			
Occupation							3.75	8	.879
Student	7	(8)	3	(7)	4	(9)			
Homemaker	8	(9)	4	(9)	4	(9)			
Laborer	4	(5)	2	(4)	2	(4)			
Skilled/Trade/Technician	14	(16)	8	(18)	6	(13)			
Clerical/Service/Sales	16	(18)	6	(14)	10	(22)			
Farming	3	(3)	1	(2)	2	(4)			
Arts/Sports/Recreation	4	(5)	3	(2)	1	(2)			
Management	11	(12)	7	(16)	4	(8)			
Professional	22	(25)	10	(23)	12	(27)			

Table 4.3

Disease Characteristics of Participants

Characteristic	Total (n = 89)		Control Group (n = 44)		Education Group (n = 45)		Comparison		
	n	(%)	n	(%)	n	(%)	χ^2	df	p
Disease Type							0.93	1	.229
Ulcerative Colitis	32	(36)	18	(41)	14	(31)			
Crohn's Disease	57	(64)	26	(59)	31	(69)			
Years of Disease							10.13	8	.256
<1	4	(4)	0	(0)	4	(9)			
1-4	13	(15)	5	(11)	8	(18)			
5-9	28	(32)	14	(32)	14	(31)			
10-15	16	(18)	6	(14)	10	(22)			
16-20	11	(12)	7	(16)	4	(9)			
21-25	8	(9)	5	(11)	3	(7)			
26-30	5	(6)	4	(9)	1	(2)			
31-35	3	(3)	2	(5)	1	(2)			
>35	1	(1)	1	(2)	0	(0)			
Medications									
Steroids	12	(13)	9	(20)	3	(7)	2.20	1	.123
Azathiaprine/6-MP	31	(35)	9	(20)	9	(20)	0.40	1	.363
Methotrexate	32	(36)	1	(2)	1	(2)	0.03	1	.689
5-ASA	34	(38)	22	(49)	12	(27)	2.51	1	.095
Antibiotics	6	(7)	3	(7)	3	(7)	0.10	1	.539
Monoclonal Antibody	7	(8)	3	(7)	4	(9)	0.57	1	.360
Osteoporosis Therapy	22	(25)	13	(29)	9	(20)	0.13	1	.469
Alternative Therapy	9	(10)	6	(13)	3	(7)	0.48	1	.376
Co-Morbid Illness	44	(49)	26	(59)	21	(47)	1.38	1	.168
Miss Medications	48	(54)	23	(52)	27	(60)	0.54	1	-.301

Table 4.4

Disease Severity of Participants

Activity Index		Total			Control Group			Education Group		
		n	M	SD	n	M	SD	n	M	SD
CDAI[a]	T1[b]	44	160.35	110.19	24	188.33	117.07	20	126.77	93.34
CDAI	T3[c]	39	153.82	132.31	23	173.13	144.71	16	126.06	110.66
AI[d]	T1	22	113.14	32.71	13	114.08	37.76	9	111.78	25.82
AI	T3	24	110.50	36.10	14	116.50	42.24	10	102.10	24.86

Activity Index				Comparison					
	df	t	p	df	t	p	df	t	p
CDAI	38	0.89	.379	22	0.74	.447	15	0.43	.675
AI	19	1.17	.258	11	-0.08	.940	7	2.06	.078

Note. [a]CDAI = Crohn's Disease Activity Index.
[b]T1 = Baseline.
[c]T3 = 8 weeks post education.
[d]AI = Activity Index for ulcerative colitis.

Table 4.5
Participant Co-morbid Illness

Co-Morbid Illness	Incidence of Illness	Total
Central Nervous System		
Migraines	4	
Tremors	1	5
Cardiovascular		
Hypertension	6	
Heart Valves	1	
Chronic Anemia	1	
Vasculitis	1	9
Pulmonary		
Asthma	8	
Tumor	1	9
Gastrointestinal		
Celiac Disease	1	
Peptic Ulcer Disease	2	
Vitamin B12 Deficiency	1	4
Genitourinary		
Nephrolithiasis	2	
Polycystic Kidney Disease	1	
Polycystic Ovaries	1	
Endometriosis	1	
Hypogonadism	1	
Prostate Cancer	1	
Recurrent UTI	1	8
Endocrine		
Diabetes	3	
Hypothyroidism	2	
Hyperlipidemia	2	7
Musculoskeletal		
Fibromylagia	1	
Osteoarthritis	13	
Osteoporosis	7	
Back Pain	2	
Rheumatoid Arthritis	1	
Ankylosing Spondylitis	1	
Scoliosis	1	
TMJ	1	27
Psychiatric		
Depression	4	
Bipolar Disorder	1	
Panic Attacks	1	6
Integumentary/ENT		
Psoriasis	1	
Eczema	1	
Cataracts	1	3

Table 4.6

Inflammatory Bowel Disease Education Characteristics of Participants

Education Category	Total (n = 89)		Control Group (n = 44)		Education Group (n = 45)		Comparison		
	n	(%)	n	(%)	n	(%)	χ^2	df	p
Study Participation	38	(43)	16	(36)	22	(49)	1.43	1	.164
Prior Education Program	14	(16)	6	(14)	8	(18)	0.29	1	.404
Internet Use	48	(54)	21	(47)	27	(60)	1.35	1	.171
CCFCSG Attendance[a]	20	(22)	9	(20)	11	(24)	0.20	1	.422
CCFC Member[b]	23	(26)	6	(13)	17	(38)	6.77	1	.009*

Note. *$p < .05$.

[a] CCFCSG = Crohn's and Colitis Foundation of Canada Support Group.

[b] CCFC = Crohn's and Colitis Foundation of Canada.

Table 4.7

Demographic Characteristics of Participants Compared by Gender

Characteristic	Males (n = 38)		Females (n = 51)		Comparison		
	n	(%)	N	(%)	χ^2	df	p
Age Range					2.09	5	.836
17 – 24	4	(11)	5	(10)			
25 – 34	7	(18)	9	(18)			
35 – 44	9	(24)	17	(33)			
45 – 54	11	(29)	10	(20)			
55 – 64	6	(16)	7	(14)			
65 – 74	1	(2)	3	(5)			
Education Level					3.03	3	.387
Junior High	4	(11)	3	(6)			
High School	13	(34)	21	(41)			
College/Trade/Technical School	10	(26)	17	(33)			
University	11	(29)	10	(20)			
Occupation					28.14	8	.000*
Student	3	(8)	4	(8)			
Homemaker			8	(16)			
Laborer	2	(5)	2	(4)			
Skilled/Trade/Technician	12	(32)	2	(4)			
Clerical/Service/Sales	2	(5)	14	(27)			
Farming	1	(2)	2	(4)			
Arts/Sports/Recreation			4	(8)			
Management	7	(18)	4	(8)			
Professional	11	(29)	11	(22)			

*Note. $p < .05$

Table 4.8

Disease Characteristics of Participants Compared by Gender

Characteristic	Male (n = 38)		Females (n = 51)		Comparison		
	n	(%)	n	(%)	χ^2	df	p
Disease Type					0.09	1	.472
Ulcerative Colitis	13	(34)	19	(37)			
Crohn's Disease	25	(66)	32	(63)			
Years of Disease					16.03	8	.042*
<1			4	(8)			
1 – 4	3	(8)	10	(20)			
5 – 9	14	(37)	14	(27)			
10 – 15	6	(16)	10	(20)			
16 – 20	5	(13)	6	(12)			
21 – 25	7	(18)	1	(2)			
26 – 30	2	(5)	3	(6)			
31 – 35			3	(6)			
>35	1	(2)					
Medications							
Steroids	9	(24)	9	(18)	0.52	1	.324
Azathiaprine/6-MP	15	(39)	18	(35)	0.19	1	.417
Methotrexate	1	(2)	1	(2)	0.05	1	.673
5-ASA	19	(50)	27	(53)	0.06	1	.489
Antibiotics	1	(2)	6	(12)	2.48	1	.118
Monclonal Antibody	6	(16)	8	(16)	0.00	1	.601
Osteoporosis Therapy	14	(37)	12	(24)	1.94	1	.124
Alternative Oral Therapy	5	(13)	6	(12)	0.04	1	.541
Co-Morbid Illness	21	(55)	30	(59)	0.11	1	.452
Miss Medications	21	(55)	29	(57)	0.02	1	.526
Surgery (Crohn's Disease only)	15 (n = 25)	(60)	16 (n = 32)	(50)	0.63	1	.284

Note. *p < .05.

Table 4.9

Inflammatory Bowel Disease Education Characteristics of Participants Compared by Gender

Characteristic	Male ($\underline{n}$ = 38)		Females ($\underline{n}$ = 51)		Comparison		
	$\underline{n}$	(%)	$\underline{n}$	(%)	χ^2	$\underline{df}$	$\underline{p}$
Prior IBD Study	14	(37)	23	(45)	0.28	1	.377
IBD Education Program	6	(16)	8	(16)	0.00	1	.607
Use Internet	23	(61)	25	(49)	1.16	1	.194
CCFCSG Attendance[a]	7	(18)	13	(14)	0.63	1	.299
CCFC Membership[b]	8	(21)	15	(16)	0.79	1	.260

Note. [a]CCFCSG = Crohn's and Colitis Foundation of Canada Support Group.
[b]CCFC = Crohn's and Colitis Foundation of Canada.

Table 4.10

Demographic Characteristics of Participants Compared by Disease

Characteristic	Ulcerative Colitis ($\underline{n}$ = 32)		Crohn's Disease ($\underline{n}$ = 51)		Comparison		
	$\underline{n}$	(%)	$\underline{n}$	(%)	χ^2	$\underline{df}$	$\underline{p}$
Age Range					4.58	5	.469
17 - 24	1	(11)	8	(10)			
25 – 34	7	(18)	9	(18)			
35 – 44	11	(24)	15	(33)			
45 – 54	6	(29)	15	(20)			
55 – 64	6	(16)	7	(14)			
65 - 74	1	(2)	3	(5)			
Education Level					10.92	3	.012*
Junior High			6	(11)			
High School	8	(25)	27	(47)			
College/Trade/Technical School	12	(38)	15	(26)			
University	12	(38)	9	(16)			
Occupation					13.88	8	.085
Student			7	(12)			
Homemaker	2	(6)	6	(11)			
Laborer			4	(7)			
Skilled/Trade/Technician	6	(19)	8	(14)			
Clerical/Service/Sales	5	(16)	11	(19)			
Farming			3	(5)			
Arts/Sports/Recreation	1	(3)	3	(5)			
Management	6	(19)	5	(9)			
Professional	12	(38)	10	(18)			

*Note. $\underline{p} < .05$.

Table 4.11
Disease Characteristics of Participants Compared by Disease

Characteristic	Ulcerative Colitis (n = 32)		Crohn's Disease (n = 51)		Comparison		
	n	(%)	n	(%)	χ^2	df	p
Years of Disease					8.68	8	.370
<1	3	(9)	1	(2)			
1 – 4	6	(19)	7	(12)			
5 – 9	10	(31)	18	(32)			
10 – 15	3	(9)	13	(23)			
16 – 20	3	(9)	8	(14)			
21 – 25	4	(13)	4	(7)			
26 – 30	1	(3)	4	(7)			
31 – 35	1	(3)	2	(4)			
>35	1	(3)					
Miss Medications	18	(56)	32	(56)	0.00	1	.585
Co-Morbid Illness	21	(55)	30	(59)	0.11	1	.452

Table 4.12
Inflammatory Bowel Disease Education Characteristics of Participants Compared by Disease

Characteristic	Ulcerative Colitis (n = 32)		Crohn's Disease (n = 51)		Comparison		
	n	(%)	n	(%)	χ^2	df	p
Prior IBD Study	7	(22)	31	(54)	8.85	1	.003*
IBD Education Program	5	(16)	9	(16)	0.00	1	.618
Use Internet	20	(63)	28	(49)	1.48	1	.160
CCFCSG Attendance[a]	6	(18)	14	(27)	0.40	1	.362
CCFC Membership[b]	5	(16)	18	(35)	2.72	1	.079

Note. *$p < .05$.
[a] CCFCSG = Crohn's and Colitis Foundation of Canada Support Group.
[b] CCFC = Crohn's and Colitis Foundation of Canada.

Inflammatory Bowel Disease Knowledge

Inflammatory bowel disease knowledge was assessed by three methods. Perceived IBD knowledge was examined by a 10-point visual analogue scale. Knowledge levels were tested with the Knowledge Questionnaire (KQ) and the Crohn's and Colitis Knowledge Questionnaire (CCKNOW). The questionnaires each assessed knowledge in five topic categories: (a) diet, (b) anatomy and physiology, (c) general IBD knowledge, (d) complications, and (e) medications. General IBD knowledge included questions regarding symptoms and disease management other than diet, complications, and medications. The anatomy and physiology questions assessed understanding of the structure and function of the gastrointestinal tract.

Knowledge Questionnaire Scores

The Knowledge Questionnaire has 37 True/False/Don't Know questions. No differences were found for baseline knowledge scores for the control and education groups ($\underline{M} = 17.24$, $\underline{SD} = 5.81$; $\underline{M} = 17.13$, $\underline{SD} = 7.00$, respectively)($\underline{t} = -0.1$, $\underline{p} = .923$). There were significant differences in mean knowledge scores [$\underline{F}$ (1.463, 1585.70) = 96.71, $\underline{p} = .000$] and "don't know" responses [$\underline{F}$ (1.418, 2273.79) = 91.19, $\underline{p} = .000$] for the participants over time. Pairwise comparisons of correct responses revealed that statistically significant differences were found between T1 and T2 ($\underline{p} = .000$), T1 and T3 ($\underline{p} = .000$), but not between T2 and T3 ($\underline{p} = 1.000$). Significantly increased scores over time occurred in all KQ sub-categories for the participants (Table 4.13).

A significant difference was found between groups for total score and "don't know" responses (Figures 4.1 and 4.2, respectively). Total KQ correct scores were increased for both groups at T2 and T3, but were significantly higher for the education group [$\underline{F}$ (1.463, 330.64) = 20.16, $\underline{p} = .000$]. The education group had significantly fewer "don't know" responses at T2 and T3 than the control group [$\underline{F}$ (1.418, 484.95) = 19.45, $\underline{p} = .000$]. On KQ sub-categories, differences between groups were significant for general IBD knowledge, complications, and medications only (Table 4.13).

As noted previously, it was anticipated that some control group participants would read the provided literature. A follow up survey revealed that 25 (57%) control group participants had read the literature (readers). At baseline, the readers had a higher mean score of 18.37, SD = 5.03 than those who did not (non-readers) (M = 14.93, SD = 6.09) but the difference was not statistically significant (t = 1.93, p = .06) Readers continued to have higher mean scores over time, but the difference between the readers and non-readers was not significant [F (1.67, 27.72) = 2.37, p = .111].

The effects of demographic, disease, and prior IBD education variables on KQ scores at baseline were examined (Tables 4.14, 4.15, 4.16, respectively). No statistically significant differences were found for demographic or disease variables. Nor was there a difference for Internet use or study participation. Significantly higher baseline scores were found for participants who had benefited from prior formal education (M = 20.50, SD = 6.76) versus those who did not (M = 16.59, SD = 6.03; t = 2.91, p = .031), however no difference was found between those with prior education and those without over time [F (1.373, 11.50) = 0.51, p = .534]. Participants who attended the CCFCSG had higher baseline total scores (M = 21.70, SD = 5.39) than those who had not (M = 15.90, SD = 5.93)(t = 3.55, p = .001), and the difference persisted over time [F (1.936, 75.378) = 3.55, p = .048]. Those who were CCFC members had higher mean KQ baseline total scores (M = 21.17, SD = 5.58) than non-members (M = 15.82, SD = 5.94) (t = 3.78, p = .000), but the difference did not persist over time [F (1.393, 37.01) = 1.69, p = .196]. Chi square analysis of control and education group baseline scores considering previous education programs (χ^2 = 9.92, p = .448), CCFCSG attendance (χ^2 = 13.27, p = .276), and CCFC membership (χ^2 = 12.63, p = .556) revealed no statistically significant differences.

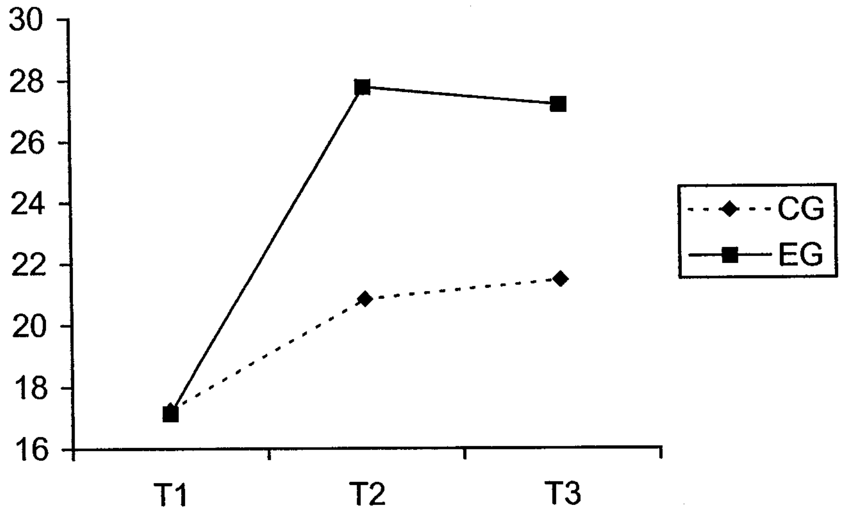

Figure 4.1. Comparison of Knowledge Questionnaire mean total correct responses by group over time.

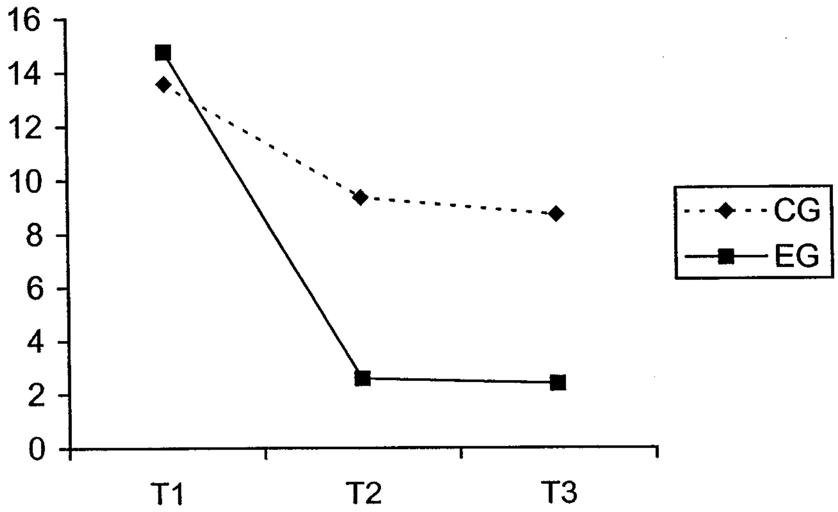

Figure 4.2. Comparison of Knowledge Questionnaire total mean "don't know" responses by group over time.

Table 4.13

Knowledge Questionnaire Scores Over Time and Between Groups

Category		Time			Time and Group		
	df	F	MS	p	F	MS	p
Correct	1.463[a]	96.71	1585.70	.000*	20.16	330.64	.000*
Don't Know	1.418	91.19	2273.79	.000*	19.45	484.95	.000*
Diet	1.537	10.98	22.08	.000*	0.92	1.85	.380
A & P	1.684	3.32	3.30	.048*	1.14	1.13	.317
Knowledge	1.733	49.62	116.08	.000*	17.52	40.98	.000*
Complications	1.529	62.89	166.17	.000*	13.14	34.71	.000*
Medications	1.829	26.38	61.16	.000*	3.16	7.33	.050*

Mean Scores Over Time

Category	Total (n =69)			Control Group (n =38)			Education Group (n =31)		
	T1[b]	T2	T3	T1	T2	T3	T1	T2	T3
Correct[c]									
M	17.19	23.96	24.04	17.24	20.84	21.47	17.13	27.77	27.19
SD ±	6.33	6.21	6.12	5.81	6.34	6.81	7.00	3.23	3.03
%	(46)	(65)	(65)	(47)	(56)	(58)	(46)	(75)	(73)
Don't Know									
M	14.12	6.32	5.88	13.58	9.37	8.74	14.77	2.58	2.39
SD ±	7.78	6.96	7.01	7.63	7.83	8.13	8.05	2.84	2.62
%	(38)	(17)	(16)	(36)	(25)	(23)	(40)	(7)	(6)
Diet									
M	1.65	2.45	2.51	1.61	2.16	2.34	1.68	2.81	2.71
SD ±	1.15	1.13	2.03	0.97	1.13	2.58	1.35	1.05	1.04
%	(41)	(61)	(63)	(39)	(54)	(59)	(42)	(70)	(68)
A & P									
M	1.36	1.62	1.75	1.39	1.47	1.79	1.32	1.81	1.71
SD ±	0.89	0.89	1.40	0.92	0.98	1.79	0.87	0.75	0.69
%	(45)	(54)	(58)	(46)	(49)	(60)	(44)	(60)	(57)
Knowledge									
M	5.65	7.62	7.64	5.76	6.50	6.79	5.52	9.00	8.68
SD ±	2.33	2.44	2.27	2.59	2.55	2.56	1.98	1.37	1.28
%	(51)	(69)	(69)	(52)	(59)	(62)	(50)	(82)	(79)
Complications									
M	4.46	6.61	6.81	4.55	5.74	5.92	4.35	7.68	7.90
SD ±	2.02	1.89	1.96	1.67	1.93	1.98	2.40	1.17	1.27
%	(43)	(65)	(62)	(46)	(55)	(59)	(44)	(77)	(79)
Medications									
M	4.07	5.65	5.51	3.92	4.97	4.92	4.26	6.48	6.23
SD ±	2.18	2.12	2.15	2.14	2.24	2.48	2.27	1.65	1.38
%	(45)	(63)	(61)	(44)	(55)	(55)	(47)	(72)	(69)

Note. * $p < .05$.

[a] Mauchly's test of sphericity significant therefore Greenhouse-Geisser adjusted values cited.

[b] T1 = Baseline, T2 = Immediately post-education, T3 = 8 weeks post-education.

[c] Total Correct and Don't Know = 37 questions; Diet = 4 questions; A & P (Anatomy and Physiology) = 3 questions; Knowledge (General IBD Knowledge) = 11 questions; Complications = 10 questions; Medications = 9 questions.

Table 4.14

Effect of Demographic Variables on Knowledge Questionnaire Baseline Mean Scores

Variable	Total Correct at Baseline			Comparison		
	n	M	SD	t / F	Df	p
Gender				t = -0.91	87	.365
Male	38	16.50	5.95			
Female	51	17.73	6.51			
Age				F = 1.39	5	.238
17-24	9	20.44	6.75			
25-34	16	18.94	5.92			
35-44	26	17.19	6.56			
45-54	21	14.86	7.04			
55-64	13	17.08	3.71			
>64	4	15.75	4.99			
Education Level				F = 0.61	3	.609
Junior High	6	13.83	9.11			
High School	35	17.43	6.22			
College/Trade/Technical School	27	17.41	5.18			
University	21	17.52	6.94			
Occupation				F = 0.74	8	.657
Student	7	20.14	8.38			
Homemaker	8	19.13	7.12			
Labourer	4	17.50	8.58			
Skilled Trade/Technician	14	16.71	6.79			
Clerical/Service/Sales	16	18.00	5.02			
Farming	3	12.67	4.04			
Arts/Sports/Recreation	4	17.25	4.79			
Management	11	14.64	2.11			
Professional	22	17.14	7.26			

Table 4.15

Effect of Disease Variables on Knowledge Questionnaire Baseline Mean Total Scores

Variable	Total Correct at Baseline			Comparison		
	n	M	SD	t / F	df	p
Disease Type				t = -1.84	87	.070
Ulcerative Colitis	32	15.59	6.61			
Crohn's Disease	57	18.11	5.95			
Years of Disease				F = 1.48	8	.177
<1	4	14.00	8.98			
1-5	13	14.54	5.27			
6-10	28	17.57	7.18			
11-15	16	17.38	5.35			
16-20	11	22.18	3.43			
21-25	8	15.63	7.13			
26-29	5	15.40	5.27			
30-34	3	17.67	4.16			
>34	1	17.00				
Co-morbid Illness				t = -0.05	87	.960
Yes	47	17.17	6.27			
No	42	17.24	6.35			

Table 4.16
Effect of Inflammatory Bowel Disease Education Variables on Knowledge Questionnaire Baseline Mean Total Scores

Variable	Total Correct at Baseline			Comparison		
	n	M	SD	t / F	df	p
Education Program				t = 2.19	87	.031*
Yes	14	20.50	6.76			
No	75	16.59	6.03			
Internet use				t = 1.03	87	.307
Yes	48	17.83	5.97			
No	41	16.46	6.61			
Study Participation				t = 1.63	87	.106
Yes	38	18.45	6.07			
No	51	16.27	6.32			
CCFCSG Attendance[a]				t = 3.93	87	.000*
Yes	20	21.70	5.39			
No	69	15.90	5.93			
CCFC Member[b]				t = 3.78	87	.000*
Yes	23	21.17	5.58			
No	66	15.82	5.94			
Control Group Reading				t = 1.93	39	.061
Readers	27	18.37	5.03			
Non-Readers	14	14.93	6.09			

Note. $p < .05$.
[a] CCFCSG = Crohn's and Colitis Foundation of Canada Support Group.
[b] CCFC = Crohn's and Colitis Foundation of Canada.

Crohn's and Colitis Knowledge Questionnaire Scores

The CCKNOW questionnaire is comprised of 24 multiple-choice questions. In addition to a selection of four possible answers, each question also provides an opportunity to respond with "don't know". There were no differences in baseline total correct CCKNOW scores between the control and education groups ($M = 9.79$, $SD = 4.94$; $M = 11.58$, $SD = 5.64$, respectively)($t = -1.02$, $p = .310$). There was a statistically significant difference for the participants in CCKNOW scores over time [F (1.568, 984.01) = 118.87, $p = .000$]. Pairwise comparison revealed differences from T1 to T2 ($p = .000$) and T1 to T3 ($p = .000$), but not between T2 and T3 ($p = .238$). Significant differences were found over time for all CCKNOW sub-categories except knowledge of anatomy and physiology (Table 4.17).

Mean correct scores increased for both groups at T2 and T3, but the education group CCKNOW scores were significantly higher than the control group [F (1.568, 117.73 = 14.22, p = .000] (Figure 4.3). "Don't know" responses were lower for both groups, but the decrease was significantly more for the education group as compared to the control group over time [F (1.586, 121.68) = 11.12, p = .000] (Figure 4.4). Differences were found between groups for all categories with the exception of anatomy and physiology (Table 4.17).

Control group readers had significantly higher baseline CCKNOW correct response scores than non-readers (M =10.89, SD = 4.69; M = 7.57, SD = 4.42, respectively)(t = 2.19, p = .035). Although the mean scores remained higher for the readers throughout the study, the significance did not persist over time [F (2, 1.44) = 0.24, p = .777].

Demographic and disease variables had no effect on baseline CCKNOW scores (Tables 4.18 and 4.19, respectively). Internet use and study participation also made no difference. Significantly higher baseline mean CCKNOW scores were found for participants who had benefited from prior IBD education versus those who did not (M = 13.64, SD = 6.28; M = 9.52, SD = 4.57, respectively)(t = 2.91, p = .005), but there was no difference over time [F (1.493, 30.01) = 3.08, p = .065]. Those who had been members of the CCFC had significantly higher baseline scores (M = 13.48, SD = 5.01) than those who had not (M = 9.02, SD = 4.59)(t = 3.93, p = .000). The difference between members and non-members did not persist over time [F (1.481, 30.33) = 2.98, p = .07]. CCFCSG attendees also had significantly higher baseline scores than non-attendees (M = 13.50, SD = 5.39; M = 9.20, SD = 4.57)(t = 3.55, p = .001) that persisted throughout the study [F (1.508, 62.82) = 6.62, p = .005] (Table 4.20). There was no effect on baseline control and education group CCKNOW scores for IBD education (χ^2 = 11.96, p = .288), CCFCSG attendance (χ^2 = 12.46, p = .330), or CCFC membership (χ^2 = 16.52, p = .283).

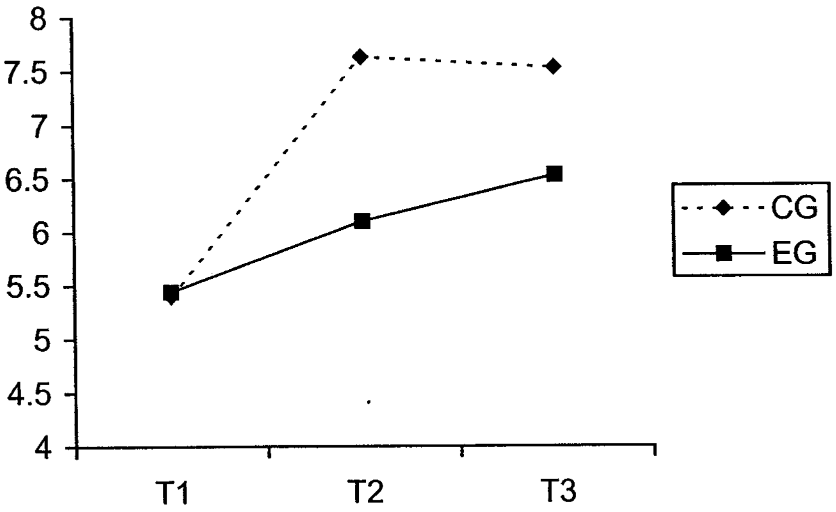

Figure 4.3. Comparison of Crohn's and Colitis Knowledge Questionnaire total mean correct responses by group over time.

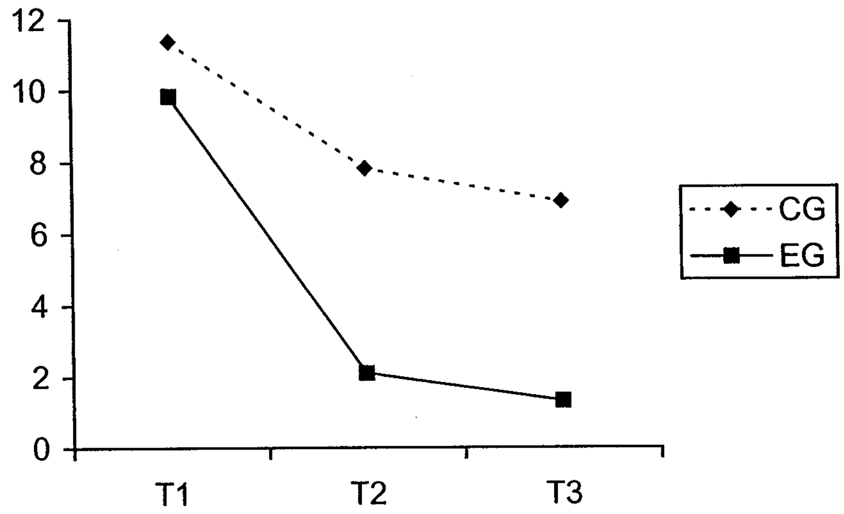

Figure 4.4. Comparison of Crohn's and Colitis Knowledge Questionnaire total mean "don't know" responses by group over time.

Table 4.17

Analysis of Crohn's and Colitis Knowledge Questionnaire Scores Over Time and Between Groups

Category		Time			Time and Group		
	df	F	MS	p	F	MS	p
Correct	1.568[a]	118.87	984.00	.000*	14.22	117.73	.000*
Don't Know	1.586	98.09	1073.48	.000*	11.12	121.68	.000*
Diet	1.749	26.96	5.52	.000*	8.82	1.81	.001*
A & P	1.826	33.83	28.33	.000*	1.10	0.92	.333
Knowledge	1.623	44.29	50.79	.000*	5.67	6.50	.008*
Complications	1.680	54.27	59.48	.000*	4.89	5.36	.013*
Medications	1.836	71.80	48.56	.000*	21.76	14.71	.000*

Mean Scores Over Time

Category	Total (n =69)			Control Group (n =38)			Education Group (n =31)		
	T1[b]	T2	T3	T1	T2	T3	T1	T2	T3
Correct[c]									
M	10.59	16.01	16.39	9.79	13.34	13.84	11.58	9.29	19.52
SD ±	5.30	5.58	4.88	4.94	5.66	4.86	5.64	3.30	2.55
%	(44)	(67)	(68)	(41)	(56)	(58)	(48)	(80)	(81)
Don't Know									
M	10.68	5.25	4.39	11.37	7.82	6.89	9.84	2.10	1.32
SD ±	5.91	5.68	5.33	6.26	6.31	5.93	5.43	2.33	1.83
%	(45)	(22)	(18)	(47)	(33)	(29)	(41)	(9)	(6)
Diet									
M	1.29	1.64	1.78	1.34	1.42	1.66	1.23	1.90	1.94
SD ±	0.69	0.62	0.48	0.67	0.72	0.58	0.72	0.30	0.25
%	(65)	(82)	(89)	(67)	(71)	(83)	(62)	(95)	(97)
A & P									
M	2.16	3.46	3.45	1.84	2.68	2.74	2.55	4.42	4.32
SD ±	1.51	1.60	1.59	1.31	1.61	1.59	1.67	0.92	1.08
%	(43)	(69)	(69)	(37)	(54)	(55)	(51)	(88)	(86)
Knowledge									
M	2.81	3.91	3.80	2.58	3.55	3.37	3.10	4.35	4.32
SD ±	1.40	1.33	1.27	1.39	1.37	1.28	1.37	1.14	1.05
%	(47)	(65)	(63)	(43)	(59)	(56)	(52)	(73)	(72)
Complications									
M	2.55	3.88	4.07	2.32	3.32	3.39	2.84	4.58	4.90
SD ±	1.69	1.64	1.40	1.56	1.69	1.35	1.83	1.29	0.94
%	(43)	(65)	(68)	(39)	(55)	(57)	(47)	(76)	(82)
Medications									
M	1.86	3.12	3.23	1.84	2.37	2.58	1.87	4.03	4.03
SD ±	1.36	1.47	1.39	1.44	1.38	1.38	1.28	0.98	0.98
%	(37)	(62)	(65)	(37)	(47)	(52)	(37)	(81)	(81)

Note. * $p < .05$.

[a] Mauchly's test of sphericity significant therefore Greenhouse-Geisser adjusted values cited.

[b] T1 = Baseline, T2 = Immediately post-education, T3 = 8 weeks post-education.

[c] Correct, Incorrect, Don't Know = 24 questions; Diet = 2 questions; A & P (Anatomy and Physiology) = 5 questions; Knowledge (General IBD Knowledge) = 6 questions; Complications = 6 questions; Medications = 5 questions

Table 4.18

Effect of Demographic Variables on Crohn's and Colitis Knowledge Questionnaire Baseline Mean Total Scores

Variable	Total Correct at Baseline			Comparison		
	n	M	SD	t / F	df	p
Gender				t = -1.21	87	.232
Male	38	9.42	4.83			
Female	51	10.73	5.21			
Age				F = 1.18	5	.326
17-24	9	10.67	6.20			
25-34	16	11.94	5.12			
35-44	26	10.96	5.62			
45-54	21	8.52	4.59			
55-64	13	9.31	4.01			
>64	4	8.25	0.96			
Education Level				F = 1.74	3	.165
Junior High	6	7.00	6.26			
High School	35	9.63	4.44			
College/Trade/Technical School	27	10.26	4.17			
University	21	11.86	6.37			
Occupation				F = 0.81	8	.598
Student	7	12.00	5.72			
Homemaker	8	9.75	5.50			
Labourer	4	8.25	5.91			
Skilled Trade/Technician	14	10.07	5.61			
Clerical/Service/Sales	16	10.25	4.46			
Farming	3	8.33	0.58			
Arts/Sports/Recreation	4	6.25	2.22			
Management	11	9.09	2.21			
Professional	22	11.59	6.19			

Table 4.19

Effect of Disease Variables on Crohn's and Colitis Knowledge Questionnaire Baseline Mean Total Scores

Variable	Total Correct at Baseline			Comparison		
	n	M	SD	t / F	df	p
Disease Type				t = -0.98	87	.332
Ulcerative Colitis	32	9.47	5.57			
Crohn's Disease	57	10.56	4.77			
Years of Disease				F = 1.06	8	.402
<1	4	9.50	6.56			
1-5	13	7.92	3.59			
6-10	28	10.54	6.38			
11-15	16	10.94	4.12			
16-20	11	13.00	4.52			
21-25	8	7.88	5.06			
26-29	5	9.40	1.52			
30-34	3	10.67	2.52			
>34	1	9.00				
Co-Morbid Illness				t = -0.33	87	.742
Yes	47	10.00	4.63			
No	42	10.36	5.56			

Table 4.20

Effect of Inflammatory Bowel Disease Education Variables on Crohn's and Colitis Knowledge Questionnaire Baseline Mean Total Scores

Variable	Total Correct at Baseline			Comparison		
	n	M	SD	t / F	df	p
Education Program				t = 2.91	87	.005*
Yes	14	13.64	6.28			
No	75	9.52	4.57			
Internet use				t = 0.83	87	.406
Yes	48	10.58	4.97			
No	41	9.68	5.19			
Study Participation				t = 1.56	87	.122
Yes	38	11.13	4.78			
No	51	9.45	5.20			
CCFCSG Attendance[a]				t = 3.55	87	.001*
Yes	20	13.50	5.39			
No	69	9.20	4.57			
CCFC Member[b]				t = 3.93	87	.000*
Yes	23	13.48	5.01			
No	66	9.02	4.59			
Control Group Reading				t = 2.19	39	.035*
Readers	27	10.89	4.69			
Non-Readers	14	7.57	4.42			

Note. *p < .05.

[a] CCFCSG = Crohn's and Colitis Foundation of Canada Support Group.

[b] CCFC = Crohn's and Colitis Foundation of Canada.

Perceived Inflammatory Bowel Disease Knowledge Ratings

Perceived IBD knowledge was assessed by a color-graded, 10-point visual analogue scale on which participants rated their level of knowledge from a little to a lot. The range of ratings at baseline, T1, and T2 were 0 to 10. There was a significant difference for the participants over time [F = (1.407, 76.14) = 31.53, p = .000]. Pairwise comparisons demonstrated differences from T1 to T2 and T1 to T3 (p = .000), but not for T2 to T3 (p = .656). Mean perceived knowledge for the control and education groups were similar at baseline (M = 5.40, SD = 2.31; M = 5.44, SD = 2.19)(t = -0.02, p = .985). The ratings were significantly higher for the education group at T2 and T3 as compared to the control group [F (1.407, 14.01) = 5.80, p = .01] (Figure 4.5)(Table 4.21). Perceived knowledge correlated positively to knowledge scores on the KQ and CCKNOW, with those achieving higher scores having higher perceived knowledge levels (Table 4.22).

No statistically significant effects were noted for demographic or disease variables on baseline perceived knowledge ratings (Tables 4.23 and 4.24, respectively). Attendees of the CCFCSG had a significantly higher mean perceived knowledge baseline score (M = 6.21, SD = 2.01) than those who had not (M = 5.11, SD = 2.11)(t = 2.08, p = .04), but the difference did not persist over time [F (1.386, 0.51) = 0.19, p = .744]. CCFC members also had significantly higher perceived knowledge baseline scores (M = 6.77, SD = 1.57) than non-members (M = 4.86, SD = 2.08)(t = 4.01, p = .000) and the difference persisted throughout the timeframe of the study [F (1.408, 8.50) = 3.41, p = .053](Table 4.25). Analysis of CCFCSG attendance and CCFC membership by control and education group revealed no difference on perceived knowledge ($\chi^2 = 15.96$, p = .456; $\chi^2 = 19.54$, p = .190, respectively).

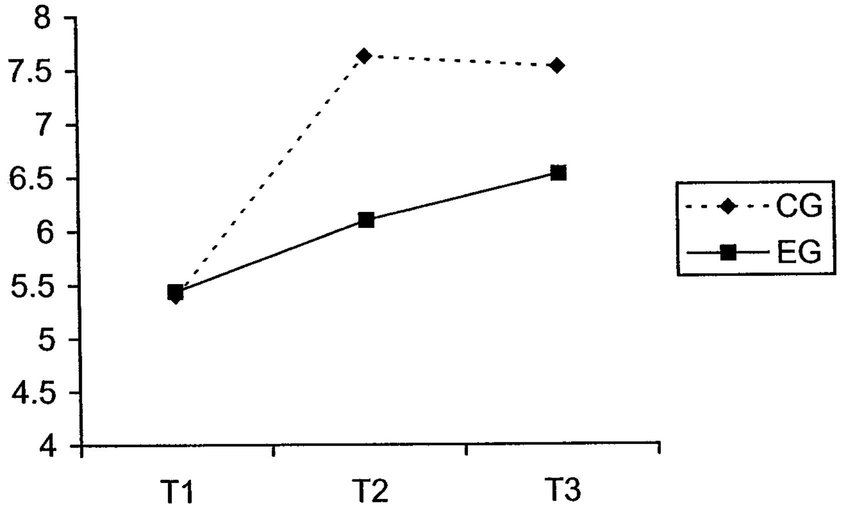

Figure 4.5. Comparison of mean perceived Inflammatory Bowel Disease knowledge ratings by group over time.

Table 4.21
Perceived Knowledge Ratings Over Time and Between Groups

	Time			Time and Group		
df	F	MS	p	F	MS	p
1.407	31.53	76.14	.000*	5.80	14.01	.010*

Mean Ratings Over Time

Time Point	Total (n = 69)		Control Group (n = 38)		Education Group (n = 31)	
	M	SD	M	SD	M	SD
T1[a]	5.42	2.24	5.40	2.31	5.44	2.19
T2	6.79	1.72	7.63	1.33	6.10	1.72
T3	6.98	1.63	7.53	1.35	6.53	1.71

Note. *p < .05.
[a]T1 = Baseline, T2 = Immediately post-education, T3 = 8 weeks post-education.

Table 4.22
Correlation of Perceived Knowledge Ratings to Knowledge Scores

Knowledge Scores	Perceived Knowledge Ratings		
	T1[a]	T2	T3
	Knowledge Questionnaire		
T1 (n =89)	.484*	--	--
T2 (n =73)		.568*	--
T3 (n =72)		--	.341*
	Crohn's & Colitis Knowledge Questionnaire		
T1 (n =89)	.557*	--	--
T2 (n =73)		.547*	--
T3 (n =72)			.450*

Note. *Correlations are significant at the 0.01 level of significance (2-tailed).
[a]T1 = Baseline, T2 = Immediately post-education, T3 = 8 weeks post-education.

Table 4.23

Effect of Demographic Variables on Baseline Mean Perceived Knowledge Ratings

Variable	Rating at Baseline			Comparison		
	n	M	SD	t / F	df	p
Gender				t = 0.47	87	.640
Male	38	5.48	2.14			
Female	51	5.27	2.13			
Age				F = 1.50	5	.198
17-24	9	5.72	1.96			
25-34	16	5.89	1.70			
35-44	26	5.62	2.21			
45-54	21	4.39	2.09			
55-64	13	5.13	2.50			
>64	4	6.51	1.47			
Education Level				F = 1.65	3	.184
Junior High	6	4.83	2.46			
High School	35	4.93	2.03			
College/Trade/Technical School	27	5.40	2.18			
University	21	6.17	2.03			
Occupation				F = 0.55	8	.813
Student	7	5.82	2.02			
Homemaker	8	5.16	2.64			
Labourer	4	5.13	2.07			
Skilled Trade/Technician	14	5.34	2.01			
Clerical/Service/Sales	16	5.22	2.01			
Farming	3	5.83	0.38			
Arts/Sports/Recreation	4	5.45	1.78			
Management	11	4.32	2.23			
Professional	22	5.88	2.38			

Table 4.24

Effect of Disease Variables on Baseline Mean Perceived Knowledge Ratings

Variable	Rating at Baseline			Comparison		
	n	M	SD	t / F	df	p
Disease Type				t = -0.02	87	.985
Ulcerative Colitis	32	5.35	2.27			
Crohn's Disease	57	5.36	2.06			
Years of Disease				F = 1.20	8	.308
<1	4	4.25	4.33			
1-5	13	4.29	1.54			
6-10	28	5.81	2.05			
11-15	16	4.84	1.67			
16-20	11	6.20	1.80			
21-25	8	5.72	2.27			
26-29	5	5.86	3.51			
30-34	3	4.67	1.15			
>34	1	6.50				
Co-Morbid Illness				t = -0.65	87	.521
Yes	51	5.23	2.23			
No	38	5.53	2.00			

Table 4.25
Effect of Inflammatory Bowel Disease Education Variables on Baseline Mean Perceived Knowledge Ratings

Variable	Rating at Baseline			Comparison		
	n	M	SD	t / F	df	p
Education Program				t = 1.41	87	.162
Yes	14	6.09	2.33			
No	75	5.22	2.08			
Internet use				t = 1.57	87	.119
Yes	48	5.68	2.01			
No	41	4.98	2.22			
Study Participation				t = 1.31	87	.193
Yes	38	5.70	2.01			
No	51	5.10	2.20			
CCFCSG Attendance[a]				t = 2.08	87	.040*
Yes	20	6.21	2.01			
No	69	5.11	2.11			
CCFC Member[b]				t = 4.01	87	.000*
Yes	23	6.77	1.57			
No	66	4.86	2.08			
Control Group Reading				t = 1.77	39	.085
Readers	27	5.85	2.44			
Non-Readers	14	4.59	1.50			

Note. *$p < .05$.
[a] CCFCSG = Crohn's and Colitis Foundation of Canada Support Group.
[b] CCFC = Crohn's and Colitis Foundation of Canada.

Medication Adherence

Medication adherence was assessed by three methods; (a) survey at baseline, (b) a set of questions on the Patient Satisfaction Questionnaire, (c) and participant self-report in the provided diaries. Baseline assessment required participants to answer the question "Do you ever miss taking your medications?" Forty-eight participants (54%) responded in the affirmative. The Patient Satisfaction Questionnaire asked participants to rate their agreement to questions about making errors with medications, forgetting medications, and whether they stop medications because of side effects. Fifty-four percent of participants had scores above the median indicating difficulty with medication adherence.

For assessment by self-report, participants were asked to make a diary entry for each instance of a missed medication and the reason for the occurrence. The data was then broken down by month for analysis of change over time. Seventy-two participants kept a diary of their missed medications. Twenty-one participants (29%) reported missing medications. There were 166 incidents of missed medications with a mean of 2.31 incidents per reporting participant (SD = 7.90, range 0 to 60). The most commonly cited reason for missing a medication was they forgot, followed by leaving medications at home, prescription ran out, and side effects. Other reasons provided by participants included "missed meals, so did not take medications" and "slept in" (Table 4.26). The education group had lower mean incidents of missed medications, but the difference was not significant over time [F (1.818, 1.42) = 1.21, p = .3] or between groups [F (1.818, 1.61) = 1.37, p = .257] (Figure 4.6)(Table 4.27).

Analysis of demographic, disease, and educational variables (Tables 4.28, 4.29, and 4.30, respectively) revealed no differences for age, education level, occupation, type of disease, years of disease, co-morbid illness, study participation, prior IBD education, or CCFC membership for medication adherence by self-report. Females missed taking medications more often than males (M = 3.80, SD = 10.23; M = 0.32, SD = 0.98, respectively)(t = -1.89, p = .036). Attendees of the CCFCSG had a significantly lower rate of non-adherence than non-attendees (M = 0.06, SD = 0.25; M = 2.95, SD = 8.87, respectively)(t = -1.29, p = .018). Internet users had a significantly higher rate of non-adherence than non-users (M = 4.17, SD = 10.82; M = 0.44, SD = 1.56, respectively) (t = 2.04, p = .048).

Table 4.26
Summary of Reasons for Missed Medications

Reason	Total Instances	M	SD
Forgot	107	9.73	17.31
Prescription Ran Out^a	12	12.00	
Side Effects	5	2.50	0.71
Left Medication at Home	23	2.88	5.30
Other	19	6.33	7.57

Note. ^{a}One individual missed 12 doses before refilling prescription.

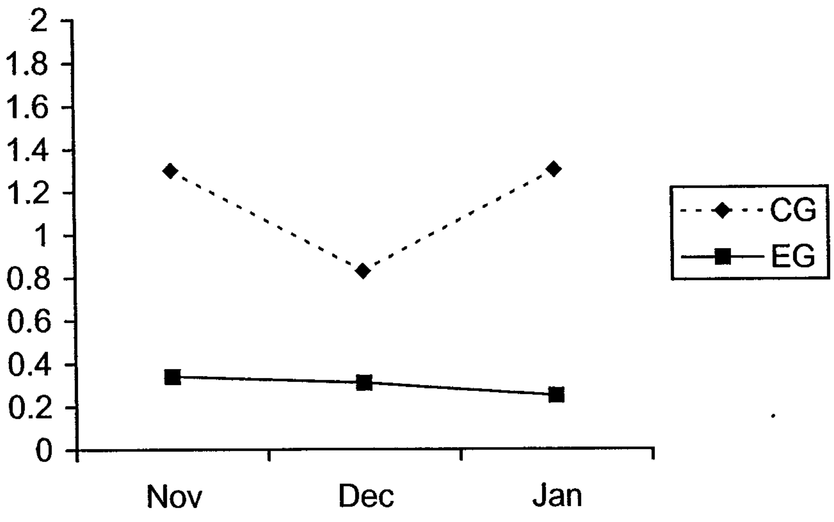

Figure 4.6. Comparison of mean incidents of missed medications per participant by group over time.

Table 4.27
Medication Adherence Over Time and Between Groups

	Time			Time and Group		
df	F	MS	p	F	MS	p
1.818	1.21	1.42	.300	1.37	1.61	.257

Mean Ratings Over Time

Timeframe	Total (n = 72)			Control Group (n = 40)			Education Group (n = 32)		
	Total	M	SD	Total	M	SD	Total	M	SD
Total	166	2.31	7.90	137	3.43	10.32	29	0.91	2.32
November	60	0.83	2.89	52	1.30	3.75	8	0.34	0.88
December	43	0.60	2.54	33	0.82	3.34	10	0.31	0.82
January	63	0.88	2.85	52	1.30	3.71	11	0.25	0.90

Table 4.28

Effect of Demographic Variables on Medication Adherence

Variable	Missed Medications			Comparison		
	n	M	SD	t / F	df	p
Gender				t = -2.17	41	.036*
Male	31	0.32	0.98			
Female	41	3.80	10.23			
Age				F = 0.51	5	.771
17-24	6	0.50	1.22			
25-34	15	2.80	5.56			
35-44	20	4.25	13.51			
45-54	15	2.07	5.01			
55-64	12	0.25	0.45			
>64	4	0.50	1.00			
Education Level				F = 0.89	3	.449
Junior High	6	0.00	0.00			
High School	28	2.39	5.26			
College/Trade/Technical School	21	4.29	13.20			
University	17	0.53	1.37			
Occupation				F = 0.81	8	.596
Student	6	0.67	1.21			
Homemaker	7	2.14	4.49			
Labourer	3	0.00	0.00			
Skilled Trade/Technician	11	0.91	1.58			
Clerical/Service/Sales	14	3.21	6.35			
Farming	2	0.00	0.00			
Arts/Sports/Recreation	3	6.33	9.29			
Management	9	7.33	19.82			
Professional	17	0.41	1.23			

Note. *$p < .05$.

Table 4.29

Effect of Disease Variables on Medication Adherence

Variable	Missed Medications			Comparison		
	n	M	SD	t / F	df	p
Disease Type				t = 1.21	27	.238
Ulcerative Colitis	26	4.19	12.20			
Crohn's Disease	46	1.24	3.55			
Years of Disease				F = 0.77	8	.629
<1	3	5.67	6.03			
1-5	10	0.10	0.32			
6-10	23	4.65	12.91			
11-15	11	1.09	2.70			
16-20	10	0.20	0.42			
21-25	7	0.00	0.00			
26-29	4	6.50	8.58			
30-34	3	0.00	0.00			
>34	1	1.00				
Co-Morbid Illness				t = 0.80	70	.429
Yes	41	2.95	9.98			
No	31	1.45	3.66			
Miss Medications[a]				t = 1.22	43	.230
Yes	37	3.38	10.51			
No	35	1.17	3.27			

Note. [a]As reported on baseline survey.

Table 4.30

Effect of Inflammatory Bowel Disease Education Variables on Medication Adherence

Variable	Missed Medications			Comparison		
	n	M	SD	t / F	df	p
Education Program				t = -0.93	70	.357
Yes	11	0.27	0.90			
No	61	2.67	8.53			
Internet use				t = 2.04	36	.048*
Yes	36	4.17	10.82			
No	36	0.44	1.56			
Study Participation				t = -1.51	49	.136
Yes	32	0.88	3.38			
No	40	3.45	10.07			
CCFCSG Attendance[a]				t = -2.43	55	.018*
Yes	16	0.06	0.25			
No	56	2.95	8.87			
CCFC Member[b]				t = -1.98	57	.052
Yes	18	0.44	0.98			
No	54	2.93	9.04			

Note. $p < .05$.

[a] CCFCSG = Crohn's and Colitis Foundation of Canada Support Group.

[b] CCFC = Crohn's and Colitis Foundation of Canada.

Quality of Life Indices

Quality of life was assessed by two questionnaires that use different approaches. The Inflammatory Bowel Disease Questionnaire (IBDQ) assesses quality of life on the basis of physical symptoms and associated effects on emotional and social well being. The Rating Form for IBD Patient Concerns (RFIPC) focuses on the worries and concerns patients have in relation to their disease.

Inflammatory Bowel Disease Questionnaire Scores

The IBDQ has 32 quality of life questions that identify physical, social, and emotional symptoms or dysfunction on a Likert scale of 1 to 7, with a rating of 1 meaning all of the time and 7 meaning none of the time. The questions are divided into dimensions of bowel symptoms (10 items), systemic symptoms (5 items), emotional function (12 items), and social function (5 items). Low scores indicate more severe disease activity and/or higher emotional and social dysfunction.

The baseline mean total IBDQ scores ranged from 74 to 214. No difference was found for IBDQ total scores at baseline between the control and education groups (M = 160.55, SD = 37.06; M = 168.06, SD = 25.10, respectively)(t = -0.91, p = .366). No difference was found over time [F (2, 643.26) = 2.17, p = .119] or between the control and education groups [F (2, 74.82) = 3.08, p = .777] for total score (Figure 4.7). No difference was found over time for any IBDQ dimension scores. Only systemic symptoms showed a statistically significant difference between groups [F (1.597, 77.22) = 3.43, p = .046] (Table 4.31). A correlation was found between disease severity as determined by the Activity Index (AI)(for ulcerative colitis) and the Crohn's Disease Activity Index (CDAI). Increased disease severity was associated with worse physical symptoms and greater psychosocial dysfunction on the IBDQ (Table 4.32). Analysis of baseline mean IBDQ scores of participants with quiescent disease as measured by the CDAI and AI for ulcerative colitis were 161.75 (SD = 31.04) for CD and 173.53 (SD = 30.23) for UC.

Analysis of the effects of demographic, disease, and educational variables (Tables 4.33, 4.34, and 4.35, respectively) at baseline revealed age, occupation, disease type, years of disease, co-morbid illness, formal IBD education, Internet use, study participation, CCFCSG attendance, and CCFC membership had no effect on baseline IBDQ scores. Females had significantly lower score total scores than males (M = 160.45, SD = 33.41; M = 173.42, SD = 26.33)(t = 2.05, p = 0.44). These differences did not persist over time [F = (2, 262.57) = 0.89, p = .412]. Females also had significantly worse scores for bowel symptoms than males (M = 50.53, SD = 13.38; M = 55.63, SD = 8.94, respectively)(t = 2.15, p = .034) at baseline, but not over the course of the study [F = (1.796, 62.29) = 1.49, p = .231]. Those whose education did not continue beyond junior high had significantly lower IBDQ mean baseline total scores [F (3, 5457.91) = 6.67, p = .000]. All IBDQ dimension scores, except systemic symptoms, were also lower in the junior high category. The differences persisted between education levels over time for total IBDQ score [F (6, 709.57) = 1.99, p = 021] and bowel symptoms only [F (6, 89.17) = 3.15, p = .045] (Table 4.36).

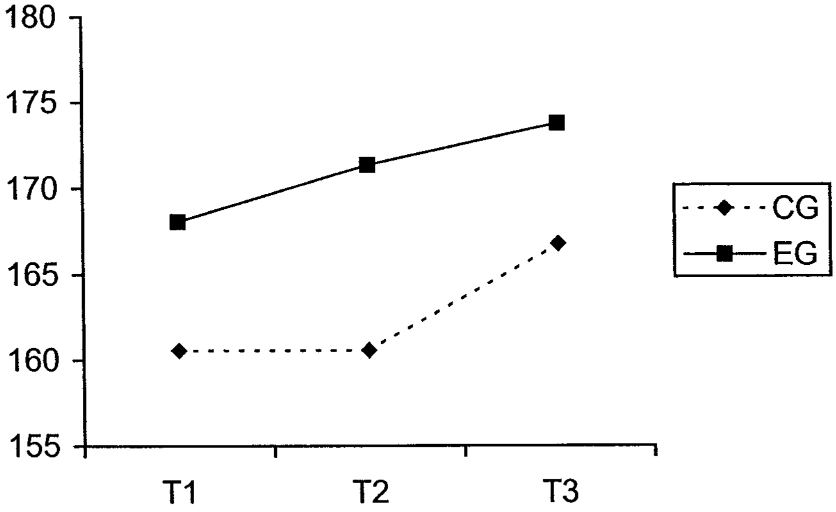

Figure 4.7. Comparison of Inflammatory Bowel Disease Questionnaire (IBDQ) mean total scores by group over time.

Table 4.31

Inflammatory Bowel Disease Questionnaire Scores Over Time and Between Groups

		Time			Time and Group		
	df	F	MS	p	F	MS	p
Total	2	2.17	643.26	.119	0.25	74.82	.777
Bowel Symptoms	1.808[a]	3.08	129.78	.055	0.69	29.20	.488
Systemic Symptoms	1.597	0.66	18.58	.488	3.43	97.22	.046*
Emotional Function	2	0.86	67.72	.424	0.36	27.85	.702
Social Function	1.826	1.37	26.30	.258	0.30	5.84	.719

Mean Scores Over Time

Category	Total (n =69)			Control Group (n =38)			Education Group (n =31)		
	T1[b]	T2	T3	T1	T2	T3	T1	T2	T3
Total									
M	163.93	165.41	169.90	160.55	160.55	166.76	168.06	171.35	173.74
SD ±	32.24	31.50	31.07	37.06	33.62	33.17	25.10	28.08	28.35
Bowel Symptoms									
M	51.64	52.38	54.19	50.39	50.08	52.74	53.16	55.19	55.97
SD ±	12.39	11.21	10.45	13.77	12.41	11.74	12.41	8.95	8.48
Systemic Symptoms									
M	22.77	22.83	23.64	23.34	21.61	23.89	22.06	24.32	23.32
SD ±	6.13	8.22	6.21	6.67	6.41	6.14	5.42	9.91	6.37
Emotional Function									
M	60.16	61.01	62.19	57.97	59.97	60.55	62.84	62.29	64.19
SD ±	13.17	12.73	13.98	16.07	13.05	12.93	7.83	12.42	15.14
Social Function									
M	29.37	29.16	30.25	28.85	29.11	29.79	30.00	29.23	30.81
SD ±	6.19	6.58	5.62	6.95	6.89	6.23	5.14	6.30	4.81

Note. *p < .05.

[a] When Mauchly's test of sphericity significant, Greenhouse-Geisser adjusted values cited.

[b] T1 = Baseline, T2 = Immediately post-education, T3 = 8 weeks post-education.

Table 4.32

Correlation of Inflammatory Bowel Disease Questionnaire Scores to Knowledge Scores, Perceived Knowledge and Disease Severity

Parameter		Inflammatory Bowel Disease Score		
		T1	T2	T3
	Perceived Knowledge Rating			
T1	(n =89)	.293**	--	--
T2	(n =73)		.156	--
T3	(n =72)			.259*
	Knowledge Questionnaire			
T1	(n = 89)	.064	--	--
T2	(n = 73)		.103	--
T3	(n = 72)			.237*
	Crohn's and Colitis Knowledge Questionnaire			
T1	(n = 89)	.186	--	--
T2	(n = 73)		.172	--
T3	(n = 72)			.230
	Crohn's Disease Activity Index (participants with Crohn's disease only)			
T1	(n = 44)	-.623**	--	--
T3	(n = 39)		--	-.567**
	Activity Index (participants with ulcerative colitis only)			
T1	(n = 22)	-.629**	--	--
T2	(n = 24)		--	-.505*

Note. * Correlation is significant at the .05 level (2 tailed).
** Correlation is significant at the .01 level (2 tailed).
[a]T1 = Baseline, T2 = Immediately post-education, T3 = 8 weeks post-education.

Table 4.33

Effect of Demographic Variables on Inflammatory Bowel Disease Questionnaire Baseline Mean Total Scores

Variable	Baseline Total Score			Comparison		
	n	M	SD	t / F	df	p
Gender				t = 2.05	87	.044
Male	38	173.42	26.33			
Female	51	160.45	33.41			
Age				F = 0.48	5	.793
17-24	9	162.11	25.56			
25-34	16	164.31	37.18			
35-44	26	165.73	33.13			
45-54	21	162.76	29.74			
55-64	13	178.00	25.87			
>64	4	161.00	34.80			
Education Level				F = 6.67	3	.000*
Junior High	6	123.17	35.86			
High School	34	165.50	24.99			
College/Trade/Technical School	27	157.95	33.83			
University	21	182.94	25.00			
Occupation				F = 1.04	8	.414
Student	7	161.43	28.84			
Homemaker	8	154.63	40.81			
Labourer	4	147.25	29.92			
Skilled Trade/Technician	14	166.93	28.11			
Clerical/Service/Sales	16	165.88	35.63			
Farming	3	191.33	15.14			
Arts/Sports/Recreation	4	144.00	45.80			
Management	11	176.73	24.38			
Professional	22	169.64	27.40			

Note. *$p < .05$.

Table 4.34

Effect of Disease Variables on Inflammatory Bowel Disease Questionnaire Baseline Mean Scores

Variable	Baseline Total Score			Comparison		
	n	M	SD	t / F	df	p
Disease Type				t = 1.73	87	.087
Ulcerative Colitis	32	173.53	30.23			
Crohn's Disease	57	161.75	31.04			
Years of Disease				F = 0.76	8	.638
<1	4	145.50	33.05			
1-5	13	170.23	21.49			
6-10	28	160.18	37.91			
11-15	16	170.63	28.50			
16-20	11	159.73	37.27			
21-25	8	180.50	22.54			
26-29	5	172.80	20.32			
30-34	3	170.67	10.02			
>34	1	186.00				
Co-morbid Illness				t = - 1.21	87	.229
Yes	51	162.55	33.77			
No	38	170.61	26.85			

Table 4.35

Effect of Inflammatory Bowel Disease Education Variables on Inflammatory Bowel Disease Questionnaire Baseline Mean Total Scores

Variable	Baseline Total Score			Comparison		
	n	M	SD	t / F	df	p
Education Program				t = 0.05	87	.962
Yes	14	166.36	34.39			
No	75	165.92	30.70			
Internet use				t = 0.81	87	.421
Yes	48	168.46	31.25			
No	41	163.10	31.05			
Study Participation				t = - 0.35	87	.725
Yes	38	164.63	26.47			
No	51	167.00	34.37			
CCFCSG Attendance[a]				t = - 0.58	87	.566
Yes	20	162.45	32.07			
No	69	167.01	30.98			
CCFC Member[b]				t = 1.60	87	.114
Yes	23	174.83	29.33			
No	66	162.91	31.32			

Note. [a]Crohn's and Colitis Foundation of Canada Support Group.

[b]CCFC = Crohn's and Colitis Foundation of Canada.

Table 4.36

Effect of Education Level on Inflammatory Bowel Disease Questionnaire Scores

Dimension	df	Time F	Time MS	Time p	Time and Group F	Time and Group MS	Time and Group p
Total	2	1.99	547.05	.140	2.59	709.57	.021*
Bowel Symptoms	1.836[a]	3.15	123.04	.051*	2.28	89.17	.045*
Systemic Symptoms	1.562	0.34	10.32	.659	0.75	22.88	.577
Emotional Function	2	0.91	69.45	.404	1.48	112.71	.190
Social Function	1.825	0.65	11.90	.510	1.97	36.06	.081

Mean Scores Over Time

Dimension	Junior High (n =6)		High School (n =26)		College/Trade (n =20)		University (n =17)	
	M	SD	M	SD	M	SD	M	SD
Total								
T1[b]	123.17	35.86	165.50	24.99	157.95	33.83	182.94	25.00
T2	144.83	37.72	162.15	27.33	169.70	28.42	172.59	37.31
T3	131.50	23.76	169.69	28.30	172.65	27.38	180.53	33.21
Bowel Symptoms								
T1	39.67	11.22	52.38	11.29	49.70	13.08	57.00	10.99
T2	46.00	9.42	52.54	9.86	53.60	12.06	52.94	12.80
T3	44.33	6.86	53.12	10.84	55.85	8.93	57.35	10.91
Systemic Symptoms								
T1	17.33	5.92	23.12	5.56	21.35	6.14	24.82	5.65
T2	17.83	3.19	22.08	5.66	24.00	11.53	24.35	7.87
T3	17.50	3.39	23.50	5.97	23.70	5.99	25.94	6.49
Emotional Function								
T1	45.83	15.84	59.88	10.39	58.05	14.95	68.12	8.64
T2	54.00	17.46	58.73	11.58	62.45	11.88	65.29	12.93
T3	48.50	12.05	63.58	13.26	61.20	14.58	66.06	12.93
Social Function								
T1	20.33	9.46	30.13	4.51	28.85	6.63	32.00	3.41
T2	25.33	7.87	29.12	6.64	29.65	5.92	30.00	6.91
T3	21.17	5.74	30.27	4.89	31.90	4.83	31.47	4.77

Note. *$p < .05$.

[a] When Mauchly's test of sphericity significant, Greenhouse-Geisser adjusted values cited.

[b] T1 = Baseline, T2 = Immediately post-education program, T3 = 8 weeks post-education program.

Rating Form of Inflammatory Bowel Disease Patient Concerns

The Rating Form of Inflammatory Bowel Disease Patient Concerns (RFIPC) assesses patients' worries and concerns in relation to their disease with a series of 25 questions. Patients rate the degree of concern on a 0 to 100, non-incremental, 10 cm visual analogue scale. Answers are subsequently measured and assigned the appropriate numeric value for statistical analysis. The questions are divided into four indices, impact of disease (13 questions), body stigma (2 questions), sexual intimacy (3 questions), and complications (4 questions). Three questions that do not fit into the indices are evaluated individually. These questions assess the degree of concern about being treated differently, transmitting the disease to others, and the ability to bear children. In keeping with the method of reporting in the literature, the questions were ranked by mean total response for each question and comparative analysis was undertaken for group, disease type, and gender.

Frequency analysis revealed that the most significant worry for all participants was concern about energy level, followed by having an ostomy, medication effects, having surgery, and the uncertain nature of the disease. The control group had the same top four concerns, and the education group had the same top three concerns as total participants. The control group's fifth most significant concern was access to quality health care. The education group rated concern about the uncertain nature of the disease as fourth and the ability to achieve full potential as fifth. No statistical difference was noted between the control and education groups on any of the 25 items (Table 4.37).

Analysis by disease revealed that those with CD had the same top three concerns as the total participants; energy level, having an ostomy, and medication effects. Concern about the ability to achieve full potential and access to quality health care were ranked fourth and fifth, respectively. Ulcerative colitis participants rated having an ostomy bag as the greatest concern, followed by energy level, medication effects, having surgery, and the uncertain nature of the disease (Table 4.38). Those with CD had significantly greater concern than those with UC about the ability to perform sexually ($\underline{M} = 3.32$, $\underline{SD} = 3.19$; $\underline{M} = 1.92$, $\underline{SD} = 2.70$, respectively)($\underline{t} = -2.10$, $\underline{p} = .031$), feeling alone ($\underline{M} = 3.79$, $\underline{SD} = 3.36$; $\underline{M} = 2.30$, $\underline{SD} = 2.85$, respectively)($\underline{t} = -2.12$, $\underline{p} = .030$), and having financial difficulties ($\underline{M} = 4.97$, $\underline{SD} = 3.71$; $\underline{M} = 3.17$, $\underline{SD} = 3.31$, respectively)($\underline{t} = -2.28$, $\underline{p} = .025$).

Females, like the total participants, were most concerned about energy level, having an ostomy, and medication effects. The uncertain nature of the disease and having surgery were the next most significant concerns. Males were most worried about energy level, access to quality health care, having an ostomy bag, medication effects, and developing cancer (Table 4.39). Females had significantly greater concern than males about the uncertain nature of the disease (M = 6.16, SD = 2.71; M = 4.45, SD = 2.89, respectively)(t = -2.87, p = .005), energy level (M = 7.20, SD = 2.75; M = 5.86, SD = 3.19; respectively)(t = -1.21, p = .036), ability to achieve full potential (M = 7.07, SD = 3.37; M = 5.20, SD = 3.48; respectively)(t = -2.56, p = .012), dying early (M = 3.85, SD = 3.56; M = 2.45, SD = 2.63; respectively)(t = -2.14, p = .035), passing the disease on to others (M = 6.15, SD = 3.47; M = 4.67, SD = 3.19, respectively) (t = -2.07, p = .042), and attractiveness (M = 2.28, SD = 3.40; M = 1.08, SD = 2.03, respectively)(t = -1.94, p = .041).

Table 4.37

Ranked Total Participant Scores and Comparison by Group for Rating Form for Inflammatory Bowel Disease Concerns Items

Disease-Related Concern[a]	Total (n = 89)		Control Group (n = 44)			Education Group (n = 45)			Group Comparison (df =87)	
	M	SD	M	SD	Rank	M	SD	Rank	t	p
Energy level	6.61	3.10	6.27	3.01	1	6.93	3.01	1	-0.99	.329
Having an ostomy bag	6.27	3.53	5.91	3.64	2	6.63	3.42	2	-0.20	.338
Effects of medications	5.88	3.14	5.84	3.18	3	5.91	3.14	3	-0.09	.927
Having surgery	5.52	3.41	5.53	3.56	4	5.50	3.30	6	0.58	.973
Uncertain nature of disease	5.43	2.92	5.11	2.89	9	5.73	2.94	4	-0.98	.325
Access to quality medical care	5.40	3.63	5.52	3.87	5	5.28	3.43	7	-0.57	.759
Ability to achieve full potential	5.34	3.44	5.08	3.20	10	5.60	3.68	5	-0.18	.484
Pain or suffering	5.09	3.14	5.12	3.34	8	5.06	2.96	8	0.44	.931
Loss of bowel control	5.07	3.46	5.38	3.42	6	4.77	3.50	11	0.84	.406
Developing cancer	5.05	3.06	5.21	3.08	7	4.90	3.07	9	0.56	.561
Feeling out of control	4.65	3.59	4.51	3.77	11	4.80	3.44	10	-0.70	.704
Feelings about my body	4.58	3.07	4.45	3.13	21	4.70	3.04	12	0.20	.701
Financial difficulties	4.32	3.66	4.08	3.70	15	4.56	3.64	14	-0.39	.540
Being a burden to others	4.27	3.38	4.21	3.29	14	4.34	3.51	15	-0.96	.856
Dying early	4.09	3.38	4.29	3.31	13	3.89	3.48	17	-0.76	.576
Passing the disease to others	4.03	3.82	3.48	3.82	18	4.56	3.79	13	-1.07	.181
Producing unpleasant odours	3.08	3.37	3.96	3.39	16	3.65	3.37	19	0.31	.662
Loss of sexual drive	3.62	3.36	3.23	3.52	21	3.99	3.20	16	0.04	.287
Attractiveness	3.60	2.98	3.35	3.21	19	3.83	2.76	18	0.26	.452
Intimacy	3.44	3.18	3.51	3.06	17	3.37	3.32	17	-1.35	.844
Feeling alone	3.25	3.25	3.34	3.36	20	3.16	3.18	21	-0.96	.800
Feeling dirty or smelly	2.92	2.99	2.81	3.00	22	3.02	3.00	22	0.54	.846
Ability to perform sexually	2.81	3.08	2.63	3.09	23	2.00	3.10	23	0.67	.574
Being treated as different	2.66	2.89	2.52	3.00	24	2.79	2.81	24	0.93	.665
Ability to have children	1.77	2.94	1.47	2.54	25	2.06	3.29	25	0.70	.344

Note. [a]Arranged by degree of concern for total participants.

Table 4.38

Ranked Scores and Comparison by Disease for Rating Form for Inflammatory Bowel Disease Concerns Items

Disease-Related Concern	Ulcerative Colitis (n = 32)			Crohn's Disease (n = 47)			Comparison (df = 87)	
	M	SD	Rank	M	SD	Rank	t	p
Energy level	6.43	3.50	2	6.73	2.71	1	-0.45	.674
Having an ostomy bag	6.96	3.16	1	5.88	3.69	2	1.39	.150
Effects of medications	6.30	3.14	3	5.64	3.12	3	0.95	.342
Having surgery	6.25	3.39	4	5.10	3.39	6	1.54	.128
Uncertain nature of disease	6.05	2.92	5	5.08	2.86	7	1.51	.134
Access to quality medical care	5.23	3.69	8	5.50	3.63	5	-0.33	.745
Ability to achieve full potential	5.05	3.65	10	5.50	3.34	4	-0.59	.556
Pain or suffering	5.18	3.02	9	5.04	3.23	8	0.21	.835
Loss of bowel control	5.35	3.65	7	4.91	3.37	10	0.57	.570
Developing cancer	5.78	2.92	6	4.70	3.09	13	0.65	.110
Feeling out of control	4.32	3.98	12	4.84	3.37	11	-0.65	.519
Feelings about my body	4.34	3.31	11	4.71	2.95	12	-0.54	.593
Financial difficulties	3.17	3.31	18	4.97	3.71	9	-2.28	.025*
Being a burden to others	3.82	3.10	15	4.52	3.53	14	-0.94	.351
Dying early	4.27	3.38	13	3.98	3.41	16	0.70	.701
Passing the disease to others	4.06	3.92	14	4.01	3.80	15	0.05	.957
Producing unpleasant odours	3.65	3.16	16	3.89	3.50	18	-0.33	.743
Loss of sexual drive	3.06	3.44	19	3.93	3.31	17	-1.17	.244
Attractiveness	3.48	3.13	17	3.66	2.92	21	-0.28	.780
Intimacy	2.83	3.06	20	3.77	3.22	20	-1.35	.181
Feeling alone	2.30	2.85	22	3.79	3.36	19	-2.12	.030*
Feeling dirty or smelly	2.45	2.49	21	3.25	3.23	23	-1.21	.229
Ability to perform sexually	1.92	2.70	24	3.32	3.19	22	-2.10	.031*
Being treated as different	2.18	2.74	23	2.92	2.96	24	-1.17	.246
Ability to have children	1.82	2.78	25	1.74	3.05	25	0.12	.909

Note. *$p < .05$.

Table 4.39

Ranked Scores and Comparison by Gender for Rating Form for Inflammatory Bowel Disease Concerns Items

Disease-Related Concern	Male (n = 38)			Female (n = 51)			Comparison (df = 87)	
	M	SD	Rank	M	SD	Rank	t	p
Energy level	5.86	3.19	1	7.20	2.75	1	-1.21	.036*
Having an ostomy bag	4.09	3.55	3	4.49	3.76	2	-0.51	.512
Effects of medications	5.15	3.20	4	6.42	2.98	3	-1.93	.057
Having surgery	4.41	3.32	6	3.85	3.44	5	0.77	.446
Uncertain nature of disease	4,45	2.89	10	6.16	2.71	4	-2.87	.005*
Access to quality medical care	2.51	2.75	2	2.67	3.12	8	-0.04	.676
Ability to achieve full potential	5.20	3.48	7	7.07	3.37	6	-2.56	.012*
Pain or suffering	5.29	3.73	8	5.48	3.60	10	-0.25	.801
Loss of bowel control	4.45	3.17	9	5.53	3.62	7	-1.46	.147
Developing cancer	3.16	2.77	5	3.93	3.12	9	-1.21	.230
Feeling out of control	4.16	3.34	17	4.35	3.44	11	-0.26	.792
Feelings about my body	3.96	3.83	13	4.03	3.85	13	-0.15	.884
Financial difficulties	3.00	2.93	14	3.76	3.34	14	-1.12	.265
Being a burden to others	3.05	2.95	12	6.16	2.71	12	0.22	.826
Dying early	2.45	2.63	11	3.85	3.56	11	-2.14	.035*
Passing the disease to others	4.67	3.19	15	6.15	3.47	15	-2.07	.042*
Producing unpleasant odours	2.36	2.87	16	3.15	3.22	16	-1.21	.229
Loss of sexual drive	4.83	2.85	21	5.28	3.22	21	-0.07	.497
Attractiveness	1.08	2.03	18	2.28	3.40	22	-1.94	.041*
Intimacy	2.91	3.13	19	4.14	3.47	20	-1.72	.089
Feeling alone	3.87	3.34	23	5.23	3.69	18	-1.79	.077
Feeling dirty or smelly	4.16	2.94	20	4.89	3.16	23	-1.11	.271
Ability to perform sexually	4.58	3.06	24	5.47	3.17	22	-1.33	.187
Being treated as different	3.92	3.47	22	3.72	3.32	24	0.28	.780
Ability to have children	4.65	3.35	25	5.86	3.44	25	-1.65	.102

Note. *p < .05.

Mean RFIPC total score for total participants at baseline was 115.94, (SD = 54.87, range 2.6 to 234.3). Index scores ranged from 2.6 to 124.4 for impact of disease, 0 to 20 for body stigma, 0 to 29.8 for sexual intimacy, and 0 to 40 for complications. The range scores for concerns about being treated differently, transmission of disease, and ability to bear children were each, 0 to 10. Details of the mean total and index scores are provided in Table 4.40.

No statistically significant differences were found over time for the participants on total RFIPC scores [F (2, 210.48) = 0.31, p = .732]. Analysis by RFIPC index showed a significant difference over time for the complications index [F (2, 129.35) = 4.14, p = .018]. Pairwise comparisons revealed a significant decrease from T2 to T3 for complications (M = 22.42, SD = 11.07; M = 19.55, SD = 10.99, respectively). No significant differences were found between the education and control groups for mean total RFIPC score [F (2, 854.50) = 1.27, p = .285] (Figure 4.8). No significant differences were found between the education and control groups on RFIPC index scores with the exception of "being treated differently" [F (2, 10.60) = 4.02, p = .02] (Table 4.40). An association was found between RFIPC total mean scores and disease severity for the AI (for ulcerative colitis), but not for the CDAI. There was no association between perceived knowledge levels and RFIPC total mean scores (Table 4.41).

Comparison of RFIPC baseline scores for the demographic variables gender, age, and occupation showed no significant difference (Table 4.42). Years of disease and co-morbid illness also had no effect on RFIPC scores (Table 4.43). Furthermore, IBD education accounted for no differences (Table 4.44). A significant difference was found for sexual intimacy between those with UC and CD at baseline (M = 7.22, SD = 8.31; M = 11.32, SD = 8.62, respectively)(t = -2.22, p = .029), but this difference did not persist over time [F (2, 2.81) = 0.09, p = .916]. Significant differences for total RFIPC scores [F (3, 12937.60) = 4.70, p = .004], impact of disease [F (3, 3880.58) = 4.43, p = .006], body stigma [F (3, 114.74) = 3.58, p = .017)], sexual intimacy [F (3, 294.78) = 4.40, p = .006], and being treated differently [F (3, 40.94) = 5.81, p = .001] were found when education level was considered. Baseline, mean total and index RFIPC scores were higher for those with only junior high education. Post hoc analysis by Bonferroni revealed that those with junior high education had greater concerns than those with high school for total RFIPC (p = .028) and body stigma (p = .042). Significant differences were found between junior high and university education levels for impact of disease (p = .005), body stigma (p = .042), sexual intimacy (p = .005), and total RFIPC score (p = .028). Being treated differently was a greater concern for those with junior high as compared to those who completed high school (p = .001), college/trade/technical school (p = .004), or university (p = .001). The differences did not persist between education levels over time on any measure (Table 4.45).

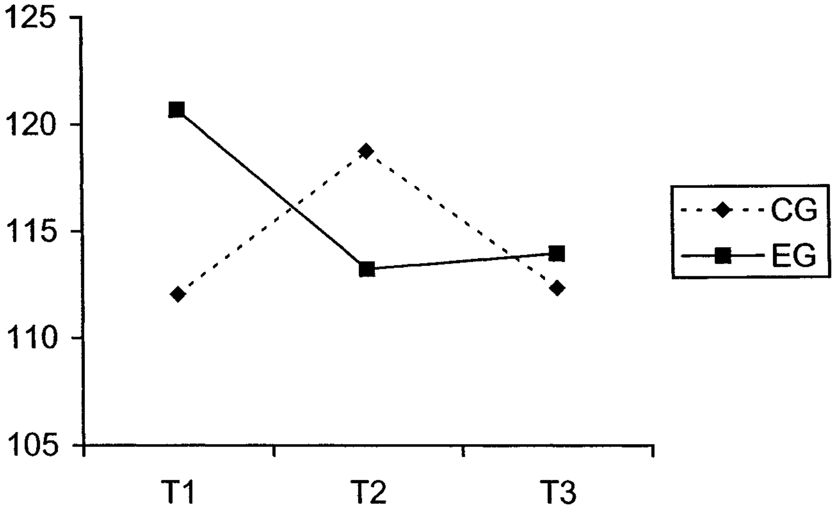

Figure 4.8. Comparison of Rating Form for Inflammatory Bowel Disease Patient Concerns (RFIPC) mean total scores by group over time.

Table 4.40

Rating Form for Inflammatory Bowel Disease Patient Concerns Over Time and Between Groups

Category	df	Time			Time and Group		
		F	MS	p	F	MS	p
Total	2	0.31	210.48	.732	1.27	854.50	.285
Disease Impact	2	1.43	308.37	.244	1.58	340.69	.211
Body Stigma	1.543[a]	2.46	55.04	.103	1.95	43.64	.157
Sexual Intimacy	1.724	0.92	21.36	.388	0.90	20.78	.397
Complications	2	4.14	129.35	.018*	1.26	39.21	.288
Disease Transmission	1.599	0.48	2.83	.578	0.14	0.86	.819
Childbearing	2	0.83	2.80	.437	0.55	1.84	.580
Treated Differently	2	0.33	0.86	.721	4.02	10.60	.020*

Mean Scores Over Time

Category	Total (n = 69)			Control Group (n = 38)			Education Group (n = 31)		
	T1[b]	T2	T3	T1	T2	T3	T1	T2	T3
Total									
M	115.94	116.29	113.08	112.06	118.77	112.36	120.68	113.24	113.97
SD ±	54.87	62.62	63.09	60.99	74.94	68.88	46.85	44.12	56.30
Disease Impact									
M	66.65	66.02	62.94	64.25	67.26	63.83	69.60	64.51	61.85
SD ±	30.82	31.75	35.49	33.14	36.19	37.53	27.97	25.79	33.40
Body Stigma									
M	7.30	7.67	8.71	7.53	8.32	8.12	7.03	6.87	9.43
SD ±	6.01	6.29	8.73	6.13	6.58	7.06	5.94	5.92	10.49
Sexual Intimacy									
M	10.85	11.94	11.67	9.93	11.91	11.01	11.98	11.97	12.48
SD ±	8.70	8.69	9.33	8.78	9.01	9.62	8.60	8.43	9.06
Complications									
M	21.02	22.42	19.55	20.69	23.39	19.52	21.42	21.23	19.60
SD ±	10.91	11.07	10.99	12.29	12.49	11.72	9.12	9.09	10.21
Disease Transmission									
M	4.60	4.71	4.96	4.12	4.39	4.49	5.20	5.11	5.53
SD ±	3.67	3.27	4.01	3.71	3.48	3.59	3.59	2.99	4.47
Childbearing									
M	2.17	2.00	1.75	2.07	2.08	1.54	2.30	1.90	2.01
SD ±	3.04	2.64	2.57	2.97	2.97	2.58	3.16	2.21	2.58
Treated Differently									
M	3.05	3.35	3.23	3.01	3.99	3.37	3.11	2.57	3.05
SD ±	2.91	2.91	3.18	3.10	3.11	3.19	2.70	2.47	3.22

Note. *$p < .05$.

[a] When Mauchly's test of sphericity significant, Greenhouse-Geisser adjusted values cited.

[b] T1 = Baseline, T2 = Immediately post-education program, T3 = 8 weeks post-education program.

Table 4.41

Correlation of Rating Form for Inflammatory Bowel Disease Patient Concern Scores to Perceived Knowledge, Knowledge Scores, and Disease Severity

Parameter	Inflammatory Bowel Disease Score		
	T1[a]	T2	T3
Perceived Knowledge Rating			
T1 (n =89)	- .208	--	--
T2 (n =73)		- .096	--
T3 (n =72)			- .104
Knowledge Questionnaire			
T1 (n = 89)	-.090	--	--
T2 (n = 73)		-.227	--
T3 (n = 72)			-.133
Crohn's and Colitis Knowledge Questionnaire			
T1 (n = 89)	-.130	--	--
T2 (n = 73)		-.238*	--
T3 (n = 72)			-.153
Crohn's Disease Activity Index (participants with Crohn's disease only)			
T1 (n = 44)	.273	--	--
T3 (n = 39)		--	.066
Activity Index (participants with ulcerative colitis only)			
T1 (n = 22)	.456*	--	--
T2 (n = 24)		--	.421*

Note. * Correlation is significant at the .05 level (2 tailed)
** Correlation is significant at the .01 level (2 tailed).
[a] T1 = Baseline, T2 = Immediately post-education program, T3 = 8 weeks post-education program

Table 4.42

Effect of Demographic Variables on Rating Form for Inflammatory Bowel Disease Concerns on Baseline Mean Total Scores

Variable	Baseline Total Score			Comparison		
	n	M	SD	t / F	df	p
Gender				t = -1.77	87	.081
Male	38	98.19	58.75			
Female	51	119.03	52.11			
Age				F = 1.78	5	.125
17-24	9	99.16	71.66			
25-34	16	123.79	50.78			
35-44	26	117.70	60.71			
45-54	21	111.44	46.28			
55-64	13	74.02	42.37			
>64	4	141.45	58.28			
Education Level				F = 4.70	3	.004*
Junior High	6	172.35	46.65			
High School	35	113.79	51.01			
College/Trade/Technical School	27	128.37	45.03			
University	21	84.68	56.67			
Occupation				F = 1.00	8	.442
Student	7	73.70	56.42			
Homemaker	8	134.45	61.93			
Labourer	4	98.65	41.44			
Skilled Trade/Technician	14	123.28	51.19			
Clerical/Service/Sales	16	103.64	48.56			
Farming	3	142.83	82.02			
Arts/Sports/Recreation	4	137.35	49.65			
Management	11	103.63	63.70			
Professional	22	105.16	56.12			

Note. *$p < .05$

Table 4.43

Effect of Disease Variables on Rating Form for Inflammatory Bowel Disease Concerns Baseline Mean Total Scores

Variable	Baseline Total Score			Comparison		
	n	M	SD	t / F	df	p
Disease Type				t = - 0.34	87	.738
Ulcerative Colitis	32	107.47	51.91			
Crohn's Disease	57	111.62	58.10			
Years of Disease				F = 0.65	8	.730
<1	4	100.81	9.76			
1-5	13	130.11	57.57			
6-10	28	118.40	67.01			
11-15	16	100.98	43.74			
16-20	11	103.29	53.47			
21-25	8	101.13	67.52			
26-29	5	110.28	29.64			
30-34	3	64.80	32.88			
>34	1	85.00				
Co-morbid Illness				t = - 0.50	87	.621
Yes	51	107.59	55.27			
No	38	113.54	56.81			

Table 4.44

Effect of Inflammatory Bowel Disease Education Variables on Rating Form for Inflammatory Bowel Disease Concerns on Baseline Mean Total Scores

Variable	Baseline Total Score			Comparison		
	n	M	SD	t / F	df	p
Education Program				t = 0.34	87	.734
Yes	14	114.81	68.58			
No	75	109.26	53.45			
Internet use				t = - 0.35	87	.728
Yes	48	108.22	58.35			
No	41	112.37	53.05			
Study Participation				t = 0.18	87	.858
Yes	38	111.36	51.82			
No	51	109.21	58.91			
CCFCSG Attendance[a]				t = 0.42	87	.673
Yes	20	114.79	59.63			
No	69	108.78	54.88			
CCFC Member[b]				t = -1.33	87	.188
Yes	23	96.93	55.74			
No	66	114.73	55.36			

Note. [a]Crohn's and Colitis Foundation of Canada Support Group.
[b]CCFC = Crohn's and Colitis Foundation of Canada.

Table 4.45

Effect of Education Level on Rating Form for Inflammatory Bowel Disease Patient Concerns Scores

Category		Time			Time and Group		
	df	F	MS	p	F	MS	p
Total	2	0.08	49.85	.928	1.42	946.17	.210
Impact of Disease	2	0.40	87.05	.669	1.22	262.78	.302
Body Stigma	1.526	0.94	20.80	.374	1.68	37.35	.153
Sexual Intimacy	1.778	0.68	14.87	.494	1.40	30.83	.226
Complications	2	3.72	114.28	.027*	1.47	45.19	.193
Disease Transmission	1.613	0.30	1.73	.694	0.97	5.61	.440
Childbearing	2	1.35	4.51	.264	0.92	3.09	.481
Treated Differently	2	0.06	0.17	.940	1.39	3.78	.222

		Mean Scores Over Time							
Category		Junior High (n =6)		High School (n =26)		College/Trade (n =20)		University (n =17)	
		M	SD	M	SD	M	SD	M	SD
Total	T1[a]	172.35	45.65	113.79	51.01	128.37	45.03	84.68	56.67
	T2	165.20	65.98	116.84	67.18	116.45	42.00	98.00	70.06
	T3	174.52	51.31	116.06	60.86	108.08	51.51	92.74	72.49
Disease Impact	T1	96.18	20.67	66.22	28.37	73.63	27.27	48.69	32.11
	T2	88.18	34.37	65.51	30.70	68.29	24.01	56.32	38.29
	T3	97.68	21.48	62.60	34.57	63.17	29.93	50.92	40.87
Body Stigma	T1	13.10	7.29	7.02	5.70	7.35	5.05	5.64	6.33
	T2	12.32	9.04	7.85	6.24	6.23	4.74	7.45	6.66
	T3	13.40	7.63	10.67	11.46	6.11	4.58	7.11	7.05
Sexual Intimacy	T1	19.17	6.53	11.70	9.02	11.67	8.17	5.67	6.74
	T2	19.50	8.64	13.40	8.58	10.23	7.87	9.02	8.43
	T3	19.18	7.52	13.32	9.37	9.73	9.10	8.79	8.84
Complications	T1	28.18	8.53	20.29	11.19	23.42	9.05	16.79	11.98
	T2	32.17	14.01	21.91	10.08	22.12	9.32	20.10	12.48
	T3	29.27	11.01	20.17	10.78	17.82	10.06	17.22	11.32
Disease Transmission	T1	5.72	4.14	4.05	3.83	5.09	3.63	4.49	3.48
	T2	6.08	3.54	4.44	3.40	5.59	3.03	3.61	3.07
	T3	6.52	3.58	5.17	4.93	5.47	3.09	3.48	3.38
Childbearing	T1	2.68	3.75	1.63	2.83	2.60	3.34	2.32	2.86
	T2	0.90	1.12	2.19	2.96	1.94	2.68	2.17	2.54
	T3	1.87	3.11	1.56	2.35	2.03	2.85	1.69	2.58
Treated Differently	T1	7.17	2.28	2.39	2.71	3.37	2.63	2.24	2.59
	T2	6.65	3.37	3.43	2.85	2.65	2.33	2.88	2.87
	T3	6.60	4.09	2.96	2.85	2.83	3.01	2.90	2.99

Note. [a]T1 = Baseline, T2 = Immediately post-education program, T3 = 8 weeks post-education program.

Perceived Health Status

Perceived health status was assessed using a color-graded, non-incremental, 10-point visual analogue scale. Participants were asked to rate their health from poor to excellent. The mean perceived health rating for the participants at baseline ranged from 1.75 to 10. A significant increase in mean perceived health ratings was observed over time [F (1.814, 12.40) = 7.94, p = .001](Table 4.46). Pairwise comparisons revealed significant increases in perceived health from T1 to T3 (p = .002). The education group had higher perceived health ratings at T2 and T3 than the control group, but the difference was not statistically significant [F (1.814, 3.66) = 2.34, p = .106](Figure 4.9).

Perceived knowledge ratings and perceived health status demonstrated no relationship at baseline, however as perceived knowledge increased at T2 and T3, perceived health also increased. There was no correlation found between knowledge scores and perceived health. A positive correlation was found between perceived health status and the IBDQ total score at all time points. Those who rated their perceived health high also had higher scores on the IBDQ. Participants with a higher rate of worries and concerns on the RFIPC had lower perceived heath ratings. High CDAI scores correlated with lower perceived health at T1 and T3, but this was not a consistent finding with the AI (for ulcerative colitis) (Table 4.47).

Effects of demographic, disease, and IBD education variables (Tables 4.48, 4.49, and 4.50, respectively) on baseline perceived health status revealed a difference only for disease type. CD sufferers had a significantly lower perceived health status then those with UC (M = 5.76, SD = 2.09; M = 6.83, SD = 1.99, respectively)(t = 2.36, p = .021). The difference did not persist over time [F (1.826, 0.64) = 0.40, p = .650].

Table 4.46

Perceived Health Ratings Over Time and Between Groups

	Time			Time and Group		
df	F	MS	p	F	MS	p
1.814	7.94	12.40	.001*	2.34	3.66	.106

Mean Ratings Over Time

Time Point	Total (n = 69)		Control Group (n = 38)		Education Group (n = 31)	
	M	SD	M	SD	M	SD
T1^a	6.18	2.13	6.13	2.24	6.24	2.02
T2	6.62	1.85	6.19	1.80	7.16	1.79
T3	6.98	1.85	6.78	1.82	7.21	1.87

Note. *p < .05.

^{a}T1 = Baseline, T2 = Immediately post-education program, T3 = 8 weeks post-education program.

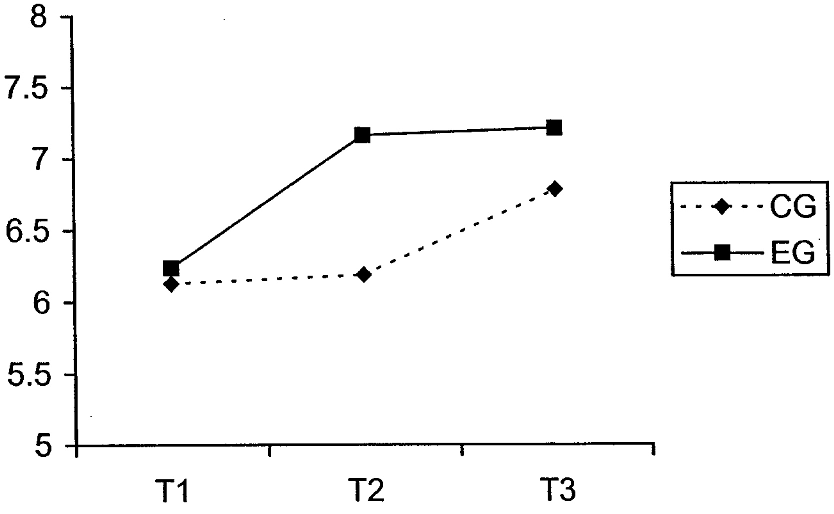

Figure 4.9. Comparison of mean Perceived Health ratings by group over time.

Table 4.47

Correlation of Perceived Health to Perceived Knowledge, Knowledge Scores, Disease Severity, and Quality of Life Indices

Parameter	Perceived Health Rating		
	T1[a]	T2	T3
Perceived Knowledge Rating			
T1 (n =89)	.202	--	--
T2 (n =73)		.319**	--
T3 (n =72)			.412**
Knowledge Questionnaire			
T1 (n =89)	.006	--	--
T2 (n =73)		.247*	--
T3 (n =72)			.115
Crohn's & Colitis Knowledge Questionnaire			
T1 (n =89)	.070	--	--
T2 (n =73)		.299*	--
T3 (n =72)			.137
Crohn's Disease Activity Index			
T1 (n =44)	-.398**	--	--
T2 (n = 0)		--	--
T3 (n =39)			-.364*
Ulcerative Colitis Activity Index			
T1 (n =22)	-.201	--	--
T2 (n = 0)		--	--
T3 (n =24)			-.482*
Inflammatory Bowel Disease Questionnaire			
T1 (n =89)	.609**	--	--
T2 (n =73)		.632**	--
T3 (n =72)			.616**
Rating Form for Inflammatory Bowel Disease Patient Concerns			
T1 (n =89)	-.236*	--	--
T2 (n =73)		-.333**	--
T3 (n =72)			-.244*

Note. * Correlation is significant at the .05 level (2 tailed).

** Correlation is significant at the .01 level (2 tailed).

[a]T1 = Baseline, T2 = Immediately post-education program, T3 = 8 weeks post-education program.

Table 4.48

Effect of Demographic Variables on Baseline Mean Perceived Health Status

Variable	Rating at Baseline			Comparison		
	n	M	SD	t / F	df	p
Gender				t = 1.23	87	.222
Male	38	6.46	2.16			
Female	51	5.91	2.06			
Age				F = 0.95	5	.454
17-24	9	5.64	1.97			
25-34	16	6.70	2.06			
35-44	26	6.50	2.10			
45-54	21	5.49	1.96			
55-64	13	5.98	2.34			
>64	4	6.69	2.72			
Education Level				F = 1.63	3	.189
Junior High	6	4.79	2.11			
High School	35	6.15	2.09			
College/Trade/Technical School	27	5.93	2.13			
University	21	6.80	1.99			
Occupation				F = 1.11	8	.366
Student	7	5.32	1.81			
Homemaker	8	6.16	1.82			
Labourer	4	4.44	1.90			
Skilled Trade/Technician	14	6.04	2.58			
Clerical/Service/Sales	16	6.02	2.13			
Farming	3	8.08	1.51			
Arts/Sports/Recreation	4	5.31	3.38			
Management	11	6.95	1.24			
Professional	22	6.35	2.07			

Table 4.49

Effect of Disease Variables on Baseline Mean Perceived Health Status

Variable	Rating at Baseline			Comparison		
	n	M	SD	t / F	df	p
Disease Type				t = 2.36	87	.021*
Ulcerative Colitis	32	6.83	1.99			
Crohn's Disease	57	5.76	2.09			
Years of Disease				F = 0.47	8	.876
<1	4	5.81	2.30			
1-5	13	6.65	1.69			
6-10	28	5.60	2.35			
11-15	16	6.36	1.97			
16-20	11	6.18	2.76			
21-25	8	6.44	2.15			
26-29	5	5.40	1.28			
30-34	3	4.75	0.66			
>34	1	7.75				
Co-Morbid Illness				t = -1.60	87	.114
Yes	51	5.84	2.10			
No	38	6.55	2.07			
Miss Medications				t = -1.20	87	.233
Yes	48	5.90	2.02			
No	41	6.43	2.20			

Note. *p < .05.

Table 4.50
Effect of Inflammatory Bowel Disease Education Variables on Baseline Mean Perceived Health Status

Variable	Rating at Baseline			Comparison		
	n	M	SD	t / F	df	p
Education Program				t = 0.86	87	.392
Yes	14	6.59	2.13			
No	75	6.06	2.11			
Internet use				t = 1.07	87	.286
Yes	48	6.36	2.01			
No	41	5.88	2.21			
Study Participation				t = -0.02	87	.984
Yes	38	6.14	2.08			
No	51	6.15	2.15			
CCFCSG Attendance[a]				t = 0.56	87	.580
Yes	20	6.38	2.18			
No	69	6.08	2.10			
CCFC Member[b]				t = 0.74	87	.462
Yes	23	6.42	2.29			
No	66	6.05	2.05			

Note. [a]Crohn's and Colitis Foundation of Canada Support Group.
[b]CCFC = Crohn's and Colitis Foundation of Canada.

Health Care Utilization

Health care utilization was assessed by self-report in the provided patient diaries. Participants were asked to report each visit to a physician or hospital admission that related to IBD and the associated complications. For physician visits, participants documented the reason for the visit and who initiated the appointment. Hospitalizations were recorded as emergency or ward admissions. The reasons for the admission and total days in hospital were also documented.

In order to confirm the veracity of the diaries, 15 patients were randomly selected for audit. Hospital and participating gastroenterologist's records were reviewed. Additionally, letters were sent to the selected participants' family doctor requesting confirmation of visits for IBD related concerns. The audited participants' self reports were 100% accurate as compared to the hospital and gastroenterologist's records.

Thirteen of the selected family doctors responded to the request for information. Again, participant reports were 100% accurate.

There was a total of 58 cases of health care utilization related to IBD during the course of the study composed of 49 visits to a physician and 9 hospital admissions. Patients initiated 18 visits to the doctor, the balance (n = 31) were physician initiated. Thirty-three of the visits were for treatment follow-up, and 16 for assessment of symptoms. Of the hospitalizations, four were emergency visits and five were admissions to the ward. Hospital stays ranged from two to seven days for a total of 25 inpatient days. Six of the admissions were for disease exacerbations, the rest were for IBD related complications (nephrolithiasis, fistulotomy, fistula)(Table 4.51).

Comparison of the groups revealed that, although the education group had a lower rate of health care utilization (M = 0.63, SD = 0.91) than the control group (M = 0.95, SD = 1.54), the difference did not reach statistical significance (t = 1.06, p = .294). (Table 4.52). A positive relationship was found between those who missed medications as reported in the patient diaries and higher health care utilization, specifically attributable to more physician visits. Higher disease severity scores on the CDAI and AI for ulcerative colitis were associated with more frequent physician visits. No relationship was found between perceived health, perceived knowledge, knowledge scores, or QOL indices and health care utilization (Table 4.53).

No effect was observed on health care utilization for demographic or disease variables (Tables 4.54 and 4.55, respectively). Internet use, study participation, CCFCSG attendance and CCFC membership had no effect on health care utilization (Table 4.56). Those who had attended a prior education program had significantly lower health care utilization than those who did not (M = 0.36, SD = 0.50; M = 0.89, SD = 1.38, respectively)(t = -1.23, p = 0.31).

Table 4.51
Health Care Utilization of Participants

Description	Number of Incidents	n	M	SD
Total Health Care Utilization	58	72	0.81	1.30
Physician Visits	49	28	0.68	1.16
Physician Initiated	31	23	1.35	0.57
Patient Initiated	18	13	1.38	1.39
Follow-up	33	24	1.38	0.12
IBD Symptoms	16	11	1.45	1.51
Hospitalization	9	9	0.13	0.33
Emergency	4	4	1.00	0.00
Ward Admission	5	5	1.00	0.00
Admission days	25	5	5.00	2.12
Exacerbation	6	6	1.00	0.00
Complications	3	3	1.00	0.00

Table 4.52
Health Care Utilization Between Groups

Description	Control Group (n =40)		Education Group (n =32)		Comparison	
	M	SD	M	SD	t	p
Total Health Care Use	0.95	1.54	0.63	0.91	1.06	.294
Number of Physician Visits	0.80	1.38	0.53	0.80	0.98	.332
Total Hospitalizations	0.15	0.36	0.09	0.30	0.71	.480

Table 4.53

Correlation of Health Care Utilization to Medication Adherence, Disease Severity, Perceived Health, Perceived Knowledge, Knowledge Scores, and Quality of Life Indices

Parameter (At 8 weeks post-education)	Total Health Care Utilization	Number of Physician Visits	Hospitalizations
Medication Adherence	.307**	.360**	-.058
Crohn's Disease Activity Index	.259	.319*	-.007
Activity Index (for ulcerative colitis)	.387	.406*	.009
Perceived Health Status	-.125	-.138	-.007
Perceived Knowledge	.007	.006	.050
KQ Total Score[a]	-.197	-.221	.003
CCKNOW Total Score[b]	-.233	-.222	-.111
IBDQ[c]	-.186	-.195	-.044
RFIPC[d]	.050	.048	.029

Note. * Correlation is significant at the .05 level (2 tailed).
** Correlation is significant at the .01 level (2 tailed).
[a] KQ = Knowledge Questionnaire.
[b] CCKNOW = Crohn's and Colitis Knowledge Questionnaire.
[c] IBDQ = Inflammatory Bowel Disease Questionnaire.
[d] RFIPC = Rating Form for Inflammatory Bowel Disease Patient Concerns.

Table 4.54

Effect of Demographic Variables on Total Health Care Utilization

Variable	Total Health Care Utilization			Comparison		
	n	M	SD	t / F	df	p
Gender				t = -0.91	70	.365
Male	31	0.65	1.05			
Female	41	0.93	1.46			
Age				F = 0.57	5	.725
17-24	6	0.83	1.17			
25-34	15	1.27	1.87			
35-44	20	0.80	1.11			
45-54	15	0.53	1.13			
55-64	12	0.58	1.24			
>64	4	0.75	0.50			
Education Level				F = 1.04	3	.383
Junior High	6	1.17	1.47			
High School	28	0.64	1.03			
College/Trade/Technical School	21	1.14	1.82			
University	17	0.53	0.72			
Occupation				F = 0.60	8	.773
Student	6	1.17	1.17			
Homemaker	7	0.43	0.79			
Labourer	3	1.67	2.08			
Skilled Trade/Technician	11	0.45	0.93			
Clerical/Service/Sales	14	1.14	2.03			
Farming	2	0.50	0.71			
Arts/Sports/Recreation	3	0.33	0.58			
Management	9	0.56	1.13			
Professional	17	0.88	1.05			

Table 4.55

Effect of Disease Variables on Total Health Care Utilization

Variable	Total Health Care Utilization			Comparison		
	n	M	SD	t / F	df	P
Disease Type				t = 0.58	70	.567
Ulcerative Colitis	26	0.92	1.62			
Crohn's Disease	46	0.74	1.08			
Years of Disease				F = 1.50	8	.538
<1	3	1.67	2.08			
1-5	10	0.60	0.84			
6-10	23	1.22	1.76			
11-15	11	0.82	1.25			
16-20	10	0.60	0.70			
21-25	7	0.14	0.38			
26-29	4	0.25	0.50			
30-34	3	0.67	1.15			
>34	1					
Co-Morbid Illness				t = -0.19	70	.852
Yes	41	0.78	1.11			
No	31	0.84	1.53			

Table 4.56

Effect of Inflammatory Bowel Disease Education Variables on Health Care Utilization

Variable	Total Health Care Utilization			Comparison		
	n	M	SD	t / F	df	p
Education Program				t = -1.23	70	.031*
Yes	11	0.36	0.50			
No	61	0.89	1.38			
Internet use				t = 0.18	70	.857
Yes	36	0.83	1.34			
No	36	0.78	1.27			
Study Participation				t = -1.06	70	.294
Yes	32	0.63	0.75			
No	40	0.95	1.60			
CCFCSG Attendance[a]				t = -0.85	70	.399
Yes	16	0.56	0.73			
No	56	0.88	1.42			
CCFC Member[b]				t = -1.16	70	.251
Yes	18	0.50	0.86			
No	54	0.91	1.40			

Note. *p < .05.

[a] CCFCSG = Crohn's and Colitis Foundation of Canada Support Group.

[b] CCFC = Crohn's and Colitis Foundation of Canada.

Patient Satisfaction

Participant Satisfaction with IBD Medical Care

Participant satisfaction with medical care was assessed with a 16-item questionnaire that addressed facilitating understanding disease through information sharing (4 items), meeting information needs (4 items), provision of medication education (4 items), and understanding of provided information (2 items). Several of the survey questions specifically addressed physician education of participants within the context of the assigned categories. Separate analysis of these items was included because doctors are the primary care providers and most significant source of medical information (4 items). As described previously, three questions addressed medication adherence and were not included in the total satisfaction score. The questionnaire utilized a four point Likert scale with one being "strongly disagree" and four "strongly agree". Additionally, space for comments was provided for each question.

The mean score for patient satisfaction with IBD medical care was 41.31, SD = 8.08, range 18 to 55. The mean satisfaction score for physician education was 12.86, SD = 3.06, range 4 to 16. Control group total satisfaction scores were significantly lower than the education group satisfaction scores ($t = -3.54$, $p = .001$). Control group satisfaction scores were also significantly lower for facilitation of disease understanding through information sharing and meeting information needs ($t = -3.51$, $p = .001$; $t = -3.13$, $p = .001$, respectively)(Table 4.57).

There was no correlation between total satisfaction with IBD medical care and disease severity or perceived health. A positive correlation was found between perceived knowledge and satisfaction with care; thus those with higher perceived knowledge had higher satisfaction scores. High scores on the IBDQ, indicating fewer physical symptoms and less psychosocial dysfunction, correlated with higher satisfaction scores. Correlation with the RFIPC revealed that those who had greater worries and concerns had lower satisfaction scores (Table 4.58).

Analysis of the effects of demographic, disease, or IBD education variables revealed no significant differences in overall satisfaction with IBD medical care (Tables 4.59, 4.60, and 4.61, respectively). Participant comments reflected a desire for more information and the need for indepth, understandable literature. Assistance in understanding written information was identified. Several comments, particularly from the control group, indicated a lack of confidence in understanding of the disease and how to manage medications, symptoms, and psychosocial effects. Comments regarding provision of information about medications indicated health care providers were inconsistent with this need. Some participants expressed frustration with lack of time for discussion with their physicians. Generally, comments were favorable about the education efforts of physicians. Participant comments are provided in Table 4.62.

Table 4.57
Patient Satisfaction with Medical Care Between Groups

Category	Total (n = 71)		Control Group (n =40)		Education Group (n =31)		Comparison (df = 69)	
	M	SD	M	SD	M	SD	t	p
Total Satisfaction	41.31	8.08	38.60	8.63	44.81	5.76	-3.45	.001*
Disease Understanding	12.39	2.48	11.55	2.51	13.48	2.00	-3.51	.001*
Information Needs Met	13.00	2.92	12.10	3.36	14.16	1.68	-3.13	.001*
Medication Education	9.72	2.84	9.23	3.19	10.35	2.20	-1.68	.097
Medication Understanding	6.52	1.40	6.25	1.50	6.87	1.20	-1.88	.064

Table 4.58

Correlation of Patient Satisfaction with Medical Care to Disease Severity, Perceived Health Status, Perceived Knowledge, Knowledge Scores, and Quality of Life Indices

Parameter (8 weeks Post-education)	Satisfaction with IBD Medical Care
Disease Severity	
CDAI[a]	.040
AI[b]	-.378
Perceived Health Status	.060
Perceived Knowledge	.349**
KQ Total Score[c]	.388*
CCKNOW Total Score[d]	.432**
IBDQ Total Score[e]	.260*
RFIPC Total Score[f]	-.315**

Note. * Correlation is significant at the .05 level (2 tailed).
** Correlation is significant at the .01 level (2 tailed).
[a]CDAI = Crohn's Disease Activity Index
[b]AI = Activity Index (for ulcerative colitis)
[c]KQ = Knowledge Questionnaire
[d]CCKNOW = Crohn's and Colitis Knowledge Questionnaire
[e]IBDQ = Inflammatory Bowel Disease Questionnaire
[f]RFIPC = Rating Form for Inflammatory Bowel Disease Patient Concerns

Table 4.59
Effect of Demographic Variables on Patient Satisfaction with Medical Care

Variable	Total Satisfaction Score			Comparison		
	n	M	SD	t / F	df	p
Gender				t = -1.82	69	.073
Male	30	39.30	8.49			
Female	41	42.78	7.53			
Age				F = 1.26	5	.291
17-24	4	42.50	8.66			
25-34	15	42.80	7.77			
35-44	21	42.62	6.70			
45-54	15	37.33	9.01			
55-64	12	40.25	8.79			
>64	4	45.75	8.42			
Education Level				F = 0.55	3	.648
Junior High	6	41.33	9.07			
High School	26	39.96	7.41			
College/Trade/Technical School	22	43.00	7.89			
University	17	41.18	9.26			
Occupation				F = 0.89	8	.530
Student	4	40.00	4.08			
Homemaker	7	40.43	9.47			
Labourer	3	36.33	11.93			
Skilled Trade/Technician	11	43.09	6.58			
Clerical/Service/Sales	14	43.29	6.17			
Farming	2	41.50	14.85			
Arts/Sports/Recreation	3	33.00	9.54			
Management	10	39.10	8.28			
Professional	17	42.82	8.95			

Table 4.60

Effect of Disease Variables on Patient Satisfaction with Medical Care

Variable	Total Satisfaction Score			Comparison		
	n	M	SD	t / F	df	p
Disease Type				t = 0.11	69	.913
Ulcerative Colitis	27	41.44	9.52			
Crohn's Disease	44	41.23	7.18			
Years of Disease				F = 1.87	8	.080
<1	3	45.00	6.08			
1-5	10	41.60	10.04			
6-10	21	42.05	8.05			
11-15	12	42.83	4.90			
16-20	10	43.70	7.86			
21-25	7	31.57	7.72			
26-29	4	40.00	6.38			
30-34	3	44.33	7.23			
>34	1	34.00				
Co-Morbid Illness				t = 0.36	69	.541
Yes	41	41.61	7.93			
No	30	40.90	8.40			

Table 4.61

Effect of Inflammatory Bowel Disease Education Variables on Patient Satisfaction with Medical Care

Variable	Total Satisfaction Score			Comparison		
	n	M	SD	t / F	df	p
Education Program				t = -0.26	69	.797
Yes	11	40.73	10.04			
No	60	41.42	7.77			
Internet use				t = 1.60	69	.114
Yes	36	42.81	7.73			
No	35	39.77	8.25			
Study Participation				t = 0.33	69	.746
Yes	32	41.66	7.18			
No	39	41.03	8.83			
CCFCSG Attendance[a]				t = -0.28	69	.782
Yes	16	40.81	8.85			
No	55	41.45	7.93			
CCFC Member[b]				t = 1.27	69	.208
Yes	17	43.47	6.72			
No	54	40.63	8.41			

Note. [a]CCFCSG = Crohn's and Colitis Foundation of Canada Support Group.
[b]CCFC = Crohn's and Colitis Foundation of Canada.

Table 4.62

Patient Satisfaction with IBD Medical Care Survey Comments

1. I understand what inflammatory bowel disease is.

Control Group
- I understand enough for me. I don't claim to know 100%.
- I understand some things, but not the hows and whys.
- I feel that my knowledge is patchy, at best. Having celiac disease as well makes things complicated.

Education Group
- I believe that people should know a lot about any serious disease they have.
- But I always think I know more than I do.
- As pertaining to my colon.

2. I have received enough information about my disease.

Control Group
- I just wish I had time to read it all.
- Not during the course of my illness, but recently during this study I have.
- I would like to learn more.
- Having specialized info to blend the info for both of my diseases would be great (Celiac).
- Additional information will cause my concerns to run amuck.

Education Group
- There is always more to learn.
- If I have not, it would be my fault.
- Always room for more.
- I would like to take the class that I missed on nutrition.
- An individual should try to keep informed on the newest medical information.
- I believe you can't know everything. I imagine there will always be something to learn about my disease.
- An individual should try to keep informed on the newest medical information.

3. My doctor gives me explanations about my disease I understand.

Control Group
- I don't' feel like the info/knowledge I have has come from my doctor.
- And the possibility of contracting cancer.
- There is barely much discussion time during a visit.

Education Group
- Have not seen a doctor in a while.
- Dr. F/DF are great. My family doctor on the other hand is not so knowledgeable, but fills out necessary prescriptions.

4. I have been given written information that I understand.

Control Group
- No not ever, during the time I have been ill.
- Have not gone thru info extensively.
- Would be helpful to sit down with someone who would consult on both diseases.
- Information received from you.

Education Group
- I've certainly been given information, but whether I understand it all is another question.

(table continues)

Table 4.62. *(continued)*

5. I am able to get the information I want about my disease. Control Group • There's not much out there. • Most info seems to repeat itself. These questionnaires 'opened my eyes' to see that there is more to learn. • From literature or my older sister who has experienced surgery as a result of IBD. Education Group • The internet is a wealth of information. • Just have to ask.
6. My doctor explains why I need to take the medications and how they work. Control Group • I feel I know the minimal amount in regard to the medication and how it works most effectively. • At each examination every 12-14 mos. • Long term side effects are not stressed and alternatives are not offered if there is long term serious side effects. Education Group • Just have to ask. • Dr. F and DF do.
7. My doctor explains the side effects of my medications. Control Group • He did. • He told me the side effects of steroids, but not about the Pentasa I now take. • I am not aware if Asacol has side effects. • When changes are indicated. Education Group • He did. • I get pamphlets from the pharmacy when I get new drugs.
8. I make mistakes when taking my medications. Control Group • Generally, just forgetting to take them. • Forget to take them sometimes. • Never, I always take medication properly. • Miss taking pills sometimes. • I take it regularly. • I feel I know the minimal amount in regards to the medication and how it works most effectively. • I often forget to take my pills. Education Group • I'm sure I did.
9. I understand why I need to take my medications for IBD. Control Group • Somewhat. • I would like to know more.

(table continues)

Table 4.62. *(continued)*

10. I understand how my medications work.

Control Group
- No really, just general information about how they work, but not in detail.
- Not totally.
- Other than the chemistry.

Education Group
- Not taking any now.

11. My pharmacist explains my medications to me.

Control Group
- Somewhat.
- I don't really ask.
- Also supplies written info.

12. I forget to take my medications sometimes.

Control Group
- Sometimes get distracted and forget.
- Never.
- On rare occasions.

Education Group
- Sometimes get distracted and forget.
- Sometimes I just forget, other times I just get lazy.

13. Sometimes I do not take my medications because of side effects.

Control Group
- Forgetting to take them has side effects.
- No, not so
- I don't know what they are.
- I get very itchy skin when I start taking pills (if I haven't been taking them for awhile).
- No side effects.
- I used to.

Education Group
- If it works, I would put up with the side effects.

14. My doctor explains to me how to take care of my disease.

Control Group
- Somewhat – but he is not open to other suggestions to help me try and bedside manner is discouraging to want to talk to him.
- I know I need to take medicine, but not much else.
- He made sure I had dietician support when I was first diagnosed. Since diagnosis have had not time with doctor unless I am in for a procedure.
- After 40+ years, I have learned what foods I should avoid or have in moderation.

Education Group
- Dr. F and DF do.

(table continues)

Table 4.62 *(continued)*

15. I understand what I need to do to take care of my disease.

Control Group
- Somewhat, it's scary leaving this all up to the patient. There should be a lot more support!
- Experience was my best educator.

16. I feel confident about taking care of my disease.

Control Group
- Need to remember my pills!
- No, I don't. I'm terrified every time I get a flare-up! This is not a disease to take lightly. It's horrible, embarrassing, and degrading! All the testing, accidental soiling, gas etc., it's very difficult to feel confident about this disease!!
- I feel defeated. I feel that no matter how hard I try taking care of myself, nothing works. (i.e., taking pills regularly and over a long period of time, eating, sleeping. Low stress, etc.) I don't feel I am getting a handle on my disease(s) (celiac).
- Sometimes I decrease my Pentasa prematurely and need to increase it again, but on the whole, I think I've got the hang of it.
- Experience was my best educator.

Education Group
- You cannot be confident with this type of disease.

Education Program Participant Satisfaction

Participants received a 14-item questionnaire that utilized a 4-point Likert scale, with 1 being "strongly disagree" and 4 "strongly agree". The questions were divided into two categories, improved disease understanding and satisfaction with education program presentation methods. Additionally, space was provided for participants to make a comment for each question. The mean satisfaction score for the education program was 49.97, SD = 6.51, range 33 to 56. Mean satisfaction score for the nine questions addressing improved disease understanding was 31.44, SD = 5.08, range 19 to 36. Satisfaction with program presentation mean score was 18.81, SD = 1.57, range 14 to 20.

No difference in satisfaction was found when demographic variables were considered (Table 4.63). Those with UC were significantly more satisfied (M = 53.70, SD = 3.16) with the education program than those with CD (M = 48.27, SD = 6.98) (t = 2.34, p = .005)(Table 4.64). No difference was seen in satisfaction when years of disease and co-morbid illness were considered. Prior IBD education variables also had no effect on education program satisfaction (Table 4.65).

Participants' comments about the presentation indicated general satisfaction with the program. Most indicated an increased understanding of the disease and management. There were several comments indicating the need for more time and information on managing the psychosocial aspects of the disease. The comments are detailed in Table 4.66.

Table 4.63
Effect of Demographic Variables on Education Program Satisfaction

Variable	Total Satisfaction Score			Comparison		
	n	M	SD	t / F	df	p
Gender				t = -1.80	30	.082
Male	10	47.00	7.93			
Female	22	51.32	5.44			
Age				F = 0.76	5	.588
17-24	3	47.33	8.50			
25-34	8	50.00	5.71			
35-44	9	49.67	6.48			
45-54	7	48.00	8.50			
55-64	4	54.50	1.29			
>64	1	56.00				
Education Level				F = 0.59	3	.626
Junior High	2	56.00	0.00			
High School	12	49.50	5.00			
College/Trade/Technical School	12	49.75	7.85			
University	6	49.33	7.53			
Occupation				F = 1.37	8	.261
Student	3	43.67	4.16			
Homemaker	3	50.67	3.06			
Labourer	1	56.00				
Skilled Trade/Technician	3	45.67	11.68			
Clerical/Service/Sales	8	51.25	5.12			
Farming	1	56.00				
Arts/Sports/Recreation	1	56.00				
Management	4	45.50	7.19			
Professional	8	52.38	5.68			

Table 4.64
Effect of Disease Variables on Education Program Satisfaction

Variable	Total Satisfaction Score			Comparison		
	n	M	SD	t / F	df	p
Disease Type				t = 2.33	30	.026*
Ulcerative Colitis	10	53.70	3.16			
Crohn's Disease	22	48.27	6.98			
Years of Disease				F = 1.69	8	.164
<1	3	54.00	3.46			
1-5	7	52.00	5.16			
6-10	9	51.33	6.14			
11-15	7	46.57	5.65			
16-20	3	49.67	8.50			
21-25	2	40.50	10.61			
26-29	0					
30-34	1	55.00				
>34	0					
Co-Morbid Illness				t = 0.62	70	.541
Yes	16	50.69	6.27			
No	16	49.25	6.88			

Note. *p < .05.

Table 4.65
Effect of Inflammatory Bowel Disease Education Variables on Education Program Satisfaction

Variable	Total Satisfaction Score			Comparison		
	n	M	SD	t / F	df	p
Education Program				t = 2.32	30	.818
Yes	5	50.60	7.50			
No	27	49.85	6.47			
Internet use				t = -0.13	30	.897
Yes	19	49.84	6.38			
No	13	50.15	6.96			
Study Participation				t = -1.65	30	.110
Yes	16	48.13	7.07			
No	16	51.81	5.52			
CCFCSG Attendance[a]				t = -0.37	30	.711
Yes	7	49.14	8.51			
No	25	50.20	6.03			
CCFC Member[b]				t = -1.69	30	.102
Yes	11	47.36	7.46			
No	21	51.33	5.68			

[a] CCFCSG = Crohn's and Colitis Foundation of Canada Support Group.
[b] CCFC = Crohn's and Colitis Foundation of Canada.

Table 4.66
Education Program Satisfaction Survey Comments

1. The education program improved my knowledge about IBD.

- Because of the lack of understanding or what causes IBD education is really the only way to cope.
- Program gave better indepth knowledge about the disease and medications, diet and the progression of IBD.
- I am fortunate because my medical care professionals over the years have been very informative.
- I learned more in those few nights then in nine years.
- I was able to get an insight into how others are dealing with it (i.e. the lady with the ostomy).
- Very informative.
- Immune system was educational.
- Areas of surgery, meds, how disease operates.
- It was very informative and I now have a better understanding what I have to do to stay healthy.
- This was an excellent program. I'm happy I was included.

2. The education program helped me understand how to better manage my disease.

- Taught me more about signs of flare-ups.
- A lot of information was presented and whatever I retained has helped me to understand why meds help.
- I wish I would've learned back then.
- I understand the medication use better.
- I learned a lot about the different medications I am on.
- Hot Topics & Burning Questions I think was a great idea. I think it could help a lot if patients, especially the younger ones who I think would really benefit from this class. I wish it were there when I was a kid. I had a lot of questions, but was too embarrassed to ask.
- What about stress management?
- Certain dangerous foods, side effects to meds.
- The diet section helped me a lot.

3. The instructors were helpful and answered my questions.

- Very open with Q & A's.
- Always attempted to answer questions, some of my questions were too involved.
- Excellent teachers and medical staff.
- It was great, but more time in smaller groups would have been even better.
- Wonderful group of people.
- Very knowledgeable.
- If they were not sure on a question, we had the answer the following week. It wasn't forgotten.
- Lovely.
- Every question was addressed, some answers require further investigation.
- The best they could. I had some very strange questions.
- The instructors were very helpful.

(table continues)

Table 4.66. *(continued)*

4. I understood the information presented in the education program.

- For the most part, some I could not care about, but this is my choice.
- Easily, instructors very thorough.
- Level of presentation was not overwhelming and brought to the average person's level.
- Very well presented.
- Very good instructors.
- Good explanations.
- Instructors were quite clear, and accommodated for each person's learning curve.
- There is some stuff I missed, but I'm sure I can get the information if I want it.
- Sometime I felt I wasn't able to understand all of the amount of information given to us.

5. The written information from the education program is helpful.

- Help understand better.
- Always need to take time to read the info.
- Wide variety of information was given. I am sure more detailed info is available for specific patient conditions.
- I will refer back to it in the future.
- Especially the binder and discussion information in overheads.
- Because now I have a reference to refer back when I am unaware of medicine/disease management.
- Point of reference.
- I now have sources which I can refer to at a later date, if necessary.
- I learn by seeing things.

6. I would recommend taking the education program to other patients.

- Understand the IBD better.
- If nothing else, other patients to compare with.
- Definitely, the more info, the better the decision. Pro-active approach.
- All patients with IBD would benefit from the material and understanding what is happening during the disease.
- I also feel that an education program should involve family members so the information is clear and understandable to those closest to the situation. The only times family members get involved is during a crisis.
- The information was extremely helpful, however I would not recommend this program to a patient who is dealing with anxiety related to IBD.
- It should be forced upon patients – just so you're secure with yourself.
- Very helpful for me to be able to ask questions as they were generated in class.
- I have already told others about the program.
- I think they really need a similar class for kids. It's very informative.
- Especially the younger patients.
- Definitely, knowledge is power.
- It was very educational and easy to understand.
- I personally would encourage any patient (given the opportunity) to take this program.

Table 4.66. *(continued)*

7. My information needs were met by the education program. • A few questions were not answered, lack of research at this point. • All areas of IBD were covered but there are always specific questions which arise after classes were done. • There is so much info, full-time classes would not be enough. • What about the psychological effects of the disease, as hard to manage as the physical sometimes? • I would like further education along the psychological effects of the disease. • Thank you for asking me to do this study. I enjoyed myself and learned what I wanted to know.
8. The education program improved my understanding of how my medications work. • Not on any meds, need more lifestyle answers: cost, B.C. coverage, long-term side effects. • I was impressed with the how and why medications are used and when each is appropriate. • Not specifically, but generally. • Quite clear on effects and side effects. Difficult to remember the names of drugs. • I now know why my medication is so important to take.
9. The education program helped me better understand the side-effects of my medications and how to manage them. • Not on meds, learned realistic aids in countering side effects. • Helpful ideas which I never tried before were revealed by others in the class. • Talking to others in the group was helpful also. • Not sure on management, but yes to side-effect information. • Still have a problem with the understanding of prednisone.
10. The education program helped me feel more confident about managing my medications. • It gave me better knowledge of when to take medications. • No lack of confidence here. • Knowledge about the disease & meds helped me to understand why my body reacts to each therapy. • I've managed them diligently for 31 years before the course. • Sometimes I forget to take them.
11. The education program helped me better understand how diet affects my disease. • Everyone is affected by diet so differently I could not. • Definitely, started using "subdue". • I believe that what works for some doesn't for other and vice versa. • Especially because I tend to avoid milk. • And I am seeing nutritionist. • Somewhat, a lot was learned through trial and error. • Very much, I had no idea as to the dangers of popcorn. • I would still like to find out more about the diet part of my disease.

(table continues)

Table 4.66. *(continues)*

12. The education program helped me understand the role of surgery in managing my disease.

- Too late, only one surgery left – removal of all small intestine = live on TPN.
- I learned that surgery may eventually be a course of action during the progression of IBD.
- If it ever becomes necessary for me, it doesn't seem as frightening.
- I think it made people more comfortable with the idea of surgery, when it's explained on their level.
- Learned that along time ago.
- Have undergone 4 associated surgeries. Course detailed the next surgical steps which may be required.
- Missed the class on surgery.

13. The education program helped me better understand how the disease affects my life generally.

- I can say that my life has been totally changed because of this disease, but education is one more weapon to fight with.
- Did not realize how may different areas affected (emotional, mentally, fears, stress, etc.)
- You don't need the program to tell you how the disease affects my life, but was valuable to patients, none-the-less!
- Would like to deal more with mental effects to better control emotions and depression.
- I now understand how to handle my disease effectively.

14. The education program provided me with information about how to manage the impact of the disease on my life.

- I hope I can say yes to this question when it comes time to face the bigger parts of this disease. For now I am fairly comfortable with my life.
- Yes, but would like a more indepth micro look at the current impact, and any possible counter attacks to better balance my life.
- The program helped me with information on managing my disease, but am grateful for the staff and doctors to help along the way.
- Now, I just have to be strong and avoid the nasties (in my case sugars) and take my medication ALWAYS and consistently.
- And I have added vitamins to my daily meds.
- It's a great program for anyone with the disease, or their spouses! Thanks Barb.

(table continues)

Table 4.66. *(continues)*

Additional comments appended by participants at the end of the survey.

- I luv u guys!
- Went into the program with absolutely no knowledge of IBD or what to expect. Program was very informative in all areas and is definitely helping me to manage the disease and know what it's all about. It's a great program and hopefully it continues so everyone gets the opportunity to attend. Thank you.
- Love you guys!
- The IBD Education Program is a wonderful idea. So much good information – too much for me to absorb quickly (Thurs. night seemed to be the only time I had to think about it). The information binder will be great to have on hand when questions do arise. Thank you so much Barb – glad you chose this area for your masters. Good Luck
- The Education Program was so helpful. I would hope that it could be an on-going thing. Glad that you picked IBD for your masters program. Good luck.
- I just want to say that being a part of your study was one of the best things I have done since I got colitis. I really enjoyed it and learned a lot. Thank you so much.
- This was the best course I have ever been to. It should be made available to everyone. It was incredible how much there is to learn. Thank you.
- Two months ago, I was so overwhelmed by everything I was finding out about my diagnosis of UC – the real life picture was one of no control, loss of independence and worry. Your study was perfect timing for me. Dr. F told me that if I learned more, that I could learn to manage this and I wouldn't feel so overwhelmed. Well, he was right and now I feel like I have a tool kit to manage my UC. Your course has completely eliminated a lot of fear and paranoia! I am far more able to deal with bad days as I know why and how to deal with it. I have visited the dietician and learned a great deal on diet which has been great. I have tried to make lifestyle changes to better deal with my eating habits. I am trying to take an intelligent and planned approach to live life to its fullest, including UC and its challenges. My belief is that knowledge is life and offers life's options to you. Your course has done this for me. I'm your biggest fan. Everyone should do this. Thanks everyone, especially Barb and Donna. I know you spend a lot of personal time doing this – I'm grateful.
- As you can see, a very satisfied student!

CHAPTER FIVE

Discussion

The purpose of this study was to evaluate the effects of a formalized education program for patients with inflammatory bowel disease (IBD). A random controlled trial design was used, with data collection at baseline (T1), immediately post-education (T2), and 8 weeks post-education (T3). The primary outcomes assessed were knowledge, perceived knowledge level, and medication regimen adherence. Secondary outcomes included quality of life (QOL) indices, perceived health status, health care utilization, and patient satisfaction. Correlation analysis was undertaken to assess relationships between the outcome variables. Effects of demographic, disease, and prior IBD education on the outcomes were also evaluated.

Study Participants

The information mail-out followed by telephone contact was a successful recruitment strategy. Fifty-two percent (n = 167) of those contacted and eligible were enrolled in the study. A noteworthy finding was, that of those who declined (n = 67), 83% indicated they would like to participate in an education program if offered in the future. This finding is consistent with reports in the literature that patients with IBD want more information about their disease (Jones, Gallacher, Lobo, & Axon, 1993; Kennedy et al., 1998; Mansfield, Tanner, & Bramble, 1997; Marshall, 1979; Martin, et al., 1992; Mayberry, Morris, Calcraft, & Rhodes, 1985; Probert & Mayberry, 1991; Rees, Mayberry, & Calcraft, 1983; Scholmerich, Sedlak, Hoppe-Seyler & Gerok, 1987; Ward, Shah, Eaden, & Mayberry, 1998).

Reasons for declining participation provided insight to barriers faced by patients in accessing a formalized IBD education program. Timing of classes was an issue for 54% of patients. Evening classes were too late and/or conflicted with other demands such as work, school, and family issues. Distance from the classes was also a concern. The geographic area served by the participating gastroenterologists extends several hundred kilometres from the hospital. Only those patients who were within a two-hour driving time were included in the mail-out. Of those that declined, 20% felt it was too far to drive. Driving long distances in poor weather and conflicts with employment/education prevented eight of the education group participants from attending all the education program classes. Illness was a problem for 4% of those who declined participation and attendance for three of the education program participants. Lack of transportation was a barrier for 3% of those that declined. Recruitment and attrition data was not provided in the cited literature.

The education (n = 45) and control groups (n = 44) were homogeneous and characteristic of IBD populations. Comparison of baseline scores for knowledge, perceived knowledge, quality of life, perceived health status, and medication adherence (by survey) demonstrated no statistically significant differences between the groups. The education group had significantly more Crohn's and Colitis Foundation of Canada (CCFC) members than the control group, but this had no significant effect on the outcome variables. Analysis by gender demonstrated differences for years of disease and occupation. A diagnosis of less than five years was significantly higher for females. The employment distribution was similar to that of the general population with more females in clerical/service/sales positions and males in skilled trade/technician occupations. Disease comparison revealed a higher rate of post-secondary education in the ulcerative colitis (UC) group. More Crohn's disease (CD) participants had been in IBD studies. The discrepancy in study participation was not unexpected and reflects the research focus of the participating gastroenterologists.

Inflammatory Bowel Disease Knowledge

Baseline knowledge scores were low for both the Knowledge Questionnaire (KQ)(46%) and Crohn's and Colitis Knowledge Questionnaire (CCKNOW)(44%). These findings are supportive of the current literature that identifies a lack of IBD knowledge in patients (Eaden, Abrams & Mayberry, 1999; Jones Gallacher, Lobo & Axon, 1993; Marshall, 1979; O'Sullivan and Morain, 1999).

Mean total knowledge scores increased for both groups over the course of the study, but were significantly higher for the education group. The substantially increased scores after the education program supports the preponderance of findings in the literature that educational interventions improve patient knowledge (Brown, 1990;

Devine & Refschneider, 1995; Devine & Westlake, 1996 Devine, 1996; Rotor et al., 1998). Additionally, the findings support the report by Zernicke and Henderson (1998) that structured education is superior to ad hoc education in improving patient knowledge. Education group knowledge scores were unchanged from immediately post education (T2) to eight weeks post-education program (T3). Devine and Refschneider (1995) noted diminished effects of education interventions on knowledge scores with time, particularly beyond four weeks in a meta-analysis of psychoeducational interventions for hypertensive adults. The meta-analysis did not specifically include an analysis of factors that may affect knowledge retention. In this study, the education group had an intensive, twelve hour program that included reinforcement of presented material, varied teaching methods, and provision of written material for enhanced understanding and later reference. The incorporation of adult teaching and learning principles in the education program may have conferred a benefit to retaining the learned information.

Significantly improved scores for all education categories were noted for both groups on both questionnaires, with the exception of anatomy and physiology on the CCKNOW. The education group had significantly higher scores than the control group on the KQ and CCKNOW for general IBD knowledge, complications, and medications. Anatomy and physiology scores were not significantly different between groups for either questionnaire. Diet scores were significantly higher for the education group on the CCKNOW, but not for the KQ. All five topics were covered during the course of the education program, however the participants demonstrated the greatest interest in understanding the process of their disease and therapeutic management. This may have contributed to the higher scores in the IBD knowledge, complications, and medications categories.

Knowledge scores improved over the course of the study for the control group. Factors that may have influenced the change are provision of IBD literature to the participants and response to testing. At baseline (T1), those who later read the literature (readers) had significantly higher knowledge scores than those who did not. Readers' knowledge scores remained higher than readers, however the difference was not statistically significant over time. Test familiarity may have contributed to higher scores in non-readers. Alternatively, some test questions may have prompted non-readers to seek information leading to subsequently answer correctly. The overall higher knowledge scores for readers may reflect an information-seeking attitude and consequent better knowledge base. Increased knowledge after providing written patient information is reported in the literature, however this education method was found to have only a small effect size in a meta-analysis of educational interventions by Theis and Johnson (1995). The sample size of 38 may not be large enough to appreciate the difference between groups, particularly if the effect is small. Readability of the pamphlets may also be consideration. Estey, Musseau, and Keehn (1994) noted that literature should be written at grade eight or less to enhance understanding. With the exception of a handout on medication management, the provided pamphlets were written at or above grade 10. Additionally, the readers having previously received the pamphlets, may have been familiar with the information thus did not significantly enhance their knowledge base.

Demographic factors reported in the literature to influence scores were age, education, and professional occupation, however no effect was found for these variables in this study. Prior IBD education and participation in the CCFC or CCFC Support Group (CCFCSG) provided a benefit in perceived knowledge levels at baseline. The difference did not persist over time for those with prior IBD education and CCFC members. The difference may have been reduced as those without prior education improved their knowledge level in the education program. The attendees of the CCFC Support Group however, had higher knowledge scores throughout the study. This is likely a reflection of the more frequent opportunity for education afforded by regular contact with the medical professional facilitator of the group and information sharing with others who have the disease. The finding of higher knowledge scores for members of lay IBD organizations is in keeping with previous reports in the literature (Eaden, Abrams & Mayberry, 1999; Jones Gallacher, Lobo & Axon, 1993). Higher scores after formal education is in keeping with reports in the literature (Brown, 1990; Devine & Refschneider, 1995; Devine & Westlake, 1996 Devine, 1996; Rotor et al., 1998).

Perceived Inflammatory Bowel Disease Knowledge

Perceived IBD knowledge was similar between the control and education groups at baseline, but increased in both groups at T2 and T3, with the education group having significantly higher ratings. Increased knowledge scores correlated positively with improved perceived knowledge ratings. Members of the CCFC and CCFCSG had higher perceived IBD knowledge ratings. As noted previously, higher knowledge scores have been found for those who are members of lay organizations. Membership in lay organizations provides greater access and exposure to patient information, education seminars, and exchange of information with others who have the disease. There are no published studies that address the effect of education on perceived knowledge, however it is reasonable to expect greater confidence in one's knowledge level after a formal education program.

Exposure to written information alone may not be sufficient to significantly increase confidence in one's knowledge level. Although there was a slight increase in the control group mean ratings of IBD knowledge level at T2 and T3, it is not explainable by higher ratings among readers. Readers' ratings did not increase significantly as compared to non-readers. The small increase in ratings may have been in response to the repeated testing using the same questions. As the participants completed the tests each time, they may have gained some confidence in their responses and this was reflected in their knowledge ratings.

Medication Adherence

Although there was a trend of higher medication adherence in the education group as compared to the control group, the difference was not significant. In meta-analysis studies of education interventions, improved medication adherence has been found (Devine, 1996; Devine & Pearcy, 1996; Mazzuca, 1982; Rotor et al., 1998). One meta-analysis of 10 studies found a decrease in medication adherence (Mullen, Mains & Velex, 1992). Schreiber et al. (1999) found improved medication adherence in a group of IBD patients that were educated with a CD-ROM. The short duration and small sample size of this study may not have permitted sufficient time to appreciate the benefits of the education program on medication adherence. Additionally, interpretation of the data should be with caution, as the accuracy of self-reporting must be considered. Response to the survey questions about non-adherence revealed that over 50% of participants missed medications, however only 29% actually reported missing medications. This may reflect failure of participants to maintain diaries accurately. Consideration must also be given to the wording of the survey questions that included a broad timeline, whereas the study was only for three months, thus those who missed medications infrequently would not be captured.

Analysis of demographic variables revealed a gender difference, with females missing medications more often. This finding may reflect an actual difference or greater accuracy in reporting. Internet users also had a higher rate of non-adherence. Although the reasons for seeking information on the Internet were not examined, dissatisfaction with current treatment modalities may lead to lower medication adherence and the search for alternative methods of managing the disease. CCFCSG attendees had a significantly higher rate of adherence. Those attending may have a greater awareness of their disease leading to more conscientious medication management. There are no reports in the cited literature that specifically addressed factors aside from education interventions on medication adherence.

Quality of Life

Meta-analyses of educational interventions have found small to moderate positive effect sizes for psychological outcomes (Brown, 1990; Devine, 1996; Devine & Pearcy, 1995; Devine & Westlake, 1996; Rotor et al., 1998). No significant improvement in QOL scores for the education group was found on either the Inflammatory Bowel Disease Questionnaire (IBDQ) or the Rating Form for IBD Patient Concerns (RFIPC). In their study of the effects of an education intervention with IBD patients, Schreiber et al. (1999) did not observe any change in quality of life indices, however found improvement in a disease-time trade off test indicating some positive psychological benefit of the education. Verma, Tsai, and Giaffer (2001) found no difference in QOL scores for IBD patients with higher patient information scores by questionnaire, however this study did not specifically assess effects of educational interventions.

Increased anxiety after education interventions of up to 20% of participants has been reported (Hawkey & Hawkey, 1989; Mayberry & Rhodes, 1989; Smart, Mayberry, Calcraft, Morris, & Rhodes, 1986). Verma, Tsai, and Giaffer (2001) suggest that higher knowledge levels may raise anxiety and have a deleterious effect on QOL indices.

Alternatively, the effect of heightened anxiety from patient education on QOL indices may be secondary to the immediacy of the testing to the intervention. Like this study, Schreiber et al. (1999) conducted the study over a time frame of three months, testing participants immediately after the intervention. Examination of QOL indices more remotely from the intervention may ameliorate any anxiety effect and demonstrate the positive psychological benefits reported elsewhere in the literature. A further consideration is that QOL is affected by multiple interactive factors. The sample size in this study may be inadequate to assess the effects of a single variable given the complexity of QOL analysis.

Increased disease severity correlated with poorer QOL scores. This finding is in keeping with Drossman et al. (1991), Martin et al. (1992) and Turnbull and Vallis'(1995) reports of greater psychosocial dysfunction in the presence of symptomatic disease. Irvine et al., (1994) and Martin et al. (1992) both reported higher levels of psychological dysfunction in IBD patients in remission as compared to normal controls. Findings in this study were similar as patients with quiescent disease had mean IBDQ scores that indicated psychosocial dysfunction. Perceived IBD knowledge did not consistently correlate with IBDQ scores and there was no positive correlation with RFIPC scores. In a study of 250 IBD patients, Moser et al. (1995) found a strong correlation between perceived disease knowledge level and RFIPC scores. Those who had higher perceived knowledge had lower concerns. The sample size in this study may not have been sufficient to clearly identify a relationship between perceived knowledge and QOL scores.

Analysis of the demographic, disease, and IBD education variables on baseline QOL total scores revealed that only education level, gender, and disease type were found to have an effect. Females had lower total scores and reported more bowel symptoms at baseline then males when assessed with the IBDQ, however the difference did not persist over time. Those whose education did not extend beyond junior high school had significantly lower total IBDQ scores at baseline than those with higher education. The dimensions bowel symptoms, emotional function, and social function were also significantly lower. Only bowel symptoms and total score remained significantly lower over the course of the study. Higher RFIPC baseline total scores and greater anxiety about impact of disease, body stigma, sexual intimacy, and being treated differently were found for those with junior high education. These differences did not persist over time. The ability to perform sexually was of greater concern for participants with CD than those UC on the RFIPC at baseline, but not over time. It is unclear why there was a change over time on the QOL scores and the small sample size does not permit more indepth statistical analysis.

Gender differences have not been reported for IBDQ scores, however Maunder et al. (1999) reported females had greater sensitivity to disease symptoms on the RFIPC. In this study, there are no specific gender differences in disease severity, disease type, or perceived health that may contribute to the difference. The lower scores on QOL indices for those with lower education are in keeping with reports in the literature (Drossman et al.,1991b). Those with lower education may have less developed coping mechanisms and lower ability to comprehend disease information thus experience greater disease related anxiety.

The greater concern about sexual intimacy for CD participants is reflective of issues related to sexuality for IBD patients noted in the literature. Maunder et al. (1999) reported a lower level of concern about sexual performance and intimacy in CD patients as compared to UC patients on the RFIPC. They suggested that lower than normal reporting could be due to reluctance to address a sensitive issue or a sense of resignation over poor sexual performance. Drossman et al. (1991b) and Moser et al. (1995) reported no significant differences between UC and CD patients on the sexual intimacy index of the RFIPC. In studies that compared the sexual function of IBD patients with normal controls, females with IBD reported dyspareunia more frequently and higher rates of infrequent or no intercourse for CD women was found. Patients cited numerous IBD symptom related fears that affected their sexual activity (Moody & Mayberry, 1993; Moody, Probert, Rhodes, & Mayberry, 1992). Although there is no consistent finding of specific concerns by disease, the finding of greater concern for the CD participants about sexual intimacy is in keeping with the evidence that IBD can have a negative impact on sexual function.

Analysis of RFIPC items revealed that energy level was the top most concern by gender, disease type, and the sample. Having an ostomy and medication side effects were ranked second and third by females and CD sufferers. UC patients ranked having an ostomy above energy level followed by medication side effects. Males ranked access to quality health care as second and having an ostomy as third with medication side effects as fourth. It is important to note that energy level, having an ostomy, and medication side effects rank among the top concerns for all groups, a similar finding in other studies (Drossman et al., 1991b; Maunder Toner, de Rooy & Moskovitz, 1999; Moser et al. 1995). Fatigue is a predominant symptom in IBD and can severely limit psychosocial function (Mitchell et al., 1988). Surgical intervention with creation of an ostomy is a significant body-altering event with associated psychological effects. Many medications have significant side effects with which patients have to cope. Fear and worry are natural responses to the potential adverse effects associated with these therapies (Schlomerich, et al., 1987).

Analysis of RFIPC item concerns by gender revealed females had greater concern than males regarding the uncertain nature of the disease, energy level, the ability to achieve full potential, dying early, passing the disease on to others, and attractiveness. Drossman (1991b) noted significantly higher scores for females on the impact of disease and body stigma indices. Moser et al. (1995) found no significant differences on RFIPC index scores when socio-demographic variables were examined, however females had greater concern than males about being a burden, passing the disease on to others, and being treated differently. Maunder et al. (1999) found females had greater concern about body feelings, attractiveness, feeling alone, and ability to have children. Maunder et al. (1997) noted higher RFIPC scores for females among patients who sought psychological counseling. Although the concerns of females are unique in each study, there is a consistent finding that they experience greater anxiety than men suggesting females have a greater sensitivity to the psychological effects of IBD.

Disease comparison of RFIPC items in this study revealed CD participants had significantly greater concern about the ability to perform sexually, feeling alone, and having financial difficulties than their UC counterparts. Drossman et al. (1991b) reported greater concern in CD patients for suffering, being a burden to others, decreased energy, and financial difficulties. Maunder, Toner, de Rooy and Moskovitz (1999) found no significant difference between disease groups. Moser et al. (1995) reported greater concern for UC patients about loss of bowel control and feeling dirty or smelly. No consistent pattern of disease specific concerns is found in the literature and likely reflects the unique experience of specific populations.

Perceived Health Status

The education group had higher perceived health ratings at T2 and T3 than the control group, but the difference was not significant. Interestingly, increased perceived knowledge ratings correlated with increased perceived health scores at T2 and T3 indicating some positive benefit of the education program. The small sample size may not have been sufficient to fully appreciate the effect of education on perceived health. Additionally, heightened disease awareness post-education may affect perceived health ratings negatively.

Perceived health ratings correlated significantly with IBDQ and RFIPC scores at all time points. Higher perceived health status was associated with lower psychosocial dysfunction, a finding that is in keeping with that reported by Drossman et al. (1991b). Increased psychosocial distress likely has a deleterious effect on overall perception of health and well being.

Disease severity had an effect on perceived health status. Higher Crohn's Disease Activity Index (CDAI) scores were associated with lower perceived health. The ulcerative colitis Activity Index (AI) scores did not consistently correlate with perceived health ratings, however disease activity was only mild for UC participants as compared to moderately severe in those with CD. Mean perceived health ratings at baseline were significantly lower for those with CD than for UC participants. This suggests that perceived health status is most significantly affected when disease is more severe. This is in keeping with Drossman et al.'s (1991) report of lower perceived well being in CD patients that was attributed to more severe disease.

Health Care Utilization

Robinson, Thomson and Willen, (1999) reported decreased utilization in IBD patients who had been educated in disease self-management. In this study, the education group had a lower rate of health care utilization than the control group, but the difference was not significant. When demographic, disease, and education variables were considered, the only significant finding was that those who had benefited from previous formal IBD education had lower health care utilization. This suggests that, in the long term, education may reduce health care utilization and would be consistent with meta-analysis findings of education interventions that assessed health care utilization (Gibson et al., 2000; Pakkala & Merinder, 2000). The short duration and small study size in this study may not have permitted full appreciation of the benefits of formal education on health care utilization.

Medication non-adherence was associated with higher health care utilization, specifically with more frequent physician visits. This finding is not specifically reported in the health care utilization by IBD patients (DeBoer et al., 1998; Drossman, 1991). Therapeutic management of IBD requires long term maintenance therapy and lapses in medication adherence may predispose patients to disease exacerbations leading to more frequent physician visits. Additionally, some of the medications have significant side-effects which may lead to non-adherence and more frequent visits to address the drug related symptoms.

Drossman et al. (1991a) reported that poorer psychosocial function, weight loss, and steroid use were associated with greater health utilization. Drossman, Li, Leserman, and Patrick (1992) report that perceived well being was the most significant factor affecting physician visits. De Boer et al. (1998) reported disease activity, poor emotional functioning, impaired social function, and disease burden were predictive of increased health care utilization. In this study, only disease severity correlated with health care utilization, specifically with greater frequency of physician visits. The small sample size may not have been adequate to appreciate the various factors that influence health care utilization.

Patient Satisfaction

Overall, the mean patient satisfaction with medical care score was high. The education group had a significantly higher mean score than the control group. Higher perceived knowledge was associated with higher patient satisfaction, further demonstrating a positive benefit of formal education on patient satisfaction. Education group participants reported a significantly greater degree of satisfaction with disease understanding and meeting of information needs than the control group. Comments provided by control group participants on the Patient Satisfaction Survey indicated a lack of confidence in disease management. Increased knowledge of the disease and approach to medical management may contribute to a greater understanding of the prescribed therapeutic regimen, help patients to identify concerns that need to be addressed by medical staff, and provide a greater sense of confidence when approaching health professionals. Patient satisfaction was not a factor considered in the cited education or IBD literature.

An association with patient satisfaction and QOL indices was found. Higher patient satisfaction with medical care was associated with lower psychosocial dysfunction. Emotional and social distress related to the disease may contribute to an overall lower level of satisfaction that is consequently reflected in the satisfaction with medical care. Additionally, patient comments on the Patient Satisfaction Survey indicated frustration with the lack of time to address concerns to health care providers. Patient interactions with health care professionals are often limited to short clinic visits that tend to focus on physical symptoms and medical management. These time constraints are not conducive to managing the psychosocial issues that may be problematic to the patient. Demographic, disease, and IBD education variables had no effect on patient satisfaction with medical care.

Satisfaction with the education program was high. Participants were highly satisfied with their increased understanding of the disease and program presentation methods. Ulcerative colitis patients were significantly more satisfied with the program than those with CD. A possible contributor to the difference in satisfaction is that patient literature usually discusses IBD in a broad sense with a greater focus on CD as it is a more extensive disease with more complications than UC. The education program clearly delineated the differences in the disease presentations, symptoms, medical management, and self-management. Much of the information provided may have been new to those with UC and the specific focus on their disease may have resulted in a greater sense of satisfaction with the program. Overall, participant comments on the education program were positive. Several comments expressed a desire for more information and time spent on the psychosocial aspects of the disease. From the educator's perspective, shorter classes over a six to eight weeks and smaller class size would have facilitated a more intimate sharing experience and been less exhausting for the participants.

Limitations of the Study

The main limitation of the study was the small sample size and short study duration. Medication adherence, psychosocial effects, and health care utilization are long-term outcomes that would have been better assessed with a study duration that extended to six months. Repeat testing of knowledge scores with the same instrument over a short time frame may have increased test familiarity.

Implications of the Findings

Analysis of the recruitment data revealed a strong desire for IBD education and multiple barriers to access. Education interventions need to be designed that consider patient needs. Innovative programs that are flexible and accessible to those who live in rural areas need to be developed. Technology such as the Internet, teleconferencing, or interactive computer based education may provide effective means of overcoming some of the barriers of time, geography, illness, and transportation. Additionally, the population that declined participation and expressed no need or desire for education should be considered. Assessment of the motivation for declining participation and their IBD knowledge would provide insight for health care providers as to the need for and approach to education best suited for this group.

Significant differences between the education and control groups were found for knowledge scores, perceived knowledge, and patient satisfaction. Positive trends were identified for medication adherence, perceived health, and health care utilization. Although positive effects of education interventions on QOL indices are reported in the literature, no effect was found in this study. The short duration of the study and small sample size may not have been sufficient to fully appreciate the benefits of the education program. Further study over a period of six months with a larger sample size would better elucidate the benefits of education in this population.

Long-term psychosocial effects were found in this study as assessed by the IBDQ, a finding in keeping with the literature. Comprehensive IBD management includes support for disease associated psychosocial concerns. The perceived health visual analogue scale may have potential as an efficient tool to assess psychosocial distress in the clinic setting where long QOL questionnaires are difficult to use. Further corroboration of the relationship of the perceived health visual analogue scale to IBDQ and RFIPC scores and as a screening tool for psychosocial distress in the clinic setting should be undertaken.

Conclusion

Findings of the study supported the hypotheses that those in the formal education program had significantly higher knowledge scores, perceived IBD knowledge, and patient satisfaction than those receiving standard care. The data did not support the hypotheses of improved quality of life (QOL) indices, higher perceived health, and lower health care utilization in the education group as compared to the control group. Although there was a trend for greater medication adherence in the education group, the difference did not reach statistical significance. No difference between groups was found on quality of life indices. Mean perceived health status was higher in the education group after the intervention, but the difference did not meet statistical significance. A difference was not found between the groups for health care utilization, although the mean rate of utilization was lower for the education group. Higher perceived IBD knowledge ratings correlated with higher perceived health ratings. Lower perceived health ratings correlated with poorer quality of life indices. Lower patient satisfaction scores also correlated with poorer quality of life indices. Those with higher rates of medication non-adherence utilized health care more frequently.

Analysis of demographic, disease, and prior IBD education variables revealed members of the CCFC and CCFCSG had higher perceived IBD knowledge and knowledge scores, but the difference did not persist over time. Medication adherence was significantly better for males and attendees of the CCFCSG. Females and Internet users had poorer medication adherence than non-users. Those with higher educational preparation had better quality of life scores. Lower baseline perceived health scores were found for Crohn's disease (CD) participants than those with ulcerative colitis (UC), but this did not persist over time. Demographic, disease, or IBD education variables did not affect health care utilization or patient satisfaction.

Patient education is essential to comprehensive IBD management, conferring benefits of improved knowledge, perceived knowledge, and patient satisfaction. Potential benefits may include improved quality of life, better medication adherence, and lower health care utilization. Identification of knowledge deficits and patient concerns in the population provides valuable insight for educational interventions by health care practitioners working with these patients. Finally, the clearly demonstrated positive benefits of a formal IBD education program in this sample provides evidence to change current practices of relying on ad hoc, informal teaching during IBD Outpatient Clinics and reliance on written materials for patient education.

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Appendix A

Knowledge Questionnaire

1. The following things may be caused by Crohns' disease or ulcerative colitis:

Red eyes. T F DK

Dry mouth. T F DK

High blood pressure. T F DK

Painful joints. T F DK

Anemia. T F DK

2. Concerning your bowel:

The large bowel connects the outlet of the stomach to the back passage. T F DK

Crohn's disease affects the small bowel only. T F DK

Ulcerative colitis may affect any part of the bowel. T F DK

The small bowel absorbs protein from food into the bloodstream. T F DK

The small bowel absorbs water from drinks into the bloodstream. T F DK

3. The chances of your children inheriting Crohn's disease/ulcerative colitis are:

Less than 25%. T F DK

Greater than if you did not have the disease. T F DK

Children of the same sex as you will probably inherit the disease. T F DK

4. Blood tests are often performed in the colitis clinic for the following purposes:

To check for your cholesterol level. T F DK

To find out your blood group. T F DK

To help assess whether your bowel is inflamed. T F DK

To check whether you are short of vitamins. T F DK

5. Steroid tablets used in treating Crohn's disease or ulcerative colitis:

May weaken your muscles. T F DK

May cause thinning of bones. T F DK

May cause nosebleeds. T F DK

(Jones, Gallacher, Lobo, & Axon, 1993)

6. **When you are well, the following tablets are used in the long-term to prevent Crohn's disease/ulcerative colitis from becoming active again:**

Loperamide (Imodium)	T	F	DK
Azathioprine (Imuran)	T	F	DK
Prednisone (Deltasone)	T	F	DK
Rantidine (Zantac)	T	F	DK
Sufasalazine (Salazopyrin)	T	F	DK
Mesalazine (Asacol)	T	F	DK

7. **Regarding surgical operations in Crohn's disease and ulcerative colitis:**

Most people with Crohn's disease will require an operation at some point during the course of their illness.	T	F	DK
Most people with ulcerative colitis will require an operation at some point during the course of their illness.	T	F	DK
Following an operation, Crohn's disease may occur again elsewhere in the bowel.	T	F	DK
Following an operation to remove the large bowel, ulcerative colitis may occur again elsewhere in the bowel.	T	F	DK
Removing part of the bowel can cause more frequent bowel movements.	T	F	DK

8. **Regarding diet in Crohn's disease and ulcerative colitis:**

Most people with Crohn's disease and ulcerative colitis do not need to be restricted to a low residue (low fiber) diet.	T	F	DK
You should avoid sugary foods.	T	F	DK
You need not restrict your alcohol intake because you have Crohn's disease/ulcerative colitis.	T	F	DK
You should avoid milk.	T	F	DK

9. **If you start with an episode of diarrhea, you should:**

Continue to eat as you normally would.	T	F	DK
Wait a while, but see your doctor if it persists for more than 3 weeks.	T	F	DK

(Jones, Gallacher, Lobo, & Axon, 1993)

Knowledge Questionnaire Score Sheet

 # √: _____ **%√:** _____ **# DK :** _____ **% DK:** _____

Diet:

8a ______
8b ______
8c ______
8d ______

_____/4 = _____%

A & P:

2a ______
2d ______
2e ______

_____/3 = _____%

General IBD Knowledge:

2b ______
2c ______
3a ______
3b ______
3c ______
4a ______
4b ______
4c ______
4d ______
9a ______
9b ______

_____/11 = _____%

Complications:

1a ______
1b ______
1c ______
1d ______
1e ______
7a ______
7b ______
7c ______
7d ______
7e ______

_____/10 = _____%

Medications:

5a ______
5b ______
5c ______
6a ______
6b ______
6c ______
6d ______
6e ______
6f ______

_____/9 = _____%

Appendix B

Crohn's and Colitis Knowledge Questionnaire

1. People with inflammatory bowel disease are never allowed to eat dairy foods:
   a. True.
   b. False.
   c. Don't know.

2. Elemental feeds are sometimes used to treat Crohn's disease and ulcerative colitis. They:
   a. Always contain a lot of fibre.
   b. Are very easy to digest.
   c. Come in the form of tablets.
   d. Don't know.

3. Proctitis:
   a. Is a form of colitis that affects the rectum or back passage only.
   b. Is a form of colitis that affects the whole of the large bowel.
   c. Don't know.

4. Patients with inflammatory bowel disease are probably cured if they have been symptom free for 3 years:
   a. True.
   b. False.
   c. Don't know.

5. Inflammatory bowel disease runs in families:
   a. True.
   b. False.
   c. Don't know.

6. Patients with inflammatory bowel disease can get inflammation in other parts of the body as well as the bowel:
   a. True.
   b. False.
   c. Don't know.

7. A fistula:
   a. Is an abnormal track between 2 pieces of bowel or between the bowel and skin.
   b. Is a narrowing of the bowel that may obstruct the passage of the contents.
   c. Don't know.

8. The terminal ileum:

   a. Is a section of the bowel just before the anus.
   b. Is a section of the bowel just before the large intestine.
   c. Don't know.

(Eaden, Abrams, & Mayberry, 1999)

9. During a flare-up of inflammatory bowel disease:
   a. The platelet count in the blood rises.
   b. The albumin level in the blood rises.
   c. The white cell count in the blood falls.
   d. Don't know.

10. Steroids (such as (prednisolone/prednisone/budesonide/hydrocortisone):
    a. Can only be taken by mouth.
    b. Can be given in the form of an enema into the back passage.
    c. Cannot be given directly into the vein.
    d. Don't Know

11. Immunosuppressive drugs are given to inflammatory bowel disease patients to:
    a. Prevent infection in the bowel by bacteria.
    b. Reduce inflammation in the bowel.
    c. Don't know.

12. Sulphasalazine:
    a. Controls the level of sulphur in the bloodstream.
    b. Can be used to reduce the frequency of flare-ups.
    c. Cannot be used to prevent flare-ups.
    d. Don't know.

13. An example of an immunosuppressive drug used in inflammatory bowel disease is:
    a. Sulphasalazine.
    b. Mesalazine.
    c. Azathioprine.
    d. Don't know.

14. If a woman has Crohn's disease:
    a. She may find it more difficult to become pregnant.
    b. She should not have children.
    c. Her pregnancy will always have complications.
    d. She should stop all medication during her pregnancy.
    e. Don't know.

15. Which one of the following statements is false?
    a. Ulcerative colitis can occur at any age.
    b. Stress and emotional events are linked with the onset of ulcerative colitis.
    c. Ulcerative colitis is least common in Europeans and North Americans.
    d. Patients with ulcerative colitis have an increased risk of developing bowel cancer.
    e. Don't know.

16. Male patients who take sulphasalizine:
    a. Have reduced fertility levels that are reversible.
    b. Have reduced fertility levels that are not reversible.
    c. The drug does not have any effect on male fertility.
    d. Don't know.

(Eaden, Abrams, & Mayberry, 1999)

17. The length of the small bowel is approximately:
    a. 2 feet.
    b. 12 feet.
    c. 20 feet.
    d. Don't know.

18. The function of the large bowel is to absorb:
    a. Vitamins.
    b. Minerals.
    c. Water.
    d. Don't know.

19. Another name for an ileorectal anastomosis operation with formation of a reservoir is:
    a. Purse
    b. Pouch.
    c. Stoma.
    d. Don't know.

20. If a part of the bowel called the terminal ileum is removed during surgery the patient will have impaired absorption of:
    a. Vitamin C.
    b. Vitamin A.
    c. Vitamin B12.
    d. Don't know.

21. Patients with inflammatory bowel disease need to be screened for cancer of the colon. Which one of the following statements about screening is false?

    Screening should be offered to all patients with ulcerative colitis:
    a. Which affects only the rectum.
    b. Which has lasted for 8-10 years.
    c. Which started before the age of 50.
    d. Don't know.

22. There are millions of tiny "hairs" in the small bowel to increase the absorptive surface. They are called:
    a. Villi.
    b. Enzymes.
    c. Bile salts.
    d. Crypts.
    e. Don't know.

23. Which one of the following is not a common symptom of inflammatory bowel disease?
    a. Abdominal pain.
    b. Change in bowel habit.
    c. Headache.
    d. Fever.
    e. Don't know.

(Eaden, Abrams, & Mayberry, 1999)

24. If a child has inflammatory bowel disease, he/she probably will not:
    a. Live beyond the age of 45.
    b. Be as tall as his or her friends.
    c. Be as intelligent as his or her friends.
    d. Don't know.

(Eaden, Abrams, & Mayberry, 1999)

CCKNOW Question Score Sheet

 # √: _____ **%√:** _____ **# DK :** _____ **% DK:** _____

Diet:

1. _____
2. _____

_____/2 = _____%

A & P:

8. _____
17. _____
18. _____
20. _____
22. _____

_____/5 = _____%

General IBD Knowledge:

3. _____
4. _____
5. _____
9. _____
15. _____
23. _____

_____/6 = _____%

Complications:

6. _____
7. _____
14. _____
19. _____
21. _____
24. _____

_____/6 = _____%

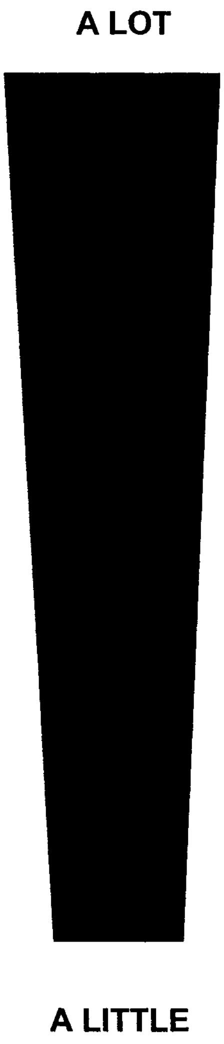
Medications:

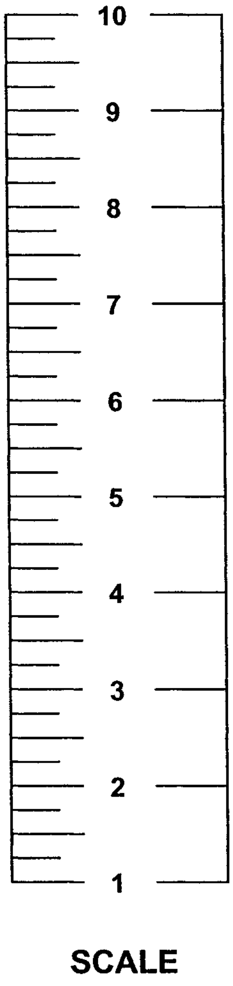
10. _____
11. _____
12. _____
13. _____
16. _____

_____/5 = _____%

Appendix C

Visual Analogue Scale for Perceived IBD Knowledge





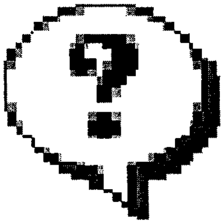
Please draw a line across the graph to rate how much you know about inflammatory bowel disease.

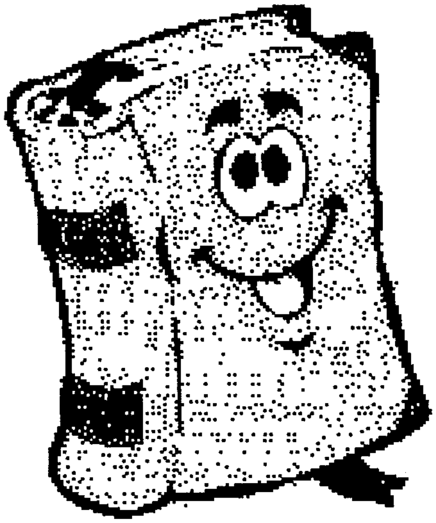
(Numerical Scale for grading response)

Appendix D

Capital
Health

PATIENT DIARY



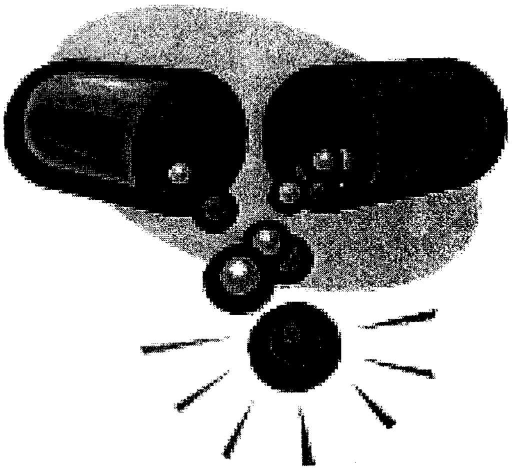


The Inflammatory Bowel Disease Education Study

MEDICATION MANAGEMENT

Directions for keeping the Medication Management Record:

1. On the day you start the study, please record of the medications you are taking on the Medication Record. Each time your doctor stops a medication, changes the dose or frequency, or starts you on a new medication, write down the new information on the Medication Record. It is important to record the reason for the change.
2. Please record each time you do not take your medications as directed by your doctor. You may select a reason for not taking your medication from the list or write down your own reason in the comment section.
3. If you have any questions or do not have enough forms, please contact the researcher at 407-3422.



MEDICATION RECORD

Please record:

1. The name(s) of the medication(s) you are taking (including ones you take just when needed).
2. The dose prescribed by the doctor.
3. How much of the medication you take each time (eg. the number of pills).
4. When you take the medication.
5. Why you take the medication.

Medication Name	Dose	Amount	Times	Reason

RECORD OF MEDICATIONS NOT TAKEN

Please record:

1. **Date medication was not taken.**
2. **Time medication was not taken.**
3. **Name of medication not taken.**
4. **Reason medication was not taken.**

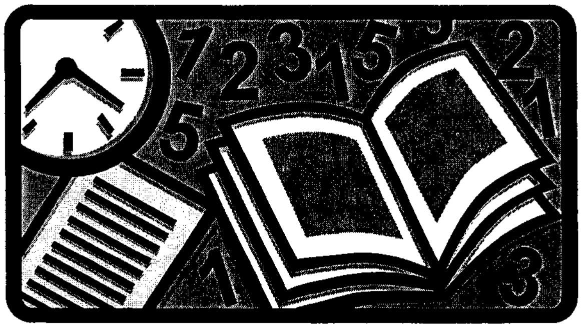
Date	**Time**	**Medication Name**	**Reason**	**Comments**
			___ Forgot to take ___ Prescription ran out ___ Medication side-effects ___ Left medication at home	
			___ Forgot to take ___ Prescription ran out ___ Medication side-effects ___ Left medication at home	
			___ Forgot to take ___ Prescription ran out ___ Medication side-effects ___ Left medication at home	
			___ Forgot to take ___ Prescription ran out ___ Medication side-effects ___ Left medication at home	

f you did not miss any medications during the study, please mark circle. ○

Crohn's Disease Symptom Record

Directions for completing the Symptom Record:

1. On the seven days before your next doctor's appointment, complete the chart each day.
2. Record each bowel movement on the chart right after going to the bathroom.
3. Before going to bed, record scores for abdominal pain and.well being. Your answer should describe the average pain or well being for the last 24 hours.
4. When you are notified of the date to return your Patient Diary, complete the chart for the seven days before the due date.
5. If you have any questions or need more forms, please call the researcher, Barbara Waters at 407-3422.



CROHN'S DISEASE SYMPTOM RECORD

Month: ____________	Date	Date	Date	Date	Date	Date	Date
Number of liquid or very soft stools							
Abdominal Pain 0 = none 1 = mild 2 = moderate 3 = severe							
General Well being 0 = Generally well 1 = slightly under par 2 = poor 3 = very poor 4 = terrible							

Record each bowel movement on the chart right after going to the bathroom. Before going to bed, record average pain or well being for the last 24 hours.

Do you have, or have you had, any of the following symptoms since your last doctor's appointment?

____ sores in your mouth or on your skin

____ anal fissure, fistula, perirectal abscess

____ other bowel fistula

____ fever (temp >37.8°C or 100°F oral)

____ red swollen joints or aching muscles

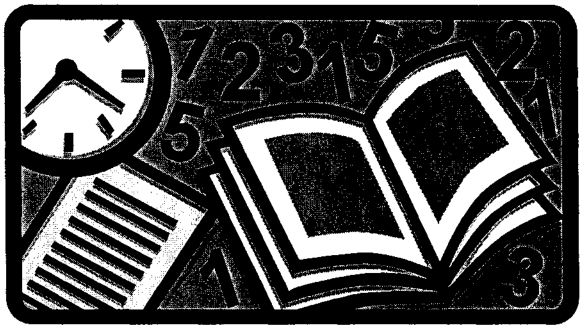
____ eye inflammation

Next Doctor's appointment:____________________

Ulcerative Colitis Symptom Record

Directions for completing the Symptom Record:

1. On the seven days before your next doctor's appointment, complete the chart each day.
2. Record each bowel movement on the chart right after going to the bathroom. Note the kind of stool you are passing and whether there is blood present.
3. When you are notified of the date to return your Patient Diary, complete the chart for the seven days before the due date.
4. If you have any questions or need more forms, please call the researcher, Barbara Waters at 407-3422.



ULCERATIVE COLITIS SYMPTOM RECORD

Month: ____________	**Date**	**Date**	**Date**	**Date**	**Date**	**Date**	**Date**
Number of liquid or very soft stools							
Blood in the stool 0 = None or little 1 = Present							

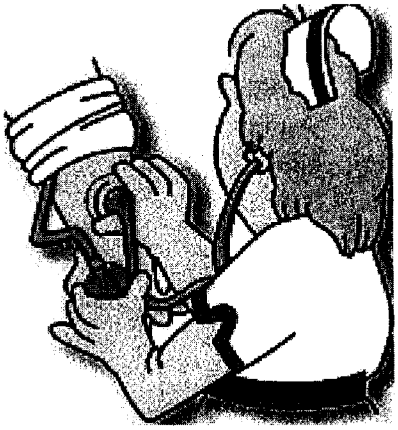
Record each bowel movement on the chart right after going to the bathroom. Note the kind of stool you are passing and whether there is blood present.

Next Doctor's appointment:____________________

Health Care Visit

Directions for tracking health care visits:

1. Each time you see your family doctor or bowel disease specialist about problems related to your inflammatory bowel disease, please record the information in the Physician Visit Record
2. Record the date of the visit, whether the appointment was made at the direction of your doctor or by you, the reason for seeing the doctor, whether your medications were changed, any tests that were ordered or done, and when your next appointment date is.
2. Each time you are admitted to emergency or to a ward in the hospital for problems related to your inflammatory bowel disease, please record the information on the Hospital Visit Record.
3. Record the dates of your stay, whether the visit was to emergency or you were admitted to the ward, the reason for the visit, whether your doctor sent you to hospital, whether your medications were changed, any tests you had, surgeries done, and when your next appointment date is.
4. If you have any questions or need more forms, please call the researcher at 407-3422.



PHYSICIAN VISIT RECORD

Date	Doctor	Appointment Requested by	Reason for Appointment	Medication Changes	Tests Ordered	Next Appointment
		____ Patient ____ Doctor		_____ Yes* _____ No		
		____ Patient ____ Doctor		_____ Yes* _____ No		
		____ Patient ____ Doctor		_____ Yes* _____ No		
		____ Patient ____ Doctor		_____ Yes* _____ No		

*Please record the medication changes on your Medication Record

If you did not visit your physician during the study, please mark the circle: ○

HOSPITAL VISIT RECORD

Admission Date	Type of Admission	Days in Hospital (if admitted to ward)	Reason for Admission	Medication Changes	Tests or Surgery	Next Doctor's Appointment
	___ **Emergency** only ___ Admitted to ward		(Dr. sent to hospital Y N)	_____ Yes* _____ No		
	___ **Emergency** only ___ Admitted to ward		(Dr. sent to hospital Y N)	_____ Yes* _____ No		
	___ **Emergency** only ___ Admitted to ward		(Dr. sent to hospital Y N)	_____ Yes* _____ No		
	___ **Emergency** only ___ Admitted to ward		(Dr. sent to hospital Y N)	_____ Yes* _____ No		

*Please record the medication changes on your Medication Record

If you were not in hospital during the study, please mark the circle: ○

Appendix E

Inflammatory Bowel Disease Questionnaire

This questionnaire is designed to measure the effects of you inflammatory bowel disease on you daily function and quality of life. You will be asked about symptoms you have been having as result of your bowel disease, the way you have been feeling in general, and how your mood has been.

On this questionnaire there are 32 questions. Each question has a graded response numbered from 1 through 7. Please read each question carefully and answer the number which best describes how you have been feeling in the past 2 weeks.

EXAMPLE:

How often have you felt unwell as a result of you bowel problem in the past 2 weeks?

1. All of the time.
2. Most of the time.
3. A good bit of the time
4. Some of the time.
5. A little of the time.
6. Hardly any of the time.
7. None of the time.

If you are having trouble understanding a question, STOP for a moment? Think about what the question means to you. How is it affected by your bowel problem? Then answer the question as best you can. You will have the chance to ask the nurse questions after completing the questionnaire. This take only a few minutes to complete.

How frequent have your bowel movements been during the last 2 weeks? Please indicate how frequent your bowel movements have been during the last 2 weeks by picking one of the options from

1. Bowel movements as or more frequent than they have ever been.
2. Extremely frequent.
3. Very Frequent.
4. Moderate increase in frequency of bowel movements.
5. Some increase in frequency of bowel movements.
6. Slight increase in frequency of bowel movements.
7. Normal, no increase in frequency of bowel movements.

(Guyatt, Mitchell, Irvine, Singer, Williams, Goodacre, & Tompkins, 1989)

1. How often has the feeling of fatigue or of being tired and worn you been a problem for you during the past 2 weeks? Please indicate how often the feeling of fatigue or tiredness has been a problem for you during the last 2 weeks by picking one of the options from

   1. All of the time.
   2. Most of the time.
   3. A good bit of the time.
   4. Some of the time.
   5. A little of the time.
   6. Hardly any of the time.
   7. None of the time.

2. How often during the last 2 weeks have you felt frustrated, impatient, or restless? Please choose an option from

   1. All of the time.
   2. Most of the time.
   3. A good bit of the time.
   4. Some of the time.
   5. A little of the time.
   6. Hardly any of the time.
   7. None of the time.

4. How often during the last 2 weeks have you been unable to attend school or do you work because of your bowel problems? Please choose an option from

   1. All of the time.
   2. Most of the time.
   3. A good bit of the time.
   4. Some of the time.
   5. A little of the time.
   6. Hardly any of the time.
   7. None of the time.

5. How much of the time during the last 2 weeks have your bowel movements been loose? Please choose an option from

   1. All of the time.
   2. Most of the time.
   3. A good bit of the time.
   4. Some of the time.
   5. A little of the time.
   6. Hardly any of the time.
   7. None of the time.

(Guyatt, Mitchell, Irvine, Singer, Williams, Goodacre, & Tompkins, 1989)

6. How much energy have you had during the last 2 weeks? Please choose an option from

    1. No energy at all.
    2. Very little energy.
    3. A little energy.
    4. Some energy.
    5. A moderate amount of energy.
    6. A lot of energy.
    7. Full of energy.

7. How often during the last 2 weeks did you feel worried about the possibility of needing to have surgery because of your bowel problem? Please choose an option from

    1. All of the time.
    2. Most of the time.
    3. A good bit of the time.
    4. Some of the time.
    5. A little of the time.
    6. Hardly any of the time.
    7. None of the time

8. How often during the last 2 weeks have you had to delay or cancel a social engagement because of your bowel problem? Please choose an option from

    1. All of the time.
    2. Most of the time.
    3. A good bit of the time.
    4. Some of the time.
    5. A little of the time.
    6. Hardly any of the time.
    7. None of the time.

9. How often during the last 2 weeks have you been troubled by cramps in your abdomen? Please choose an option from

    1. All of the time.
    2. Most of the time.
    3. A good bit of the time.
    4. Some of the time.
    5. A little of the time.
    6. Hardly any of the time.
    7. None of the time.

(Guyatt, Mitchell, Irvine, Singer, Williams, Goodacre, & Tompkins, 1989)

10. How often during the last 2 weeks have you felt generally unwell? Please choose an option from

    1. All of the time.
    2. Most of the time.
    3. A good bit of the time.
    4. Some of the time.
    5. A little of the time.
    6. Hardly any of the time.
    7. None of the time.

11. How often during the last 2 weeks have you been troubled because of fear of not finding a washroom (bathroom, toilet)? Please choose an option from

    1. All of the time.
    2. Most of the time.
    3. A good bit of the time.
    4. Some of the time.
    5. A little of the time.
    6. Hardly any of the time.
    7. None of the time.

12. How much difficulty have you had, as result of your bowel problems, doing leisure or sports activities you would have like to have done during the last 2 weeks? Please choose an option from

    1. A great deal of difficulty; activities made impossible.
    2. A lot of difficulty.
    3. A fair bit of difficulty.
    4. Some difficulty.
    5. A little difficulty.
    6. Hardly any difficulty.
    7. No difficulty; the bowel problems did not limit sports or leisure activities.

13. How often during the last 2 weeks have you been troubled by pain in the abdomen? Please choose an option from

    1. All of the time.
    2. Most of the time.
    3. A good bit of the time.
    4. Some of the time.
    5. A little of the time.
    6. Hardly any of the time.
    7. None of the time.

(Guyatt, Mitchell, Irvine, Singer, Williams, Goodacre, & Tompkins, 1989)

14. How often during the last 2 weeks have you had problems getting a good night's sleep, or been troubled by waking up during the night? Please choose an option from

    1. All of the time.
    2. Most of the time.
    3. A good bit of the time.
    4. Some of the time.
    5. A little of the time.
    6. Hardly any of the time.
    7. None of the time.

15. How often during the last 2 weeks have you felt depressed or discouraged? Please choose an option from

    1. All of the time.
    2. Most of the time.
    3. A good bit of the time.
    4. Some of the time.
    5. A little of the time.
    6. Hardly any of the time.
    7. None of the time.

16. How often during the last 2 weeks have you had to avoid attending events where there was no washroom (bathroom, toilet) close at hand? Please choose an option from

    1. All of the time.
    2. Most of the time.
    3. A good bit of the time.
    4. Some of the time.
    5. A little of the time.
    6. Hardly any of the time.
    7. None of the time.

17. Overall, in the last 2 weeks, how much of a problem had you had with passing large amounts of gas? Please choose an option from

    1. A major problem.
    2. A big problem
    3. A significant problem.
    4. Some trouble
    5. A little trouble.
    6. Hardly any trouble.
    7. No trouble.

(Guyatt, Mitchell, Irvine, Singer, Williams, Goodacre, & Tompkins, 1989)

18. Overall, in the last 2 weeks how much of a problem have you had maintaining, or getting to, the weight you would like to be at. Please choose an option from

    1. A major problem.
    2. A big problem
    3. A significant problem.
    4. Some trouble
    5. A little trouble.
    6. Hardly any trouble.
    7. No trouble.

19. Many patients with bowel problems often have worries and anxieties related to their illness. These include worries about getting cancer, worries about never feeling any better, and worries about having a relapse. In general, how often during the last 2 weeks have you felt worried or anxious? Please choose an option from

    1. All of the time.
    2. Most of the time.
    3. A good bit of the time.
    4. Some of the time.
    5. A little of the time.
    6. Hardly any of the time.
    7. None of the time.

20. How much of the time during the last 2 weeks have you been troubled by a feeling of abdominal bloating? Please choose an option from

    1. All of the time.
    2. Most of the time.
    3. A good bit of the time.
    4. Some of the time.
    5. A little of the time.
    6. Hardly any of the time.
    7. None of the time.

21. How often during the last 2 weeks have you felt relaxed and free of tension? Please choose an option from

    1. All of the time.
    2. Most of the time.
    3. A good bit of the time.
    4. Some of the time.
    5. A little of the time.
    6. Hardly any of the time.
    7. None of the time.

(Guyatt, Mitchell, Irvine, Singer, Williams, Goodacre, & Tompkins, 1989)

22. How much of the time during the last 2 weeks have you had a problem with rectal bleeding with your bowel movements? Please choose an option from

    1. All of the time.
    2. Most of the time.
    3. A good bit of the time.
    4. Some of the time.
    5. A little of the time.
    6. Hardly any of the time.
    7. None of the time.

23. How much of the time during the last 2 weeks have you felt embarrassed as a result of your bowel problem? Please choose an option from

    1. All of the time.
    2. Most of the time.
    3. A good bit of the time.
    4. Some of the time.
    5. A little of the time.
    6. Hardly any of the time.
    7. None of the time.

24. How much of the time during the last 2 weeks have you been troubled by a feeling of having to go to the bathroom even though your bowels were empty? Please choose an option from

    1. All of the time.
    2. Most of the time.
    3. A good bit of the time.
    4. Some of the time.
    5. A little of the time.
    6. Hardly any of the time.
    7. None of the time.

25. How much of the time during the last 2 weeks have you felt tearful or upset? Please choose an option from

    1. All of the time.
    2. Most of the time.
    3. A good bit of the time.
    4. Some of the time.
    5. A little of the time.
    6. Hardly any of the time.
    7. None of the time.

(Guyatt, Mitchell, Irvine, Singer, Williams, Goodacre, & Tompkins, 1989)

26. How much of the time during the last 2 weeks have you been troubled by accidental soiling of your underpants? Please choose an option from

    1. All of the time.
    2. Most of the time.
    3. A good bit of the time.
    4. Some of the time.
    5. A little of the time.
    6. Hardly any of the time.
    7. None of the time.

27. How much of the time during the last 2 weeks have you felt angry as a result of your bowel problem? Please choose an option from

    1. All of the time.
    2. Most of the time.
    3. A good bit of the time.
    4. Some of the time.
    5. A little of the time.
    6. Hardly any of the time.
    7. None of the time.

28. To what extent *has your bowel problem* limited sexual activity during the last 2 weeks?

    1. No sex as a result of bowel disease.
    2. Major limitation as a result of bowel disease.
    3. Moderate limitation as a result of bowel disease.
    4. Some limitation as a result of bowel disease.
    5. A little limitation as a result of bowel disease.
    6. Hardly any limitation as a result of bowel disease.
    7. No limitation as a result of bowel disease.

29. How much of the time during the last 2 weeks have you been troubled by nausea or feeling sick to your stomach? Please choose an option from

    1. All of the time.
    2. Most of the time.
    3. A good bit of the time.
    4. Some of the time.
    5. A little of the time.
    6. Hardly any of the time.
    7. None of the time.

(Guyatt, Mitchell, Irvine, Singer, Williams, Goodacre, & Tompkins, 1989)

30. How much of the time during the last 2 weeks have you felt irritable? Please choose an option from

    1. All of the time.
    2. Most of the time.
    3. A good bit of the time.
    4. Some of the time.
    5. A little of the time.
    6. Hardly any of the time.
    7. None of the time.

31. How often during the past 2 weeks have you felt a lack of understanding from others? Please choose an option from

    1. All of the time.
    2. Most of the time.
    3. A good bit of the time.
    4. Some of the time.
    5. A little of the time.
    6. Hardly any of the time.
    7. None of the time.

32. How satisfied, happy, or pleased have you been with your personal life during the past 2 weeks? Please choose one of the following options from

    1. Very dissatisfied, unhappy most of the time.
    2. Generally dissatisfied, unhappy.
    3. Somewhat dissatisfied, unhappy.
    4. Generally satisfied, pleased.
    5. Satisfied most of the time, happy
    6. Very satisfied most of the time, happy
    7. Extremely satisfied, could not have been more happy or pleased.

(Guyatt, Mitchell, Irvine, Singer, Williams, Goodacre, & Tompkins, 1989)

IBDQ Score Sheet

Bowel Symptoms

1 _____
5 _____
9 _____
13 _____
17 _____
20 _____
22 _____
24 _____
26 _____
29 _____

Total _____

Systemic Symptoms

2 _____
6 _____
10 _____
14 _____
18 _____

Total _____

Emotional Function

3 _____
7 _____
11 _____
15 _____
19 _____
21 _____
23 _____
25 _____
27 _____
30 _____
31 _____
32 _____

Total _____

Social Function

4 _____
8 _____
12 _____
16 _____
28 _____

Total _____

Sum Total

BSx _____
SSx _____
EFx _____
SFx _____

Total _____

Appendix F

Rating Form for IBD Patient Concerns

At times, people have worries, fears, or concerns about their disease that may affect their overall health and well being. The purpose of this questionnaire is to identify the worries and concerns you may have because of your inflammatory bowel disease. Each question identifies a possible fear, worry, or concern you may have in relation your disease and asks you to rate how much it affects you. Please consider each question carefully and mark a line at the point on the scale that most closely reflects how much you are affected.

1. Because of your condition, how concerned are you with the uncertain nature of your disease?

Not at all — **A Great Deal**

0 — **100**

2. Because of your condition, how concerned are you with feeling dirty or smelly?

Not at all — **A Great Deal**

0 — **100**

3. Because of your condition, how concerned are you with the effects of medications?

Not at all — **A Great Deal**

0 — **100**

4. Because of your condition, how concerned are you with developing cancer?

Not at all — **A Great Deal**

0 — **100**

(Drossman, Leserman, Li, Michell, Zabami, & Patrick, 1991)

5. Because of your condition, how concerned are you with your energy level?

Not at all **A Great Deal**

0 **100**

6. Because of your condition, how concerned are you with the ability to perform sexually?

Not at all **A Great Deal**

0 **100**

7. Because of your condition, how concerned are you with being a burden on others?

Not at all **A Great Deal**

0 **100**

8. Because of your condition, how concerned are you with producing unpleasant odours?

Not at all **A Great Deal**

0 **100**

9. Because of your condition, how concerned are you with loss of bowel control?

Not at all **A Great Deal**

0 **100**

10. Because of your condition, how concerned are you with dying early?

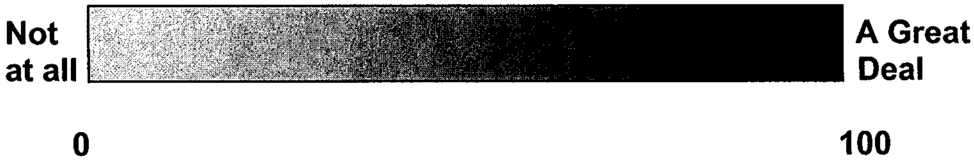
Not at all **A Great Deal**

0 **100**

(Drossman, Leserman, Li, Michell, Zabami, & Patrick, 1991)

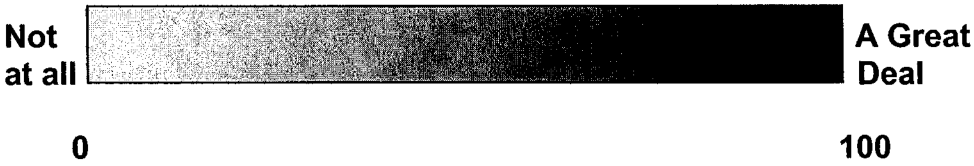
11. Because of your condition, how concerned are you with the ability to achieve your full potential?

12. Because of your condition, how concerned are you with intimacy?

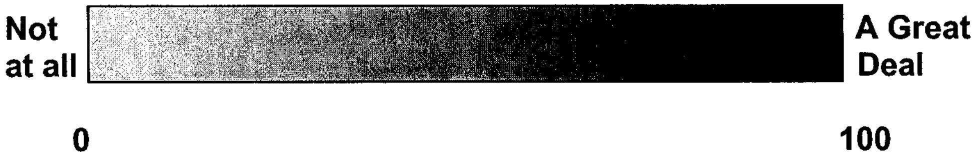


13. Because of your condition, how concerned are you with feelings about your body?

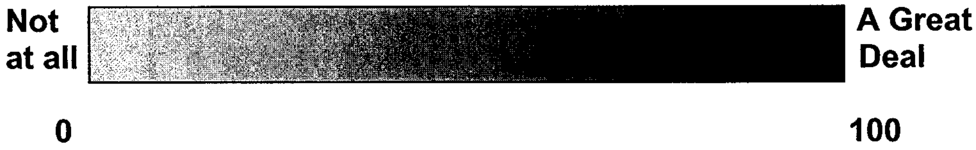
14. Because of your condition, how concerned are you with having an ostomy bag?



15. Because of your condition, how concerned are you with your attractiveness?



16. Because of your condition, how concerned are you with loss of sexual drive?



(Drossman, Leserman, Li, Michell, Zabami, & Patrick, 1991)

17. Because of your condition, how concerned are you with having access to quality medical care?

Not at all **A Great Deal**

0 **100**

18. Because of your condition, how concerned are you with having surgery?

Not at all **A Great Deal**

0 **100**

19. Because of your condition, how concerned are you with feeling alone?

Not at all **A Great Deal**

0 **100**

20. Because of your condition, how concerned are you with passing the disease to others?

Not at all **A Great Deal**

0 **100**

21. Because of your condition, how concerned are you with the ability to have children?

Not at all **A Great Deal**

0 **100**

22. Because of your condition, how concerned are you with financial difficulties?

Not at all **A Great Deal**

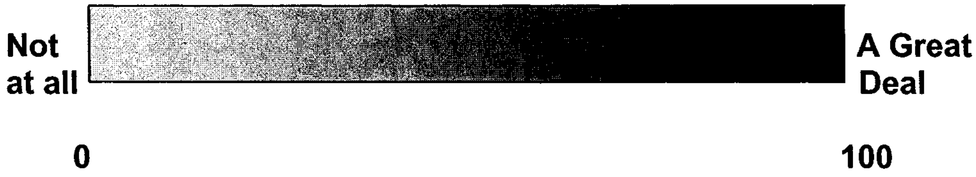
0 **100**

(Drossman, Leserman, Li, Michell, Zabami, & Patrick, 1991)

23. Because of your condition, how concerned are you with being treated as different?

24. Because of your condition, how concerned are you with pain or suffering?

25. Because of your condition, how concerned are you with feeling out of control?



(Drossman, Leserman, Li, Michell, Zabami, & Patrick, 1991)

RFIPC Score Sheet

Impact of Disease

1 ______
3 ______
5 ______
7 ______
9 ______
11 ______
13 ______
15 ______
17 ______
19 ______
22 ______
24 ______
25 _____

Total ______

Body Stigma

2 ______
8 ______

Total ______

Sexual Intimacy

6 ______
12 ______
16 ______

Total ______

Complications

4 ______
10 ______
14 ______
18 ______

Total ______

Not included in indices

20 ______
21 ______
23 ______

Sum Total

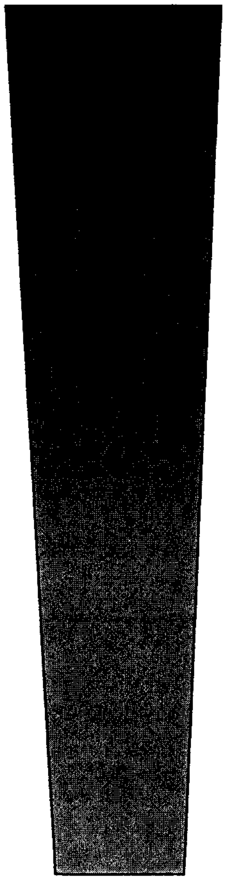
IOD ______
BS ______
SI ______
COM ______
20 ______
21 ______
23 ______

Total ______

Appendix G

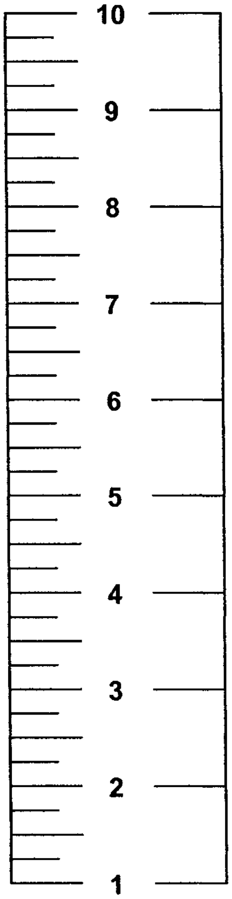
Visual Analogue Scale for Perceived Health Status

EXCELLENT



POOR

Please draw a line across the graph to rate how good your health is generally.



SCALE

(Numerical Scale for grading response)

Appendix H

Patient Satisfaction Questionnaire

Instructions: Please read the following items and circle the number that corresponds with how you best agree or disagree.

1 = strongly disagree **4 = strongly agree**

1. I understand what inflammatory bowel disease is.

   1 2 3 4

   Comments: ______________________________

2. I have received enough information about my disease.

   1 2 3 4

   Comments: ______________________________

3. My doctor gives me explanations about my disease that I understand.

   1 2 3 4

   Comments: ______________________________

4. I have been given written information about my disease I understand.

   1 2 3 4

   Comments: ______________________________

5. I am able to get the information I want about my disease.

   1 2 3 4

   Comments: ______________________________

6. My doctor explains why I need to take the medications and how they work.

   1 2 3 4

   Comments: ______________________________

7. My doctor explains the side-effects of my medications.

1 2 3 4

Comments: ______________________________

____

8. I make mistakes when taking my medications.

1 2 3 4

Comments: ______________________________

____

9. I understand why I need to take my medications for IBD.

1 2 3 4

Comments: ______________________________

____

10. I understand how my medications work.

1 2 3 4

Comments: ______________________________

____

11. My pharmacist explains my medications to me.

1 2 3 4

Comments: ______________________________

____

12. I forget to take my medications sometimes.

1 2 3 4

Comments: ______________________________

____

13. Sometimes I do not take my medications because of side-effects.

1 2 3 4

Comments: ______________________________

____

14. My doctor explains to me how to take care of my disease.

1 2 3 4

Comments: ____

____

15. I understand what I need to do to take care of my disease.

1 2 3 4

Comments: ____

____

16. I feel confident about taking care of my disease.

1 2 3 4

Comments: ____

____

Pt. Satisfaction Survey - Care

Disease Understanding
______ 1
______ 14
______ 15
______ 16

Information Needs
______ 2
______ 3
______ 4
______ 5

Medication Education
______ 6
______ 7
______ 11

Understand Medications
______ 9
______ 10

Medication Adherence
______ 8
______ 12
______ 13

Physician Care
______ 3
______ 6
______ 7
______ 14

Appendix I

CROHN'S DISEASE ACTIVITY INDEX

DATE: ______________________________

# of Stools	1 2 3 4 5 6 7 (# / day)	____ Sum	X 2 = _____
Abdominal Pain 0 = none 1 = mild 2 = moderate 3 = severe	1 2 3 4 5 6 7 (Average Rating / day)	____ Sum	X 5 = _____
General Well being 0 = Generally well 1 = slightly under par 2 = poor 3 = very poor 4 = terrible	1 2 3 4 5 6 7 (Average Rating / day)	____ Sum	X 7 = _____
Extraintestinal Symptoms	____ Arthritis/arthralgia ____ Iritis/uveitis ____ Skin/oral lesions ____ Perianal disease ____ Other fistula ____ Fever (>37.8°C/100°F)	____ Sum	X 20 = _____
Lomotil/Opiates (diarrhea)	0 = no 1 = yes	____	X 30 = _____
Abdominal Mass	0 = none 2 = questionable 5 = definite	____	X 10 = _____
Hematocrit ♂ (47 - hematocrit) ♀ (42 - hematocrit)	Normal - Actual ______ - ______	____	X 6 = _____
Body Weight Weight: ______ Height: ______ Standard Weight: ______	(Wt / Std Wt x 100) - 100 ______________________ (+) if underweight (-) if overweight	____	X 1 = _____
		TOTAL	

Quiescent (<150) Active (150 - 450) Severe (>450)

(Best, Becktel, Singleton, & Kern, 1976)

Appendix J

ACTIVITY INDEX FOR ULCERATIVE COLITIS

DATE: ______________________________

Variable		Factor	Subtotal
Bloody Stool		X 60	A
# of Stools per Day		X 13	B
ESR		X 0.5	C
HB		X 4	D
Albumin		X 15	E
			+ 200
		TOTAL	

Mild (<150) Moderate (150 – 220) Severe (>220)

FORMULA

A + B + C - D - E + 200

(Seo, Okada, Yao, Ueki, Arima, & Okamura, 1992)

Appendix K

Class 1
The IBD Story
Lesson Plan

1. **Introduction** (30 minutes)
    - Introduction of participants
    - Hand out Education Binders
    - Explanation of format
    - Agenda
    - Review of topics

2. **Presentation** (60 minutes)
    - Digestive Tract
    - The Immune System

3. **Coffee Break** (15 minutes)

4. **Presentation** (60 minutes)
    - What is IBD
    - Ulcerative Colitis
    - Crohn's Disease

5. **Conclusion** (15 minutes)
    - Plans for next class
    - Homework

Class 1
The IBD Story
Lesson Plan

Introduction

Participant Introduction
- Participants will be provided with name tags and education binders as they come in
- Attendance list will be circulated

Hand Out
- Education Binders are provided for everyone to keep so they may refer to the information in the future
- The information from each class will be provided
- Includes Glossary of Terms, Burning Questions and Hot Topics Forms, References
- During the study, request that the information provided is not shared with other patients
- Encourage them to share what they are learning with their significant others

Explanation of format and Agenda
- The education program is designed to be interactive
- There will be formal instruction, discussion groups, guest speakers
- Participants are encouraged to ask questions
- A box for Burning Questions and Hot Topics is provided at the front of the class
- This box is there for those questions that may not be comfortable asking in a group, questions or ideas for topics that participants may think of outside of class (write them down and pop them into the box), or for feedback about the classes
- Encourage participants to review the topics on the agendas in the binder and think about what they feel they need to know – if questions or ideas are given in advance, we can better prepare
- The provided agendas are a loose schedule that will be adjusted as needed for the class needs – on the final day there is a section for Class Topics
- This time may be used as catch up and to address items of interest for the class – eg: learning relaxation exercises
- Review agenda

Review of Topics
- Overview of topics for upcoming classes

Presentation

- Factual presentation about IBD covering basic anatomy and physiology of the digestive system and the immune system, pathophysiology of IBD, causes, natural history, symptoms and diagnosis
- A slide presentation format will be utilized
- Participants will be provided with handouts of the slide presentation with sections to write their own notes

Conclusion

- Reminder about next week's topic
- Encourage use of Burning Questions and Hot Topics
- Remind them to bring their binders

Facilitators: Barbara Waters, RN, BScN, ANP, Division of Gastroenterology
Donna Fisher, RN, Research Nurse, GILDR

Class 2
Treatment of IBD
Lesson Plan

1. **Introduction**	(15 minutes)

- Introduction of participants
- Hand outs
- Agenda

2. **Presentation**	(75 minutes)

- Medical Management Of IBD
  Guest Speaker - Gastroenterologist
- Medication Management Part I

3. **Coffee Break**	(15 minutes)
4. **Presentation**	(70 minutes)

- Surgical Management
  Guest Speaker – Surgeon

5. **Conclusion**	(5 minutes)

- Plans for next class
- Homework

Class 2
Treatment of IBD
Lesson Plan

Introduction

Participant Introduction

- Participants will be provided with name tags and handouts as they come in
- Attendance list will be circulated
- Review agenda

Presentation

Medical Management of IBD

- Guest Speaker Gastroenterologist with a slide presentation that discusses medical management of IBD and how to appropriately take medications and a review of medications for IBD
- Participants will be provided with handouts of the slide presentation with sections to write their own notes
- Review medications and side-effects including how to manage

Surgical Management of IBD

- Guest speaker Surgeon will review indications for surgery, types of surgery performed and outcomes

Conclusion

- Ask participants to think about next week's topics
- Come prepared with some thoughts on how they feel about IBD and how it affects their life
- Ideas of what they do to cope with the disease
- Encourage use of Burning Questions and Hot Topics
- Remind them to bring their binders

Facilitators: Barbara Waters, RN, BScN, ANP, Division of Gastroenterology
Donna Fisher, RN, Research Nurse, GILDR

Class 3
Living with IBD I
Lesson Plan

1. **Introduction** (10 minutes)
    - Hand outs
    - Name Tags
    - Agenda

2. **Presentation** (90 minutes)

    Concurrent Sessions

    - Diet and IBD
      Guest Speaker, Registered Dietician

    - Irritable Bowel Syndrome
    - Cancer – What's my risk?
    - Hot Topics

    (Groups switch after 45 minutes)

3. **Coffee Break** (15 minutes)

4. **Presentation** (60 minutes)

    Concurrent Sessions

    - Medication Management II - What works, What doesn't
    - Living with IBD – Symptoms Management
    - Living with IBD - How IBD Makes Me Feel

    (Groups switch after 40 minutes)

5. **Conclusion** (5 minutes)
    - Plans for next class
    - Reminder to bring Education Binders
    - Homework

Class 3
Living with IBD I
Lesson Plan

Introduction

- Participants will be provided with name tags and handouts as they come in
- Groups to be Split
- Concurrent Sessions of 45 minutes each
- Attendance list will be circulated
- Indicate that part of the class will be in a discussion format and the information generated during this portion will be consolidated into handouts for next week
- Review agenda

Presentation

Diet and IBD

- Guest Speaker, Registered Dietician

- Irritable Bowel Syndrome (fact or fiction game)
- Cancer – What's my risk?
- Hot Topics/Burning Questions

Medication Management

- Review of medications and management
- Have patients identify the number one reason they miss medications and one thing they do to remember then on an index card
- Compile on transparency
- Facilitate discussion about medications

Symptom Management

- Break out into small groups to identify coping mechanisms for assigned symptoms
- Instructors to spend time with each group facilitating and reinforce earlier teaching about symptom management
- Information to be written on provided transparencies
- Presentation of the information by each group
- Short class discussion for further input for each symptom
- The information collected will be compiled as a handout for the next class

How IBD Makes Me Feel

- Large group brainstorm to identify feeling words for "How IBD Makes Me Feel"
- Grouping of words to identify specific issues – i.e. depression, stress, lack of self-esteem

- Discussion about the issues identified (depression, stress, etc.)
- Discussion Groups – break into small groups to talk about what methods people use to cope and prepare list
- Instructors facilitate discussions
- Groups present list of ideas and instructors compile the list to be handed out later

Conclusion

- Ask participants to think about next week's topics
- Encourage use of Burning Questions and Hot Topics
- Remind them to bring their binders

Facilitators: Barbara Waters, RN, BScN, ANP, Division of Gastroenterology
Donna Fisher, RN, Research Nurse, GILDR

Class 4
Living with IBD II
Lesson Plan

1. **Introduction**	(5 minutes)
• Hand outs • Agenda	
2. **Presentation**	(70 minutes)
• Guest Speaker – Living with an Ostomy • Life issues in IBD	
3. **Coffee Break**	(15 minutes)
4. **Presentation**	(45 minutes)
• Hot Topics Requests	
5. **Conclusion**	(40 minutes)
• Wind up • Questionnaires	

Class 4
Living with IBD II
Lesson Plan

Introduction

Handouts and Agenda

- Participants will be provided with name tags and handouts as they come in
- Attendance list will be circulated
- Review agenda
- Indicate that part of the class will be in a discussion format and the information generated during this portion will be consolidated into handouts for next week

Presentation

Living With An Ostomy

- Guest Speaker, Patient with Ostomy

Life Issues in IBD

- Large group brainstorm session for issues confronted living with IBD plus supplemental topics identified from questionnaires
- Factual presentation on life problems presented by IBD (topics will focus on issues such as life insurance, work, school, relationships/dating, and sex, fertility, and childbearing)
- Group discussion of the topics identified by participants as a priority (format will be dependent upon the type of subject matter)

Class Topics

- Topics as suggested by the class
- May include guest speakers

Conclusion

- Thank you for participation
- Compilation of any notes from last class will be mailed
- Questionnaires

Facilitators: Barbara Waters, RN, BScN, ANP, Division of Gastroenterology
Donna Fisher, RN, Research Nurse, GILDR

Appendix L

Dear

Education is an important part of care, especially for those with chronic illnesses. Heart disease, diabetes, and asthma are some of the chronic diseases that we provide formal patient education for now. During the next four months, we are conducting a study on the benefits of a formal education program for patients with inflammatory bowel disease.

The study will compare the knowledge and quality of life between two groups of patients. One group will take a formal education program about their disease and the second group will continue to receive their regular care. Enclosed is a pamphlet that provides more information about the study and what is expected from participants. Please note that the group who receive regular care may take the education program after the study is completed.

Please read the pamphlet carefully. In the next two weeks, Barbara Waters, the nurse who is conducting the study will call you. She will answer your questions and discuss whether you would like to take part in the study. If you wish to participate, we will arrange to enroll you during a special clinic prior to November 15, 2001. If you already have an appointment before that, you may be enrolled at that time. If you wish to speak to someone about the study sooner, you may call Barbara Waters at 407-3422.

Thank you for considering our study.

Yours sincerely,

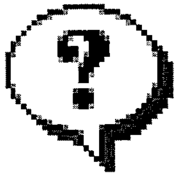
Stage 3 Post-Education
During the last stage, you will:
1. See your doctor as usual.
2. Write down your medication use, doctor and hospital visits, and symptoms in the Patient Diary.
3. Do the booklet of questions at the end of January 2002.
4. Return your Patient Diary.

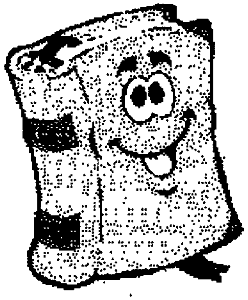
Privacy
The personal information you give will be kept private. You will be given a study number that will be used when we collect information to help keep your privacy. Only general information about the study will be published.

Participation
Being a part of the study would be very helpful. Your care will not be affected by your choice to participate in the study or not. You may drop out of the study at any time for any reason with no affect on your care. If you choose to take part in the study but are not in the education group, you will be given the chance to take the education program after the study is finished.

Thank you for taking the time to read this information and thinking about being a part of the study.

Capital
Health





The Inflammatory Bowel Disease Education Study

Purpose of the Study

The purpose of the Inflammatory Bowel Disease Education Study is to help us learn how a classroom education program about Inflammatory Bowel Disease (IBD) may help patients with Crohn's Disease or Ulcerative Colitis. We are asking patients with IBD to take part in the study for four months from October 2001 to January 2002.

Goals

The goals of the study are to find out how an education program will affect:

1. Knowledge
2. Quality of life
3. Medication use
4. Health Care Use

Study

In order to take part, you must have Crohn's Disease or Ulcerative Colitis. You must speak and read English well and be willing to go to the education program. If you take part, you will be assigned by chance to join the standard care group or education group.

Everyone will receive the current information used for IBD patients in our clinics. The doctors and nurses who take care of you will provide information and answer your questions as usual. If you are in the education group, you will also go to a classroom education program on Thursdays from 7:00 to 10:00 p.m., November 15th to December 6th, 2001. The education program will contain detailed information about IBD. There will also be information about nutrition and how to take care of your disease. Topics of interest to those taking part in the classes will also be included. There are three stages in the study, the start-up stage, education stage, and post-education stage.

Stage 1 Start-Up

If you take part, you will:

1. Get a full explanation about the study.
2. Sign a Consent Form and Release of Medical Information.
3. Be selected to join the standard care or education group.
4. Fill in a Patient Profile about yourself and your medical history.
5. See your doctor during this appointment. You will be asked to write down your symptoms for the last week.
6. Do the booklet of questions (about 45 minutes).
7. Get a Patient Diary.
8. Get the current information booklets about IBD your doctor uses.

Stage 2 Education

If you are in the Standard Care Group, you will:

1. See your doctor as usual.
2. Write down your medication use, doctor and hospital visits, and symptoms in the Patient Diary.
3. Do the booklet of questions at the end of November 2001.

If you are in the Education Group, you will:

1. See your doctor as usual.
2. Attend the Education Program.
3. Write down your medication use, doctor and hospital visits, and symptoms in the Patient Diary.
4. Do the booklet of questions at the end of November 2001.

Appendix M

Effects of a Formalized Education Program for Adults with Inflammatory Bowel Disease

Principal Investigator:	Barbara Waters, RN, BScN Phone: 407-3422
Supervisor:	Louise Jensen, RN, PhD Phone: 492-6795 Rene Day, RN, PhD Phone: 492-6841 Dr. Richard Fedorak, Director, Division of Gastroenterology Phone: 407-6941

Inflammatory bowel disease (IBD) is a chronic disease that has many effects on patients' health. Patients with IBD have physical problems and need to see the doctor often. Their disease may cause a lower quality of life. They also lack information about their disease. Education is an important part of care for IBD patients. Presently there are no formal education programs for IBD. Patients with other long- term illnesses who get formal education about their disease enjoy many benefits. They know more about their disease and follow the treatment plan more closely. They see the doctor less often and have fewer problems with their disease. They also have a better quality of life. Research about education for patients with IBD will help us learn how we can best help patients learn about their disease. The purpose of this study is to identify and describe the effects of a formal education program for adults with IBD.

If you choose to be in the study, the researcher will obtain your written consent for the study and a release of medical information form. You will get a sealed envelope that will include the current IBD information used in our clinics, a

Patient Diary, and a booklet of questions. The Patient Diary is to keep a record of your drugs and health care visits. Before each health care visit, you will need to monitor your symptoms and record them for one week. Your medical records may be reviewed to check the information you record in you diary. You will be asked to complete the booklet of questions about IBD during your clinic visit. It will take about 45 minutes. The booklet has questions about how the disease affects you, your current symptoms, and medical history. You will also rate your health status and knowledge level about IBD. Information about your age, sex, level of education, and work will be collected. You will also be asked whether you have been in other studies or belong to any IBD groups. During your clinic visit with the doctor, you will have a physical examination. Blood tests that are part of the standard care for IBD will be taken.

In the sealed envelope you will find a letter that assigns you to either the standard of care or the standard of care plus formal education group. The doctors and nurses who take care of you will give you information and answer your questions as usual. If you are in the education group, you will also be asked to attend a classroom education program on Thursday evenings from 7:00 to 10:00 p.m., November 15 to December 6, 2001. The education program will provide detailed information about IBD. There will also be information about nutrition and how to take care of your disease. Topics of interest to those taking part in the classes will also be included. Four to eight weeks after joining the study and again two months later, you will be asked to complete the booklet of questions about IBD again. Your Patient Diary will be returned when you complete the last booklet.

We hope the study will help us understand what patients want to know about their disease and how formal education can help them. Everyone will continue to receive the current standard of care. There are no expected risks to being in the study. Those who are in the education group may receive some benefit from learning more about their disease. The non-education group will be offered the full education program after the study is finished.

All the information about the study is private and will be stored in a locked cabinet. Some of the information for the study will be from your medical records. Everything will be kept confidential except as required by professional ethical codes and/or law. The findings of the study may be published and/or presented at conferences, however your name will not be used at any time.

It is your choice whether you would like to be in the study. Whether you choose to take part or not will not affect your care. You may drop out of the study at any time without giving a reason. Dropping out of the study will not affect your care. If you drop out of the study, your information will be destroyed and not used in the study.3/3

If you have any questions at any time about the study, please contact Barbara Waters, RN, BScN, Advanced Nurse Practitioner, Division of Gastroenterology at 407-3422. If you have any concerns about any part of this study, you may contact the Patients Concerns Office of the Capital Health Authority at 407-1040. This office has no link with the researcher.

Patient Consent

Effects of a Formalized Education Program for Adults with Inflammatory Bowel Disease

Principal Investigator:	Barbara Waters, RN	Phone: 407-3422
Supervisor:	Louise Jensen, RN, PhD	Phone: 492-6795
	Rene Day, RN, PhD	Phone: 492-6841
	Dr. Richard Fedorak, Director, Division of Gastroenterology	Phone: 407-6941

Do you understand that you have been asked to be in a research study? Yes No

Have you read and received a copy of the attached Information Sheet? Yes No

Do you understand the benefits and risks involved in taking part in this research study? Yes No

Have you had an opportunity to ask questions and discuss this study? Yes No

Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect your care. Yes No

Has the issue of confidentiality been explained to you? Do you understand who will have access to your records? Yes No

This study was explained to me by: ______________________________

I agree to take part in this study.

Research Participant Signature	Date	Witness Signature
Printed Name		Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator of Designee	Date

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH SUBJECT.

Readability Analysis

(Microsoft Office 2000)

Flesch Reading Ease Score

Rates text on 100-point scale; the higher the score, the easier it is to understand the document. For most standard documents, aim for a score of approximately 60-70.

The formula for the Flesch Reading Ease Score is

206.835 – (1.015 x ASL) – (84.6 x ASW) where:

ASL = average sentence length (the number of words divided by the number of sentences)

ASW = average number of syllables per word (the number of syllables divided by the number of words)

Flesch-Kincaid Grade Level Score

Rates text on a U.S. grade-school level. For example, a score of 8.0 means that an eighth grader can understand the document. For most standard documents, aim for a score of approximately 7.0 to 8.0.

The formula for the Flesch-Kincaid Grade Level Score is:

(.39 x ASL) + (11.8 x ASW) – 15.59

Counts	
Words	783
Characters	3704
Paragraphs	7
Sentences	50

Averages	
Sentences per paragraph	7.1
Words per sentence	15.7
Characters per word	4.6

Readability	
Passive Sentences	26.0%
Flesch Reading Ease	59.9%
Flesch-Kincaid Grade Level	8.7

Authorization for Release of Medical Information

I, ______________________________ have agreed to participate in the Inflammatory Bowel Disease Education Study. I understand that data may be collected from my medical records for the purposes of the study. I have been advised that the information collected may include my medical history, treatments related to inflammatory bowel disease, and diagnostic test results. I am also aware that the researcher may review my records regarding health care visits for problems related to my inflammatory bowel disease during the period of the study. This may include requesting information from my family physician, gastroenterologist, and reviewing my hospital records. I understand that any information collected will be kept strictly confidential and stored in a manner to protect my privacy.

I authorize the release of medical information as described above for the Inflammatory Bowel Disease Education Study.

______________________________ ______________________________
Signature of Patient Date

____
Signature of Witness

Appendix N

Patient Profile

1. What is your medical diagnosis? Please mark the correct circle.

1. Ulcerative Colitis ○ 2. Crohn's Disease ○

2. What year were you diagnosed with inflammatory bowel disease: _________

3. Have you had surgery for your inflammatory bowel disease in the past? Please mark the correct circle.

1. Yes ○ 2. No ○

If yes, please list the type of surgery and the year you had the operation:

________________________ ________________________

________________________ ________________________

________________________ ________________________

4. Do you have any additional health problems? Please list:

________________________ ________________________

________________________ ________________________

________________________ ________________________

5. What is your gender? Please mark the correct circle.

1. Male ○ 2. Female ○

6. Do you ever miss taking your medications?

1. Yes ○ 2. No ○

7. **What is your age?**
17-25 years 1
25-34 years 2
35-44 years 3
45-54 years 4
55-64 years 5
65-74 years 6
75-84 years 7
85 years and over 8

8. **What is (was) your occupation?**
Student..1
Homemaker..2
Labourer..3
Skilled Trade/Technician..4
Clerical/Service/Sales..5
Farming 6
Arts/Sports/Recreation..7
Management..8
Professional..9

9. **What is the highest completed level of education?**
Elementary School..1
Junior High School..2
High School..3
College, Trade, Technical School..4
University 5

10. **Have you been or are you a participant in a study about inflammatory bowel disease?**
Since April 2001..1
Prior to April 2001 2
Never..3

11. **Have you ever attended an education program about inflammatory bowel disease?**

1. Yes ○ 2. No ○

12. **Who has provided you with information about inflammatory bowel disease?**
Doctor..1
Clinic Nurse..2
Dietician 3
Psychologist..4
Pharmacist..5

13. **Do you use the Internet to find information on inflammatory bowel disease?**

1. Yes ○ 2. No ○

14. **Do you attend or have you ever attended the Crohn's and Colitis Foundation of Canada Support Group at the University of Alberta Hospital?**

Since April 2001..1
Prior to April 2001 2
Never...3

15. **Are you or have you ever been a member of the Crohn's and Colitis Foundation of Canada?**

Since April 2001..1
Prior to April 2001 2
Never...3

Appendix O

Patient Satisfaction Questionnaire
IBD Education Program

Instructions: Please read the following items and circle the number that corresponds with how you best agree or disagree.

1 = strongly disagree **4 = strongly agree**

1. The education program improved my knowledge about IBD.

   1 2 3 4

   Comments: ______________________________

   ____

2. The education program helped me understand how to better manage my disease.

   1 2 3 4

   Comments: ______________________________

   ____

3. The instructors were helpful and answered my questions.

   1 2 3 4

   Comments: ______________________________

   ____

4. I understood the information presented in the education program.

   1 2 3 4

   Comments: ______________________________

   ____

5. The written information from the education program is helpful.

   1 2 3 4

   Comments: ______________________________

   ____

6. I would recommend taking the education program to other patients.

   1 2 3 4

   Comments: ______________________________

   ____

7. My information needs were met by the education program.

   1 2 3 4

   Comments: ______________________________

   ____

8. The education program improved my understanding of how my medications work.

   1 2 3 4

   Comments: ______________________________

   ____

9. The education program helped me better understand the side-effects of my medications and how to manage them.

   1 2 3 4

   Comments: ______________________________

   ____

10. The education program helped me feel more confident about managing my medications.

    1 2 3 4

    Comments: ______________________________

    ____

11. The education program helped me better understand how diet affects my disease.

    1 2 3 4

    Comments: ______________________________

    ____

12. The education program helped me understand the role of surgery in managing my disease.

    1 2 3 4

    Comments: ______________________________

    ____

13. The education program helped me better understand how the disease affects my life generally.

1 2 3 4

Comments: ____

____

14. The education program provided me with information about how to manage the impact of the disease on my life.

1 2 3 4

Comments: ____

____

Patient Education Program Satisfaction Questionnaire

Score Sheet

Knowledge

______ 1

______ 2

______ 8

______ 9

______ 10

______ 11

______ 12

______ 13

______ 14

Presentation

______ 3

______ 4

______ 5

______ 6

______ 7

Appendix P

Date

Dear Dr.:

Re:

_______________________________ is currently participating in the Effects of a Formalized Education Program for Adults with Inflammatory Bowel Disease Study at the University of Alberta Hospital. The purpose of this study is to assess the effects of a structured psychoeducational program for IBD patients. One of the outcome measures we are assessing is health care utilization. Patients have maintained a record of their IBD related physician visits. The records of ten percent of study participants are being audited for accuracy.

Your patient has been randomly selected for audit. We would appreciate your assistance in completing a Physician Visit Record for each **IBD related visit** during the timeframe of __________________ to ___________________. If your patient has not had any IBD related visits during the specified timeframe, please indicate this in the box below.

Attached please find a copy of your patient's consent to participate in the study, a release of medical information, and blank Physician Visit Records. A stamped, self-addressed envelope has also been included for your convenience.

Thank you for your assistance. Should you have any questions or concerns, please contact the undersigned 407-3422 for further information.

Yours truly,

Barbara Waters, RN, BScN
Master of Nursing Candidate
Faculty of Nursing

____________________ had no IBD physician visits: ☐

Physician Visit Record

1. Was the visit requested by the patient or initiated by the physician as follow up?

   Patient initiated: ○ Physician initiated: ○

2. Please describe the reason for the visit:

   ____

   ____

   ____

3. Please describe any medication changes:

   ____

   ____

   ____

4. Please list any tests that were ordered:

   ____

   ____

5. Was the patient referred elsewhere for follow up? Yes ____ No ____

   If yes, please specify: ______________________________

6. Does the patient have a follow up appointment? Yes ____ No ____

   If yes, when? __________________________________