Psychosocial factors contributing to medication non-adherence, health-related quality of life, and disease activity in patients with inflammatory bowel disease

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Psychosocial Factors Contributing to Medication Non-Adherence, Health-Related Quality of Life, and Disease Activity in Patients with Inflammatory Bowel Disease

by

Alejandra H. Faust

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Abstract

Symptoms of inflammatory bowel disease (IBD) are chronic and are characterized by periodic exacerbations followed by symptom-free intervals. Symptoms can have a detrimental impact on quality of life. Medication non-adherence in adults with IBD has been well-documented in the literature; continuous medication use is necessary to prevent flares of the disease. Therefore, the purpose of the present study was three-fold: (1) to examine associations between medication non-adherence, disease activity, and health-related quality of life (HRQOL), (2) to examine if group differences were present for patients who were high versus low in anxiety or depression in terms of their medication non-adherence, disease activity and HRQOL, and (3) to examine the contributions of coping and social constraint on disclosure to medication non-adherence, disease activity, and HRQOL. The present study was retrospective; 80 patients with IBD completed questionnaires, as part of routine care in a tertiary referral center. Results demonstrated a negative association between disease activity and HRQOL. Medication non-adherence was not associated with disease activity. In addition, patients high in anxiety or depression had diminished quality of life compared to patients low in anxiety. Regression results did not support the hypothesis that social constraint moderated the relationship between coping and HRQOL; however, the use of engagement coping approached negative significance with HRQOL. Regressions testing the mediating effects of medication non-adherence on the relations between both social constraint and coping on disease activity were not performed because results showed that medication non-adherence was not significantly related to disease activity. Results did reveal that
participants who reported increased social constraint reported increased intentional and unintentional non-adherence. Also, disengagement coping significantly contributed to disease activity. In conclusion, the present study adds to the current knowledge regarding the role of both coping and social constraint in individuals with IBD. Future research is warranted to clarify the role of coping and social constraint on medication nonadherence, HRQOL, and disease activity.
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Introduction

1. Background Information on Inflammatory Bowel Disease

1.1 Definition of Inflammatory Bowel Disease

Crohn’s disease and ulcerative colitis comprise inflammatory bowel disease (IBD), an idiopathic disease of the gastrointestinal system that is characterized by chronic inflammation. Crohn’s disease can involve any part of the gastrointestinal tract, from the mouth to the anus, typically in a discontinuous manner. In contrast to Crohn’s disease, ulcerative colitis is characterized by inflammation involving the colon only. Typically, the inflammation involves the rectum and extends proximally in a continuous fashion (Brzezinski, 2001).

1.2 Etiology of Inflammatory Bowel Disease

Both genetic and environmental factors play a role in the pathogenesis of IBD. First-degree relatives have a ten to fifteen-fold risk of developing IBD. In addition, approximately 10% of patients with IBD have a first-degree relative with IBD. Concordance rates for monozygotic twins are 67% for Crohn’s disease and 20% for ulcerative colitis, whereas concordance rates for dizygotic twins are 8% for Crohn’s disease and 0% for ulcerative colitis, which lends support to a genetic component.

Environmental factors also play an important role in the pathogenesis. IBD is more common in industrialized nations and is increasing in frequency in countries that are becoming industrialized. Currently, the only environmental factor that has been shown to have a clear association with IBD is cigarette smoking. Cigarette smoking is inversely associated with ulcerative colitis, but is positively associated with Crohn’s disease. Therefore, current cigarette smokers are at a decreased risk for developing
ulcerative colitis. In contrast, both current and former smokers are at increased risk of developing Crohn’s disease (Brzezinski, 2001; Friedman & Blumberg, 2001; Loftus, 2004).

1.3 Epidemiology

Between 1 and 1.5 million Americans are affected with IBD (Loftus, 2007). IBD is more common in the northern parts of the Western world, among whites, and among Ashkenazi Jews in Europe or North America. However, both Crohn’s disease and ulcerative colitis occur in individuals from any ethnicity. In addition, a higher prevalence of IBD is found in urban areas and in higher socioeconomic classes. In general, IBD affects males and females equally (Brzezinski, 2001; Friedman & Blumberg, 2001). However, there is a slight female predominance in Crohn’s disease and a slight male predominance in ulcerative colitis (Loftus, 2004). IBD is generally thought to have a bimodal age of presentation. Its peak onset is between the ages of 15 and 30. A second peak occurs between the ages of 60 and 80 (Brzezinski, 2001; Friedman & Blumberg, 2001).

1.4 Clinical Presentation of IBD

The site of involvement and the behavior of the disease determine the clinical manifestations in individuals with Crohn’s disease. The ileum and colon are most frequently involved in patients with Crohn’s disease. However, isolated involvement of the small or large bowel is present in 33 and 20% of cases respectively. Patients with inflammatory disease behavior typically present with non-bloody diarrhea, abdominal pain (most frequently in the lower right quadrant), weight loss, and systemic signs.
Patients with obstructing Crohn’s disease present with postprandial abdominal pain, bloating, nausea, vomiting, obstipation, and weight loss. Diarrhea can be present, but is usually short lived, correlating with resolution of an episode of obstruction.

Patients with penetrating Crohn’s disease develop fistulas from a segment of bowel to another segment of bowel, the abdominal wall, or other organs. The fistulas usually are associated with severe transmural inflammation or a concomitant obstruction. Patients also can develop fistulas from the rectum to the perianal region; this complication occurs in about 25% of patients. Patients with nonpenetrating-nonstricturing Crohn’s have the least severe disease, followed by obstructing Crohn’s, followed by fistulizing Crohn’s. Extraintestinal manifestations (including, arthritis, skin conditions, inflammation of the eye, liver and kidney disorders, and bone loss) can occur in patients with disease in any location and with any phenotype (Brzezinski, 2001; Legnani & Kornbluth, 2003; Schwarz & Blanchard, 1990).

Patients with ulcerative colitis typically present with bloody diarrhea, tenesmus, passage of mucus, and crampy abdominal pain. The subtypes of ulcerative colitis are defined by the anatomic region of involvement. Patients can have (1) proctitis, which is limited to the rectum, (2) left-sided disease, which extends from the rectum proximally to the splenic flexure, or (3) pancolitis, which involves the colon proximal to the splenic flexure. Patients who have proctitis have the least severe disease, whereas those with pancolitis have the most severe disease (Legnani & Kornbluth, 2003). The symptoms, severity, and prognosis of the disease often are determined by the extent of the disease. Patients with involvement of the entire colon are more likely to require prednisone to control symptoms, develop cancer, become hospitalized, or undergo colectomy. Other
symptoms in moderate to severe disease can include anorexia, nausea, vomiting, fever, and weight loss (Brzezinski, 2001; Schwarz & Blanchard, 1990). Extraintestinal manifestations can occur, as in patients with Crohn’s disease.

1.5 Diagnosis of IBD

IBD is diagnosed based on patients’ history, clinical features, laboratory tests, and endoscopic and histological features. In approximately 15% of cases, it is not possible to differentiate between Crohn’s disease and ulcerative colitis; in these cases, patients are diagnosed with indeterminate colitis or IBD, type undetermined (Brzezinski, 2001; Friedman & Blumberg, 2001).

1.6 Treatment of IBD

Because of the chronic nature of IBD, treatment is based on the stage of disease. In patients with active bowel symptoms, medications are prescribed to induce a clinical remission. Once a patient enters remission, the physician either will continue the same agent used to induce remission or start a maintenance drug. This is most applicable in patients that require treatment with steroids, as other drugs are begun to facilitate steroid withdrawal and maintenance of remission. In order to prevent a relapse, chronic medical therapy is required in patients with IBD. Treatment with medication is required during flare-ups, as well as during remission, to ensure that patients remain asymptomatic and to prevent future complications. Treatment for individuals with IBD is pyramid-based. Patients with less severe disease are treated with milder agents. As disease severity increases, more efficacious, but potentially more toxic, medications are added (Brzezinski, 2001; Friedman & Blumberg, 2001).
Corticosteroids are an effective medication for inducing remission in patients with active IBD. However, they are typically only used for the induction of remission since they do not maintain remission and have significant long-term side-effects. Anti-inflammatory medications, such as sulfasalazine and other 5-amiosalicylic (5-ASA) compounds, are indicated for the treatment of patients with ulcerative colitis with mild to moderate active disease and those with Crohn’s colitis. These agents can be used in the maintenance of remission. Antibiotics are used in patients with Crohn’s disease who have colonic or perianal involvement. In contrast, antibiotics are not used as part of the standard treatment of active or quiescent ulcerative colitis (Brzezinski, 2001; Friedman & Blumberg, 2001).

In patients with steroid-refractory or steroid dependent disease, fistulizing disease, or perianal disease, immunosuppressive agents (e.g., azathioprine and 6-mercaptopurine) are used. For those patients with active Crohn’s disease who are not responding to conventional medical treatment (including immunosuppressive agents), biologic agents (e.g., infliximab, adalimumab, certolizumab, natalizumab) are used (Brzezinski, 2001; Friedman & Blumberg, 2001).

Finally, when patients have a fulminant presentation, toxic colitis, symptomatic strictures, or severe disease that is not responsive to medical treatment, they are best treated with surgery. An additional indication for surgery is dysplasia or cancer. For patients with ulcerative colitis, the entire colon must be removed, regardless of the extent of the disease. Patients with Crohn’s disease undergo segmental resections. However, surgery is not curative in patients with Crohn’s disease, as one third of patients will need
to undergo a second operation or more in their lifetime (Brzezinski, 2001; Friedman & Blumberg, 2001).

1.7 Extraintestinal Manifestations of IBD

Extraintestinal manifestations are seen in about 25% of patients with IBD. Oral ulcerations, ocular involvement, disease of the skin, and several forms of arthritis are associated with IBD, in its active or inactive state. In addition, several diseases can develop as a result of malabsorption of macronutrients or vitamins and minerals, such as gallstones, kidney stones, vitamin B12 deficiency, vitamin D deficiency, osteoporosis, and choleretic diarrhea. Osteoporosis also can occur as a result of vitamin D deficiency and/or steroid use.

Patients with IBD, especially those with ulcerative colitis, are at increased risk for developing colon cancer. The increased risk is associated with the extent and duration of the colitis. Patients with Crohn’s disease involving the colon also have an increased risk of colorectal cancer; however patients with isolated small bowel involvement do not have an increased risk (Brzezinski, 2001).

2. Medication Non-Adherence

2.1 Definition of Medication Non-Adherence

Due to the chronic nature of, unpredictable course of, and treatment for IBD, patients are at risk for non-adherence with prescribed treatment regimens. Non-adherence has been operationalized as not only failing to take some or all of the prescribed doses of a medication, but also overconsumption of a prescribed dose, disrupted timing of prescribed doses, and discordant behavior with prescribed treatment regimens (e.g.,
following a diet, attending clinics/appointments, and lifestyle modifications) (Bernal et al., 2006; D’Incà et al., 2008; Kane, 2007; López-Sanromán & Bermejo, 2006).

In addition to looking at patients’ overall non-adherence, researchers have examined whether non-adherence is intentional or unintentional. Intentional non-adherence has been defined as stopping medication when one is feeling better or worse. In contrast, unintentional non-adherence has been defined as being forgetful or careless about taking medications (Sewitch, Leffondré, & Dobkin, 2004).

2.2 Medication Non-Adherence Rates

As previously discussed, IBD is managed with drug-therapy that is used to induce remission, maintain remission, and prevent future complications (such as the development of colorectal cancer, strictures, fistulas, and extraintestinal manifestations of the disease). Diseases in which adherence is optimal are generally of short-duration and characterized by one or more symptoms, whose manifestations are predictable and continuous and can be easily and quickly controlled with a prescribed medication (e.g., an isolated headache). Diseases that are characterized by unpredictable courses, with long periods of quiescence or low activity, are considered high-risk situations for non-adherence. Thus, it is not surprising that non-adherence to medical therapy is widespread among patients with IBD. In IBD, medication non-adherence rates for short-term therapy range from 20-40% and are as high as 70% for long-term therapy (Bernal et al., 2006; D’Incà et al., 2008; Kane, Cohen, Aikens, & Hanover, 2001; Kane, 2007; López-Sanromán & Bermejo, 2006; Mantzaris et al., 2007; Sewitch et al., 2003; Nigro, Angelini, Grosso, Caula, & Sategna-Giudetti, 2001).
2.3 Factors Associated with Overall Medication Non-Adherence

Non-adherence to prescribed treatment regimens in patients with IBD has been found to be associated with four categories: (1) illness-related characteristics (Kane et al., 2001; Kane, 2007; López-Sanromán & Bermejo, 2006; Sewitch et al., 2003), (2) patient characteristics (Ediger et al., 2007; Kane et al., 2001; Kane, 2007; López-Sanromán & Bermejo, 2006; Mantzaris et al., 2007), (3) treatment-related characteristics (Ediger et al., 2007; Kane et al., 2001; Kane, 2007; López-Sanromán & Bermejo, 2006; Mantzaris et al., 2007), and (4) patient-doctor relationship characteristics (Ediger et al., 2007; Kane et al., 2001; López-Sanromán & Bermejo, 2006; Sewitch et al., 2003). See Table 1 for a more detailed explanation of the relationship between non-adherence and the four categories. There also are illness factors, treatment factors, and patient-doctor relationship factors that are associated with increased adherence, including longer disease duration, prescription of certain types of medications (such as steroids) and scheduled follow-up appointments (Sewitch et al., 2003).

2.4 Factors Associated with Intentional and Unintentional Medication Non-adherence

While most researchers have examined patients’ overall medication non-adherence, some research has differentiated between intentional and unintentional medication non-adherence. The research findings suggest that it may be important for physicians to make the distinction between intentional and unintentional medication adherence so that patients will receive optimal care. Patients who report being non-adherent, primarily report being non-adherent unintentionally (Bernal et al., 2006; Sewitch et al., 2003). Some factors that have been shown to be positively associated with
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intentional medication non-adherence include shorter duration of disease, being under the physician’s care for more than one year, not scheduling follow-up appointments, uncertainty about positive health effects from medication, higher perceived stress, and greater patient-physician discordance. Shorter disease duration and uncertainty regarding positive health effects from medication also have been found to be associated with increased risk for unintentional non-adherence. In contrast to intentional non-adherence, variables positively associated with unintentional non-adherence include younger age, less active disease, new patient status, no recommendation to consult another health professional, no prescription for steroids, and lower patient-physician discordance (Sewitch et al., 2003).

2.4 Implications of Medication Non-Adherence

Medication non-adherence is not trivial, as optimal adherence aids in preventing disease flare-ups (Bernal et al., 2006; Kane, 2007; López-Sanromán & Bermejo, 2006; Robinson, 2008) and maintaining an improved quality of life (Kane, 2007). In fact, Kane (2008) found that at 12-month follow-up, 61% of patients with ulcerative colitis who were non-adherent had a relapse, compared to 11% of adherent patients. Adherence also plays a role in the prevention of colorectal cancer (Bernal et al., 2006; López-Sanromán & Bermejo, 2006; Kane et al., 2001; Kane, 2007; Robinson, 2008).

Maintaining remission also has important societal implications. Since medication non-adherence is associated with disease relapse, and disease relapse is associated with greater health-care utilization, it follows that non-adherence is associated with an increase in health-care utilization. Moreover, greater health care utilization is associated with an increase in cost. In fact, disease relapse is associated with a two to three-fold increase in
cost for non-hospitalized cases and with a twenty-fold increase for hospitalized cases. In addition, disease relapse is associated with a poor quality of life and an increase in work absenteeism (Bernal et al., 2006; D’Incà et al., 2008; Kane et al., 2001; Waters, Jensen, & Fedorak, 2005).

3. Health-Related Quality of Life (HRQOL)

3.1 Definition of HRQOL

HRQOL is a multidimensional and subjective concept that incorporates physical, psychological, and social aspects of health perception and health functioning (de Boer, Grootenhuis, Derk, & Last, 2008; Larsson, Lööf, Rönblon, & Nordin, 2008). More specifically, HRQOL has been defined as the physical, psychological, and social domains of health that are influenced by an individual’s experiences, beliefs, expectations and perceptions (Van der Zaag-Looneh, Grootenhuis, Last, & Derkx, 2004).

3.2 Factors Associated with HRQOL

Researchers have found several factors influencing HRQOL in patients with IBD. Much of the research has focused on the association between disease-related variables and HRQOL. Most research has not found a significant difference in HRQOL for patients with Crohn’s disease compared to patients with ulcerative colitis. (Casellas, López-Vivancos, Casado, & Malegelada, 2002; Graff et al., 2006; Guthrie et al., 2002; Moreno-Jiménez, López Blanco, Rodrígues-Muñoz, & Garrosa Hernández, 2007). However, Larsson and colleagues (2008) found that patients with Crohn’s disease reported poorer HRQOL than patients with ulcerative colitis. In addition, Guthrie et al. (2002) did not find differences in overall HRQOL, but found that patients with Crohn’s disease report less energy/vitality than patients with ulcerative colitis.
Most research suggests that rather than disease type predicting HRQOL, the level of disease activity is associated with HRQOL. Patients with active disease report a poorer HRQOL than patients with quiescent disease (Casellas et al., 2002; Farrokhyar, Marshall, Easterbrook, & Irvine, 2006; Graff et al., 2006; Larsson et al., 2008; Mittermaier et al., 2004). In fact, patients with quiescent disease report similar HRQOL and general quality of life as healthy controls (Graff et al., 2006; Graff et al., 2009). Researchers have found that not only does disease activity modulate HRQOL, but that decreased disease severity and longer disease duration are associated with a higher HRQOL (Casellas et al., 2002; Guthrie et al., 2002; Waters et al., 2005).

In addition to disease-type and activity, some demographic variables have been found to be associated with HRQOL. Adult males with IBD have reported a significantly higher HRQOL than females (Casellas et al., 2002). However, there are mixed research findings for gender and HRQOL for adolescents with IBD. One study found HRQOL to be particularly impaired in adolescent males (de Boer et al., 2005), while another study found adolescent females to report significantly lower HRQOL (Van der Zaag-Loonen et al., 2004). In addition to gender, Casellas et al. (2002) found that higher levels of education were associated with improved HRQOL.

Psychological variables also have been found to be related to HRQOL in patients with IBD. Researchers have found that higher levels of neuroticism, anxiety, and depression and lower levels of self-esteem are independently associated with lower levels of overall HRQOL (Farrokhyar et al., 2006; Graff et al., 2006; Guthrie et al., 2002; Moreno-Jiménez et al., 2007; Walker et al., 2008; Waters et al., 2005).
3.3 Implications of HRQOL

Given the chronic nature of IBD, as well as the complications associated with it, patients can experience considerable impairments in their HRQOL. In an attempt to continually improve patient care, it is important for clinicians to better understand variables influencing HRQOL. Research currently shows an inverse relationship between anxiety, depression, and disease activity with HRQOL. Additional treatment research is needed that examines the impact of psychosocial treatment (addressing anxiety and depression) on HRQOL.

Not only does diminished HRQOL have negative impact on the individual, but it also has a negative societal impact. Diminished HRQOL is likely resulting in greater health care utilization, which is associated with increased medical costs. Thus, having a better understanding of factors contributing to diminished HRQOL would not only result in improved HRQOL for the individual patient, but also would lessen the associated medical costs (Casellas et al., 2002; Guthrie et al., 2002; Smith, Watson, & Palmer, 2002).

4. Coping and Stress

4.1 Definition of Coping

Coping is the process through which an individual manages the demands of the person-environment relationship that are appraised as stressful and the emotions/thoughts they generate (Lazarus & Folkman, 1984). Thus, as proposed by Lazarus and Folkman, coping is not a state or a disposition, but rather a process an individual goes through in an attempt to adapt to a situation. For an event to require coping, the individual must have appraised it as stressful.
Because coping strategies cannot be defined as effective or ineffective independent of the context in which they are implemented, the appraisal of the environmental stressor is of great importance. Individuals’ coping strategies appear to differ for events that are appraised as controllable versus uncontrollable, such that individuals attempt to alter stressors that they believe they can control, and adapt to those that they believe are out of their control (Connor-Smith et al., 2000).

Categorization of coping is a necessary tool for research. There have been several different types of categorization; this paper will focus on engagement versus disengagement coping. An individual who uses engagement coping is responding either to the source of the stress itself or towards his/her emotions or thoughts. Examples of engagement coping include problem solving, emotional regulation, acceptance, and cognitive restructuring. In contrast, an individual who utilizes disengagement coping is responding away from the stressor or his/her emotions or thoughts. Types of disengagement coping are avoidance, denial, and wishful thinking (wishing that the problem would disappear) (Connor-Smith et al., 2000).

4.2 Factors Associated with Coping

Research on coping for individuals with IBD is in its nascence. Research has compared general coping styles of individuals with IBD to that of healthy individuals. Some researchers have found no significant differences between young adults with IBD and their healthy peers in the use of task-oriented coping, emotion-oriented coping, and avoidance coping (Calsbeek, Rijken, Bekkers, VanBerge, Henegowen, & Dekker, 2006). However, other researchers found that adolescents with IBD reported using avoidant coping significantly more than their healthy peers (Van der Zaag-Looneh et al., 2004). In
contrast to coping research on adolescents with IBD, coping research on adults with IBD has yielded some different findings. Kinash et al. (1993) found that adults with IBD used problem-focused coping significantly more frequently than emotion-focused coping, and Jones, Wessinger, and Crowell (2006) found that adults with IBD reported using social support coping with the highest frequency. Moreover, Jones et al. (2006) found that IBD patients reported using avoidance, confrontative, and acceptance coping more than problem-focused coping.

In addition to examining differences in coping styles between healthy individuals and individuals with IBD, research has examined differences in coping based on disease-type and activity. Significant differences in coping styles have not been found between individuals with ulcerative colitis and Crohn’s disease (Kinash et al., 1993; Larsson et al., 2008). Further, Larsson et al. (2008) did not find significant differences in coping style for patients with quiescent versus active disease (Larsson et al., 2008). This was the only study that examined the relation between coping and disease activity; however, this study examined general coping style and failed to look at situational coping (coping with IBD). Thus, the relationship between coping with IBD and disease activity remains unknown.

In contrast to the null findings examining the association between coping and disease type and activity, some studies have reported a significant relation between coping and depression in patients with IBD. For example, researchers have found that passive coping and emotion-focused coping are positively associated with depression (Crane & Martin, 2004; Kinash et al., 1993). Also, while Dekkers et al. (2001) found no direct relationship between psychological variables and coping, they found that coping moderated the relation between stress and anxiety in IBD patients; patients who reported
low levels of problem-focused coping and a high number of daily hassles, reported increased anxiety.

Most of the research on coping in patients with IBD has focused on its relationship between general coping and HRQOL; although Van der Zaag Looneh et al. (2004) examined both general and situational coping. Optimistic coping (Moskovitz, Maunder, Cohen, McLeod, & MacRae, 2000; Smolen & Topp, 1997; Van der Zaag-Looneh et al., 2004), and social support seeking (Moskovitz et al., 2000) have been positively associated with HRQOL in patients with IBD, as has problem-focused coping in IBD and other chronically ill patients (Dubey & Agarwal, 2007; Moskovitz et al., 2000). In contrast to the positive association between these types of coping and HRQOL, Petrak et al. (2001) did not find a direct relationship between active coping and HRQOL; they found that in IBD patients with active disease, active coping is negatively associated with HRQOL. In contrast, MacPhee, Hoffenberg, and Feranchak (1998) found no association between coping and quality of life in individuals with IBD, while other researchers have found a negative association between emotional expression, evasive, self-blame, and fatalistic coping and HRQOL in patients with IBD (Moreno-Jiménez et al., 2007; Moskovitz et al., 2000; Smolen & Topp, 1997), as well as in patients with asthma and chronic obstructive pulmonary disease (Hesslink et al., 2004). Depressive coping (defined as social withdrawal, irritability, and pessimistic thinking) also has been shown to be negatively associated with HRQOL in IBD patients (Petrak et al., 2001). In addition, humor has been shown to be negatively associated with general quality of life in chronically ill patients (Dubey & Agarwal, 2007).
4.3 Implications of Coping Styles

While there is some research on the relation between coping and HRQOL in IBD patients, there is a paucity of research examining how coping predicts disease activity and medication non-adherence in patients with IBD. In fact, no research has examined the relationship between coping and medication non-adherence; only one study (Larsson et al., 2008) examined how coping predicts disease activity, and this study did not find a significant direct relationship between these variables. Larsson et al. failed to look at how coping with IBD is associated with disease activity; therefore, the relationship between situational coping (coping with IBD) and disease activity still needs to be examined.

Most of the research examining the role of general coping as a predictor variable has focused on its association with HRQOL. Overall, the research findings show a positive association between engagement coping (optimistic coping and seeking social support) and HRQOL and a negative association between disengagement coping (avoidant, use of humor, and pessimistic coping) and HRQOL. Mixed findings have been reported for the relation between problem-focused coping (a form of engagement coping) and HRQOL. These conflicting findings appear to be associated with disease activity; patients who are experiencing a flare in symptoms that engage in problem-focused coping have a poorer HRQOL. In addition, emotional expression (another form of engagement coping) has been found to have an inverse association with HRQOL. Unlike problem-focused and emotional expression coping, positive thinking and seeking social support have been associated with increased HRQOL. The amount of control that patients perceive they have over their IBD when their disease is active is likely diminished
compared to when disease is quiescent; this is likely contributing to the mixed findings between coping type and HRQOL.

It is intuitive that effective coping serves a critical role in patients’ functional adaptation to their IBD (Kinash et al., 1993). In addition, the type of coping that patients employ is likely associated with their disease activity and treatment regimen adherence. It is unclear whether there is a direct relationship between coping and HRQOL or whether this relationship is moderated by an additional variable. More research in this area is necessary; once a better understanding of the role of coping is established, clinical trials addressing patients’ coping can be developed, and medical treatment can begin to incorporate patients’ coping into treatment regimens. This would likely result in improvements to patients’ HRQOL, medication adherence, and disease activity.

5. Anxiety and Depression

5.1 Definition of Anxiety and Depression

Anxiety disorders are comprised of 12 sub-types in the adult population in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV); all these subtypes are characterized by anxiety as a core symptom (American Psychological Association, 2000). Anxiety is comprised of fear, worry, apprehension, and dread (Bjelland, Dahl, Haug, & Neckelmann, 2002). It is important to note that not everyone who has anxiety has an anxiety disorder. In contrast to anxiety, depression is centered on sadness and is associated with sorrow, hopelessness, and gloom (Bjelland et al., 2002). There are 3 subtypes of depressive disorders in the adult population (American Psychological Association, 2000).
5.2 Factors Associated with Anxiety and Depression and IBD

Several researchers have examined the association between depression, anxiety, and IBD. Schwarz and Blanchard (1990) reported inconsistent findings for levels of anxiety and depression in patients with Crohn’s disease and little to no elevations of any psychopathology in patients with ulcerative colitis, as compared to healthy controls. Similarly, Levenstein (2002) found lower levels of anxiety and depression in ulcerative colitis patients than in controls. In contrast, other researchers have found increased levels of anxiety and depression in both Crohn’s disease and ulcerative colitis patients (Addolorato et al., 1997; Walker et al., 2008). More specifically, Walker et al. (2008) found that IBD patients have higher rates of panic disorder, generalized anxiety disorder, obsessive-compulsive disorder, and major depression and lower rates of social anxiety disorder and bipolar disorder than a matched community sample. Walker et al. (2008) argued that some of the inconsistent findings for prevalence rates can be attributed to methodological differences, as many studies have used screening measures, which indicate elevations in anxiety or depression, but do not indicate actual depressive disorders or anxiety disorders.

Similar to the discrepancies found in the levels of anxiety and depression for IBD patients, as compared to healthy controls, inconsistencies have been reported in the levels of anxiety and depression for Crohn’s disease patients versus ulcerative colitis patients. Some researchers have found higher levels of both anxiety and depression, or depression alone, in patients with Crohn’s disease, as compared to patients with ulcerative colitis (Guthrie et al., 2002; Kinash et al., 1993; Larsson et al., 2008). However, other studies
have found no significant differences in the prevalence of anxiety and depression between Crohn’s disease and ulcerative colitis patients (Farrokhyar et al., 2006).

Researchers also have compared levels of anxiety and depression among IBD patients with quiescent disease and with active disease versus healthy controls. Larsson et al. (2008) found that patients with quiescent disease reported lower levels of anxiety and depression. In addition, other researchers have reported increased levels of depression, anxiety, and psychological distress in patients with active disease (Angelopoulos et al., 1996; Graff et al., 2006; Levenstein, 2002; Porcelli et al., 1996; Searle & Bennett, 2001).

5.3 Implications of Anxiety and Depression

It appears that patients with IBD experience greater levels of anxiety and depression when their disease is active. Elevated anxiety and depression have been associated with decreased HRQOL, and increased depression has been associated with medication non-adherence. Thus, it is important for clinicians to screen for anxiety and depression, so that treatment (or a referral for treatment) addressing anxiety and depression can be provided. It is likely that when patients’ mental health needs are addressed, noticeable improvements in medical health will follow.

6. Social Constraint

6.1 Definition of Social Constraint

Social constraint on disclosure is the perception of feeling unsupported, misunderstood, or alienated from one’s social network when seeking social support to discuss a stressor or a traumatic event. It is important to note that social constraints are transactional, malleable, and change over time, just as relationships change over time (Lepore & Revenson, 2007).
6.2 Social Support/Social Constraint and IBD

Only one research study has examined the role of social constraint on disclosure in IBD patients. Rogala et al. (2008) found that IBD patients were less likely to report that they had someone who understood their problems (high levels of social constraint) than healthy controls. However, they did find that these patients reported having good social support. These findings illustrate that IBD patients can have a good social support network, but feel constrained in discussing stressors related to their IBD.

In contrast to the lack of research on social constraint among patients with IBD, some researchers have examined outcomes associated with the related construct of social support in patients with IBD. Joachim (2002) found no differences in perceived social support between Crohn’s patients and patients with ulcerative colitis, and that IBD patients reported high levels of social support. In contrast, Jones et al. (2006) found that IBD patients reported less social support than healthy controls. Thus, it is possible that social constraint is contributing to the mixed research findings regarding perceived social support in IBD patients.

Limited research has been conducted examining whether social support has an impact on disease activity, but the findings point to an inverse relationship between social support and disease activity (Graff et al., 2006). Maunder et al. (2007) found that patients with ulcerative colitis who were single or separated had a higher incidence of active disease than those who were married or living in common-law relationships. They also found that being single or separated was associated with lower perceived social support.
In addition, research has begun to examine the relationship between perceived support and HRQOL. Moskovitz et al. (2000) found that patients who report higher perceived social support also report higher HRQOL.

6.3 Factors Associated with Social Constraint

No studies have examined demographic variables that might contribute to social constraint on disclosure or whether social constraint on disclosure contributes to other physical and mental health outcomes in patients with IBD. Therefore, the relevant literature on the role of social constraint on disclosure in other chronically ill adults will be reviewed.

Research on the contributions of demographic variables to social constraint on disclosure amongst adults with chronic and/or terminal illnesses has been conducted. For example, several studies have found that age is inversely related with social constraint in adults with rheumatoid arthritis and with cancer (Danoff-Burg, Revenson, Trudeau, & Paget, 2004; Zakowski et al., 2003). Surprisingly, other demographic variables have not been found to have a direct association with perceived levels of social constraint.

Most of the research that has examined the role of social constraint in chronically ill adults has examined the association between perceived social constraint and psychological distress. Overall, researchers have found a positive association between social constraint and psychological distress in adults with rheumatoid arthritis and cancer (Cordova, Cunningham, Carlson, & Andrykowski, 2001; Danoff-Burg et al., 2004; Lepore & Helgeson, 1998; Manne, Ostroff, Winkel, Grana, & Fox, 2005; Revenson, Schiaffino, Majerovitz, & Gibofsky, 1991; Schmidt & Andrykowski, 2004; Zakowski et al., 2004). In addition, research findings suggest that gender moderates the relationship
between social constraint and psychological distress in adults with cancer. More specifically, men experience significantly higher levels of distress in association with perceived social constraint from spouse/partner than women. In contrast, gender differences have not been found for perceived social constraints from family/friends in association with distress (Zakowski et al., 2003).

Not only is perceived social constraint associated with psychological distress but also it is associated with intrusive thoughts. For example, social constraint has been found to be positively associated with elevated levels of intrusiveness in patients with cancer (Cordova et al., 2001; Schmidt & Andrykowski, 2004). Zakowski et al. (2003) found that men experienced higher levels of intrusive thoughts in association with perceived spousal constraint than did women. Lepore and Helgeson (1998) found that perceived social constraint exacerbated the relation between intrusive thoughts and mental health in males with prostate cancer.

Researchers also have begun to look at the association between perceived social constraint on disclosure and quality of life and with chronic illness symptoms. Hoffman, Meier, and Council (2002) found that, for adults with chronic pain living in rural areas, social constraint was negatively associated with quality of life. In addition, perceived social constraint was positively associated with the intensity of the chronic pain symptoms.

Researchers have examined the association between social constraint on disclosure and specific types of coping. Researchers have found a positive association between high levels of social constraint and high levels of avoidance coping in adults with cancer (Cordova et al., 2001; Manne et al., 2005; Schmidt & Andrykowski, 2004;
Zakowski et al., 2004). In contrast, optimism has been found to be inversely associated with perceived social constraint (Lepore & Ituarte, 1999). Importantly, it appears that coping skills may mitigate the negative effects of social constraint on psychological adjustment, as expressing emotions in the form of written disclosure has been found to buffer the effects of social constraint on psychological distress (Zakowski et al., 2004).

6.4 Implications of Social Constraint

It is important for clinicians to take into account not only if patients have social support but also how patients perceive their support network in terms of their ability to discuss their IBD. Patients might report having an extensive support network, but not be able to discuss their IBD symptoms or complications due to perceived social constraint. Moreover, if a person is constrained in discussing IBD-related thoughts and feelings due to avoidant, critical or unhelpful responses, the potential benefits of talking are likely to be negated (Lepore & Revenson, 2007). The negative ramifications of perceived social constraints in other chronic illnesses are evident based on its positive associations with increased psychological distress and intrusiveness, as well as with poorer quality of life. In addition, perceived social constraint appears to be associated with increased use of maladaptive coping strategies, such as avoidance and is inversely associated with the use of optimistic coping. Due to the likely negative impact of perceived social constraint on disclosure on medication adherence, disease activity, and HRQOL, it is important for clinicians to assess for patients’ perceived social constraint (patients’ levels of social support within the context of IBD).
7.1 Overall Summary

There is limited research to date that has examined coping as a predictor of medication non-adherence, disease activity, and HRQOL in IBD patients, and there is no research that has examined the role of social constraint on disclosure as a predictor of these outcome variables in patients with IBD. The limited research on coping in patients with IBD has found that disengagement coping is inversely associated with HRQOL, and some studies have found that engagement coping is positively associated with HRQOL. The only study that examined the relation between coping and disease activity failed to detect significant findings, however, this study failed to take into account the context of the coping. Thus, the relation between coping with IBD and disease activity needs greater examination. In addition, research on the relation between coping and medication non-adherence is nonexistent. In contrast to the lack of research on social constraint and coping with IBD, the impact of depression and anxiety to health-related behaviors and outcomes has received greater attention. For example, studies have found that increased depression and anxiety are inversely associated with HRQOL, and positively associated with medication non-adherence and disease activity.

Research has demonstrated that medication non-adherence is associated with increased disease activity, and that increased disease activity is associated with diminished HRQOL. Improving medication adherence aids in the prevention of disease flares, healthcare costs, colorectal cancer, and work absenteeism. Thus, in order to enhance patient care and reduce societal costs, research is needed to identify psychological factors that are likely to play a role in improving patient adherence. Toward this end, the present study has three goals. The first goal was to replicate
previous research by demonstrating significant relations among medication non-adherence, disease activity, and HRQOL. The second goal was to investigate whether there were group differences in HRQOL, disease activity, and levels of adherence for patients high in anxiety and depression compared to those low in anxiety and depression. The third goal was to examine the contributions of coping and social constraint on disclosure to medication non-adherence, disease activity, and HRQOL.

8.1 Purpose of the Present Study and Hypotheses

A. Hypotheses pertaining to relationship between medication non-adherence, disease activity, and HRQOL:

1. Medication non-adherence (overall, intentional, and unintentional) would be positively associated with disease activity and inversely associated with HRQOL.
2. Disease activity would be negatively correlated with HRQOL.

B. Hypotheses pertaining to group differences in HRQOL, disease activity, and levels of adherence:

1. IBD patients with high levels of depression would have higher levels of medication non-adherence (overall, intentional, and unintentional), disease activity, and diminished HRQOL compared to IBD patients with low levels of depression.
2. IBD patients with high levels of anxiety would have higher levels of medication non-adherence (overall, intentional, and unintentional), disease activity, and diminished HRQOL compared to IBD patients with low levels of anxiety.
C. Hypotheses examining the contributions of coping and social constraint to medication non-adherence, disease activity, and HRQOL:

1. Social constraint would moderate the relationship between coping and HRQOL (see Figure 1).

   a. First, the moderating effect of social constraint on the relation between engagement coping and HRQOL was examined. It was expected that high levels of social constraint would be associated with decreased HRQOL for high levels of engagement coping, whereas low levels of social constraint would be associated with increased HRQOL for high levels of engagement coping. In contrast, it was expected that low levels of engagement coping would be associated with decreased HRQOL, irrespective of the level of perceived social constraint. See Figure 2 for a depiction of the expected interaction between social constraint and engagement coping.

   b. The moderating effect of perceived social constraint on the relationship between disengagement coping and HRQOL also was examined. It was expected that high levels of social constraint would be associated with decreased HRQOL for low levels of disengagement coping, whereas low levels of social constraint would be associated with increased HRQOL for low levels of disengagement coping. It was expected that high levels of disengagement coping would be associated with decreased HRQOL, irrespective of the perceived level of social constraint. See Figure 3 for a
Figure 1: Theoretical Model of Predictors of HRQOL in Patients with IBD
Figure 2: Social Constraint Moderating the Relationship between Engagement Coping and HRQOL in Patients with IBD
Figure 3: Social Constraint Moderating the Relationship between Disengagement Coping and HRQOL in Patients with IBD
depiction of the expected interaction between social constraint and disengagement coping.

2. A model examining the extent to which medication non-adherence (overall, intentional, and unintentional) mediates the relations between coping (engagement and disengagement) and disease activity, as well as the relations between social constraint and disease activity was tested (see Figure 4 illustration of theoretical model). It was expected that:

   a. There would be direct effects of coping and social constraint on disclosure on medication non-adherence and disease activity. Increased disengagement coping and social constraint would be positively associated with medication non-adherence and disease activity. Increased engagement coping would be inversely associated with medication non-adherence and disease activity.

   b. Patients’ overall medication non-adherence would mediate the relationship between social constraint and disease activity and between coping and disease activity.

Method

Participants

This study was a retrospective chart review that examined clinical data obtained at patients’ first appointment to the Inflammatory Bowel Disease Program at the University of Maryland (UMB). The UMB IBD program is a tertiary referral center, which indicates that the majority of the patients had moderate to severe disease. All the participants included in this study were new patients to the IBD program at UMMC, but not
Figure 4: Theoretical Model Predicting Medication Non-Adherence and Disease Activity in Patients with IBD
necessarily newly diagnosed patients. A power analysis was conducted to determine the number of participants necessary to minimize Type II statistical error. Based on a medium effect size ($R^2 = .20$), with Type I error (alpha) of .05, a power of .80 or Type II error of .20, and 4 predictors, a sample size of 53 was needed (Cohen, 1988); thus, this study needed to examine data from a minimum of 53 patients.

Data from a total of 92 patients, who were seen between June of 2008 and March of 2009, were analyzed. Eleven of these patients did not have a confirmed diagnosis of IBD and one patient did not meet the inclusionary criteria regarding age; therefore, only data from 80 patients was analyzed. Of the 80 participants, 46.3% had a confirmed diagnosis of ulcerative colitis, 52.5% had a confirmed diagnosis of Crohn’s disease, and 1.2% had a diagnosis of indeterminate colitis. The mean age of participants was 37.17 ($S.D. = 13.48$, range = 19-73) and 51% of the patients were female. The majority of the sample was Caucasian (77.5%); the remaining participants were African-American (15%), Asian-American (6.3%), and other or not specified (1.2%). Due to the majority of the sample being Caucasian, for analytical purposes, race was grouped into Caucasian and non-Caucasian. In terms of marital status, 39.2% were single, 55.7% were married, 3.8% were divorced or separated, and 1.3% were widowed. In terms of highest education level achieved, 51.3% reported a high school degree or less, 28.8% reported an associate or bachelor degree, and 17.5% reported a masters, professional, or doctorate degree. Finally, in terms of cigarette smoking history, 65% reported never having smoked cigarettes, 22.5% reported being former smokers, and 12.5% reported being current smokers. Of the patients with ulcerative colitis, 78.4% reported never having smoked, 18.9% reported being former smokers, and 2.7% reported being current smokers. Of the
patients with Crohn’s disease, 54.8% reported never having smoked, 26.2% reported being former smokers, and 19% reported being current smokers.

In addition to gathering demographic information from participants, data regarding disease location was obtained. For patients with Crohn’s disease, data regarding disease behavior also was gathered. See Table 2 for descriptive statistics regarding disease location and disease behavior.

Measures

The data that was analyzed was gathered from measures administered as part of patients’ standard of care for their initial visit to the UMB IBD program. All demographic information (e.g., age, gender, race, marital status, level of education) and health and disease history variables (e.g., duration of disease, diagnosis, time since diagnosis, diagnosis phenotype/location, smoking history (e.g., never smokers, former smokers, or current smokers), and severity of a substance problem (measured via the Addiction Severity Index), disease activity, as well as psychosocial variables, was gathered from patients’ charts.

1. Disease Activity. Data on disease activity was measured via the Harvey Bradshaw Index (HBI; Harvey & Bradshaw, 1980) for patients with Crohn’s disease and the Simple Clinical Colitis Activity Index (SCCAI; Walmsley, Ayres, Pounder, & Allan, 1998) for patients with ulcerative colitis and indeterminate colitis. Both the HBI and the SCCAI have high convergent validity. Both of these indices were completed by gastroenterologists to assess the level of disease activity. The score derived from the HBI is based on five items that assess general well-being, abdominal pain, number of liquid stools per day, abdominal mass, and complications/extraintestinal manifestations. The
Table 2: Disease Behavior and Location in Patients with Inflammatory Bowel Disease

Evaluated at the UMB IBD Program

<table>
<thead>
<tr>
<th>Disease Location</th>
<th>Ulcerative Colitis</th>
<th>Crohn’s Disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proctitis</td>
<td>5.4%</td>
<td></td>
</tr>
<tr>
<td>Left-Sided</td>
<td>29.8%</td>
<td></td>
</tr>
<tr>
<td>Extensive/Pancolitis</td>
<td>64.8%</td>
<td></td>
</tr>
<tr>
<td>L1</td>
<td></td>
<td>22%</td>
</tr>
<tr>
<td>L2</td>
<td></td>
<td>17.1%</td>
</tr>
<tr>
<td>L3</td>
<td></td>
<td>46.3%</td>
</tr>
<tr>
<td>Isolated L4</td>
<td></td>
<td>4.9%</td>
</tr>
<tr>
<td>Upper Tract Involvement Overall</td>
<td></td>
<td>14.6%</td>
</tr>
<tr>
<td>Disease Behavior</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-stricturing/Non-Penetrating</td>
<td></td>
<td>44.7%</td>
</tr>
<tr>
<td>Stricturing</td>
<td></td>
<td>31.6%</td>
</tr>
<tr>
<td>Penetrating</td>
<td></td>
<td>23.7%</td>
</tr>
<tr>
<td>Perianal Involvement</td>
<td></td>
<td>31.0%</td>
</tr>
</tbody>
</table>
score derived from the SCCAI is based on 6 items that assess for bowel frequency, daytime versus nighttime bowel movements, urgency, blood in the stool, general well-being, and extraintestinal manifestations. For the purpose of data analyses, the data from both of these measures was dummy-coded to represent quiescent or active disease. Remission/quiescent disease was defined by scores less than 3 for the SCCAI (Higgins et al., 2005) and by scores less than 5 for the HBI (Harvey & Bradshaw, 1980).

2. **Medication Non-adherence.** Data on medication non-adherence was gathered via the Morisky Medication Adherence Scale (Morisky, Green, & Levine, 1986), a 4-item binary questionnaire that assesses overall medication non-adherence, intentional non-adherence, and unintentional non-adherence. Good internal consistency, with $\alpha = .61$, was reported for patients with high blood pressure (Morisky et al., 1986), and moderate internal consistency was reported with an IBD cohort, with $\alpha = .50$ for overall non-adherence, .52 for intentional non-adherence, and .54 for unintentional non-adherence (Sewitch et al., 2003). Four different levels of non-adherence were measured. Patients were categorized as intentionally non-adherent if they responded affirmatively to only the intentional non-adherence items and as unintentionally non-adherent if they responded affirmatively only to the unintentional non-adherence items. Overall non-adherence was categorized as an affirmative response to any of the four items. Both intentional and unintentional non-adherence was categorized by an affirmative response to either of the two intentional items and an affirmative response to either of the two unintentional items (Sewitch et al., 2003).
3. **Health-related quality of life.** Data on HRQOL was gathered via the Short Inflammatory Bowel Disease Questionnaire (SIBDQ; Irvine, Zhou, & Thompson, 1996). The SIBDQ is a 10-item self-report measure assessing health-related quality of life in patients with IBD. Five domains of HRQOL were assessed: (1) systemic (2) social, (3) bowel, (4) emotional, and (5) overall. Each item was scored on a 7-point graded scale, from 1 (a severe problem) to 7 (not a problem at all), giving an absolute SIBDQ score range from 10 (poor HRQOL) to 70 (optimum HRQOL). The SIBDQ has good internal consistency, with $\alpha = .78$ and good test-retest reliability (coefficient = .65) (Irvine et al., 1996). For the present study, the internal consistency of the SIBDQ was excellent ($\alpha = .87$). In addition, the SIBDQ has good convergent and discriminant validity. For the purpose of data analyses, the four individual domain scores, as well as overall HRQOL score, were analyzed.

4. **Coping.** Coping with IBD was assessed via the situational version of the COPE (Carver, Scheier, & Weintraub, 1989), a 64-item self-report scale. Adults were asked to indicate how often they used particular coping strategies on a four-point Likert scale ranging from (1) I usually don’t do this at all, to (4) I usually do this a lot. Carver *et al.* (1989) reported that the internal consistencies for all the subscales were high, with $\alpha$ coefficients higher than .60; the only exception to this was for mental disengagement, with $\alpha = .45$. In addition, the measure appears to have moderate test-retest reliability. The COPE has some limitations based on the construction of the measure (Stanton, Danoff-Burg, Cameron, & Ellis, 1994; Stanton, Kirk, Cameron, & Danoff-Burg, 2000). The venting of emotions subscale has items that confound coping efforts with emotional outcome, specifically psychological distress. Given this confound, as researchers have
stated (Stanton et al., 1994; Stanton et al., 2000), it is not surprising that emotion-focused coping strategies have been found to be associated with measures of distress or psychopathology. Given the potential implications of this limitation, the Emotional Approach Coping Scale and the Emotional Expression Coping Scale (Stanton et al., 1994; Stanton et al., 2000) were used as substitutes for the Focus on and Venting of Emotions subscale of the COPE for the present study. The emotional approach coping scale measures active attempts to acknowledge and understand emotions. The internal consistency for the emotional approach scale was .72 and for the emotional expression scale was .82, and their test-retest reliabilities were .73 and .72, respectively (Stanton et al., 2000).

Thus, the COPE version utilized in this study measured 10 subscales of engagement coping (active, planning, suppression of competing activities, use of instrumental support, use of emotional support, positive reinterpretation and growth, acceptance, turning to religion, emotional approach, and emotional expression) and 5 subscales of disengagement coping (denial, behavioral disengagement, mental disengagement, humor, and substance use). The allocation of the subscales into engagement coping versus disengagement coping was derived from prior research (Connor-Smith et al., 2000; Danoff-Burg, Prelow, & Swenson, 2004; Thorson & Powell, 1993) and conceptual reasoning. For data analyses, the mean value of the 10 subscales of engagement coping and the mean value of the 5 scales of disengagement coping was utilized. To facilitate the interpretation of the coping scales, all scores were multiplied by 100, so that patients’ scores ranged from 0 to 100, as opposed to from 0 to 1. The internal consistency of the engagement and disengagement subscales was calculated for the
current study, and yielded Cronbach alphas of .96 for engagement and .68 for disengagement coping.

5. Anxiety and Depression. Anxiety and depression were assessed via the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). The HADS is a 14-item self-report scale designed to measure depression and anxiety in patients with a physical illness; it does not include somatic symptoms of anxiety and depression. According to Zigmond and Snaith (1983), the internal consistencies for both scales are high; for anxiety, $\alpha$ ranged from .68 to .93 (mean of .83) and for depression, $\alpha$ ranged from .67 to .90 (mean of .82). In the present study, the internal consistencies for anxiety ($\alpha = .87$) and for depression ($\alpha = .85$) also were high. Optimal balances between sensitivity and specificity have been achieved most frequently when a cutoff score of 8+ was used for both anxiety and depression, yielding sensitivities and specificities of .80 for both subscales. Based on these findings, patients who scored 8 or greater on depression and 8 or greater on the anxiety subscales were coded as having high depression or high anxiety. The HADS has good to very good concurrent validity, with correlations ranging from .61 to .83 (Bjelland et al., 2002).

6. Social Constraint on Disclosure. Social constraint on disclosure was assessed via the social constraints questionnaire, a measure adapted from a social constraints’ questionnaire developed by Lepore and Helgeson, (1998) for use with cancer patients. The internal consistencies for the social constraint questionnaire in Lepore and Helgeson’s (1998) study with cancer patients were very good, with $\alpha=.85$ for constraint with friends and .79 for constraint with family. Modifications to the wording of this
measure were made to reflect inflammatory bowel disease. The new 12-item measure assessed the degree of perceived social constraint on disclosure when discussing inflammatory bowel disease with friends (first six questions) and with one’s partner/spouse (last six questions). Patients indicated how frequently they experience each social constraint question over the previous month on a 4-point scale, ranging from never to always. For data analyses, overall social constraint was calculated by computing the mean of all 12 items (6 items for patients who do not have a significant other).

**Procedure**

Prior to analyzing this retrospective data, approval from the Institutional Review Board of the University of Maryland Medical Center and of the University at Albany, SUNY was obtained. This was a retrospective chart review in which data from new patients to the UMB IBD program, who were first seen for a clinical office visit between June of 2008 and February of 2009, were analyzed. The data analyzed were gathered from a standard battery of measures, which were discussed in the prior section.

Inclusion criteria for this study included patients who were 18 years or older at the time of their first visit and patients with a confirmed diagnosis of ulcerative colitis, Crohn’s disease, or indeterminate colitis. Exclusion criteria included patients without a confirmed diagnosis of IBD and patients with incomplete information available in the medical record.
Results

Preliminary Statistical Analyses

All variables were examined using SPSS (v.18.0) for missing data, normality, homoscedasticity, outliers, and multicollinearity. In terms of missing values for the predictor variables, there were 2 missing values for engagement coping and 1 missing value for disengagement coping. For these cases, mean substitution was used to replace the missing values. There were no missing values for social constraint or for any of the dependent variables.

All of the continuous predictor and outcome variables were screened for normality by examining the values of skewness and kurtosis, frequency histograms, and normal probability plots (Tabachnick & Fidell, 2001). HRQOL and disengagement coping were normally distributed. However, both engagement coping ($z = -2.16, p < .05$), and perceived social constraint ($z = 6.57, p < .05$) violated the assumption of normality. Due to the slight negative skew exhibited by engagement coping, the following transformations were conducted: reflection, followed by the square root (Tabachnick & Fidell, 2001). This transformation aided in the distribution of the variable both in terms of the skew ($z = 1.65, p > .05$), as well as the visual aspect evidenced via frequency histograms and normal probability plots. Thus, regression analyses utilized both the original variable (engagement coping) and the transformed variable (reflected and square root of engagement coping). In contrast, since social constraint was positively skewed, the following transformations were attempted: square root, logarithm, and inverse. None of these transformations appeared to correct the violation of normality. Upon closer examination of the spread of the variable, it became evident that the variable would be...
better represented as a dichotomous variable. In fact, 32.5% of this sample denied experiencing social constraint with respect to their IBD. Thus, the variable was re-coded as perceiving no social constraint (32.5% of the sample) and perceiving any amount of social constraint (67.5% of the sample). The recoded dichotomized social constraint variable was used for statistical analyses.

Examination of the data for multivariate outliers did not reveal any cases that exceeded the Cook’s cutoff distance value of 1.00; therefore, the influence of any particular case was not seen as problematic. In addition, multicollinearity was assessed via examination of a correlation matrix with all the variables (Tabachnick & Fidell, 2001). None of the variables were highly correlated (as evidenced by none of the correlation values exceeding or equaling .90); therefore, multicollinearity was not a problem for the present study.

In addition, the frequencies for all the dichotomous predictor and outcome variables were examined. See Table 3 for the frequencies of depression, anxiety, social constraint, disease activity, and medication non-adherence (overall, exclusively intentional, exclusively unintentional, and both intentional and unintentional). All variables, with the exception of exclusive intentional non-adherence/adherence, had sufficient spread to be utilized in further analyses.

*Group Differences in Health-Related Quality of Life, Medication Non-Adherence, and Disease Activity*

Independent sample t-tests were conducted to examine group differences for patients high in anxiety versus those low in anxiety in overall HRQOL, as well as the
<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td></td>
</tr>
<tr>
<td>1. High</td>
<td>48.8</td>
</tr>
<tr>
<td>2. Low</td>
<td>51.2</td>
</tr>
<tr>
<td>Depression</td>
<td></td>
</tr>
<tr>
<td>1. High</td>
<td>26.2</td>
</tr>
<tr>
<td>2. Low</td>
<td>73.8</td>
</tr>
<tr>
<td>Social Constraint</td>
<td></td>
</tr>
<tr>
<td>1. None</td>
<td>32.5</td>
</tr>
<tr>
<td>2. Some</td>
<td>67.5</td>
</tr>
<tr>
<td>Disease Activity</td>
<td></td>
</tr>
<tr>
<td>1. Quiescent</td>
<td>40</td>
</tr>
<tr>
<td>2. Active</td>
<td>60</td>
</tr>
<tr>
<td>Overall Medication Adherence/Non-Adherence</td>
<td></td>
</tr>
<tr>
<td>1. Adherent</td>
<td>42.5</td>
</tr>
<tr>
<td>2. Non-Adherent</td>
<td>57.5</td>
</tr>
<tr>
<td>Intentional Medication Adherence/Non-Adherence</td>
<td></td>
</tr>
<tr>
<td>1. Adherent</td>
<td>88.8</td>
</tr>
<tr>
<td>2. Non-Adherent</td>
<td>11.2</td>
</tr>
<tr>
<td>Both Intentional and Unintentional Medication Adherence/Non-Adherence</td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>1. Adherent</td>
<td>77.5</td>
</tr>
<tr>
<td>2. Non-Adherent</td>
<td>22.5</td>
</tr>
</tbody>
</table>
four subscales of HRQOL (bowel, social, systemic, and emotional). Patients who were high in anxiety reported significantly lower HRQOL compared to those low in anxiety $t(78) = 5.15, p < .05$. Similarly, independent sample t-tests were conducted to examine group differences for those high in depression versus low in depression in overall HRQOL, as well as the four subscales of HRQOL. Patients high in depression reported significantly lower HRQOL compared to those low in depression, $t(78) = 5.91, p < .05$. Bonferroni adjustments were made for the analyses that examined the subscales of HRQOL. See Table 4 for group differences in HRQOL.

In addition, independent sample t-tests were conducted to examine group differences in HRQOL for those experiencing some social constraint versus no social constraint. Patients with some level of social constraint ($M = 42.57, S.D. = 14.02$) reported significantly lower overall HRQOL than patients with no level of social constraint ($M = 50.27, S.D. = 14.61$), $t(78) = 2.27, p < .05$. Independent sample t-tests revealed no significant difference in overall HRQOL for patients who were non-adherent compared to those that were adherent.

In addition, chi-square analyses were conducted to test for significant group differences in anxiety, depression, and social constraint in patients’ disease activity. There were significant group differences in depression; $\chi^2(1, N = 80) = 5.21, p < .05$). Among patients high in depression, 81% had active disease; whereas among patients low in depression, only 52.5% had active disease. Significant group differences in disease activity were not found for patients who were high in anxiety versus low in anxiety nor for patients perceiving some social constraint versus no social constraint.
Table 4: Differences in HRQOL between Patients High or Low in Anxiety and Depression Evaluated at the UMB IBD Program

<table>
<thead>
<tr>
<th>HRQOL</th>
<th>High Anxiety</th>
<th></th>
<th>Low Anxiety</th>
<th></th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td></td>
</tr>
<tr>
<td>Overall</td>
<td>37.59</td>
<td>12.32</td>
<td>52.20</td>
<td>13.01</td>
<td>5.15*</td>
</tr>
<tr>
<td>Bowel</td>
<td>9.64</td>
<td>4.30</td>
<td>12.34</td>
<td>4.59</td>
<td>2.71**</td>
</tr>
<tr>
<td>Social</td>
<td>6.92</td>
<td>3.47</td>
<td>9.42</td>
<td>3.67</td>
<td>3.12**</td>
</tr>
<tr>
<td>Systemic</td>
<td>4.56</td>
<td>3.08</td>
<td>7.15</td>
<td>3.51</td>
<td>3.49**</td>
</tr>
<tr>
<td>Emotional</td>
<td>6.92</td>
<td>3.59</td>
<td>12.76</td>
<td>4.72</td>
<td>6.20**</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>HRQOL</th>
<th>High Depression</th>
<th></th>
<th>Low Depression</th>
<th></th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td></td>
</tr>
<tr>
<td>Overall</td>
<td>31.57</td>
<td>9.72</td>
<td>49.88</td>
<td>12.94</td>
<td>5.91*</td>
</tr>
<tr>
<td>Bowel</td>
<td>8.00</td>
<td>3.99</td>
<td>12.10</td>
<td>4.38</td>
<td>3.77**</td>
</tr>
<tr>
<td>Social</td>
<td>5.48</td>
<td>3.79</td>
<td>9.17</td>
<td>3.28</td>
<td>4.26**</td>
</tr>
<tr>
<td>Systemic</td>
<td>3.19</td>
<td>2.75</td>
<td>6.85</td>
<td>3.29</td>
<td>4.55**</td>
</tr>
<tr>
<td>Emotional</td>
<td>4.71</td>
<td>2.53</td>
<td>11.76</td>
<td>4.48</td>
<td>6.82**</td>
</tr>
</tbody>
</table>

*p<.05; **p<.01

Note. df for all of the above t-tests was 78.
Chi-square analyses also were conducted to examine whether patients high or low in anxiety and depression differed in medication non-adherence (overall, exclusively unintentional, and both intentional and unintentional); no significant group differences were found. In addition, chi-square analyses were conducted to examine group differences in medication non-adherence for those high versus low in social constraint. Significant differences were found for patients who reported both intentional and unintentional non-adherence \( \chi^2 (1, N=80) = 7.69, p<.05 \). Among patients perceiving some social constraint, 31.5% had both intentional and unintentional non-adherence. Conversely, among patient perceiving no social constraint, 3.8% had both intentional and unintentional non-adherence. However, there were no significant differences in overall medication non-adherence or unintentional non-adherence, as a function of whether patients reported no social constraint or some social constraint.

Finally, chi-square analyses were conducted to examine group differences in social constraint. Significant group differences in social constraint were found for patients low versus high in anxiety, \( \chi^2 (1, N = 80) = 7.35, p < .05 \). Among patients with high levels of anxiety, 82.1% perceived some level of social constraint; whereas among patients low in anxiety, 53.7% perceived some level of social constraint. No significant group differences were found in terms of depression.

**Correlations among Coping, Social Constraint, Depression, Anxiety, Health-Related Quality of Life, Disease Activity, and Medication Non-Adherence**

Pearson correlations were conducted to examine the relationships between engagement coping, disengagement coping, and HRQOL. Engagement was positively correlated with disengagement coping. In addition, disengagement coping was
significantly negatively correlated with HRQOL. There was no significant relationship between engagement coping and HRQOL. See Table 5 for Pearson correlations.

Point-biserial correlations were conducted to examine the relationship between coping, disease activity, and medication non-adherence. In addition, point-biserial correlations were conducted to examine the association between HRQOL, disease activity, and medication non-adherence. Disengagement coping was positively associated with disease activity. Disease activity was negatively associated with HRQOL (see Table 5). Engagement coping was not significantly associated with disease activity, nor were significant relationships found between either type of coping and medication non-adherence, or between medication non-adherence and HRQOL.

Point-biserial correlations also were conducted to examine the relationship between depression, anxiety, coping and HRQOL, and between social constraint, coping and HRQOL. A significant negative relationship was found between both depression and anxiety and HRQOL and a positive association was found between depression and anxiety and disengagement coping. In addition, a significant positive relationship was found between social constraint and engagement and disengagement coping and a significant negative relationship was found between social constraint and HRQOL. See Table 5 for point-biserial correlations.

Tests for Covariates

In order to assess for potential covariates for hierarchical and logistic regression analyses, Pearson correlations, point-biserial correlations, chi-square analyses, and one-way ANOVAs were conducted to examine the relationship between the outcome
Table 5. Correlations between Coping, Social Constraint, Anxiety, Depression, Disease Activity, and Health-Related Quality of Life

<table>
<thead>
<tr>
<th></th>
<th>1.</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
<th>5.</th>
<th>6.</th>
<th>7.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Social Constraint</td>
<td>1</td>
<td>-.25*</td>
<td>N/A</td>
<td>.27*</td>
<td>.33*</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>2. HRQOL</td>
<td>____</td>
<td>1</td>
<td>-64*</td>
<td>-.18</td>
<td>-.35*</td>
<td>-.50*</td>
<td>-.56*</td>
</tr>
<tr>
<td>3. Disease Activity</td>
<td>____</td>
<td>____</td>
<td>1</td>
<td>.16</td>
<td>.24*</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>4. Engagement Coping</td>
<td>____</td>
<td>____</td>
<td>____</td>
<td>1</td>
<td>.44*</td>
<td>.12</td>
<td>-.03</td>
</tr>
<tr>
<td>5. Disengagement Coping</td>
<td>____</td>
<td>____</td>
<td>____</td>
<td>____</td>
<td>1</td>
<td>.33*</td>
<td>.23*</td>
</tr>
<tr>
<td>6. Anxiety</td>
<td>____</td>
<td>____</td>
<td>____</td>
<td>____</td>
<td>____</td>
<td>1</td>
<td>N/A</td>
</tr>
<tr>
<td>7. Depression</td>
<td>____</td>
<td>____</td>
<td>____</td>
<td>____</td>
<td>____</td>
<td>____</td>
<td>1</td>
</tr>
</tbody>
</table>

*p < .05
variables and all demographic variables. One-way ANOVAs were conducted to examine the relationship between the categorical demographic variables (marital status and smoking) and t-tests were conducted to examine the relationship between race, diagnosis, gender, and HRQOL. The only significant relationship was between smoking and HRQOL \( (F(2, 77) = 5.31, p < .05) \). Tukey post-hoc comparisons of the three groups indicated that never smokers \( (M = 48.15, SD = 14.19) \) reported significantly higher HRQOL than current smokers \( (M = 33.0, SD = 12.87) \) at \( p < .05 \). Comparisons between former smokers and the other two groups were not statistically significant at \( p < .05 \).

In addition, chi-square analyses were conducted to examine the relations between the categorical demographic variables (marital status, race, diagnosis, gender, and smoking) and disease activity and medication non-adherence. The only statistically significant relationship found was between diagnosis and unintentional non-adherence \( (\chi^2(2, 80) = 6.01, p = .05) \). Among patients who were unintentionally non-adherent, 64.9% had Crohn’s disease and 32.4% had ulcerative colitis. Finally, Pearson and point-biserial correlations were conducted to test for potential additional covariates. Both education \( (r = -.23) \) and age at diagnosis \( (r = .26) \) were significantly correlated with disease activity, \( p < .05 \). Therefore, as level of education achieved increased, disease activity decreased. Similarly, as the age at which patients were diagnosed was older, patients’ disease activity increased. No other demographic variables were significantly associated with disease activity. Level of education also was positively associated with HRQOL \( (r = .27, p < .05) \). In addition, correlations were conducted to examine if any demographic variables were significantly associated with medication non-adherence. Age \( (r = -.24, p < .05) \) and severity of illicit drug use \( (r = .31, p < .05) \) were the only
demographic variables significantly associated with both intentional and unintentional non-adherence, such that increased age was associated with decreased non-adherence and that greater severity of drug use was associated with increased non-adherence. No demographic variables were significantly associated with overall non-adherence. Finally, correlation analyses did not reveal any significant relationships between demographic variables and HRQOL.

In summary, several variables were found to be significantly associated with the outcome variables of interest. Smoking history and level of education were significantly associated with HRQOL. Type of diagnosis was significantly associated with unintentional non-adherence. Age and severity of drug use were significantly associated with people who were both intentionally and unintentionally non-adherent. No demographic variables were significantly associated with overall non-adherence. Finally, highest level of education achieved and age at diagnosis were significantly associated with disease activity.

**Regressions Predicting HRQOL**

A series of three hierarchical regressions were conducted to examine the extent to which perceived social constraint on disclosure moderated the relationship between coping and HRQOL in patients with IBD. Variables for the regression were selected based on theoretical interest. The first hierarchical regression examined the moderating effect of social constraint on the relationship between engagement coping and HRQOL. The covariates were entered on the first step (highest level of education achieved and smoking history), the main effect variables (engagement coping and social constraint) were entered on the second step, and the two-way interaction term (social constraint x
engagement coping) was entered on the third step. The overall model was significant and explained 25% of the variance in HRQOL, $R = .50$, $F (5, 72) = 4.70$, $p < .05$. Smoking history and social constraint significantly accounted for the variance in patients’ HRQOL; however, the interaction term was not significant. In addition, engagement coping approached significance in accounting for the variance in HRQOL ($p = .06$). See Table 6 for regression coefficients. This same regression was repeated with the engagement coping variable transformed. Highest level of education achieved and smoking history were entered on the first step, social constraint and the reflection and square root of engagement coping were entered on the second step, and the two-way interaction term (social constraint x transformed engagement coping) was entered on the third step. The overall model was still significant and explained 24% of the variance in HRQOL, $R = .49$, $F (5, 72) = 4.63$, $p < .05$. However, with the transformation, only smoking history significantly accounted for the variance in patients’ HRQOL ($t = -2.86$, $p < .05$), although engagement coping transformed approached significance ($t = 1.88$, $p = .06$). Again, the interaction term was not significant.

The final hierarchical regression conducted examined the moderating effect of social constraint on the relationship between disengagement coping and patients’ HRQOL. The covariates were entered on the first step (highest level of education achieved and smoking history), the main effect variables (disengagement coping and social constraint) were entered on the second step, and the two-way interaction term (social constraint x disengagement coping) was entered on the third step. The overall model was statistically significant and accounted for 27% of the variance, $R = .52$, $F (5, 72) = 4.70$, $p < .05$. Smoking history and social constraint significantly accounted for the variance in patients’ HRQOL; however, the interaction term was not significant. In addition, engagement coping approached significance in accounting for the variance in HRQOL ($p = .06$). See Table 6 for regression coefficients. This same regression was repeated with the engagement coping variable transformed. Highest level of education achieved and smoking history were entered on the first step, social constraint and the reflection and square root of engagement coping were entered on the second step, and the two-way interaction term (social constraint x transformed engagement coping) was entered on the third step. The overall model was still significant and explained 24% of the variance in HRQOL, $R = .49$, $F (5, 72) = 4.63$, $p < .05$. However, with the transformation, only smoking history significantly accounted for the variance in patients’ HRQOL ($t = -2.86$, $p < .05$), although engagement coping transformed approached significance ($t = 1.88$, $p = .06$). Again, the interaction term was not significant.
Table 6: Hierarchical Regression Coefficients for Predictors of HRQOL

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Unstd. B</th>
<th>Std. B</th>
<th>Std Error</th>
<th>t</th>
<th>95% Confidence Intervals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smoking history</td>
<td>-6.06</td>
<td>-.29</td>
<td>2.17</td>
<td>-2.79*</td>
<td>-10.38 to -1.74</td>
</tr>
<tr>
<td>Education</td>
<td>2.88</td>
<td>.15</td>
<td>2.04</td>
<td>1.41</td>
<td>-1.19 to 6.95</td>
</tr>
<tr>
<td>Engagement Coping (Eng)</td>
<td>-.55</td>
<td>-.66</td>
<td>.28</td>
<td>-1.94**</td>
<td>-1.11 to 0.02</td>
</tr>
<tr>
<td>Social Constraint (SCS)</td>
<td>-25.22</td>
<td>-.81</td>
<td>11.33</td>
<td>-2.23*</td>
<td>-47.80 to -2.65</td>
</tr>
<tr>
<td>Eng X SCS</td>
<td>.31</td>
<td>.95</td>
<td>.18</td>
<td>1.75</td>
<td>-.04 to .66</td>
</tr>
</tbody>
</table>

*Note.* Values for the table were obtained from the last step of each regression. For smoking history, 0 = never smokers and 2 = current smokers.

* * p<.05, ** p = .06
72) = 5.41, \( p < .05 \). Smoking history was the only variable that significantly accounted for the variance in patients’ HRQOL (\( t = -2.56, \ p < .05 \)).

**Mediation Model Testing**

This study sought to examine whether medication non-adherence mediated the relationship between coping/social constraint and disease activity. This proposed model was examined in accordance with the guidelines set forth by Baron and Kenny (1986). In order to be able to test for mediation, one must first demonstrate that there is a significant relationship between the mediator (non-adherence) and the criterion variable (disease activity). Next, one must demonstrate that there is a significant relationship between the independent variables (engagement coping, disengagement coping, and social constraint) and the mediator (non-adherence). If significant associations are found, then the initial conditions are met in order for mediation to occur. Once significant associations have been demonstrated, the direct path between the independent variables and the dependent variable should be tested. Next, one should test for the impact of the independent variables on disease activity, after having controlled for the mediator (non-adherence). Mediation is said to exist if the relationship between the independent variables and disease activity no longer exists after having controlled for non-adherence or if the relationship is significantly weakened after having controlled for non-adherence.

**Regressions Predicting Disease Activity**

Three sets of logistic regressions were planned to examine whether medication non-adherence (overall, unintentional, both intentional and unintentional) mediated the relationship between social constraint, disengagement coping, and engagement coping and disease activity. However, prior to conducting these separate regressions, chi-square
analyses examining the relation between non-adherence (overall, unintentional, and both intentional and unintentional) and disease activity were conducted; no significant associations were found. Since the first condition for mediation was not met, the proposed mediation model was not examined.

As a result, one logistic regression was conducted examining the independent contributions of engagement coping, disengagement coping, and social constraint on disease activity. The demographic variables (highest education level achieved and age at diagnosis) that were significantly associated with disease activity were entered on the first step as covariates. Engagement coping, disengagement coping, and social constraint were entered on the second step. The overall model was significant, $\chi^2 (5, N=78) = 17.94, p < .05$ (see Table 7). The factors significantly contributing to disease activity were age at diagnosis and disengagement coping. For every one unit increase in age at diagnosis, the odds of disease activity increased by 4.4 and for every one unit increase in the use of disengagement coping, the odds of disease activity increase by 1.08.

Regressions Predicting Medication Non-Adherence

Three logistic regressions were conducted to examine the contributions of coping and social constraint to overall non-adherence, unintentional non-adherence, and both unintentional and intentional non-adherence. Since no demographic variables were significantly associated with overall medication non-adherence, no covariates were entered into this regression. In the first regression model examining predictors of overall medication non-adherence, disengagement coping, engagement coping, and social constraint were entered. The overall model was not significant.
Table 7: Logistic Regression Analysis Examining Effects of Coping and Social Constraint on Disease Activity

<table>
<thead>
<tr>
<th>Step/Predictor</th>
<th>OR</th>
<th>95%CI</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age at diagnosis</td>
<td>4.40*</td>
<td>1.44 to 13.49</td>
</tr>
<tr>
<td>Education</td>
<td>.53</td>
<td>.27 to 1.05</td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disengagement Coping</td>
<td>1.08*</td>
<td>1.00 to 1.64</td>
</tr>
<tr>
<td>Engagement Coping</td>
<td>1.01</td>
<td>.98 to 1.04</td>
</tr>
<tr>
<td>Social Constraint</td>
<td>.99</td>
<td>.98 to 1.01</td>
</tr>
</tbody>
</table>

*Note. Values for the odds ratios and confidence intervals are provided for the step on which they entered the model.

* *p* < .05
The next logistic regression conducted examined predictors of unintentional medication non-adherence. Type of diagnosis (i.e. ulcerative colitis versus Crohn’s disease) and level of education were entered on the first step as covariates. Disengagement coping, engagement coping, and social constraint were entered on the second step. The overall model was not significant.

The final regression conducted examined predictors of both unintentional and intentional medication non-adherence. Age and severity of drug use were entered on the first step as covariates. Disengagement coping, engagement coping, and social constraint were entered on the second step. The overall model was significant; $\chi^2 (5, \ N = 80) = 21.25$, $p<.05$; the only factor significantly contributing to both unintentional and intentional medication non-adherence was perceived social constraint. For every one unit increase in perceived social constraint, the odds of both unintentional and intentional medication non-adherence increased by 11.75 ($OR = 11.75$, 95% CI = 1.34 to 103.25). However, due to the wide confidence interval range, these results should be interpreted with caution.
Discussion

The purpose of the present study was three-fold. First, this study hoped to replicate prior research by demonstrating significant relations among medication non-adherence, disease activity, and HRQOL. Next, it sought to investigate whether group differences in HRQOL, disease activity, and levels of adherence were present for patients high in anxiety and depression versus those low in anxiety and depression. Lastly, this study sought to examine the contributions of coping and social constraint on disclosure on medication non-adherence, disease activity, and HRQOL.

Summary of Findings

In summary, there were numerous significant findings with important implications for clinicians, as well as for future studies. A considerable percentage of the participants seen at this tertiary referral center reported elevated anxiety (49%), elevated depression (26%), and some level of perceived social constraint (67.5%). Elevated levels of anxiety and depression were found to be associated with diminished HRQOL. In addition, high levels of depression were associated with increased disease activity; elevated levels of anxiety were associated with increased perception of social constraint and increased social constraint was associated with increased intentional and unintentional non-adherence. Increased social constraint also contributed to diminished HRQOL. Thus, it is important for clinicians not only to be aware of and evaluate for the presence of psychological distress and social support (specifically in regards to IBD), but also to help normalize the presence of these factors in patients with IBD, inform patients of its impact on HRQOL and disease activity, and to encourage and direct patients to receive appropriate services. In addition, future outcome studies are needed to evaluate
the effect of mental health treatment (individual, group, and wait-list control group) on these variables.

In addition, the present study found a high rate of overall non-adherence (44%), which was concordant with that found in the literature. This is important data that clinicians can present to their patients to aid in the patient-physician relationship and to optimize adherence, HRQOL, and disease activity.

The present study also found that the type of coping utilized and perceived social constraint contribute to HRQOL, disease activity, and non-adherence. More specifically, increased use of disengagement coping is associated with diminished HRQOL, increased disease activity, increased social constraint, and increased anxiety and depression. Thus, this data should aid physicians in informing patients of the negative impact disengagement behaviors have on them and on factors associated with their disease. In addition, when examining predictors of HRQOL, engagement coping approached significance. Therefore, the use of engagement coping contributed to improved HRQOL; this again has important implications for physicians to be able to better aid their patients.

Synopsis of Hypotheses

Much of the present study was exploratory in nature, as there is a paucity of literature examining the contributions of coping and perceived social constraint on HRQOL, disease activity and non-adherence. Prior research demonstrated an inverse association between medication non-adherence and disease activity and between disease activity and HRQOL. Thus, the present study hoped to better elucidate the role of depression/anxiety, coping, and social constraint with respect to these variables. More specifically, high levels of depression and anxiety were expected to be associated with
increased non-adherence and disease activity and with decreased HRQOL. In addition, high levels of social constraint were expected to be associated with diminished HRQOL in the presence of high levels of engagement coping, whereas low levels of social constraint were expected to be associated with improved HRQOL in the presence of low levels of engagement coping. Similarly, it was expected that high levels of social constraint would be associated with diminished HRQOL for low levels of disengagement coping and with increased HRQOL for high levels of disengagement coping. In addition, it was expected that coping, social constraint, and non-adherence would contribute to the level of disease activity. More specifically, non-adherence was expected to mediate the relations between coping and disease activity and between social constraint and disease activity. A better understanding of factors associated with non-adherence, disease activity, and HRQOL would inform future research in confirming the present findings and would result in improved patient care.

Associations Among Medication Non-Adherence, Disease Activity and HRQOL

Like prior research, the present study found a negative association between disease activity and HRQOL. This finding replicates past research (Casellas et al., 2002; Farrokhyar, Marshall, Easterbrook, & Irvine, 2006; Graff et al., 2006; Irvine, 2008; Larsson et al., 2008; Mittermaier et al., 2004), which also has found that those with active IBD disease report diminished HRQOL. In fact, Irvine (2008) reported that disease activity is the most important factor contributing to patients’ HRQOL. Thus, it is important for physicians to be aware of this relationship in order to assess whether patients are experiencing a worsening in their physical, psychosocial, or both areas of their health. Patients experiencing a flare in their disease appear to be at risk for a
diminishment in HRQOL and might be in need of some additional psychological services in order to address these worsening symptoms. In addition, it is important for physicians to empower patients by providing them with the treatment option least likely to interfere with their HRQOL, while maintaining the disease in remission (Irvine, 2008).

The hypothesis that there would be a positive association between disease activity and medication non-adherence was not supported in the present study. Prior research with IBD patients demonstrated a positive association between disease activity and medication non-adherence (Kane et al., 2001; Kane, 2007; Kane, 2008; López-Sanromán & Bermejo, 2006; Sewitch et al., 2003). It is important to examine possible explanations for the failure to replicate these findings. Methodological differences might have contributed in part to this; the manner in which medication non-adherence was measured in the present study was through a binary questionnaire that categorizes patients as being overall non-adherent, intentionally non-adherent, or unintentionally non-adherent. While this questionnaire provides valuable information, it differs from some of the other methods utilized by other researchers. Some researchers measured adherence behaviors on a continuum; therefore, they were able to measure the degree of non-adherence (Ediger et al., 2007; Kane, 2007). Other researchers did not rely on self-report, but measured adherence via pharmacy medication refills (Kane, 2003). It is possible that patients in the present study underestimated their non-adherence, particularly their intentional non-adherence, contributing to the null finding between adherence and disease activity. However, this is unlikely since the overall non-adherence rate of 56.2% found in the present study is concordant with rates reported in the literature (20-40% for short-term therapy and up to 70% for long-term therapy). It also is likely that since this was patients’
first appointment, the patient-physician relationship had not yet been established. Therefore, this likely contributed to patients underreporting their levels of intentional non-adherence. An alternate explanation is that variables such as financial pressures, cost of medication, and depression mediate the relationship between non-adherence and disease activity and in fact account for this significant relationship. In fact, the highest education level achieved by the participants in the present study appeared to be greater than participants in other studies. The present sample included 51% who received a high school degree or less, 29% who received an associate or bachelor degree, and 17.5% who received a masters or professional degree. Prior research reported only between 25% and 32% of participants receiving a university degree or greater (Ediger et al., 2007; Graff et al., 2006; Larsson et al., 2008). Factors such as education and socio-economic status might have contributed to this null finding. In addition, this single time point might have failed to capture the relationship. Future research with a more diverse population and with multiple time points would help to clarify this relationship.

The present study also failed to replicate prior research findings examining the relation between HRQOL and non-adherence; a negative association between HRQOL and non-adherence was not supported in the present study. There are mixed findings regarding this relationship in the literature. Some researchers have not found a significant relationship (Kane et al., 2001; Mantzaris et al., 2007), while other researchers have (Hommel, Davis, & Baldassano, 2008; Irvine, 2008; López-Sanroman & Bermejo, 2006). Again, the methodology utilized to measure non-adherence might be contributing to these null findings. In addition, it is likely that since this study only had one data point, it failed
to find the relationship. Future studies that examine these variables over multiple time points are likely to find a relationship.

**Group Differences in Disease Activity, Medication Non-Adherence, and HRQOL**

Group differences were expected between patients who were high in depression or high in anxiety compared to those low in depression or in anxiety. More specifically, it was hypothesized that patients high in depression or high in anxiety would have increased disease activity and medication non-adherence, and diminished HRQOL, as compared to patients low in depression or in anxiety. The present study found partial support for these hypotheses.

It was hypothesized that patients high in depression or anxiety would experience diminished HRQOL compared to patients low in depression or anxiety; this was supported in the present study. Both in the present study and in prior research, HRQOL has been found to be associated with disease activity. Although group differences in anxiety were not found for disease activity, they were found for HRQOL. It is crucial for physicians to better understand all variables that directly and indirectly influence HRQOL; as this understanding increases, physicians will be better equipped to address all underlying factors contributing to HRQOL in patients with ulcerative colitis and Crohn’s disease. This will yield to improvements in care and more appropriate healthcare utilization.

As previous research has shown, there were significant group differences for patients high in depression compared to those low in depression (Angelopoulos et al., 1996; Graff et al., 2006; Larsson et al., 2008; Levenstein, 2002; Porcelli et al., 1996; Searle & Bennett, 2001) in disease activity. More specifically, more patients who scored
as having possible or probable depression reported disease activity than patients without depression. It is important for physicians to be aware of this relationship as patients’ disease activity is likely contributing to their mental health, and their mental health, in turn, is contributing to their disease activity. Patients who experience an increase in depression may be more likely to be aware of their disease symptoms and be more likely to seek medical attention. Some of the symptoms that patients with depressed mood experience include: diminished interest in activities, fatigue, weight loss, diminished ability to concentrate. These symptoms overlap with symptoms that patients with active disease can experience. Thus, it might be difficult to parse apart whether disease activity, depressed mood, or a combination of the two contributes to these symptoms. It is crucial that physicians assess for depression in their patients and provide appropriate referrals for mental health care, and be aware of the impact of the disease not only on patients’ physical health but also on their emotional well-being. It also might be of importance for providers to evaluate for mucosal inflammation in patients with high depression scores to tease out which symptoms are from depression and which are from IBD. Addressing patients’ depression is likely to result in a noticeable improvement in medical health and will improve the care that patients receive. In addition to providing improved care, if depressed mood is contributing to disease activity, addressing mental health would likely reduce unnecessary healthcare utilization, as well as healthcare cost. 

In contrast to prior research (Angelopoulos et al., 1996; Graff et al., 2006; Larsson et al., 2008; Levenstein, 2002; Porcelli et al., 1996; Searle & Bennett, 2001), the present study did not find a significant group difference between patients high in anxiety and low in anxiety in terms of disease activity. It is likely that this discrepancy is related
to our definition of anxiety in the present study (Addolorato et al., 1997; Levenstein, 2002; Schwartz & Blanchard, 1990; Walker et al., 2008). The inconsistencies regarding levels of anxiety are likely attributable to methodological differences. The present study, like some prior research, utilized a screening measure to assess for elevations in anxiety. However, the present study did not measure the presence of clinical anxiety disorders. It is likely that group differences are present for those with a diagnosis of an anxiety disorder.

The hypothesis that patients high in depression or anxiety would be more non-adherent compared to patients low in depression or anxiety was not supported in the present study. Again, this might be partly explained by the manner in which these constructs were measured. Thus, patients with clinical levels of anxiety or depression might indeed be more non-adherent than patients who do not meet diagnostic criteria for depression or an anxiety disorder. More research is necessary to examine whether screening patients for elevations in symptoms of depression and anxious mood versus meeting DSM diagnostic criteria for clinical depression and/or anxiety would yield different findings. Alternatively, the manner in which non-adherence was measured – categorical adherence versus non-adherence as opposed to measuring the degree of adherence, might have yielded different results. It also is possible that depression and anxiety do not directly influence patients’ level of adherence.

Social Constraint as a Moderator between Coping and HRQOL

It was hypothesized that social constraint would moderate the relationship between coping (engagement/disengagement) and HRQOL. This relationship was examined twice for engagement coping since the use of engagement coping was not-
normally distributed in the current sample. In fact, a greater amount of patients reported using engagement coping than would have been expected. Thus, the statistical analyses examined the hypothesis first without transforming the variable of engagement coping and then by transforming the variable. When no transformation was conducted, the present study found that perceived social constraint independently contributed to patients’ HRQOL. Engagement coping approached significance (both when it was transformed and not). However, when the engagement coping variable was transformed, social constraint no longer significantly contributed to HRQOL. Moreover, when engagement coping was not transformed, it was shown to have a negative relation with HRQOL, whereas, when it was transformed, it was shown to have a positive relation. It is difficult to interpret these findings due to the normality assumption being violated. It is likely that with a larger sample size and multiple time points, clarity regarding the relationship amongst these variables would be found.

In addition, it was expected that social constraint would moderate the relationship between disengagement coping and HRQOL. Nicholas et al. (2007) found that individuals experiencing social constraint had greater difficulty coping with their IBD. Thus, it would follow that these individuals likely used more disengagement coping and experienced diminished HRQOL. The present study failed to find support for this hypothesis. In addition, neither disengagement coping nor social constraint independently contributed to HRQOL. It is likely that dichotomizing social constraint contributed in part to the null finding; in future studies it would be desirable to measure not only whether individuals perceive to be unsupported or alienated from their social support network regarding their disease but also the degree to which they perceive such social
constraint. In addition, specific types of disengagement coping likely influence patients’ HRQOL (such as avoidance or denial), whereas other types of coping might not influence HRQOL directly. It also is likely that perceived control over one’s disease moderates the relationship between disengagement coping and HRQOL. In fact, research (Graff et al., 2009; Voth & Sirois, 2009) has found that the attributions of mastery or responsibility are associated with decreased use of avoidance coping and increased psychological adjustment. In addition, Voth and Sirois (2009) found that the attribution of self-blame was associated with increased avoidance coping and poor psychological adjustment. Thus, for patients who do not perceive to have control over their disease, the use of disengagement coping could be quite beneficiary in terms of HRQOL; this form of coping would be functioning much like cognitive or behavioral distraction. In contrast, for patients who perceive to have control over their disease, the use of disengagement coping would likely result in diminished HRQOL. Therefore, in future research, it would be important to examine whether factors such as attributions and perceived control mediate the relationship between coping and HRQOL, as attribution does with psychological adjustment.

Contributions of Coping on Medication Non-adherence, Disease Activity, and HRQOL

The hypothesis that there would be direct effects of coping on HRQOL was partially supported. More specifically, increased engagement coping was expected to be positively associated with HRQOL, whereas increased disengagement coping was expected to be inversely associated with HRQOL. Engagement coping approached significance ($p = .06$). Due to the skewed distribution of the use of engagement coping in the present study, the interpretation of its influence needs to be done with some caution.
When engagement coping was transformed, a positive association with HRQOL was found, which replicates findings from prior research (Moskovitz et al., 2000; Smolen & Topp, 1997; Van der Zaag-Looneh et al., 2004). However, when engagement coping was not transformed, its relation with HRQOL also approached significance, but it was inversely associated. It is possible that since the patient-physician relation had not been established yet (as this was patients’ first visit), patients over-reported the use of engagement coping to present themselves in a more positive light. Thus, it seems likely that there is a positive relation between these two, since the transformed engagement coping normalized the variable; however, additional research elucidating this relation would be beneficial.

In contrast to prior research (Dorrian, Dempster, & Adair, 2009; Moreno-Jiménez et al., 2007; Moskovitz et al., 2000; Petrak et al., 2001; Smolen & Topp, 1997), the use of disengagement coping was not found to directly influence patients’ HRQOL. One possible interpretation of this finding is that it is not of importance whether patients utilize disengagement coping (i.e., using avoidance or denial), but rather it is of importance whether they are using engagement coping strategies (i.e. problem solving, seeking information, seeking social support). Alternatively, it is likely that not all types of disengagement coping directly influence patients’ HRQOL but certain types of disengagement coping have a direct impact. Moreover, the perceived control over one’s disease likely moderates the relationship between disengagement coping and HRQOL. In fact, Dorrian, Dempster, and Adair (2009) found that illness perception accounted for patients’ adjustment and QOL; Nicholas et al. (2007) found that patients reported diminished perceived control with disease activity.
The hypothesis that there would be direct effects of coping on disease activity was partially supported. More specifically, increased use of engagement coping was expected to be inversely associated with disease activity, whereas increased use of disengagement coping was expected to be positively associated with disease activity. Only one prior study examined the relationship between coping and disease activity; this study found no direct association (Larsson et al., 2008). However, this study looked at individuals’ general coping, as opposed to looking at how they cope with their IBD, specifically. Thus, the hypotheses for the present study were exploratory in nature. The present study found support for a significant association between disengagement coping and disease activity. Increased use of disengagement coping was positively associated with disease activity. It is intuitive that the use of disengagement coping likely influences disease activity, in that if patients’ are using avoidance or denial, this will have a direct impact on their behaviors and on their disease. Support was not found for an association between the use of engagement coping and disease activity. It is possible that one needs to examine specific types of engagement coping and see if specific types are associated with quiescent disease. In addition, when patients’ disease is active, they might have to restrict activities due to the nature of the disease. Some of the limitations that might result from a severe flare include patients’ ability to actively cope and engage and plan on how to cope. For example, patients might exercise as a form of relaxation; however, when patients’ disease is active, they might need to restrict their daily routines. Alternatively, it is possible that other variables are mediating the relationship between engagement coping and disease activity (such as medication adherence and perceived control over one’s disease). If patients perceive to have control over their disease, the use of engagement
coping is likely to be adaptive. However, if patients do not perceive to have control over their IBD, the use of engagement coping strategies is likely to be maladaptive. It also is important to remember that coping is an ongoing process. Thus, examining coping over an extended time period might result in a negative association between engagement coping and disease activity.

It also was hypothesized that there would be a direct relationship between coping and medication non-adherence, such that there would be a positive association between disengagement coping and non-adherence and an inverse association between engagement coping and non-adherence. These hypotheses were not supported in the present study. Prior research has not examined these relationships, so the hypotheses pertaining to engagement and disengagement coping were exploratory in nature. It is possible that a lack of association between coping and adherence is explained by the cross sectional nature of the study; alternatively, type of coping does not influence unintentional non-adherence. Perhaps being cognizant of one’s coping style is likely to have a direct impact when individuals chose to be non-adherent, in contrast with individuals who forget to take their medications. It was not possible to explore this in the present study, since most individuals denied being intentionally non-adherent. In fact, only 11% of the participants reported being only intentionally non-adherent, 23.8% reported being only unintentionally non-adherent, and 22.5% reported being both intentionally and unintentionally non-adherent. While the percentages of unintentional and both intentional and unintentional are concordant with some of the literature, these percentages are in the low-range. The percentage of 56% found in the present study for either intentional or unintentional non-adherence is in the middle of the range found for
long-term non-adherence rates, which range up to 70%. It is possible that as the patient-physician relationship becomes more positively established, self-report regarding non-adherence will be more reliable and may yield different findings than in the present study; alternatively a long-term patient-physician relationship may improve adherence.  

Contributions of Social Constraint on Disclosure on Medication Non-Adherence and, Disease Activity

The present study’s hypotheses predicted a direct association between social constraint and medication non-adherence, as well as with disease activity. A positive relationship was expected between social constraint and medication non-adherence and disease activity; the results provided partial support for this hypothesis. An increase in perceived social constraint was indeed found to be associated with patients reporting both unintentional and intentional non-adherence. Thus, it is important for physicians to be aware of patients who report not having people to talk to or confide in about their disease. These patients are likely to be at increased risk for forgetting and also purposely not adhering to their medical regimen.

In contrast, no significant association was found between social constraint and disease activity, or between social constraint and overall non-adherence or unintentional non-adherence. Prior research (Graff et al., 2006; Maunder et al., 2007) found an inverse association between social support and disease activity. Thus, it seemed likely that social constraint would be positively associated with disease activity. Failing to find a significant association between social constraint and disease activity and between social constraint and other forms of non-adherence is likely attributable to methodological reasons; future studies examining the degree of non-adherence, as well as the degree of
social constraint, might find significant relationships. An additional explanation for failing to find this relationship is that other variables are mediating the relationship between social constraint and disease activity. Prior research with adults with rheumatoid arthritis and with cancer found a positive association between psychological distress and social constraint (Cordova et al., 2001; Danoff-Burg et al., 2004; Lepore & Helgeson, 1998; Manne et al., 2005; Revenson et al., 1991). In addition, prior research with adults with cancer found a positive association between social constraint and disengagement coping (Cordova et al., 2001; Manne et al., 2003; Schmidt & Andrykowski, 2004; Zakowski et al., 2004) and an inverse association between engagement coping and social constraint (Lepore & Ituarte, 1999). Thus it is possible that variables such as psychological distress and coping are mediating the relationship between social constraint and disease activity in patients with IBD. In addition, it is likely that social constraint is influential in those that are intentionally non-adherent. The present study was not able to examine predictors of intentional non-adherence as too few participants endorsed this. However, this might explain why increased social constraint was associated with increased intentional and unintentional non-adherence. Individuals who are intentionally non-adherent may behave in manners that are off-putting, which results in individuals not wishing to listen or be supportive regarding the disease. Finally, the sample size was sufficient to find moderate to large effects; however, it probably was not sufficiently large to capture small to moderate effects.
Medication Non-Adherence as a Mediator between Social Constraint, Coping, and Disease Activity

The hypothesis that medication non-adherence would mediate the relationship between social constraint, coping, and disease activity was not supported. In fact, the only significant predictor of disease activity was disengagement coping. Patients who utilized greater amounts of disengagement coping were found to be at greater risk for active disease. This finding extends prior research with patients with Crohn’s disease that found that patients least likely to relapse were those that utilized avoidance coping the least (Bitton et al., 2008). These findings highlight the importance of physicians evaluating and tending to not only the physical aspects of patients’ IBD but also to how patients perceive and cope with their disease. Physicians who are aware of this problem can either attempt to address coping strategies or can make appropriate mental health referrals that address them. It is important to not only be aware of behaviors negatively impacting disease but also to offer alternate behaviors with a beneficial outcome.

It is likely that individuals’ utilization of disengagement coping strategies influences non-adherence, disease activity, and social constraint, independently. It also is likely that it is not whether individuals perceive social constraint (cognitive domain), but rather how they behave in response to such perception that influences disease activity.

That the present study did not find support for mediation might be explained by design confound. Conceptually, non-adherence is a behavioral form of disengagement coping. Thus, it might not be possible to examine non-adherence and disengagement coping in the same model, as these two factors might not be independent of one another.
Limitations

While the present study contributes to the literature and to patient care, there were several limitations. Because the patients were seen at a tertiary referral center, most of the patients had moderate to severe disease. Therefore this patient population may not be representative of all patients with IBD, and might not reflect how all patients with IBD cope. It would be interesting to assess whether individuals with mild disease cope differently than those with moderate to severe disease. However, it provided an initial step toward acquiring information that is currently unknown regarding the function of coping and social constraint in IBD patients with moderate to severe disease.

Another limitation is that no control group was utilized, as this was a retrospective study. Therefore, one was not able to draw comparisons between IBD patients and healthy controls. However, the information that was generated from this study provided useful information for future studies and for treatment of patients with IBD with moderate to severe disease.

A third limitation was the small sample size. While the sample size was adequate for the proposed statistical analyses; a sample size of 80 is relatively small for logistic regression analyses. It may be possible that this contributed to some of the null findings; a larger sample size might find additional support for some of the proposed hypotheses if the effect sizes are small to moderate.

In addition to the population limitations, another critique is that patients self-reported their medication adherence levels. While it would have been preferable to have corroborating pharmacy refill data or electronic monitoring, that was not feasible since this was a retrospective study. However, Sewitch et al. (2003) found that self-reported
non-adherence to medications with an IBD cohort correlated well with pill counts, electronic monitoring, and pharmacy refill data. Therefore, the information that was generated with patients’ self-report regarding their medication adherence provided valuable information about variables influencing their treatment.

Another methodological limitation is the dichotomous nature of the adherence and social constraint variables. Measuring the degree of adherence and social constraint is likely to provide additional valuable information to the literature. However, due to the smaller sample size and the amount of individuals who denied experiencing social constraint, it was not feasible to measure this variable on a continuum. Although measuring the degree of these two variables, as opposed to the presence/absence, would likely yield richer data, dichotomizing these variables still added to our current knowledge. This is particularly the case with the social constraint variable, which had not been examined in patients with IBD.

In addition, the clinical utility of the information generated from the COPE might have been limited. Although the situational version of the COPE was utilized, allowing the present study to look at how individuals have been coping with their IBD, a coping instrument specifically addressing stressors and challenges faced by individuals with IBD may be more informative. Dorrian, Dempster, and Adair (2009) came to a similar conclusion when analyzing the data that they collected with the COPE with an IBD sample.

Finally, the data only represented one point in time (the baseline visit). It is possible that patients’ responses regarding their adherence behaviors, coping, and perceived social constraint would change as the patient-physician relationship became
more established and as patients developed greater comfort with their physician. Moreover, it is likely that patients’ responses regarding their coping behaviors would change as a function of the level of disease activity and of their perceived control over their disease. Because no research has looked at the role of social constraint in patients with IBD and there has been so little research conducted on the role of coping, this single time-point still adds to the current knowledge-base regarding the influence of these psychosocial variables on medication non-adherence, disease activity, and HRQOL. Therefore, information from the present study provides baseline data for longitudinal studies, as well as clinical trial research. Further, our findings will help IBD providers understand the impact of psychological disease and social support on disease outcomes and assist in guiding support services for patients.

Future Directions

There are several directions for future research based on the findings from the present study. For example, future research should collect prospective data on anxiety, depression, social constraint, coping, non-adherence, disease activity and HRQOL over multiple time points. This methodology would elucidate whether a relationship exists amongst these variables. Multiple points in time would help clarify the role of both coping and social constraint, as both of these variables can change in response to stressors and one’s environment. As Blount et al. (2008) stated, it is important that research be of clinical utility. Discovering the situations in which particular coping strategies are adaptive can lead toward more effective interventions that target teaching effective coping strategies given particular situations and stressors. For example, adaptive coping strategies might differ when the disease is active versus quiescent.
In addition, future research should examine the role that the patient-physician relationship plays in patients’ self-report. It is likely that a moderately to highly discordant patient-physician relationship would confound patients’ reports regarding their perceived constraint and adherence behaviors.

Taking into account the above modifications, clinical trial research would be highly valuable to this field. Clinical trials including both a control group and a treatment group whose coping, depression/anxiety, and social constraint are being addressed would yield valuable clinical information to gastroenterologists. In fact, Miehsler et al. (2008) found that individuals with IBD with impaired social support were in need of psychological intervention. That said, the present study demonstrated that gastroenterologists need to be aware of the presence of depression/anxiety, the types of coping being employed by their patients, as well as whether they perceive that they have support in regards to their IBD. With this knowledge, gastroenterologists either need to address these variables directly, offer group therapy, or provide appropriate mental health referrals. Future research also should examine if there are differences in outcomes based on whether mental health/behavioral treatment for elevated anxiety, depression, and perceived social constraint is provided as part of the medical office visit, as part of group therapy targeting individuals with IBD, as part of individual psychotherapy, or a wait-list control-group.
References


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