THESIS

INTERNALIZING SYMPTOMS, MEDICATION ADHERENCE, AND PERCEIVED SOCIAL

SUPPORT IN INDIVIDUALS WITH INFLAMMATORY BOWEL DISEASE

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ABSTRACT

INTERNALIZING SYMPTOMS, MEDICATION ADHERENCE, AND PERCEIVED SOCIAL

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This study examined the role of perceived social support (PSS) for individuals with inflammatory bowel disease (IBD). Patients were recruited for this study from online forums consisting of Facebook support groups, Twitter followers, and email. This study investigated sociodemographic and disease-related predictors of disease severity for individuals with IBD, as well as whether or not perceived social support moderates the relationship between disease severity, internalizing symptoms, quality of life, and medication adherence. A sample size of 155 individuals self-reporting with inflammatory bowel disease (ulcerative colitis or Crohn's disease) completed questionnaires related to disease severity, disease type, disease duration, quality of life, depression, anxiety, stress, perceived social support, and medication adherence. The study findings suggest that anxiety and stress are potential predictors of scores on disease severity for this population. Results also suggests that perceived social support is likely to have (or had in this sample) a significant, moderating relationship between disease severity and anxiety, disease severity and stress, and disease severity and the full depression, anxiety and stress scale (DASS). Anxiety was also found to moderate the relationship between disease severity and adjusted quality of life (QoL) scale. PSS did not moderate the relationship between disease severity and the abbreviated medication adherence rating scale (MARS) generated by principle component analysis. It is important to note that future research should include a more randomized, representative sample, allowing for more conclusive findings. Understanding the

psychological impact associated with this disease provides continued evidence for the need

support individuals coping with IBD.

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Introduction

Inflammatory bowel disease (IBD)

Gastrointestinal disorders have been significantly underrepresented in psychological literature, particularly inflammatory bowel disease (IBD). As medical practitioners discover more factors contributing to the etiology and physiology of gastrointestinal disorders, research concerning the psychosocial effects of the illness remains well behind in comparison (Graff, Walker, & Bernstein, 2009; Wen & Fiocchi, 2004). In order to understand why the psychosocial effects of IBD are so emotionally taxing, it is essential to first understand the biology and physical impact of the disease (Matthews, Gallo & Taylor, 2010). Exploring the biological mechanisms involved in IBD disease etiology serves to elucidate the complexity of the illness.

IBD is a chronic, autoimmune disease of the gastrointestinal tract affecting approximately 1.6 million Americans (Kilham, Lerner, & Griffiths, 2014). The average age of onset for IBD is between 15-25 years old (Saunders, 2014). Rates of IBD are the most prevalent amongst Jewish individuals than any other ethnic group, and are much higher in European countries (Molodecky et al., 2012). It is a disease in which the chemistry of the bowel is significantly altered by inflammation, bleeding ulcers, and mucosal secretions (Podolsky, 1991). As the chemistry of the bowel is affected, so too, is its ability to function normally. This physiological alteration results in increased bowel urgency, excessive diarrhea, undigested food, fatty deposits in the stool, loss of blood, persistent fatigue, extreme weight loss and anemia (Podolsky, 1991; Opheim, Fagermoen, Bernklev, Jelsness-Jorgensen, & Moum, 2014). An individual experiencing these symptoms typically receives a formal diagnosis from a gastroenterologist, via colonoscopy, to confirm the presence of active disease. The two major diseases that are encompassed within IBD

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are Crohn's disease (CD) and ulcerative colitis (UC) (Shorter, Huizenga, Spencer, & Guy, 1972). These two diseases are grouped together because of similarities in symptom presentation. Despite their similarities, understanding the differences between the UC and CD is vital for research and treatment purposes. Refer to Table 1.

Table 1. Disease Differences between UC and CD

Disease	Ulcerative Colitis	Crohn's Disease
Location	Colonic mucosa only (large intestine and colon)	Transmural mucosa, which includes entire gastrointestinal tract from mouth to anus
Inflammation	Inflammation occurs in a continuous pattern in affected areas	Inflammation may be in patches and intermittent
Pain	Pain is usually in the lower left side of the abdomen	Pain is usually in the lower right side of the abdomen
Appearance	Colon wall is thinner and shows continuous inflammation, ulcers do not extend beyond inner lining	Colon wall is thicker and may have a rocky appearance, ulcers are deep and may extend into all layers of the bowel wall
Bleeding	Bleeding from rectum during bowel movements is not common	Bleeding from rectum during bowel movements is very common
Complications	Fistulas, fissures, and strictures common	Not common in UC; severe anemia common
Treatment	5-Aminosalicylates (5-ASAs) and steroids are common, recent success with anti-TNF-α medications	Steroids are common, not as many 5 ASAs are used, first to show success with anti-TNF-α medications
Surgery	Total colectomy (removal of large intestine and colon) is considered a 'cure'-patient can then have internal or external pouching system	Bowel resections to remove significant diseased portions are possible, but colectomy is not a 'cure' because it is pervasive in the entire gastrointestinal tract and could result in more surgeries

The difference in presentation between UC and CD can result in vastly different treatment plans and prognoses for patients (Schurman, Cushing, Carpenter, & Christenson, 2011). Patients with UC have the option of a colectomy, which is a surgery to remove the entire colon. For patients with UC, surgery is considered the only option that could potentially rid the body of all diseased portions of the intestines (the entire large intestine can be removed as well)

(Moris, 2014). CD, in comparison, involves transmural mucosa that can affect the entire gastrointestinal tract, which extends from the mouth to the anus. Although patients with UC can receive a curative form of surgery that removes the entire diseased portion of the large intestine. Patients with CD can only manage their disease with bowel resections and medication (Moris, 2014).

Individuals needing surgical intervention with UC typically receive either an internal or external pouching system. The most common surgery for UC is a procedure that results in an ileal pouch anal anastomosis (IPAA) (Hahnloser et al., 2007). This is a surgery that is completed by diverting the lower portion of the small intestine (the ileum) through a small opening in the abdominal wall, called a stoma (Hallbook, Hass, Wanstrom, & Sjodahl, 1997). A pouching system is then attached to the outside of the skin and around the stoma to collect waste from the opening. An ileostomy can be permanent, in which case, the external pouching system would remain indefinitely. An individual who has had this procedure, often colloquially referred to as 'j-pouch' surgery, has the option of a reversal surgery. The j-pouch is created from the lower portion of the ileum that is pulled down and sewn together in the shape of a 'j' (Martin et al., 2011). In a reversal surgery, the mucosa that has created the stoma is disconnected from the outside of the skin and reconnected internally (Ba'ath et al., 2007). The internal pouching system made from the lower portion of the ileum (the j-pouch) then acts as the waste removal system for the body (Martin et al., 2011). While this surgery helps eliminate life-threatening symptoms, it is associated with the development of other complications, including; incontinence, pouchitis (inflammation and bleeding in the j-pouch), pelvic sepsis, and cuffitis (Hallbook et al., 1997; Hahnloser et al., 2007; Martin et al., 2011).

These surgical processes involve substantial health risks, and are associated with high levels of pain and discomfort. Patients can potentially experience negative, psychological and emotional effects as they transition through this process (Bekkers et al., 1995). The emotional and psychological changes that occur when adapting to their illness can then result in other personal and social struggles for individuals with the disease. Many patients lose their jobs due to prolonged sick leave, undergo financial strain due to medical bills, and lose friendships and relationships as a result of the debilitating, often isolating symptoms (Taft, Keefer, Artz, Bratten, & Jones, 2011). Levels of perceived stigma increase these feeling of isolation and exclusion (Saunders, 2014; Joachim & Acorn, 2000; Looper & Kirmayer, 2004). It is not uncommon for individuals with IBD to feel an overall loss of identity because the illness has usurped a great deal of the personal and professional agency they once possessed (Taft et al., 2011; Joachim, 2002).

The severity of symptoms in CD can potentially be more traumatic and life-threatening than that of the symptoms of UC (Cámara, Gander, Begré & von Känel, 2011). In CD a thickness in the intestinal wall occurs, resulting in a rocky, callous presentation (Farrell & Savage, 2012). Bowel obstructions can occur when the intestinal wall has become too thick to allow food or other substances to pass through; bowel obstructions are more common for individuals with CD than individuals with UC (Yaffe & Korelitz, 1983). The small intestine is responsible for the body's nutrient absorption, and as such, individuals with CD are at greater risk of malabsorption complications and food-induced bowel obstructions (Massironi et al., 2013). CD can surface in any part of the gastrointestinal (GI) tract, and often does so without any apparent pattern, unlike the gradual, predictable spread of UC. The removal of severely diseased portions in CD will never completely eliminate the disease from the GI (Podolsky,

1991). Individuals that have had a portion of their small intestine removed may develop a condition referred to as 'short bowel syndrome' in which the remaining intestine is too short to allow for nutrient absorption (Kaufman, Mazariegos, & Reyes, 2006). This syndrome often leaves patients completely dependent on total parenternal nutrition (TPN), which is an intravenous method of receiving nutrients (Rajendran & Kumar, 2010). Unlike UC, where a temporary ileostomy is an option, individuals with CD often need a permanent external pouching system, or which can be either an ileostomy or a colostomy, as the disease progresses and their nutrient absorption rates decline (Cosnes et al., 2005). A colostomy is a rerouting of the large intestine that connects the colon the abdominal wall. When individuals with UC receive their ileostomy, this reduces their dependence on invasive medications with significant side effects, whereas individuals with CD will still require these medications as part of lifelong, disease management (Kaufman, et al., 2006).

Stoma creations can cause severe physical, emotional and social challenges for individuals, and can significantly reduce QoL (Ross et al., 2007). Those living with a permanent colostomy are also at risk for experiencing a higher degree of struggle with the physical aspect of their condition and the resultant psychosocial adjustment (Follick, Smith, & Turk, 1984). The visual impact of having an external, waste system can be traumatic for some, who now view their bodies as tainted, and unattractive (Muller, Prosser, Bampton, Mountfield, & Andrews, 2009). The presence of a colostomy intensifies the stigma associated with IBD, and can cause further isolation (Taft et al., 2011).

Pathogenesis

Despite extensive research in the field, there is still no known etiology for the disease, but genetic, environmental, and immunological factors are believed to contribute (Sajadinejad et al.,

2012). However, a compilation of animal studies, research in human genetics and a series of randomized clinical trials have generated new information pertaining to factors involved in the pathogenesis of IBD (Sartor, 2006). Specific genetic factors which contribute to the development of IBD have been identified with the advancement in research techniques (Gordon, Moller, Andersen, & Harbord, 2015; Basso et al., 2014).

Recent studies have illustrated that having first-degree relatives with CD and UC is a significant predicting factor in the development of IBD (Moller et al., 2015). Twin studies have revealed a high concordance rate in monozygotic (MZ) (identical) twins for each subsequent disease. MZ twins presenting with CD are estimated to have a 50% rate of concordance and those presenting with UC are estimated to have approximately 19% concordance, suggesting a strong genetic link in the passing and manifestation of IBD (Halfvarson, Bodin, Tysk, Lindberg, & Järnerot, 2003; Brant, 2011; Sheehan, Moran, Shanahan, 2015; Orholm et al., 1991). Some researchers report lower concordance rates between MZ twins and dizygotic (DZ) twins suggesting that there is a 30.3% concordance rate between MZ twins with CD, and a 15.4% concordance rate for MZ twins with UC (Cho & Brant, 2011). Cho and colleagues (2011) suggest that the concordance rate is 3.6% for DZ twins with CD, and 3.9% for DZ twins with UC.

Ongoing research in IBD twin studies is now looking beyond concordance rates and is examining the role of gut microbiota associated with the disease (Cosnes, Gower-Rousseau, Seksik, & Cortot, 2011). The basis for studying the microbiota in twins stems from discovering a recent trend of increased occurrence of IBD in societies becoming more industrialized (Cosnes, et al., 2011). Researchers want to examine whether or not there is a correlation between this industrialization in societies and a shift in healthy microbiota in the intestines. Cosnes and

colleagues (2011) assert that the trend in transitioning societies to more 'Westernized environments' appears to show an increase in UC first, followed by an increase in CD. Changes in environmental stressors, changes in diet and socioeconomic status alter what the gut is exposed to, which impacts the balance of microbiota (Cosnes et al., 2011).

Perhaps most promising in the realm of genetic hypotheses surrounding development of IBD is the usage of genome wide studies (GWAs) for progressive research in the genetic and microbiome areas. Approximately 160 loci have been identified in the pathology of IBD, suggesting an array of genes associated with its etiology (Knights, Lassen, Xavier, 2013). These loci are associated with the etiopathogenesis of IBD, and some have been identified as specific for CD, some specific for UC, and some encompass both diseases (Hold et al., 2014; Jostins et al., 2012). One of the original genes in these discoveries was the caspase recruitment domain family member 15 (CARD15), which is observed in 25-35% of CD patients and is hypothesized to double the likelihood of developing CD with a heterozygous allele combination, and to increase the likelihood by 20-fold with a homozygous allele combination (Maloy & Powrie, 2011). CARD15 is also referred to as nucleotide-binding oligomerization domain containing 2 (NOD2). A mutation in this gene can result in amino acid substitutions that prevent recognition of pathogenic bacteria, potentially resulting in a dysbiotic intestinal biota as a result (Sartor, 2006).

As genetic research surrounding the pathogenesis of IBD has increased in the last decade, so, too, has research examining microbial involvement in the potential etiology of the disease (Hold et al., 2014). This research considers the continuous, abnormal inflammatory response between communal microbes in a host (host-mutualism). The said host of these microbes has been deemed genetically susceptible, or a carrier of one, or more, of the 160 loci currently

associated with the disease (Khor, Gardet, & Xavier, 2011). This idea of dysbiosis, or imbalance of healthy and harmful gut microbiomes, has become integral to the understanding of IBD. However, researchers are still mystified as to whether this change of normal gut microbiomes as a result of host-microbial mutualism is a result of, or a contributing factor to, the development of IBD (Khor et al., 2011). Researchers do not know which existed first, the microbial imbalance impacting the disease, or the disease leading to microbial imbalance (Knowles & Mikocka-Walus, 2015). Knowles and researchers (2015) also do not know if there are shifts in the microbiota during the course of the disease, and how this might impact the prognosis and treatment symptoms. Hold et al. (2014) posits that the shift of looking for external environmental triggers, to those within our own bodies, or an 'in-vironment' triggers has shed further light on the connection of gut bacteria to immune system function.

The specific genes that impact the pathogenesis of IBD are all associated with immune system responses, the mucosal functioning of the intestines, and in elimination of deleterious bacterial (Sartor, 2006). The immune system response of greatest concern that has been identified in IBD involves an over-activation of T-cells. There is an imbalance between Th-1 cells and Th-2 cells for individuals with IBD (Knowles et al., 2015; Lo, Arsenescu & Friedman, 2013). Medications targeting the deactivation of the tumor necrosis factor-alpha (TNF-α), a pro-inflammatory protein secreted by macrophages and other immune cells, have resulted in symptom reduction for individuals with both CD and UC (D'Haens & Daperno, 2006). Due to the efficacy of the antibodies in regulating the immune response, these medications, such as Remicade (Infliximab), Imuran (Azathioprine) and Humira (Adalimumab), are utilized in the treatment of a wide variety of autoimmune disorders--in addition to IBD (Osbourn, Jermutus, & Duncan, 2003).

Similar to genetic and immunological factors, environmental factors are hypothesized to alter mucosal barrier function, immune system responses, and the bacterial microenvironment of the intestines (Sartor, 2006). The fact that some individuals develop IBD in childhood and others in adulthood, seems to suggest that there are environmental factors associated in the manifestation of the disease in individuals born with a genetic predisposition (Graham & Xavier, 2013). Multiple environmental factors (outside of the emphasis on societies becoming more industrialized correlating with an increased prevalence of IBD) are suggested as triggers for IBD, such as smoking, diet, antibiotics, nonsteroidal anti-inflammatory drugs (NSAIDS), infections and stress (Loftus Jr., 2004, Loftus Jr, Shivashankar, Tremaine, & Zinmeister, 2014). Each of these factors is said to impact susceptibility to inflammation, a symptom central to the classification of IBD. The recognition of genetic, immunological, and environmental influences as contributing factors to the development and exacerbation of IBD, only further illustrates the complexity of the disease (Halfvarson et al., 2003).

As there is no known certain etiology for IBD, it is not surprising that there is also no accepted, universal medical treatment that targets both forms of the disease, or one that treats all symptoms. Medical professionals work with their patients to try and find the most effective treatment for their illness, which can sometimes result in a trial-and-error approach (Červený et al., 2007). This difference in patient response to varying treatments in IBD can potentially expose individuals to harmful medications, sometimes even resulting in enrollment of experimental drug studies where long-term side effects are unknown (Červený et al., 2007). Symptom relief and control are often the foci of most IBD medical interventions, but there is no definitive explanation as to why certain individuals respond positively to steroids and immuno-suppressants and others do not (Ordás, Feagan, & Sandborn, 2012; Buchman, 2001). The course

of the disease is unique for each individual, which also makes it difficult for researchers and medical professionals to predict which patient's symptoms will return if they have gone into remission at one point in time.

The symptoms of IBD are considered relapsing-remitting and are often unpredictable in their onset and severity. As such, they create a pervasive set of personal and social stressors (Griffiths, 2004). For instance, it often becomes difficult for patients with IBD to attend social events due to the unpredictability of the disease symptoms, and the need to be near restroom facilities at all times. Individuals with IBD may, therefore, begin isolating themselves in their homes and withdrawing from their social networks (Nicholas et al., 2007).

Factors Influencing Medication Adherence in IBD

Given that IBD has been deemed an idiopathic, chronic illness that has no cure, an adherence to a specific treatment regimen is essential for symptom management (Kane, Huo, Aikens, & Hanauer, 2003). Individuals with IBD may then attempt to control symptoms by using a vast array of powerful medications and invasive treatments in order to regain a semblance of control over their body's functionality and retain social interactions (Červený et al., 2007). These treatments are also associated with a separate host of debilitating side effects in addition to the existing IBD symptoms, potentially deterring individuals from medication adherence altogether (Kane et al., 2003; Birnie, McLeod, & Watkinson, 1981; Brawley & Culos-Reed, 2000; DiMatteo, Lepper, & Croghan, 2000; DiMatteo). Medication adherence is most commonly defined as the ratio between the medications prescribed by a medical practitioner to the amount of medication consumed by the patient in the same interval of time (Greenley et al., 2015).

According to Schurman and colleagues (2009), individuals who do not adhere to a treatment plan do so for either 'volitional' and/or 'non-volitional' reasons. Non-volitional nonadherence is generally categorized as forgetting to take medication, misplacing medication, not being able to obtain medication for financial reasons, or not fully understanding the guidelines for which to take medication (Schurman et al., 2009). Volitional, or intentional, nonadherence is a purposeful choice to alter the treatment plan, often based on the perceived physical, social, or emotional health of the patient themselves (Schurman et al., 2009). IBD has been identified as an illness where individuals struggle with adherence to their medical treatment plans, despite the need for long-term, medical care (Ediger et al., 2007; Lopez-Sanroman & Bermejo, 2006).). It is estimated that between 16-66% of individuals with IBD adhere to treatment plans, illustrating a high degree of variance in medication adherence between patients (Schurman et al., 2009; Hommel, Davis, & Baldassano, 2008). Further research needs to examine the factors contributing to such large variance in medication adherence.

Treatment regimens for IBD are usually tailored to each individual patient by a medical professional, and targets their particular symptoms and needs (Ediger et al., 2007). These plans and can vary drastically in frequency of need, dosage, or delivery method for individuals with IBD (Schurman et al., 2009). Treatment plans can include oral medications, enteral medications, injections, infusion-based medications, supplements for malnutrition, and dietary restrictions (O'Sullivan & O'Morain, 2006; Greenley et al., 2015). Most IBD, anti-inflammatory medications are consumed on a daily basis (or multiple times a day), and are administered orally or rectally. Alternatively, intravenous immunosuppressants (Humira, Imuran, Remicade) are delivered via infusions (lasting approximately 3-5 hours at an infusion site) that occur approximately every 6-8 weeks (Schurman et al., 2009). Barriers in obtaining IBD medication

exist for patients in both accessibility and practicality, potentially increasing nonadherence. These barriers exist in addition to the often serious physical or emotional side effects that can emerge as a result of these medications (Selinger et al., 2013). Painful, physical side effects of IBD medications include weight gain, pancreatitis, immunological suppression, increased risk of cancer, and rashes or skin irritation, which may act as deterrents to remain on treatment plans (Kane, Huo, Aikens, & Hanauer, 2003; Hommel et al., 2008). Individuals have also reported intentionally altering their treatment plan because they believed they could work towards improved physical, social or emotional outcomes with a different approach (Schurman et al., 2009; Mikocka-Walus, Andrews, von Känel & Moser, 2013).

Researchers hypothesize that there may be a multitude of factors, or barriers, contributing to medication adherence in the IBD population (Nahon et al., 2011; Lindberg, Ebbeskog, Karlen, Oxelmark, 2013). Additionally, research has shown that it is difficult to accurately study medication adherence within the IBD population due to a current lack of reliable and valid measures of adherence (Schurman et al., 2009). Repeated studies assessing medical adherence in patients of chronic illnesses have illustrated the difficulty of studying this behavior in a reliable way (Ediger et al., 2007). In past research, the most common methods of studying adherence have included self-report, pill count, or biological testing (including blood draws and urinalyses) (Nahon et al., 2011). Some studies have examined patients in remission stages of the illness, and researchers assert that rates of relapse are higher in patients not adhering to appropriate medical treatment than patients who are following their prescribed plan (Kane et al., 2003). Lopez-Sanroman and Bermejo (2006), suggest that, outside of measurement issues, there are four main factors that influence medication adherence in individuals with IBD: illness, treatment type (as has already been discussed as a potential barrier), patient characteristics, and the relationship

between the patient and the doctor. Patient illness perceptions and individual characteristics, can greatly impact decisions to seek medical care, as well as the degree to which patients adhere to medical treatment plans (Rochelle & Fidler, 2012). Males have reported higher rates of nonadherence to medication plans within this population, as well as individuals with higher numbers of prescribed medications, individuals that are younger, individuals with higher rates of disease severity, and individuals experiencing psychiatric comorbidity (Ediger et al., 2007). Higher psychiatric comorbidity associated with increased rates of medication nonadherence suggests that the degree of internalizing symptoms experienced by IBD patients might also contribute to medication adherence (Selinger et al., 2013). It is more difficult to adhere to treatment plans when anxiety and depression are high (Grenard et al., 2011; DiMatteo, 2004). DiMatteo, Lepper, & Croghan (2000) conducted a meta-analyses investigating the link between anxiety and depression and their relationship to treatment nonadherence. The likelihood of nonadherence to treatment plans is estimated to triple in depressed individuals (DiMatteo, Lepper, & Croghan, 2000). Depressed individuals might experience negative attitudes towards the efficacy of medication and are less optimistic that it could ease their symptoms (Kane, Khatibi, & Reddy, 2008). Because belief in the efficacy of the treatment is central to medication adherence, it is not surprising that this depression-related hopelessness acts as a deterrent (DiMatteo, Lepper, & Croghan, 2000).

Patient-physician relationships are an important component in medication adherence (Kane et al., 2008). Patients have the best outcome with medication adherence when they collaborate with their doctors about the treatment plan (Kane et al., 2008). This relationship can be categorized as a form of social support, and discord within the patient-physician relationship can negatively impact feelings towards treatment plans (Sewitch et al., 2003). As a form of

social support, medical professionals might also influence attitudes towards treatment plans for patients (Sewitch et al., 2003). If individuals have a better rapport with their doctors and nurses, this might also impact their beliefs about the efficacy of their medications and how they take them (Ghosh, 2008).

Patient characteristics impacting medication adherence include the degree to which patients perceive their levels of social support (Haapamäki, Turunen, Roine, Färkkilä & Arkkila, 2009). Patients may adhere to treatment regimens more if they have social support, as they may have more help in adjusting to adverse reactions or changes in their disease severity (Camara et al., 2011). Having social support may increase patient self-efficacy and the belief that they possess the ability to manage their illness Bonsaksen, Lerdal, & Fagermoen, 2012). In having other individuals check-in with, and hold one accountable, an individual might be more likely to continue taking their medications regularly (Camara et al., 2011). There is also a sense of solidarity and unity in experiencing an illness with others who understand the difficulties, which can provide hope and strength for a patient (Sewitch et al., 2003). A patient who has more hope that their condition will improve is also a patient more likely to continue treatment (Horne & Weinman, 1999).

A lack of medication adherence not only increases health risks for individual patients, but it can become a financial burden on society as well (Horne et al., 1999). These patients tend to have more hospitalizations, an increased number of urgent care visits, and higher treatment costs (Kane et al., 2008). According to Horne and colleagues (1999), in addition to the direct financial loss accompanied with medical costs, a lack of treatment adherence contributes to a loss of productivity and increased absenteeism at places of work. Higgins and colleagues (2009) suggest that patients who are nonadherent to treatment plans can generate up to 12.5% more in

healthcare costs (via disease relapse and other complications) than adherent patients. In studying factors that encourage medication adherence, the resulting individual and societal costs can potentially be reduced.

Although most widely used, self-report measures of medication compliance tend to show inflated measures of compliance most likely resulting from a 'faking-good' attitude (Morisky, Ang, Krousel-Wood & Ward, 2008). Kane et al. (2012) suggests that there is no acceptable, self-report medication adherence scale that captures the rates of medication adherence in the IBD population. It is suggested that a disease-specific medication adherence scale be generated to fully comprehend the effect of the unique barriers to medication adherence for individuals with IBD (Kane at al., 2012). Due to the consistency in reported high rates of nonadherence within the IBD population, it is vital to continue to uncover which factors might be most predictive in improving these rates. Our study used a general, self-report measure of medication adherence and might have impacted the reported levels of adherence that were collected.

Nutrition and IBD

Environmental factors, including changes in dietary preparation and intake, have significantly contributed to the rising incidence of IBD throughout the world (Skrautvol & Na Den, 2011). Diet and food preparation in more developed nations are said to have contributed to a negative shift in the microbiome of individuals in these populations (Skrautvol et al., 2011). This phenomenon, referred to as the hygiene hypothesis, suggests that a microbiome that has been insufficiently colonized by healthy bacteria, leaves individuals much more susceptible to the development of autoimmune disorders, such as IBD (Voreades, Kozil, & Weir, 2014). Various environmental factors can alter an individual's intestinal microbiota, such as diet, smoking, or exposure to antibiotics (Ryu et al., 2008). Exposure to these environmental factors

is linked to the development of IBD, which suggests that the composition of an individual's microbiome is also connected to the immune system (Ryu et al., 2008). As a result of this connection, individuals with autoimmune disorders often attempt to alter the bacteria in their microbiomes, as the shift in active, intestinal bacteria could possibly improve the function of their immune systems. When comparing the possible environmental factors that could impact an individual's microbiome, research suggests that the commitment to a long-term diet has the most influence in building and changing the intestinal make-up (Ryu et al., 2008). More empirical evidence has emerged regarding the importance of diet in both the potential prevention of IBD, as well as in the management of the illness after diagnosis (Olendzki et al., 2014).

Malnutrition is a common complication for individuals with IBD. IBD often prevents patients from fully digesting specific foods, also preventing the full absorption of nutrients. However, researchers have yet to study a diet that works across the entire IBD population (Vidarsdottir, Johannsdottir, Thorsdottir, Bjornsson, & Ramel, 2016). Some patients have reported symptom reduction after eating certain foods, and others have said that those very same foods made their symptoms a great deal worse (Vidarsdottir et al., 2016). Due to the fact that no specific diet plan has been effective for this population as a whole, it is suggested that each patient formulate their own plan based on their individual disease experience (Vidarsdottir et al., 2016). Patients often begin avoiding certain foods altogether based on what helps manage their symptoms, however, avoiding nutrient dense foods could result in significant vitamin and nutrient deficiencies Vidarsdottir et al., 2016). Researchers suggest that individuals in the IBD population most commonly report responding negatively to, are dairy products, processed meats, raw fruits and vegetables, soft drinks, alcohol, and fast food (Vidarsdottir et al., 2016). The fact

that raw fruits and vegetables commonly exacerbate patient symptoms, presents particular concern in regards to potential vitamin deficiency (Vidarsdottir et al., 2016).

As a result of these nutritional deficits, researchers have also begun to study the role of probiotics and prebiotics in helping restore balance in a diseased microbiome, such as those affected by inflammatory bowel disease (Gentschew & Ferguson, 2012). Although prebiotic and probiotic use cannot prevent the occurrence of IBD, some research suggests that it can help increase the rates of remission in patients with IBD (Gentschew et al., 2012). Furthermore, patients can consume such probiotic bacteria in numerous states, including capsule form (Penner & Fedorak, 2005). Research has illustrated increased rates of disease remission in IBD patients taking high doses of VSL #3, a potent prebiotic. While research concerning the nutritional deficits of individuals with IBD is gaining attention, it is clear that a wide gap in this literature currently exists (Tinsley et al, 2016). Tinsley and colleagues (2016) suggest that significantly more research is needed to determine the ways in which we can increase nutrient consumption, and absorption, within this patient population.

Disease Severity and Quality of Life

Chronic illness literature has produced significant evidence that coping with a long-term disease can result in a reduced quality of life (QoL) for individual sufferers (Lim, Jin, & Ng, 2012). QoL is generally defined as a "person's interpretation of their position in life in relation to the value systems in which they inhabit, their cultural background, and how this perception also incorporates their personal goals, standards, expectations, and concerns (Apaz et al., 2009)." Irvine (2004), described quality of life for individuals suffering from a chronic illness as the extent of the disease's impact on a patients function, behavior and performance as well as their perceptions beliefs and attitudes. Estimates of QoL for individuals with IBD has generally been

assessed using self-report measures (Pallis, Vlachonikolis, & Mouzas, 2002). There is debate, however, as to the extent of the relationship between QoL and disease activity, or severity (Guthrie et al., 2002). Some research suggests that the greater the disease activity in patients with IBD, the more reduced their QoL is reported to be. Rochelle and colleagues (2013) suggest that patients who believed their active symptoms would only last a short time had higher rates of QoL than patients who believed their IBD would have long-lasting, serious consequences for their lives. In short, individuals who believed their suffering had an end point, were able to enjoy higher levels of QoL (Rochelle et al., 2013). Individuals with this disease often waver between hope that their disease will remain manageable, and fear that it will debilitate them beyond functionality (Lynch & Spence, 2008). This incessant uncertainty and experience of emotional extremes can significantly worsen QoL for patients with IBD (Lynch & Spence, 2008).

QoL measurements are common in research associated with chronic illness, and, in particular, research examining IBD adjustment (Rochelle et al., 2013; Lynch & Spence, 2008; Kalafateli et al., 2013). Studies have illustrated mixed results regarding whether or not duration of disease (measured in years after diagnosis) affects QoL for patients (Huppertz-Hauss et al., 1993; Jäghult, Saboonchi, Johansson, Wredling,& Kapraali, 2011). Some research suggests that the newer the diagnosis, the lower the QoL reported by individuals (Otley et al., 2006). Other studies report that there is no difference in measured QoL at time of diagnosis and in subsequent measures several years later, suggesting that time to adjust to treatments and to the disease did not improve QoL for the patient (Han et al., 2005). Kalafateli and colleagues (2013) posit that duration of disease has no impact on scores reported on the IBDQ and measures of QoL, and is consistent for patients with either CD or UC. Medical complications related to IBD are also

more likely to develop the longer an individual experiences the disease, potentially reducing quality of life (Casellas, Lopez-Vivancos, Casado, & Malagelada, 2002). The extent to which IBD patients believe medication is controlling their high, disease activity is positively predictive of QoL (Rochelle et al., 2013; Faust, Halpern, Danoff-Burg & Cross, 2012).

Chronic illnesses can interrupt life trajectory to such an extent for its sufferers that it has been conceptualized as a biographical disruption (Bury, 1982). A biographical disruption refers to the jarring impact that a chronic illness has on an individual's level of function and ability to remain active in their daily life (Williams, 1984). Williams's 1984 suggests that a diagnosis of a chronic illness changes the way in which an individual constructs their life narrative. It requires the individual to construct their past, present and future identities in a way that responds to physical and psychosocial limitations that may be a result of their illness. Individuals with IBD who maintain greater levels of normative functioning have higher levels of QoL than individuals who experience a disruption in their daily living (Rochelle & Fidler, 2013). Research suggests that it is important for individuals with IBD to project (even if what they are experiencing is vastly different) an appearance that their normal functioning has been minimally impaired, as the maintenance of a daily routine is associated with greater control over their illness, and higher QoL (Rochelle & Fidler, 2013). The longer the duration of a chronic illness, the more biographical disruptions can occur, shifting perspectives pertaining to an individual's disease and their QoL (Paterson, 2013).

Additionally, the Shifting Perspective Model suggests that as an individual experiences shifts in the severity and symptoms of chronic illness, they also shift in their levels of QoL and their ability to cope effectively (Paterson, 2001). The model posits that a struggle with a chronic illness presents a dialectical experience that includes both illness and wellness (Paterson, 2001).

At times, the illness is at the forefront of attention, most commonly when the physiological symptoms are severe or are *perceived* as severe.   Perception of the illness is vital to the relationship an individual has with their disease, and can strongly influence how their psychological adjustment to the illness progresses (Graff et al., 2009). The longer an individual copes with a chronic illness, perceptions and perspective might also change as a result of life experience. Perceptions also shift continuously based on disease severity and individual's physiological and psychological adaptation to their pain and experience (Paterson, 2001).

Qualitative data was collected in an open-response format on several questions in this survey, and suggests that this model is particularly relevant to our population. Individuals often noted that their responses on item measures would have looked dramatically different if they had answered during their worst flare-ups. A "flare-up" of the disease, which is a sudden increase in severity of symptoms that can result in prolonged hospitalizations and rigorous courses of medications to try and calm down the inflammation in the system (Mackner & Crandall, 2005). This suggests that great oscillation can occur between positive and negative reports of QoL given the status of the disease, which could have impacted the results of this study. In order to garner the most accurate picture of relationships between disease severity, internalizing symptoms, medication compliance, and QoL, research in the future should seek participants with full-blown, active IBD symptoms. This will represent what the greatest needs are for a participant when their illness is at its most impactful state. Having this information can contribute to how we construct treatment plans for patients with IBD as we seek to enhance their QoL.

Internalizing Symptoms and IBD

A widely cited study, referred to as the Manitoba IBD cohort, has highlighted some of the psychological struggles that individuals with IBD experience (Walker et al., 2008). Walker and

colleagues (2008), suggest that individuals with IBD have a twofold increased risk of developing a lifetime diagnosis of depression than non-disease controls. Individuals with IBD also experience significantly higher rates of anxiety and stress than do normal controls, both of which are associated with an exacerbation of disease severity (Berrill et al., 2013, Maunder, 2005). Gray and colleagues (2011) found evidence to support the impact of addressing internalizing symptoms, such as anxiety and depression, in improving rates of medication adherence in the adolescent, IBD patient population. In targeting the reduction of these psychological symptoms, adolescents are better able to overcome barriers to medication adherence (Hommel et al., 2008). Barriers to medication adherence potentially impacted by internalizing symptoms might be decreased attention to details, such as forgetting when to take one's medication, as well as what dosage to consume. The link between internalizing symptoms and IBD can further be explained in terms of neurological connection to the gastrointestinal tract.

The brain-gut axis, or relationship between psychological, sociological, and biological symptoms, appears to play a significant role in disease management for individuals with IBD (Drossman, 2005). There is a relationship between internalizing symptoms, state of colonic mucosa, the inflammatory response, and the hypothalamic-pituitary-adrenal axis (HPA) (Grover, Herfarth & Drossman, 2009). There is a bidirectional relationship between the brain and the gut, and researchers now suggest that dysfunctional microbiota in the intestines can contribute to the development of mood disorders, such as anxiety and depression (Foster & McVey Neufeld, 2013). Having a mental disorder prior to diagnosis can also increase the chances of disease relapse, as can an ongoing mental disorder during the course of the disease (Kessler et al., 2003). Some individuals are formally diagnosed with a type of mental health disorder prior to their

diagnosis of IBD, while others develop psychological symptoms after the manifestation of the physical IBD symptoms.

Physical symptoms of IBD highly impact psychological and psychosocial adjustment for IBD patients, however, medical practitioners can often miss this connection (Pallis, et al., 2002, Knowles et al., 2015). Belief in having little control over the course of their disease has been associated with higher rates of depression of individuals with IBD (Rochelle & Fidler, 2013; Dudley-Brown, 2002). Depression has shown to reduce patient response to medications, increasing rates of relapse (Knowles et al., 2015). The rates of depression for individuals with IBD increase as disease symptoms worsen, suggesting a cyclical pattern of physical and psychological symptoms (Maunder, 2005). A link exists between depression and poor nutritional intake for individuals with IBD, and can be heightened by avoidance of food or negative relationships with food (Knowles et al., 2015). Poor nutrition can increase the likelihood of extraintestinal manifestations, or complications spreading to other bodily organs, occurring for individuals with IBD (Patil & Cross, 2013; Veloso, 2011).

Depression has also been identified as one of the greatest predictors of QoL within individuals in the IBD community, along with rates of active disease (Gomez-Gil et al., 2008). Individuals who report that their illness is associated with serious, long-term consequences, tend to have difficulty with healthy expression and exhibit maladaptive coping strategies (Jones, Wessinger, & Crowell, 2006). Difficulty with emotional expression and representation has been associated with poor psychological adjustment rates, slower levels of recovery, and a high amount of overall distress (Moss-Morris et al., 1996; Rochelle & Fidler, 2013).

Higher rates of anxiety within these populations and can be detrimental to symptom management, which can reduce QoL (MacPhee, Hoffenberg & Feranchak, 1998; Rochelle & Fidler, 2013). In a study examining neural pathways and responses to stressors using fMRI technology, individuals with Crohn's disease were shown to have a weaker habituation to stress than individuals in the general population (Agostini et al., 2013). Habituation to stress is seen as a protective factor for the body to decrease the stress response and prevent over-activation of the sympathetic and parasympathetic nervous systems. Researchers also suggest that there might be a shift in neuronal response to microbiota in patients with IBD that is associated with stress and anxiety (Knowles et al., 2015). Bacterial lumen first contacts sensory neurons, and these sensory neurons synapse with enteric motor neurons (Foster et al., 2013). Enteric motor neurons are vital in impacting intestinal motility (Foster et al., 2013). The sensory neurons are less excitable in patients with IBD, suggesting that enteric nervous system neurons can have electrophysiolocial responses to gut bacteria. This also suggests that the brain can alter responses based on gut microbiota, also potentially explaining the association with mood disorders and the gut (Foster et al., 2013; Agostini et al., 2013).

The elevated levels of depression and anxiety, and decreased reported QoL present in the IBD population suggest a need to discover effective methods of coping with the associated strain of the illness. Research suggests that elevated levels of depression in this population can increase rates of morbidity and mortality, and can result in a less optimistic prognosis for patients (Persoons et al., 2005). There is also evidence to suggest that depressed individuals experience reduced cognitive functioning, which might contribute to forgetting to take one's medication, or ingesting the wrong kind of medication (DiMatteo, Lepper, & Croghan, 2000; Morís, 2014). An association with CD and major depressive disorder has been empirically supported, which

highlights some of the common maladaptive coping factors associated with both physical and physiological diseases (pessimism, catastrophizing thoughts, noncompliance of treatment plan) (Ringel & Drossman, 2001).

Early research regarding the origin of the disease initially cited stress as the cause of the illness, however, it was later established that stress and anxiety are exacerbating factors to an already active, biologically-based disease (Garrett, Brantley, Jones, & McKnight, 1991; Graff et al., 2009).   This distinction was vital to the prognosis and course of treatment that gastroenterologists would give their patients, as well as impacting the direction of future research investigating the etiology of the disease. It is apparent that depression, anxiety and stress can be exacerbating factors of IBD, in addition to the biological course each patient experiences (DiMatteo, 2004).   Patients with depressive symptoms experience a statistically greater number of relapses after a period of remission than individuals who do not experience statistically high depressive symptoms (Mittermaier, Beier, Tillinger, Gangl, & Moser, 1998).

Levenstein and colleagues (2000) also asserted that active disease occurs for UC patients when stress levels are high, further supporting the link between UC and stress. Levels of depression are also higher during periods of active disease (Graff et al., 2009). Further research examining the effects of stress on individuals with IBD suggests that individuals with Crohn's disease experience posttraumatic stress as a result of their illness, and that subsequent studies are needed to determine the impact of their experience, as posttraumatic stress is a widely accepted threat to an individual's overall well-being (Purc-Stephenson, 2014; Camara et al., 2008).

Conceptualizing IBD within the Biopsychosocial Model and the Uncertainty in Illness Theory

The deleterious impact of stress on the body's functioning is well-documented and well-supported. Research suggests that short and long-term psychosocial stressors are as equally

damaging to a body's ability to remain at a healthy functioning level as physical stressors (Sapolsky, 2004). The biopsychosocial model was developed to include multiple factors associated with a person's health, suggesting that a person's health or illness should be viewed from a biological, psychological, and social perspective (Shorter, 2005). The theory is that within the intersectionality of these components, researchers and medical professionals can better understand the trajectory of someone's health, as well as the course of their illness. According to Gatchel and colleagues (2014), the biopsychosocial model "describes chronic pain and disability as a complex and dynamic interaction among physiological, psychological, and social factors that perpetuate, and even worsen, one another, resulting in chronic and complex pain syndromes." Individuals with IBD experience a unique interaction of these factors, which can impact the course of the disease, as well as how frequently one shifts between remission and relapse (Drossman, 2005). There is literature examining the shifting disease model from which IBD is conceptualized (Paterson, 2001). This literature includes examining IBD from the biopsychosocial model. At an International Conference on Functional Gastroentological Disorders held in 2003, researchers and medical personnel first suggested the shift from the biomedical model to the biopsychosocial model in addressing GI disorders (Drossman, 2005). Disease, as it is conceptualized within the biomedical model, focuses on biological shifts in an individual's tissues, cells, and potential organ malfunction. Illness, as encompassed by the biopsychosocial model, includes the biological changes of disease, but also incorporates an individual's subjective interpretation of feeling ill or disabled (Fleisher & Feldman, 1999).

In addition to the overarching factors included in the biopsychosocial model, an individual has internal and external resources that help them deal with stressors they encounter. Individuals with chronic illnesses are forced to pool those resources on a regular basis in moving

forward against the challenges of their illnesses (Camara et al., 2011). Internal resources include personality factors relating to hardiness, optimism, personal control and disclosure, which all impact an individual's ability to adaptively encounter the obstacles associated with their illness (Flett, Baricza, Gupta, Hewitt, & Endler, 2011). External resources for dealing with stress include relationships, social ties, and social support (Penninx, Kreigsman, van Eijk, Boeke, & Deeg, 1996). In the vein of chronic illness and health management, strong social support has been linked to faster recovery rates and fewer medical complications, lower mortality rates, and less distress in the face of chronic and terminal illnesses (Straub, 2012; Koloski, Talley, & Boyce, 2002).

The Impact of Perceived Social Support for Individuals with IBD

Social support can be defined as any aid, encouragement, and benevolence available through relationships and environment (Camara, Lukas, Begre, Pittet, & van Kanel, 2011). The psychological benefits of social support in helping individuals cope with a variety of chronic illnesses are well-documented (Gallant, 2003). The need to match the growing population of affected individuals with adaptive coping strategies and social support becomes clearer as the rates of psychological trauma associated chronic illnesses also increase (Camara et al., 2011). Benefits of providing social support for individuals with chronic illnesses include greater positive emotions, better moods, and higher perceived control (Uchino, 2006). Individuals who have a greater support system tend to cope with physical and psychological symptoms more effectively than individuals who do not, and also report higher levels of overall QoL (Sewitch et al., 2001).

PSS can moderate stress in addition to having health-related benefits outside of regulating stress levels (Penninx et al., 1996). Camara et al. (2011) suggest that

PSS is particularly influential in impacting health-related outcomes. Conversely, low PSS is correlated with poor health-related outcomes, more serious prognoses, and potentially higher rates of morality (Camara et al., 2011; Reblin & Uchino, 2008). Individuals with IBD often isolate themselves from friends and family, who are vital sources of social support, feeling as though they do not understand the struggles they experience with their disease (Purc-Stephenson, 2014). Social support can significantly help individuals with IBD cope with the physical symptoms of the illness, as well as the psychological and emotional impact of the disease (Camara et al., 2011; Donoghue & Siegel, 2000). A vital component of seeking social support for the IBD community lies in the willingness to open up to a group or an individual about the illness, as well as having access to a support network that can provide information and acceptance (Carlsson, Bosaeus, & Nordgren, 2003). Individuals with IBD feel a strong connection to others with their illness, feeling as though they have community that is free of stigma. There is a consistent pattern of individuals with IBD to seek out others who have their disease through support groups, online communities, and medical appointments (Purc-Stephenson et al., 2014, Knowles & Mikocka-Walus, 2014). There is currently a dearth of literature that discusses the impact of social support in the IBD population; more research is necessary to understand the benefits social support can potentially provide for this community (Purc-Stephenson et al., 2014).

A theoretical model that incorporates chronic illness characteristics and the benefit of social support is the uncertainty of illness theory (UIT) (Mishel, 1990). This model addresses what individuals with IBD struggle with during the course of their illness, aligning with the physical and emotional consequences of unpredictability in chronic disease progression. The UIT was generated to examine the uncertainty a patient goes through during phases of an illness,

including the diagnostic period, the treatment phase, or in addressing an acute illness with worsening symptoms (Mishel, 1988). Mishel (1990) generated the reconceptualized uncertainty in illness theory (RUIT) in order to address the experience of chronic illness and living with a continuous process of uncertainty rather than a finite period of time as her previous model addressed. Uncertainty, as conceptualized by this model, is the inability to determine or foresee illness-related complications of events (Mishel, 1990). The uncertainty in IBD inhibits some patients from engaging in the construction of a new, cognitive schema as it pertains to their identity as person with a chronic illness (Mishel, 1990). The difficulty of redefining one's identity in the context of a chronic illness, is that the uncertainty of symptom severity can result in a wide spectrum of patient QoL. For example, on one end of the spectrum patients may be hospitalized during severe disease phases, but, on the other end of the spectrum, they can also resume their somewhat normal, daily routines when their symptoms are under control. Due to this uncertainty, it is difficult for individuals to plan life events around the state of their physical health (Camachio, Verstappen, & Symmons, 2012). The physical resources that are required to fight IBD consume a significant amount of physical and cognitive energy, and can often leave individuals feeling weak and depleted (Tinsley et al., 2016). Individuals with severe symptoms can feel as though they have lost control of their bodily functions, which can increase feelings of stigmatization and embarrassment (Hall, Rubin, Dougall, Hungin, & Neely, 2005). This uncertainty can create a sense of personal and social helplessness for individuals with IBD (Camacho, Verstappen & Symmons, 2012). Mishel's model (1990) suggests a method of management for these unpredictable symptoms through changes in cognitive schemas and increased social support.

There are three central components to Mishel's (1990) model: 1) antecedents of uncertainty, 2) appraisal of uncertainty, and 3) coping with uncertainty. The RUIT includes two additional concepts, which include self-organization and probabilistic thinking. This model is designed to explain the experiences of an individual living with a remitting-relapsing disease, with the potential for relapse always present (Mishel, 1990). The RUIT suggests that although uncertainty of one's illness is difficult as the individual adjusts to their diagnosis, but, in time, there is personal growth that can occur through this process (Mishel, 1990).

The appraisal of uncertainty within the RUIT model refers to the ability to attach a positive or negative value to the uncertainty of the illness. This appraisal can further be conceptualized to explain individuals who view their illness as a threat versus those who can view the experience as an opportunity for growth (Mishel, 1990). In the coping portion of the model, if an individual is coping with an appraisal of uncertainty base on a perception of threat, they may engage in activities that potentially decrease management and predictability of symptoms. If an individual believes in the potential for positive growth even in the face of uncertainty, they will be more likely to engage in activities that are biopsychosocially adaptive within the context of unpredictability (Mishel, 1990). The addition of self-organization, or the restructuring of one's guiding life principles, allows for an integration of uncertainty into a new, positive pattern of living (Mishel, 1990). Hence, a new cognitive schema is created in which the individual integrates the uncertainty of their illness into their life, also allowing them to concurrently construct a meaningful identity (Mishel, 1990). Individuals who view their illness experience as an opportunity for growth tend to be less negatively impacted by external events around them, and they also develop more coping strategies that help reduce internalizing symptoms (Mishel, 1990).

Mishel (1990) asserts that strong social support and connection with 'similar others' can contribute to viewing an illness in a more positive light, which can then lead to an opportunity for the illness to become an opportunity for growth. Similar others, or other individuals suffering from the same illness (or related illness), can provide a number of resources to other individuals experiencing their disease, including: information, encouragement, and effective strategies they have obtained from experience with the illness. Disease severity and symptom stability are contributing factors in levels of uncertainty experienced by patients. These factors are considered to antecedent factors in the RUIT model (Mishel, 1990). Erratic disease patterns contribute to feelings of long-term uncertainty and feelings of hopelessness.

The fact that the onset of IBD is, on average, fairly early in an individual's life, individuals are forced to live with an unpredictable disease course and a potentially significantly reduced quality of life for decades. There is often a psychological strain that results from the endurance of this symptom management for such a long period of time, that it often requires patients to seek some source of social support to aid in coping (Graff et al., 2009). The utilization of the RUIT could help patients focus on shifting the perspective of their illness as a deficit and begin to see it as an advantageous chance to focus on growth and development, especially in terms of interpersonal relationships and social support.

Rates of depression and anxiety are commonly much higher in chronic illness populations in comparison to the average population, increasing the need for social support to help manage their psychological distress (Graff et al., 2009). We have discussed the relationship between IBD and greater prevalence of internalizing symptoms, such as depression, anxiety and stress (occurring in large part due to loss of control and autonomy for patients), but we have not discussed the mitigating factors of social support on these psychological burdens. Individuals in

the IBD population that are also battling higher levels of anxiety and depression tend to have longer, more severe flare ups than individuals who do not suffer from high levels of anxiety and depression, increasing spontaneous relapse rates. Levels of depression and anxiety can potentially be easier to manage if an individual has social support and resources to help attenuate the effects of said psychological distress (Camara et al., 2011).

Research examining the impact of support groups on reducing stress surrounding a chronic illness have been done in other populations coping with chronic illnesses, such as cancer (Stange et al., 2006). Patients battling cancer have also been conceptualized using the uncertainty of illness theory, supporting its strength in addressing chronic illness concerns (Lee, 2006). These studies suggest that availability of community resources, access to information, components of acceptance, and relief of family members are all contributing factors in helping an individual attach a positive association to unpredictability, which helps reduce depression and anxiety surrounding an individual's disease (Stange et al., 2006). As it pertains to the RUIT, participation in support groups for specific illnesses is likely to reinforce community and understanding in a way that shows other individuals coping and thriving with a chronic illness (Kagee, & van der Merwe, 2006). Studies suggest that individuals with chronic illnesses who perceive higher levels of social support tend to manage this depression and anxiety surrounding their illness more effectively (DiMatteo, 2004). Similarly, it is possible that individuals with IBD whose depression/anxiety is better managed by social support are also better able to manage their physiological symptoms (DiMatteo, 2004; Mittermaier et al., 2004)

IBD and other related GI disorders have been overlooked in social support literature, further highlighting the need to examine PSS with the intended study (Crane & Martin, 2004; Graff et al., 2009). Camara et al. (2011) studied the impact of social support on the development

of adverse effects in individuals with CD, discovering that social support was one of the highest predictors in reducing negative outcomes associated with IBD (1.5-fold reduced symptomology per 1 standard deviation on social support scale, *ENRICHD Social Support Inventory)* (Camara et al., 2011

Purpose of Study

This study had two major aims; first, to examine whether or not PSS acts as a mitigating factor for levels of anxiety and depression for individuals with IBD. Although chronic illness literature has established PSS as beneficial for anxiety and depression, this literature has not been looked at within the IBD patient population specifically. The second aim of the study was to assess whether PSSt moderates the relationship between depression and medication adherence within the IBD patient population. Research suggests that depression reduces rates of medication adherence in chronic illness populations, but PSS has not been examined as a potential moderating variable in IBD-related studies (Camara et al., 2011). Consequently, 5 research questions were investigated in this study:

Research Question 1:

Do levels of perceived social support predict disease severity above and beyond internalizing symptoms, medication adherence and QoL?

Research Question 2:

Does perceived social support moderate the association between IBD disease severity and internalizing symptoms (depression, stress, and anxiety) for individuals diagnosed with IBD?

Research Question 3:

Does perceived social support moderate the association between IBD disease severity and medication adherence?

Research Question 4:

Does depression moderate the association between disease severity and medication adherence?

Research Question 5:

Does anxiety moderate the association between disease severity and QoL?

Method

Study Design

This study used a cross sectional design to examine the relationship among IBD disease severity on various physical and psychological outcomes, as well as illness related attitudes. This study used a convenience sample and, as such, the participants were not randomly selected. The independent variables included: age, sex, IBD disease type (UC or CD), IBD duration, QoL (SF-36), depression, anxiety, stress, PSS, online support, and medication adherence. Data were obtained via self-report questionnaires in an online survey during the fall of 2015. Disease severity, as measured by the IBDQ, was the dependent variable in this study. Moderation analyses were conducted following the hierarchical linear regression.

Power Analysis

A power analysis was conducted to determine the number of participants needed to detect the expected effect size of the variables of interest in this study. In order to determine the sample size necessary for adequate statistical power, G*Power was utilized with a specification of an a priori analysis in a linear multiple regression. The regression included twelve independent variables (the number used for our study) with a set alpha level of .01 and a hypothesized effect size (.15). G*Power calculated that the number of participants needed for an actual power of .99 in this regression analyses was 123.

Participants

Initially, missing data was to be replaced by the mean of that variable. However, upon exploration of the data, dropout, consenting but not even beginning the survey, was pronounced, over 50%. Based on this discovery, these individuals were dropped and the original sample size decreased from 306 to 155. The participants included in analyses still had some missing responses, but had answered at least one question in every scale.

Thirty males (19.4%) and 125 females (80.6%) who ranged in age from 19-69 years old ($M = 37.60$, $SD = 12.44$) participated. More than half, 59.4%, of participants were from the United States, 11.6% from Canada, and 29% selected 'other', which included: England ($n = 21$), the Netherlands ($n = 2$), Scotland ($n = 2$), Romania ($n = 1$), New Zealand ($n = 7$), Australia ($n = 9$), Singapore ($n = 1$), Germany ($n = 1$) and India ($n = 1$). Participants identified as Caucasian (92.3%), African American (1.3%), Hispanic (1.3%), Asian (1.3%), Native American (.6%), and Other (3.2%). The highest percentage of participants made an annual salary of less than $20,000 or between $20,000-$29,000 per year (49.6% combined). A little under half, 45.8%, of participants rated their disease as severe, 41.9% as moderate, and 11.6% mild.

Procedures

Participant recruitment.

Participants were recruited via social media forums. The two social media forums utilized most heavily were Twitter and Facebook. Individual requests were tweeted to people who had identified themselves as having either Crohn's disease or ulcerative colitis. Individuals identified their connection to IBD on Twitter by including their disease in their username or in a caption hashtag visible on their profile. On Facebook, a general post was made on the investigator's profile page. Other requests were sent to established, Facebook support groups.

These support groups were identified in doing a general search on the site using keywords including: Crohn's disease, IBD, ulcerative colitis, ileostomy, or colostomy. Finally, the prompt and link to the survey was distributed via email. Together these methods generated a snowball effect of individuals passing along the survey.

Participants clicked on the link to the survey, which took them to an informed consent page. This page outlined the purpose of the study, identified relevant parties to contact with questions regarding the study, and a brief description of how long the following survey might take. Participants were allotted an unlimited time period to complete the survey and were allowed to step away from their computer and resume again should they need a break. If completed in one sitting, the survey assessment took approximately 25 minutes. The surveys were designed and administered online through the Qualtrics survey package, which is provided access to students at Colorado State University.

Measures

Inflammatory Bowel Disease Questionnaire

The IBDQ was administered to assess disease severity of symptoms for participants with Inflammatory Bowel Disease (IBDQ; Guyatt et al., 1989). The IBDQ consists of 32 questions broken down into 4 distinct subscales, which include bowel related symptoms (10 items), systemic function (5 items), social function (12 items), and emotional status (5 items) (Magalhaes, Castro, Carvalho, Moreira & Cotter, 2014). The questions are scored on a 1-7 Likert scale, with 1 indicating the highest severity of the disease. Although this has not been noted in literature, the counterintuitive scoring system (that lower scores indicate higher disease severity) used by the IBDQ lends itself to more complicated analysis, and might be improved with revision. Hlavaty and colleagues (2006) proposed that scores greater than or equal to 170

signified remission. For the purpose of our study we examined severity on a continuous scale and simply correlated lower scores with higher severity, and higher scores with lower severity. The test-retest reliability of the IBDQ for Irvine (1996), ranged between α=.77-.94 and had a strong, consistent intraclass correlation coefficients (ICCs) of .90-.97. Pallis (2004) also reviewed a national collection of data pertaining to the IBDQ, which reported the test-retest reliability of the English IBDQ, which yielded an (α = .72-.89). In a cross-cultural look at the reliability of the IBDQ, Verissimo (2008) established an internal reliability of (α = .92), and a mean α = .82 for the four subscales. For this study, the Inflammatory Bowel Disease Questionnaire alpha was .95.

RAND 36-Item Health Survey

Quality of life (QoL) was assessed with The Short Form-36 (SF-36) Health Survey (Hays, Sherbourne, & Mazel, 1993). . The SF-36 is a 36-item survey, broken down into 8 subscales, that has been widely used to assess generic QoL health issues in individuals with chronic illnesses (Revicki, Rentz, Luo & Wong, 2011); Jenkinson, Coulter, & Wright, 1993). Each scale is directly transformed into a 0-100 scale on the assumption that each question carries equal weight, and the eight scaled scores are the weighted sums of the questions in their section (Revicki et al., 2011). The lower the score, the more dissatisfaction an individual has with their overall QoL (a score closer to 0 indicates a poorer QoL, whereas a score closer to 100 indicates a greater QoL) (McColl, Han, Barton & Welfare, 2004). Bernklev and colleagues (2005) conducted a study examining the reliability of the separate subscales as reported through Chronbach's alpha for both CD and UC, which yielded physical functioning CD (α = .85) and UC (α = .91), social functioning CD (α = .80) and UC (α = .81), role limitations due to physical problems CD (α = .88) and UC (α = .89), role limitations due to emotional problems CD (α =

.72) and UC (α = .74), mental health CD (α = .84) and UC (α = .81), energy and vitality CD (α = .86) and UC (α = .86), pain CD (α = .90) and UC (α = .88), and general perception of health CD (α = .83) and UC (α = .81). The SF-36 is reliable and generalizable, having been utilized in empirical studies of more than 200 illnesses (McHorney, Ware Jr & Raczek, 1993; Ware, 2000). Short-Form 36 alpha was .65 in this study (subscale) alphas include: physical functioning was .94, role limitations due to physical health was .93, role limitations due to emotional issues was .87, energy fatigue was .89, emotional well-being was .89, social functioning was .90, pain was .90, and general health .83). Depression, Anxiety, and Stress Scale alpha was .97 (the depression subscale was .94, the anxiety subscale was .91, and the stress subscale was .96) in this study.

Medication Adherence Rating Scale

Medication adherence was assessed with the MARS**,** a ten item, dichotomous questionnaire assessing compliance to prescribed medication regimens (Thompson, Kulkarni, Sergejew, 2000). Thompson and colleagues (2000) generated this scale for a psychiatric population, and illustrated that the scale had adequate reliability (α = .75). The scale is measured by self-report yes / no answers that are scored 0 / 1 respectively. The scores will range from 0-10, with 0 indicating a score of low medication adherence, and 10 indicating a score of high medication adherence (Thompson et al., 2000). Fialko and colleagues (2008) conducted a large scale validation study of the MARS, yielding a lower overall alpha (α = .75) than Thompson and colleagues (2000). The researchers conducted internal reliability tests of the three separate categories that are represented in the MARS, which include medication adherence behavior (α = .67), attitudes towards taking medication (α = .44), and negative side effects and attitudes to psychotropic medication (α = .53). The Medication Adherence Rating Scale alpha was .55 for

this study (adherence behavior scale was .75, attitude taking meds .15, body when taking meds .41). Given this low reliability, a principal components analysis was conducted on the MARS scale. The scale was reduced to 4 items, yielding a reliability of $\alpha = .75$. This 4 item scale was used in the analyses.

Depression Anxiety and Stress Scale

The DASS is a 42-item scale that assesses depression, anxiety and stress, and as such, is broken down into three, 14-item subscales (DASS; Lovibond & Lovibond, 1995). Respondents are asked to use a 4-point severity/frequency scale to rate the extent to which they have experienced each state (depression, anxiety, stress) over the past week. Each question is scored from 0 (Did not apply to me at all) to 3 (Applied to me very much, or most of the time), so that 42 is the highest possible score on each of the three subscales (for a total of 126 on the total DASS). Higher scores indicate higher rates of depression, anxiety and stress. Multiple studies have shown the internal reliability of the Depression Anxiety Stress Scale, illustrating consistent reliability (DASS, Lovibond & Lovibond, 1995; Brown et al., 1997; Antony et al., 1998). Antony and colleagues (1998) reported reliability on the three separate scale, Depression ($\alpha = .97$), Anxiety ($\alpha = .92$), and Stress ($\alpha = .95$). Crawford and colleagues (2003) also reported reliability of the scales Depression ($\alpha = .93$), Anxiety ($\alpha = .95$), and Stress ($\alpha = .90$). In addition to being psychometrically strong, the DASS might be one of the few scales effective at differentiating between anxiety and depression (Page, Hooke & Morrison, 2007). This scale was effective at differentiating anxiety and depression in this study. Depression, Anxiety, and Stress Scale alpha was .98 (the depression subscale was .97, the anxiety subscale was .91, and the stress subscale was .96).

Multidimensional Perceived Social Support (MSPSS)

The MSPSS is a 12-item scale that assesses perceptions of available social support (Zimet, Dahlem, Zimet, & Farley, 1988). The overall scale is reliable, with strong internal consistency (α = .84). The scale is broken down into three separate subscales that assess PSS from family (α = .81), friends (α =.90) and significant others (α = .83) (Zimet et al., 1988). Items are answered on a 7-point Likert scale ranging from 1 (very strongly disagree) to 7 (very strongly agree). Higher scores on the MSPSS indicate higher rates of PSS (Zimet, Powell, Farley, Werkman & Berkoff, 1990). For this study, the MSPSS yielded an α = .97 (significant other subscale was α = .97, family support was α = .96, and friendship support was α = .97).

Online Social Support

Four questions were generated ("I seek emotional help from online support groups," "Online support groups provide me with anonymity in sharing my feelings," "I can talk about my problems with others online because it is often a shared experience," and "Online support groups are more accessible to me given my condition") to examine the importance of online social support for participants. These questions were asked following completion of the MSPSS items. These questions were answered on a 7-point Likert scale ranging from 1, very strongly disagree, 7, very strongly agree. Higher scores on this scale (totals closer to 28) indicate greater usage and reliance upon online social support. Examination of internal consistency in this study yielded (α = .90), supporting the retention of these questions and their utilization in correlation analyses. The online support scale had a strong correlation with the MSPSS scale, which has been established as a reliable and valid measure of social support. Therefore, the online support scale was included in the regression analyses for this study.

Data Analysis

To begin preliminary analysis for this study, all analyses were performed in the Statistical Package for the Social Sciences (SPSS IBM, 2013) and, a priori, $p < .05$ was set as the level of statistical significance. The data was then examined for missing items, which resulted in excluding participants from the analysis to a total of 155 for the analyses (Howell, 2008; Osborne, 2012). Data were checked for accuracy and errors by the researcher before preliminary analyses were conducted. Descriptive statistics were then conducted to examine the data (Table 3). Correlation analyses were also conducted for all independent variables and the dependent variable (Table 5).

Scales were scored according to the specific instructions of the authors of each scale. Various scales and subscales were recoded and summed for the purpose of future analyses. Sex was dummy coded (female = 0, male = 1), as was diagnosis type (ulcerative colitis = 0, Crohn's = 1). First, descriptive plots and statistics including range, mean, standard deviation, skew and kurtosis were performed to examine the normality of each variable in our study. There were no apparent issues with normality based on the results of the descriptive statistics.

Next, the assumptions of regression procedures were examined. We studied several behaviors relating to similar constructs in this study, and as such, there was a probability that there was high correlation amongst variables. Collinearity relates to the potential adverse effects of correlated independent variables on the estimation of regression statistics (Kraemer & Blasey, 2004). Multicollinearity refers to the collinear relations among more than two variables. When multicollinearity becomes an issue, the model may potential become unreliable as the measures are examining the same construct (Kraemer & Blasey, 2004). Signs that suggest multicollinearity include inconsistencies between a significant R^2

when the regression coefficients are not statistically insignificant, or when the regression coefficients would change significantly should certain independent variables be eliminated (or inserted) from the model. SPSS computes tolerance (1- R^2) for evaluation in the analysis. Multicollinearity is suggested to be a problem if the tolerance output is less than 1- R^2. These methods of detecting multicollinearity were utilized in examination of the regression output. The variables were centered for the hierarchical regression as a result of detecting several potential issues with multicollinearity (Table 3.).

Then, the reliability of each measure was examined. Subscales as well as total scores for each predictor variable was tested in reliability analysis. Reliability analyses were conducted for each measure to assess the extent to which all the items measured the same construct, and therefore, connected to the inter-relatedness of the items within the test (Tavakol & Dennick, 2011). Should a scale render poor reliability, further examination was necessary to see whether or not items needed to be dropped from the scale, whereby improving internal reliability. The internal consistencies for measures used in the study ranged from .55 to .97; subsequently, two scales were further examined based on findings of poor reliability. The 'General Health Perceptions' subscale was dropped in the SF-36 scale (with the lowest alpha, .83), increasing the overall Cronbach's alpha from .65 to .73.

The Medication Adherence Rating scale had poor reliability with an alpha was .55, further investigation was conducted to see if using one of the subscales would be more reliable with this population. This is the first time the MARS has been tested for reliability within the IBD population, and was originally designed to assess a psychiatric population. The first subscale, four items measuring medication adherence behaviors, yielded the highest alphas of the subscales, .75. Then a principal components analysis (PCA) was conducted on the MARS scale.

A PCA identifies factors, or principal components, that account for the most variance. This helps decipher what factors are the most salient in the measure for that population. In completing the analysis on the 11 items in the MARS scale used in the study, the first principal components yielded eigenvalues over 1, and accounted for approximately 65% of the variance in responses. The scree plot was also consistent with this 4 item selection, as the descension point stopped at the fourth item and transitioned into what is referred to as rubble items in the remainder of the figure.

A correlation analysis was conducted between the independent and dependent variables as a way to avoid potential confounding variables. There was evidence of online support and disease type as a possible confounding variable in this study, because both were significantly correlated with the dependent and independence variables. These variables were subsequently controlled for in the hierarchical regression as well as the moderation analysis. Following this step, the hierarchical regression was designed to determine the order of variable inclusion. As the hierarchical regression was planned, we entered individual factors in the model first, and then included social support and medication adherence. Data were collected on one occasion for each participant, which all were single, independent samples. Upon running each analysis, scatter plots were also examined to check if each independent variable illustrated a normal distribution pattern with the dependent variable.

Statistical analysis.

A hierarchical linear regression (HLR) was conducted for the purposes of this study. Although the study is exploratory in the sense that there is limited literature regarding the topic, it is not exploratory in a statistical sense. Therefore, a hierarchical linear regression was used instead of a standard regression. HLR is useful in predicting illness-related severity and

behaviors, and was, therefore, appropriate for this study. A written model of the regression

equation used for this study can be viewed below:

$$Y_1 = a + b_1X_1 + b_2X_2 + b_3X_3 + b_4X_4 + b_5X_5 + b_6X_6 + b_7X_7 + b_8X_8 + b_9X_9 + b_{10}X_{10} + b_{11}X_{11}$$

For the purposes of this study, Y_1 = symptom severity as measured by the IBDQ, X_1 = age,

X_2 = sex, X_3 = disease diagnosis, X_4 = disease duration, X_5 = QoL, X_6 = depression, X_7 =

anxiety, X_8 = stress, X_9 = perceived social support, X_{10} = online support, and X_{11} = medication

adherence. The regression correlation coefficients for the independent variables used in the

study are represented via b1-b11. A regression analysis was used to obtain predicted values of

the dependent variable given the specific influence of the independent variables. The R^2 was

then examined in order to establish the amount of variance accounted for in the dependent

variable as a result of the regression with the independent variables.

Variables were then entered hierarchically into the analysis and chosen based on the

multicollinearity analyses and examination of confounding variables. As sociodemographic

variables can potentially confound the relationship between the independent variables and

disease severity, the dependent variable, they were tested first in the regression: age and sex.

The variables entered second in the analysis were disease related variables: disease type

(dichotomous variable, 0 = ulcerative colitis, 1= Crohn's disease), disease duration (in years),

and QoL. The variables entered third in the analyses were internalizing symptoms: depression,

anxiety and stress. The variables entered fourth in the analysis were PSS measures as well as

online support; the variables entered fifth in the analyses was medication adherence. Disease

type and online support were identified as potential confounding variables. As such, an

interaction term created by the product of two variables was added as the sixth model in the

analyses.

Variables entered into the HLR were centered to avoid multicollinearity. In addition to protecting against multicollinearity, suppressor variables were also considered. Suppressor variables are those that enhance the effects of other variables in the set of independent/predictor variables, potentially showing that they account for more of the predicted variance in the dependent variable than they actually do (Tabachnick & Fidell, 2013). There was an indication of the presence of social support as a suppressor variable in each progressive model, as it also did not present with opposite signs in the zero-order correlation output compared to the β weight and semi-partial correlation output, and was consistent with correlation directions of previous output See Table 4.

Finally, six moderation models were examined in SPSS. In order to test whether the effect of independent variables on the dependent variable is conditional on another variable, moderation analyses were conducted. Interaction terms were created to assess the combined effects of PSS and the full DASS scale and medication adherence on disease severity. Product terms were also created to assess the combined effects of medication adherence and depression on disease severity, the combined effects of QoL and anxiety on disease severity, the combined effects of PSS and anxiety on disease severity, and the combined effects of PSS and stress on disease severity. The moderation, regression equations containing the interactions:

Model 1-6: $Y_1 = b_1X + b_2Z + b_3XZ + b_0$

where 1. Y_1 = disease severity, X = perceived social support, Z = full DASS, 2. Y_1 = disease severity, X = perceived social support, Z = medication adherence, 3. Y_1 = disease severity, X = medication adherence, Z = depression, 4. Y_1 = disease severity, X = Qol , Z = anxiety, 5. Y_1 = disease severity, X = perceived social support, Z = anxiety, and 6. Y_1 = disease severity, X =

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perceived social support, Z = stress. The moderation interaction term is achieved when the

predictor variable (X) is multiplied with the moderating variable (Z) to form a new variable

(XZ). Moderation was indicated by a significant interaction term. Significant moderation models

were then examined using the PROCESS macro provided by Hayes (2013) for the purpose of

probing the simple slopes and visualizing the interaction. PROCESS macro automatically

centers variables during analyses. We did not center variables in the initial moderation analyses

as we did in the hierarchical linear regression model. To eliminate superfluous analyses, the

significant models were probed in PROCESS macro. We ultimately probed 3, significant

models that illustrated that the moderator variable, or the combination of the moderator variable

and the independent variable, influenced the dependent variable.

Results

The sample consisted of 155 participants. Descriptive analyses were conducted, as well as an independent samples t-test, to compare the means of the variables by diagnosis, which was dummy coded (ulcerative colitis = 0, Crohn's disease = 1). The independent samples t-test showed that patients with Crohn's disease (m = 16.26) had a significantly longer duration with IBD than individuals with UC (m =9.05) ($p < .001$). Those with CD (m = 19.86) also reported significantly higher rates (m = 18.51) of online social support seeking ($p < .05$). Results can be seen in Table 2.

Table 7 includes the results of the HLR. A regression equation was used to examine the extent to which sociodemographic variables (age, sex) disease related variables (diagnosis type, disease duration), internalizing symptoms (anxiety, depression, and stress), medication adherence, and PSS might explain IBD disease severity (IBDQ). In the equation, age and sex were entered first. The disease-related variables, disease type (Crohn's disease or ulcerative colitis) disease duration (in years), and overall health and well-being (QoL) were entered second. Levels of PSS and online support was entered third. Internalizing symptoms (anxiety, stress, and depression) were entered fourth. Medication adherence was entered fifth. In order to control for potential confounding variables, the sixth regression model included the interaction term between disease type and online social support.

Table 7. includes the results of the disease severity predictive model conducted via hierarchical linear regression. The modified SF-36 scale was used for this regression, which featured 31 items (the General Health subscale was excluded, which included 5 items). The overall predictive model was significant, $F(11, 97) = 10.94$, $p < .001$, $R^2 = .55$. Together, the

variables accounted for 55% of the variance in disease severity. The adjusted $R^2 = .50$, which

represents a medium effect size (Cohen, Cohen, West & Aiken, 2003). Similar to the previous

regression, the second model entered into the regression, including disease related variables was

significant, F (5, 105) = 3.60, $p = .01$ (the change in significance went from $p = .05$ to $p = .01$

with the adjusted SF-36 scale in this model), as well as the third model, which was entry of

internalizing symptoms, F (8, 102) = 13.49, $p = <.001$, and the fourth model, which was entry of

the social support variables, F (10, 100) = 11.81, $p = < .001$. Findings also indicated that with

the modified scale, QoL was now the most significant predictor of disease severity within this

model $t = -2.93$, $p = .004$. Stress became the second most significant predictor of disease

severity in the model $t = -2.147$, $p = .03$. Lower scores on the IBDQ represent greater disease

severity, this indicates that the higher scores are on anxiety, the lower the scores on the IBDQ.

Anxiety ($sr = -.13$, $p = .07$), and social support ($sr = -.13$, $p = .07$) were the next most predictive

factors, but were not significant. Age, disease type, duration of diagnosis, medication adherence,

depression, and online support were also not significant predictors of disease severity, all $ps > .1$.

Social support was a potential suppressor in this model. See Table 4.

After examining six moderation models, specified below, via their interaction terms in

SPSS output, significant models were further inspected using the Process macro provided by

Hayes (2013) to visualize the interaction and probe simple slopes. Moderation analyses were

performed to examine: 1) If the effect of disease severity ($M = 135.02$, $SD = 36.34$) on

internalizing symptoms, DASS Sum, ($M = 33.66$, $SD = 27.64$) was moderated by PSS ($M = 4.96$,

$SD = 1.70$); 2) (Table 8.), if the effect of disease severity on medication adherence $(M = 16.74$,

$SD = 11.68$) was moderated by PSS (Table 9.), 3) if the effect of disease severity on medication

adherence was moderated by depression ($M = 10.99$, $SD = 10.19$) (Table 10), 4) whether the

effect of disease severity on QoL was moderated by anxiety ($M = 9.65$, $SD = 8.81$) (Table 11), 5) whether the effect of disease severity on anxiety was moderated by PSS (Table 12); and, 6) whether the effect of disease severity on stress ($M = 14.21$, $SD = 10.66$) was moderated by PSS (Table 13). The interaction terms for the second moderation model ($p > .74$) and third moderation model ($p > .46$) were not significant. Thus, neither social support nor depression moderated the effect of disease severity on medication adherence.

When the original QoL scale was used for Moderation Model 4, it did not yield a significant interaction term ($p = .19$). However, the analyses were run a second time after the 'General Health' subscale was dropped to increase the scale's reliability. The interaction term was not found to be significant ($p = .12$), but the overall model was significant ($F (3, 127) = 4.97$, $p = .003$, $R^2 = .11$. Although the interaction term did not yield a significant effect, this model was probed in process due to the change that occurred in using the modified Sf-36 scale. Probing Moderation Model 4 resulted in significant moderation results at the 50th and the 75th percentile of the moderator between disease severity and anxiety, which will be discussed in more detail below. Moderation Model 1 ($F (3, 121) = 44. 59$, $p < .001$, $R^2 = .53$, Moderation Model 5 ($F (3, 124) = 39.91$, $p < .001$, $R^2 = .49$, and Moderation Model 6 ($F (3, 121) = 29.40$, $p < .001$, $R^2 = .42$ also had significant interaction terms.

Moderation Model 1

The slopes of [Y on X] internalizing symptoms on disease severity were significantly different from zero and from each other for the 25th percentile of the moderator ($b = -.54$, $SE = .06$), $t = -9.26$, $p < .001$, 50th percentile of the moderator ($b = -.43$, $SE = .05$), $t = -8.34$, $p < .001$, and 75th percentile of the moderator ($b = -.37$, $SE = .06$), $t = -5.91$, $p < .001$. Findings from this analysis indicate that the effect of disease severity on internalizing symptoms was more

pronounced at lower levels PSS (Figure 1).

Moderation Model 4

The slopes of [Y on X] QoL (the modified scale) on disease severity was not significantly different from zero and from each other for the 25th percentile of the moderator ($b = -.06$, $SE = .04$), $t = -1.75$, $p = .08$. However, significant results were found in the model at the 50th percentile of the moderator ($b = -.08$, $SE = .03$), $t = -2.38$, $p = .019$, and 75th percentile of the moderator ($b = -.13$, $SE = .04$), $t = -3.11$, $p = .002$. Findings from this analysis indicate that the effect of disease severity on QoL was more pronounced at higher levels of anxiety (Figure 2).

Moderation Model 5

The slopes of [Y on X] anxiety on disease severity were significantly different from zero and from each other for the 25th percentile of the moderator ($b = -.16$, $SE = .02$), $t = -8.55$, $p < .001$, 50th percentile of the moderator ($b = -.13$, $SE = .02$), $t = -7.43$, $p < .001$, and 75th percentile of the moderator ($b = -.12$, $SE = .20$), $t = -5.60$, $p < .001$. Findings from this analysis indicate that the effect of disease severity on anxiety was more pronounced at lower levels of perceived social support (Figure 3)

Moderation Model 6

The slopes of [Y on X] stress on disease severity were significantly different from zero and from each other for the 25th percentile of the moderator ($b = -.18$, $SE = .03$), $t = -7.00$, $p < .001$, 50th percentile of the moderator ($b = -.15$, $SE = .02$), $t = -6.33$, $p < .001$, and 75th percentile of the moderator ($b = -.13$, $SE = .27$), $t = -4.56$, $p < .001$. Analysis findings indicate that the effect of disease severity on stress was more pronounced at lower levels of (Figure 4).

Discussion

IBD causes physical and psychological disruption for individuals who battle the disease (Keeton, Mikocka-Wallus, & Andrews, 2014). Previous research illustrates a relationship between IBD disease activity and a reduced QoL. Research also suggests that greater disease severity is associated with higher levels of anxiety and depression, with low rates of medication adherence (Greenley et al., 2015). Perceived social support is an important contributor to adjustment factors associated with IBD (Schwenk, 2014). This examined the extent to which perceived social support moderates the association between disease severity and QoL, and between disease activity and various internalizing symptoms (depression, anxiety and stress). There are no published studies that have examined these questions in an IBD population. This study also examined the factors that potentially moderate the relationship between disease severity and medication adherence, depression and perceived social support within this population. It is important to note that, while this study looked at moderating relationships, it was, ultimately, an exploratory study. This study relied on a convenience sample drawn from online sources. A more representative sample selected randomly from the IBD population would allow this study's findings to generalize to that population.

Research concerning the use of online support systems for individuals with chronic illnesses is novel. According to Yao and colleagues (2015), stigmatized patients with chronic illnesses who seek online support also experience improved levels of QoL. This research suggests that those who perceive themselves most excluded from social networks benefit the most from online support systems (Yao, Zheng, & Fan, 2015). Individuals with IBD experience high levels of perceived stigma (Saunders, 2014). An issue preventing individuals within the

IBD patient population from seeking support outside of the home may be the physical restrictions imposed upon them due to the severity of their symptoms. Speaking anecdotally as a therapist who works closely with chronic illness populations, and those with GI disorders in particular, cancellation rates due to unpredictable disease complications are quite high. This is a difficult hurdle to overcome in achieving therapeutic goals; it is difficult to accomplish meaningful progress with clients when attendance is sporadic. Online support provides the convenience of accessing connection and social support from one's home, or hospital bed. It is not uncommon for individuals to post photos of themselves in their hospital beds on these Facebook support group pages, to which they get an overwhelming response of positive, caring messages from others within the IBD patient population. Being able to connect with others who understand their pain and the impact of this illness, provides a sense of solidarity and understanding that they cannot find with anyone else in their social network. Due to the relationship that exists between this patient population and online support seeking behavior, research pertaining to the efficacy and effectiveness of online therapeutic interventions is an important direction for treating these individuals. Sessions conducting acceptance and commitment therapy (ACT) could be constructed and broadcast through online forums, and individuals could join in for group sessions via Skype or other video chat options available from their computer. This therapy option could increase the rates of patient participation in sessions, which, by extension, could potentially improve their quality of life and help in reduction of internalizing symptoms.

Perceived Social Support

Findings indicated perceived social support was significantly correlated to disease severity and internalizing symptoms. The greater individuals scored on social support, the lower

they reported their disease activity to be. When higher rates of perceived social support were reported, higher levels of stress, anxiety and depression were also reported. Previous evidence suggests that higher perceived social support correlates with an overall decrease in distress related to inflammatory bowel disease (Rini, Jandorf, Valdimarsdottir, Brown & Itzkowitz, 2008). This study's findings illustrate that perceived social support also helps moderate the association between disease severity and internalizing symptoms, providing greater evidence as to its impact on minimizing the effects of physical and psychological components of IBD. The benefits provided from higher perceived social support contribute to the overall well-being of an individual with IBD. These results provide more evidence as to the benefits of social support in managing chronic illnesses and the associated distress of unpredictable symptoms. As physicians and other medical personnel interact with patients with IBD, it is important that they consider the positive impact of social support in helping minimize the burden of disease management on patients with chronic illnesses (Houtum, Rijken, Heijmans & Groenewegen, 2015). Houtum and colleagues (2015) discuss their breakdown of self-management tasks and support needs in 4 distinct categories 1) medical management (taking medications correctly, 2) communication with healthcare providers (visiting for appointments and asking questions), 3) coping with the consequences of the illness (coping with pain, emotions, and an uncertain future), and 4) making lifestyle choices (exercising enough, new diet). Reduced anxiety surrounding IBD can further help reduce hospital and office visits, can increase levels of medication adherence, and can decrease the potential for the occurrence of extraintestinal manifestations (EIMs) (Patil et al., 2013; Veloso, 2011).

Previous literature suggests that social support might be important for psychosocial adjustment in this population, and this study provides evidence that social support, does, in fact,

help patients manage their disease more effectively. Individuals who rate higher levels of perceived social support in previous studies have also associated that support with having greater control over their illness (Joachim, 2002; Rochelle et al., 2013). One of the predictors of high anxiety in the IBD population is loss of control that ensues with chronic, relapsing-remitting symptoms (Sandborm, 2014). A factor that helps them feel more in control can benefit them a great deal. Perhaps this also helps explain the allure of online social support—one has more control over the interactions when they are conducted online. Individuals with IBD can feel anxious and stressed in social interactions with individuals as they never know if/when it might be interrupted by their disease symptoms (Taft, Keefer, Leonhard & Nealon-Woods, 2009). The relationship between anxiety and stress and the severity of disease activity was found to be significantly impacted by perceived social support in the context of our study. The greater the social support, the lower the disease severity, and the lower the levels of anxiety and stress (Joachim, 2002; Rochelle et al., 2013). This suggests that perceived social support has a significant impact on reducing stress/anxiety and disease severity. Social support seems to be an important factor in helping reduce anxiety in individuals with IBD, which is associated with lower disease severity (Kane, 2008; Rochelle et al., 2013). Previous literature suggested that social support might be important for psychosocial adjustment in this population, and this study provides evidence that social support, does, in fact, help patients manage their disease more effectively. Individuals who rate higher levels of perceived social support in previous studies have also associated that support with having greater control over their illness (Joachim, 2002; Rochelle et al., 2013). One of the predictors of high anxiety in the IBD population is loss of control that ensues with chronic, relapsing-remitting symptoms (Sandborn et al., 2014). A factor that helps them feel more in control can benefit them a great deal.

Solomon and colleagues (2012) conducted a randomized control trial to assess the efficacy of web-based interventions for patients with a range of chronic illnesses and conditions. These researchers wanted to examine the extent to which their intervention increased patient activity in self-management interventions (SMIs). SMIs are strategies that patients can utilize to improve disease management, and include programs that help educate them about various aspects of their illness, help them learn ways to incorporate self-care into their routine, and that work to bolster confidence in their overall ability to manage their illness independently (Solomon, Wagner, & Goes, 2012). These strategies are effective at increasing a patient's engagement in disease-management techniques, which contributes to feelings of more control and stability surrounding their illness (Solomon et al., 2012). Patients with IBD feel as though there should be more resources offering psychological support to help cope with the burden of disease management (Mikocka-Walus et al., 2013). Mikocka-Walus and colleagues (2013) assert that psychotherapy is significantly underused in the IBD population as a way to cope with their chronic symptoms and increase feelings of competency concerning disease management. Use of Cognitive Behavioral Therapy (CBT) has shown initial, positive results for IBD patients who attend psychotherapy sessions (Mikocka-Walus et al., 2013). However, barriers such as restricted physical ability seem to be preventing patients from seeking psychotherapy as a treatment modality. As such, Mikocka-Walus and colleagues (2013) also suggest that online forms of psychotherapy and intervention may be the answer to providing IBD patients with the psychological support they need.

Internalizing Symptoms

The significant models in our study suggest that levels of high anxiety and stress are associated with severe disease activity and reduced QoL. Lower levels of disease severity is

associated with lower levels of stress and anxiety (Rochelle et al., 2013). Although the full

DASS scale showed a significant relationship with disease severity, when depression was

isolated from the scale, it was not found to be a significant predictor of disease activity. Hence,

the two most prevalent predictors were stress and anxiety. It is unclear, based on previous

research, which is more impactful on which—whether individuals with high anxiety develop

more severe symptoms, or, that people who already have very severe symptoms experience

extreme stress/anxiety as a result of the complications and disruptions caused by their illness.

Therefore, there is evidence that lower levels of anxiety were associated with lower levels of

disease severity and overall QoL.

Although the absence of a diagnostic interview prohibited determination of clinical

diagnoses, our study highlights the importance of perceived levels of disease severity and overall

well-being as it pertains to anxiety and stress, and therefore, the importance of perceived social

support. How the participants *perceive* pain and associated support impacts their levels of stress

and anxiety (Rochelle et al., 2013). This is consistent with the reconceptualized uncertainty in

illness theory (RUIT), suggesting that those who view their illness as a continuous, unpredictable

threat will remain highly anxious about its prognosis (Mishel, 1990). Those who view their

illness as a potential for post-traumatic growth and opportunity will be less likely to associate the

symptoms with such distress (Mishel, 1990; Calhoun & Tedeschi, 1989; Calhoun, Cann,

Tedeschi & McMillan, 2000). Future research examining post-traumatic growth and disease

severity might continue to inform this theory and its relationship to IBD.

Medication Adherence

Although perceived social support was found to attenuate levels of stress and anxiety

associated with disease severity, we did not find that perceived social support increased

medication adherence based on levels of disease severity. The medication adherence scale was dichotomous and did not provide a wide range of options to show where individuals fall on a continuum of taking their medications, whereby reducing potential variability in the study of adherence patterns. This does not allow us to examine where on the spectrum of medication adherence individuals with higher rates of disease activity and internalizing symptoms fall. There are several potential explanations that might account for our results related to medication adherence.

Medication plans are developed with the intent of helping patients with IBD manage and control their symptoms, but can sometimes result in more negative side effects than positive, leaving individuals with IBD feeling more frustrated and hopeless in the attempt to manage and control their symptoms. Controlling symptoms for an IBD patient might result in less diarrhea, greater absorption of nutrients, lower levels of blood loss and anemia, more control of incontinence, and more energy to engage in daily tasks that have been restricted with the illness symptoms (Vavricka et al., 2015). Effective treatment plans also lessen the pain that individuals with IBD experience, and may prevent against the development of EIMs, allowing for an improved QoL (Vavricka et al., 2015).

This population was also recruited from support groups and individuals active in discussing their disease experience. The support and online network of individuals on these forums could also impact how individuals perceive the benefits of their medication plans. It is common for individuals to publish their personal experiences with various medications with others online, providing information for others wanting to know what medications are available and working most effectively (Coulson, 2015). People have the opportunity to ask questions pertaining to the maintenance of this disease that is beyond the scope of doctors and nurses (Coulson, 2015). This might make an individual more hesitant to even attempt taking this medication. Individuals readily discuss treatment plans, new medications, medication complications, and various management techniques on these forums. Facebook, Twitter, and Youtube have become a valuable resources for people to connect with others who are struggling with this disease, perhaps providing higher levels of perceived social support (Frohlich & Zmyslinski-Seelig, 2012). However, we did not find that perceived social support was predictive of medication adherence in our model. Perceived social support did not impact levels of medication adherence in our study, suggesting that more investigation is needed to fully understand what increases the likelihood of patients with IBD to adhere to their treatment plans. Although this study yielded significant results contributing to the understanding of the role of perceived social support in mitigating disease symptoms and internalizing symptoms in individuals with IBD, this study had numerous limitations. First, instead of using a medication adherence scale with items that only allowed for a dichotomous choice, it would be more informative to use items on a likert-type scale for measuring adherence. The adherence scale

was originally designed for a psychiatric population, and not for individuals with chronic, physical illnesses. A more reliable measure that was constructed for individuals with IBD or other chronic, autoimmune disorders might provide for a more precise understanding of the interaction between medication adherence, disease severity, and internalizing symptoms. Previous studies examining IBD and medication adherence suggest that this population is at high risk for medication non-adherence (Ediger et al., 2007).

This survey was conducted through via online questionnaire. Participants clicked on the posted survey link and were directed to the consent page on the questionnaire. Some participants commented that they had technical difficulty moving on from a page after they had completed questions, and that they sometimes had error codes when clicking on the initial link. These hurdles might have deterred individuals from participating in the survey, or in continuing a survey they had already started, contributing to the high dropout rate (45%). In examining the response rate per question, it became clear that there was a significant drop in answers in the latter half of the survey. Disease severity questions were present early in the questionnaire, and had fewer drop-outs than other measures. This suggests that the survey was too long to sustain the attention of participants and needs to be shorter in the future in order to facilitate greater completion numbers. There might be a correlation of individuals from higher socioeconomic statuses having a computer and therefore, having access to the survey. These individuals might also have had better access to healthcare and social support, which could have impacted our response rates.

It is important to note the limitations in our comprehensive sample. Members of existing IBD, online support groups were sampled, which could be perceived as sampling bias. Individuals in these support groups might have already had low levels of perceived social support in comparison to other individuals with IBD, as they were already utilizing a source of

online support. Individuals utilizing online social support resources might also be exhibiting very severe symptoms, which may make it difficult to leave their homes to seek outside support. Disease severity is a significant variable in our study, which can alter greatly between patients who have active disease versus quiescent, or dormant, disease. According to Bonaz and Bernstein (2013), patients who were asymptomatic during the period of testing (whose disease was inactive for that period of time) had QoL scores that aligned closely with individuals from a non-IBD sample. This is critical to discuss in the findings of this study, as some feedback was given by participants, is support of this research after they had completed the survey. The link was posted on social media pages, and individuals had the ability to comment at the bottom of the entire post if they wanted to, with no connection to the data they had already submitted to Qualtrics. A common theme in the comments was that they could have answered the survey as two different people—one prior to surgery or effective treatment management when their symptoms were very severe, or one post-surgery or effective treatment management where their symptoms were greatly improved and controlled. Individuals stated that because they answered the survey questions based on their current state (predominantly those in the more controlled state with less severe symptoms), they answered questions far more positively than they would have been when their disease was in a severe flare. Although we ask participants if they have had surgery as a result of their struggles with IBD, we do not ask about symptoms pre-operation (assuming their surgery had been more than 4 weeks ago, as this is the longest stretch of time our survey asks the participant to respond to restrospectively).

More asymptomatic responses could have impacted the relationships between variables that we investigated, including lower scores on the IBDQ, better QoL, less anxiety, less depression, and less need for dependence on social support (Sewitch et al., 2001). The

medication adherence piece would likely be impacted as well, as individuals having gone through a body-altering surgery, as well as those who have had success with their medications, might be more conscientious with symptom management having experienced traumatic phases of uncontrollable disease. Those individuals might take more precautions and preventative measures to reduce the likelihood of symptom recurrence and improve overall disease prognosis, like adherence to their prescribed treatment plan.

In addition to have such great variance in the health status of respondents, we depended on self-reported measures to assess severity of Inflammatory Bowel Disease. Previous studies have recruited participants from medical facilities and have been able to ascertain more accurate diagnoses of disease. This study did not verify formal diagnoses with medical practitioners, and depended on the subjective interpretation of individuals who reported the symptoms of their disease. While perceived severity and perceived support were measures we utilized, these are, nonetheless, subjective.

There is also not a disease-specific measure for seeking social support related primarily to IBD, it is quite general. The literature suggests that different chronic illnesses require different kinds of support, as is probably true of each individual. It will be difficult to ascertain what category of support people need more or would be most willing to reach out for: financial, medical, social, familial, spiritual, or any other facet that might help them better cope with their illness. There has simply not been an examination of social support within the realm of the IBD population.

Although perceived social support was not a moderating factor in medication adherence, it appears highly correlated to anxiety. Our measures of medication adherence may not have been comprehensive enough to fully understand how it is impacted by disease severity and perceived social support. Given the influence of internalizing symptoms on disease severity, more research

concerning the types of social support that provide the most help to this population should be conducted. In addition to examining the types of social support that are most impactful, method of delivery in said support should also be examined. Seeking support via an online forum is easier for this population to access given their physical limitations, as such, therapy interventions that can be viewed online may be a novel approach to providing mental health support to the IBD patient population.

Table 1.
Disease Differences between UC and CD

Disease	Ulcerative Colitis	Crohn's Disease
Location	Colonic mucosa only (large intestine and colon)	Transmural mucosa, which includes entire gastrointestinal tract from mouth to anus
Inflammation	Inflammation occurs in a continuous pattern in affected areas	Inflammation may be in patches and intermittent
Pain	Pain is usually in the lower left side of the abdomen	Pain is usually in the lower right side of the abdomen
Appearance	Colon wall is thinner and shows continuous inflammation, ulcers do not extend beyond inner lining	Colon wall is thicker and may have a rocky appearance, ulcers are deep and may extend into all layers of the bowel wall
Bleeding	Bleeding from rectum during bowel movements is not common	Bleeding from rectum during bowel movements is very common
Complications	Fistulas, fissures, and strictures common	Not common in UC; severe anemia common
Treatment	5-Aminosalicylates (5-ASAs) and steroids are common, recent success with anti-TNF-α medications	Steroids are common, not as many 5 ASAs are used, first to show success with anti-TNF-α medications
Surgery	Total colectomy (removal of large intestine and colon) is considered a 'cure'-patient can then have internal or external pouching system	Bowel resections to remove significant diseased portions are possible, but colectomy is not a 'cure' because it is pervasive in the entire gastrointestinal tract and could result in more surgeries

Table 2.

Descriptive Statistics: Combined and by Diagnosis

	Crohn's Disease (*n*=84, 54.2%)	Ulcerative Colitis (*n*=69, 44.5%)			Combined (*n*=155)
	Mean ± *SD*	Mean ± *SD*	*F*	*p*	Mean ± *SD*
Age	39.06 ± 12.64	36.15±12.11	.87	.35	37.60±12.44
Duration	16.26±12.58	9.05±7.37	15.86	<.001**	135.02±35.34
IBDQ Sum	129.03±36.64	143.02±34.36	.25	.62	12.93±11.07
SF-36	42.16±9.43	42.91±8.50	1.25	.27	42.45±9.02
Depression	11.67±10.61	9.67±9.26	2.48	.12	10.99±10.19
Anxiety	10.19±9.11	8.59±8.15	1.76	.19	9.65±8.81
Stress	14.66±11.06	13.15±9.86	1.12	.29	14.21±10.66
Full DASS	35.32±28.34	30.13±25.58	2.19	.14	33.66±27.64
SocSupAvg	5.02±1.71	4.88±1.71	.00	.98	4.96±1.70
Online Sup	19.86±5.09	18.51±6.73	6.67	.01*	19.29±5.91
MARS4	6.51±1.44	6.61±1.44	.02	.88	6.54±1.44

Note: The following table illustrates an independent samples T-test between individuals by diagnosis (ulcerative colitis or Crohn's disease). The table illustrates what is significant at p < .05*, and p < .001**. The means and standard deviations of the combined sample size is included on the right side of the table.

Table 3.
Multicollinearity Diagnostics

Dependent Variable ($1 - R^2$)	Independent Variable	Tolerance
Disease Severity (1 - .498 = .502)		
	SF36Avg	.913
	Anxiety	.282*
	Stress	.253*
	Depression	.299*
	Social Support	.750
DASS Sum (1 - .497 = .503)		
	Disease Severity	.942
	Social Support	.942
Medication Adherence (1 - .003 = .997)		
	Disease Severity	.957*
	Social Support	.957*
Medication Adherence (1-.003 = .997)		
	Disease Severity	.625*
	Depression	.625*
SF36Avg (1-.018 = .982)	Disease Severity	.570*
	Anxiety	.570*
Anxiety (1 - .466 = .534)		
	Disease Severity	.958
	Social Support	.958
Stress (1 - .401 = .599)		
	Disease Severity	.959
	Social Support	.959

*Indicates tolerance statistic is less than 1 - R^2 and thus multicollinearity would present a problem without mean-centering.

Table 4.

Suppression Diagnostics

Dependent Variable	Independent Variable	Zero-order correlation	Beta Weight	Semi-partial correlation (unique variance accounted for)	Suppression Indicated
Disease Severity					
	SF36Avg	-.143	-.143	-.136	N
	Anxiety	-.164	-.321	-.171	N
	Stress	-.164	-.209	-.105	N
	Depression	-.182	-.269	-.147	N
	Social Support	.061	-.134	-.116	Y (negative or net)

Table 5.
Correlations (N = 155)

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Age	1												
2. Sex	.12	1											
3. Disease Type	-.12	.02	1										
4. Disease Duration	.55**	.07	-.32**	1									
5. Disease Severity	-.04	-.05	.19*	-.13	1								
6. QoL	.13	-.04	.04	.00	-.14	1							
7. Depression	-.12	-.15	-.10	-.02	-.61**	-.05	1						
8. Anxiety	-.09	.06	-.09	-.05	-.65**	.04	.76**	1					
9. Stress	-.14	.15	-.07	.05	-.61**	-.11	.81**	.80**	1				
10. DASS	-.15	.11	-.10	.01	-.66**	-.04	.93**	.90**	.94**	1			
11. Perceived Social Support	-.09	-.08	-.04	-.01	.21*	-.10	-.47**	-.33**	-.37**	-.43**	1		
12. Online Support	-.01	-.07	-.12	.01	-.27**	-.07	.30**	.28**	.26**	.30**	-.07*	1	
13. Medication Adherence	.16*	.07	.03	.00	.06	.13	-.06	-.21*	-.19*	-.15	-.02	-.11	1

Note. Sex was dummy coded (0 = female, 1 = male), diagnosis type was also changed into a categorical variable (0 = ulcerative colitis, 1 = Crohn's disease), lower scores on the IBDQ indicate greater disease severity.

p < .05, **p* < .01

Table 6.
Characteristics of Sample

	Crohn's Disease # of Participants	Ulcerative colitis # of Participants
Age (*N* = 149)		
20-30 years	24	29
31-40 years	24	17
41-50 years	14	11
51-60 years	16	7
61-70 years	3	4
Gender (*N* = 155)		
Males	16	14
Females	69	56
Ethnicity (*N* = 153)		
Caucasian	80	62
African American	0	2
Hispanic	2	0
Asian	1	1
Native American	0	1
Other	1	3
Country of Origin (*N* = 153)		
United States	51	40
Canada	10	8
Other	23	21
Level of Income (*N* = 152)		
0-20,000	28	24
21-40,000	21	16
41-60,000	14	10
61-80,000	5	6
Over $80,000	15	13
Level of education (*N* = 152)		
8th Grade diploma	1	1
High School	19	14
Associate's Degree	13	8
Bachelor's Degree	28	18
Graduate Degree	13	17
Other	9	11
Classify Disease (*N* = 153)		
Mild	8	10
Moderate	35	29
Severe	41	30
Mental Illness Diagnosis (*N* = 132)		
Depression	20	23
Anxiety	39	28
Other	12	10

Note: Total: *N* = 155. Missing data is indicated in table.

Table 7.
Predictors of Disease Severity in IBD Patient Population

	Model 1 (R²= .02)				Model 2 (R²= 15)				Model 3 (R²=51)				Model 4 (R²=54)				Model 5 (R²= 55)				Model 6 (R²= 55)			
	B β	t	SE		B	β	t	SE	B	β	t	SE	B	β	t	SE	B	β	t	S E	B	β	t	SE
Age	-.13	-.04	-.44	.30	.18	.06	.56	.33	-.18	-.06	-.70	.26	-.19	-.06	-.74	.26	-.14	-.05	-.60	.26	-.16	-.05	-.59	.26
Sex	-13.75	-.14	-1.44	9.56	-14.18	-.14	-1.56	9.07	.89	.01	.12	7.18	1.81	.02	.26	7.06	1.90	.02	.27	7.04	2.25	.02	.32	7.11
Duration					-.31	-.09	-.80	.40	.00	.00	.00	.31	.05	.01	.16	.30	.03	.01	.09	.30	.03	.01	.10	.30
Dx Type					12.69	.18	1.89*	6.73	7.29	.10	1.39	5.22	5.53	.08	1.07	5.17	5.38	.08	1.04	5.16	5.51	.08	1.06	5.19
New SF-36					-.92	-.28	-3.03	.30	-.71	-.21	-2.87*	.25	-.76	-.23	-3.10	.25	-.72	-.22	-2.93**	.25	-.73	-.22	-2.95**	.25
Dep									-.65	-.19	-1.59	.41	-.81	-.24	-1.94	.42	-.67	-.20	-1.55	.43	-.67	-.20	-1.56	.43
Anxiety									-.88	-.23	-1.69	.52	-.81	-.21	-1.59	.51	-.97	-.25	-1.85	.52	-.95	-.25	-1.79	.53
Stress									-.88	-.27	-1.92	.46	-.93	-.29	-2.06*	.45	-.97	-.30	-2.15*	.45	-.10	-.31	-2.18*	.46
Social Support													-2.98	-.14	-1.82	1.64	-3.03	-.15	-1.18	1.63	-3.08	-.15	-1.87	1.65
Online Support													-.72	-.11	-1.53	.47	-.79	-.12	-1.33	.47	-.55	-.08	-.75	.73
MARS																	-2.37	-.09	-1.65	1.88	-2.34	-.09	-1.23	1.89
Online*Dx																					-.41	-.05	-.43	.94

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Table 8.

Moderation effect of Perceived Social Support on the Relationship between Disease Severity and the full Depression, Anxiety, and Stress Scale

Predictor	*se*	CI$_{95\%}$ Lower	Upper	t	*p*
IBDQSum	-0.62	-1.59	0.35	-0.10	-.18
PSS	-0.08	-0.12	-0.04	-0.40	-.43
IBDQ x PSS	0.10	0.03	0.16	0.23	-.23

Note. N = 123: Fit for model R^2 = 53, $F(3, 108)$ = 14.52, $p < .01$.

Table 9.

Moderation effect of Perceived Social Support on the Relationship between Disease Severity and Medication Adherence

Predictor	*se*	CI$_{95\%}$ Lower	Upper	t	*p*
IBDQSum	.00	-.19	.12	-.38	.70
PSS	.08	-.01	.01	-.45	.65
IBDQxPSS	0.10	0.03	0.16	.04	.97

Note. N = 128: Fit for model R^2 = .01, $F(5, 122)$ = .14, p =.98

Table 10.

Moderation effect of Depression on the Relationship between Disease Severity and Medication Adherence

Predictor	*se*	CI$_{95\%}$ Lower	Upper	t	*p*
IBDQSum	.00	-.01	.01	.27	.78
Depression	.02	-.03	.03	.07	.94
IBDQxDep	.00	-.00	.00	-.08	.93

Note. N = 135: Fit for model R^2 = .01, $F(5, 129)$ = .26, p =.93

Table 11.

Moderation effect of Anxiety on the Relationship between Disease Severity and Quality of Life

Predictor	*se*	CI$_{95\%}$ Lower	Upper	t	*p*
IBDQSum	.05	-.13	.04	-1.11	.27
Anxiety	.37	-.04	1.42	1.87	.06
IBDQxAnxiety	-.00	-.01	.00	-1.89	.06

Note. N = 125: Fit for model R^2 = .12, $F(5, 119)$ = 3.11, p = .01.

Table 12.

Moderation effect of Perceived Social Support on the Relationship between Disease Severity and Anxiety

Predictor	*Se*	CI$_{95\%}$ Lower	Upper	t	*P*
IBDQ	.05	-.35	-.15	-5.08	<.001
PSS	1.23	-6.19	-1.31	-3.05	<.01
IBDQxPSS	-.00	.00	.04	2.29	.02

Note. N = 125: Fit for model R^2 = .49, $F(5, 120)$ =22.76 , p < .001.

Table 13.

Moderation effect of Perceived Social Support on the Relationship between Disease Severity and Stress

Predictor	*se*	CI$_{95\%}$ Lower	Upper	t	*P*
IBDQ	.06	-.39	-.14	-4.29	< .001
SS	1.56	-7.40	1.22	-2.76	.01
IBDQxPSS	.02	-.001	.05	1.92	.06

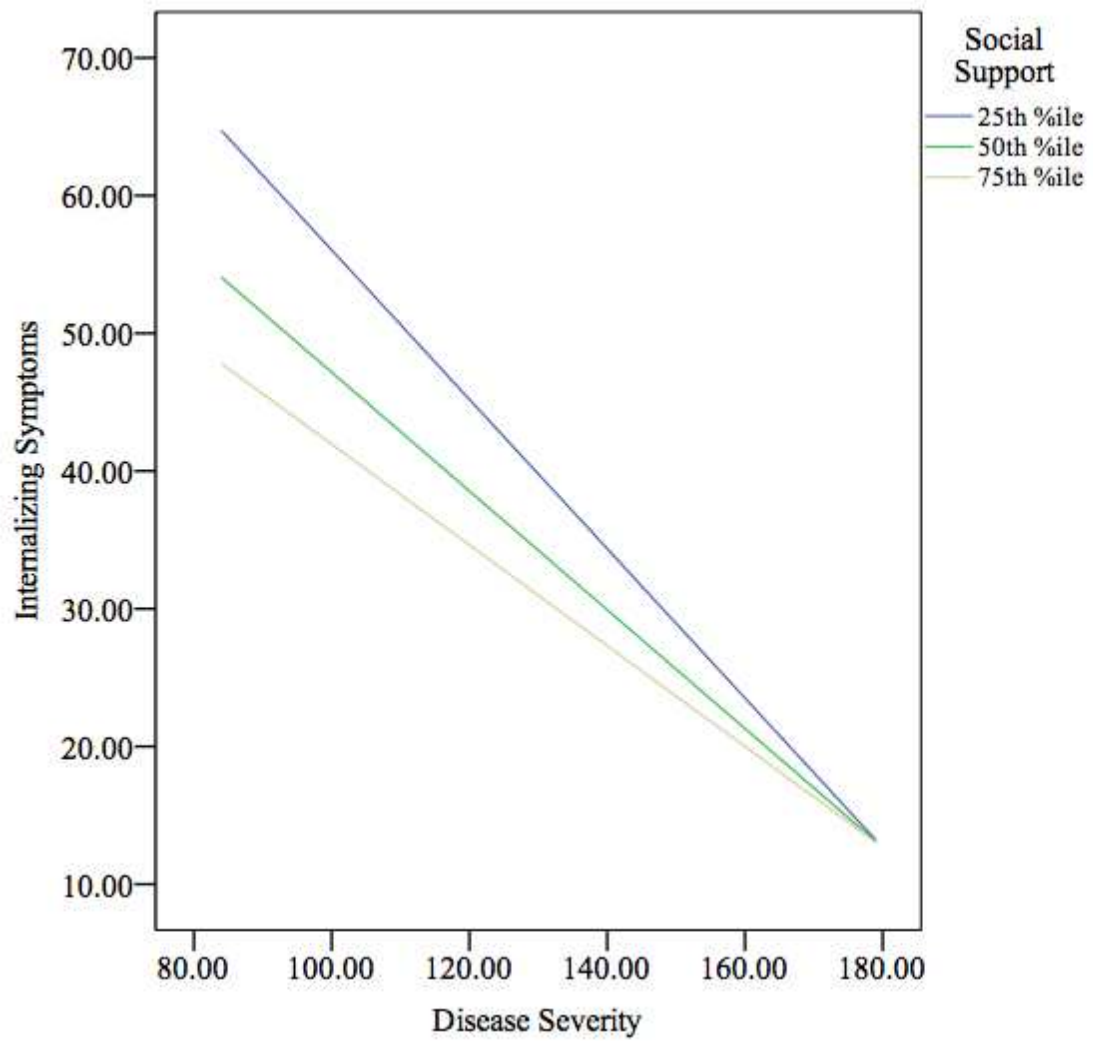*Note. N* = 123: Fit for model R^2 = .42, $F(5, 117)$ = 16.73, p < .001.

Figure 1. Moderation of social support on internalizing symptoms and disease severity
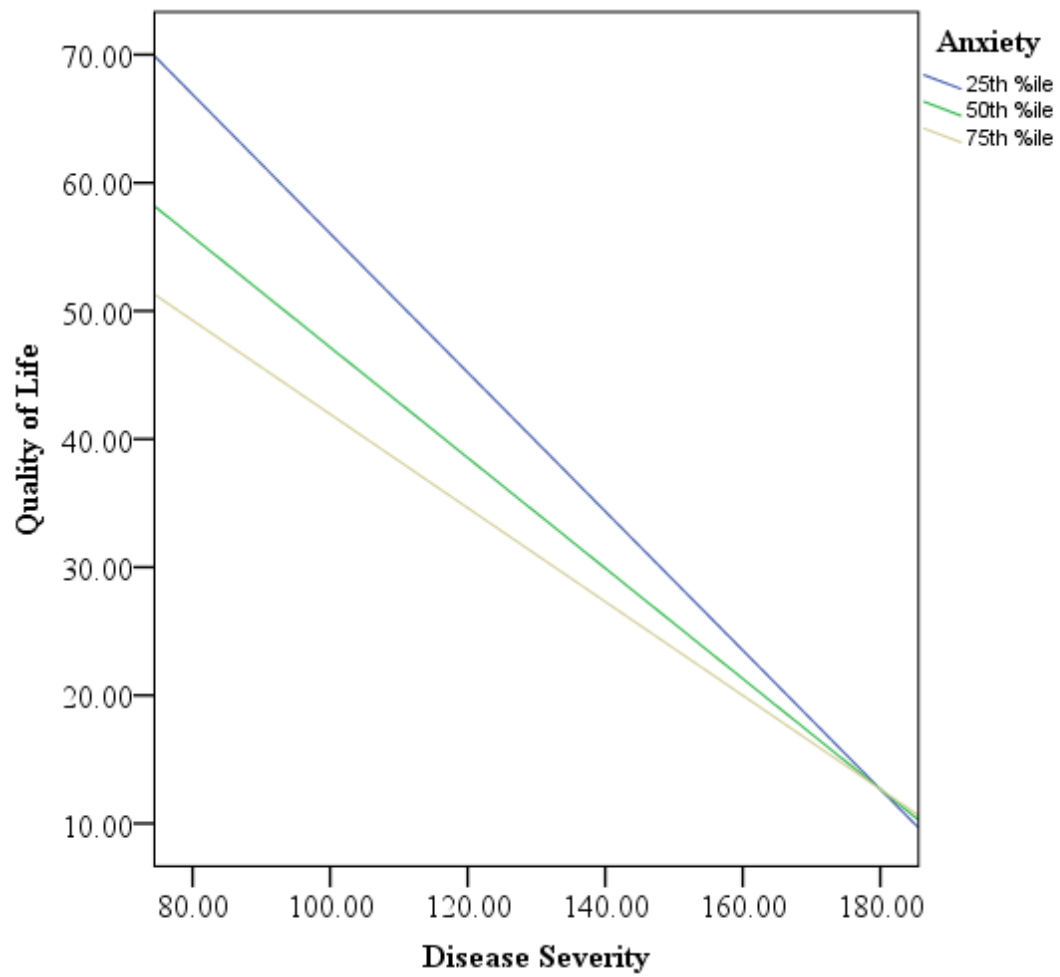
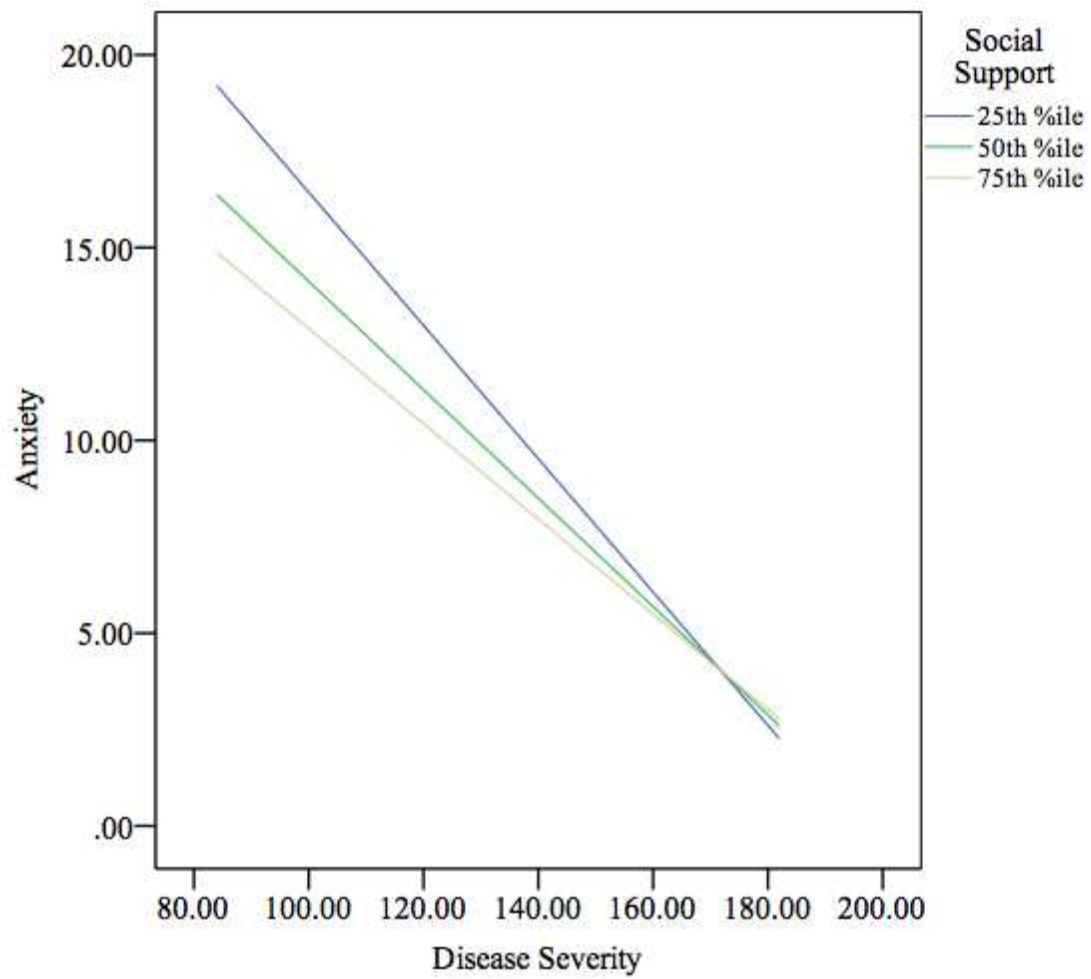Figure 2. Moderation of anxiety between disease severity and quality of life

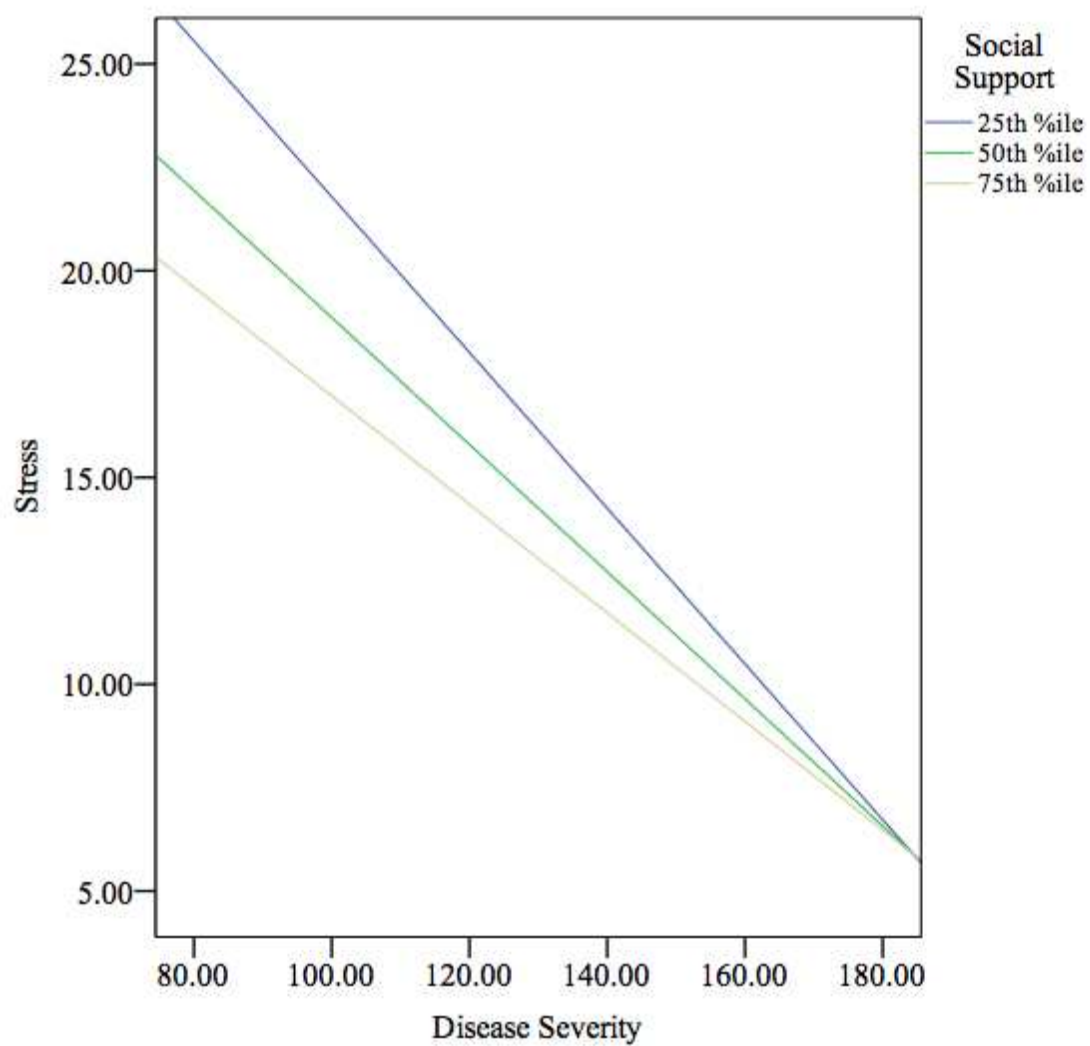Figure 3. Moderation of social support between anxiety and disease severity

Figure 4. Moderation of social support on stress and disease severity

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Appendix

Letter of Informed Consent

Participants will read the following prior to responding to the questionnaires at each point:

Elise Bascom, B.S. will be facilitating this study. I am a graduate student in Psychology at CSU (supervised by Dr. Evelinn Borrayo). I suffered from ulcerative colitis for almost 10 years before needing a J-pouch operation. My own personal struggle with IBD, a temporary ileostomy, and the lack of social support and information I received during the process, inspired me to devote my time researching how I could help the IBD community and educate others about our struggles.

It is of great importance that you answer these questions as truthfully as possible. Your answers are completely confidential and will, at no time, be shared with anyone other than the research team involved in the study. The first screen you encounter will ask you a series of 22 sociodemographic and disease-related questions to aid our knowledge of participant characteristics. You will then be asked to complete five separate questionnaires for the purpose of this study in this order: the Inflammatory Bowel Disease Questionnaire (IBDQ), the Rand 36-Item Short Form Health Survey (SF-36), the Medication Adherence Rating Scale (MARS), the Depression, Anxiety and Stress Scale (DASS), and the Multidimensional Scale of Perceived Social Support (MSPSS). Should all questions be answered, the five questionnaires will include a combined total of 130 responses.

Participant Information Sheet

All personal information documented on this form will remain completely confidential.

The contact details you provide will be filed separately from the following questionnaire. The lead researcher of the study will be the only individual who has access to this information.

Thank you for your participation in this study!

Demographic Information

Today's Date: _ _/ _ _ / _ _

Date of birth: _ _/ _ _ / _ _   **Age:** __ __   **Sex:**   o Female   o Male

Is English your first language?   Yes / No

What is your country of residence?
1. **United States**
2. **Canada**
3. **Other (please specify)** _____

What is your ethnicity?
☐ **White/Caucasian**
☐ **Black/African American**
☐ **Hispanic**
☐ **Asian**
☐ **Native American**
☐ **Other ethnic group-_____**

What is your current employment status?

o Full time	o Retired
o Part time	o Sick leave
o Unemployed	o Homemaker
o Student	o Other …………………..……..…(please specify)

What is your current level of income?

o Under $20,000	o $50,000-$59,999
o $20,000-$29,999	o $60,000-$69,999
o $30,000-$39,999	o $70,000-$79,999
o $40,000-$49,999	o Over $80,000

What is the highest level of education you completed?

o 8th grade Diploma	o Master's Degree
o High school Diploma/GED	o Doctoral Degree

o Associate's Degree   o Other……………….(please specify)

o Bachelor's Degree

What is your marital status?

o Married   o Divorced

o Living together   o Separated

o Single   o Widowed

o Dating/in a relationship

How many children do you have?

a) No. of daughters: _____

b) No. of sons: _____

c) None

Have you ever been diagnosed by a professional with one (or multiple) of the following mental health conditions?

a) Depression

b) Anxiety

c) Other (please specify) _____

Have you ever been formally diagnosed with an Inflammatory Bowel Disease? Yes / No

With which form of IBD have you been diagnosed:

a) Crohn's disease

b) Ulcerative Colitis

c) Diverticulitis

Would you classify your disease as:

    a) Mild

    b) Moderate

    c) Severe

Are you currently taking any medications?   Yes / No

If yes, please give details …………………………………………………………………

Have you had surgery in which one of the following was performed: bowel resection, temporary ileostomy/colostomy, or permanent ileostomy/colostomy as a result of your IBD? Yes / No

       If Yes, which? ………………………………………......

Have you had a previous hospital admissions for your condition?   Yes/No

       If Yes, how many? ……………………

For how many years have you struggled with IBD? ....

Have any of your immediate/extended family members been formally diagnosed with IBD?
Yes / No
If Yes, who?...………………….

Have you been diagnosed with any other autoimmune disorder or other serious, medical condition in addition to IBD? Yes/No
If Yes, what? ....

Could you briefly describe your relationship with your GI doctor or the main physician with whom you have built a treatment plan?

Inflammatory Bowel Disease Questionnaire

The Inflammatory Bowel Disease Questionnaire (IBDQ)
This questionnaire is designed to find out how you have been feeling during the last 2 weeks. You will be asked about symptoms you have been having as a result of your inflammatory bowel disease, the way you have been feeling in general and how your mood has been. Please select one answer for each of these questions. If you are unsure about how to answer any question, just give the best answer you can. Do not spend too much time answering, as your first thoughts are likely to be the most accurate.

1. How frequent have your bowel movements been during the last 2 weeks?
    a. Bowel movements as or more frequent than they have ever been
    b. Extremely frequent
    c. Very frequent
    d. Moderate increase in frequency of bowel movements
    e. Some increase in frequency of bowel movements
    f. Slight increase in frequency of bowel movements
    g. No increase in frequency of bowel movements

2. How often has a feeling of fatigue or of being tired and worn out been an issue for you in the past 2 weeks?
    a. All of the time
    b. Most of the time
    c. A good bit of the time
    d. Some of the time
    e. A little of the time
    f. Hardly any of the time
    g. None of the time

3. How often during the last 2 weeks have you felt frustrated, impatient or restless?
    a. All of the time
    b. Most of the time
    c. A good bit of the time
    d. Some of the time
    e. A little of the time
    f. Hardly any of the time
    g. None of the time

4. How often during the last 2 weeks have you been unable to attend school or work because of your bowel problems?
    a. All of the time
    b. Most of the time
    c. A good bit of the time
    d. Some of the time
    e. A little of the time
    f. Hardly any of the time
    g. None of the time

5. How much of the last 2 weeks have your bowel movements been loose?
    a. All of the time
    b. Most of the time
    c. A good bit of the time
    d. Some of the time
    e. A little of the time
    f. Hardly any of the time
    g. None of the time
6. How much energy have you had during the last 2 weeks?
    a. No energy at all
    b. Very little energy
    c. A little energy
    d. Some energy
    e. A moderate amount of energy
    f. A lot of energy
    g. Full of energy
7. How often during the last 2 weeks did you feel worried about the possibility of a surgery because of your bowel problem?
    a. All of the time
    b. Most of the time
    c. A good bit of the time
    d. Some of the time
    e. A little of the time
    f. Hardly any of the time
    g. None of the time
8. How often during the last 2 weeks did you have to cancel or delay a social function because of your bowel problem?
    a. All of the time
    b. Most of the time
    c. A good bit of the time
    d. Some of the time
    e. A little of the time
    f. Hardly any of the time
    g. None of the time
9. How often during the last 2 weeks have you been distracted by cramping in your abdomen?
    a. All of the time
    b. Most of the time
    c. A good bit of the time
    d. Some of the time
    e. A little of the time
    f. Hardly any of the time

g.   None of the time
10. How often during the last 2 weeks have you felt generally unwell?
    a.   All of the time
    b.   Most of the time
    c.   A good bit of the time
    d.   Some of the time
    e.   A little of the time
    f.   Hardly any of the time
    g.   None of the time
11. How often during the last 2 weeks have you been troubled by the thought of not being able to find a restroom (bathroom, toilet)?
    a.   All of the time
    b.   Most of the time
    c.   A good bit of the time
    d.   Some of the time
    e.   A little of the time
    f.   Hardly any of the time
    g.   None of the time
12. How much difficulty have you had, as a result of your bowel problems, doing sports or leisure activities you would have like to have done during the last 2 weeks?
    a.   A great deal of difficulty, activities made impossible
    b.   A lot of difficulty
    c.   A fair bit of difficulty
    d.   Some difficulty
    e.   A little difficulty
    f.   Hardly any difficulty
    g.   No difficulty, the bowel problems did not limit sports or leisure activities
13. How often during the last 2 weeks have you been troubled by pain in your abdomen?
    a.   All of the time
    b.   Most of the time
    c.   A good bit of the time
    d.   Some of the time
    e.   A little of the time
    f.   Hardly any of the time
    g.   None of the time
14. How often during the last 2 weeks have you had trouble getting a good night's sleep, or was troubled by waking up in the night?
    a.   All of the time
    b.   Most of the time
    c.   A good bit of the time
    d.   Some of the time
    e.   A little of the time

f. Hardly any of the time
g. None of the time

15. How often during the last 2 weeks have you felt depressed or discouraged?
    a. All of the time
    b. Most of the time
    c. A good bit of the time
    d. Some of the time
    e. A little of the time
    f. Hardly any of the time
    g. None of the time

16. How often during the last 2 weeks have you had to avoid attending events where there was no restroom (bathroom, toilet) close at hand?
    a. All of the time
    b. Most of the time
    c. A good bit of the time
    d. Some of the time
    e. A little of the time
    f. Hardly any of the time
    g. None of the time

17. Overall, in the last 2 weeks, how much of a problem have you had with passing large amounts of gas?
    a. A major problem
    b. A big problem
    c. A significant problem
    d. Some trouble
    e. A little trouble
    f. Hardly any trouble
    g. No trouble

18. Overall, in the last 2 weeks, how much of a problem have you had in getting to or maintaining the weight you would like to be at?
    a. A major problem
    b. A big problem
    c. A significant problem
    d. Some trouble
    e. A little trouble
    f. Hardly any trouble
    g. No trouble

19. Many patients with bowel problems often have worries or anxieties related to their illness. Worries about getting cancer, never feeling better or having a relapse. How often in the last 2 weeks have you felt worried or anxious?
    a. All of the time
    b. Most of the time

c. A good bit of the time
   d. Some of the time
   e. A little of the time
   f. Hardly any of the time
   g. None of the time
20. How much of the time during the last 2 weeks have you been troubled by feeling of abdominal bloating?
   a. All of the time
   b. Most of the time
   c. A good bit of the time
   d. Some of the time
   e. A little of the time
   f. Hardly any of the time
   g. None of the time
21. How much of the time during the last 2 weeks have you felt relaxed and free of tension?
   a. All of the time
   b. Most of the time
   c. A good bit of the time
   d. Some of the time
   e. A little of the time
   f. Hardly any of the time
   g. None of the time
22. How much of the time during the last 2 weeks have you had problems with rectal bleeding with your bowel movements?
   a. All of the time
   b. Most of the time
   c. A good bit of the time
   d. Some of the time
   e. A little of the time
   f. Hardly any of the time
   g. None of the time
23. How much of the time during the last 2 weeks have you felt embarrassed as a result of your bowel problem?
   a. All of the time
   b. Most of the time
   c. A good bit of the time
   d. Some of the time
   e. A little of the time
   f. Hardly any of the time
   g. None of the time
24. How much of the time during the last 2 weeks have you been troubled by a feeling of having to go to the bathroom even though your bowels are empty?

a. All of the time
b. Most of the time
c. A good bit of the time
d. Some of the time
e. A little of the time
f. Hardly any of the time
g. None of the time

25. How much of the time during the last 2 weeks have you felt tearful or upset?
    a. All of the time
    b. Most of the time
    c. A good bit of the time
    d. Some of the time
    e. A little of the time
    f. Hardly any of the time
    g. None of the time

26. How much of the time during the past 2 weeks have you been troubled about accidentally soiling your underpants?
    a. All of the time
    b. Most of the time
    c. A good bit of the time
    d. Some of the time
    e. A little of the time
    f. Hardly any of the time
    g. None of the time

27. How much of the time during the past 2 weeks have you felt angry as a result of your bowel problems?
    a. All of the time
    b. Most of the time
    c. A good bit of the time
    d. Some of the time
    e. A little of the time
    f. Hardly any of the time
    g. None of the time

28. To what extent have your bowel problems limited your sexual activity during the last 2 weeks?
    a. No sex as a result of bowel disease
    b. Major limitation as a result of bowel disease
    c. Moderate limitation as a result of bowel disease
    d. Some limitation as a result of bowel disease
    e. A little limitation as a result of bowel disease
    f. Hardly any limitation as a result of bowel disease
    g. No limitation as a result of bowel disease

29. How much of the time during the last 2 weeks have you been troubled by nausea or feeling sick to your stomach?
    a. All of the time
    b. Most of the time
    c. A good bit of the time
    d. Some of the time
    e. A little of the time
    f. Hardly any of the time
    g. None of the time
30. How much of the time during the last 2 weeks have you felt irritable?
    a. All of the time
    b. Most of the time
    c. A good bit of the time
    d. Some of the time
    e. A little of the time
    f. Hardly any of the time
    g. None of the time
31. How often during the last 2 weeks have you felt a lack of understanding from others?
    a. All of the time
    b. Most of the time
    c. A good bit of the time
    d. Some of the time
    e. A little of the time
    f. Hardly any of the time
    g. None of the time
32. How satisfied, pleased or happy have you felt with your personal life during the last 2 weeks?
    a. Very dissatisfied, unhappy most of the time
    b. Generally dissatisfied, unhappy
    c. Somewhat dissatisfied, unhappy
    d. Generally satisfied, pleased
    e. Satisfied most of the time, happy
    f. Very satisfied most of the time, happy
    g. Extremely satisfied, could not have been more happy or pleased

Rand 36-Item Health Survey Questionnaire

1. In general, would you say your health is:
   a. Excellent
   b. Very good
   c. Good
   d. Fair
   e. Poor
2. Compared to one year ago, how would you rate your health?
   a. Much better now than one year ago
   b. Somewhat better now than one year ago
   c. About the same
   d. Somewhat worse than one year ago
   e. Much worse than one year ago

The following items are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
3. Vigorous activities such as running, lifting heavy objects, participating in strenuous sports	1	2	3
4. Moderate activities such as moving a table, pushing a vacuum cleaner, bowling or playing golf	1	2	3
5. Lifting or carrying groceries	1	2	3
6. Climbing several flights of stairs	1	2	3
7. Climbing one flight of stairs	1	2	3
8. Bending, kneeling, stooping	1	2	3
9. Walking more than a mile	1	2	3
10. Walking several blocks	1	2	3

11. Walking one block	1	2	3
12. Bathing of dressing yourself	1	2	3
During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**?			
13. Cut down the amount of time spent on work or other activities	1	2	3
14. Accomplished less than you would like	1	2	3
15. Were limited in the kind of work or other activities	1	2	3
16. Had difficulty performing the work or other activities (for example, it took extra effort)	1	2	3
During the **past 4 weeks,** have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?			
17. Cut down the amount of time you spent on work or other activities	1	2	3
18. Accomplished less than you would like	1	2	3
19. Didn't do work or other activities as carefully as possible	1	2	3

20. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? **(Circle One Number)**
1. Not at all   2. Slightly   3. Moderately   4. Quite a bit   5. Extremely

21. How much bodily pain have you had in the last 4 weeks **(Circle One Number)**
1. Not at all   2. Slightly   3. Moderately   4. Quite a bit   5. Extremely

22. During the **past 4 weeks,** how much did **pain** interfere with your normal work (including both work outside the home and housework)? **(Circle One Number)**

1. Not at all   2. Slightly   3. Moderately   4. Quite a bit   5. Extremely

How much of the time during the past 4 weeks . . . **(Circle One Number on Each Line)**
   23. Did you feel full of pep?

1. All of the time 2. Most of the time 3. A good bit of the time 4. A little of the time 5. None of the time

24. Have you been a very nervous person?

1. All of the time   2. Most of the time   3. A good bit of the time   4. A little of the time 5. None of the time

25. Have you felt so down in the dumps that nothing cheers you up?

1. All of the time   2. Most of the time   3. A good bit of the time   4. A little of the time 5. None of the time

26. Have you felt calm and peaceful?

1. All of the time   2. Most of the time   3. A good bit of the time   4. A little of the time 5. None of the time

27. Did you have a lot of energy

1. All of the time   2. Most of the time   3. A good bit of the time   4. A little of the time 5. None of the time

28. Have you felt downhearted and blue?

1. All of the time   2. Most of the time   3. A good bit of the time   4. A little of the time 5. None of the time

29. Did you feel worn out

1. All of the time   2. Most of the time   3. A good bit of the time   4. A little of the time 5. None of the time

30. Have you been a happy person?

1. All of the time   2. Most of the time   3. A good bit of the time   4. A little of the time 5. None of the time

31. Did you feel tired?

1. All of the time   2. Most of the time   3. A good bit of the time   4. A little of the time 5. None of the time

32. During the past 4 weeks how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)

1. All of the time   2. Most of the time   3. A good bit of the time   4. A little of the time 5. None of the time

How True of False is each of the following statements for you?

33. I seem to get sick a little easier than most people

1. Definitely True   2. Mostly True   3. Don't Know   4. Mostly False   5. Definitely False

34. I am as healthy as anybody I know

1. Definitely True   2. Mostly True   3. Don't Know   4. Mostly False   5. Definitely False

35. I expect my health to get worse

1. Definitely True   2. Mostly True   3. Don't Know   4. Mostly False   5. Definitely False

36. My health is excellent

1. Definitely True   2. Mostly True   3. Don't Know   4. Mostly False   5. Definitely Fal

Medication Adherence Rating Scale
1. Do you ever forget to take your medication?   Yes/No
2. Are you careless at times about taking your medication? Yes/No
3. When you feel better, do you sometimes stop taking your medication? Yes/No
4. Sometimes if you feel worse when you take the medication, do you stop taking it? Yes/No
5. I take my medication only when I am sick. Yes/No
6. It is unnatural for my mind and body to be controlled by medication. Yes/No
7. My thoughts are less focused on my illness when I am on medication Yes/No
8. By staying on medication, I can prevent getting sick Yes/No
9. My body feels weird, not at all normal on medication Yes/No
10. Medication makes me feel tired and sluggish. Yes/No

Changed Question 7 as per committee approval: My thoughts are clearer on medication. Yes/No
Changed Question 9 as per committee approval: I feel weird, like a 'zombie' on medication Yes/No

Depression, Anxiety, and Stress Scale

Depression, Anxiety, and Stress Scale
Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you *over the past week*. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:
0: Did not apply to me at all
1: Applied to me to some degree, or some of the time
2: Applied to me to a considerable degree, or a good part of the time
3: Applied to me very much, or most of the time

1. I found myself getting upset by quite trivial things
       0   1   2   3
2. I was aware of dryness of my mouth
       0   1   2   3
3. I couldn't seem to experience any positive feeling at all
       0   1   2   3
4. I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)
       0   1   2   3
5. I just couldn't seem to get going
       0   1   2   3
6. I tended to over-react to situations
       0   1   2   3
7. I had a feeling of shakiness (eg, legs going to give way)
       0   1   2   3
8. I found it difficult to relax
       0   1   2   3
9. I found myself in situations that made me so anxious I was most relieved when they ended
       0   1   2   3
10. I felt that I had nothing to look forward to
       0   1   2   3
11. I found myself getting upset rather easily
       0   1   2   3
12. I felt that I was using a lot of nervous energy
       0   1   2   3
13. I felt sad and depressed
       0   1   2   3
14. I found myself getting impatient when I was delayed in any way (eg, lifts, traffic lights, being kept waiting)
       0   1   2   3
15. I had a feeling of faintness

0   1   2   3

16. I felt that I had lost interest in just about everything
            0   1   2   3
17. I felt I wasn't worth much as a person
            0   1   2   3
18. I felt that I was rather touchy
            0   1   2   3
19. I perspired noticeably (eg, hands sweaty) in the absence of high temperatures or physical
    exertion
            0   1   2   3
20. I felt scared without any good reason
            0   1   2   3
21. I felt that life wasn't worthwhile
            0   1   2   3
22. I found it hard to wind down
            0   1   2   3
23. I had difficulty in swallowing
            0   1   2   3
24. I couldn't seem to get any enjoyment out of the things I did
            0   1   2   3
25. I was aware of the action of my heart in the absence of physical exertion (eg, sense of
    heart rate increase, heart missing a beat)
            0   1   2   3
26. I felt down-hearted and blue
            0   1   2   3
27. I found that I was very irritable
            0   1   2   3
28. I felt I was close to panic
            0   1   2   3
29. I found it hard to calm down after something upset me
            0   1   2   3
30. I feared that I would be "thrown" by some trivial but unfamiliar task
            0   1   2   3
31. I was unable to become enthusiastic about anything
            0   1   2   3
32. I found it difficult to tolerate interruptions to what I was doing
            0   1   2   3
33. I was in a state of nervous tension
            0   1   2   3
34. I felt I was pretty worthless
            0   1   2   3
35. I was intolerant of anything that kept me from getting on with what I was doing
            0   1   2   3
36. I felt terrified

0 1 2 3

37. I could see nothing in the future to be hopeful about

    0 1 2 3

38. I felt that life was meaningless

    0 1 2 3

39. I found myself getting agitated

    0 1 2 3

40. I was worried about situations in which I might panic and make a fool of myself

    0 1 2 3

41. I experienced trembling (eg, in the hands)

    0 1 2 3

42. I found it difficult to work up the initiative to do things

    0 1 2 3

Multidimensional Scale of Perceived Social Support

Multidimensional Scale of Perceived Social Support

Instructions: We are interested in how you feel about the following statements. Read each statement carefully.   Indicate how you feel about each statement.

Circle the "1" if you **Very Strongly Disagree**
Circle the "2" if you **Strongly Disagree**
Circle the "3" if you **Mildly Disagree**
Circle the "4" if you are **Neutral**
Circle the "5" if you **Mildly Agree**
Circle the "6" if you **Strongly Agree**
Circle the "7" if you **Very Strongly Agree**

1. There is a special person who is around when I am in need.
      1   2   3   4   5   6   7
2. There is a special person with whom I can share my joys and sorrows
      1   2   3   4   5   6   7
3. My family really tries to help me.
      1   2   3   4   5   6   7
4. I get the emotional help and support I need from my family.
      1   2   3   4   5   6   7
5. I have a special person who is a real source of comfort to me.
      1   2   3   4   5   6   7
6. My friends really try to help me.
      1   2   3   4   5   6   7
7. I can count on my friends when things go wrong
      1   2   3   4   5   6   7
8. I can talk about my problems with my family.
      1   2   3   4   5   6   7
9. I have friends with whom I can share my joys and sorrows.
      1   2   3   4   5   6   7
10. There is a special person in my life who cares about my feelings.
      1   2   3   4   5   6   7
11. My family is willing to help me make decisions.
      1   2   3   4   5   6   7
12. I can talk about my problems with my friends.
      1   2   3   4   5   6   7

Online Social Support Questionnaire

Additional Questions

13. I seek emotional help from online support groups.
    1 2 3 4 5 6 7
14. Online support groups provide me with anonymity in sharing my feelings.
    1 2 3 4 5 6 7
15. I can talk about my problems with others online because it is often a shared experience.
    1 2 3 4 5 6 7
16. Online support groups are more accessible to me given my condition.
    1 2 3 4 5 6 7