

Illness Representations, Catastrophizing Coping Style and  
Health-Related Quality of Life  
In Adults with Irritable Bowel Syndrome

By

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## **Abstract**

**TITLE:** Illness representations, catastrophizing coping style & health-related quality of life in adults with irritable bowel syndrome.

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**Background:** Irritable Bowel Syndrome (IBS) is a common syndrome, affecting 25-45 million people in the United States. Individuals with IBS experience a worse health-related quality of life (HRQOL), as compared to others with chronic diseases. Despite the fact that an individual's functional conceptualization of their disease has been shown to assist in their coping successfully with chronic illness, little research has examined how adults conceptualize or cognitively represent IBS. Furthermore, little research has examined whether outcomes might be influenced by an individual's catastrophizing coping style.

**Purpose:** The purpose of this study is to examine the role of the Common Sense Model of Illness Representation in adults with IBS. The study focused on specific components of illness representation and their relationship to HRQOL outcome. The study further examined whether a catastrophizing coping style acted as a mediator in the relationship between the components of illness representation and perceived HRQOL.

**Sample:** Sampling was completed in both the community and in gastroenterology specialty clinics, family medicine and women's health clinics in Idaho, Connecticut, Missouri, Michigan, Pennsylvania and New Jersey. One hundred and one individuals with IBS between the ages of 30-50 years who were

able to read and speak English and did not have a new diagnosis of an organic lower gastrointestinal disorder were recruited.

Methods: Data was collected at a single point in time. Instruments used included The Revised Illness Perception questionnaire (IPQ-R), the Catastrophizing subscale of the Coping Strategies Questionnaire, and the Irritable Bowel Syndrome-Quality of Life Measure (IBS-QOL).

Data Analysis: Descriptive statistics were calculated to describe the components of illness representation, catastrophizing coping style and health-related quality of life (HRQOL) variables. Pearson's correlation coefficients were computed to quantify the association between the components of illness representation and HRQOL, as well as the components of illness representation and catastrophizing coping style, and catastrophizing coping style and HRQOL. A three-step regression analysis was performed to examine catastrophizing coping style as a mediator in the relationship between the components of illness representation and HRQOL.

Results: Participants who view their IBS as having a great number of symptoms, negative consequences, chronic in nature, poor control (personal & treatment), poor understanding and negative emotional impact were found to have poorer HRQOL. In addition, catastrophizing coping style was used more frequently in those with a greater number of symptoms, who reported more negative consequences, higher chronicity and greater negative emotional impact. The more frequent use of catastrophizing coping style was associated with poorer HRQOL. Finally, a regression analysis was used according to the

statistical mediation model developed by Baron & Kenny (1986). This statistical method was used to analyze the mediator impact of catastrophizing coping style on the relationship of illness representation and HRQOL. The results of this analysis indicated catastrophizing coping style fully mediated the relationship between personal control and HRQOL. In addition, the relationship between the remaining components of illness representation and HRQOL were partially mediated indicating catastrophizing coping style was at least one mediator in this relationship.

Conclusion: This study expands the understanding of how individuals who suffer from IBS cognitively and emotionally represent their disease. Through this understanding, methods may be developed for integrating patients' illness beliefs and coping style into the management of their IBS.



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## **Chapter One**

### **Introduction**

An individual's personal view of their illness is established through a variety of factors. These factors can be described as an individual's belief of what caused the illness, its consequences, the chronicity of the illness, the symptoms associated with the illness and the sense of control the individual has over the illness. Leventhal, Diefenbach & Leventhal (1992) identify these personal views of illness as Illness Representations. The personal views of illness representation an individual develops are found to influence their coping style and their outcomes.

Irritable Bowel Syndrome (IBS) is a chronic, recurring, and episodic gastrointestinal dysmotility disorder which is characterized by abdominal pain or discomfort, and altered bowel habits (Berg, Goettsch, van den Boom, Smout & Herings, 2006; Drossman, Camilleri, Mayer, & Whitehead, 2002). It is one of the most common syndromes seen by gastroenterologists and primary care providers (Drossman, et al., 2002), accounting for 28% of the referrals to gastroenterologists and 12% of the annual office visits to primary care providers (Manabe, Tanaka, Hata, Kusunoki & Harumma, 2009). IBS is estimated to affect between 25 and 45 million people in the United States, approximately 10%-15% of the entire population (Mayer, 2008). Women, in particular, are affected, as two-thirds of individuals with IBS are female (Sandler, Everhart, Donowitz, Adams, Cronin, Goodman, Gemmen, Shah, Avdic, & Rubin, 2002).

Although IBS is not a life-threatening disease, the patient's perspective of the nature of IBS, in terms of symptom patterns and its implications on daily functioning, cognitive, emotional and behavioral responses can impact the patient's functional status and sense of well-being (Drossman, Chang, Schneck, Blackman, Norton & Norton, 2009; Dean, Aguilar, Barghout, Kahler, Frech, Groves, & Ofman, 2005; Farndale & Roberts, 2011; Gralnek, Hays, Kilbourne, Naliboff & Mayer, 2000; Rey, Garcia-Alonso, Moreno-Ortega, Alvarez-Sanchez & Diaz-Rubio, 2008). Functional status and sense of well-being are also known as health-related quality of life (HRQOL). Individuals with IBS seeking medical care report poorer HRQOL, as compared to those without IBS (Seres, Kovacs, Kovacs Kerekgyarto, Sardi, Demeter, Meszaros & Tury, 2008). Psychological factors and gastrointestinal (GI) symptoms have been found to have an impact in determining their HRQOL. Abdominal pain and discomfort are the most frequently reported GI symptoms (Drossman et al., 2009; Lea & Whorwell, 2001; Seres et al., 2008), whereas, psychological distress (anxiety, depression and somatization) (Drossman et al., 2009) and cognitive and behavioral factors (coping and adapting) are the most frequently reported psychological factors impacting HRQOL (Jones, Wessinger & Crowell, 2006) in those with IBS.

A social cognitive model that offers a theoretical perspective for researching the influence of cognitive and emotional factors as influences on HRQOL is the Common Sense Model of Illness Representation (CSM) (Leventhal, Diefenbach, & Leventhal, 1992; Leventhal, Meyer & Nerenz, 1980). The key constructs of the CSM are Illness Representations, or the individual's



beliefs about their illness. A synopsis of the model is presented here; however, a more detailed description is provided in the Theoretical Framework section of Chapter 2.

The CSM conceptualizes that the patient's coping and outcome with the disease are facilitated by organized cognitive and emotional illness representations (Leventhal, Brisette, & Leventhal, 2003). Illness representations are personal beliefs that the patients have about their illness. These beliefs are based on both past and present experience of symptoms, in addition to pre-existing knowledge of the disease, and are moderated by the patient's personal, social and cultural context. There are six components of illness representations formed by the individual. These include; 1) identity, the label and symptoms an individual associates with their illness, 2) cause, their beliefs about the etiology of the illness, 3) timeline, the duration of the illness, 4) consequences, the outcome related to the illness, 5) cure/control, or the controllability of the illness, and 6) the emotional representations, the belief about the negative emotional impact of their disease. It is important for researchers and clinicians to understand how the components of illness representation direct an individual's preference for treatment and coping styles, which in turn affect their adaptation to the disease and their health-related outcomes (Hale, Treharne & Kitas, 2007).

The impact of the components of illness representation on the quality of life of individuals with chronic disease has been investigated in a number of studies. These include studies of kidney disease requiring hemodialysis (Fowler & Baas, 2006), rheumatoid arthritis (Carlisle, John, Fife-Schaw & Lloyd, 2005),

chronic fatigue syndrome (Edwards, Suresh, Lynch, Clarkson & Stanley, 2001; Moss-Morris & Chalder, 2003; Moss-Morris, Petrie & Weinman, 1996) and IBS (Rutter & Rutter, 2002; Rutter & Rutter, 2007). A strong illness identity (attributing symptoms to an illness), a long duration and serious consequences of an illness have repeatedly been found to have a negative effect on the well-being of the individual. Specific to IBS, Rutter & Rutter (2002) found individuals who reported poorer control and more serious consequences of their IBS were found to have poorer quality of life, as compared to individuals who reported better control and less serious consequences.

Many of the previous studies using CSM have demonstrated relationships between the components of illness representation and outcomes (Edwards, Suresh, Lynch, Clarkson & Stanley, 2001; Fowler & Baas, 2006; Moss-Morris & Chalder, 2003), but have not examined the role of coping styles in their research despite the fact that the CSM theorizes that a relationship between the components of illness representation and outcome is mediated by coping styles (Leventhal, et al., 1992). These coping styles specify how the association between the components of illness representation and outcome occurs.

The concept of coping is broad and encompasses both behavioral and cognitive regulatory processes. Coping can be defined as the effort an individual takes to master demands that are perceived as exceeding his or her resources (Monat & Lazarus, 1991). In the broad context, coping has been categorized into two areas: problem-focused coping and emotion-focused coping. Problem-focused coping generally refers to acting on the stressor, whereas emotion-

focused coping refers to managing the emotions associated with the stressor (Lazarus, 1993). Acting on the stressor with problem-focused coping has been shown to be more effective than emotion-focused coping, although in a situation where nothing useful can be done to change the situation problem-focused coping may fail (Lazarus, 1993). A conceptual problem with dividing coping into these 2 categories is that there are more dimensions into which coping can be classified. The concept of cognitive (what you think) style as compared to behavioral (what you do) style covers both the problem-focused and emotion-focused categories. For example, a problem-focused cognitive coping style can be “planning”, whereas a problem-focused behavioral style can be “taking direct action”, and emotion-focused cognitive coping style can be “denial”, whereas an emotion-focused behavioral coping style can be “seeking social support” (Garnefski, Kraaij & Spinhoven, 2001). Cognitive and behavioral coping need to be separated into different dimensions, as thinking and acting are two different processes occurring at different times.

Cognitive coping styles have been operationalized as self-blame, rumination, acceptance, blaming others, catastrophizing and positive reappraisal of a situation (Garnefski, Legerstee, Kraaij, Van den Kommer & Teerds, 2002). Self-blame, catastrophizing and rumination cognitive coping styles have been shown to play a role in the relationship between negative life events and the more frequent reporting of depression and anxiety symptoms (Garnefski et al., 2002). As a result, these cognitive coping styles are described as maladaptive.

Although coping styles are dynamic, those who suffer from IBS display greater tendencies toward utilizing catastrophizing coping style (Lackner, Quigley & Blanchard, 2004). Catastrophizing coping style, a cognitive coping style, has been shown to be a robust predictor of outcomes such as pain levels, physical functioning and depression in individuals with IBS (D. Drossman, personal communication, January 22, 2010; Drossman et al., 2000). Catastrophizing coping style is characterized by the tendency to focus on and exaggerate the threat of symptoms. In addition, the individual negatively evaluates their own ability to deal with discomforts (Hunt, Milonova, & Moshier, 2009; Keefe, Lipkus, Lefebvre, Hurwitz, Clipp, Smith & Porter, 2003).

Rutter & Rutter (2002) examined the role of coping as a mediator between illness representation and quality of life in individuals with IBS; however, they did not examine catastrophizing coping style specifically. The authors found that an adaptive coping style of acceptance mediated the relationship between the consequence illness representation variable and quality of life. Individuals who reported fewer serious consequences were more likely to accept the illness, and this acceptance added significantly to the variance explained in the perception of quality of life.

Although few studies have examined the relationship between illness representation and outcomes, only one study has considered coping as a mediator between one specific illness representation variable (consequence) and quality of life in a sample of retired individuals with IBS recruited from a self-help group in the United Kingdom (Rutter & Rutter, 2002). My study was the first of its

kind to describe the components of illness representation in adults with IBS in the United States (U. S.). This study further examined the role of catastrophizing coping style as a potential mediator in the relationship between illness representation and HRQOL.

### **Study Purpose & Specific Aims**

The purpose of this cross-sectional study was to examine the role the Common Sense Model of Illness Representation plays in adults who suffer from IBS. The specific focus was on the components of illness representation and their relationship to the outcome of HRQOL. The study further examined whether catastrophizing coping style acted as a mediator in the relationship between each of the components of illness representation and perceived HRQOL.

The specific aims for this study are 1) to describe the components of illness representation in adults with IBS, 2) to describe the level of HRQOL experienced by this population, 3) to quantify the associations between the components of illness representation and HRQOL, 4) to identify the level of catastrophizing coping style that is used in this population, 5) to quantify the associations between the components of illness representation and catastrophizing, 6) to quantify the association between catastrophizing and HRQOL, and 7) to examine the potential mediating effect of catastrophizing coping style on the relationship between the components of illness representation and HRQOL.

## **Significance to Nursing**

Understanding cognitive and emotional aspects of chronic disease is important for developing new knowledge and strategies for improving patient outcomes such as HRQOL. My goal was to establish a basis for developing interventions focused on addressing illness representations and/ or cognitive coping. Through the findings of this study, the daily lives of persons affected by IBS can potentially improve.

Results of this study can be utilized by nurses and nurse practitioners so they may educate others about IBS, by providing clear representations of IBS to help patients accurately represent their disease, cognitively and emotionally. It is my hope that the findings from this study will raise awareness around potential dysfunctional beliefs about IBS, as well as the use of catastrophizing coping style. Identifying and minimizing these dysfunctional beliefs and coping behavior may enhance patients' greater satisfaction and HRQOL. There are many individuals with IBS in the United States. Their care involves many disciplines and practice settings. Given this, the results of this study will provide insight for healthcare providers caring for this population, including primary care providers, gastroenterologists, physician assistants, psychologists, and counselors. As a result, these providers will be better prepared to help individuals with IBS understand and cope with their illness. Raising awareness about the components of illness representation and coping with IBS may also provide the insight to develop interventions that can enhance HRQOL.

## Chapter Two

### Review of the Literature

This section provides an overview of the prevalent data for IBS in the United States. The section goes on in greater detail describing the diagnostic criteria for IBS, the pathophysiology of IBS and the concept of the Brain-Gut Axis. This then leads to a discussion of factors thought to contribute to the development of IBS, healthcare provider and patient belief discrepancies and current treatments. Finally, a theoretical framework that lends itself to examination of the relationship of illness representations and health-related quality of life will be described, as well as the role of catastrophizing coping style as a potential mediator between the components of illness representation and HRQOL.

Irritable Bowel Syndrome is one of the most common syndromes seen by gastroenterologists and primary care providers (Drossman, et al., 2002), accounting for 28% of the referrals to gastroenterologists and 12% of the annual office visits to primary care providers (Manabe, et al., 2009). IBS is estimated to affect between 25 and 45 million people in the United States, approximately 10%-15% of the entire population (Mayer, 2008). Women, in particular, are affected, in that two-thirds of individuals with IBS are female (Sandler, et al., 2002).

Interpreting epidemiologic studies of IBS is difficult because there is a lack of clear pathologic features of IBS (Drossman et al., 2002). Research has shown that American, Asian, and European studies demonstrate a common

prevalence of IBS. There is no clear racial or ethnic difference with similar prevalence between whites, blacks, and Hispanics (Drossman et al., 2002).

IBS can affect individuals at any age; however, approximately 50% of individuals with IBS report symptoms beginning around age thirty. The prevalence of IBS declines with age. This decline is attributed to a higher incidence of organic diseases and medication use that together may alter colonic function and cloud the diagnosis. In addition, the reduced perception of pain in the elderly may also be a contributing factor (Bennett & Talley, 2002).

The diagnosis of IBS does not increase risk of mortality or morbidity, such as inflammatory bowel disease or colorectal cancer (Mach, 2004; Norgaard, Farkas, Pedersen, Erichsen, de la Cour, Gregersen & Sorensen, 2011). However, psychological morbidities are associated with IBS, in that individuals with IBS seeking medical care suffer from more psychological disturbances, are more likely to have abnormal personality profiles, express higher concern for their health and are more fearful of illness, as compared to those without IBS (Mach, 2004).

Irritable Bowel Syndrome is part of a larger group of functional gastrointestinal disorders. The term functional gastrointestinal disorder is applied to disorders of the body's normal activity in terms of the movement of the intestines, the sensitivity of the nerves of the intestines, or impairment of the way in which the brain controls some of these functions. Structural abnormalities are not identified by endoscopy or x-ray. There are no abnormal biomarkers consistent with IBS. Therefore, functional gastrointestinal disorders are identified



by the characteristics of the symptoms (Drossman, 2006). The Rome diagnostic criteria, discussed below, categorize the functional gastrointestinal disorders and define symptom based diagnostic criteria for each category. IBS is characterized by symptoms of abdominal pain or discomfort that is associated with disturbed defecation. IBS is diagnosed by identifying positive symptoms consistent with the condition by using specific diagnostic criteria and also by excluding other conditions that may have similar clinical presentations, including either organic or other functional disorders.

### **The Diagnostic Criteria**

Due to the lack of diagnostic tests to assist in a definitive diagnosis of IBS, diagnosis depends primarily on meeting symptom-based criteria. Four sets of diagnostic criteria have been developed, including the Manning, Rome I, Rome II and most recently, Rome III.

In 1978, Dr. A. P. Manning and his associates established six criteria to assist in the diagnosis of Irritable Bowel Syndrome from organic bowel disease. The six criteria included: 1) onset of pain associated with more frequent bowel movements, 2) onset of pain associated with looser bowel movements, 3) pain relieved by defecation, 4) visible abdominal bloating, 5) subjective sensation of incomplete evacuation more than 25% of the time, and 6) mucorrhea more than 25% of the time (Manning, Thompson, Heaton, & Morris, 1978). These criteria were nonspecific toward frequency and defecatory patterns and were found to be less reliable in men (Lehrer & Lichtenstein, 2009).

A little over 10 years later, a consensus panel of the International Congress of Gastroenterology met in Rome, Italy and developed the “Rome criteria”. The Rome criteria differed from the Manning criteria by adding a measurement of chronicity, addressing more specifically constipation-type symptoms, and requiring two or more of the altered defecatory patterns (Drossman 2006; Saito, Locke, Talley, Zinsmeister, Fett & Melton, 2000).

In 1990, the Rome criteria were revised to Rome II. The new criteria added the presence of the pain symptom, and included three or more of the altered defecation patterns. The Rome II criteria also added a frequency measurement of both the pain and altered defecation pattern (Drossman, 2006).

Over time, the Rome criteria have become more refined than the Manning criteria. Currently, Rome III diagnostic criteria classify functional GI disorders into six major domains for adults. These domains include 1) functional esophageal disorders, 2) functional gastroduodenal disorders, 3) functional bowel disorders, 4) functional abdominal pain syndrome, 5) functional gallbladder and sphincter of Oddi disorders, and 6) functional anorectal disorders (Drossman, 2006).

Criteria of irritable bowel syndrome, one of the functional bowel disorders, are described in the Rome III criteria as recurrent abdominal pain or discomfort (uncomfortable sensation not described as pain) at least 3 days per month in the last 3 months (with onset at least 6 months previously of recurrent abdominal pain or discomfort), associated with two or more of the following: (1) improvement with defecation, (2) onset associated with a change in frequency of

stool, (3) onset associated with a change in form (appearance) of stool (Drossman, 2006).

Irritable Bowel Syndrome is further classified into subtypes by predominant stool patterns. These four subtypes include: (1) IBS with constipation (IBS-C), hard or lumpy stools  $\geq 25\%$  and loose (mushy) or watery stools  $\leq 25\%$  of bowel movements, (2) IBS with diarrhea (IBS-D), loose (mushy) or watery stools  $\geq 25\%$  and hard or lumpy stools  $\leq 25\%$  of bowel movements, (3) Mixed IBS (IBS-M), hard or lumpy stools  $\geq 25\%$  and loose (mushy) or watery stools  $\geq 25\%$  of bowel movements, (4) unsubtyped IBS, insufficient abnormality of stool consistency to meet criteria for IBS-C, IBS-D, or IBS-M (Drossman, 2006). Although IBS continues to be a diagnosis of exclusion, Rome III criteria provide objective guidelines to aid in the diagnosis of IBS. This provides support for a valid diagnosis of IBS.

### **Pathophysiology**

Irritable Bowel Syndrome is a disorder of the bowel function, not a disorder due to anatomic abnormality. IBS has been described as involving the interaction of several mechanisms in defining the pathophysiology. These mechanisms include abnormal intestinal motility, increased visceral sensation, perception of visceral events, and abnormal psychosocial factors (Drossman et al., 2002, Manabe et al., 2009).

Normally the principal functions of the bowel or large intestine are to (1) absorb water and electrolytes from the chyme (digested food, water, & digestive enzymes), and (2) store the fecal matter so a passage of a soft, well-formed stool

occurs (Guyton & Hall, 2000). The large intestine propels the stool from the cecum, where the chyme first enters from the small intestine, to the rectum where the stool is stored until it can be evacuated. The movement from the cecum to the rectum occurs slowly, through rhythmic contractions of the large intestine.

### **Abnormal Intestinal Motility**

In individuals with IBS these rhythmic contractions of the large intestine do not function in an organized fashion. Unfortunately, at this time it is not known exactly why the motility is altered in these individuals. It is known that abnormal motility, such as increased contractions (contributing to diarrhea) or decreased contractions (contributing to constipation) are a major part of IBS. These alterations, however, demonstrate only part of the syndrome. It has been found that individuals with a primary symptom of pain have significantly more contractions that are higher in amplitude (or contractility), as compared to healthy controls who do not suffer from IBS (Mach, 2004). However, symptoms of pain, incomplete emptying of the bowels and bloating cannot be attributed simply to abnormal gastrointestinal motility (Drossman et al., 2002).

The abdominal pain these individuals experience has been reported primarily as crampy or as a generalized ache. Individuals have also commonly described the pain characteristics as sharp, dull, gas-like, or even a nondescript pain. The intensity and location of the abdominal pain can vary even within a single person. Temporary relief from the abdominal pain may occur with defecation; however, ingestion of food may exacerbate the discomfort. The

abdominal pain experienced can interfere with daily activity due to its severity.

Individuals experience varying levels and combinations of abdominal discomfort and pain (Drossman, et al., 2002).

### **Visceral Hypersensitivity**

Current research suggests the autonomic nervous system modulates the visceral sensitivity, and the central nervous system influences both the motility and secretory activity (Mach, 2004, Manabe et al., 2009). It has further been theorized that the subtle abnormalities in the autonomic nervous system are the basis for the symptoms reported by those with IBS, the particularly pain and discomfort (Manabe et al., 2009). In the study by Mayer and colleagues (2002), distension of the gut was found to activate nerve fibers which line the gut and transmit signals to higher centers in the brain to register pain. In individuals with IBS, pain levels were experienced at much lower levels of distention, as compared to healthy non-IBS suffers. This hypersensitivity of the gut is termed visceral hypersensitivity (Mayer et al., 2002). In addition, individuals with IBS were more aware and sensitive to normal intestinal activity. In a study by Van Der Veek, Van Rood & Masclee, (2008), the authors found that individuals with IBS experienced lower pain thresholds and greater intensity of pain perception during rectal balloon dilation, when compared to healthy controls without IBS. This further supported the work by Garnett (1999) that found individuals with diarrhea- predominant IBS (IBS-D) demonstrated lower thresholds for sensation of gas, stool and discomfort in the distal colon. It is known that the central nervous system (CNS) responds to the impulses from all parts of the body. It is

presumed that in individuals with IBS the CNS pathways may be hyperactive and exaggerate the sensation of abdominal activity and pain (Manabe et al., 2009).

### **The Brain-Gut Axis**

As mentioned previously, the pathogenesis of IBS is poorly understood. The roles of abnormal dysmotility and visceral hypersensitivity are theorized as contributing to the pathophysiology of IBS. However, current research is seeking a greater understanding of the relationship between the brain and the gut to deepen the understanding of the etiology of IBS. The relationship of the brain to the gut has been termed “The Brain-Gut Axis”. The Brain-Gut Axis is a bi-directional pathway linking emotional and cognitive centers of the brain with peripheral functioning of the GI tract (Drossman, 2006). See Figure 1. Through this pathway extrinsic factors, such as vision & smell, or enteroceptive information, such as emotion or thought, can affect GI sensation, motility, and secretion (Drossman, 2006; Mach, 2004; Mayer, 2008). Conversely, visceral afferent communication to the brain can affect perceptions of pain, mood and behavior. Stress, anxiety or even recall of adverse memories can have a physiologic effect on motility, secretion, and blood flow in the GI tract (Drossman, 2006; Mach, 2004; Mayer, 2008).

The Brain-Gut Axis is dependent on peripheral and central events, in addition to an individual's experience. Psychological distress specific to IBS, anxiety and depression, have been found to enhance the perception of painful events (Blomhoff, Jacobsen, Spetalen, Vatn, & Malt, 2000). An individual's maladaptive coping style may contribute to psychological distress and, in turn,

stimulate activation of the Brain-Gut Axis, thus contributing to the experience of IBS.

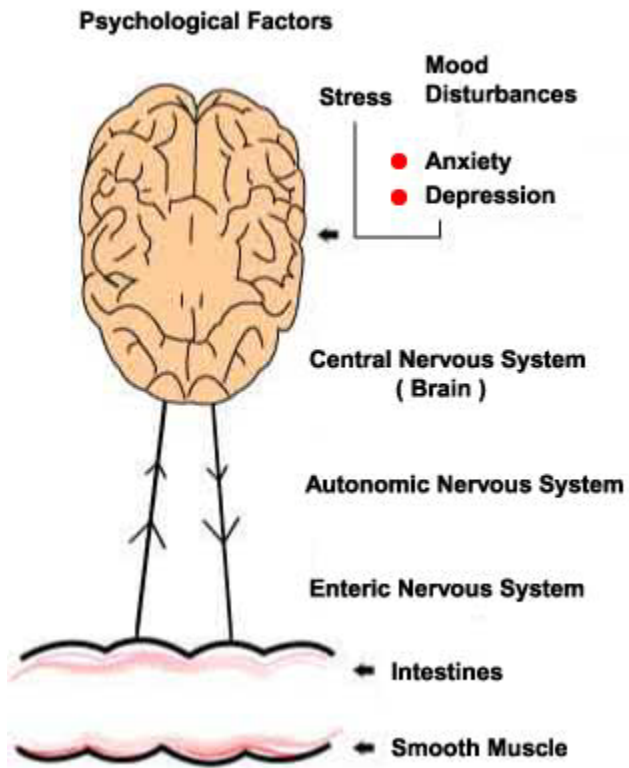


Figure 1. The Brain-Gut Axis (Mayer, 2008).

A pictorial representation of The Brain-Gut Axis including psychological factors, central nervous system, autonomic nervous system, enteric nervous system, intestines and smooth muscle bidirectional effect.



## **Factors Thought to Influence IBS**

### ***Familial Association***

Although individuals with IBS voice a positive family history, the role of “nature” and “nurture” has received little attention in the literature. Few studies have demonstrated that IBS cases cluster in families. Hotoleanu, Popp, Trifa, Nedelcu & Dumitrascu (2008) described Whorwell’s pioneering work from 1986 with familial aggregation of IBS, reporting that 33% of individuals with IBS were found to have a family history of IBS, as compared to age, sex and social class matched controls without IBS reporting only 2%.

In another study completed by Locke, Zinsmeister, Talley & Melton (2000), the authors found a predominately female population (52.4%, N=643) demonstrated an association between having IBS and having a first-degree relative with abdominal pain and bowel dysfunction. The authors further described that having a spouse reporting bowel dysfunction did not increase the likelihood of IBS. The authors were unsure if this was due to reporting bias, or possibly GI symptom reporting may reflect familial aggregation of another disorder, such as anxiety or depression. They propose both environmental and genetic factors may be contributing factors.

In studies involving the research of twins, minor roles for genetic components have been identified (Levy, Jones, Whitehead, Feld, Tally & Corey, 2001; Morris-Yates, Talley, Boyce, Nandurkar & Andrews, 1998). Levy and Colleagues (2001), found IBS to be two times higher in monozygotic twins, as compared to dizygotic twins (17.2 % vs 8.4%,  $p=0.03$ ; N=6060 twin pairs).

However, a history of IBS in a parent was found to be a more potent predictor of IBS in a twin than the presence of IBS in the other twin ( $p < 0.001$ ).

Although familial clustering of IBS has been noticed, and genetic factors have been assessed, no single pathophysiologic mechanism explains entirely the clinical manifestations of IBS. Both environmental and genetic contributions need to be considered. Physical and sexual abuse have been associated with IBS and abuse may be affecting multiple family members (Drossman et al., 2002; Hungin, Change, Locke, Denniss, & Barghouts, 2005; Locke et al., 2000; Morris-Yates et al., 1998; Talley et al., 1994). Issues such as child rearing and learned illness behavior may also be playing a role in the familial clustering (Levy, Whitehead, Von Korff, Saunders & Feld, 1997). It is not clear whether the familial association is due to reporting bias, environmental factors or genetic factors. It may be that familial associations result from a similar environmental exposure in individuals with a genetic predisposition (Locke et al., 2000).

### ***The Post Infectious Influence***

In the U.S., Italy and the United Kingdom (U.K.), infectious enteritis is common, occurring on average 1.4 times per year per person (Barbara, Cremon, Pallotti, De Giorgio, Stanghellini, & Corinaldesi, 2009). Usually, most cases recover rapidly and completely; however, symptoms can persist for many years and eventually some individuals may meet the criteria for diagnosis of IBS. Post infectious irritable bowel syndrome features are similar to those of the irritable bowel syndrome-diarrhea subgroup. Six percent to seventeen percent of

individuals with IBS believe their symptoms began with an infective illness (Spiller & Garsed, 2009).

Post infectious IBS has been defined as an acute onset of new IBS symptoms, occurring immediately following an acute illness, in an individual who previously did not meet Rome criteria for IBS. (Spiller & Garsed, 2009).

Research has shown that after a bacterial infection, with resulting mucosal ulceration from bacteria such as *Campylobacter jejuni* and *Escherichia coli* O157:H7, post infectious IBS is found more frequently than with an insult of viral origin (Wheeler, Sethi, Cowden, Wall, Rodrigues, Tompkins, Hudson, & Roderick, 1999). Analysis of viral origin suggests that the norovirus infection can produce new IBS symptoms in about 25% of cases after 3 months; however, by 6 months the incidence was no different in infected individuals, as compared to controls (Wheeler et al., 1999). This suggests that post infectious IBS following viral gastroenteritis is transient.

Efforts for identification of risk factors for post infectious IBS have been made and several studies have shown that individuals with post infectious IBS display more anxiety and depression than those who do not develop IBS after an episode of acute gastroenteritis (Thabane, Kottachchi, & Marshall, 2007). Other risk factors suggested to influence the development of IBS after an infection are still being debated, but include female gender, younger age, long duration of the acute illness and the specific type of bacterial infection (Barbara et al., 2009).

Acute infectious gastroenteritis is an accepted etiological factor of IBS. Current theories suggest that post infectious IBS causes are connected to the

persistence of mucosal abnormalities such as low grade intestinal inflammation, and increased mucosal permeability in combination with psychological facilitating factors (Barbara et al., 2009).

### ***The Role of Psychosocial Factors***

The influence of psychosocial factors in IBS is fundamental and critical to the understanding of IBS and effective treatment. Healthcare providers are trained to look for pathophysiologic explanations, but IBS does not have a clear pathophysiologic explanation. IBS is a result of complex interactions of biological, psychological and social factors. Therefore, it is important to consider the influence of psychosocial factors on IBS. Psychosocial factors that have been found to adversely affect individuals with IBS and their clinical outcomes have been noted to include: 1) a history of emotional, sexual or physical abuse (Drossman, Li, Leserman, Toomey & Hu, 1996), 2) stressful life events (Hertig, Cain, Jarrett, Burr, & Heitkemper, 2007), 3) psychological state (Drossman et al., 2002), and 4) maladaptive coping style (Drossman et al., 2002). A model of these influencing factors is displayed in Figure 2.

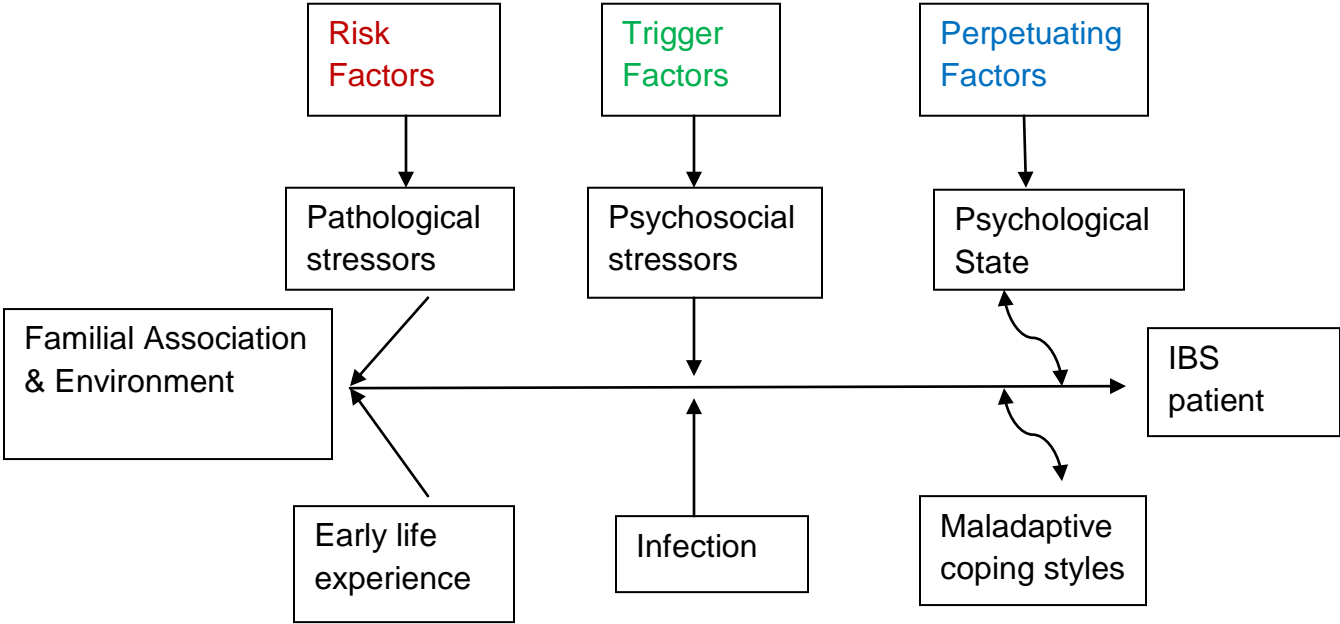


Figure 2. Influencing factors of IBS symptoms.

Factors found to influence both the development and persistence of IBS symptoms. (Adapted and modified from Mayer et. al., 2001).

Individuals with IBS are particularly susceptible to exacerbation of gastrointestinal symptoms from psychological stress. Stress can be defined as an acute threat to the homeostasis of an individual. This stress may be physical, psychological or both (Mayer, Naliboff, Chang & Coutinho, 2001). Pathological stress and early life experiences have been noted to be “risk factors” in the development of IBS. Pathological stress is described as trauma in the form of acute, life-threatening stress episodes experienced as an adult, such as rape or posttraumatic stress (Mayer et al., 2001). Early life experiences, such as abuse, neglect or loss of a primary caregiver, also play a role in the development of IBS (Mayer et al., 2001).

Historically, an individual's abuse history has been repeatedly associated with IBS. In a 1990 study by Drossman and colleagues, individuals with IBS were found to be 1.9 times more likely to report sexual abuse and 11.4 times more likely to report physical abuse (N=206), as compared to individual's with other gastrointestinal organic diseases (inflammatory bowel disease, acid/peptic disease or liver disease). Over the years, research has provided similar results. In 1993, Longstreth & Wolde-Tsadik evaluated 1,264 individuals at a health maintenance organization (HMO). The authors found that 5.2% of patients without IBS reported having had unwanted sexual intercourse, whereas 9.6% of patients with IBS, reporting less severe symptoms, and 22.2% of patients reporting severe symptoms, reported having had unwanted sexual intercourse. Most recently, Blanchard, Keefer, Payne, Turner & Galovski (2002) continue to provide support for the association of abuse and IBS. These authors report

59.6% (N=34) of the female IBS sample acknowledged some form of abuse (physical or sexual) as children (age less than 13 years old), and 38.6 % (N=22) reported some form of abuse as adolescents or adults (age 14 years or older). These studies suggest that traumatic events may sensitize an individual to the manifestation of IBS. Such traumatic events as physical or sexual abuse may predispose an individual to psychological distress which would lead to exaggerated reactions to stress and present itself as symptoms of IBS. Evidence that supports this is the consistent finding of higher levels of anxiety, depression, and somatization in individuals with IBS, and the increased likelihood of individuals with psychological distress developing IBS after an infection of the gastrointestinal tract.

In addition to pathological stress and early life experiences, psychosocial stressors such as sustained threatening life events have been noted to be trigger factors in the development of IBS. These types of stressors occur throughout life and can result in transient changes in response to stress and can contribute to symptom exacerbation. Examples of threatening events include enforced changes at work, housing crises, interaction with law enforcement officials, illness, caring for a family member with physical and/or emotional issues and loss of close interpersonal relationships (Creed, Craig & Farmer, 1988).

In a study by Bennett, Tennant, Piesse, Badcock & Kellow (1998), psychosocial stressors were assessed in 117 IBS outpatients at 3 time points, study entry, 6 and 16 months after study entry. The authors found that IBS symptoms did not improve over the 16 months. This lack of IBS symptom

improvement was strongly predicted by the presence of a chronic (greater than 6 month) threatening event, such as serious illness of self or another, relationship difficulties or changes, lawsuits, business failure, or housing difficulties. With regard to the individual's symptom intensity levels, 97% of the variance was explained by the chronic threatening event. Personality and mood state did not influence the outcome of symptom intensity. The chronic threatening stressor was a superior predictor over age, sex, emotional distress and personality, suggesting that the experience of the stressor and cognitive and behavioral efforts to deal with the stressor demonstrate a primary link between extended exposure to the threat and the outcome of symptom intensity. The findings of this study are important to the clinical management of individuals with IBS. The evidence provided demonstrates that a threatening chronic stressor, such as an individual's representation of the seriousness of their IBS, can inhibit improvement.

In addition to risk and trigger factors, factors thought to play a role in perpetuating IBS are also important to consider. These perpetuating factors include psychological state and maladaptive coping styles. The most frequently reported comorbid psychiatric disorders seen in IBS include: anxiety disorders, such as panic and generalized anxiety; mood disorders, such as depression; and somatoform disorders, such as hypochondriasis and somatization disorder (Drossman, Creed, Olden, Svedlund, Toner, & Whitehead, 1999; Lacy, Weiser, Noddin, Robertson, Crowell, Parratt-Engstrom & Graus, 2007; Nicholl, et al., 2007; Levy, et al., 2001). The prevalence of a psychiatric disorder ranges from



40% to over 90% among individuals with IBS in tertiary care centers (Drossman et al., 2002). This differs from healthy controls (<20%) and in those with similar abdominal symptoms explained by underlying organic GI disease (<25%) (Levy et al., 2006). In the study by Locke and colleagues (2004), individuals were selected from the community (N=222) and those with functional GI disorders displayed psychological differences from healthy controls. Individuals with IBS were found to have higher levels of somatization (74%), depression (80%), and anxiety (73%), as compared to non-IBS controls, 38%, 38%, and 35% respectively. There was no significant difference identified between those with IBS and the healthy controls with regard to age, gender, education level or type of response (in person or by mail) (Locke et al., 2004).

These psychosocial factors adversely affect individuals with IBS. IBS is described as a functional syndrome. The diagnosis is determined by meeting specific criteria (ROMEIII criteria) and excluding organic disease. Measuring HRQOL will give insight into the impact IBS has on the patient's psychological functioning.

### ***The Healthcare Provider and Patient Belief Discrepancies***

Due to the lack of objective pathophysiologic findings some medical professionals believe IBS is not a pathological condition, but rather the individual's overreaction to normal bodily sensations (Longstreth & Burchette, 2003). Because of this, IBS is often viewed as a purely psychological condition (Drossman et al., 2002; Johnson & Johnson, 2006; Mach, T., 2004; Nicholl, et al., 2008; Rutter & Rutter, 2002). In the study by Longstreth & Burchette (2003),

family physicians were found to have difficulty deciding on practice strategies for the treatment of IBS patients, as well as difficulty satisfying these IBS patients. These physicians were also found to experience relatively long visit times with IBS patients, and they had a low level of confidence in diagnosing IBS, as well as a low level of satisfaction in caring for IBS patients. In the same study, only 49% (N= 50) of family physicians were able to identify the Rome II IBS classification criteria. This lack of knowledge of clinical manifestations of IBS could inhibit proper care. Longstreth & Burchette (2003) further describe that, despite an educational intervention focused on the diagnosis and treatment of IBS, there was no statistically significant difference in increased diagnostic confidence, difficulty in satisfying the patient, time consumption of office visit, sense of physician satisfaction or difficulty in deciding on a practice strategy in this population of physicians, when treating IBS patients. The difficulties and lack of knowledge about some important aspects of the disorder can interfere with patient care and patient satisfaction.

Individuals with IBS have voiced concern over the delegitimization of their symptoms and have become weary and mistrustful of healthcare providers who disregard their illness experiences (Bengtsson, Ohlsson, & Ulander, 2007). These individuals also express concern that their ambiguous symptoms are often trivialized and dismissed by healthcare providers as psychosomatic in origin (Johnson & Johnson, 2006). Both the healthcare providers' level of knowledge and belief that the symptoms are in relation to stress, as well as stereotypical gender beliefs that women are "more emotional" than men and, as a result, suffer

from more psychological problems, threaten the legitimacy of the women's experience with IBS. This, in turn, potentially can hinder diagnosis and treatment for physiological symptoms.

In the study by Drossman, and colleagues (2009), individuals have also expressed a sense of stigma. They believe that society does not accept IBS as an explanation for their feelings or behaviors such as absenteeism from work or disinterest in intimacy. They expressed frustration with the "quick fix" treatment. Participants of this study described being told "you need to just relax" or "just try to focus on something else" by healthcare providers (Drossman et al., 2009). This can be interpreted as devaluing the complexity and severity of the disorder.

These contrasting views may contribute to the difficult healthcare provider-patient interaction. Healthcare providers need to anticipate that patients will experience psychosocial factors that influence their coping and their HRQOL. Many IBS individuals attribute their IBS to somatic causes and may be searching for a treatment that fits these attributions.

## **Current Treatments for IBS**

### ***Medical treatment, Diet and Medications***

In the past, treatments for IBS were from the perspective that IBS was strictly a motility disorder. The goal was to improve intestinal motility through the use of fiber supplementation. Fiber has been established to successfully treat constipation, yet its value for the treatment of diarrhea is controversial and has been proven not to be helpful for pain (Cook, Irvine, Campbell, Shannon, Reddy, & Collins, 1990). Currently, the treatment strategy is a stepwise method based

on the nature and severity of the symptoms. When treatment plans are being developed, healthcare providers also consider correlation of symptoms to food, defecation, functional impairment, psychosocial issues and the comorbidity of psychiatric illness.

For individuals with mild symptoms such as infrequent symptoms, no psychosocial difficulties, absence of illness behavior and psychiatric diagnosis, treatment focuses on maintaining a therapeutic provider-patient relationship, education about the disease, reassurance, and dietary or lifestyle changes (Drossman et al., 2002). Schmulson and colleagues (2006) have reported improvements in physical functioning, pain, emotional health and general health perceptions after individuals with IBS received an intervention of reassurance and a thorough explanation focusing on physiology and management of IBS.

In addition to the benefits of symptom management in IBS, physical activity has also been found to improve physical functioning and physical role. In a study by Johannesson & colleagues (2011), individuals enrolled in a 12- week physical activity program reported improvements in IBS symptoms after increasing their physical activity, as compared to a control group. In this longitudinal study, physically active IBS patients were noted to have a lower risk of experiencing symptom deterioration, as compared to physically inactive patients. Therefore, physical activity is recommended as a primary treatment modality in IBS (Johannesson, Simren, Strid, Bajor, & Sadik, 2011).

Although many individuals often attribute their symptoms to specific foods, research does not consistently support any type of food contributing to specific

symptoms in all patients (Atkinson, Sheldon, Shaath, & Whorwell, 2004; Simren, Mansson, Langkilde, Svedlund, Abrahamsson, Bengtsson, & Bjornsson, 2001).

The experience of symptoms may be a generalized effect of eating. However, certain dietary items, including fatty foods, beans, gas-producing foods, alcohol, caffeine, lactose and fiber, have correlated with particular symptoms for some patients (Nanda, James, Smith, Dudley & Jewell, 1989; Simren et al., 2001).

Many individuals with IBS can identify particular foods that trigger their symptoms and will institute exclusion of these offending foods from their diet with noticeable relief of their symptoms (Atkinson, Shelfdon, Shaath & Whorwell, 2004; Drisko; Fletcher, & Schneider, 2006; Locke, Zinsmeister, Talley, Fett, & Melton, 2000; Muller-Lissner, Kaatz, Brandt, Keller, & Layer, 2005; Simren, et al., 2001). In addition, a recent study completed by Ligaarden & Forup (2011), reported that individuals with IBS who were found to have low vitamin B<sub>6</sub> levels experienced more severe symptom severity. The clinical implications of this solitary study of low vitamin B<sub>6</sub> levels are unclear at this time and further investigation is required.

Pharmacologic agents such as anticholinergics, antidiarrheals, and low-dose tricyclic antidepressants are reserved for those with considerable symptom-related distress and higher physiological gut reactivity (Drossman et al., 2002). In individuals with severe symptoms (constant pain, psychiatric comorbidity, history of sexual or physical abuse, poor coping) the use of antidepressants, referral to mental health professionals or a pain control specialist are the focus of management, in addition to maintaining their relationship with their primary care provider for continued psychosocial support through regular visits (Drossman et

al., 2002; Frissora & Cash, 2007; Mayer, 2008). Despite the findings that these therapies have proven more effective than placebo for subsets of individuals with IBS in randomized controlled trials, therapeutic challenges persist. These challenges have focused current interest in gut microflora-mucosa interactions linked to inflammatory and immune processes that may contribute to enteric neuromuscular dysfunction (Brenner, Moeller, Chey, & Schoenfeld, 2008). Given this current interest, supplements such as probiotics are becoming a novel therapeutic agent, gaining in popularity.

Probiotics have been defined as live microbiologic organisms that, when ingested in adequate amounts, provide a health benefit (Quigley, 2008). Probiotics may be found in foods and supplements. There have been studies showing successful therapeutic treatment of inflammatory bowel disease (Malchow, 1997), pouchitis (Mimura, Rizzello, Helwig, Poggioli, Schreiber, Talbot, Nicholls, Gionchetti, Campieri & Kamm, 2004), and refractory *Clostridium difficile* colitis (Surawicz, McFarland, Elmer, & Chin, 1999) with probiotics. Currently, there are hypotheses speculating beneficial treatment for IBS symptoms such as pain/discomfort, bloating/distention and bowel movement difficulty (O'Mahony, McCarthy, Kelly, Hurley, Luo, Chen, O'Sullivan, Keily, Collins, Shanahan, & Quigley, 2008; Whorwell, Altringer, Morel, Bond, Charbonneau, O'Mahony, Kiely, Shanahan, & Quigley, 2006). The exact mechanism of action is not currently known. It is thought that the binding of the probiotic to small and large bowel epithelium and production of substances with antibiotic properties may inhibit attachment and invasion of pathogenic

organisms (Brenner, et al., 2009). It is also suggested that the probiotics modulate gastrointestinal luminal immunity by changing the cytokine and cellular status from a pro-inflammatory to an anti-inflammatory state (O'Mahony, et al., 2005). The probiotics have also been suggested to convert undigested carbohydrates into short chain fatty acids that become nutrients for colonocytes and change the gut motility (Brenner et al., 2009). Due to the mechanism of action, probiotics may lead to improved symptoms in individuals with IBS.

In a meta-analysis completed by Brenner et al. (2009), only one probiotic, *B. infantis* 35624, was found to have consistent efficacy in two studies. The limitation to both studies was that they were both of short duration, four to eight weeks. During these studies abdominal pain/discomfort, bloating/distention, bowel movement difficulty and improvement of the symptom severity score and global improvement scores were identified. Other studies included in this meta-analysis were limited by deficient study design, which raises the question of sufficient data on other microbacteria benefits for effective treatment of IBS. Randomized control trials to validate the efficacy of probiotic use in IBS for relief of symptoms are few. Despite the lack of scientific data, many individuals use these agents to minimize their symptoms.

Other medications, such as antispasmodics, are used to decrease motility and in the treatment of pain and bloating. These medications have been utilized but research has shown their helpfulness to be inconsistent (Schoenfeld, 2005; Talley, 2003). In addition, laxatives can treat symptoms of constipation but will

not treat the global symptoms, such as abdominal pain, bloating, and rectal urgency (Schoenfeld, 2005; Talley, 2003).

Presently there is no universally accepted pharmacological treatment or dietary supplement to treat the full spectrum of gastrointestinal symptoms that are associated with IBS (Blanchard, 2005). Treatments of IBS are primarily focused at symptom management and often do not provide relief to the level of patients' expectations (Mayer, 2008). To the individual suffering from IBS, the treatment of their symptoms by "trial and error" may be very frustrating.

### ***Psychological treatments***

The shortcomings of medical treatments, coupled with the psychosocial factors' influence on the expression and trajectory of IBS, have advanced the need for psychological treatments (Lackner et al., 2007). Psychological treatments are often considered when IBS symptoms are moderate to severe and individuals have failed to respond to medical treatments. In addition, psychological treatments are utilized when there is evidence that stress or psychological factors are contributing to GI symptom exacerbations (Drossman et al., 2002). Interpersonal psychotherapy, cognitive behavioral therapy (CBT) and relaxation & stress management have been extensively researched in randomized controlled studies and found to demonstrate improvement of bowel symptoms (Greene & Blanchard, 1994; Payne & Blanchard, 1995; van Dulmen, Fennis, & Bleijenberg, 1996), decrease of abdominal pain (Guthrie, Creed, Dawson & Tomenson, 1991) and a decrease in the frequency of medical visits (Drossman et al., 2002). However, it is unclear from current research which



psychological intervention techniques are most effective. Cognitive behavioral therapy (CBT) has been used in the majority of trials supporting psychological therapies (Lackner et al., 2007). CBT is based on two underlying assumptions (1) symptoms are acquired or learned and reflect specific skills deficits in areas of cognitive and behavioral functioning, and (2) teaching and rehearsing skills in order to change behaviors and thinking patterns can improve these deficits and relieve symptoms (Lackner et al., 2007). Typically, there are five components of CBT protocols. These 5 include (1) the understanding of information about stress and its relationship to IBS; (2) one's awareness of precursors and consequent events associated with IBS flares; (3) strategies focused at problem-solving around stressors that aggravate symptoms; (4) exercises focused at muscle relaxation for cultivating lower physiologic arousal and a viewed increased mastery of symptom control, and finally (5) cognitive restructuring for modifying threat appraisals that underlie both physiological and emotional reactivity (Lackner et al., 2007).

It is speculated that the therapeutic value of CBT reduces comorbid psychological distress characteristics in those who suffer from moderate to severe symptoms of IBS. It is also theorized that CBT helps patients experience less distress because they have learned more effective strategies for improving their bowel problems (Lackner et al., 2007). Either way, CBT has been found to be helpful in those suffering from moderate to severe symptoms of IBS.

### ***Complementary and Alternative Treatments***

Individuals who have experienced frustration with traditional medical treatments have been found to turn to complementary therapies such as yoga, tai-chi, and meditation (Kuttner, Chambers, Hardial, Israel, Jacobson, & Evans, 2006), as well as herbal supplements/teas, homeopathic therapies, acupuncture, massage, aromatherapy, chiropractic treatment and colon cleansing (Al van Tilbur, Palsson, Levy, Feld, Turner, Drossman & Whitehead, 2008). It is estimated that one third of individuals who suffer with IBS report using Complementary and Alternative Medicine (CAM) (Al van Tilbur et al., 2008). However, CAM use is not driven solely by frustration or dissatisfaction with traditional medical care. In the Al van Tibur et al. study (2008), CAM use was associated with younger-aged females with higher education level. The sample group was also described as suffering from more severe IBS symptoms, found to have higher depression, anxiety and somatization scores, experienced a lower quality of life and was willing to spend more money on non-prescription drugs.

Studies examining the effectiveness of yoga among adults to improve health outcomes are increasing. Yoga has shown benefits in managing painful conditions such as migraine (Reilly, 1994), carpal tunnel syndrome (Garfinkel, Singhal, Katz, Allan, Reshetar, & Schumacher, 1998), and multiple sclerosis (Oken, Kishiyama, Zajdel, Bourdette, Carsen, Haas, Hugos, Draemer, Lawrence & Mass, 2004). In a study by Taneja, Deepak, Poojary, Acharya, Pandey & Sharma (2004), the benefits of yoga in those who suffer from IBS were noted after a one month intervention of completing yoga practices twice daily. It was

hypothesized that the Suryya Nadi pranayama (right nostril breathing) and a set of 12 asanas (yogic poses) would increase sympathetic tone and sympathetic stimulation which, in turn, would return the autonomic imbalance toward normal and improve gut dysmotility (Taneja et al., 2004).

These findings indicate that although both standard medical care and yoga interventions led to improvement, yoga resulted in a greater improvement of the bowel symptom score and the autonomic symptom score. The anxiety score improved in the yoga group, as compared to the conventional treatment group (Taneja et al., 2004). These findings are consistent with another study by Guthrie and colleagues (1991), in which the authors reported that yoga treatment reduced depression, anxiety and patient visits in a sample of IBS-D patients.

These studies provide promising data regarding the valuable benefits of yoga intervention in individuals who suffer from IBS. Although the benefits noted in the previously-mentioned studies are promising, potential barriers exist, such as acceptance as treatment for IBS within the medical community, and feasibility of treatment (both financially and time requirements), barriers which would need to be considered and addressed with further research.

### **Summary**

IBS does not fit a simple pathophysiologic model. Given the fact that there are no clear diagnostic markers for IBS, the basis for diagnosis is on ROME III criteria. In addition, the Brain-Gut Axis, as well as familial association, environment, pathological stress, early life experiences, psychosocial stressors, infection, psychological state and maladaptive coping styles influence both an

individual's physiological and psychological responses to IBS. These responses include distress, psychiatric disorders, beliefs and coping styles. Due to the lack of understanding of the mechanisms contributing to IBS, further investigation between the relationship of components of illness representations of the disorder and catastrophizing coping style utilized can assist in the development of interventions focused at cognitive behavioral changes to improve HRQOL.

### **Theoretical Framework**

This section provides a discussion and literature review of Leventhal Meyer & Nerenz's (1980) Common Sense Model of Illness Representation (CSM). Also discussed is the concept of coping, as posed by Lazarus & Folkman (1993), and coping styles, as posed by Rosenstiel & Keefe (1983). Lastly, the relationship between components of illness representation and coping will be discussed, as well as the potential mediator effect of the specific coping style of catastrophizing.

#### **The Common Sense Model of Illness Representation**

The Common Sense Model of Illness Representation (CSM) provides a framework that integrates social and contextual factors with an individual's cognition and affect. This is formulated to explain illness-related behavior (Horne & Weinman, 2002; Leventhal et al., 1992). This self-regulative model integrates both cognitive and emotional illness representations, coping styles used to manage the components of illness representation and criteria used to evaluate the outcomes of the coping process (Leventhal et al., 1992).

An individual's experience of symptoms of illness can be characterized by how these symptoms are viewed as a health-threat (Shaw, 1999). The health-threat is a result of the individuals' perception and interpretation of the symptoms in their own terms (Shaw, 1999). This appraisal is dependent upon the individuals' own personal construction of what IBS is, how it occurred and identifying the likely outcomes. These personalized perceptions of IBS are represented in the Common Sense Model of Illness Representation framework (Diefenbach & Leventhal, 1996; Leventhal et al., 1980). Illness representations are defined as the patients' beliefs and expectations about an illness or somatic symptom (Leventhal, Diefenbach & Leventhal, 1992). The CSM of Illness representation postulates that illness representations determine the persons' assessment of an illness situation and health behavior (Leventhal et al., 1992). The framework conceptualizes that individuals use parallel cognitive and emotional processing to develop an illness representation which, in turn, influences the coping style that is selected and performed to cope with the illness, which then influences the outcome (Leventhal, et al, 1992). Implicit to the model is the proposal that coping styles influence outcomes. This model illustrates a mediational relationship that exists between the components of illness representation, coping styles and health-related outcome, meaning coping styles are hypothesized to mediate the components of illness representation and health-related outcome relationship (Leventhal, et al, 1992). See Figure 3.

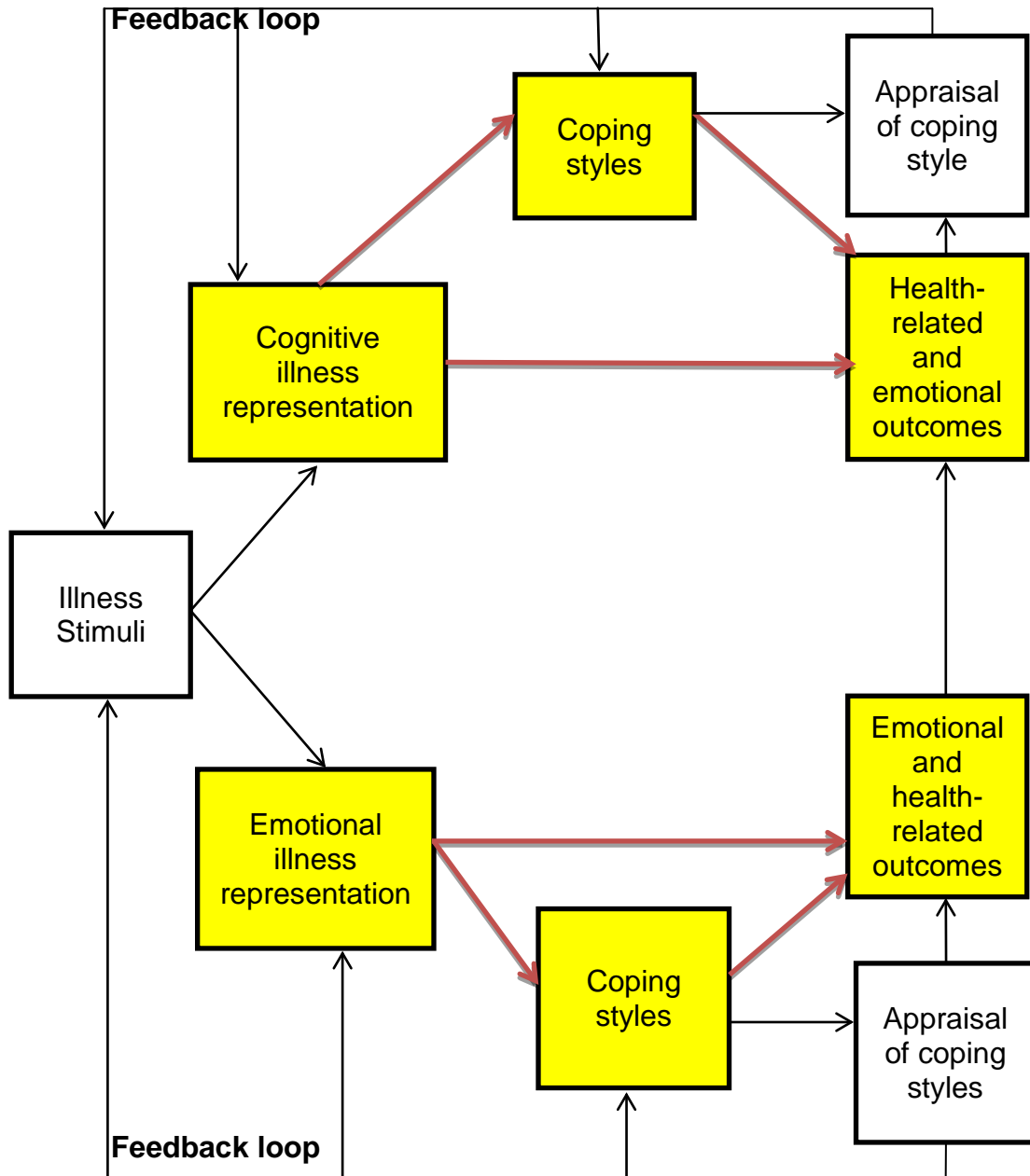


Figure 3. The Common Sense Model.

Schematic of the Common Sense Model of Illness Representation (adapted from Leventhal, et al, 1992). Highlighted boxes represent focus areas of this study.

### ***Illness Representations***

Leventhal and colleagues (1992) suggest that patients form ideas about their illness around five representation components. These five representation components are: Identity, cause, time-line, consequences, and cure/control (Leventhal et al., 1992). *Identity* is the presence or absence of an illness. This includes the labels applied to the illness and the symptoms the individual views as being part of the illness. *Cause* is the belief about what may be the cause of the illness, such as genetic factors, infection, stress, or trauma. *Time-line* is the individuals' perceived time frame for the development and duration of the illness threat. It is their view of how long the problem will last and whether it is seen as acute, chronic or episodic. *Consequences* are the considered effects the individual is expecting from their illness and their views on the impact upon psychological, social, physical and economic functioning. And finally, *Cure/Control*, the individuals' expectation as they recover from or their belief that the illness is a controllable illness. Although these components are distinct, as each one can have a specific effect on coping and outcomes, they are not necessarily independent (Weinman, Petrie, Moss-Morris & Horne, 1996).

Emotional processing, as mentioned earlier, occurs simultaneously with the development of the cognitive illness representation components. This emotional representation that is developed is a subjective experience of the individual that creates feeling states such as depression, anxiety and anger (Diefenbach & Leventhal, 1996). The emotional representation can have either a positive impact, such as when it is associated with an action plan and an

individual is motivated to access healthcare, or a negative impact may occur, if the emotion is overwhelming and action is not taken (Diefenbach & Leventhal, 1996). The emotional representations can influence cognitive illness representation components which, in turn, can affect the progression of chronic disease, decisions to seek healthcare, interpretation of somatic states, and decision behaviors addressing the somatic states (Leventhal et al., 1992).

The CSM of Illness Representation has been instrumental in understanding individuals' adaptation in such illnesses as chronic fatigue syndrome (Karasz & McKinley, 2007), rheumatoid arthritis (Carlisle, John, Fife-Shaw, & Lloyd, 2005), coronary artery disease (Aalto, Aro, Weinman, Heijmans, Manderbacka, & Elovainio, 2006), and diabetes (Scollan-Koliopoulos, O'Connell, & Walker, 2007). However, The Common Sense Model of Illness Representation has had little utilization in IBS.

### **The Concept of Coping**

Coping has been defined from a variety of perspectives using various theoretical frameworks. The coping literature, as it relates to chronic illness, includes information related to illness representation and the relationship of these representations to coping styles. This section will define coping, coping styles and how catastrophizing, a specific maladaptive coping style, will be examined as a potential mediator between the components of illness representation and HRQOL.



## **Coping Defined**

The concept of coping is very broad and encompasses both behavioral and cognitive regulatory processes. Chronic illnesses with unpredictable courses are known to tax an individual's adaptive abilities (Forsythe, Dunbar, Hennigar, Sullivan, & Gross, 2008; Hulisz, 2004; Spiegel, Gralnek, Bolus, Change, Dulai, Mayer & Naliboff, 2004). Adaptive abilities or coping is defined as "the effort taken either action-oriented or intrapsychic, to manage, master, tolerate or minimize environmental and internal demands and conflicts which tax or exceed a person's resources" (Lazarus & Folkman, 1993).

There are numerous labels given to the term coping. Coping strategies generally represent concrete behaviors and cognitions in reaction to a stressor such as illness. Particular strategies can be grouped or changed and implemented in response to individual stressors (Lazarus & Folkman, 1993). Whereas, coping style encompasses combinations of thoughts, beliefs and behaviors as a result of the stress experience (Burke, 1996). The term style is often used interchangeably with strategy in the coping literature. However, coping styles have been found to be stable over time and situations because they are influenced by personality traits (Burke, 1996). Both prior experience and previous learning have been noted to influence coping styles.

## **Coping Styles**

Development of specific ways to tolerate and/or minimize disruptions in health can be described as coping styles. Specific to pain research, coping styles focus on both cognitive and behavioral styles (Franco, Garcia & Picabia,

2004). Rosenstiel & Keefe (1983) have described cognitive coping styles as diverting attention, reinterpreting pain sensations, coping self-statements, ignoring pain sensations, praying/hoping and catastrophizing, whereas behavioral coping styles are identified through increased behavioral activities and increasing pain behavior. Research has recognized these types of coping styles as important factors in determining how individuals adjust to chronic illness (Drossman, et al., 2000; Garnefski, Grol, Kraaij, & Hamming, 2009; Keefe, Brown, Wallston & Caldwell, 1989; Lackner, Quigley, & Blanchard, 2004; Riedl, Maas, Fliege, Stengel, Schmidtman, Klap, & Mönnikes, 2009; Rosenstiel & Keefe, 1983).

In individuals with the same chronic illnesses, physical, psychological and psychosocial functioning, as well as coping styles, can vary widely between individuals (Drossman et al. 2002). An individual's representation of a stressful situation influences the coping style used and may have important effects on their health (Leventhal et al., 1992; Rao, 2009; van Dulmen, Fennis, & Bleijenberg, 1996). Drossman and colleagues (2000) reported that IBS patients who viewed their illness pessimistically or perceived little ability to control their symptoms were likely to have poorer outcomes. The importance of cognitive processes stems from research demonstrating that patients with IBS characteristically show greater perceptual response to normal visceral events, focus on visceral stimuli and mislabel internal sensation that those without IBS construe as benign (Lackner et al., 2004). When looking at all of the cognitive processes, the construct of catastrophizing has received attention in both the

pain literature and IBS literature. Catastrophizing has been noted to be a robust predictor with regard to pain levels, daily dysfunction defined as dysfunction of behavior including work, recreational activities, sleep or rest, social interaction, mobility, ambulation, communication, home management, eating behavior, and alertness (Drossman et al., 2000). Individuals who report higher levels of catastrophizing have been found to report lower pain threshold levels to finger-pressure, poorer daily function, and more psychiatric disorders (Drossman et al., 2000). Therefore, the specific coping style of catastrophizing will be examined as a potential mediator in the relationship between the components of illness representation and HRQOL.

### **Catastrophizing Coping Style as a Potential Mediator**

In recent years, the coping literature has converged on the idea that the consequences of a stressful event are dependent upon various factors such as appraisals and an individual's coping styles (Bal, Van Oost, Bourdeaudhuij, & Crombez, 2003). Of these factors, coping has been found to be an important predictor for stress-related problems (Day & Livingstone, 2001; Henderson, Fogel, & Edwards, 2003). Stress has been shown to enhance the perception of painful events in those with IBS (Drossman et al., 2002).

Catastrophizing has been broadly perceived as an exaggerated negative "mental set" brought to bear during actual or anticipated pain experience (Sullivan, Thorn, Haythornthwaite, Keefe, Martin, Bradley & Lefebvre, 2000). Catastrophizers are described as those who have a tendency to magnify or exaggerate the threat value or seriousness of pain sensations (Sullivan et al.,

2000). The concept of catastrophizing is emerging as an enduring mode of responding to painful experiences. Contrary to the trait conceptualization, catastrophizing has been regarded as a modifiable, situation-specific cognitive style. In the 1980's and early 1990's, catastrophizing was shown to change with targeted interventions (Sullivan et al., 2000). In pain research, catastrophizing has been defined as "a method of cognitively coping that is characterized by negative self-statements and overly negative thoughts and ideas about the future" (Keefe, et al., 1989). When catastrophizing coping style is used, the individual unrealistically assumes that in a particular situation, the worst possible outcome will occur (Keefe, et al., 1989). Catastrophizing is associated with heightened pain experiences (Sullivan et al., 2000). The relationship between catastrophizing and pain has been observed across measures and in various patient groups. The pain research has focused much of its attention on those suffering from Rheumatoid Arthritis (RA). Similar to individuals with RA, those with IBS experience fluctuations in pain, the primary symptom of IBS, over time. Keefe and colleagues, (1989) completed a longitudinal study that demonstrated that patients with RA found to have high levels of catastrophizing coping style tended to have worse outcomes than those who were initially found to have low levels of catastrophizing. In the same study, individuals with high catastrophizing coping style scores demonstrated poorer outcomes with regard to pain levels, physical functioning and depression. These findings suggest that catastrophizing coping style is a maladaptive coping style in RA patients. In addition, studies in patients with soft tissue injury (Sullivan, Stanish, Waite, Sullivan & Tripp, 1998),

those who suffer from hemophilia (Santavirta, Björvell, Solovieva, Alaranta, Hurskainen & Konttinen, 2001), and in sufferers from chronic pain (Jensen, Turner & Romano, 2001) who demonstrated a tendency toward catastrophizing coping style, have also been found to demonstrate greater pain and functional limitations.

Although catastrophizing coping style has been most extensively studied in the context of chronic pain populations, catastrophizing coping style has important implications for understanding IBS. As with individuals with RA, those with IBS note unpredictable pain of variable intensity and duration. This pain has been described as the most distressing symptom of IBS (Camilleri, Chey, Mayer, Northcutt, Heath, Dukes, McSorley & Mangel, 2001). Various studies have examined coping style effects in the IBS population (Drossman et al., 2000; Jones, Wessinger, & Crowell, 2006); however, few if any have examined the specific coping style of catastrophizing (Drossman et al., 2001). Drossman and colleagues (2000) have examined the effect of catastrophizing coping style on IBS symptoms and found that catastrophizing coping style levels at baseline predicted long-term illness behaviors such as higher healthcare utilization and activity limitation; however, this study did not examine catastrophizing coping styles' relationship between the components of illness representation and HRQOL.

In addition to catastrophizing coping style, components of illness representations have also been found to be significantly correlated with outcomes such as psychiatric morbidity (Carlisle, John, Fife-Shaw & Lloyd, 2005;

Rutter & Rutter, 2007), functional status (Carlisle, et al., 2005; Lelieveld, Armbrust, van Leeuwen, Geertzen, Sauer & van Weert, 2009), and quality of life (Fowler & Baas, 2006; Rutter & Rutter, 2002, 2007; van Korlaar, Vossen, Rosendaal, Bovill, Cushman, Nud, Cameron, & Kaptein, 2009).

The CSM of Illness Representation postulates that an individual's belief about an illness directs procedures for coping with the illness (Leventhal, et al, 1992). Researchers have further found a strong direct relationship between illness representations and outcome measures (Riedl et al., 2009). This model further offers that a mediational relationship exists, between components of illness representations and outcome, where coping is the mediator.

A mediator is defined as a variable that specifies how an association occurs between an independent variable and an outcome variable (Baron & Kenny, 1986; Bennett, 2000; MacKinnon, Fairchild & Fritz, 2007). In order for a mediator effect to be measured, a relationship between an independent variable and an outcome variable must be present, either conceptually or statistically. As mentioned previously, illness representations and quality of life have been noted to have a significant relationship, statistically and conceptually (Rutter & Rutter, 2002; Rutter & Rutter, 2007).

In the study by Rutter & Rutter (2002), the mediational role of coping between components of illness representations and quality of life was examined in a retired adult sample in England. The results demonstrated that acceptance, an adaptive coping style, mediated the effect of one particular component of illness representation, consequence, and quality of life, meaning those

individuals who reported fewer serious consequences were more likely to accept the illness. Acceptance added a significant 6% to the variance explained in perception of quality of life.

Acceptance is an adaptive, emotion-focused, active approach coping style (Lazarus & Folkman, 1988). Although this coping style has been used in individuals with IBS, a greater proportion has been shown to use a maladaptive coping style, catastrophizing coping style (Drossman et al., 2001; Keefe, et al., 1989). Therefore, examining catastrophizing coping style as a mediator is supported.

***Relationship of Catastrophizing Coping Style to Anxiety, Depression and Somatization***

Research has consistently demonstrated that individuals who suffer from IBS have a higher percentage of anxiety, depression and somatic symptoms, when compared to those without IBS (Drossman et al., 2002; Ringström, Abrahamsson, Strid & Simren, 2007; Van Der Veek, Van Rood, & Masclee, 2008). Although there is an increased representation of anxiety, depression and somatic symptoms in those with IBS, these psychological representations are not necessary for the diagnosis of IBS (Drossman et al., 2002). Anxiety, depression and somatic symptoms have also been found to influence HRQOL (Creed, Guthrie, Ratcliffe, Fernandes, Rigby, Tomenson, Read & Thompson, 2005; Naliboff, Balice, & Mayer, 1998). In addition, depression and anxiety have been positively correlated with catastrophizing coping style (Lackner et al., 2004; Sullivan et al., 2000). These relationships were in the moderate range and not

sufficiently high to be considered supportive of construct redundancy (Geisser et al., 1995; Haaga, 1990; Jensen, Turner, Romano & Karoley, 1991; Keefe et al., 1989; Sullivan et al., 2001). Although catastrophizing coping style is correlated with various indices of emotional distress, studies indicate that it has unique properties not shared by measures of psychological distress.

### **Hypotheses and Research Questions**

The goal of this study was to evaluate the components of illness representation, catastrophizing coping style and quality of life in a sample of individuals with IBS. Information evaluating the impact of the components of illness representations on catastrophizing coping style and HRQOL is lacking. It is my goal that the results of this study will add to the body of literature, and hopefully result in the development of interventions that are useful in understanding and modifying components of illness representations and individual coping strategies, ultimately enhancing HRQOL.

A hypothesis of this study is that individuals who report more symptoms (a strong illness identity), longer timelines, more serious consequences and less perceived control experience poorer HRQOL, while those with more frequent use of catastrophizing coping style experience poorer HRQOL. In addition, it is further hypothesized that catastrophizing coping style will mediate the relationship between the components of illness representation and HRQOL. Catastrophizing coping style will account for a significant percentage of the variance explained in HRQOL. To provide support for these assumptions, the following questions will be investigated:



1. How do adults with IBS cognitively represent their disease?
2. How do individuals with IBS rate their HRQOL?
3. How is the association between the components of illness representation and HRQOL quantified?
4. What level of catastrophizing coping style is used in this sample?
5. How is the association between the components of illness representation and catastrophizing quantified?
6. How is the association between the catastrophizing and HRQOL quantified?
7. Does catastrophizing coping style mediate the relationship between the components of illness representation (identity, consequence, timeline-acute/chronic, treatment control & personal control, illness coherence, timeline cyclical and emotional representation) and HRQOL?

### **Conceptual Definitions of the Variables**

The following section will conceptually define the variables of this study.

#### **Conceptual Definitions of Demographics**

“Demographics” is conceptually defined as gender, race, marital status, time since diagnosis with IBS, education level, employment status, medication(s) taken for anxiety and/or depression, pain level in past 7 days, comorbidities and symptom(s) experienced in last 7 days.

In addition, psychological distress was considered a demographic variable.

### **Conceptual Definition of Psychological Distress: Anxiety, Depression, Somatization and Global Severity Index (GSI)**

“Anxiety” is conceptually defined as a set of symptoms, such as restlessness, nervousness, tension and panic, which are usually associated with anxiety (Derogatis & Melisaratos, 1983).

“Depression” is conceptually defined to include a range of symptoms, such as dysphoric affect and mood, withdrawal of interest in activities of daily living, loss of vital energy, feelings of hopelessness and futility (Derogatis & Melisaratos, 1983).

“Somatization” is conceptually defined as psychological distress which arises from the perception of bodily dysfunction. Complaints typically focus on autonomic mediation such as cardiovascular, gastrointestinal, and respiratory systems. In addition, generalized aches and pains, as well as discomfort localized in the musculature, are also manifestations (Derogatis & Melisaratos, 1983).

“Global Severity Index” is conceptually defined as the overall level of psychological distress, including anxiety, depression and somatization.

The final demographic variable is pain level.

### **Conceptual Definition of Pain Level**

“Pain level” is conceptually defined as the experience of abdominal pain/discomfort. Abdominal pain is defined as an unpleasant sensation occurring in varying degrees of severity as a consequence of IBS. Abdominal pain includes the descriptors of abdominal cramping, or discomfort not described as

“pain” (Drossman et al., 2009). The pain is contained within the abdominal area, which is between the chest and hips.

Numeric rating scales (NRS) are widely used in non-IBS pain literature, such as chronic migraine headache, diabetic neuropathy, osteoarthritis, chronic low back pain and fibromyalgia (Dworkin, Turk, Farrar, et al., 2005; Farrar, Troxel, Stott, Duncombe, & Jensen, 2008; Farrar, Young, LaMoreaux, Werth, & Poole, 2001). IBS is a multi-symptom disorder and in order to be diagnosed with IBS one needs to report abdominal pain. Abdominal pain is the principal driver of IBS illness severity and affects HRQOL more than any other bowel symptom (Lembo, Ameen, & Drossman, 2005; Spiegel, Gralnek, Bolus, et al, 2004; Spiegel, Strickland, Naliboff, Mayer, & Chang, 2008). IBS is very much an abdominal pain syndrome, which suggests that it can be measured in the same manner as other pain conditions by using a NRS.

### **Conceptual Definitions of the Components of Illness Representation**

“Identity” is conceptually defined as the symptoms the individual endorses as relating to IBS.

“Consequences” are conceptually defined as the number of items identified by the individual as being impacted by their IBS.

“Timeline, acute/chronic” is conceptually defined as the degree to which the individual identified with statements related to the duration of their IBS.

“Control/Cure” is conceptually defined as the degree to which the individual believed that the IBS could be controlled or cured. Control/cure can further be defined as “personal control” or the degree to which the individual

believes in their own ability to control symptoms and “treatment control”, which refers to the degree the individual believes in the ability of the healthcare provider to intervene and control symptoms.

“Illness Coherence” is conceptually defined as the degree to which individuals identify with statements indicating that they understand their illness.

“Timeline, cyclical” is conceptually defined as the degree to which the individual identified with statements indicating a recurring nature of illness, with waxing and waning of symptoms.

“Emotional Representation” is conceptually defined as the subjective feelings of the emotion related to the illness and treatment.

“Cause” is conceptually defined as the degree to which the individual endorses causal items as contributing to the onset of IBS.

### **Conceptual Definition of Health-Related Quality of Life**

Health-related quality of life is conceptually defined as an individual’s ability to function physically, emotionally, and socially within their environment that is consistent with a level of functioning acceptable to their own expectations (Patrick, et al., 1998).

### **Conceptual Definition of Catastrophizing Coping Style**

“Catastrophizing coping style” is conceptually defined as a reflection of elements of helplessness and pessimism in relation to an individual’s ability to deal with an actual or anticipated pain experience (Rosenstiel & Keefe, 1983).

## Chapter 3

### Research Design and Methods

#### Purpose and Aims

The purpose of the proposed study is to address a gap in scientific literature regarding the utilization of the Common Sense Model of Illness Representation in an adult population who suffer from IBS. The study examined the relationships between the components of illness representation, catastrophizing coping style and HRQOL.

The proposed study addressed seven specific aims. The **specific aims** included:

- 1) to describe the components of illness representation in adults with IBS,
- 2) to describe the level of HRQOL experienced by this population,
- 3) to quantify the association between the components of illness representation and HRQOL,
- 4) to identify the level of catastrophizing coping style utilized in this population,
- 5) to quantify the association between the components of illness representation and catastrophizing,
- 6) to quantify the association between catastrophizing and HRQOL and,
- 7) to examine the potential mediating effect of catastrophizing coping style on the relationship between the components of illness representation and HRQOL in adults with IBS.

### **Implications and Significance to Nursing**

The significance of the proposed study is to expand the understanding of how individuals who suffer from IBS represent their disease, and how catastrophizing coping style affects the relationship between the components of illness representation and HRQOL. Identifying dysfunctional cognitions, in addition to understanding the role of catastrophizing coping style, may offer the best chance for enhancing an individual's HRQOL.

### **Research Design, Method Overview & Rationale**

This study was a cross-sectional descriptive study that explored the role of the components of illness representation, catastrophizing coping style and HRQOL in individuals with IBS. Generally, descriptive or exploratory studies are completed when little is known about a particular phenomenon (Walker, 2005). Descriptive research study design was chosen so that thoughts, beliefs and behaviors mentioned in the specific aims of this study could be explored and described. Descriptive studies are "concerned with and designed only to describe the existing distribution of variables, without regard to causal or other hypotheses" (Grimes & Schulz, 2002, p. 145). A major strength to descriptive study design is that it can provide clues toward variables being studied and their potential impact on outcomes particular to this study HRQOL. Data obtained from this descriptive study provided information in the hope to further develop hypotheses and prompt interventional studies to explore these hypotheses. One possible disadvantage to descriptive study design was it does not provide answers toward causal relationships. In addition, cross-sectional descriptive

research provides a “snapshot” of an individual’s thoughts, feelings or behaviors at a particular time point (Stangor, 2004). Despite these possible disadvantages, it was believed that further exploration was needed in this area. Therefore, cross-sectional descriptive study design was used to describe what actually exists, determine the frequency with which it occurs in this particular sample and categorize the information obtained. Through these results a knowledge base will be provided for future research.

### **Methodology**

One-hundred adults, ages 30 to 50, with a diagnosis of IBS as defined by Rome III criteria were needed for this study. Data collection occurred at a single point in time. Participants completed the questionnaire in the privacy of their own home, at a time that was convenient for them. The estimated time to complete the survey packet was less than one hour.

### **Setting and Sampling Method**

**Setting.** Clinics, including gastrointestinal specialty clinics, family medicine clinics and women’s health clinics in Idaho, Oregon, and Connecticut served as recruitment sites.

**Sampling.** The research was conducted at multiple sites to facilitate recruitment of a sufficiently large sample and to decrease the possibility the sample may be biased by geographic or clinical similarity. This was considered a benefit, because an outcome effect found in one clinic setting may not hold if other clinics were to be used (Shadish, Cook & Campbell, 2002). Overall, approximately 1200 individuals with an IBS diagnosis were noted to be at the

participating clinics. See Appendix A, for estimated number of patients with IBS for specific clinics. Further notation of contact person information and location of clinics is also represented.

### **Sample and Eligibility Criteria**

Eligibility criteria for potential participants was as follows: (1) between the ages of 30 and 50 years, (2) met Rome III criteria for a diagnosis of IBS, (3) able to read and speak English, (4) without a new diagnosis (meaning within the past 6 months) of an organic gastrointestinal disorder involving the lower gastrointestinal tract, such as but not limited to Crohn's disease, ulcerative colitis, microscopic colitis, collagenous colitis, colonic strictures or malignancy.

The age eligibility criteria was selected on the basis that the proposed study was interested in examining the impact IBS has on adults. In addition, individuals on average initially present for IBS related healthcare between the ages of 30 and 50 years. There is a decrease in reporting frequency among older adults (Drossman et al., 2002).

Participants who are unable to read and speak English were not included in this study. The resources of this small project did not allow inclusion of non-English-speaking individuals. I fully recognize communication barriers represent an additional risk factor for adults with IBS navigating through social contexts, such as healthcare systems and social service agencies. Thus, I fully recognize the importance of future collaboration with non-English-speaking participants and will consider doing so as part of an ongoing program of research.



Although IBS impacts those with organic gastrointestinal disorders, the focus of this study was to examine those without newly-diagnosed organic lower gastrointestinal disorders. Newly-diagnosed organic gastrointestinal disorders often require a period of adaptation, stabilization or adjustment, which occurs over time (Sharpe & Curran, 2005). Prior to adjustment, components of illness representation, catastrophizing coping style and HRQOL, the primary variables to be examined in this study, can be different than in those with chronic disorders (Sharpe & Curran, 2005). Therefore, individuals with newly diagnosed (meaning less than 6 months) organic lower gastrointestinal disorders were not included in this study, as adjustment most likely would not have occurred (Sharpe & Curran, 2005).

### **Instrument Materials**

#### **Demographic data**

A demographic questionnaire has been developed to gather specific information to describe the participants. Items include gender, race, marital status, time since diagnosis with IBS, education level, employment status, medication(s) taken for anxiety and/or depression, pain level in past 7 days, comorbidities and symptom(s) experienced in last 7 days.

These demographic data are operationally defined through items D1-D11 on the study questionnaire, using categorical, ordinal response and open-ended format. The demographic section was estimated to take less than 3 minutes to complete. See Appendix B.

In addition to the aforementioned demographic variables, psychological distress defined as depression, anxiety and somatization were measured to further describe this sample. In addition, a global severity index (GSI) or the overall psychological distress level reported by this sample was calculated (see below). It was thought since a high proportion of those with IBS suffer from psychological distress (Levy et al., 2006 & Locke et al., 2004) it was important to assess the level of psychological distress in this sample. The Brief Symptom Inventory-18 was chosen to assess the level of psychological distress.

### **Brief Symptom Inventory-18**

Psychological symptoms of depression, anxiety and somatization were assessed by using the Brief Symptom Inventory-18 (BSI-18) to further describe the sample. It was estimated that the BSI-18 would take less than 4 minutes to complete.

The BSI-18 is an 18 item version of the Symptom Checklist-90-R. The BSI-18 questionnaire measures the degree of psychological distress along three symptom dimensions: depression, anxiety and somatization, over the past week. Individuals completing the questionnaire are asked how much they were bothered by each of the 18 symptoms. Their responses are on a 5-point Likert scale (“not bothered at all” to “extremely bothered”). The BSI-18 includes 3 subscales: depression, anxiety and somatization, as well as a Global Severity Index (GSI), which provides the individual’s overall level of psychological distress (Derogatis & Melisaratos, 1983).

“Anxiety” is operationally defined as the sum of the item ratings in questions identified as B3, B6, B9, B12, B15, & B18 (see Appendix B). A higher score implies a greater level of anxiety.

“Depression” is operationally defined as the sum of the item ratings in questions identified as B2, B5, B8, B11, B14, & B17 (see Appendix B). A higher score implies a greater level of depression.

“Somatization” is operationally defined as the sum of the item ratings in questions numbered B1, B4, B7, B10, B13 B16 (see Appendix B). Higher score implies greater level of somatization.

“Global Severity Index” is operationally defined as the sum of all questions noted from B1-B18 (see Appendix B). A higher score implies a greater overall level of psychological distress.

The BSI-18 has good internal consistency (Cronbach’s  $\alpha=0.74-0.89$ ) and test-retest reliabilities ( $\alpha=0.68-0.90$ ), as well as excellent convergent validity with the SCL-90-R ( $r=0.92-0.98$ ) (Derogatis & Melisaratos, 1983; Gaylord, Whitehead, Coble, Faurot, Palsson, Garland, Frey & Mann, 2009).

***Comparison with other instruments***

An alternative instrument, the Hospital Anxiety and Depression Scale (HADS) was also considered for this proposed study. The HADS is a 14 item scale focusing on two aspects of psychological distress: anxiety and depression. The HADS has demonstrated robust internal consistency, as well as very good concurrent validity, when compared to the SLC-90. However, the HADS does not include a somatization scale. As mentioned previously, somatic

hypervigilance is thought to play a role in visceral hypersensitivity. Therefore, addition of the somatization scale was considered to be beneficial. The depression, anxiety and global scales of the BSI-18 meet the needs of this study based on conventional thinking regarding depression and anxiety are the primary dimensions of psychological distress.

The final demographic variable to be assessed was the intensity of the abdominal pain experienced over the past 7 days. Not only is abdominal pain the single most distressing symptom in IBS (Camilleri et al., 2001), it is also a defining symptom in the diagnosis of IBS. Therefore, assessment of abdominal pain in the past 7 days was added to further describe this sample. The average pain numeric rating scale was used so volunteers could rate their typical abdominal pain intensity in the past 7 days.

### **Average Pain Numeric Rating Scale**

An 11- point numeric rating scale (NRS), whose anchors range from 0 (“no pain”) to 10 (“worst pain possible”), was used to rate the typical intensity of abdominal pain this sample experienced in the past 7 days. The pain measure demonstrated sound psychometric properties (Jensen, Karolev & Braver, 1986) and has been used previously with individuals with IBS (Lackner, Gudleski, & Blanchard, 2004; Lackner & Quigley, 2005; Spiegel, Bolus, Harris, et al., 2009). It was estimated to take less than 1 minute to complete this question.

“Pain” is operationally defined as the item rating of the average pain NRS form specifically numbered D1 (see Appendix B). A higher score implies a greater level of average pain in the past 7 days.

### ***Comparison with other instruments***

The NRS is simple to administer and score. It can be administered either in written form or verbally. This is an advantage over a visual analog scale (VAS), which can only be assessed in written form. Although this study will be providing questionnaires in written form, it has been noted that if one is visually impaired, the questionnaires may be verbally read to the participant. Given the ease of use and verbal option, the NRS has been chosen.

### **Illness Representation**

The IPQ-R was used to quantify the components of illness representation. These components included identity, consequences, timeline-acute/chronic, treatment control, personal control, illness coherence and emotional representation. There are 3 sections to the questionnaire. It was estimated to take approximately 30 minutes to complete this questionnaire.

The first section encompasses the identity scale. This consists of 14 commonly experienced symptoms (pain, sore throat, nausea, breathlessness, weight loss, fatigue, stiff joints, sore eyes, wheeziness, headaches, upset stomach, sleep difficulties, dizziness, and loss of strength). The participant is asked to indicate whether they have experienced any of the symptoms since their IBS diagnosis and whether they believe that the symptoms listed were related to their illness (measuring somatization rather than illness identity-matching symptoms with illness) (Moss-Morris, Weinman, Petrie, Horne, Cameron & Buick, 2002). Identity was operationally defined as the sum of the number of ratings endorsed in both columns one and two of the symptom

subscale in Appendix B, questions numbered QS1-14. Possible scores range from 0-28. Higher scores represent strongly held beliefs about the number of symptoms attributed to the illness.

The second section consists of 50 questions regarding consequences, timeline- acute/chronic, timeline cyclical, control/cure, coherence and emotional dimensions. These are rated on a 5- point Likert scale. The 5- point scale consists of: strongly disagree, disagree, neither agree nor disagree, agree, and strongly agree (Moss-Morris, et al., 2002).

“Consequences” is operationally defined as the sum of the item ratings numbered IP 6, 7, 8, 9, 10, & 11, listed on the questionnaire in Appendix B. Possible scores range from 6-30. High scores represent strongly-held beliefs about the negative consequences of the illness.

“Timeline- acute/chronic” is operationally defined as the sum of the item ratings in questions identified as IP 1, 2, 3, 4, 5, & 18, listed on the questionnaire in Appendix B. Possible scores range from 6-30. High scores represent strongly-held beliefs about the chronicity of the condition.

“Timeline, cyclical” is operationally defined as the sum of item ratings numbered IP 29, 30, 31, & 32, listed on the questionnaire in Appendix B. Possible scores range from 4-20. High scores represent strongly-held beliefs about the cyclical nature of the condition.

“Control/Cure” subscale is further divided into “personal control” (the degree to which the individual believes in their own ability to control symptoms), and “treatment control” (the degree to which the individual believes in the ability

of the healthcare provider to intervene and control symptoms). “Personal control” is operationally defined as the sum of the item ratings numbered IP 12, 13, 14, 15, 16, & 17, listed on the questionnaire in Appendix B. “Treatment control” is operationally defined as the sum of the item ratings numbered IP 19, 20, 21, 22, & 23, listed on the questionnaire in Appendix B. Possible scores on the “personal control subscale range from 6-30 and possible scores on the “treatment control” subscale range from 5-25. High scores represent positive beliefs about the controllability of their IBS.

“Illness Coherence” is operationally defined as the sum of the item ratings numbered IP 24, 25, 26, 27, & 28, listed on the questionnaire in Appendix B. Possible scores range from 5-25. High scores represent positive beliefs about a personal understanding of their IBS.

“Emotional Representation” is operationally defined as the sum of the item ratings numbered IP 33, 34, 35, 36, 37, & 38, listed on the questionnaire in Appendix B. High scores represent a greater emotional impact of IBS.

The third and final section consists of 18 questions addressing the causal dimension. The principal components of these 18 questions include psychological attributions, risk factors, immunity and accident or chance. These questions also follow the same 5 point Likert-type scale as mentioned above (Moss-Morris, et al, 2002.). “Cause” is operationally defined as the grouping of items into those who do/do not believe in a specific causal factor. These are then categorized to represent the most often indicated cause for the IBS illness on items numbered C1-18 (see Appendix B).

All the subscales demonstrated good internal reliability with Cronbach's alphas ranging from 0.79, for the timeline cyclical dimension, to 0.89 for the timeline acute/chronic dimension, 0.84 for consequences, 0.80 for control/cure (Moss-Morris, et al., 2002).

The test-retest reliability was conducted over a 3 week period. The Pearson's correlations were computed and generally showed good stability over this time frame. The correlations ranged from 0.60 to 0.88, with one exception, personal control, which was 0.46. The highest correlations were found in identity beliefs and attributions (Moss-Morris, et al., 2002).

***Comparison with other instruments.***

The Illness Perception Questionnaire (IPQ) was the original instrument developed to provide a quantitative assessment of the five components of illness representation-identity, consequences, timeline, cure/control, and cause- noted in the CSM. The IPQ was adopted in a variety of studies and was successful in predicting different aspects of adaptation and recovery in various chronic illnesses. After 6 years of use, feedback from experienced researchers led to the development of the revised measure, the IPQ-R. One major revision to the measure was the addition of the emotional representations. Emotional representations were overlooked in the IPQ despite the fact that parallel cognitive and emotional representations are the core of the CSM framework. As a result, the IPQ-R was extended to include measures of emotional representation of illness and illness coherence. IPQ-R has also improved the ability to assess perceived timeline by adding a second subscale addressing a cyclical timeline.



Addition of the cyclical timeline allows the measure to be used in populations whose illness cannot be captured on a simple acute/chronic dimension. The IPQ-R strengthened the psychometric properties of the IPQ by improving the reliability of the subscales. Therefore, the IPQ-R will be used in this study.

**Health-related quality of life**

The IBS-QOL is a self-report questionnaire that consists of 34 items measuring IBS symptom bothersomeness, functional status, perceived quality of life and social disability specific to IBS. Participants rate each item on a 5-point Likert response scale to assess how much each item describes the respondent's feelings to a particular statement. The responses range from not at all, to extremely or a great deal, with additional anchors at slightly, moderately, and quite a bit. It is operationally defined as the sum of the item ratings in questions identified as QL1-34 on the questionnaire (see Appendix B). All 34 items are scored through summative scaling to derive an overall total score. The total score range is transformed to a 0-100 scale ranging from 0 (poor quality of life) to 100 (greatest quality of life) (Patrick, Drossman & Frederick, 1997). It is estimated to take less than 15 minutes to complete this questionnaire.

Internal consistency reliability: Cronbach's alphas have been reported to show high internal consistency at 0.95. Each of the subscales has high alpha values ranging from 0.74 (social reaction) to 0.92 (dysphoria) with the exception of the relationships subscale, which has been reported at 0.65 (Patrick, Drossman & Frederick, 1997).

Reproducibility that has been assessed with intraclass correlation coefficient (ICC) was reported at 0.86 with the average retest period of 7 days. Within the subscales, the ICC ranged from 0.76 (food avoidance) to 0.89 (body image), with the exception of relationship, which was reported at 0.69 (Patrick, et al., 1997).

***Comparison with other instruments.***

There are numerous instruments available to assess HRQOL. One approach would be the global approach. This is the simplest approach. The global approach consists of asking individuals directly to rate their quality of life, for example, on a 10 point scale from “very poor” to “excellent”. A major problem with this method is that individuals may take very different factors into account when deciding on their rating. In addition, the rating obtained may not be comparable from person to person (Palsson, 2009).

Another approach is using general functional status questionnaires, such as the Sickness Impact Profile (SIP) or the Medical Outcomes Study Short Form 36 (SF-36). These general measures can be applied to a variety of diseases and make it possible to compare statistically the difference of how medical conditions affect quality of life. However, the general questions do not address specific ways a particular disorder impacts on an individual’s life. In knowing this, unique and important aspects of how a particular disorder affects a person’s well-being and function may be missed. Therefore, I have decided to use a disease-specific questionnaire to fully evaluate the impact IBS has on HRQOL.

There are 2 additional quality of life questionnaires specifically developed for IBS. These include the Irritable Bowel Syndrome Quality of Life Questionnaire (IBSQOL) (Hahn, Kirchoerfer, Fullerton & Mayer, 1997), and the IBS-36 (Groll, Vanner, Depew, DaCosta, Simon, Groll, Roblin & Paterson, 2002). In addition, there is a questionnaire that has been developed to be used for both IBS and Functional Dyspepsia; the Functional Digestive Disorders Quality of Life Questionnaire (FDDQL) (Chassany, Marquis, Scherrer, Read, Finger, Bergmann, Freitag, Geneve & Caulin, 1999).

The IBSQOL is a slightly shorter instrument (30 items) with adequate reliability; however, the construct validity was limited, as it has not been compared to other standardized questionnaires (Hahn et al., 1997). The IBS-36 has excellent reliability and construct validity, but it is slightly longer (36 items) than the IBS-QOL and asks individuals to reflect on their quality of life over the previous 2 months, as compared to the previous month in the IBS-QOL. The final questionnaire that was considered for evaluation of HRQOL in IBS addresses functional dyspepsia in addition to IBS. The FDDQL has been found to have limited construct validity, and consists of 43 questions. The concern for burden and proprietary requirements, in addition to the focus of 2 functional gastrointestinal disorders, excluded this questionnaire from use in this proposed study.

Ultimately, the IBS-QOL was chosen as the quantitative measure for evaluation of HRQOL in this study, because of the excellent reliability and validity, and conciseness.

## **Catastrophizing**

The catastrophizing subscale of the Coping Strategy Questionnaire was used to assess the level of catastrophizing coping style used. The catastrophizing subscale consists of 6 items measured with a 7-point Likert rating scale ranging from 0 (never do that) to 6 (always do that), indicating how frequently the catastrophizing coping style is used. Catastrophizing is operationally defined as the sum of the item ratings in questions identified as CT1-6 on the catastrophizing subscale of the coping strategies questionnaire (see Appendix B). The subscale has a maximum score of 36 and a minimum score of 0. The implication is that the higher the score, the more often catastrophizing coping is utilized. The catastrophizing subscale was estimated to take less than 3 minutes to complete.

The catastrophizing subscale has repeatedly demonstrated sound psychometric properties (Drossman et al., 2000; Main & Waddell, 1991; Rosenstiel & Keefe, 1983; Swartzman, Gwadry, Shapiro & Teasell, 1994; Tuttle, Shutty & DeGood, 1991). The internal consistency reliability of this subscale Cronbach's alphas reported has been 0.78 (Rosenstiel & Keefe, 1983), 0.86 (Swartzman et al., 1994) and 0.91 (Keefe, Brown, Wallston & Caldwell, 1989). The subscale has also been reported to have a high degree of stability over a 6 month period ( $r=0.81$ ,  $p<0.001$ ) (Keefe et al., 1989).

### ***Comparison with other instruments***

The Pain Catastrophizing Scale (PCS) was considered to assess catastrophizing coping style. The PCS was developed in the hopes of expanding

the CSQ (Sullivan, Bishop & Pivik, 1995). The PCS has 3 subscales: rumination, helplessness, and magnification. The helplessness subscale includes 5 of the 6 CSQ catastrophizing subscale items. The PCS has primarily been used in studies of pain severity (Blankstein, Chen, Diamant & Davis, 2010; Sullivan, et al., 1998), social support (Cano, 2004), pain duration (Blankstein, et al., 2010) and pain-related disability in the following 7 areas of daily living; home, social, recreational, occupational, sexual, self-care, and life support in those with soft-tissue injuries (Sullivan, et al., 1998) outcomes. The PCS has been found to be a robust predictor of these outcomes specifically with regard to pain severity. The PCS has not had much utilization in predicting HRQOL in individuals with IBS.

The CSQ catastrophizing subscale was ultimately chosen for this proposed study because of its reliability and extensive use, particularly in the IBS population (Drossman et al., 2000; Franco et al., 2004; Keefe, et al., 1989; Lackner, et al., 2004; Robinson, Riley, Myers, Sadler, Ian, Kvaal, Geisser & Keefe, 1997; Rosenstiel & Keefe, 1983). In addition, Williams & Keefe (1991) focused on assessing the use and effectiveness of cognitive and behavioral coping styles in chronic pain patients. The Coping Strategy Questionnaire (CSQ) was used to determine the extent to which individual's reported using the cognitive coping and behavioral coping styles when they experienced pain. The authors examined whether the cognitive behavioral coping styles differed in patients in three pain belief groups. The results reported that patients belonging to the group characterized by the belief that pain was enduring and mysterious

were less likely to use behavioral coping style. In addition, they were more likely to catastrophize and less likely to rate their coping style as effective in controlling and decreasing pain, as compared to patients believing their pain to be understandable and of short duration. Individuals with IBS have been noted to label their abdominal pain as long lasting and unpredictable (Drossman et al., 2009). In addition, the abdominal pain has been described as the most distressing symptom of IBS (Camilleri et al., 2001) and a greater proportion of those with IBS have been shown to catastrophize. These findings support the use of catastrophizing subscale of the CSQ, as pain is the cornerstone of IBS diagnosis and the most distressing symptom experienced.

### **Study Procedures**

#### **Recruitment and Data Collection**

A sample of 192 participants was screened for participation in this study. See data analysis section for a full description of determination of sample size power analysis. A typical participant response rate of 52-78% is anticipated; it is proposed that a total of 128-192 potential participants were to be contacted in order to enroll 100 participants. All participants completed a one-time, in-home self-administered questionnaire. The time required to complete the questionnaire was estimated to be less than one hour. Recruitment occurred by two means: (1) a review of the ICD-9 billing code data base and (2) by flyer advertisement and “snowball” recruitment.

A review of the ICD-9 billing code data base was performed to include those who had previously consented to participate in research while undergoing

care at the participating facilities. The focus of the data base search was for Irritable Bowel Syndrome diagnosis code (ICD-9 code 564.1). Those with an active IBS diagnosis from the previous 12 months were considered candidates for this study. Potential participants who met the screening criteria through ICD-9 code review and met inclusion criteria were sent a study packet, which included a letter inviting them to participate, a questionnaire, and a self-addressed stamped envelope in which they could elect to use to return the completed questionnaire. See Appendices B and D.

Recruitment through flyer and “snowball” effect was also performed. An informational flyer was developed noting information about the study, and how to contact the investigator to become a participant. Collaborating sites where these materials were posted were sites where adults with IBS were likely to be seen. These sites were known to me through my community connections fostered through my employment as a nurse practitioner for the past 14 years. Recruitment efforts focused on flyers occurred at the family, women’s health, and gastrointestinal health clinics. After posting the informative flyer, I also met with agency staff to discuss referring potentially eligible participants to the study.

When potential participants contacted me by telephone requesting to participate in the study, in response to seeing a flyer, they were screened for enrollment by using the IRB approved phone script to confirm the potential participant met the inclusion criteria. The purpose and benefits of the study were also reviewed with the potential participant. Verbal confirmation of desire to

participate in the study was obtained, as well as contact information for the forwarding of the study packet. See appendix E.

Those who met the criteria and wished to participate were then mailed a study packet that included the invitation letter, the Primary Investigators' (PI) and co-investigators' secure telephone numbers for the participant to call and ask questions they might have about the study. The packet also included an information sheet explaining the study (see Appendix B), a study questionnaire and a stamped self-addressed envelope. Completion of the study questionnaire was noted to take less than one hour. Return of the completed questionnaires constituted consent to participate in the study.

### **Human Participants Research Protection**

All study materials (flyers, advertisements, information sheet explaining the study, telephone scripts and safety protocols) were approved by the Oregon Health & Science University Institutional Review Board (IRB) before beginning the study. All contacts with participants and potential participants were in accordance with these IRB approved procedures. The participants were reassured of the ability to terminate study involvement at any time. It was noted that refusal to participate would in no way affect the participant's involvement in participating health clinics or services provided by those clinics. Individuals who refused to participate in the study were thanked and asked to share their reason(s) for refusing to participate in the study. Reasons for refusal were kept in the Refusal Documentation Log. See Appendix F.



### **Privacy and Confidentiality**

An information sheet was used in place of a signed informed consent form. See Appendix B. An information sheet described in detail the purpose of the study. Subjects in this study were anonymous, as there was no link between the information they provided on the questionnaire and their identity. Each volunteer received one questionnaire. No identifying information, such as name or address, was requested on the questionnaire that was returned to me. The information provided by the volunteers for mailing of the questionnaires was destroyed at the time the materials were mailed and the return envelopes had a preprinted research team address in the destination address section and in the return address section. Since this was an anonymous survey, there was no risk of loss of confidentiality. Return of the completed questionnaire constituted agreement to participate in this study.

### **Managing and Storing Data**

The data collected was kept confidential through a password protected computer access on my computer, LeeAnne Sherwin, co-investigator. All hard copies of the questionnaires were kept in a locked file cabinet in my home. The data obtained was only made available to those who were directly involved in this study. The results of this study have been reported in the aggregate form.

### **Potential Benefits of the Proposed Research to the Participants and Others**

Participants in this study may not have directly benefited from being in the study. Participation in this study may have allowed the participants to process and gain insight and understanding into their life experiences with IBS. It is my

hope that this study will help to expand the understanding of how individuals who suffer from IBS represent their disease and how these representations are related to HRQOL. In addition, understanding the affect the level of catastrophizing coping style used has on the relationship of the components of illness representation and HRQOL will contribute to bettering the HRQOL of those with IBS.

### **Planned Data Analysis**

#### **Sample Size**

The sample size minimum goal was 100 participants providing completed questionnaires. The sample size was estimated using the software Power Analysis and Sample Size or PASS (NCSS, 2009) for testing the meditation hypothesis. A power of 0.80 and an alpha level of 0.05 were used for this analysis. In the analysis, an assumption was made that the overall regression model  $R^2$  would be 38%, with an additional 6% accounted for by the mediator variable. To the best of my knowledge, studies with catastrophizing coping style as a mediator variable have not been performed. Rutter and Rutter (2002) examined whether quality of life was influenced by IBS patients' representation of their illness and assessed the mediating role of coping. Only one coping style, acceptance, mediated the effect of the consequence component of illness representation. Those individuals who reported fewer serious consequences were more likely to accept the illness. When the authors examined these variables in a hierarchical regression with two illness representation components (consequence and cure/control) at the first step and acceptance at the second,

acceptance added a significant 6% to the variance explained in perception of quality of life ( $R^2$  change=0.063,  $F(1,203)= 19.06$ ,  $p<0.001$ ) (Rutter & Rutter, 2002).

In past research of individuals with IBS, the response rate typically has been 52%-78% (Choung, Herrick, Locke, Zinsmeister & Talley, 2009; Kang, Firwana, Green, Mathews, Poullis, Barnaba, Tan, & Lim, 2011; Neal, Hebden & Spiller, 1997; Roalfe, Roberts & Wilson, 2008; Shaw, Beebe, Jensen & Adlis, 2001; Thijssen, Jonker, Leu, van der Veck, Vidakovic-Vukic, van Rood, Clemens & Masclee, 2010; White, Savas, Dacik, Elserag, Graham, Fitzgerald, Smith, Tan, & El-Serag, 2010; Weiser, Lacy, Noddin & Crowell, 2007). Theoretically, due to the typical high response rate for this population, as few as 128 and as many as 192 potential participants needed to be approached to achieve 100 useable responses. Recruitment continued until 100 completed questionnaires were obtained. The minimum proposed sample size of 100 was a feasible number to recruit and would provide variability.

### **Statistical Analysis**

The statistical Package for Social Sciences for Windows (IBM SPSS version 19.0.0, Chicago, Illinois) will be used for data analyses. Specific data analysis plans have been developed and are summarized below in Table 2.

*Table 1.* Data analysis summary. Summary of data analysis plan as related to the specific aims.

Aim	Variable	Measure	Analysis
Describe the components of illness representation in adults with IBS.	Illness Representation	Illness Perception Questionnaire-revised (IPQ-R)	Descriptive statistics including means and standard deviations of the subscales of the components of illness representation (identity, timeline, consequences, personal control, treatment control, illness coherence, timeline cyclical and emotional representations) were calculated. Cronbach's alpha reliabilities will also be calculated.
Describe the level of health-related quality of life (HRQOL) experienced by this population.	HRQOL	Irritable Bowel Syndrome-Quality of Life (IBS-QOL)	Descriptive statistics including the mean and standard deviation of HRQOL were calculated
Quantify the association between the components of illness representation & HRQOL.	Illness representation	IPQ-R	Pearson correlation coefficients were calculated between the components of illness representation & HRQOL
	HRQOL	IBS-QOL	

Table 1. Continued, data analysis summary

Identify the level of catastrophizing coping style that is used by this population.	Catastrophizing coping style	6 item catastrophizing subscale of the Coping Strategies Questionnaire (CSQ)	Descriptive statistics including the mean and standard deviation of catastrophizing coping style were calculated
Quantify the association between the components of illness representation & catastrophizing.	Illness representation	IPQ-R	Pearson correlation coefficients were calculated between the components of illness representation and catastrophizing coping style.
	Catastrophizing coping style	6 item catastrophizing subscale of the Coping Strategies Questionnaire (CSQ)	
Quantify the association between catastrophizing and HRQOL.	Catastrophizing	6 item catastrophizing subscale of the Coping Strategies Questionnaire (CSQ)	Pearson correlation coefficients were calculated between catastrophizing coping style and HRQOL.
	HRQOL	IBS-QOL	
Examine the potential mediator effect of catastrophizing coping style on the relationship between the components of illness representation and HRQOL in adults with IBS.	Illness representation,	IPQ-R	After confirming assumptions, regression analyses according to the model for statistical mediation developed by Baron & Kenny (1986) were computed.
	Catastrophizing coping style,	6 item Catastrophizing subscale of the Coping Strategies Questionnaire (CSQ)	
	HRQOL.	IBS-QOL	

## **Analysis of Primary Aims**

The following section discusses the data analysis plan for the seven primary aims of this study.

Descriptive statistics were calculated from the demographic data to describe the sample.

The purpose of study aim 1 was to describe the components of illness representation in adults with IBS.

The planned data analysis for aim 1 was to calculate descriptive statistics, including means and standard deviations, of the subscales of the components of illness representation (identity, timeline, consequences, personal control, treatment control, illness coherence, timeline cyclical and emotional representations). Reliability was evaluated by examining the internal consistency of the instrument subscales. Cronbach's alphas reliabilities coefficients have been reported.

The purpose of study aim 2 was to describe the level of HRQOL experienced by this population.

The planned data analysis for aim 2 was to calculate descriptive statistics, including mean and standard deviation of HRQOL.

The purpose of aim 3 was to quantify the association between the components of illness representation and HRQOL.

The planned data analysis for aim 3 calculated Pearson correlation coefficients between the components of illness representation and HRQOL.

The purpose of aim 4 is to identify the level of catastrophizing coping style used by this population.

The planned data analysis for aim 4 was to calculate descriptive statistics, including the mean and standard deviation of catastrophizing coping style.

The purpose of aim 5 was to quantify the association between the components of illness representation and catastrophizing coping style.

The planned data analysis for aim 5 was to calculate Pearson correlation coefficients between the components of illness representation and catastrophizing.

The purpose of aim 6 was to quantify the association between catastrophizing coping style and HRQOL.

The planned data analysis for aim 6 was to calculate Pearson correlation coefficients between catastrophizing coping style and HRQOL.

The purpose of aim 7 was to examine the potential mediator effect of catastrophizing coping style on the relationship between the components of illness representation and HRQOL in adults with IBS.

The planned data analysis for aim 7 was to confirm single order relationships among the variables. This was completed by calculating Pearson correlation coefficients, as stated earlier. As per Baron & Kenny (1986), a mediator effect should only be tested when a direct association between an independent variable and an outcome variable exists. Therefore, once the components of illness representation and HRQOL, the components of illness representation and catastrophizing coping style and catastrophizing coping style

and HRQOL correlation coefficients were confirmed, three regression analyses were calculated according to the model for statistical mediation developed by Baron & Kenny, 1986. This statistical method sought to analyze the mediational impact catastrophizing coping style had on the relationship between the components of illness representation and HRQOL.

In the first step of the regression model, catastrophizing coping style was regressed on each component of illness representation (these were done individually, Chapter 4, "Examination for Mediation" section). It was hypothesized this would show the individual components of illness representation as a significant predictor of catastrophizing (Baron & Kenny, 1986). In the second analysis, HRQOL will be regressed on each of the components of illness representation. It was hypothesized that this would show the individual components of illness representation as a significant predictor of HRQOL (Baron & Kenny, 1986). In the third and final equation, HRQOL was regressed on both catastrophizing coping style and each individual component of illness representation. It was hypothesized that a mediator effect would be present and catastrophizing coping style was a significant predictor of HRQOL, and the component of illness representation and HRQOL direct relationship would become non-significant (Baron & Kenny, 1986). See Figure 4.



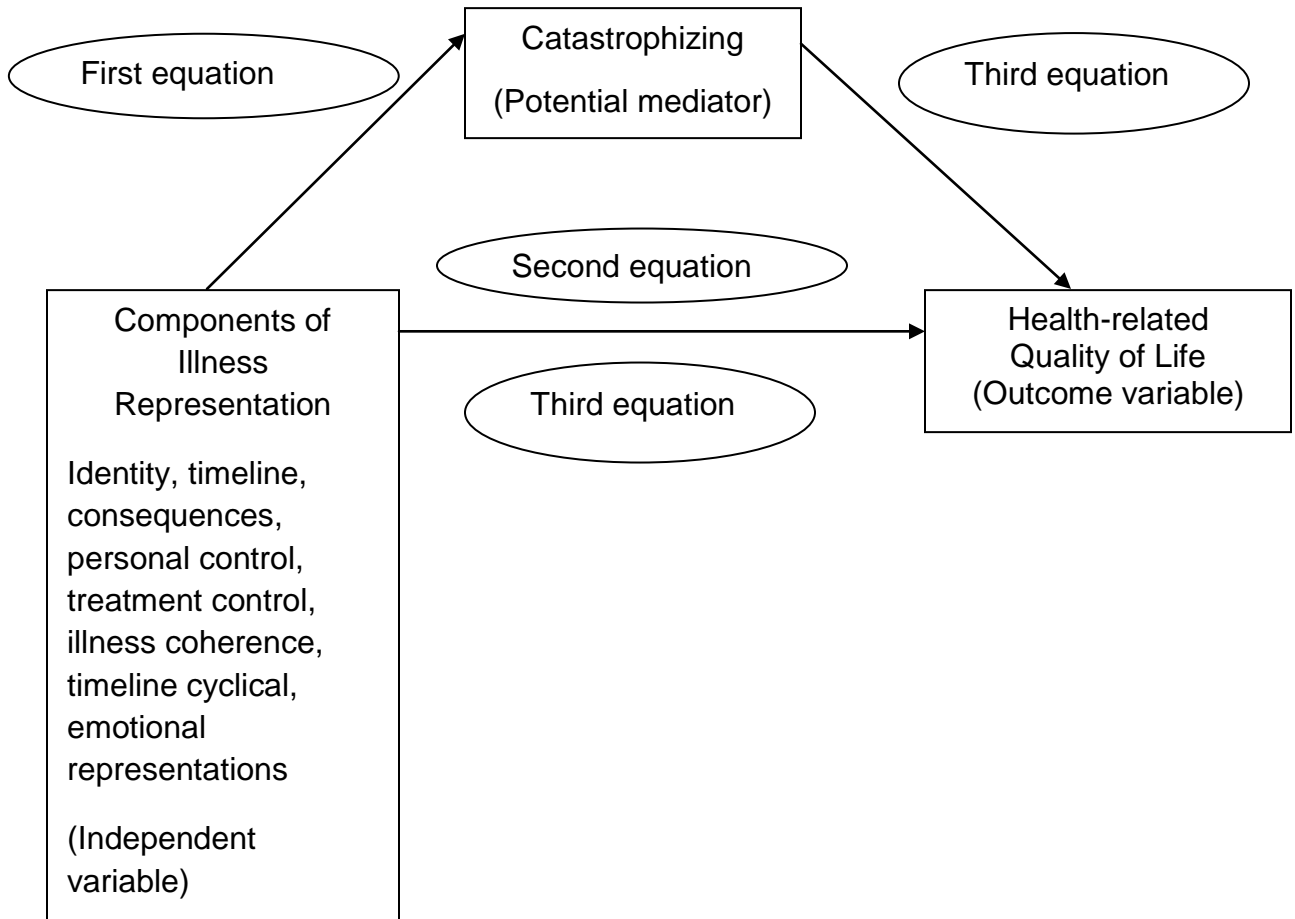


Figure 4. Mediation model.

Graphic model representing the analytical plan of evaluation for mediation. Following Baron & Kenny (1986) method, three regression analyses were performed to examine catastrophizing coping style as a mediator in the relationship between the components of illness representation and health-related quality of life. In the first equation, catastrophizing coping style was regressed on each component of illness representation (see list). In the second equation, health-related quality of life was regressed on each component of illness representation. And in the third equation, health-related quality of life was regressed on both an individual component of illness representation and catastrophizing coping style (Baron & Kenny, 1986; Bennett, 2000).

## Statistical Assumptions

### Assumptions for Regression

Assumptions for regression analyses include: 1. representative sample of the population being studied, 2. normal distribution, 3. Homoscedasticity, and 4. linear relationships.

The sample is assumed to be “representative” of the population. This assumption is based on the development of a good sampling plan and a reasonably large sample. At the completion of this study a clear discussion of the population to which this study can be generalized has been provided (see Chapter 5).

Scatter plots were used to check for normal distribution of the variables. This was done to examine for both outliers and linear associations. Residual analyses were used to test the linear model assumptions. When the relationships are linear and the dependent variable (HRQOL) is normally distributed for each value of the independent variable (components of illness representation), the residual distribution will be approximately normal (Munro, 2005, p.289). This was assessed using a histogram and residual plot of the standardized residuals. The residual analysis shows a violation of the normality assumption; therefore, the data was transformed. For complete discussion see Chapter 4, “Examining for Mediation”.

To assess the assumption of homoscedasticity, the residuals were plotted against the predicted values and the components of illness representation. It was anticipated the data would form a straight line from the lower left corner to the

upper right corner when the model fit the data. A pattern of changing distance from zero was not noted (such as a megaphone distribution); therefore, consideration for transformation of variables was not needed. If the residual plot showed a lack of linear relationship, such as curvilinear pattern the relationship may not be linear. This did not occur, and a nonlinear model was not needed to be used as a possible solution.

Lastly, multicollinearity was checked to exclude independent variables that were highly correlated with each other. High correlations ( $>0.8$ ), large  $R^2$  without significant coefficients, unstable regression weights such as dramatic changes in coefficients when other variables were added or removed, or unexpected coefficients and direction of coefficients would be indicative of multicollinearity. Checking for multicollinearity was completed by examining the correlation matrix of both parametric and non-parametric tests. Multicollinearity issues were not found.

## **Data Management**

### **Data Verification**

#### ***Preparing for data collection***

It is acknowledged that, despite well-prepared data collection protocol, human error can occur. Careful design of the questionnaire can contribute to complete and accurate data collection. Data items were used both letters and numbers to facilitate data entry. To enhance readability, questions were arranged with adequate spacing. Questions only appeared on the front side of all data collection forms. When possible, coding instructions, such as 1=female,

2=male, appeared on the data collection form. Each of the data collection forms was numbered. A codebook was kept with details for data coding.

### ***Entering data***

The co-Investigator, LeeAnne Sherwin, manually entered the data into an Excel file. A logbook was kept for decisions made for data entry when problems or questions arose. Numbering of items on the excel sheet to match the questionnaire form was used to insure accuracy of the data entry i.e. QS1, IP 1, D 1, and so forth.

### ***Verifying data entry accuracy***

Dual data entry has been shown to be superior to visual checking, resulting in fewer data entry errors (Barchard, Scott, Weintraub & Pace, 2008; Schneider & Deenan, 2004). Dual data entry was used in this study. Data was entered once into one dataset and then a second time into another dataset by LeeAnne Sherwin. The data was then checked for errors by comparing the two datasets electronically. When discrepancies were found, they were corrected in both datasets. This provides 100% data verification. There is a chance that the same error may have occurred in both datasets. If this occurred, the error would not be detected. The likelihood of these errors occurring is far less likely than errors occurring in the visual data verification method (Barchard et al., 2008). After both data sets were corrected, the primary dataset was used for data analysis.

### ***Handling Missing Data***

If > 10% of returned questionnaires were found to have incomplete data,

then mean substitution would have been performed to handle the missing data.

It was anticipated that missing data at the item level might occur when one or more items on the questionnaire were not answered by a respondent. An analysis to verify whether the data were missing completely at random or missing at random would have been completed. Missing completely at random (MCAR) data exists when missing data are randomly distributed throughout the sample across all observations and the missing data are not dependent upon another variable (Munro, 2005). Missing at random (MAR) data occurs when missing data are not randomly distributed across all observations but are randomly distributed within one or more subsamples of the study participants, such as missing answers to gender or education level (Munro, 2005).

Testing for MCAR or MAR would have been done using t-tests to determine if differences in the mean subscale scores occurred between those without missing responses and those with missing responses. If there was no significant difference occurring, then a mean subscale score would have been calculated and inserted to replace missing values prior to analysis. By doing this, the number of participant responses available for analysis would increase.

A disadvantage for mean replacement is that it invalidates the variance estimates calculated from the standard variance formulas by understating the data's true variance. It also distorts the distribution of values and can also lessen the observed correlation the variable may have with other variables. This occurs because all the missing data have a constant value which reduces the variance

(Munro, 2005). Despite these disadvantages, mean substitution provides an advantage for having a complete data set for all cases and is easy to implement.

### **Potential Study Limitations**

#### **Selection Bias and Self-Report**

The participants of this study were volunteers. This raises the question: are certain types of individuals more likely to participate in the study and will they respond to the questionnaires differently than those who decide not to participate? (Shadish et al., 2002). Despite self-report and self-selection to participate in this study, it was hoped that participants being assessed could and would accurately describe their current symptoms and behavior to the best of their recollection. Response styles of social desirability and extreme responses can contribute to distortions (Sadish et al., 2002). In an attempt to minimize the impact, there were notations within the study questionnaire explaining that the information provided would be kept confidential. In addition, the request to answer the questions honestly was also stressed.

#### **Limited Generalizability**

An attempt to expand generalizability was made by planning on collecting data from more than a single setting. Participating settings included gastrointestinal specialty clinics, family medicine clinics and women's health clinics. Limited numbers of IBS diagnosed individuals are noted in non-gastrointestinal specialty clinics. Due to these limited numbers, there was a risk of recruiting primarily from gastrointestinal specialty clinics, which may limit generalizability due to the fact that individuals presenting to specialty clinics may

have less controllable disease. Participants requiring referrals to gastrointestinal specialty clinics may represent the disease differently, utilize catastrophizing coping styles more often or even have worse HRQOL. Therefore, generalization of findings is considered dependent on the number of participants recruited from the various settings (see Chapter 4, “Sample” & “Participant Characteristics” sections).

### **Ethical Considerations**

The study protocol was submitted to Oregon Health & Science University Institutional Review Board (IRB) for formal approval. All IRB approvals were obtained in writing and documentation of the approval has been retained by the co-investigator, LeeAnne Sherwin.

### **Conflict of Interest**

The co-investigator, LeeAnne Sherwin, did not anticipate any financial gain from this study. There are no known conflicts of interest with regard to employment or affiliations with any agencies involved in this study.

## **Chapter 4**

### **Results**

This study examined the role of the Common Sense Model of Illness Representation in adults with IBS. The specific aims of this study were to describe the components of illness representation, the levels of catastrophizing coping style and the level of health-related quality of life experienced by those with IBS. In addition, catastrophizing coping style was examined as a mediator in the relationship between the components of illness representation and health-related quality of life in adults with IBS. Study results are reported in this chapter. First, the characteristics of the sample are described. Second, internal consistency reliability coefficients of the research instruments observed in this sample are presented. Third, the results of the correlation and regression analysis used to test the mediation hypotheses are reported.

### **Sample**

The sample for this study was recruited from community-based practices in Idaho, Connecticut, Missouri, Michigan, Pennsylvania, and New Jersey and through “snowball” recruitment. The eligibility criteria required potential participants to be diagnosed with IBS, between the ages of 30-50 years, able to read and speak English and without a new diagnosis of an organic gastrointestinal disorder involving the lower gastrointestinal tract (see Chapter 3). A total of 192 volunteers were screened for participation. Five volunteers were excluded because they did not meet the eligibility criteria. Four did not meet the age limits and one did not have a diagnosis of IBS. One questionnaire was



returned by the U.S. Postal Service marked “unable to forward.” This resulted in a final sample of 186 participants. One hundred and one completed questionnaires were returned to the researcher, producing a 54% response rate.

### **Missing Data**

Two subjects returned questionnaires without responding to the questions about comorbid conditions and symptoms experienced in the past seven days. The missing data rate was 2%; therefore, no data imputation was performed, as the rate was below the preset 10% of missing data criterion (see Chapter 3, p. 82) (Munro, 2005).

### **Descriptive Statistics**

The means, standard deviations, range, Cronbach’s alphas, skewness and kurtosis information for the Illness Representation Questionnaire-revised, catastrophizing coping style subscale, and the Irritable Bowel Syndrome Quality of Life measures are presented in Table 6. The components of illness representation variables demonstrated a normal distribution; however, catastrophizing coping style and health-related quality of life did not. The level of catastrophizing coping style was positively skewed, indicating that more of the participants used lower levels of catastrophizing coping style, while a small proportion of participants used higher level catastrophizing coping style. Health-related quality of life was found to be negatively skewed, meaning a greater proportion experienced higher levels of health-related quality of life.

## **Participant Characteristics**

One hundred and one participants provided completed questionnaires (54% response rate). Of the 101 participants, 79 were female and 22 male. The participants were recruited from 7 outpatient clinics across the United States. Seventy-five completed questionnaires came from GI subspecialty outpatient private practices, 20 came from women's health and family practice private outpatient settings. Six were uncategorized, as they came from response to advertisements posted in GI subspecialty, women's health and family practice offices. The mean age was 42.1 years (range 30-50 years of age). Ninety-six percent were Caucasian, 3% African American and 1% reported other.

Ninety-eight percent of the participants reported experiencing at least one comorbid condition and on average, 3.6 comorbidities were reported (see Table 4 for specific comorbid listings). Headache/migraine was the most frequently reported comorbidity (57.6%), followed by heartburn/reflux (45.5%), lactose intolerance (41.4%) and insomnia (36.4%). Also reported were the symptoms the participant had experienced in the past 7 days. These symptoms were typical of IBS and are listed in Table 5. Sixty-two percent reported experiencing 6 or more symptoms in the past 7 days. The most frequently reported symptoms were abdominal pain (91%), diarrhea (61%), abdominal bloating (73%), gas/flatulence (71%), stomach noises (64%) and nausea (59%). This sample was also asked to report their pain level in the past 7 days, and the mean pain level reported was 4.7 (range 0, no pain to 10, worst pain ever).

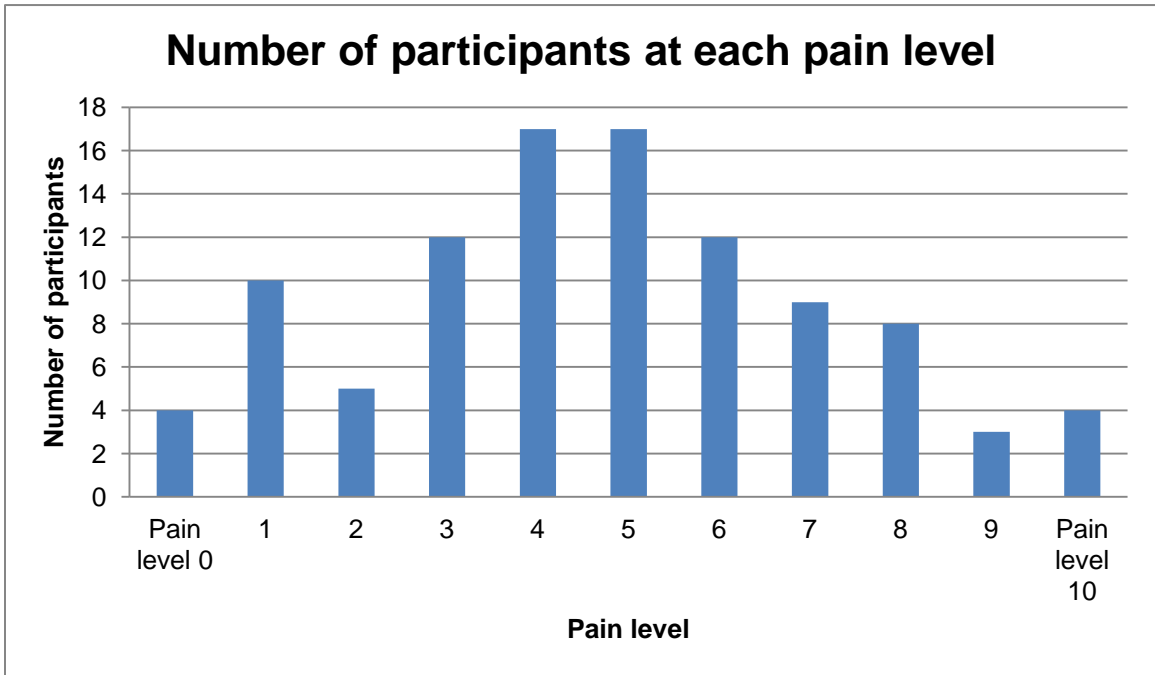
Volunteers reported relatively low psychological distress. The mean scores reported were; depression 3.61 (SD 4.82), anxiety 4.73 (SD 5.14), somatization 5.92 (SD 5.72) and global severity index 14.27 (SD 13.48) (see Table 2). Sixty percent had been diagnosed with IBS for greater than 5 years. Fifty-five percent were taking medications for the treatment of anxiety and/or depression. Sixty-nine percent were married, 49.5% held a Bachelor's degree or higher, and 58.4% were employed full-time. See Tables 2 & 3 for additional demographics.

Table 2. Characteristics of the sample, N=101

<b>Characteristics</b>	<b>Percent</b>
<b>Gender</b>	
Female	78.2%
Male	21.8%
<b>Race</b>	
Caucasian	96%
<b>Marital Status</b>	
Married	69.3%
Not married living with partner	5%
Single	11.9%
Separated	3%
Divorced	10.9%
<12 months	15.8%
>12 months < 5 years	23.8%
>5 years <10 years	28.7%
> 10 years	31.7%
<b>Education</b>	
Some high school	4%
High school/GED	9.9%
Some college	23.8%
Associate's degree	12.9%
Bachelor's degree	28.7%
Master's degree	16.8%
Doctorate/post doctorate	4%
<b>Employment</b>	
Not employed	25.7%
Part-time or less	15.8%
Full-time	58.4%

<b>Characteristics</b>	<b>Mean (SD) Range</b>
<b>Psychological Distress</b>	
Depression	3.61 (4.82) 0-22
Anxiety	4.73 (5.14) 0-24
Somatization	5.92 (5.72) 0-24
Global severity index	14.27 (13.48) 0-68
<b>Medications taken</b>	
for depression	38.6%
for anxiety	15.8%
for both depression & anxiety	11%
<b>Characteristics</b>	
Age	42.1 (5.84) 30-50
Pain Level	4.7 (2.51) 0-10

*Table 3.* Distribution of participants according to pain level. Number of participants at each pain level in past 7 days (Range: 0=none to 10=worst pain possible), N=101.



*Table 4.* Comorbidity distribution. Percentage of participants self-reporting comorbidity, N=99.

<b>Comorbidity</b>	<b>Percent</b>
Fibromyalgia	12.9%
Heartburn/Reflux	44.6%
Asthma	16.8%
Headache/Migraine	56.4%
Back pain	38.6%
Insomnia	35.6%
Lactose Intolerance	40.6%
Food Allergy	18.8%
History of Abdominal Surgery	18.8%
Dysmenorrhea	8.9%
TMJ	18.8%
Chronic Fatigue	23.8%
Chronic Pelvic Pain	16.8%
Cystitis	6.9%

*Table 5.* Symptom distribution. Percentage of participants self-reporting symptoms experienced in the past 7 days, N=99.

<b>Symptom</b>	<b>Percent</b>
Abdominal pain, gas, cramping	91.1%
Diarrhea	69.3%
Constipation	53.5%
Abdominal bloating	72.3%
Nausea	58.4%
Stomach noises	63.4%
Mucus in stool	32.7%
Gas/flatulence	32.7%
Urgency to have a bowel movement	53.5%
Feeling of incomplete emptying	51.5%
No symptoms in past 7 days	1%

Once the completed questionnaires were returned and recruitment ended, the data were input into an excel file for verification. Data entry was verified for accuracy using dual data entry (see Chapter 3, verifying data entry). After corrections, the primary data set was used for analyses.

**Reliability: Internal Consistency**

The initial analysis began by calculating internal consistency reliability coefficients (Cronbach's alphas). Descriptive statistics and internal consistency reliability coefficients of the scales and subscales were calculated. Cronbach's alphas ranged from 0.79-0.96, which demonstrated moderate to excellent internal consistency. See Table 6 for means (*M*), standard deviations (*SD*), range, and Cronbach's alphas ( $\alpha$ ).

**Description of the Components of Illness Representation**

The revised Illness Perception Questionnaire (IPQ-R) specific to IBS was used to quantify the components of cognitive and emotional illness representations of IBS. All of the eight subscales of the IPQ-R were used for this study (see Table 6). The IPQ-R showed moderate to excellent internal consistency reliability. Overall, participants suffered from a number of symptoms attributed to IBS, considered their IBS to have negative consequence, held strong beliefs that their IBS was chronic and cyclical in nature, believed they had a moderate amount of control and a fair understanding of their disease and held a moderate belief of the negative emotional impact of their IBS.



### **Description of Catastrophizing Coping Style**

The level of catastrophizing coping style was measured with the catastrophizing subscale of the Coping Strategy Questionnaire (CSQ). A greater score implied the more often catastrophizing coping style is used. The scale had excellent internal consistency reliability. Individuals reported a low level of catastrophizing (see Table 6).

### **Description of Health-related Quality of Life**

The level of health-related quality of life was measured with the IBS-QOL. A greater score represented a better quality of life. This scale had excellent internal consistency reliability (see Table 6). The participants experienced slightly better than moderate health-related quality of life.

Table 6. Means, Standard deviations, Ranges and Cronbach’s alphas of measures.

Measure	M	SD	Possible Range of scores	α
Illness Representation				
• Identity <sup>a</sup>	12.09	5.78	0-28	0.89
• Consequences <sup>b</sup>	19.54	4.80	6-30	0.80
• Timeline a/c <sup>c</sup>	24.46	4.25	6-30	0.86
• Timeline cyclic <sup>d</sup>	13.53	2.55	4-20	0.79
• Personal control <sup>e</sup>	18.86	4.94	6-30	0.86
• Treatment control <sup>f</sup>	14.57	4.43	5-25	0.86
• Illness coherence <sup>g</sup>	14.19	5.24	5-25	0.92
• Emotional rep <sup>h</sup>	18.23	5.50	6-30	0.87
Catastrophizing <sup>i</sup>	9.20	8.46	0-36	0.90
IBS-QOL <sup>j</sup>	63.32	22.87	0-100	0.96

Note: Above table is reporting untransformed (original) means. <sup>a</sup>Identity subscale of the revised Illness Perception Questionnaire (IPQ-R), a higher score equaled a more strongly held belief about the number of symptoms attributed to IBS. <sup>b</sup>Consequences subscale of IPQ-R, a higher score represents strongly held beliefs about the negative consequences of IBS. <sup>c</sup>Timeline a/c= timeline acute/chronic subscale of the IPQ-R, higher score represents strongly held beliefs about the chronicity of IBS. <sup>d</sup>Timeline cyclic subscale of the IPQ-R, a higher score represents strongly held beliefs about the cyclical nature of IBS. <sup>e</sup>Personal control and <sup>f</sup>Treatment control subscales of the IPQ-R, a higher score represents positive beliefs about the controllability of IBS. <sup>g</sup>Illness coherence subscale of IPQ-R, a higher score represents positive beliefs about their personal understanding of IBS. <sup>h</sup>Emotional rep= emotional representation subscale of IPQ-R, a higher score represents strongly held beliefs about the negative emotional impact of IBS. <sup>i</sup>catastrophizing=catastrophizing subscale of the Coping Strategy Questionnaire (CSQ), a higher score implies the more often catastrophizing coping style is used. <sup>j</sup>IBS-QOL measures health-related quality of life, a higher score indicates a better quality of life.

## Relationships among the Variables

Prior to conducting regression analysis, Munro (2005) recommends assessment of multicollinearity among predictor variables with correlations greater than 0.80. High correlations ( $\geq 0.80$ ) are considered problematic, suggesting measurement of the same construct.

In an attempt to assess for multicollinearity and to confirm the assumptions associated with mediation (see Examining for Mediation section in this Chapter), both parametric and non-parametric tests were conducted. Pearson's correlation coefficients were conducted between the components of illness representation, catastrophizing coping style and health-related quality of life. Results are presented in Table 7 and discussed below. Spearman's rank order correlation coefficients were calculated for the ordinal demographic variables. These demographic variables included pain in the past seven days, time since diagnosis, age and education level. Results are presented in Table 8 and discussed below. High correlation coefficients ( $>0.8$ ) were not found; therefore, multicollinearity was not a concern.

First, correlations between the individual components of illness representation were examined. Participants who reported more symptoms (strong illness identity) reported more serious consequences, less perceived control, poorer understanding of their IBS and a greater emotional impact. The cyclical nature (timeline cyclical) was not associated with any of the components of illness representation.

Second, the relationship between the components of illness representation and health-related quality of life was examined. A poorer health-related quality of life was associated with participants who reported more symptoms (strong illness identity), more negative consequences, more chronic nature of their IBS, less perceived control and understanding of their IBS, and a greater negative emotional impact.

Third, the relationships between the components of illness representation and catastrophizing coping style were examined. All but one of the illness representation components (timeline cyclical) was significantly correlated to catastrophizing coping style. Those reporting a strong illness identity, more negative consequences, a more chronic nature of their IBS, and a more negative emotional impact were more likely to use catastrophizing coping style, in contrast to those who believed they had better control and understanding of their IBS.

Fourth, the relationships between catastrophizing coping style and health-related quality of life were noted to have a strong inverse relationship, meaning those who used the catastrophizing coping style more often were more likely to have lower health-related quality of life scores.

Spearman's rank order correlation coefficients were calculated for the demographic ordinal variables. Pain level experienced in the past seven days was noted to have positive weak to moderate significant correlations with identity consequences, timeline acute/chronic, and catastrophizing coping style, indicating those reporting greater levels of pain in the past seven days were more likely to report more symptoms, experience more consequences, describe their

IBS as chronic in nature, and use catastrophizing coping strategy more often. In contrast, the pain level experienced in the past seven days was inversely correlated to personal control, treatment control, illness coherence, health-related quality of life and education level. Those who believed they had better personal or treatment control, a better understanding of their IBS, a better health-related quality of life and higher education level were likely to report lower pain levels.

Time since diagnosis was found to have only a weak positive correlation to timeline, cyclical, indicating those with a greater time since diagnosis reported a more cyclical nature to their IBS.

Age was not found to correlate with any of the variables examined in the Spearman's rank order correlation (see Table 8).

Education level was noted to have weak negative correlations with identity, consequences, emotional representation and catastrophizing coping style. Those with lower levels of education were more likely to report higher number of symptoms associated with their IBS, more negative consequences, a greater negative emotional impact, and use catastrophizing coping style more often. Weak positive correlations were found in health-related quality of life and personal control variables. Individuals with higher levels of education were more likely to report better health-related quality of life and more personal control.

Table 7. Pearson's correlation coefficients. N=101

	HRQOL	CCS	Identity	Conseq.	Timeline a/c	Personal control	Tx co.	Illness co.	Timeline cyclical
CCS	-0.76**	1							
Identity	-0.47**	0.39**	1						
Conseq.	-0.72**	0.54**	0.44**	1					
Timeline a/c	-0.34**	0.27**	0.15	0.43**	1				
Personal control	0.39**	-0.39**	-0.25*	-0.41**	-0.30**	1			
Tx co.	0.39**	-0.35**	-0.24*	-0.58**	-0.44**	0.61**	1		
Illness co	0.40**	-0.33**	-0.27**	-0.32**	-0.23**	0.54**	0.35**	1	
Timeline cyclical	-0.18	0.20	0.16	0.01	0.11	0.04	-0.10	-0.09	1
Emo. Rep.	-0.71**	0.65**	0.35**	0.65**	0.28**	-0.44**	-0.43**	-0.38**	0.11

\* $p < 0.05$ , \*\* $p < 0.01$

HRQOL=health-related quality of life, CCS=catastrophizing coping style, Conseq.=consequences, Timeline a/c=timeline acute/chronic, Tx co.=treatment control, Illness co.=illness coherence, Emo. Rep.= emotional representation.

Table 8. Spearman's rank order correlation coefficients. *N*=101

	Pain level	Time dx	Education level
HRQOL	-0.54**	-0.02	0.23*
CCS	0.60**	0.02	-0.22*
Identity	0.40**	0.06	-0.38**
Conseq.	0.50**	-0.02	-0.26*
Timeline a/c	0.40**	0.14	0.11
Personal control	-0.40**	0.18	0.20*
Tx co.	-0.45**	-0.05	0.09
Illness co.	-0.31*	0.13	0.10
Timeline cyclical	0.11	0.27**	0.08
Emo. Rep.	0.36**	-0.10	-0.20*
Pain level	1.00	0.05	-0.40
Time dx	0.50	1.00	0.15
Age	-0.10	0.16	0.60
Education level	-0.40**	0.15	1.00

\**p*<0.05, \*\**p*<0.01

HRQOL=health related quality of life, CCS=catastrophizing coping style, Conseq.=consequences, Timeline a/c=timeline acute/chronic, Tx co.=treatment control, Illness co.=illness coherence, Emo. Rep.=emotional representation, Time dx=time since diagnosis.

## Examining for Mediation

In order to test for a mediator effect of catastrophizing coping style, between the components of illness representation and health-related quality of life, associations first need to be established to verify this relationship. Pearson's correlation coefficients were computed to examine for relationships (see Table 7). All components of illness representation, except for the timeline cyclical component, were found to have moderate to strong relationships. Regression analysis was performed to examine catastrophizing coping style acting as a mediator in the relationship between the components of illness representation and health-related quality of life. Three regression analyses for each of the components of illness representation that showed a significant association with health-related quality of life were performed, consistent with the Baron & Kenny (1986) method.

Kolmogorov-Smirnov and Shapiro-Wilks tests were used to assess goodness of fit of the regression residuals to normality (See Appendix G). Violation of normality was observed. When substantial negative skewness was noted, a logarithmic<sub>10</sub> transformation was applied, as suggested by Tabachnick & Fidell (2007) and Howell (2007). When moderate negative skewness was noted, the square-root computation was used. See Appendix G for Kolmogorov-Smirnov (K-S) and Shapiro-Wilk (S-W) results of goodness of fit of the regression residuals to normality, before and after transformation.

The remaining analyses tested the possibility of catastrophizing coping style acting as a mediator in the relationship between the components of illness



representation and health-related quality of life. This was examined using regression analyses as suggested by Baron & Kenny (1986). Each of the analyses followed the same process, which was; step 1, establishing a relationship between the independent variable (the component of illness representation) and the mediator (catastrophizing coping style), step 2, establishing a relationship between the independent variable and the outcome variable (health-related quality of life) and step 3, establishing a relationship between the mediator variable and the outcome variable. The analyses figures are presented in Figures 5-11.

The first relationship examined was between identity and health-related quality of life. In step 1 of the regression analyses, catastrophizing coping style was regressed on identity. Identity explained 15% of the variance in catastrophizing coping style ( $R^2=0.15$ ,  $F_{(1,99)}=17.16$ ,  $p<0.001$ ). As the illness identity regression coefficient (identifying a greater number of symptoms associated with their IBS) increased, the catastrophizing coping style regression coefficient increased. In step 2, health-related quality of life was regressed on identity, and 22% of the variance in health-related quality of life was accounted for by the identity variable ( $R^2=0.22$ ,  $F_{(1,99)}=27.38$ ,  $p<0.001$ ), meaning those reporting a stronger illness identity (identifying a greater number of symptoms associated with their IBS) reported a lower level of health-related quality of life. In step 3, catastrophizing coping style ( $\log_{10}$ ) and identity were entered. Catastrophizing coping style ( $\log_{10}$ ) accounted for 50% of the variance in health-related quality of life and identity decreased to account for 4% of the variance in

health-related quality of life ( $R^2=0.55$ ,  $F_{(2,98)}=58.71$ ,  $p<0.001$ ). As seen in Figure 4, the regression coefficients ( $\beta$ ) linking identity and health-related quality of life remained significant after adding the mediator catastrophizing coping style ( $\log_{10}$ ). Despite the persistent significance, the regression coefficient was substantially reduced in the final step. This reduced direct association is consistent with partial mediation (Baron & Kenny, 1986; Bennett, 1999; MacKinnon, Fairchild & Fritz, 2007; Rucker, Preacher Tormala, & Petty, 2011). The reduced direct association between identity and health-related quality of life, when catastrophizing coping style is in the model, supports the hypothesis that catastrophizing coping style is at least one of the mediators in the relationship between identity and health-related quality of life. There might be other mechanisms by which identity exerts its influence on health-related quality of life or it may have direct as well as indirect effects. It is true that part of the effect of identity is mediated by catastrophizing coping style, but it is possible that other parts are either direct or mediated by other variables not included in the model.

The second relationship examined was between consequences and health-related quality of life. In step 1, consequences accounted for 30% of the variance in catastrophizing coping style ( $R^2=0.30$ ,  $F_{(1,99)}=42.54$ ,  $p<0.001$ ). As the consequences regression coefficient increased, the catastrophizing coping style regression coefficient also increased. In step 2, 52% of the variance in health-related quality of life was accounted for by consequences ( $R^2=0.52$ ,  $F_{(1,99)}=105.50$ ,  $p<0.001$ ). Individuals with greater perceived negative consequences associated with their IBS reported a lower level of health-related

quality of life. In step 3, catastrophizing coping style (square-root) and consequences were entered. Catastrophizing coping style (square-root) accounted for 55% of the accounted variance in health-related quality of life, and consequences decreased to account for 14% of the variance in health-related quality of life ( $R^2=0.69$ ,  $F_{(2,98)}=107.59$ ,  $p<0.001$ ). As seen in Figure 5, the regression coefficients ( $\beta$ ) linking consequences and health-related quality of life remained significant after adding the mediator catastrophizing coping style (square-root). However, the regression coefficient was substantially reduced in the final step. The reduced direct association between consequences and health-related quality of life, when catastrophizing coping style is in the model, supports the hypothesis that catastrophizing coping style is at least one of the mediators in the relationship between consequences and health-related quality of life. This suggests that catastrophizing coping style (square-root) partially mediates or only partially explains how or why consequences and health-related quality of life relationships exist.

The third relationship examined was between timeline acute/chronic and health-related quality of life. In step 1, timeline acute/chronic accounted for 9% of the variance in catastrophizing coping style (square-root) ( $R^2=0.09$ ,  $F_{(1,99)}=9.28$ ,  $p<0.05$ ). As the timeline acute/chronic regression coefficient increased, the catastrophizing coping style regression coefficient also increased. In step 2, 15% of the variance in health-related quality of life (square-root) was accounted for by timeline acute/chronic ( $R^2=0.15$ ,  $F_{(1,99)}=59.50$ ,  $p<0.001$ ). Individuals with a greater perceived chronic timeline of their IBS reported a lower

level of health-related quality of life. In step 3, catastrophizing coping style (square-root) and timeline acute/chronic were entered. Catastrophizing coping style (square-root) accounted for 54% of the variance in health-related quality of life (square-root). Timeline acute/chronic decreased to account for 3% of the variance in health-related quality of life (square-root) ( $R^2=0.57$ ,  $F_{(2,98)}=63.91$ ,  $p<0.001$ ). As seen in Figure 6, the regression coefficients ( $\beta$ ) linking timeline acute/chronic and health-related quality of life remained significant after adding the mediator catastrophizing coping style ( $\log_{10}$ ). However, the regression coefficient was substantially reduced in the final step. The reduced direct association between timeline acute/chronic and health-related quality of life, when catastrophizing coping style is in the model, supports the hypothesis that catastrophizing coping style is at least one of the mediators in the relationship between timeline acute/chronic and health-related quality of life. This suggests that catastrophizing coping style (square-root) partially mediates or only partially explains how or why the timeline acute/chronic and health-related quality of life (square-root) relationship exists.

The fourth relationship examined was personal control and health-related quality of life. In step 1, personal control accounted for 14% of the variance in catastrophizing coping style (square-root) ( $R^2=0.14$ ,  $F_{(1,99)}=16.48$ ,  $p<0.001$ ). As the personal control regression coefficient increased, the catastrophizing coping style regression coefficient decreased. In step 2, personal control accounted for 15% of the variance in health related quality of life ( $R^2=0.15$ ,  $F_{(1,99)}=17.31$ ,  $p<0.001$ ). Individuals with greater perceived personal control of their IBS

reported a higher level of health-related quality of life. In step 3, catastrophizing coping style (square-root) and personal control were entered. Catastrophizing coping style (square-root) accounted for 55% of the variance in health-related quality of life. Personal control decreased to 1% of the variance accounted for in health-related quality of life ( $R^2=0.56$ ,  $F_{(2,98)}=62.48$ ,  $p>0.05$ ). As seen in Figure 7, the regression coefficients ( $\beta$ ) linking personal control and health-related quality of life did not remain significant after adding the mediator catastrophizing coping style ( $\log_{10}$ ). The effect of personal control on HRQOL becomes non-significant in the final step of the analysis, which demonstrates full mediation. All the effects of personal control are mediated by catastrophizing coping style. This suggests that catastrophizing coping style (square-root) fully mediates or explains how or why the personal control and health-related quality of life relationship exists.

The fifth relationship to be examined was between treatment control and health-related quality of life. In step 1, treatment control accounted for 12% of the variance in catastrophizing coping style (square-root) ( $R^2=0.12$ ,  $F_{(1,99)}=12.91$ ,  $p<0.001$ ). As the treatment control regression coefficient increased, the catastrophizing coping style regression coefficient decreased. In step 2, treatment control accounted for 15% of the variance in health-related quality of life ( $R^2=0.15$ ,  $F_{(1,99)}=17.52$ ,  $p<0.001$ ). Individuals with a greater perceived treatment control of their IBS reported a higher level of health-related quality of life. In step 3, catastrophizing coping style (square-root) and treatment control were entered. Catastrophizing coping style (square-root) accounted for 55% of the variance in health-related quality of life. Treatment control decreased to 2%

of the variance accounted for in health-related quality of life ( $R^2=0.57$ ,  $F_{(2,98)}=64.52$ ,  $p<0.001$ ). As seen in Figure 8, the regression coefficients ( $\beta$ ) linking treatment control and health-related quality of life remained significant after adding the mediator catastrophizing coping style (square-root). However, the regression coefficient was substantially reduced in the final step. The reduced direct association between treatment control and health-related quality of life, when catastrophizing coping style is in the model, supports the hypothesis that catastrophizing coping style is at least one of the mediators in the relationship between treatment control and health-related quality of life. This suggests that catastrophizing coping style (square-root) partially mediates or only partially explains how or why the treatment control and health related quality of life relationship exists.

The sixth relationship to be examined was between illness coherence and health-related quality of life. In step 1, illness coherence accounted for 11% of the variance in catastrophizing coping style (square-root) ( $R^2=0.11$ ,  $F_{(1,99)}=11.73$ ,  $p<0.001$ ). As the illness coherence regression coefficient increased, the catastrophizing coping style regression coefficient decreased. In step 2, illness coherence accounted for 16% of the variance in health-related quality of life ( $R^2=0.16$ ,  $F_{(1,99)}=18.98$ ,  $p<0.001$ ). Individuals with a greater illness coherence reported higher level of health-related quality of life. In step 3, catastrophizing coping style (square-root) and illness coherence were entered. Catastrophizing coping style accounted for 55% of the variance in health-related quality of life. Illness coherence decreased to 3% of the variance accounted for

in health-related quality of life ( $R^2=0.58$ ,  $F_{(2,98)}=66.58$ ,  $p<0.001$ ). As seen in Figure 9, the regression coefficients ( $\beta$ ) linking illness coherence and health-related quality of life remained significant after adding the mediator catastrophizing coping style (square-root). However, the regression coefficient was substantially reduced in the final step. The reduced direct association between illness coherence and health-related quality of life, when catastrophizing coping style is in the model, supports the hypothesis that catastrophizing coping style is at least one of the mediators in the relationship between illness coherence and health-related quality of life. This suggests that catastrophizing coping style (square-root) partially mediates or only partially explains how or why the illness coherence and health related quality of life relationship exists.

The seventh and final relationship to be examined was emotional representation and health-related quality of life. Transformation of both variables was attempted in the hope of meeting normality. The best fit could only be achieved on the Kolmogorov-Smirnov test with transforming catastrophizing (square-root) and un-transformed health-related quality of life (see Table 14). In step 1, emotional representation accounted for 39% of the variance in catastrophizing coping style (square-root) ( $R^2=0.39$ ,  $F_{(1,99)}=62.84$ ,  $p<0.001$ ). As individuals' perceived emotional representation increased, catastrophizing coping style use increased. In step 2, emotional representation accounted for 50% of the variance in health-related quality of life ( $R^2=0.50$ ,  $F_{(1,99)}=99.85$ ,  $p<0.001$ ). Individuals with a greater perceived emotional representation of IBS reported lower levels of health-related quality of life. In step 3, catastrophizing coping

style (square-root) and emotional representation were entered. Catastrophizing coping style (square-root) accounted for 55% of the variance in health-related quality of life. Emotional representation decreased to 10% of the variance accounted for in health-related quality of life ( $R^2=0.65$ ,  $F_{(2,98)}=90.02$ ,  $p<0.001$ ). As seen in figure 10, the regression coefficients ( $\beta$ ) linking emotional representation and health-related quality of life remained significant after adding the mediator catastrophizing coping style (square-root). However, the regression coefficient was substantially reduced in the final step. The reduced direct association between emotional representation and health-related quality of life, when catastrophizing coping style is in the model, supports the hypothesis that catastrophizing coping style is at least one of the mediators in the relationship between emotional representation and health-related quality of life. This suggests that catastrophizing coping style (square-root) partially mediates or only partially explains how or why the illness coherence and health related quality of life relationship exists.

The results of this study are consistent with the literature. The sample characteristics were found to be typical of those who suffer from IBS. Pearson's correlations of illness representations and HRQOL were as expected: those volunteers who held stronger beliefs of; 1. number of symptoms associated with their IBS, 2. negative consequences, 3. chronicity of their IBS, 4. less control and understanding of their IBS, and 5. greater emotional impact all suffered from poorer HRQOL. Catastrophizing coping style was inversely associated with HRQOL. Furthermore, catastrophizing coping style fully mediated the



relationship between personal control and HRQOL. Catastrophizing coping style was also found to partially mediate the remaining relationships of the components of illness representation and HRQOL. These findings are consistent with the study hypotheses.

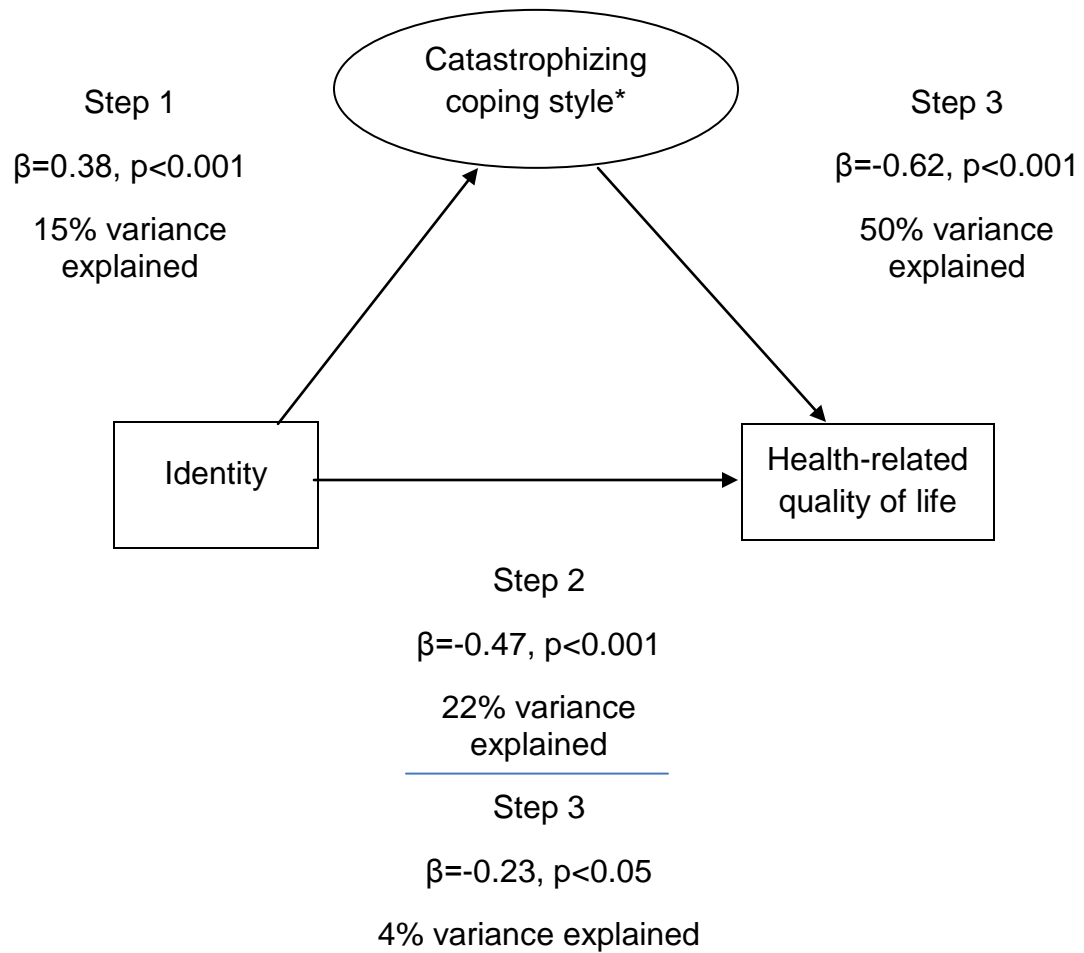
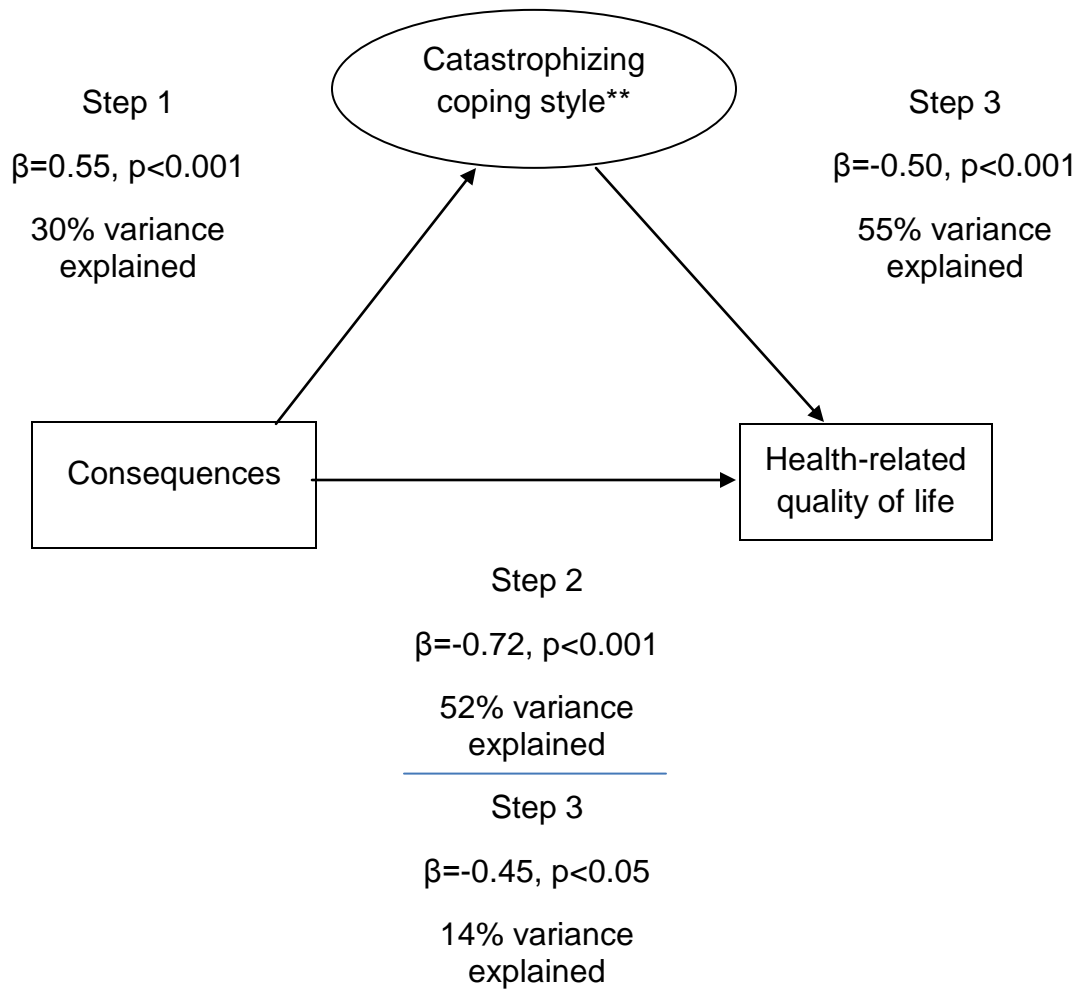
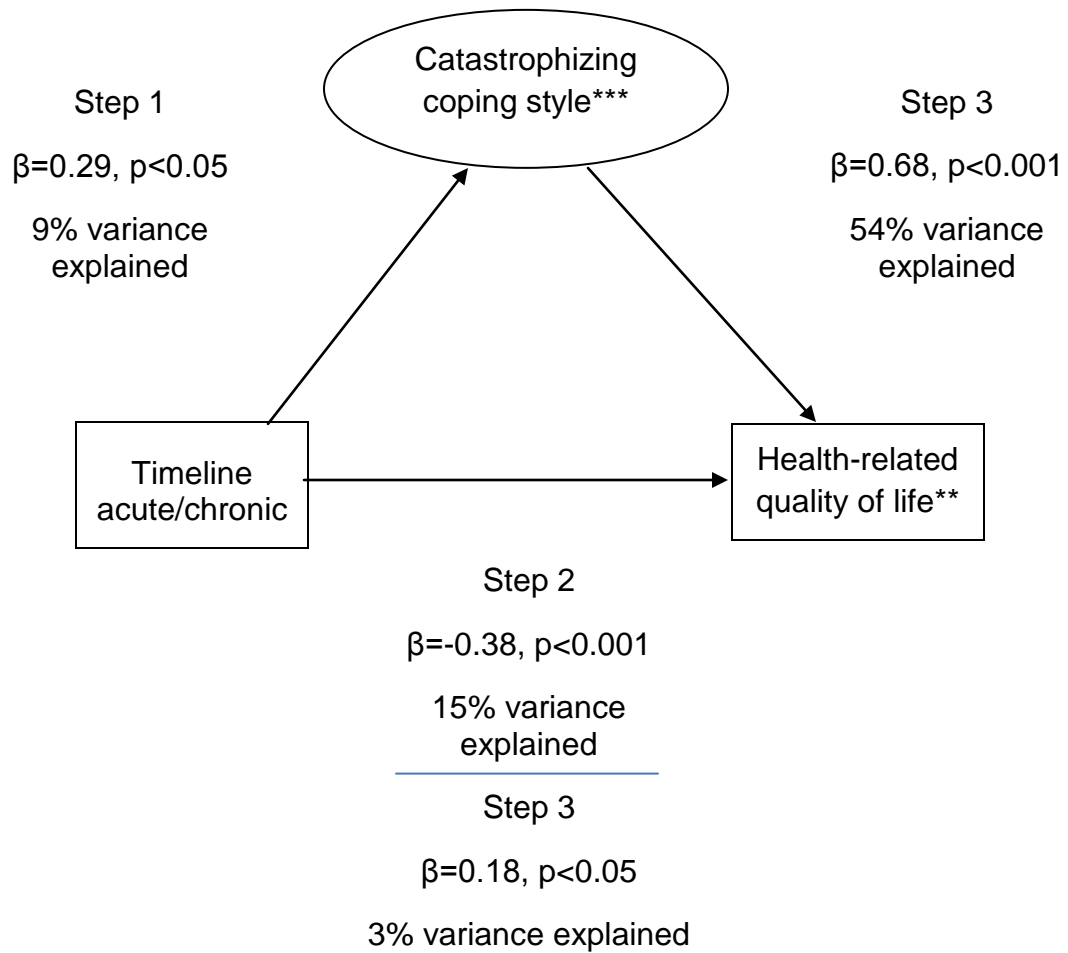


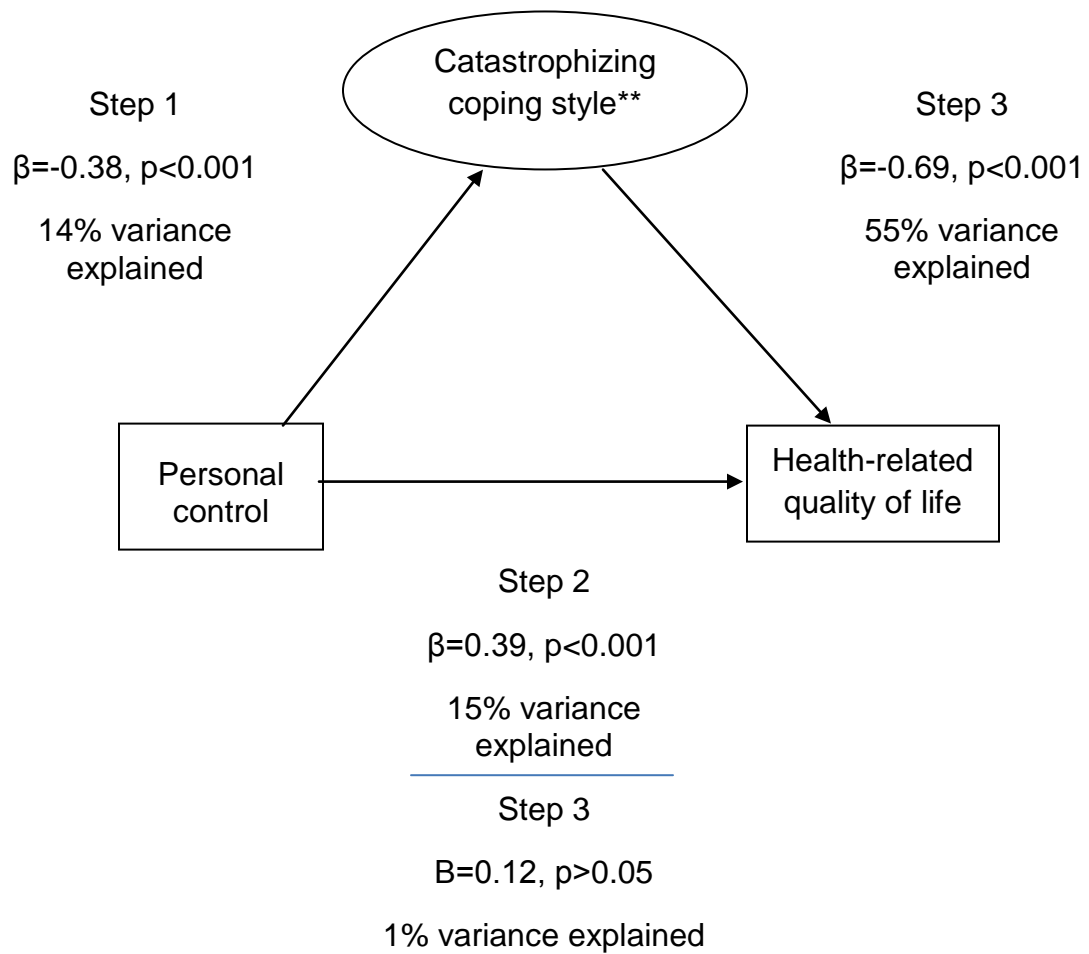
Figure 5. Statistical analysis of mediator effect. Catastrophizing coping style partially mediates the relationship between identity & health-related quality of life. \*Data transformed using  $\log_{10}$  catastrophizing coping style



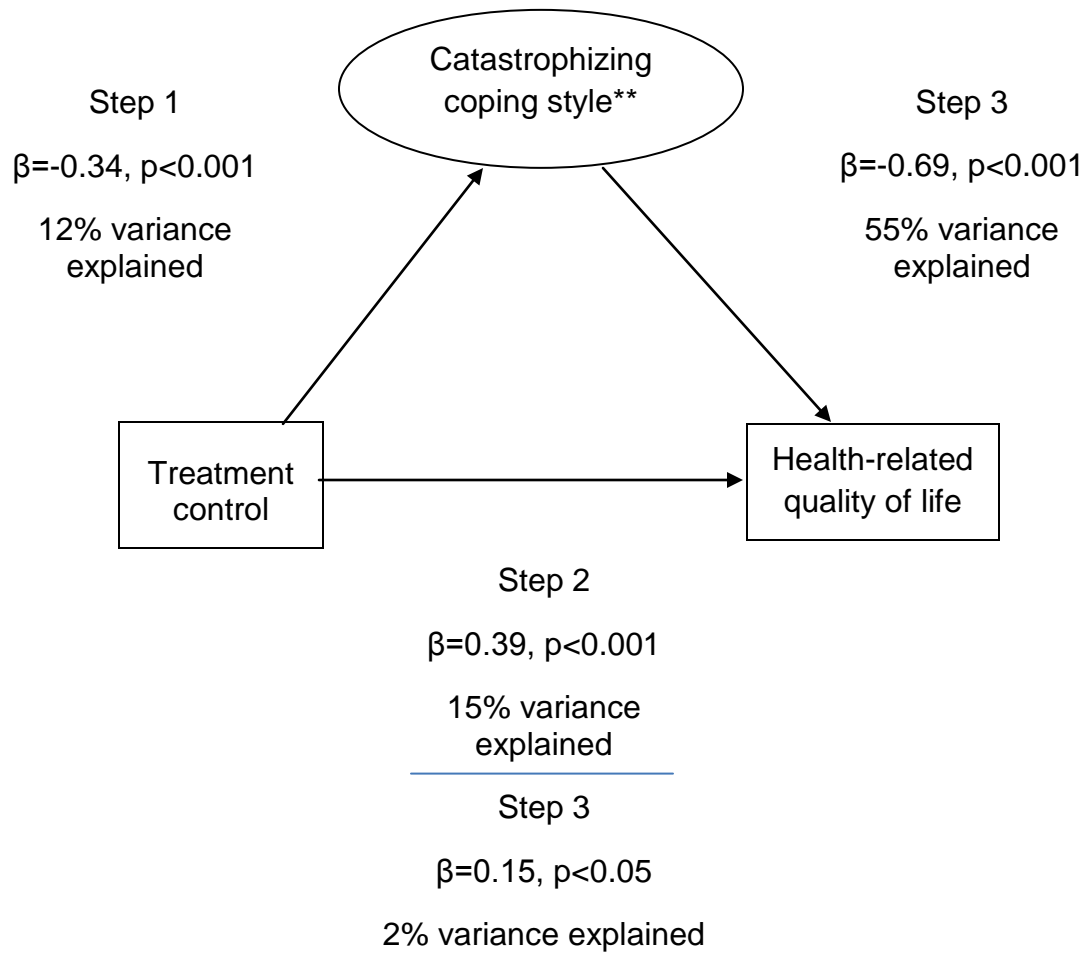
*Figure 6.* Statistical analysis of mediator effect. Catastrophizing coping style partially mediates the relationship between consequences & health-related quality of life. \*\*Data transformed using square root catastrophizing coping style.



*Figure 7.* Statistical analysis of mediator effect. Catastrophizing coping style partially mediates the relationship between timeline acute/chronic & health-related quality of life. \*\*\*Data transformed using square root of catastrophizing coping style and the square root of health-related quality of life.



*Figure 8.* Statistical analysis of mediator effect. Catastrophizing coping style **fully** mediates the relationship between personal control & health-related quality of life. \*\*Data transformed using square root of catastrophizing coping style



*Figure 9.* Statistical analysis of mediator effect. Catastrophizing coping style partially mediates the relationship between treatment control & health-related quality of life. \*\*Data transformed using square root of catastrophizing coping style.

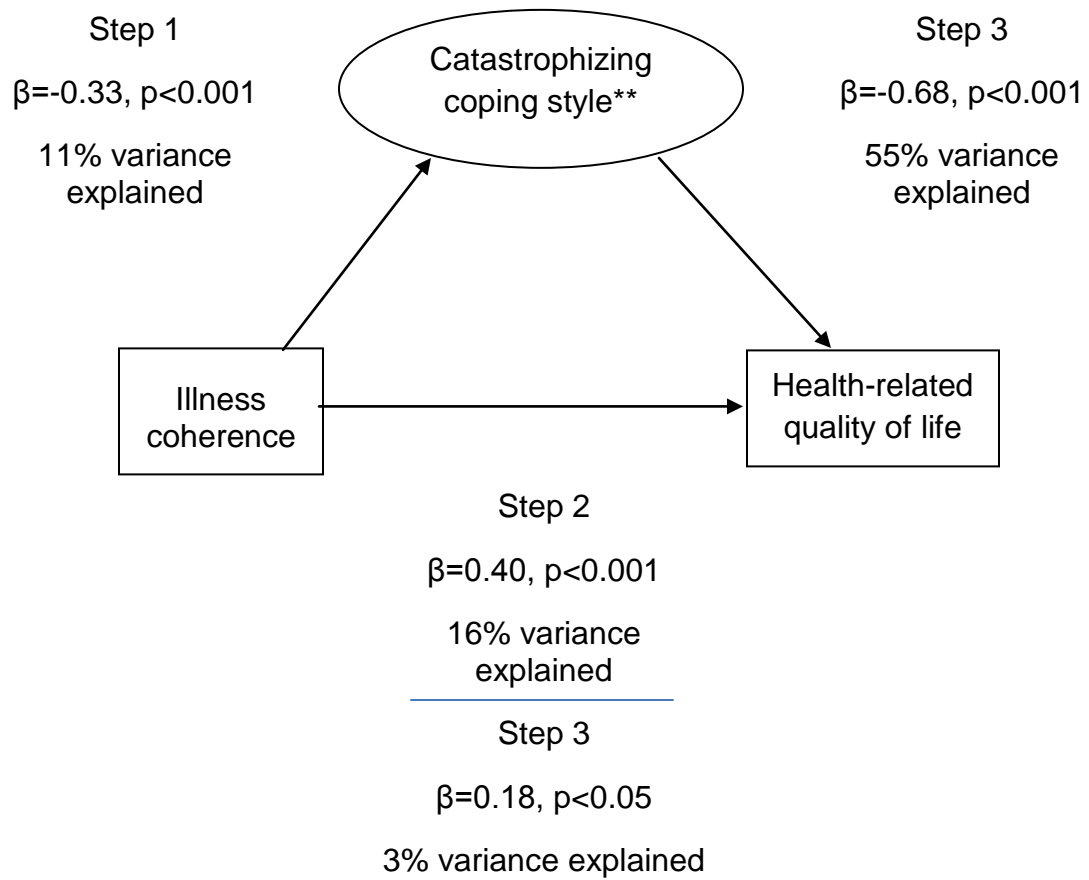
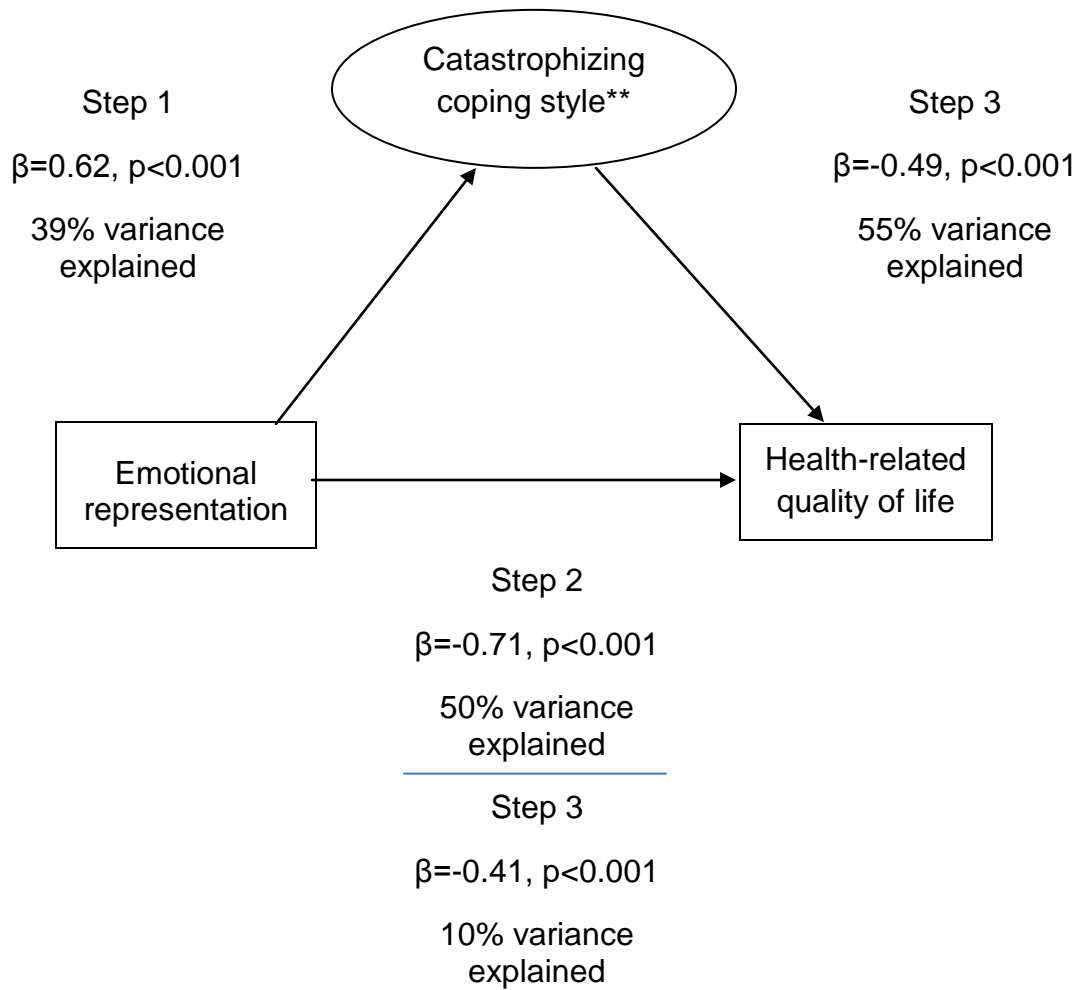


Figure 10. Statistical analysis of mediator effect. Catastrophizing coping style partially mediates the relationship between illness coherence & health-related quality of life. \*\*Data transformed using square root of catastrophizing coping style.



*Figure 11.* Statistical analysis of mediator effect. Catastrophizing coping style partially mediates the relationship between emotional representation & health-related quality of life. \*\*Data transformed using square root of catastrophizing coping style.



## Summary

The results of this study are unique, as I am unaware of other studies examining the importance of the Common Sense Model in adults with IBS and the role catastrophizing coping style plays in the relationship between the components of illness representation and HRQOL. This study supports current literature citing that the components of illness representation play an important role in predicting outcomes. Specific to this study, those volunteers who view their illness with greater number of symptoms, greater negative consequences, more chronic in nature, less personal or treatment control, more negative emotional impact and higher levels of pain reported in the past seven days, experience poorer HRQOL. In addition, the use of catastrophizing coping style was found to be associated with poorer HRQOL levels.

The statistical method used to analyze the mediation impact of catastrophizing coping style in the relationship between the components of illness representation and HRQOL, found that catastrophizing coping style acted as a full mediator in the relationship between personal control and health-related quality of life and as a partial mediator in the relationships between the remaining components of illness representation and health-related quality of life. These findings have important implications for future research.

## **Chapter 5**

### **Discussion**

The purpose of this study was to examine the role the Common Sense Model of Illness Representation has in adults who suffer with IBS. The study focused on the specific components of illness representation and their relationship to the outcome of health-related quality of life. In addition, the study focused on the role catastrophizing coping style played in this relationship, specifically acting as a mediator. The findings add to the body of knowledge needed to generate effective interventions to ultimately improve the health-related quality of life of adults with IBS.

There have been few published studies that have examined the Common Sense Model of Illness Representation in those with IBS (Rutter & Rutter, 2002; Rutter & Rutter, 2007). None to date have addressed catastrophizing coping style as a mediator in the relationship between the components of illness representation and health-related quality of life. The Common Sense Model of Illness Representation was the theoretical framework that guided this study. As IBS is a biopsychosocial disorder, this framework provides a strong foundation to aid in the understanding of the complex interplay of the physiological, behavioral and psychological factors defining IBS.

The results of this study support the hypotheses of the Common Sense Model of Illness Representation (Leventhal et al., 1998) as applied to IBS. The results also support the findings of other studies that suggest that illness representation plays an important role in illness outcomes, such as quality of life,

physical functioning, general health perception and mood disturbance (Kaptein, Bijsterbosch, Scharloo, Hampson, Kroon, Kloppenburg, 2010; Koloski, Boyce, Jones & Talley, 2012; Fischer, Scharloo, Abbink, Van't Hul, van Ranst, Rudolphus, Weinman, Rabe, & Kaptein, 2010; Gould, Brown & Bramwell, 2010; Rozema et al., 2009; Rutter & Rutter, 2002, 2007; Quiles & Terol, 2010; Riedl et al., 2009; van Korlaar, et a., 2009). In addition, the results further show that volunteers' illness representations are important predictors of health-related quality of life, and confirm that catastrophizing coping style mediates the relationship between the components of illness representation and health-related quality of life.

The Common Sense Model was used to test the relationship of the components of illness representation with health-related quality of life in adults with IBS. Volunteers participating in this study held a moderate level of beliefs about the number of symptoms attributed to their IBS. They held strong beliefs about the negative consequences of their IBS, the chronicity, their personal and treatment control, their personal understanding and the negative emotional impact of their IBS. Overall, the frequency of catastrophizing coping style these volunteers used was similar to those obtained in patients with chronic pain and rheumatoid arthritis (Drossman et al., 2000; Keefe & Williams, 1989; 1990). They reported a moderately high health-related quality of life as compared to others with IBS (Dean et al., 2005; Drossman et al., 2000; El-Serag, 2002; Frank, 2002).

Bivariate correlations indicated that the components of illness representation were related to one another. High scoring, reflective of strongly-held beliefs about the negative consequences of their IBS, was related to a higher number of reported symptoms experienced since their IBS diagnosis and a higher number of symptoms related to their IBS, more strongly-held beliefs about the chronicity of their disease, the negative beliefs about the controllability of their IBS, their negative beliefs about their personal understanding of IBS and strongly-held beliefs about the negative emotional impact of their IBS. A strongly-held belief regarding the chronicity of their IBS was related to low personal and treatment control, poorer understanding of their IBS and a greater negative emotional impact. The greater level of personal and treatment control was associated with fewer symptoms associated with their IBS, a higher level of positive beliefs about their personal understanding of their IBS and a lower level of beliefs about the negative emotional impact of their IBS. These findings are consistent with published research (Fischer et al., 2010; Gould et al., 2010; Rozema, 2009; Rutter & Rutter, 2002)

The components of illness representation and health-related quality of life demonstrated a straight forward relationship. A greater number of symptoms identified as associated with their IBS, strongly-held beliefs about the negative consequences of their IBS, strongly-held beliefs about the chronicity of their IBS, negative beliefs about the controllability of their IBS, negative beliefs about their personal understanding of their IBS and strongly-held beliefs about the negative

emotional impact of their IBS were associated with a report of a lesser level of health-related quality of life.

The components of illness representation were also related in an understandable way to catastrophizing coping style. A greater number of symptoms attributed to their IBS, strongly held belief of the negative consequences of their IBS, a belief in the chronicity of their IBS and negative emotional impact were associated with higher levels of catastrophizing coping style. Those who held strong beliefs regarding personal and treatment control and a greater understanding of their IBS were less likely to use catastrophizing coping style.

Catastrophizing coping style was understandably related to health-related quality of life. A higher level of catastrophizing coping style was associated with a lower level of health-related quality of life.

In addition to these relationships, this study also examined the mediating role of catastrophizing coping style that Leventhal et al. (1980) predicted in the link between the components of illness representation and outcome. A series of regression analyses were conducted according to the Baron and Kenny (1986) method to test for this mediator effect. Consistent with the Common Sense Model of Illness Representation, there was a direct relationship between the components of illness representation and health-related quality of life. Identity (beliefs about the number of symptoms attributed to IBS), consequences (the beliefs about negative consequences of their IBS) and emotional representation (the beliefs about the negative emotional impact of their IBS) explained the

greatest percentages of variance in health-related quality of life. These findings are consistent with findings of Rutter & Rutter (2002) and Rozema et al. (2009). Rutter & Rutter (2002) examined a sample of 209 IBS sufferers and found the consequence component of illness representation that individuals held was an important predictor of the quality of life outcome. Rozema et al. (2009) examined a sample of 119 women with breast cancer. Similar to this study, these individuals were found to report identity, consequences and emotional representation as significant predictors of quality of life.

Catastrophizing coping style was found to be a strong predictor of health-related quality of life. These findings are important for the IBS population. Drossman (2000) found that individuals with IBS tend to use catastrophizing coping style similar to those of patients studied in pain clinics, and also noted that catastrophizing coping style predicted behaviors such as activity limitation. This study supports these findings, but also contributes to the literature, as catastrophizing coping style impacts the individual's ability to function not only physically, but emotionally and socially as well, within their environment.

Catastrophizing coping style was found to fully mediate the relationship between the personal control illness representation and health-related quality of life. Catastrophizing coping style was a significant predictor and explained a great percentage of the variance in health-related quality of life. Catastrophizing coping style was found to partially mediate the relationship between the remaining components of illness representation and health-related quality of life. These findings are important because this study is the first to examine these

relationships in adults with IBS. In addition, the findings support the hypothesis that catastrophizing coping style is at least one mediator in the relationship between the components of illness representation and health-related quality of life. The Common Sense Model (Leventhal et al., 1998) posits that illness representations are developed from both social representations of illness and the individual's experience of the illness. This study's findings show both direct and mediated relationships between the components of illness representation and health-related quality of life. This suggests that benefits may be gained by identifying and intervening with individuals with IBS who demonstrate high levels of identity, consequences and emotional representation. These results also suggest that addressing the catastrophizing coping style response may be beneficial with regard to those with IBS, in order to potentially improve their health-related quality of life.

### **Strengths of this Study**

The Common Sense Model of Illness Representation guided this study. Although the Common Sense Model of Illness Representation has been found to be an "integrated and empirically validated model of the ways people interpret and cope with illness", in addition to explaining outcomes, it has had limited use in those with Irritable Bowel Syndrome (Gould et al., 2010). Through this model, the value of understanding the role catastrophizing coping style plays in the relationship between the components of illness representation and health-related quality of life is highlighted. As a result, the potential enhancement of an individual's health-related quality of life is proposed. The strength of this study is

enhanced by using this model in conjunction with the study design and method. The sample recruited was in accordance with projected power. The majority of those recruited were from a private gastroenterology specialty clinic practices. This supports the generalizability to gastroenterology clinic populations, as twenty-eight percent of annual referrals to gastroenterology clinics are accounted for by those with IBS (Manabe et al., 2009). The measures used in this study all had excellent reliability and validity and, when available, IBS specific measures were chosen. As a result, this study has provided important results, never found before, regarding the predictive ability of the components of illness representation and the mediating effect of catastrophizing coping style in the relationship between the components of illness representation and health-related quality of life.

### **Potential Limitations**

A methodological shortcoming of this study may have been the selection of participants by an invitation mailed directly to those with an active diagnosis of IBS, through gastrointestinal specialty practices. This selected group of IBS patients may be better informed and motivated and, as a result, their illness representations or levels of catastrophizing coping style may be influenced. This selection process could potentially limit generalization of the results. In addition, I do not have data on non-responders and, as a result, it is not possible to test their similarity to responders.

Self-report measures typically have been noted as potential limitations to studies (Sadish et al., 2002). There is always a risk that individuals are unable to



remember information, such as description of personal views, feelings, distress level, and way of thinking in the past 7-30 days, depending on the specific measure. Specific to this study, it is important to note that measuring the perceptions of the volunteers could not be completed in any other way. Although they may not have remembered, it is important to remember these are their reported perceptions and in contrast may actually have strengthened this study. It is important to also note that those with IBS may feel delegitimized by their health-care providers (Bengtsson, Ohlsson, & Ulander, 2007). Asking for their perceptions may help to further validate their experience of IBS.

In addition, there is a risk participants may have wanted to present themselves in a socially desirable manner (Sadish et al., 2002). It is expected that the participants responded with their best recollection of experience. The predominance of female volunteers in this study, which was somewhat higher than the typical reported population of those with IBS, and the limited racial diversity, may limit the generalizability of the results.

The cross-sectional design has implications for the results as well. The Common Sense Model is dynamic. It is constantly updated and enriched by an individual's actions and behaviors, in order to promote health, detect risk and prevent illness. Given the premise of this model, additional research using prospective longitudinal design measuring the dimensions of the Common Sense Model across multiple time points may be beneficial. Longitudinal studies of illness representations for chronic illnesses, such as IBS, create an opportunity to examine whether illness representations change over time and whether they are

associated with changes in coping and outcomes. Interventions to prevent highly negative patterns of illness representation over time, with an emphasis on strengthening control of cognitions, may benefit functional status outcomes. As seen in a study of type 2 diabetics, an educational program focused on self-management and diabetes led to changes in the components of illness representation, with consequent positive changes in quality of life and metabolic control at a 3 month follow up (Skinner, Carey, Cradoch, Daly, Davies, Doherty, & Heller, 2006). Studies of processes examining the components of illness representation and coping over time and health outcomes are rare and would contribute to the literature.

### **Implications for Future Research**

This study did not take into consideration the role of psychological distress. Further investigation focused on the role psychological distress plays in the Common Sense Model of Illness Representation, as applied to those with IBS, may prove to be beneficial. Psychological distress in this study has been defined as depression, anxiety and somatization. Research supports that psychological distress adversely affects those with IBS, influencing both the development and persistence of IBS (Drossman et al., 2002; Levy et al., 2006). Furthermore, psychological distress has been associated with increased symptom severity and can influence treatment-seeking behavior (Jarrett et al., 1998; Whitehead et al., 1988). Particular to this study, volunteers' psychological distress was relatively low; however, over fifty percent of the volunteers were being treated for depression and or anxiety. It is possible that psychological

distress acts as a covariate affecting the components of illness representation and health-related quality of life relationship. It may also be a significant predictor of catastrophizing coping style. Investigating whether psychological distress has a direct effect or the possibility that it is an interacting variable would be beneficial, given the predominance of psychological distress in those with IBS. In addition, examining psychological distress as an outcome variable may also prove beneficial.

Despite the above limitations, this study supports the importance of understanding the components of illness representation in those with IBS and the role these perceptions play on coping style and health-related quality of life. Few studies give credence to the patients' perceptions (Bertram, S., Kurland, M., Lydick, E., Locke, G.R., & Yawn, B. P., 2001; Dixon-Woods, M. & Critchley, S., 2000). This study presents new knowledge validating the importance of understanding their perceptions and focusing direction for future research. It is clear that illness representations impact both catastrophizing coping style used by those with IBS and their overall HRQOL. Interventional research design focused on helping IBS patients accurately identify symptoms, potential consequences and negative emotional impact of their IBS, in addition to learning how to cope with their IBS, may improve HRQOL in those with IBS. Specifically, providing accurate information about which symptoms are related to IBS, the potential consequences IBS can have on social and financial life, in addition to emotional functioning, would be areas of priority.

Also, focusing attention toward lessening the level of catastrophizing coping style used may prove beneficial. As in the study by Gould et al. (2010), this study finds a negative coping style (specifically catastrophizing coping style) was associated with a negative outcome (poorer health-related quality of life). It is possible that, rather than facilitating positive coping responses, health-related quality of life might be enhanced by intervening to decrease the level of negative dysfunctional coping style, specifically lowering the level of catastrophizing coping style used.

Restructuring dysfunctional coping styles has been done through Cognitive Behavioral Therapy (CBT). Empirical evidence has been noted to favor the efficacy of CBT in improving the quality of life in those who suffer from IBS (Blanchard et al., 1992, 2007; Boyce et al., 2003; Greene & Blanchard, 1994). Cognitive Behavioral Therapy is focused on the concept that behavior is shaped by its consequences. Cognitive Behavioral Therapy recognizes that social consequences produced in the environment may affect cognitions, motor behavior and physiologic responses. Also, the individuals' response may influence the reaction they receive from their environment. Cognitive Behavioral Therapy teaches individuals how events, thoughts, emotions, actions and physiological responses are related. Change and development of new skills and strategies for coping are the focus of this therapy. Cognitive Behavioral Therapy has been shown to enhance self-management with regard to coping and minimizing the pain level experienced in IBS patients (Boyce et al., 2003; Greene et al., 1994; Levy, Olden, Naliboff, Bradley, Fancisconi, Drossman & Creed,

2005; Van Dulmen et al., 1996). Consistent with the literature, participants in this study were found to attribute non-gastrointestinal symptoms to their IBS. These non-gastrointestinal symptom attributions may lead to mismanagement of undiagnosed illnesses, in addition to mismanagement of actual IBS symptoms. Cognitive Behavioral Therapy may be especially helpful in those with IBS, as it may help them recognize how particular beliefs about symptoms may influence their coping and their health-related quality of life. Relaxation and stress management are part of CBT and are often used in those with IBS because of the reduction of autonomic arousal. In a study by Drossman et al. (2003), CBT was found to be more effective than an educational intervention, as measured by satisfaction, overall symptom relief and global well-being after 3 months. Although these participants continued to experience pain, they were noted to report they were managing their pain better which may indicate improved coping.

Irritable Bowel Syndrome is a multi-determined disorder of the “brain-gut” function, in which both cognitive and emotional areas of the brain influence bowel motility, visceral hypersensitivity and altered bowel function, resulting in psychosocial consequences (Drossman et al., 2002). In addition, the gut interacts with the brain, providing a bi-directional interaction through this “brain-gut” pathway. Cognitive and emotional stressors alter the function of the gut and impact on IBS symptoms (Toner, 2005). As a result, few effective treatments for IBS exist and management is often elusive. Medications have been found to be inconsistently adequate treatment for the full spectrum of IBS symptoms secondary to the impact of the “brain-gut” influence (Blanchard, 2005;

Schoenfeld, 2005; Tally, 2003). Medication treatment of IBS often does not provide relief to the patients' expectations (Mayer, 2008). Psychosocial factors impact on the central nervous system, autonomic nervous system and the enteric nervous system and, as a result, medications directed to control specific symptoms do not successfully work for every person, every time. Therefore, examining treatment that focuses on the psychosocial aspect may prove beneficial.

Cognitive Behavioral Therapy may be helpful in increasing one's ability to cope more effectively with IBS and, in turn, may increase their health-related quality of life. To optimize outcomes for those with IBS, future research focused toward examining the benefits of CBT is paramount.

### **Summary**

This study validates the use of the Common Sense Model of Illness Representation in adults with IBS. It provides information regarding the predictive ability of the components of illness representation and catastrophizing coping style affecting health-related quality of life. This study also provides a rationale for developing interventions that alter the components of illness representation of those with IBS which, in turn, can potentially lessen the level of catastrophizing coping style in order to positively affect health-related quality of life. In addition, this study has provided a rationale for developing interventions aimed at catastrophizing coping style in the hopes of decreasing the negative effects of this negative coping style. This study supports the findings of other studies suggesting the benefits for the use of the Common Sense Model of

Illness Representation (Leventhal et al., 1997) in examining an illness, such as Irritable Bowel Syndrome, which poses a significant challenge to many individuals across the United States. This study is the first of its kind and has contributed to the body of nursing knowledge and will impact the future of nursing care.

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**Appendix A**

**Clinics Participating in Study.**

Clinic Street address	Contact Person Phone	Provider type	Approximate number of IBS patients
Corvallis Clinic 3680 NW Samaritan Drive Corvallis, OR 97330	Chris Bell, PA-C (541) 754-1988	Gastroenterology specialty clinic	200
Gastroenterology Center of Connecticut 2200 Whitney Ave Suite #360 Hamden, CT 06518-3694	Martha McCrann, PA- C (203) 281-4463	Gastroenterology specialty clinic	400
Grand Teton Gastroenterology 2770 Cortez Idaho Falls, ID 83404	Todd Williams, MD (208) 522-4000	Gastroenterology specialty clinic	300
Lewis Clark Gastroenterology 1630 23 <sup>rd</sup> Ave, Suite 801 Lewiston, ID 83501	Jennifer Kaufman, FNP-BC (208) 743-6200	Gastroenterology specialty clinic	200
Family Care Clinic of Idaho Falls 3480 Washington Parkway Idaho Falls, ID 83404	Brian Decker, FNP- BC (208) 523 3436	Family Practice	<100
Rosemark Women's Care Specialist 2327 Coronado Idaho Falls, ID 83404	Amber Masse, FNP- BC (208) 557-2900	Women's Health	200
Southeast Idaho Family Practice 2775 Channing Way Idaho Falls, ID 83404	Cathy Arvidson, FNP- BC (208) 523-0249	Family Practice	<100

*Note: Number of IBS patients are estimates. Potential clinic sites may change.*

## Appendix B

### Participant Information Sheet

OHSU eIRB study #

OREGON HEALTH & SCIENCE UNIVERSITY (OHSU)

Information Sheet

**TITLE:** Illness Representations and Health-Related Quality of Life In an Adult Population with Irritable Bowel Syndrome: The Potential Mediating Role of Catastrophizing

**PRINCIPAL INVESTIGATOR:** Lillian Nail, RN, PhD, F.A.A.N.; (503) 494-5618

**CO-INVESTIGATORS:** LeeAnne Sherwin, RN, MS, APRN, FNP-BC; 1-877-858-4427, Jill Bennett, RN, PhD; 1-503-418-3523, Lissi Hansen, RN, PhD; 1-503-418-3357

**PURPOSE OF STUDY:** The purpose of this study is to learn more about how you view your Irritable Bowel Syndrome (IBS). In particular we are interested in knowing how you cope with your IBS. We also want to know how your coping influences your health-related quality of life. The information you provide will help build a knowledge base for future research. It is our hope having that information will form the basis for future research on ways to help people with IBS increase their health-related quality of life.

**PROCEDURES:** If you agree to participate in this study, you will be asked to complete a one time, self-administered survey about your perceptions of IBS, your mood as a result of IBS, how you cope with your IBS and your present level of health-related quality of life. The survey will take less than one hour to complete.

**RISKS AND DISCOMFORTS:** There are no known risks and discomforts in participating in this study.

**BENEFITS:** You will not personally benefit from participating in this study. However, the information you contribute may benefit others in the future.

**ALTERNATIVES:** Being in this study is voluntary. You may choose not to participate in this study.

**CONFIDENTIALITY:** None of the information collected will identify you. Because the researchers do not know who participates in the study, your identity cannot be disclosed.

**COSTS:** There is no cost to you for participating in this study.

**CONTACTS:** If you have questions about the study, please contact the **Co-Investigator LeeAnne Sherwin at 1-877-858-4427 or Principal Investigator Lillian Nail at (503) 494-5618**. If you have questions regarding your rights as a research participant, you may contact the **OHSU Research Integrity Office at (503) 494-7887**.

Returning the completed survey form demonstrates agreement to participate in this study.



## Study Questionnaire

Please note: Coding notations are written on the following questionnaire. Participants did NOT receive the questionnaire with the coding notations.

Illness Representation & Health-related quality of life in adults with IBS

Study Questionnaire

Questionnaire # \_\_\_\_\_

Thank you for your time in filling out this survey. All information you provide will be kept confidential. It is important for us to have accurate and complete information. Please answer each question honestly.

On the following pages you will find statements concerning bowel problems (Irritable Bowel Syndrome) and how they affect you.

Please choose the response that applies best to you and **circle or make an X** when appropriate to indicate your response.

If you are unsure about how to respond to a statement, please give the best response you can. **There are no right or wrong responses.**

*If you have any questions, please contact: LeeAnne Sherwin at 1-877-858-4427 or by email at [sherwinl@ohsu.edu](mailto:sherwinl@ohsu.edu) .*

**PLEASE TURN TO NEXT PAGE**

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Illness Representation & Health-Related Quality of Life  
in Adults with Irritable Bowel Syndrome (IBS)  
Study Questionnaire

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Thank you for your time in filling out this survey. All information you provide will be kept confidential. It is important for us to have accurate and complete information. Please answer each question honestly.

On the following pages you will find statements concerning your Irritable Bowel Syndrome and how it affects you.

Please choose the response that applies best to you and **circle or make an X** when appropriate to indicate your response.

If you are unsure about how to respond to a statement, please give the best response you can. **There are no right or wrong responses.**

*If you have any questions, please contact:*

*LeeAnne Sherwin (toll free) at 1-877-858-4427 or via email at [sherwinl@ohsu.edu](mailto:sherwinl@ohsu.edu) .*

**PLEASE TURN TO NEXT PAGE**

Listed below are a number of symptoms that you may or may not have experienced since being diagnosed with IBS. Please indicate by **circling YES or NO**, whether you have experienced any of these symptoms since your illness and whether you believe that these symptoms are related to your illness. 1=yes  
2=no

QS 1-14	I have experienced this symptom since my IBS			This symptom is related to my IBS	
	Column 1			Column 1	
Pain	yes	no		yes	no
Sore throat	yes	no		yes	no
Nausea	yes	no		yes	no
Breathlessness	yes	no		yes	no
Weight loss	yes	no		yes	no
Fatigue	yes	no		yes	no
Stiff Joints	yes	no		yes	no
Sore Eyes	yes	no		yes	no
Wheeziness	yes	no		yes	no
Headaches	yes	no		yes	no
Upset Stomach	yes	no		yes	no
Sleep Difficulties	yes	no		yes	no
Dizziness	yes	no		yes	no
Loss of Strength	yes	no		yes	no

**Identity scale: sum of ratings endorsed in column 1 (yes columns). Higher score=strongly held beliefs about the number of symptoms attributed to IBS. Range=0-28**

We are interested in your own personal views of how you see your Irritable Bowel Syndrome.

Please indicate how much you disagree or agree with the following statements about your Irritable Bowel Syndrome by making an **X** in the box.

**R=reverse coded: 1,4,8,15,17,18,19,23,24,25,26,27,36**

	<u>Consequences</u> :6.7.8.9.10.11(score range6-30) higher score=higher negative conseq. <u>Timeline,acute/chronic</u> :1,2,3,4,5,18(score6-30)higher score=beliefs about chronicity <u>Cure/control subdivided into</u> 1. <u>Personal control</u> :12,13,14,15,16,17(score6-30)higher=+beliefs about controllability 2. <u>Treatment control</u> :19,20,21,22,23(score5-25)higher=controllability <u>Illness coherence</u> :24,25,26,27,28(score5-25)higher=personal understanding of IBS	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Neither Agree nor Disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
IP1R	My IBS will last a short time	1	2	3	4	5
IP2	My IBS is likely to be permanent rather than temporary					
IP3	My IBS will last for a long time					
IP4R	My IBS will pass quickly					
IP5	I expect to have this IBS for the rest of my life					
IP6	My IBS is a serious condition					
IP7	My IBS has major consequences on my life					
IP8R	My IBS does not have much effect on my life					
IP9	My IBS strongly affects the way others see me					
IP10	My IBS has serious financial consequences					
IP11	My IBS causes difficulties for those who are close to me					
IP12	There is a lot which I can do to control my IBS symptoms					
IP13	What I do can determine whether my IBS gets better or worse					
IP14	The course of my IBS depends on me					
IP15R	Nothing I do will affect my IBS					

IP16	I have the power to influence my IBS					
IP17R	My actions will have no effect on the outcome of my IBS					
IP18R	My IBS will improve in time					
IP19R	There is very little that can be done to improve my IBS					
IP20	My treatment will be effective in curing my IBS					
IP21	The negative effects of my IBS can be prevented (avoided) by my treatment					
IP22	My treatment can control my IBS					
IP23R	There is nothing which can help my condition					
IP24R	The symptoms of my condition are puzzling to me					
IP25R	My IBS is a mystery to me					
IP26R	I don't understand my IBS					
IP27R	My IBS doesn't make any sense to me					

	<u>Timeline cyclical</u> :29,30,31,32(range4-20)higher score=belief about cyclical nature of IBS <u>Emotional representation</u> :33,34,35,36,37,38(score6-30)higher=greater emotional impact of IBS	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Neither Agree nor Disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
IP28	I have a clear understanding of my condition					
IP29	The symptoms of my IBS change a great deal from day to day					
IP30	My symptoms come and go in cycles					
IP31	My IBS is very predictable					
IP32	I go through cycles in which my IBS gets better and worse					
IP33	I get depressed when I think about my IBS					
IP34	When I think about my IBS I get upset					
IP35	My IBS makes me feel angry					
IP36R	My IBS does not worry me					
IP37	Having IBS makes me feel anxious					
IP38	My IBS makes me feel afraid					

We are interested in what you consider may have been the cause of your IBS. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your IBS rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your IBS. Please indicate how much you disagree or agree that they were causes for you by marking an **X** in the appropriate box.

	<u>Causal dimension:</u> C1-C18 Score by grouping into who do & do not believe in a specific causal factor. Categorize to represent most often indicated cause for IBS	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Neither agree nor disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
C1	Stress or worry					
C2	Hereditary- it runs in my family					
C3	A germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in my past					
C7	Pollution in the environment					
C8	My own behavior					
C9	My mental attitude (such as thinking about life negatively)					
C10	Family problems or worries					
C11	Overwork					
C12	My emotional state (such as feeling down, lonely, anxious, empty)					
C13	Aging					
C14	Alcohol					
C15	Smoking					
C16	Accident or injury					
C17	My personality					
C18	Altered immunity					



Please think about your life over the **past month (last 30 days)**, and look at the statements below. Each statement has five different responses. For each statement, please **circle the number** that best describes your feelings in the **past month**.

	HRQOL=sum of item ratings to derive overall total score. Total score range is transformed to 0-100 scale ranging from 0=poor QOL to 100 greatest QOL.  Transformation formula: Sum of items-lowest possible score/possible raw score rangeX100	Not at all	Slightly	Moderately	Quite a bit	Extremely
QL1	I feel helpless because of my bowel problems.	1	2	3	4	5
QL2	I am embarrassed by the smell caused by my bowel problems.	1	2	3	4	5
QL3	I am bothered by how much time I spend on the toilet.	1	2	3	4	5
QL4	I feel vulnerable to other illnesses because of my bowel problems.	1	2	3	4	5
QL5	I feel fat/bloated because of my bowel problems	1	2	3	4	5
QL6	I feel like I'm losing control of my life because of my bowel problems	1	2	3	4	5
QL7	I feel my life is less enjoyable because of my bowel problems	1	2	3	4	5
QL8	I feel uncomfortable when I talk about my bowel problems	1	2	3	4	5
QL9	I feel depressed about my bowel problems	1	2	3	4	5
QL10	I feel isolated from others because of my bowel problems	1	2	3	4	5
QL11	I have to watch the amount of food I eat because of my bowel problems	1	2	3	4	5
QL12	Because of my bowel problems, sexual activity is difficult for me	1	2	3	4	5
QL13	I feel angry that I have bowel problems	1	2	3	4	5
QL14	I feel like I irritate others because of my bowel problems	1	2	3	4	5
QL15	I worry that my bowel problems will get worse	1	2	3	4	5
QL16	I feel irritable because of my bowel problems	1	2	3	4	5
QL17	I worry that people think I exaggerate my bowel problems	1	2	3	4	5
QL18	I feel I get less done because of my bowel problems	1	2	3	4	5

	<b>HRQOL=</b> sum of item ratings to derive overall total score. Total score range is transformed to 0-100 scale ranging from 0=poor QOL to 100 greatest QOL.  Transformation formula: Sum of items-lowest possible score/possible raw score rangeX100	<b>Not at all</b>	<b>Slightly</b>	<b>Moderately</b>	<b>Quite a bit</b>	<b>Extremely</b>
QL19	I have to avoid stressful situations because of my bowel problems	1	2	3	4	5
QL20	My bowel problems reduce my sexual desire	1	2	3	4	5
QL21	My bowel problems limit what I can wear	1	2	3	4	5
QL22	I have to avoid strenuous activity because of my bowel problems	1	2	3	4	5
QL23	I have to watch the kind of food I eat because of my bowel problems	1	2	3	4	5
QL24	Because of my bowel problems, I have difficulty being around people I do not know well	1	2	3	4	5
QL25	I feel sluggish because of my bowel problems	1	2	3	4	5
QL26	I feel unclean because of my bowel problems	1	2	3	4	5
QL27	Long trips are difficult for me because of my bowel problems	1	2	3	4	5
QL28	I feel frustrated that I cannot eat when I want because of my bowel problems	1	2	3	4	5
QL29	It is important to be near a toilet because of my bowel problems	1	2	3	4	5
QL30	My life revolves around my bowel problems	1	2	3	4	5
QL31	I worry about losing control of my bowels	1	2	3	4	5
QL32	I fear that I won't be able to have a bowel movement	1	2	3	4	5
QL33	My bowel problems are affecting my closest relationships	1	2	3	4	5
QL34	I feel that no one understands my bowel problems	1	2	3	4	5

The following consists of a list of problems people sometimes have. Read each one carefully and circle the number of the response that best describes HOW MUCH THAT PROBLEM HAS DISTRESSED OR BOTHERED YOU DURING THE **PAST 7 DAYS INCLUDING TODAY**. Circle only one number for each problem. Do not skip any items. If you change your mind, draw an X through your original answer and then circle your new answer.

	How much were you distressed by: score=summative <u>Anxiety</u> :3,6,9,12,15,18(score:0-24)higher=higher anxiety <u>Depression</u> :2,5,8,11,14,17(score:0-24)higher=higher dep <u>Somatization</u> :1,4,7,10,13,16(score:0-24)higher=higher somatization <u>Global severity index</u> =sum of 3 subscales higher score implies greater overall level of psychological distress	Not at all	A little bit	Moderately	Quite a bit	Extremely
B1	Faintness or dizziness	0	1	2	3	4
B2	Feeling no interest in things	0	1	2	3	4
B3	Nervousness or shakiness inside	0	1	2	3	4
B4	Pains in heart or chest	0	1	2	3	4
B5	Feeling lonely	0	1	2	3	4
B6	Feeling tense or keyed up	0	1	2	3	4
B7	Nausea or upset stomach	0	1	2	3	4
B8	Feeling blue	0	1	2	3	4
B9	Suddenly scared for no reason	0	1	2	3	4
B10	Trouble getting your breath	0	1	2	3	4
B11	Feelings of worthlessness	0	1	2	3	4
B12	Spells of terror or panic	0	1	2	3	4
B13	Numbness or tingling in parts of your body	0	1	2	3	4
B14	Feeling hopeless about the future	0	1	2	3	4
B15	Feeling so restless you couldn't sit still	0	1	2	3	4
B16	Feeling weak in parts of your body	0	1	2	3	4
B17	Thoughts of ending your life	0	1	2	3	4
B18	Feeling fearful	0	1	2	3	4



D2. Do you have any of the following? (***Please circle those that apply***) **1=yes 2=no**

1. Fibromyalgia
2. Heartburn/reflux
3. Asthma
4. Headache/migraine
5. Backpain
6. Insomnia
7. Lactose intolerance
8. Food allergy
9. History of abdominal surgery
10. Dysmenorrhea (painful periods)
11. TMJ (temporomandibular joint disorder)
12. Chronic fatigue
13. Chronic pelvic pain
14. Cystitis

D3. Have you had any of the following symptoms in the **past 7 days**? **1=yes 2=no**

***(Please circle those that apply)***

1. Abdominal pain, gas, cramping
2. Diarrhea
3. Constipation
4. Abdominal bloating
5. Nausea
6. Stomach noises
7. Mucus in the stool
8. Gas/flatulence
9. Urgency to have a bowel movement
10. Feeling of incomplete emptying

D4 When were you diagnosed with Irritable Bowel Syndrome (IBS)?

**(Please circle one)**

1. Less than 12 months ago
2. More than 12 months but less than 5 years ago
3. More than 5 years but less than 10 years ago
4. More than 10 years ago

D5. Do you take any medications for anxiety and/or depression?

**(Please circle one)**

1. No
2. Yes Please list name, dose, how often taken below

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D6. How would you classify your race/ethnicity? **(Please circle one)**

1. White/Caucasian
2. African American
3. Hispanic
4. Asian
5. American Indian/Alaskan Native
6. Other: *please write in* \_\_\_\_\_

D7. Please **circle** your gender.

1. Female
2. Male

D8. How old are you? \_\_\_\_\_ years old

D9. What is your current marital status? (***Please circle one***)

1. Married
2. Not married, living with a partner
3. Single
4. Separated
5. Divorced
6. Widowed

D10. What is your highest level of formal education? (***Please circle one***)

1. Some high school
2. High school/Graduate Equivalent Degree (G.E.D.)
3. Some college (less than 2 years)/vocational or technical school
4. Associate's Degree (2-3 years)
5. Bachelor's Degree (4 years)
6. Master's Degree
7. Doctorate/post doctorate

D11. What is your current employment status? (***Please circle one***)

1. Not employed
2. Employed part-time or less than part-time
3. Employed full-time

**Thank you for completing this questionnaire.**

**Please return the completed questionnaire in the stamped addressed**

## Appendix C

### Lay Language Summary

OHSU eIRB study #

Illness Representation and Health-related Quality of Life in an Adult Population with Irritable Bowel Syndrome: The Potential Mediating Role of Catastrophizing.

LeeAnne Sherwin, a Board Certified Advanced Practice Registered Nurse (APRN-BC), and a PhD Candidate from Oregon Health & Science University School of Nursing, is working with Dr. Lillian Nail, Dr. Jill Bennett, and Dr. Lissi Hansen on a research study to learn more about how Irritable Bowel Syndrome (IBS) impacts people's quality of life. They are also interested in how coping styles play a role. This information will help them understand how to help those with IBS increase their quality of life. Persons who volunteer will answer a questionnaire that will take less than one hour to complete. Completing the questionnaires will take place in the participants' own home. All information will be kept confidential. The data will not contain any information that will identify the participant.

Persons who are between the ages of 30 and 50 years old, have been diagnosed with IBS or believe they have IBS, have not been diagnosed with other chronic gastrointestinal (GI) diseases such as Crohn's disease, Ulcerative Colitis, microscopic colitis, collagenous colitis, colonic strictures or cancer in the last 6 months and are able to read and speak English are invited to contact LeeAnne Sherwin at 1-877-858-4427 or email [sherwinl@ohsu.edu](mailto:sherwinl@ohsu.edu) for more information.



## Appendix D

### Participant Invitation Letter

LeeAnne Sherwin, MS, APRN-BC  
PhD Candidate, Oregon Health & Science University  
P.O. Box 3083  
Idaho Falls, ID 83402

Dear (fill name in here)

My name is LeeAnne Sherwin and I am a PhD Candidate at Oregon Health & Science University. I am working on a study on Irritable Bowel Syndrome also known as IBS with Oregon Health & Science University School of Nursing.

The study focus is to learn more about how Irritable Bowel Syndrome (IBS) impacts people's health-related quality of life. We are also interested in knowing how coping styles play a role. This information will help us better understand how to help those with IBS increase their health-related quality of life.

Your participation is entirely voluntary. This is a one-time, self-administered survey and will take less than one hour to complete. Your information will be kept confidential. The data will not contain any information that will identify you.

If you have any concerns or questions please feel free to contact me at 1-877-858-4427 or  
by Email; [sherwinl@ohsu.edu](mailto:sherwinl@ohsu.edu)

Please complete all questions and return the questionnaire to me in the enclosed stamped, addressed envelope at your earliest convenience.

Thank you for your participation.

Sincerely,

LeeAnne Sherwin, MS, APRN-BC  
Oregon Health & Science University  
1-877-858-4427  
email [sherwinl@ohsu.edu](mailto:sherwinl@ohsu.edu)

**Participant Invitation and Screening Script (PHONE)**

OHSU eIRB study #

**(LeeAnne Sherwin will be making the announcement, she will read the opening statement below):**

Hello, my name is LeeAnne Sherwin and I am a PhD Candidate at Oregon Health & Science University. I am working on a study on Irritable Bowel Syndrome also known as IBS with Oregon Health & Science University School of Nursing. Thank you very much for allowing me to talk to you about an opportunity to participate in this IBS research study.

**(Body)**

The study focus is to learn more about how Irritable Bowel Syndrome (IBS) impacts people's health-related quality of life. We are also interested in how coping styles play a role. This information will help us better understand how to help those with IBS increase their health-related quality of life. I would like to invite you if you are between the ages of 30 and 50 years old, have been diagnosed with IBS or believe you have IBS, have not been diagnosed with Crohn's disease, Ulcerative Colitis, microscopic colitis, collagenous colitis, colonic strictures or cancer in the last 6 months and are able to read and speak English to participate in this study. Your participation is entirely voluntary. This is a one-time, self-administered survey and will take less than one hour to complete. You will be able to complete the questionnaire in the privacy of your own home. The information you provide will be kept confidential. The data will not contain any information that will identify you.

**(If participant agrees to participate, then proceed with the screening. If the participant declines to participate, then read closing statement.)**

**(Read if agrees to participate)**

Since you are interested I have a few questions to ask you to be sure this study is right for you.

1. How old are you? \_\_\_\_ (needs to be between 30-50 years old)

2. Are you able to read and speak English? Yes No
3. Have you had recurrent abdominal pain or discomfort for at least 3 days per month during the previous 3 months? Yes No
4. Is the abdominal pain or discomfort relieved by passing of your bowel movement? Yes No
5. Have you had a change in how often you have a bowel movement? Yes No
6. Have you had a change in your bowel movement form or how it looks? Yes No
7. Have you been diagnosed with
  - a. Crohn's disease Yes No
  - b. Ulcerative Colitis Yes No
  - c. microscopic colitis Yes No
  - d. collagenous colitis Yes No
  - e. colonic strictures Yes No
  - f. cancer in the last 6 months? Yes No

**(If the potential participant is not within the age limit and cannot read or speak English, answers NO to 2 or more of questions 3 through 6 or answers yes any of the diseases noted in a-f in question number 7 they do not meet the inclusion criteria for the study. The following statement will be read)**

**Participant Invitation and Screening Script (continued)**

**The participant does not meet screening criteria for inclusion statement:** I am sorry because of (X) this study is not right for you. However, I do thank you for your time and willingness to help. (Conclude call)

**(If the participant is between the ages of 30-50 years old, answers Yes to questions 2-6 and No to any of the diseases noted in a-f in question**

**number 7 they may be included in the study and the following statement will be read)**

You meet the criteria for inclusion into this study, may I have your full name, mailing address including street, apartment number, town/city, state, zip code and phone number. I will be sending you a study packet that includes the questionnaires. Please complete all questions and return the questionnaire to me in the enclosed stamped, addressed envelope at your earliest convenience.

**(Closing statement)**

Thank you very much for your time.

**Appendix E**

**Contact Sheet**

Name:

Address: (include street, apt. number, city/town, state, zip)



**Appendix G**

**Goodness of Fit Tables**

Table 8. Kolmogorov-Smirnov (K-S) and Shapiro-Wilk (S-W) to assess goodness of fit of the regression residuals to normality, regression equations before and after transformation.

Variable	Standardized Residuals				Skewness	Kurtosis
	K-S	Sig	S-W	Sig		
<i>Identity</i>						
<u><i>Untransformed</i></u>						
• Step 1	0.15	0.001	0.93	0.001	1.05	1.05
• Step 2	0.09	0.04	0.98	0.13	-0.35	-0.33
• Step 3	0.11	0.01	0.96	0.01	-0.79	1.23
<u><i>Transformed*</i></u>						
• Step 1	0.08	0.13	0.98	0.08	-0.403	-0.38
• Step 2	0.09	0.04	0.98	0.13	-0.35	-0.33
• Step 3	0.06	0.20	0.99	0.67	-0.29	0.25

\*transformed using Log<sub>10</sub> catastrophizing

\*\*Standard error for skewness=0.24, standard error for kurtosis=0.48 for all equations

Table 9. Kolmogorov-Smirnov (K-S) and Shapiro-Wilk (S-W) to assess goodness of fit of the regression residuals to normality, regression equations before and after transformation.

<b>Variable</b>	<b>Standardized Residuals</b>				<b>Skewness</b>	<b>Kurtosis</b>
Consequences	<b>K-S</b>	<b>Sig</b>	<b>S-W</b>	<b>Sig</b>		
<u>Untransformed</u>						
• Step 1	0.10	0.02	0.95	0.00	0.54	-0.48
• Step 2	0.07	0.20	0.98	0.20	-0.27	0.56
• Step 3	0.08	0.11	0.95	0.02	-0.90	1.27
<u>Transformed*</u>						
• Step 1	0.08	0.09	0.97	0.02	-0.16	-0.98
• Step 2	0.07	0.20	0.98	0.20	-0.27	0.56
• Step 3	0.06	0.20	0.97	0.04	-0.66	0.71

\*transformed using square-root catastrophizing

\*\*Standard error for skewness=0.24, standard error for kurtosis=0.48 for all equations



Table 10. Kolmogorov-Smirnov (K-S) and Shapiro-Wilk (S-W) to assess goodness of fit of the regression residuals to normality, regression equations before and after transformation.

Variable	Standardized Residuals				Skewness	Kurtosis
	K-S	Sig	S-W	Sig		
Timeline Acute/Chronic						
<u>Untransformed</u>						
• Step 1	0.09	0.04	0.96	0.05	0.96	0.65
• Step 2	0.08	0.08	0.97	0.05	-0.56	0.16
• Step 3	0.11	0.01	0.94	0.01	-1.03	2.06
<u>Transformed*</u>						
• Step 1	0.06	0.20	0.98	0.23	-0.14	-0.60
• Step 2	0.07	0.20	0.99	0.78	-0.19	0.04
• Step 3	0.07	0.20	0.97	0.04	-0.28	1.61

\*Transformed using square-root catastrophizing and square-root health related quality of life

\*\*Standard error for skewness=0.24, standard error for kurtosis=0.48 for all equations

Table 11. Kolmogorov-Smirnov (K-S) and Shapiro-Wilk (S-W) to assess goodness of fit of the regression residuals to normality, regression equations before and after transformation.

Variable	Standardized Residuals				Skewness	Kurtosis
	K-S	Sig	S-W	Sig		
<i>Untransformed</i>						
• Step 1	0.08	0.08	0.96	0.00	0.87	1.49
• Step 2	0.07	0.20	0.98	0.05	-0.43	-0.24
• Step 3	0.11	0.01	0.95	0.00	-0.93	1.83
<i>Transformed*</i>						
• Step 1	0.09	0.04	0.98	0.10	-0.35	-0.35
• Step 2	0.07	0.20	0.98	0.05	-0.43	-0.24
• Step 3	0.07	0.20	0.98	0.21	-0.51	0.89

\*Transformed using square-root catastrophizing

\*\*Standard error for skewness=0.24, standard error for kurtosis=0.48 for all equations

Table 12. Kolmogorov-Smirnov (K-S) and Shapiro-Wilk (S-W) to assess goodness of fit of the regression residuals to normality, regression equations before and after transformation.

Variable	Standardized Residuals				Skewness	Kurtosis
	K-S	Sig	S-W	Sig		
Treatment Control						
<i>Untransformed</i>						
• Step 1	0.10	0.01	0.94	0.01	0.88	0.53
• Step 2	0.09	0.05	0.97	0.02	-0.49	-0.33
• Step 3	0.10	0.02	0.94	0.00	-1.06	2.00
<i>Transformed*</i>						
• Step 1	0.05	0.20	0.99	0.39	-0.15	-0.54
• Step 2	0.09	0.05	0.97	0.02	-0.49	-0.33
• Step 3	0.07	0.20	0.98	0.07	-0.61	1.01

\*Transformed using square-root catastrophizing

\*\*Standard error for skewness=0.24, standard error for kurtosis=0.48 for all equations

Table 13. Kolmogorov-Smirnov (K-S) and Shapiro-Wilk (S-W) to assess goodness of fit of the regression residuals to normality, regression equations before and after transformation.

Variable	Standardized Residuals				Skewness	Kurtosis
	K-S	Sig	S-W	Sig		
<i>Illness Coherence</i>						
<u><i>Untransformed</i></u>						
• Step 1	0.11	0.01	0.93	0.01	1.08	1.37
• Step 2	0.11	0.01	0.98	0.07	-0.39	-0.38
• Step 3	0.10	0.03	0.96	0.01	-0.80	1.27
<u><i>Transformed*</i></u>						
• Step 1	0.05	0.20	0.99	0.39	-0.14	-0.23
• Step 2	0.11	0.01	0.98	0.07	-0.39	-0.38
• Step 3	0.06	0.20	0.99	0.39	-0.42	0.47

\*Transformed using square-root catastrophizing

\*\*Standard error for skewness=0.24, standard error for kurtosis=0.48 for all equations

Table 14. Kolmogorov-Smirnov (K-S) and Shapiro-Wilk (S-W) to assess goodness of fit of the regression residuals to normality, regression equations before and after transformation.

Variable	Standardized Residuals				Skewness	Kurtosis
	K-S	Sig	S-W	Sig		
Emotional Representation						
<u>Untransformed</u>						
• Step 1	0.10	0.01	0.97	0.02	0.45	-0.10
• Step 2	0.10	0.01	0.93	0.01	-0.59	0.90
• Step 3	0.11	0.00	0.93	0.00	-1.11	2.14
<u>Transformed*</u>						
• Step 1	0.06	0.20	0.99	0.56	-0.32	0.17
• Step 2	0.07	0.20	0.98	0.05	-0.29	1.25
• Step 3	0.10	0.01	0.97	0.03	-0.09	0.86
<u>Transformed**</u>						
• Step 1	0.06	0.20	0.99	0.56	-0.32	0.17
• Step 2	0.10	0.01	0.96	0.01	-0.60	0.90
• Step 3	0.08	0.10	0.95	0.01	-0.89	1.38

\*Transformed both HRQOL and catastrophizing using square-root

\*\*Transformed only catastrophizing using square-root.

\*\*\*Standard error for skewness=0.24, standard error for kurtosis=0.48 for all equations