DISSERTATION

A QUALITATIVE STUDY OF DISEASE ADJUSTMENT: INFLAMMATORY BOWEL DISEASE POST-TRAUMATIC GROWTH

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ABSTRACT

A MIXED METHOD STUDY OF DISEASE ADJUSTMENT: INFLAMMATORY BOWEL DISEASE POST-TRAUMATIC GROWTH

The current study developed a model of post-traumatic growth to assess the multiphasic, transitional experience of patients diagnosed with inflammatory bowel disease (IBD) by a provider at the Centers for Gastroenterology in Northern Colorado. Specifically, this study examined individuals within the IBD population who have received a diagnosis of either Crohn's disease (CD) or ulcerative colitis (UC). Consensual Qualitative Research (CQR) was used to identify the primary domains and subthemes from six participant interviews. Four large domains were extracted from the data, which were used to construct a model of Inflammatory Bowel Disease Post-Traumatic Growth (IBDPTG). The four, major domains include identity loss/grief, the perception effect, identity reconstruction, and post-traumatic growth (PTG). The original model proposed for this study included all of the aforementioned domains, except for the perception effect. The trained research team involved in this study conducted three meetings to discuss and compare domain/thematic findings. We identified that participants' attitudes/beliefs about their diagnosis was a precursor to progressing to the identity reconstruction phase, and, therefore, needed its own, distinct domain. Subthemes were also identified in each of the four domains, which further captured the nuances and complexities of IBD disease management for our participants.

Participants were also asked to complete two sets of the Beck Depression Inventory-II (BDI-II), two sets of the Beck Anxiety Inventory (BAI), one Symptom Checklist 90-R (SCLR-

90-R), and the Post-traumatic Growth Inventory (PTGI). Participants were asked to retrospectively complete the first set of self-report questionnaires (BDI-II, BAI, SCL-90-R), as they reflected on their psychological state during their most severe disease experience. We then conducted a semi-structured interview with each participant that lasted approximately 60-75 minutes. After the interview portion of the study, we asked participants to complete the BDI-II and BAI based on their symptom presentation within the last two weeks. We compared the difference between levels of anxiety and depression during active and inactive disease flares. Scores on the BDI-II indicated that participants experienced high levels of depression during severe flares, but that their mood greatly improved with adjustment and mental stability. Scores on the BAI also indicated that the participants experienced higher levels of anxiety during periods of disease relapse, as opposed to periods where their disease was dormant. The SCL-90-R was used to supplement the qualitative data obtained during the interviews. The PTGI was given to the participants at the end of the study to examine whether our qualitative data captured any additional, potentially disease-related growth not yet addressed on the questionnaire. The three subthemes identified in the domain of PTG include: positive personal growth, positive social growth, and positive growth in disease perception.

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INTRODUCTION

Inflammatory Bowel Disease

Inflammatory bowel disease (IBD) is a chronic, gastrointestinal disorder that results in difficulties in bowel control, severe abdominal pain, as well as decreased nutrient absorption (Podolsky, 1991; Sartor, 2006). It is an autoimmune disorder that alters both form and function of the gastrointestinal tract, causing painful, potentially debilitating, symptoms, such as frequent diarrhea, bloody stools, increased urgency to have bowel movements, incontinence, fatty deposits in the stool, anemia, and fatigue (Podolsky, 1991; Sartor, 2006; Kilham, Lerner, & Griffiths, 2014; Opheim et al., 2014) Ulcerative colitis and Crohn's disease are the two, most prevalent IBD disorders, affecting approximately 1.6 million Americans (CCFA, 2016). It is important to note, however, that this number is a relative estimation of prevalence. Researchers and medical professionals have stated that there appears to be a lack of universal, standard criteria for IBD diagnostic purposes, which potentially skews rates of existing, reported prevalence (Kilham, Lerner, & Griffiths, 2014; CDC, 2015). Diagnoses of IBD are reportedly inconsistent and often mistakenly categorized as different diseases altogether, such as irritable bowel syndrome, gastroparesis, or gallstones (CDC, 2015). Difficulties in diagnosing IBD also exist at an international level, which may misrepresent global rates of the disease as well (CDC, 2015). It is estimated that the international prevalence of UC ranges from 0.1-16 individuals per every 100,000 people, and the international prevalence of CD ranges from 0.5-24.5 individuals per every 100,000 people. The wide range of prevalence reported in these statistics further indicates a need for a more standardized diagnostic criteria, as well as increased research examining these populations.

Despite the difficulties in obtaining a truly accurate rate of prevalence, researchers affirm that the disease is becoming more pervasive--at both national, and international levels (Ng, 2016). Upon closer examination of the areas reporting increased rates of diagnoses, researchers have begun to develop hypotheses as to what factors may be contributing to this unprecedented rise in IBD. Increasing rates of IBD have been linked to factors associated with the current industrialization of a number of developing countries, specifically affecting countries such as China, South Korea, India, Lebanon, Iran, Thailand, the French West Indies, and north Africa (Ng et al., 2016; Sheehan, Morhan, & Shanahan, 2015). It appears as though the rates of IBD in individuals of European descent are not increasing as rapidly as they are for individuals who either immigrate to a more industrialized country, or, whose country is currently experiencing dramatic economic growth (Benchimol, 2015). The most industrialized nations in the world, often referred to as the G8, include North America, Canada, France, Germany, Italy, Japan, Russia and the United Kingdom (Benchimol, 2015). Canada has the highest, reported prevalence of IBD out of the G8 countries, and a National Household Survey (2011) also revealed that Canada has the highest population of foreign-born children of the aforementioned countries (Benchimol, 2015). This is particularly relevant, as the research suggests that it is the children who immigrate to industrialized nations who are most vulnerable to the development of IBD (Ng et al., 2016). This statistic suggests that the microbiome identified in children often lacks the defense mechanisms used to protect against unfamiliar bacteria, which are mechanisms that an adult microbiome has already developed (Ng et al., 2016).

Socioeconomic growth in these developing countries is associated with a number of environmental changes that may also be adversely affecting its population (Ng et al., 2016). The environmental factors posited to have the greatest impact on the rising rates of IBD in children include, dietary alterations, decreased exposure to healthy bacteria, as well as increased exposure to antibiotics when the microbiome is in a critical period of development (Ng et al., 2016; Voreades, Kozil, & Weir, 2015). The ‘hygiene hypothesis,’ suggests that people are eliminating healthy bacteria from their systems in the pursuit of cleanliness, whereby, altering the bacterial composition of their microbiomes (Voreades, Kozil, & Weir, 2015; Rook, Lowry & Raison, 2015). The altered microbiome may result in functional impairment of the intestines, potentially creating an environment that is more susceptible to the manifestation of IBD (Voreades, Kozil, & Weir, 2015). Developing countries are producing dietary trends more consistent with industrialized, ‘Western’ cultures. Research has uncovered a link between consumption of foods containing high amounts of polyunsaturated fats, including linoleic acid, as well as Omega 6 fatty acids, and the development of IBD (Lee et al., 2015). Similarly, families who immigrate to more industrialized nations are consuming foods that are comprised of these deleterious chemical compounds (Lee et al., 2015). Popkin and colleagues (2012) have deemed this phenomenon the ‘global nutrition transition,’ and assert that it has resulted in a ‘major shift in body composition’ for members of developing countries. These processed foods introduce unknown substances to an individual’s microbiome, which is contributing to the increased incidence of gastrointestinal issues, as well as rates of obesity (Popkin, Adair, & Ng, 2011).

IBD is most frequently diagnosed in individuals between the ages of 15-25, but the disease onset can occur at any age (Baars et al., 2012). Researchers have not yet discovered a cure for IBD, which results in a lifetime of disease management for patients who are diagnosed with this illness (Gallant, 2003). Although there are a multitude of treatment options available to help individuals manage their symptoms, these medications can be costly, are frequently associated with severe side effects, and often require a lifelong commitment from patients once the treatment has started (Grenard et al., 2011). Individuals with IBD experience a series of challenging, life transitions as they cope with their illness, which can significantly impact physical, psychological, social and occupational functioning (Wolfe & Sirois, 2008). As a relapsing-remitting illness, where symptoms are body-altering and unpredictable, individuals experience increased anxiety and stress in the uncertainty of how to best keep their symptoms under control (Saha et al., 2015). Individuals experience greater overall body dissatisfaction when they are diagnosed with IBD, which includes both in times of remission, and in times where symptoms are active (Saha et al., 2015).

As a result of these major, life transitions, individuals may experience a loss of personal and professional roles from which they previously constructed their identity. Individuals with IBD may experience a loss of self-efficacy during this process (Graff, Walker & Bernstein, 2009). Low levels of self-efficacy are suggested to be a major barrier contributing to a lack of positive, behavioral health changes, such as adopting adaptive coping strategies to improve behaviors of self-management involved in chronic illness care (Keefer, Kiebles & Taft, 2011). The significant decrease in self-efficacy that patients with IBD experience may impact their social relationships (Muller, Prosser, Bampton, Mountifield, & Andrews, 2010). Disease specific measures of self-efficacy have been widely studied in other chronic illness populations, but measures assessing self-efficacy within the IBD population have only recently been introduced (Graff et al., 2016). It often becomes difficult for individuals who have IBD to maintain their relationships with friends and family, as their illness will, at times, prevent them from participating in the activities that others want to experience (Trachter, Rogers, & Leiblum, 2002). These missed social opportunities can create distance between individuals with IBD and those around them, leading to further feelings of isolation and loneliness (Voth & Sirois, 2009).

It is also common for individuals with IBD to experience difficulties within the context of romantic relationships, as their partner is often relegated to the role of caregiver when they need support (Trachter et al., 2002). Partners can sometimes feel as though they assume more of a caregiver role than that of an intimate partner or companion, which can generate strain on the dynamic of their relationship. It is common for individuals with IBD to experience issues with sexual dysfunction, which can also negatively impact the dynamics of romantic relationships (Sanders, Gawron, & Friedman, 2016). Between 40-60% of female, IBD patients report issues with sexual dysfunction, and approximately 44% of male patients also report impairment in this area of functioning (Sanders et al., 2016). Patients have reported that they would like more opportunities to openly discuss their struggles with their gastroenterologists, but often feel too self-conscious to discuss their sexual experiences (Sanders et al., 2016). Patients also reported that they are even less willing to discuss these issues with their gastroenterologist if there is a gender mis-match between patient and physician (Sanders et al., 2016). Research involving the examination of sexual dysfunction within this patient population is sparse, and existing literature lacks information about the physical and psychosocial factors that exacerbate these issues (Sanders et al., 2016; Levenstein et al., 2002).

IBD can result in significant physical changes throughout the course of the disease, contributing to negative perceptions of body image and sexual identity for individuals with IBD (Sanders et al., 2016). IBD can increase issues with incontinence, potentially creating a sense of embarrassment and anxiety for individuals wanting to engage in social and/or sexual activities (Knowles, Gass, & Macrae, 2013). Individuals often fear that they will experience incontinence during a sexual act, or that their bodies may no longer be desirable to a sexual partner (Knowles, Gass, Macrae, 2013). As a result, some individuals with IBD may avoid sexual relationships altogether. Knowles and colleagues (2013) report that the most common issues male, IBD patients experience include, erectile dysfunction, decreased libido, problems reaching an orgasm, and an overall reduction in sexual satisfaction. Women have also reported reduced sexual desire, overall reduced sexual satisfaction, significant interpersonal problems with their romantic partners (Jones, Wessinger & Crowell, 2006; Knowles et al., 2013).

Body image and social relationships greatly impact self-esteem and psychosocial adjustment for individuals with IBD (Bel et al., 2015). Difficulties in psychosocial adjustment for this patient population is strongly linked to development of both internalizing and externalizing symptoms (Furman & Collibee, 2014). Internalizing symptoms refer to such emotions as anxiety, depression and stress. Externalizing symptoms include such behaviors as aggression and emotional lability (Odell, Sander, Denson, Baldassano, & Hommel, 2011). Individuals with IBD typically report levels of anxiety and depression that are 2-3 times greater than levels reported by a healthy population control (Casati et al., 2000). Knowles and colleagues (2013) also report that increased levels of anxiety and depression exacerbate issues relating to body image, self-esteem, and a reduction in both marital and family functioning. Patients with IBD often feel as though they have lost control of their lives, which can lead to heightened levels of internalizing symptoms in fearing that they may never regain this control (Furman & Collibee, 2014). Experiencing a loss of self-control can also heighten negative perceptions of self-stigmatization, as well as perceptions of social stigmatization by others (Knowles & Mikocka-Walus, 2015; Looper & Kirmayer, 2004).

According to Earnshaw and colleagues (2013), fear of social stigmatization creates a great deal of psychological and emotional stress for individuals with chronic physical, and mental, illnesses. The fear of stigma significantly impacts how individuals with IBD cope with their diagnosis and symptoms, and can result in negative psychological distress (Casati, Toner, De Rooy, Drossman, & Maunder, 2000). Shame and embarrassment surrounding the discussion of the disease can potentially contribute to maladaptive coping strategies for individuals with IBD (Taft, Keefer, Artz, Bratten, & Jones, 2011). These maladaptive coping strategies are frequently accompanied by stress, anxiety, depression and overall reduced quality of life (Casati, Toner, De Rooy, Drossman, & Maunder, 2000; Taft et al., 2011). IBD impacts numerous facets of an individual's life, often resulting in major lifestyle changes in order to manage symptoms while trying to balance other areas of functioning (Casati et al, 2000). Research within the field of IBD has focused little on what factors contribute to smoother illness transitions for patients, which is a marked gap in the literature supporting this population.

This study examined individual factors that impact psychosocial coping to a diagnosis of IBD, as well as identifying how perception of one's illness can lead to positive/negative growth. More specifically, this study explored the concept of post-traumatic growth (PTG) within the IBD population; and, if the participant identified growth, we sought to better understand the way in which the individual felt they experienced a positive change throughout their disease transition. Matini and colleagues (2011) asked participants to describe their disease diagnosis/symptom recognition, their feelings about their illness at diagnosis, and their current feelings about their illness, but did not use the term PTG (Matini & Ogden, 2011). Park and Lechner (2006) noted that studying trauma from a chronic illness was likely to yield different experiences than trauma sustained in an accident or event. They also reported that there is a clear lack of quantitative measures that assess PTG within the chronic illness population (Park et al., 2006). Purc-Stephenson (2014) quantitatively examined PTG in individuals with arthritis and inflammatory bowel disease to test the validity of the five-factor structure of the inventory as it applies to chronic illness (2014). This was the first study that examined whether the post-traumatic growth inventory (PTGI) had application to chronic illness adjustment, in addition to its use in understanding the impact of other forms of trauma (Purc-Stephenson, 2014). Purc-Stephenson (2014) concluded that the manifestation of PTG appeared to vary depending on the type of chronic illness with which the participant was diagnosed, and that there is a significant need for research examining specific, disease-related growth (Purc-Stephenson, 2014). Purc-Stephenson and Bowlby (2015) conducted a qualitative study examining PTG in individuals with IBD. This study used ground theory to code the responses of 378 participants who answered the question, "Could you please describe the (positive/negative) effect(s) IBD has had on your life?" Within the context of Purc-Stephenson's study, 80% of IBD participants reported experiencing negative effects as a result of their illness experience (Purc-Stephenson, Bowlby, & Qadish, 2015). Purc-Stephenson (2015) discovered that 73% of their participants reported experiencing positive changes as a result of adjusting to their illness. However, when Purc-Stephenson (2015) examined the positive changes experienced by the participants, they concluded that the current PTGI does not adequately capture the growth experienced within this specific population (Tedeschi and Calhoun, 1996). The researchers stated that participants positively commented on topics not covered in the current PTGI, such as appraisals of existing friendships, openness to trying new/alternative treatments, and psychological preparedness (Purc-Stephenson et al., 2015). This elucidated some of the factors to consider in this PTG exploratory study with individuals suffering from IBD. The biopsychosocial difficulties in adaptation to IBD has been examined in previous literature. Previous IBD literature has examined the extent to which participants felt a reduction in quality of life, physical disease symptoms, the development of internalizing problems (depression and anxiety), and the social aspect of coping with the illness

(Purc-Stephenson et al., 2015). However, there is a dearth of research examining whether or not people can identify any positive areas of growth as a result of their illness experience (Park & Lechner, 2006). This researcher aimed to address the limitations from Purc-Stephenson and colleagues (2015) in order to further examine the biopsychosocial nuances of navigating changes in lifestyle due to IBD. I combined the quantitative data of the PTGI and various measures of depression and anxiety, with a qualitative, narrative perspective in order to glean more information about the complexities in disease adjustment. This researcher proposed a new model of conceptualizing a patient's adjustment to chronic illness. I sought to identify a model of IBD Post-traumatic Growth (IBDPTG) in order to further understand the unique struggles associated with this disease population. This researcher examined how individuals with IBD are influenced by varying stages of grief and loss, the impact of disease perception within the context of an individual's life, social, as well as their ability to engage in a reconceptualization of identity after diagnosis. I also sought to illuminate potential opportunities/obstacles for growth that individuals with IBD experience as a result of adjusting to their illness.

Theoretical Framework

This study focused on individual, disease transitions as a result of being diagnosed with IBD. We focused on issues concerning a loss of identity for individuals in the IBD community. Participants, and their disease experience, are conceptualized from the basis of four, overarching theories, including the biopsychosocial model, the reconceptualization of chronic illness theory, the Transtheoretical Model of Change, and narrative theory (commonly used in the conceptualization of chronic illnesses for qualitative study designs) (Williams, 1984; Charmaz, 1990; Shorter, 2005; DiClemente & Prochaska, 1998; Prochaska & Velicer, 1997).

The biopsychosocial model was developed to include multiple factors associated with a person's health, suggesting that a person's health, or illness, should be viewed from a biological, psychological, and sociological perspective (Shorter, 2005). Accordingly, this theory posits that within the intersectionality of these components, researchers and medical professionals can better understand the trajectory of someone's health, as well as the course of their adjustment to, and management of, the illness (Knowles & Mikocka-Walus, 2015). Individuals with IBD experience the interaction of these factors at varying levels of balance and imbalance, which impacts prognosis, treatment, and rates of remission/relapse (Drossman, 2005). Illness, as explained by the biopsychosocial model, includes the biological changes of disease, but also incorporates an individual's changing, subjective interpretation of their illness or disability (Fleisher & Feldman, 1999). This psychological component of disease interpretation might significantly impact an individual's perspective in regards to their overall self-worth, self-esteem, and body image (Muller et al., 2010). Subsequently, how one subjectively constructs a self-concept based on these factors can significantly influence their personal, social, and occupational roles in daily life (Werner, Isaksen, & Malterud, 2004). Significant amounts of stress and anxiety in social and psychological areas of one's life, increases the risk for a 'flare up' in their IBD symptoms, illustrating how important it is to consider both emotional and biological elements of the model (Knowles & Mikocka-Walus, 2015). It is important to note that stress cannot cause IBD, but is linked to an exacerbation of symptoms (Garrett, Brantley, Jones & McKnight, 1991).

The concept of uncertainty as a significant source of stress and anxiety in relapsing-remitting, chronic illnesses is well-documented. A theoretical model that incorporates this concept is the reconceptualized uncertainty of illness theory (RUIT) (Mishel, 1990). Mishel

(1990) created the RUIT as a way of examining various coping strategies utilized by individuals with chronic illnesses who live with a continuous process of disease and symptom uncertainty. Most illnesses with an acute onset resolve within a relatively short amount of time, and, once healed, the individual usually resumes normal daily activities without any issues. Individuals with chronic illnesses are not offered this reprieve, and, therefore, the psychological impact of a diagnosis will be vastly different than individuals whose ailments are curable (. Uncertainty, as conceptualized by this model, pertains to the inability to predict illness-related complications that may occur as a result of the disease (Mishel, 1990). Living with this type of uncertainty makes it difficult for an individual to construct a formula, or cognitive schema, from which they can build a foundation of stability in their lives. This lack of stability in one's health, can create lasting psychosocial effects that emerge even when disease symptoms are quiescent (Mishel, 1990). The physical resources that are required to fight the illness consume a significant amount of physical and cognitive energy, and can often leave individuals feeling weak and depleted (Mishel, 1990). Individuals with severe symptoms can feel as though they have lost control of their bodily functions, which can contribute to negative perceptions of body image, increased perception of stigma, increased isolation from friends and family, and decreased desire and confidence surrounding sexual intimacy (Muller et al., 2010). This uncertainty can create a sense of personal and social helplessness for individuals with IBD (Guthrie et al., 2002).

Due to the loss of control individuals with IBD have experienced in their lives, it is essential that they still find opportunities to bolster their feelings of self-esteem and self-actualization. This study, in and of itself, can be viewed as a form of intervention, in that it sought to empower individuals with IBD to share their disease experiences in narrative form. Narratives are conceptualized as an 'entity that is distinguishable from the surrounding discourse that has a beginning, middle, and an end,' and is often viewed as a forum for communicating important sociocultural experiences (Charmaz & McMullen, 2011). It can be viewed as a powerful mechanism for the emotional expression of those suffering with chronic pain and illness (Charmaz and McMullen, 2011).

The extent to which qualitative researchers have attempted to study the chronic illness experience, through a narrative perspective in particular, has steadily gained popularity (Conrad, 1987; Charmaz, 2000; Pierret, 2003; King, Klinovski, & Dubouloz, 2016; Dur et al., 2014). However, IBD has been significantly underrepresented in qualitative literature examining the illness experience from the perspective of patient narratives (Dur et al., 2014). It has been indicated by numerous studies that it is essential to increase the amount of qualitative research within the IBD population, as the subjective experience of each individual can provide vital information about patient needs (Dur et al., 2014; Graff et al., 2016). This type of research provides medical professionals with a more intimate perspective of what it means to live with IBD. Information regarding this population can impact patient conceptualizations and treatment plans (King, Klinovski, & Dubouloz, 2016; Pierret, 2003). Previous, qualitative chronic illness research has proposed models that attempt to capture the transition process in a way that is similar to the model of IBDPTG that has been generated for the purpose of this study. King and colleagues (2016) examined the ability of rehabilitation therapists to identify phases of adjustment in their patient population based on The Process Transformation Model (PTM). The PTM posits that are three, distinct stages present within a patient's adjustment to a chronic illness. However, King and colleagues (2016) have conceptualized these stages differently than we are proposing for this study with the IBDPTG. According to researchers, the PTM includes a trigger phase, a process of changing phase, and an outcome phase (King, Klinovski, &

Dubouloz, 2016). King and colleagues (2016) reported that the therapists in their study were able to identify these, distinct stages as they occurred for their patients, but that they struggled to fully understand the complex process by which patients changed the meaning they attached to their perspectives (which were also changing) and illness experiences (King et al., 2016).

King and colleagues (2016) posit that the success of the patient transformation is highly influenced by the 'readiness to change' exhibited by patients. This concept is akin to the Transtheoretical Model of Change (TMC) that psychologists have constructed to conceptualize the stages of change that occur gradually for clients receiving psychotherapy (Prochaska, 2013). This model has also been examined within the context of behavioral health interventions for multiple patient populations, including patients diagnosed with human immunodeficiency virus (HIV), patients who are substance dependent (intravenous drugs, smoking cessation, and cocaine users), as well as for patients participating in programs designed to teach healthy methods of weight control (Schwarzer, Lippke & Luszczynska, 2011). The five stages within this model include, pre-contemplation, contemplation, preparation, action, and maintenance, which details the client's journey through therapy (Prochaska, 2013). Clients in treatment present with varying phases of this model as they progress through an extended number of sessions with a psychotherapist (Schwarzer et al., 2011). The TMC was utilized in this study to inform questions regarding the way patients transition through the phases of IBDPTG. Readiness for change was a crucial component of the new, proposed model of IBDPTG.

Stages of Disease Transition

Grief/Loss. For the purpose of this study, grief was conceptualized as an individual's need to mourn the loss of their 'healthy self' from the past, present and the future, upon the manifestation of illness symptoms and official diagnoses. Individuals with chronic illnesses can feel as though they are suffering a great loss of personal identity when diagnosed with an incurable illness (Palant et al., 2015). Researchers have acknowledged that a normal reaction to a diagnosis of IBD may be accompanied by psychological distress, feelings of grief, feeling overwhelmed in acquiring knowledge about the illness including such needs as dietary alterations and a new medication regimen (Kiebles, Doerfler, & Keefer, 2010; Sewitch et al., 2001). Patients receiving a new diagnosis may feel as though they are grieving the loss of the person they were in the past, fearing that they will never be able to lead a life as enjoyable as the one they led prior to diagnosis (Kiebles et al., 2010).

Individuals with IBD may experience IBDPTG cyclically, as some individuals can feel a similar sense of grief at each 'flare-up' of their symptoms (relapsing) as they did when they were initially diagnosed, feeling as if they have made no improvement in the, depending on severity. When symptoms are active, they significantly limit patients in physical mobility, making the completion of daily tasks far more difficult than it was when they were healthy (Polodecky, 2013). Some individuals are hospitalized for extended periods of time, while others may not possess the energy and strength to leave their home (Maddux, Bass, Geraghty-Sirridge, Carpenter, & Christenson, 2013; Felton, & Revenson, 1984). These physical limitations impact a multitude of facets in one's life, which can feel as though the progress of one's life has been suspended in time, with no guarantee of when it will begin to move forward again (McCormick et al., 2012). This can result in feelings of frustration, as an individual with IBD watches healthy counterparts progressing through the milestones of their lives (Thompson, 2013).

It is not uncommon for individuals with IBD to apply for Supplemental Security Disability Income (SSDI), as the symptoms of their illness may prevent them from obtaining a steady source of income because they are incapacitated (Feagan, Bala, Yan, Olson, & Hanauer, 2005). The socioeconomic stress of managing a chronic illness is burdensome for individuals who are financially stable, and have excellent health insurance benefits to mitigate the cost of the procedures and treatments required to manage IBD (van der Valk et al.,, 2016). The fact that the management of IBD can be difficult for individuals with stable personal and professional lives, suggests that it could be financially ruinous for individuals whose fiduciary circumstances (and access to health insurance benefits) are far more precarious during the transition to IBD (Faust, Halpern, Danoff-Burg, & Cross, 2012). Although employers have different policies regarding medical leave for their employees, individuals in this patient population are rarely provided enough time off to receive adequate treatment (Faust et al., 2012). Additionally, some treatments for IBD can take weeks, or even months, to produce symptom reduction significant enough to improve a patient's quality of life and daily function (Feagan et al., 2005). When individuals are unable to work due to severity of their symptoms, by extension, they often lose their health insurance benefits (Feagan, 2005, van der Valk et al., 2016). Treatments for IBD can cost tens of thousands of dollars for disease management over the course of an individual's life span, resulting in many patients who cannot access medical treatment for IBD (Haapamäki, Turunen, Roine, Färkkilä, & Arkkila, 2009; van der Valk et al., 2016).

There is also a component of grief in losing one's future identity that is associated with adjustment to IBD (Kiebles, Doerfler, & Keefer, 2010). Individuals have often envisioned future lives for themselves that include creating/supporting a family, working towards a specific career goal, or even as simple as having the chance to pursue other hobbies and interests that they have not yet had time to experience prior to the onset of their illness (Kiebles et al., 2010). A vital component of adjusting to life with a chronic illness exists in one's cognitive flexibility, or how difficult it is for them to alter the way they conceptualize their personal identity (Dorrian, Dempster, & Adair, 2009). Perception of the illness is a strong predictor in how an individual will cope with IBD (Dorrian et al., 2009; Rochelle & Fidler, 2013). The importance of the perception of one's illness was identified in this study, as the individuals who were more optimistic about the prognosis of the disease were more likely to experience post-traumatic growth than individuals who had a negative perspective of their illness. If an individual perceives their illness to be chronic, incurable, and never likely to get better, they are more likely to report a marked reduction in quality of life in later stages of disease adjustment than are those that view their illness more positively (QoL) (Dorrian et al., 2009).

Identity Reconstruction. It is not unusual for individuals to construct their identities around activities in which they have the ability to participate in meaningful ways (Asbring, 2001). This concept of identity construction is often referred to as self-actualization (Bonsaksen, Lerdal, & Fagermoen, 2012). Individuals who are diagnosed with IBD may experience an initial loss of self-actualization, in that they are no longer capable of participating in a number of activities that once gave meaning to their life (Devlen et al., 2014). The loss of certain components of self-actualization can lead to psychosocial distress for individuals with IBD, as they are forced to re-evaluate their constructs of self (Bonsaksen et al., 2012).

As individuals with IBD become more accepting of what it will take to control their illness, and the adjustments that are necessary to regain strength and health, they begin to see past initial desires to hide their illness from those around them (McCormick et al., 2012). Individuals with IBD often feel as though they need to justify, or legitimize, their illness to others, as some members of society attribute their symptoms to psychosomatic causes (Defenbaugh, 2013; McCormick et al., 2012). Individuals whose illnesses categorized as 'invisible chronic illnesses' often encounter individuals who invalidate the veracity of their diagnosis simply because it is not visually recognizable (McCormick et al., 2012). As an individual is attempting to manage painful, disrupting symptoms, it can be devastating for individuals to feel invalidated from those they interact with on a daily basis (friends, family, co-workers, for example) (Defenbaugh, 2013; McCormick et al., 2012). Fear that one will not be able to regain any semblance of what their life looked like prior to diagnosis is quite salient amongst IBD patients, as they do not want to experience the unnecessary judgment of others for the remainder of their lives (McCormick et al., 2012; Livneh, 2001). However, as individuals become accustomed to the routine necessary to live their lives with IBD, they may begin to see their illness less as a disruption, or a potential source of judgment in their life, and begin to positively integrate their illness as a part of their overall self-identity (Livneh, H., 2001). This study examined how patients transitioned through phases of identity reconstruction, and sought to learn more information about what differs between individuals who are successful in this endeavor, from individuals who are not necessarily able to accept that their illness is now a part of their identity.

Post-Traumatic Growth (PTG). The concept of applying PTG to individuals who have experienced trauma due to chronic illness is relatively new (Purc-Stephenson, 2014). Research about PTG within the IBD population is incredibly sparse (Calhoun & Tedeschi, 2014). Camara and colleagues (2011) reported that individuals suffering from CD are likely to experience Post-traumatic Stress Disorder (PTSD) as a result of their illness experience. Using the Post-traumatic Diagnostic Scale (PDS) (rated 0-51 points), Camara and colleagues (2011) found a significant difference in disease management between individuals that scored ≥15, as opposed to individuals who scored ≤15. They reported that the individuals who scored ≥15 on the PDS had 4.3 times higher odds of disease exacerbation over an 18 month study period than individuals who scored ≤15 (Camara et al., 2011). They measured disease exacerbation through disease flares, extraintestinal manifestations, and complications/non-responsiveness to therapy or treatment. They identified a form of IBD (CD) as trauma, which was the first conceptualization of IBD as a form of PTSD. However, the study did not further examine the extent to which positive growth might have occurred post-diagnosis (patients with UC were not included in this study). Researchers reported that a significant number of individuals with autoimmune disorders have met diagnostic criteria of PTSD as a result of their experience (Camara et al., 2011; American Psychiatric Association, 2013). According to the DSM-V, developed by the American Psychiatric Association (APA), responses to PTSD can be extremely variable, but anxiety and fear are the most common symptoms that manifest with this disorder (American Psychiatric Association, 2013). However, individuals with PTSD can also experience behavioral changes that are indicative of a depressive episode (anhedonia and dysphoria), anger/aggression, or can exhibit dissociative symptoms (American Psychiatric Association, 2013). Tedeschi and Calhoun (1996) generated the Post-traumatic Growth Inventory (PTGI) for the purposes of quantitatively measuring this phenomenon in clinical populations. Clinical populations that have studied PTG from a qualitative perspective include patients diagnosed with various forms of cancer, patients suffering from autoimmune disorders, and patients with a variety of visible/invisible chronic illnesses (Camara et al., 2011). Hefferon and colleagues (2009) reported that the most research examining PTG within the chronic illness population has focused on individuals battling different forms of cancer. Researchers hypothesize that rates of PTG are higher than we might expect amongst other chronic illness populations, and strongly indicate that more research is necessary to show the mechanisms involved in this growth (Camara et al., 2011; Calhoun, Cann, Tedeschi, & McMillan, 2000).

Personal growth is commonly labeled PTG, and defined through the positive changes resulting from one's struggle to cope with a trauma or a major life crisis (Calhoun, Cann, Tedeschi, & McMillan, 2000; Linley, & Joseph, 2004). Individuals who have experienced PTSD also identified that PTG is more likely to occur should the individual have access to mental health resources, as well as opportunities to gain social support during disease adjustment (Garland, Carlson, Cook, Lansdell, & Speca, 2007; Cordova, Cunningham, Carlson, & Andrykowski, 2001). The PTGI was designed to capture trauma sustained from external events/experiences (i.e., combat experiences, sexual/physical assault, trauma responder) (Tedeschi & Calhoun, 1996). Hefferon and colleagues (2009) assert that there may need to be a different measurement of PTG for individuals who experience trauma more from an internal, psychological perspective, as that is more consistent with the experience of individuals with chronic illnesses. Unlike traumatic events that occur as one situation/event, chronic illnesses present potential stages of increased trauma based on their disease prognosis (diagnosis, surgery, complications) (Calhoun & Tedeschi, 2006).

A majority of studies examining PTG within clinical populations allot a fraction of space in the literature incorporating detailed information about individuals that did not experience PTG in comparison to their well-adjusted counterparts (Camara et al., 2011). More information is needed to also understand the negative changes that remain unresolved for certain individuals in these same domains (for example, problems in interpersonal relationships, or negative changes in self-esteem) (Camara et al., 2011). Therefore, qualitative researchers need to consider asking more open-ended questions to participants suffering from a chronic illness to specifically address factors associated with positive and negative growth that has occurred within their disease adjustment (Purc-Stephenson et al., 2015). The collection of more in-depth information surrounding positive and negative disease experiences may allow researchers to obtain a better understanding of how these events affect their overall quality of life (Camara et al., 2011). Calhoun and Tedeschi (2006) also discussed the fact that the percentage of individuals who actually develop PTSD from a traumatic event are relatively low—about 5% in men and 10% in women (Calhoun & Tedeschi, 2006). They stated that of these percentages, some individuals may grow in numerous positive ways, but that we should also be cognizant of not judging individuals who do not experience a transformation/growth, or who have had more negative reactions to the illness than positive (Calhoun & Tedeschi, 2006).

Exploratory Qualitative Study

This researcher had the opportunity to conduct a pilot study per course requirements in the Education Department Research Methods course, taught by Dr. Louise Jennings. This study was conducted in the Spring of 2016, but did not require IRB approval as the project was not a formal research study. This project included three participants with IBD, and were all members of the IBD support group that was facilitated by this researcher in Fort Collins.

In the context of this pilot study, data collection included recorded, unstructured phone interviews. Throughout the process of interviews, notes were taken in addition to recording the interview with an audio device. Additionally, memos and project journals were diligently kept in order to organize data and reactions of the researcher at the time of the interview. This researcher also paid close attention to the volume and intonation with which each participant shared their story, as it provided insight into the emotional reactions that were elicited for them as they relived their traumatic, illness experience.

Participants in this study were asked to tell their story from a timeline that included the emergence of their symptoms, up to their current health status. Questions focused on what types of metamorphoses participants experienced throughout their transition in various facets of life, including: self-esteem and body image, personal growth, physical change, sexual/intimate relationship issues, psychological well-being, social identity, as well as overall quality of life throughout the process. These interviews helped inform the researcher's questions for the purpose of this proposed study. As a result of the course project, this researcher was able to explore what types of questions facilitated more openness from the participants, which was beneficial in constructing the interview guide for this study.

Interviews were then transcribed and thematically coded in Microsoft Word. Data analysis for this quasi-pilot study was conducted from a phenomenological approach. The phenomenological approach allowed this researcher to attach meaning to participant experiences (Bazeley, 2009). Per stages in phenomenological analysis, open coding of the transcript material was conducted. Then, focused coding was used to develop categories, or clusters, of data in order to better interpret overall themes (Bazeley, 2009).

During data analysis of the pilot study, participants each shared similar, multiphasic transitional periods that took place as they adjusted to their diagnosis and subsequent disease management. Each participant experienced these phases differently. For example, a number of factors influenced different experiences within the overarching phases, and yet, the distinct phases of the IBDPTG model that will be proposed for this study, was present within each participant's narrative story. These phases differed different in length and severity based on the participant's age, the participant's marital status, diagnosis and prognosis of their illness, the amount of social support available to them, in what context the individual participant constructed their self-esteem and identity, and how willing the participant was to integrate disease management into their life.

The data collected from interviewees focused on the research questions driving this study. Coding technology was not used as a method of systematically coding data. Transcripts were read multiple times to ensure familiarity with the data at both a general and nuanced level. This familiarity with the transcripts eased the process of thematic identification and organization of data in a way that encapsulated the raw sensitivity of each participant's narrative. Findings of this study were presented by poster and manuscript during finals week of the Spring 2016 Semester at Colorado State University.

Additionally, this researcher has acquired anecdotal data in her time working as an Adjustment and Coping Consultant at the Centers for Gastroenterology (CGE) in Fort Collins that has also informed the creation of this study. This researcher worked at CGE for approximately 2 years, and has previously facilitated IBD and ostomy support groups for the benefit of helping this patient population. This researcher also conducted a quantitative study for the completion of her Master's Thesis in Counseling Psychology at Colorado State University (CSU). This study examined the relationship between IBD, perceived social support, medication adherence and internalizing symptoms. Results of numerous moderation analyses suggested that higher levels of disease severity reported in this patient population when the participant also reported low levels of perceived social support and high levels of anxiety, stress and depression (internalizing symptoms). Similarly, results also illustrated that disease severity was lower for this patient population when the participants also reported high levels of perceived social support and low levels of internalizing symptoms. This researcher is currently fulfilling her academic and departmental requirements while on a pre-doctoral internship at WellSpan Behavioral Health in York, Pennsylvania. Currently, this researcher works at two family practices, as well as a two community behavioral health clinics. This researcher works with a multi-disciplinary team on a daily basis regarding patient health and wellness, and encounters a large population of individuals who are coping with chronic illnesses (cancer, multiple sclerosis, chronic obstructive pulmonary disease (COPD), diabetes, severe spinal injury and pain, inflammatory bowel disease and fibromyalgia). This researcher has even explained this model in session with patients coping with a chronic illness to help them organize their thought processes concerning their illness(es).

Current Study

This study examined PTG in individuals with IBD from a narrative perspective, and incorporated quantitative, self-report measures that identified the patients' quality of life when their symptoms were at their worst, as well as assessing their current levels of depression, anxiety and post-traumatic growth. This study examined how varying levels of patient motivation, or 'readiness to change,' influenced the integration of self-management practices into their disease adjustment. This study also examined the role of attitudes and beliefs towards achieving PTG despite the psychosocial struggles associated with a diagnosis of IBD. The narrative provided by the participants elucidated further insight into understanding the role of body image, loss of control/autonomy, stigma/judgment, and psychological/emotional stress as they contribute to mechanisms of change for the patient. This study attempts to name and describe the elements of chronic illness adjustment by introducing the IBDPTG model. This study provided further insight into explanations for both adaptive, and maladaptive adjustment strategies patients used to help themselves cope during their disease management.

This study sought to allow the participants to explain the facets of their identity that have been impacted by IBD by controlling the narrative of their own disease experience. This study explored the themes of grief, positive/negative levels of perception related to various disease factors, the importance of strong social support, and how identity reconstruction is possible after one's initial diagnosis. This study examined the unique difficulties that an individual with IBD encounters as a result of living with their disease, and it also further emphasizes the positive impact of viewing chronic illness as an opportunity for PTG.

Research Questions

This study sought to better understand the impact of a diagnosis of IBD, and how each individual approached coping and acceptance of the illness. We sought to understand how people constructed their overall identity prior to their diagnosis, and where they felt they had noticed the greatest sense of identity loss (i.e. physical identity, occupational identity, social identity). Participants were queried as to their perceptions and attitudes towards their diagnosis as well, in an attempt to see what internal and external factors make illness transition and coping more challenging on an individual basis. This study also examined the extent of potential post-traumatic growth as a result of coping with their disease. This study sought to examine the phenomena of PTG within the IBD population.

METHODS

Consensual Qualitative Research

Hill (2012) stated that the philisophical underpinnings of Consensual Qualitative Research (CQR) are predominantly derived from a constructivist paradigm. Constructivists believe that there are a number of socially constructed phenomena that are more appropriately studied without the constraints of quantitative research paradigms (Hill, 2012). However, CQR also integrates elements of the post-positive perspective in order to increase the trustworthiness of the study.

Establishing trustworthiness

Trustworthiness, as conceptualized in CQR, is the equivalent of what quantitative studies refer to as reliability (Morrow, 2005). In qualitative research, we do not have a way to statistically examine such constructs that determine the reliability and validity of our methodology. Researcher bias is considered an inevitability in qualitative research from a constructivist perspective (Hill, 2012). Establishing quality and trustworthiness is the method utilized by qualitative researchers to ensure that they will adhere to professional, research standards (Morrow, 2005). To increase the trustworthiness of the research design, CQR suggests implementing some of the following steps (Hill, 2012).

Selecting and Training Research Team

CQR places greater emphasis on the selection of a research team than do other qualitative methods. Hill (2012) suggests that a larger research team can further address issues of study integrity. It is suggested that the research team be comprised of 2 or 3 individuals, as well as 1 or 2 auditors in the final stages of analysis. Qualitative research has been historically criticized within the field of psychology, but Hill (2012) asserts that the construction of a larger research team also addresses issues of reliability and validity. A meta-analysis conducted by Hill (2012) suggested that individuals have been recruited to CQR research teams with varying levels of education and practical experience, including undergraduate research assistants (RA) who were trained by the principal investigator.

The research team consisted of 4 Caucasian females, ages ranging from 22-30 years old. There was diversity amongst the levels of socioeconomic statuses between the 4 researchers, which did prove beneficial in the conceptualization of the patient experience and the chronic disease model from a financial standpoint. Two team members also have a diagnosis of IBD (CD and UC), which also helped in contextualizing the content for the researchers who were less familiar with the illness. This researcher requested that the additional members of the research team seek out resources that would further inform them of what IBD actually is, so that they would be familiar with wording and concepts that the participants discussed. The research team was motivated and reliable, and the individuals were selected based on the possession of these characteristics (Hill, 2012). This P.I. recruited the research assistants from introductory counseling courses, as well as other higher level psychology courses typically required for those majoring in the field.

Managing Biases and Expectations

In CQR, it is vital that researchers are aware of how their biases, personal identities, and experiences can affect their work (Hill, 2012). This process is called being reflexive (Charmaz & McMullen, 2011). This researcher sought to communicate transparency in both personal identity and professional experience (Morrow, 2005). Due to the fact that significant bias can invalidate an entire study, it was important that the researcher identified personal and professional biases prior to data collection (Charmaz & McMullen, 2001). Collaboration with the research team during this study, helped manage the potential biases of this researcher.

The primary researcher self-identifies as a 30-year-old, heterosexual female of European descent. It is relevant to note that the primary researcher, is first and foremost, a scientist attempting to uphold rigorous standards of trustworthy research. The primary researcher was also diagnosed with IBD (UC) approximately 10 years ago. Her personal experience with this disease, combined with her professional training, provides her with a unique personal perspective within this field of research. The primary researcher disclosed her diagnosis to the Centers for Gastroenterology during her clinical time at the facility, and the information was available to all patients in the practice (per a flyer advertising services she provided to the practice). This researcher acquired a significant amount of anecdotal evidence in support of the multiphasic, post-traumatic growth model during her work with patients at the Centers for Gastroenterology (her official title was: IBD Adjustment and Coping Consultant, as she worked under the supervision of a licensed psychologist, Dr. Larry Bloom).

The researcher conducted this study to fulfill the requirements of her doctoral degree in Counseling Psychology from the Department of Psychology at Colorado State University (CSU). The primary researcher has extensive experience working with individuals suffering from chronic illnesses, and IBD in particular. In addition to providing services to patients at the Centers for Gastroenterology, and working within an integrated-practice medical setting for her clinical internship, the researcher has also conducted support groups for the IBD patient population. Copious notes were collected throughout the research process to ensure this researcher recorded her internal thoughts, feelings, and reactions to the interviews. These memos included commentary about the content of the interview. Documenting these thoughts and reactions immediately after a participant interview was completed, allowed the researcher to revisit that interview with more detail and clarification later in the coding process (Hill, 2012).

This researcher was aware that, although there are striking similarities in the adjustment to IBD across individual patient experiences, each story is unique. In keeping detailed records of interviews, this researcher managed her individual biases more effectively, and was able to revisit personal reactions to the content in the interviews (Hill, 2012, Charmaz & McMullen, 2011).

Purposive Sampling

Unlike their quantitative research counterpart, qualitative research does not advocate for the recruitment of large sample sizes (Hill, 2012). Having too large of a sample size can take away from the meaning of each individual experience, which is a main tenet of qualitative research (Bowen, 2008). Hill (2012) suggests that the quantitative research may not be able to capture the detailed nuances of each participants' story, whereby, limiting the content, and context gained in interviews. CQR studies have included sample sizes varying from 3-97 participants (Hill, 2012). This study examined thematic domains and core ideas across participants, and it was important to have a large enough sample size for the purpose of cross analysis (Hill, 2012). Cross analysis examines the extent to which identified domains and themes are consistent amongst all participants (Hill, 2012). The established sample size for this study was originally set at eight participants. However, interviewing more participants became difficult when this researcher experienced personal, medical issues related to her own IBD disease management. This researcher was time-limited in data collection per the IRB approved protocol (recruiting at The Centers for Gastroenterology) as well, as her program-required clinical internship was about to begin in Pennsylvania. This researcher sought the advice of her dissertation committee on this matter. After an assessment of the sociodemographic diversity of participants and the amount of data obtained at that point, the committee unanimously agreed that 6 participants would suffice for the purpose of this study.

Participant Selection

Participants were recruited from The Centers for Gastroenterology of Northern Colorado, a clinic that treats patients in Wyoming and Colorado. The various locations treat patients with GI disorders including issues with: colon, esophagus, pancreas, intestines, liver, and stomach. Participants were asked a series of demographic and disease-related questions to determine whether or not they meet the inclusion criteria for the study. The inclusion criteria for the study required that participants were over the age of 18 years of age, and were able to conduct the interview in English. The participants needed to verify a formal diagnosis of IBD that was received from a gastrointestinal specialist. The participants then identified whether or not they had received their diagnosis at least one year prior to the interview. All six participants identify as White, Non-Hispanic in ethnicity. The participants' ages ranged from 26-67 years old. The participants included four individuals who identified as females, and two who identified as males.

Participants were asked to describe themselves from a sociodemographic standpoint initially, identifying their age, sex, date of birth, occupation, level of education, and current living circumstances (Appendix B). They were then asked to fill out a series of self-report questionnaires.

Data Collection

Each participant was read the IRB approved consent form upon arriving to the interview. Participants were reminded that because their involvement in the study was a voluntary act, they were free to desist with the interview at any time they wished, and were in no way beholden to

Table 1.
Demographic Information of Participants

Participant Pseudo-Name	Age	Job Title	Diagnosis	Duration of Illness	Marital Status	Self-Classification of illness
Susan (F)	67	Retired (IT work)	Ulcerative colitis	2 years	Married	Moderate
Kelly (F)	38	Teacher	Ulcerative colitis	5 years	Married	Moderate
Joann (F)	26	PhD Student	Crohn's disease	1.5 years	Single	Moderate
John (M)	44	Homemaker	Ulcerative colitis	5 years	Common Law Marriage	Severe
Mary (F)	26	College Admissions Counselor	Ulcerative colitis	3 years	Engaged	Moderate
Bob (M)	57	PhD Student	Crohn's disease	35 years	Single	Moderate

finish the session with the researcher should they choose not to. Participants were assured that the preservation of their rights to anonymity within the context of this study were paramount, and that all files and documentation associated with the interview would remain confidential. In order to further protect against a potential threat to anonymity, participants were asked that they *did not* identify themselves by name on the recording; this researcher also refrained from using their name throughout the interview. The participants began by answering questions of a self-report demographic survey (Appendix B).

Interview. As the primary researcher, I interviewed six participants who have been given a formal diagnosis of IBD. The interviews were in-person, semi-structured, and ranged from approximately 60-75 minutes (Interview Outline in Appendix D). Each interview was audiotaped on a recording device and was then transcribed in Microsoft Word by the research team RAs. The transcripts included the entirety of the interview, using verbatim language. The audio recordings and transcripts were kept in a file on a locked computer and will be destroyed appropriately to retain confidentiality after the conclusion of the project. The interviews occurred in a private area of the researcher's workplace (either at the Psychological Services Center or the Centers for Gastroenterology).

This researcher conducted the interview with predominantly open-ended questions, facilitating a deeper, personal connection to the interviewee's journey with IBD. This approach allowed the participants to describe the entirety of their disease experience, and did not constrain the data with *a priori* hypotheses (Bazeley, 2009). Questions were constructed in order to capture the varying experiences in transition to a diagnosis of IBD. Participants were asked to provide a detailed account of the implications that their diagnosis has had on their personal self-esteem, interpersonal relationships, and overall impairment experienced in a personal and professional context. The interviewees were encouraged to provide an honest, open account of the intimate struggles that they have experienced as part of this illness, providing a narrative that came from their experiences, pain, and coping. This researcher is aware that these participants were exposing vulnerable details about their physical and psychological experiences, and as such, they were treated with the utmost respect and compassion throughout their interview. Participants were given the opportunity at the end of the interview to provide any additional information, not yet addressed in the interview questions, which they found personally relevant to their experience.

This researcher also noted behavioral observations that participants exhibited during the interview, including a visual analysis of the state of physical health, potential emotive body language or various facial expressions during the context of the interview, or any other comments/events that may be of note during the time spent with the participant.

Measures

After demographic information was collected, the participants were asked to retrospectively complete the Beck Depression Inventory-II (BDI-II), the Beck Anxiety Inventory (BAI), and the Symptom Checklist-90 (SCL-90). The purpose of the first set of questionnaires was to further understand the patient experience when symptoms were perceived to be at their most severe. When the interview portion of the meeting concluded, the participants were asked to fill out the BDI-II and the BAI once more. They were instructed to fill out the questionnaires based on their symptom levels as presenting within the last 2 weeks prior to the interview. The participants then completed the Post-Traumatic Growth Inventory (PTGI), to compare quantitative data to the qualitative data provided by the participants during the interview. The comparison of the data was to see how closely the themes we measured in our qualitative data aligned with the participants' quantitative responses of growth areas. We identified differences in PTG within the IBD participant population that were not captured by the PTGI.

The Beck Depression Inventory (BDI-II). The BDI-II is a 21-item, multiple choice self-report measure to assess depression in adolescents and adults (Beck, Steer & Carbin, 1988). This scale collects information regarding the participant's state of hopelessness, irritability, feelings of cognitions of guilt, as well as some of the physiological side effects of depression (fatigue, weight fluctuation, or decreased libido). Research suggests that this questionnaire is an accurate and reliable measure of symptoms of depression, but it is not disease specific to either Crohn's disease or ulcerative colitis (Wang & Gorenstein, 2013). Wang and colleagues (2013) conducted a comprehensive review on the psychometric properties of the BDI-II, and their results found an internal consistency of 0.9, and a test-retest reliability between .73 and .96.

The Beck Anxiety Inventory (BAI). The BAI is a 21-item, multiple choice self-report measure to assess anxiety in adolescents and adults (Beck, Epstein, Brown, & Steer, 1988). This scale focuses on the emotional, physiological, and cognitive symptoms of anxiety, and has been widely used in psychological research since its inception (Beck et al., 1988). Research suggests that this questionnaire is an accurate and reliable measure of symptoms of anxiety, but it is also not disease specific to either Crohn's disease or ulcerative colitis. Beck and colleagues (1988) examined the psychometric properties of the BAI, which yielded an internal consistency of .92, and a test-retest reliability of .76 (Beck et al., 1988). Brenes (2007) used the BAI to assess anxiety of patients in a primary care setting, with an internal consistency of 0.93.

The Symptom Checklist-90-R (SCL-90-R). The SCL-90-R is a 90 item, multiple choice, self-report measure that is used to assess various domains of psychopathology. The SCL-90-R has primary dimensions, including assessing for: somatization, obsessive-compulsive disorder, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism. (Derogatis & Savitz, 1999). The internal consistency coefficient rating ranged from 0.90 for Depression (Derogatis, Meyer & Kourlesis, 1985). For the purpose of this study, the information gleaned from the SCL-90-R was used to supplement the qualitative data in addressing additional emotional/psychological categories that might have been missed by the BDI and BAI. We compared similarities in response patterns as further evidence that our qualitative, cross-analysis was reliable. This researcher used specific item endorsements on the SCL-90-R (a score of 3-4) to further supplement the qualitative information obtained during this study.

The Post-traumatic Growth Inventory (PTGI). The PTGI is a 21-item scale that is used for the purposes of assessing positive outcomes of individuals who have experienced some sort of trauma (Tedeschi & Calhoun, 1996). The scale assesses positive changes in five areas: 1) relating to, 2) new Possibilities, 3) personal Strength, 4) spiritual change, and 5) appreciation of life (Tedeschi & Calhoun, 1996). More recently, a confirmatory factor analysis on the PTGI suggested the scale captures three, more generalized inter-correlated PTG factors, which include 1) changes in perception of self, 2) changes in interpersonal relationships, and 3) changes in philosophy of life (Taku, Cann, Calhoun & Tedeschi, 2008). While initial psychometric testing showed that the PTGI has good reliability, qualitative research suggests that it may not capture all forms of post-traumatic growth (Cámara, Gander, Begré, & von Känel, 2011; Shakespeare-Finch, Martinek,, Tedeschi, & Calhoun, 2013)

DATA ANALYSIS

Consensual Qualitative Research (CQR) Analysis

After carefully analyzing the data and reviewing the transcripts, the research team felt as though they had thoroughly studied the content of the interviews, and were able to arrive at a consensus while identifying larger, thematic domains in the data. The research team was also able to identify subcategories within those larger domains that provided more detailed, personalized information about how participants were handling their experience with disease adjustment. This study utilized CQR when coding interviews (Charmaz & McMullen, 2011; Hill, 2012; Stiles, 1997). CQR included more tangible, methodological steps for the researcher to follow than other qualitative methods (Hill, 2012). Using this form of methodology increased the rigor of the study by including more specific steps, allowing researchers more insight into the process of coding (Hill, 2012). CQR also provided more detail regarding how the researcher of the study constructed their findings (Hill, 2012). This is beneficial, as fellow researchers may seek to replicate this study in the future, or formulate a similar study design (Hill, 2012).

According to Hill (2012), CQR utilizes an inductive approach to coding, whereby, we followed ‘bottom up’ method of analyzing the data. This ‘bottom up’ approach allowed this researcher to initially examine the data without creating theoretical constructs that might have narrowed the scope of the research in a negative way (Charmaz & McMullen, 2011). The methodology suggested using open-ended questions during the interviews, as well as selecting a small sample size (Hill, 2012). This type of analysis allowed the interviewee to attach meaning to their words, providing them with the freedom to be as descriptive and emotional as possible (Hill, 2012). The research team then became immersed in the data, so that these words, and their meanings, were upheld within the context in which they were spoken. It is crucial in qualitative research to avoid misrepresenting the words of the participants, which can occur for a number of reasons, including something as simple as recording and translating difficulties (Hill, 2012). In order to avoid this potential problem, each member of our research team listened to all audio files of the interview, while also reading a copy of the transcribed document (each RA was sent the audio file of the interview, with the accompanied transcription when it had been completed) (Hill, 2012). This research team followed the above steps of CQR analysis, and provided alternative viewpoints from that of the researcher. The research team endured of accountability, in that the process of reaching a consensus helped facilitate a more objective interpretation of the data. The use of peer debriefing and communicating was highly important during the course of this research, which is consistent with the expectations of CQR (Hill, 2012). It was vital that the research team respected the input of their peers, and worked together to generate the coding system used for this study. The cohesion of the research team allowed for extensive, in-depth conversations about the data, which served as a strong benefit in completing the study.

Stages of Analysis

Training. This researcher recruited 3 undergraduate RAs for the purpose of this study, in order to obtain multiple perspectives when analyzing data. All three RAs attended two, four hour training sessions taught by this researcher, and also completed IRB trainings in the ethics of research with human participants through Colorado State University. The RAs were introduced to the theoretical framework of Narrative Theory, Ethnographic Theory, and Phenomenological Theory for the purpose of this study (Hill, 2012). The RAs gained information about how these theories contributed to qualitative research models, as well as why they were relevant for our study. We discussed the importance of narrative theory in the context of having the participants tell their own stories and experiences with their disease adjustment, and how this provided richer data that helped elucidate each participant's unique challenges with IBD. We also discussed the importance of approaching this study using ethnographic theory, as this would allow us to examine the extent to which an individual's cultural experiences influence the how the participant perceives their illness (varying cultures may have very different experiences in their management of IBD). During training, we also talked about the importance of phenomenological theory, so that we could better understand how generalizable the study outcomes are, and if there are consistent trends across the appropriate sampled population. The RAs were also given information about conceptualizing the study utilizing the Reconceptualization of Uncertainty in Illness Theory, the biopsychosocial model, and the Transtheoretical Model of Change.

This researcher instructed the RAs in how to code using the methods of CQR (in Microsoft Word), the necessity of comparing thematic findings, the importance of participant respect and anonymity, as well as some basic education about IBD (and this researcher suggested they conduct independent research to further familiarize themselves with this illness). The research team agreed to note pauses and sighs in transcription during the audio file, as well as noting filler words such as, 'Uh' and 'Umm.' We agreed that hyphens were appropriate for natural pauses in the participants' dialogue, we bracketed the subject in several quotations if it was taken out of context, and we used ellipses if the participant's voice trailed off. For training purposes, the RAs were given the transcripts obtained from the participants during the pilot study. These RAs were not told what previous domains and sub-categories this researcher found in her pilot study. The goal was to allow the RAs to identify their own findings, without influence from data collected previously. These training exercises allowed the RAs to become familiar with the structure of the interview they would later transcribe and analyze, the content about the disease experience, and how to identify major domains and subcategories within the text. We also discussed the importance of them writing memos and reactions to the interviews as they transcribed the data.

Meetings. The members of the research team were given one month to complete their transcription of the audio file, in which they were also trained in how to handle the data so as to protect the anonymity of the participants, such as using 'I' for interviewer and 'P' for participant when transcribing (Hill, 2012). Each RA was given two interviews that they were personally responsible for transcribing. The RAs and this researcher were able to compare the audio content of each interview to the information that was written down on the document. This allowed the research team to review the content of the interviews for accuracy. The RAs were given 6 months to listen to the audio tapes, compare it to the transcribed document, and code the transcripts for future comparison with the whole team.

After this researcher moved to Pennsylvania during the course of this data analysis, meetings were held using Google Chat, which allowed the team to connect through a video conference on our laptop computers. Meetings were held on July 1st, September 2nd, and November 4th (first Saturdays of the respective month). Each meeting was scheduled at 1:00 p.m. Eastern Standard Time (EST), and were approximately 2-3 hours in length (worked around vacation and work). The RAs were asked to use line-by-line analysis in their coding process, specifically noting larger trends, and the sub-categories within those domains. Prior to each meeting, all team members were asked to construct their own list of large domains and subcategories within the transcripts. Team members each distributed their coding list (via email) one week before the meeting to compare and look for any major similarities or differences in coding and interpretation. During meetings, we were also able to process the emotional aspect of reading these transcripts, as they do delve into incredibly intimate, graphic detail about what their disease experience has been like. Research assistants were encouraged to ask as many personal questions to this researcher as possible that they felt might help elucidate their understanding of disease adjustment and overall illness experience.

During the second meeting on Google Chat, the research team discussed the need to potentially add an additional component to the model. While the team originally identified how vital illness perception was in coping with disease adjustment, the first model did not include a stage simply based on these perceptions. The team felt as though there needed to be an additional step in the model between the stages of 'grief/loss' and 'identity reconstruction.' The team identified themes within the transcripts that differentiated the process of disease perception from the action of identity reconstruction. The team discussed the fact that in order for participants to reach the stage of identity reconstruction, it was essential to understand their attitudes and beliefs about numerous disease-related issues/experiences. The research team knew about the important of disease perception based on the theoretical framework of the study, and decided that there was a difference in the cognitive/emotional processing of the disorder, as compared to the more action-oriented components of identity reconstruction. The research team was unanimous in this decision. The content was discussed, and a mutual agreement was reached that understanding positive and negative perceptions of IBD was a vital piece in determining how an individual would integrate necessary lifestyle changes for long-term disease management.

FINDINGS

Based on the data obtained from this study, a model of IBDPTG was constructed. This model can be used to conceptualize the disease experience for individuals with IBD, helping patients and medical professionals understand the disease transition from a much more intimate perspective. The original model proposed by this study identified three, primary stages of disease transition: grief/loss, identity reconstruction, and post-traumatic growth. After data collection and analysis, the model expanded to include four, primary stages of disease transition: <u>Grief/loss</u>, <u>Perception effect</u>, <u>Identity reconstruction</u>, and <u>Post-traumatic Growth</u> (Table 2). Individuals expressed a loss of multiple identities within the context of their disease experience, including their personal identity, physical identity, occupational identity, and social identity. The perception effect included the way in which the patients psychosocially reacted to their symptoms and diagnosis. The perception effect captured factors related to participants' internalization of IBD, which included themes related to depression, anxiety, personal and social stigma, conceptions of overall health, and social support. Identity reconstruction included integrating disease management at a biopsychosocial level, highlighting the fact that the chronic illness experience is comprised of significant psychosocial concerns that cannot simply be understood using the traditional biomedical model. Post-traumatic growth was identified as the last phase of the proposed model, including positive self-growth, positive social growth, as well as growth in their perceived ability to manage their symptoms and potential flares in the future.

Grief/Identity Loss

Personal Identity. All six participants stated that their illness onset created a tremendous sense of loss, in that they lamented the abilities/experiences they used to have before

Table 2.
Common Themes and Subthemes in Participants' Experiences of IBD Disease Adjustment

Themes/Subthemes	**# of Participants**
Diagnosis	
Grief/Identity Loss	*6*
Personal Identity	6
Physical Identity	6
Sex and Intimacy	5
Occupational Identity	6
Social Identity	5
Perception Effect: Psychological and Socioemotional Reactions	6
Depression	6
Isolation	6
Pain	6
Burden	6
Useless/No purpose	5
Anxiety	*6*
Uncertainty	6
Fear	6
Avoidance	6
Stigma	*6*
Societal Norms/Symptoms	*6*
Invisible vs. Visible Illness	5
Body Image	4
Health	6
Definition of 'Healthy'	6
Diet Restrictions	6
Additional Disease-related Complications	6
Medication	6
Philosophy of Treatment Approaches	6
Side Effects	6
Cost	6
Social Support	6
Family and friends	6
Support Group/Others with IBD	5
Relationships with Medical Personnel	6
Identity Reconstruction	6
Biological	6
Symptom Stability	*6*
Physical Awareness	6
Psychological	6
Acceptance is not Defeat	5
Increased Self-Worth	4
Social	6
Planning for Social Events/Travel	6
Boundary Setting	5
Post-Traumatic Growth	5
Positive Self-Growth	*5*
Strength/Resilience	5

Gratitude for Present Self	5
Knowledge about Health and Wellness	5
Positive Social Growth	*5*
Compassion for Others	*6*
Value of Quality Relationships	*6*
Asking for Help	*6*
Positive Disease Perception	*5*
Reduced Anxiety about Uncontrollable Symptoms	5
Seeking Resources/Research	6
Turning Pain into Purpose	5

they began having symptoms of IBD. This concept of loss also applied to a future that now involved limitations and the need for continuous medical management. As Kelly stated, “I used to be energetic and able to juggle so much more, but during my worst flares, I was just concerned about being able to get to the bathroom. That was a total shift for me.” John also described the extent to which his symptoms disrupted his life and said, **“**I couldn’t—I wasn’t able to be a father, I wasn’t able to be a husband, I wasn’t able to do anything.” Joann also added,

> It absolutely just felt like my life had been turned upside down. You know when you shake a snow globe at first and all the little snowy pieces just fly everywhere? That’s what my life felt like—you know just kind of standing there and all the pieces of your life are flying absolutely everywhere and you’re just like, ‘What the fuck? How did everything just change so quickly?’

Mary expressed that she knew her life had been significantly impacted by her IBD symptoms, but she did not understand the prognosis of the illness before her doctor officially diagnosed her. In reaction to the realization that she would battle her symptoms for the rest of her life, she said, “your *entire* world shifts over the course of *one* sentence that your doctor tells you. It was so overwhelming.” Participants reported that this sudden shift in functioning and health challenged their personal morals and beliefs. Joann discussed her struggle to maintain her lifestyle as a vegetarian, saying, “IBD takes a lot from you, but being vegetarian is a core value for me. It is very difficult to find certain foods that work at times, and some medications come in gelatin capsules that I can’t take. I don’t want to have to compromise something that is so important to me." Due to the severity of the symptoms and pain, we identified that individuals with backgrounds of strong religious beliefs were also greatly tested during their worst flares. As Bob said,

> My diagnosis made me think about my life—especially from the perspective of my religious beliefs—and that I had this idea that things are going to work out. It was something that I felt like God could do something. When it didn't get better, (pause) I really wondered why God wasn't make this better. That was a concern. What's going on and why is it like this, and why is God letting me go through this?

Physical Identity. Due to the nature of IBD symptoms, individuals with IBD experience dramatic changes in physical functioning. All six participants reported experiencing a loss of their physical identities during periods of increased symptom severity. Facing physical limitations and uncertainties were reportedly difficult for our participants to adjust to, particularly if the participant had been relatively healthy prior to the onset of their IBD symptoms. The SCL-90-R also addressed some of the severe, somatic symptoms that participants might have encountered during their worst flare. During their worst flare, all six participants reported 'feeling nauseous or having an upset stomach,' 'having a poor appetite,' 'feeling like something was seriously wrong with their bodies,' 'having sleep that was fitful/disturbed,' and 'feeling low in energy/slowed down.' As Susan stated,

> I (pause), I lost my identity as a healthy person. Somebody who'd taken good care of herself in spite of some serious issues with my hip. I mean, I was someone who played by the rules—they told me to quit smoking to be healthy, so I did. They said cut back your drinking, don't eat this, take these vitamins—all of that—and on and on and on. I did what they said, but it didn't matter. I completely lost my identity as a healthy person.

The participants identified the overwhelming extreme fatigue associated with their IBD symptoms. They identified feeling exhausted because of their experiences with anemia (due to blood loss), nutritional malabsorption, and interrupted sleep patterns based on the need to use the restroom at night, all of which contributed significantly to energy loss. As Kelly said,

> After I was diagnosed, I couldn't do those activities [running, cardio] like I used to be able to, because I was exhausted and could barely move some days. I would get home from work, and I would have to lay down on the couch and rest for the night.

Participants in this study also discussed the impact of potential incontinence, and how this contributed to a loss in physical identity and control. All six participants had experienced a situation (either at home or in public) where they were unable to control their physical IBD symptoms. This loss of physical identity was demoralizing for our participants, as it resulted in involuntary bowel movements at any moment. They reported that having an accidental bowel movement in public was incredibly mortifying, and it further deterred our participants' willingness to leave their homes during a flare, for fear of a repeat incident. As John frustratingly explained,

> I was at my friends, and he asked me to text when I got to his house, but he wasn't answering and I knew I had to go. When I couldn't hold it anymore, I had to go in his yard and shit. I felt so immoral and beyond embarrassed because I didn't have control over my bodily functions. And (pause) literally it almost broke my heart. It was awful.

The physical decline for the participants coping with IBD was not only debilitating, it was potentially life-threatening. John also described the extent to which his body began shutting down when he was unable to control his symptoms. He said,

> My wife smelled death. She didn't tell me that back then, but she tells me that now. She smelled it—and said she thought she was seeing the start of my, 'the start of my end,' is how she put it. I could barely move, all (pause) the only thing I could do was sleep and read. That was all I could do.

Sex and Intimacy. Participants also discussed their loss of sexual identity throughout their adjustment to IBD. Five out of six participants reported problems related to sexual functioning and intimacy in our study. Similarly, on the SCL-90-R, five out of six participants reported a 'loss of sexual interest and pleasure.' These participants reported that their physical symptoms complicated their sexual activity, as the pain in their abdomens were sometimes too sensitive to engage in sexual activity. A loss in sexual pleasure occurred for both female and male participants. As Kelly stated,

> When I was in my worst flare, the last thing I thought about was having sex. My stomach was in so much pain, I was going to the bathroom so much, and I was just exhausted. My husband knew I was really hurting and, luckily, didn't make me feel bad about it. There was just no way my body could handle it.

In addition to the pain, our participants reported that it was sometimes difficult to sleep next to their partners, as IBD increased their nightly bathroom trips. Our participants said that excess bathroom trips at night was, at times, too disruptive to their partner, and that they slept apart so as not to rouse them when they needed to have a bowel movement. Not only is sexual functioning impacted with this illness, but the intimacy of sleeping with one's partner can also be lost depending on the severity of the IBD flare. John described how IBD impacted his relationship with his wife and stated,

> We just pretty much stopped having sex altogether for a while when I was really sick. I (pause) would sleep in a different bedroom so I wouldn't wake her up when I had to go at night. It (pause) created distance, and I was in so much pain, that sex just didn't seem appealing. This was really difficult when I got the sense that my wife was feeling frustrated and rejected, and at a general loss as to how to be with me. And, eventually, I got to this point where I started contemplating, am I still a man? Can I still do things that bring men pleasure? You know, sex, eating…um, even snuggling because I couldn't lay on my side. The second I rolled over onto my side, I'd have to have a bowel movement.

John and Kelly both indicated that the lack of sexual functioning and intimacy also significantly impacted their partners. Participants reported that while they were coping with the change in their sexual relationship/identity, their partners had to re-evaluate the relationship as well. The participants' partners were described as often not knowing how to provide support to them throughout their flares. They reported that there were times when their partners tried to give them support, but were simply unaware of how best to help them. Susan stated,

> Well, I have so much pain, from this and other stuff, that our sex life kind of flagged quite a bit. My husband tries to be supportive, and has said that he is so sorry this is happening to me. I think that is hard for him, not knowing how to be as close to me now. I've noticed that (pause) he pa-pats me, and he hugs me more, and (pause), since I've gotten sick (sniffling), that's very touching, you know? Sometimes, he'll do that—touch me, comfort me—and I'll just cry (begins crying, voice is thick with emotion. Sobs).

The participants in the study described the challenges of living with a long-term partner, but the single participants also discussed how their diagnosis has influenced their want to date romantically. The single participants, Joann and Bob, reported that they face a different set of challenges within the context of their sexual identity than coupled partners do. Participants reported that IBD impacted their body and sexuality in numerous ways, including: weight fluctuations, incontinence, and reduced libido. Those participants without a romantic partner discussed their apprehension in approaching a relationship with the possibility of having to open up about their medical condition. Participants reported experiencing symptoms that made them feel undesirable to a potential partner, or feared that a partner may be deterred from being with them as a result of their illness. As Joann stated,

> This is the least desirable or sexy I have ever felt. I worry about having to tell a boyfriend or partner about my illness, and how he will respond to that. Like, (pause) will he think it's gross or too much to handle? I have always been super self-conscious of my body, and now, um, it is so much harder to find confidence that someone would want to be with me because of this. Sometimes, I feel like men will literally want to run from me if they knew all that is involved in my medical care.

Bob also discussed the difficulty of trying to broach the subject of his condition with someone should he decide he wanted to date, and said, "if I was dating someone, I would have to get to a point where the other person knows about my condition before it goes too far, or before I would know them very long. I'd need to explain that I have this thing, and I gotta' deal with it." He reported that he has, at times, avoided relationships because of his medical condition, but wasn't someone who wanted to pursue dating in general. He stated that he has now structured his life in a way that doesn't really involve romantic partnerships, for both personal and health reasons. Bob did not endorse a loss of sexual satisfaction or pleasure, as he was the participant least interested in having an intimate partner.

Occupational Identity. IBD also impacts an individual's ability to continue working at their job, or, at the very least, it is a significant strain to operate at their pre-diagnosis, performance level. All six participants reported feeling as though they lost (or might lose) their ability to work and provide for themselves/families. On the SCL-90-R, all six participants reported 'feeling blocked in getting things done' when their symptoms were severe. They reported friction at the workplace due to absences taken when they were too ill to come into work, or that their productivity suffered because they were not able to maintain their previous level of activity. Participants discussed that they also feared negative judgment and feedback from co-workers as a result of their need to slow their pace of productivity, as well as missing several days when their symptoms were particularly debilitating. Mary recounted a particularly stressful experience she had with a co-worker when she said,

> There was a guy I worked with—who I won't name because he doesn't deserve to have his name even spoken out loud—who was a total, total complete asshole about everything. And he ended up calling me out because I had to leave meetings a lot to go to the bathroom. I would never make a scene about it, always tried to be quiet. But, he made a comment once in a meeting when I left and said, 'How often does she have to get up to take a shit?' To everyone in the room. There were 15 other people in this meeting. Horrifying. And, I had to take a day off of work because I was so embarrassed.

Additionally, participants feared losing their health insurance as a consequence of job loss, as it would prove nearly impossible to continue to see specialists without financial coverage. Bob was on an academic fellowship at Purdue when his symptoms flared, and stated, "at one point, they were talking about cutting the fellowship, because I was going through these health things for so long. That was stressful for sure." Kelly also discussed the difficulty she had in managing work with her illness, and stated,

> When I was really bad, I could barely manage lesson planning and working as a teacher's assistant. Eventually, I had to take some time off because I just couldn't manage it. I never thought that would happen to me, never thought I wouldn't be able to work because of my health. It's this career I have worked so hard for, and I was too sick to even do it.

John struggled to find work that he could physically tolerate, and this contributed to a substantial amount of financial stress for him and his partner. He said, "I was rarely healthy enough to be able to do any kind of additional job—and when I say do a job, it means that I picked up under the table carpentry jobs when I could. I could only work for two or three hours at a time because of my symptoms. But that is what it has been like to try to make ends meet."

Social Identity. All six participants in this study reported feeling significant changes in their ability to socialize due to unmanageable symptoms. Participants reported that when they were in an IBD flare, they are often unable to attend as many social functions as they did in the past. They reported that it has been far more challenging to maintain an active social life because of their IBD. There is a misconception that individuals with chronic illnesses often do not want to engage in social events any longer, but the participants reported that it is the pain and fear of incontinence that sometimes prevents them from being socially active. Kelly said she "doesn't really have the time or energy to go out as much anymore." She stated that she "can still get together and do things with really close friends, but now it is easier to spend much more time at home when the symptoms are bad." Mary also stated that she was "always incredibly busy with friends or a boyfriend, and just always doing something active" prior to her diagnosis. She stated that she still tries to maintain a healthy social life, but when she reflected on how different her social life is now, she said “I have no clue how I did it before. There is just no way I could be that busy now.”

The participants in this study stated that their IBD flares are unpredictable and untimely. Unfortunately, unpredictable symptoms often resulted in participants needing to cancel plans with friends, or the plans had to be altered to accommodate specific needs for their illness (close to bathrooms, not too physically taxing, restaurants where they can find something to eat). Social isolation became an issue for individuals with IBD, as many people in their social network did not understand what they were going through. They reported that some friends stopped reaching out altogether. As Susan stated,

> I try to think of other people before myself, but, after all this illness, that makes it even harder. Because, (pause) you can’t think of anything but your pain sometimes, it is impossible to think about getting together with friends. And, then you feel bad—like you are letting them down. It is just too bad at times and you need to cancel. You find out the friends who are in it for the ‘long haul,’ and you find out which friends aren’t.

Participants also described the difficulty of hearing healthy friends offer them advice on how to manage their illness. This invalidated the experience of our participants’ problems. As John stated,

> Friends come over and talk—you know—like trying to offer their wisdom, offering their ‘healthy person wisdom’ of what helps their digestion. Yeah, it doesn’t work for any of this, and it feels totally dismissive. And they don’t get that, especially the emotional stuff. They don’t. They (pause) how can they get it? How can they?

Perception Effect: Psychological and Socioemotional Reactions

Depression

Individuals with IBD can become depressed as a result of their symptoms and level of impairment. All six participants reported feeling depressive symptoms during disease onset and severe flares. Four out of the six participants reported ‘feeling blue’ and ‘crying easily’ on the

SCL-90-R during their struggle to cope with their illness. Participants discussed their tendency to internalize their emotions about their illness experience. They described how much they struggled with feelings of isolation and how they endured extremely negative emotions due to the pain they were experiencing. For the participants in this study, it was apparent how much they feared becoming a burden on those around them, as well as feelings of hopelessness in their effort to control their symptoms. John shared, “This is the worst thing you can imagine—it consumes you and drags you down into really dark places emotionally. I would never want it for anyone.”

Isolation. Participants noted how isolated they felt during their experience with IBD, as they often felt as though people would not understand their symptoms. Susan said, “I feel much more isolated, but (sigh) I’m slowly trying to pull myself out of that.” Kelly also expressed isolation that she encountered at work, as she worried about who she should disclose her illness to, she stated,

> This disease can make you feel very alone. I am never sure about who I should share details with about my disease, and I didn’t like having to disclose it to my superiors at work. I felt like they would look at me differently, so I withdrew and just focused on what I had to do.

Bob also felt as though he couldn’t discuss his symptoms with other around him at times, and stated that when he was at his sickest he “wasn't sharing a lot of personal things with people, and there was a little bit of isolation related to that.” Participants also identified that their illness felt more isolating when they had no family nearby to help them. Five out of six participants reported ‘feeling lonely’ on the SCL-90-R throughout their extreme, disease flares.

Pain. All six participants reported that the pain they have experienced from their IBD symptoms is worse than any other medical problems they have had in the past, and that it was psychologically taxing to live in severe, consistent discomfort. Kelly said,

> Sometimes, I just had to curl up in the fetal position because of so much stomach pain. During my worst flares, I can remember that I would be curled up on the bathroom floor because I didn't even have the energy to keep running back and forth from my bed to the bathroom. Some nights, I would just be on the floor crying and crying and praying for the pain to go away.

Susan commented on the effect she believes the IBD-related pain has had on accelerating her aging process, and stated, "I haven't ever really felt bad about how I look, but pain has a way of trashing your face. People can tell when they look at you. You can see this little thing that is a mixture of, 'Oh God, that looks awful for her—and, I am so glad that's not me.'" Joann also discussed the desperation she felt when her symptoms were at their most severe, and how it made her question pain from a faith-based perspective. She reported that her questions about relief are most prominent during bouts of severe pain, and that she has no idea who, or what, could help her. For her, the moments of intense pain particularly made her question who could help her understand what was happening to her. She said the overall diagnosis of IBD didn't result in a loss of personal faith, but that when the pain was so awful, she struggled. She said,

> For me, I especially think about so many questions when I'm in the *most really intense* physical pain. I ask, 'Why aren't You helping, God? Why aren't You intervening? Like, You can stop this, God, You can stop the pain. Or, I would ask why the medications weren't working, or I would ask if this pain was going to last forever. The pain made me feel so unbelievably desperate for help, and it didn't feel like there were any answers for me in the beginning—which made me feel totally helpless and so sad.

Some participants felt as though the pain became more manageable with time, treatment, and increased knowledge about IBD symptoms in general. Bob explained that he felt less upset by his pain once he knew the source of it, and once he knew there might be potential solutions to mitigate it.

> The doctor said there was at least one X-ray that showed the situation, and he said, 'Here's the restriction in your bowel." I could see that it was next to the appendix, and I could see this constriction and it was just this little thing, smaller than this (made small circle with had). Stuff was trying to go through this really

> small opening. And, I thought, 'No wonder it hurts, right?' Having the correct diagnosis helped me to feel as though I wouldn't be at the mercy of the pain forever.

Burden. Despite the fact that our participants reported the physical and psychosocial challenges of dealing with IBD as burdensome to them personally, they also expressed a consistent worry that they would be perceived as a burden to those around them. On the SCL-90-R, four out of six participants reported severe 'feelings of guilt' associated with this illness. As Susan said, "I find myself saying things now that I have never said to my husband like, 'I am really sorry this is happening *to you*.' So yeah, I felt really angry, really scared, and really guilty because of my illness and what that means for him. He didn't ask for this either." Participants also discussed the emotional impact of not being able to contribute to their relationship in the physical and financial ways that they used to, which added to their feelings of guilt. Kelly stated,

> I know my husband would really like me to work full-time to help out financially, but I just can't do it right now. I want to focus on my health so I don't get to the point I did before, where I couldn't control it. I feel bad because I can't contribute more financially, and sometimes, I think my husband gets frustrated with the situation, which then makes me feel even worse that I can't do more.

John also discussed how much he fears he would become a burden to those around him, and stated, "You feel like people don't want to deal with you or hear about your pain." Feeling as though they have burdened others with the increased needs they now required to manage their illness, participants reported trying to figure out how they could manage procedures and appointments on their own. Bob said, "I really didn't want to have to ask for help to get to appointments or procedures if I could make it without, so I wouldn't inconvenience anyone. If I could take a bus and go somewhere, I would just do that." Susan commented on the shift in household responsibilities due to the fact that she was physically incapable at times of getting up to clean, cook, or complete other chores. She commented that her limitations in functioning put more pressure on her husband when she stated,

> Everything with the house pretty much got dumped on my husband when I was really sick. I couldn't really do anything. I was totally useless at the time. Yeah, (sigh) I just couldn't really do anything and I worried he would resent me because he had to do so much. I hated it.

Some participants discussed how they viewed IBD as a massive burden they had to carry. They reported that dealing with this illness was such an overwhelming task to manage, and that it felt even more daunting with the knowledge that they had to endure it for the rest of their lives. Due to the fact that IBD has no known etiology, participants in this study have revisited some of the unhealthy lifestyle choices they made in the past, trying to answer and understand why they now must live with the onus of a chronic illness. When the participants examined their past lifestyle choices, they often grasped at anything that could potentially be explained as a trigger for the manifestation of symptoms. Joann questioned her role in potentially contributing to the development of her illness and stated,

> I struggled with an eating disorder when I was younger, so I sometimes wonder if I did this to myself (pause), you know—gave myself IBD. Was it all the years I spent at war with my body? Was it the restricting and then over-exercising and laxatives and diet pills and binging and purging? I started to blame myself, like what if I broke my body and gave myself this disease…this burden. You know, was it me?

Mary also had thoughts of blame, and was concerned that she did something to herself that contributed to her diagnosis. She said, "on top of anxiety, you feel guilt, because you feel like, "What did I do? How did I let this happen to myself?"

Hopeless/No purpose. Participants also stated how difficult it was for them to maintain hope during the worst stages of their illness. Five of the six participants identified this as a significant struggle they faced throughout adjusting to their 'new normal.' Additionally, five of the six participants reported ‘feeling hopeless about the future’ on the SCL-90-R. Susan stated that, while the state of her physical symptoms existed on a broad spectrum of severity, so, too, did her ability to hope that she could find symptom stability. She said,

> Sometimes it was just, I had so much pain, I felt like I wasn’t myself anymore, and I was so defeated. Like, I just existed without purpose. Other times, um, it was more like, I’m not gonna’ let this mother fucker kill me—because I’m better than that. And it [depression] just went up and down and around and around. My hopelessness just depends on the day, the pain, and the way I am thinking about myself that day.

Similarly, Joann stated that she has experienced feeling as though her energy is now completely divided between trying to manage her medical condition and her life, and that she started to feel a sense of uselessness and hopelessness when her symptoms prevented her from contributing at the same academic level that she was prior to her diagnosis.

> I’m still, you know, dealing with the fatigue and diminished cognitive capacity, and so I spend so much time and effort on the medical piece—including the financial piece, that it feels like I have so little of myself left for my work and my academic pursuits. That’s been really hard, feeling like I am nowhere near as useful as I once was, and feeling like I never will be.

Participants were asked to complete the BDI-II twice for the purpose of this study. Table 3. illustrates the difference in depressive symptoms that the participants reported experiencing while in their worst flare, compared to their psychological wellness at the time of the interview.

Table 3.
Beck Depression Inventory Score Comparison: Worst Flare Versus Present Condition

Participant	**BDI-II Worst Flare**	**BDI-II Present**
Susan	36*	20
Kelly	23	1
Joann	40*	6
John	63*	10
Mary	34*	6
Bob	14	5

*Scores of 30 and above indicate severe depression

Anxiety

All six participants reported high levels of anxiety during the course of their disease adjustment for a number of reasons. Participants identified that they noticed their anxiety was worse when they had greater uncertainty as to the prognosis of their illness and how they would treat it, as well as fear that if their IBD symptoms became worse, they would not be able to cope. Mary said, “I mean, there was huge anxiety. There always is. I mean, I think that's something you deal with whenever something like this happens. That’s just a part of my new normal.”

Uncertainty. The nature of a relapsing-remitting illness is that symptom stability can be difficult to achieve. All six participants noted significant anxiety related to the inability to regulate or predict their symptom presentation. When initially diagnosed, participants reported feeling anxiety about whether or not they would ever experience relief from their symptoms. Susan said, “I went to my personal doctor and I asked, ‘is this gonna go away?’ And she explained that people sometimes improve, but, essentially, that I now had this forever. And, I just remember this distinct thought of ‘Oh my God, I have no idea what to expect and how to deal with this. This is too much.’” Kelly discussed how she also struggled with uncertainty, and stated,

> I have always been a worrier, someone with high anxiety. I will be the one whose mind is just racing at night, thinking about all the things I need to get done during the next few days. But, now I get anxiety about my illness—like, even though I am not in a flare right now, I still, in the back of my mind, am worrying about my symptoms coming back.

Participants also discussed the fact that they were unsure about the efficacy of their medications, and expressed uncertainty in how this would impact their symptoms. Mary said, “The anxiety was massive. I had to start figuring out how to cope with this because you never know what's going to happen. You have literally no control over your symptoms. You have no idea what medicine is going to work." Susan also mentioned the uncertainty she experiences in symptom management, and said,

> I've gone down to taking two pills. I do not want to go back up to three because I know enough about drugs to know they don't work forever. You build up a tolerance, and, if I do, I'll be fucked. There won't be anything I can do about it. How do I know when this will happen?

Joann talked about how she perceived a diagnosis of a relapsing-remitting illness in comparison to other illnesses that are either constant, or potentially fatal. She said,

> So, Crohn's is incurable, which has been devastating to me. In a way, if I think about it, I think maybe I would have even preferred cancer 'cause then, you know you can have chemo or radiation or surgery and then, like, it can be gone, or you don't have the symptoms anymore—or, it's terminal and that's it. But, you know, with IBD it's (pause) never gone. You have it for the rest of your life and can always feel totally, totally blindsided by a flare.

Mary also discussed the complexity of having an incurable disease, and how stressful it was to face the reality that her illness had no cure. She also used cancer as a comparative illness, similar to Joann. Mary said,

> If you don't know what causes something like this, and this has been something that's been diagnosable since the 50s, what the hell are you doing? It just doesn't make sense to me. And so that mental piece of—and I always feel so terrible when I say this--so please don't judge me for saying this—but at least if you are dealing with cancer you got two choices, either you die or you get into remission and you can live your life fairly normally after that. With IBD, there is uncertainty for the rest of your life. But, the way I've always presented it to people who don't understand, I'm like, 'imagine you got a cancer diagnosis that is never going away. Ever. No matter how hard you try to get it fixed it's never going away. Think about that for a minute.'

Fear. All six participants reported feeling a significant amount of fear about the nature of their symptoms, and that they might not be strong enough to endure the symptoms of their illness should they continue to worsen. Joann commented on how jarring it was to see blood in her stool for the first time, and the fear it caused her when she started to think about what the problem might be. She reported,

> As soon as I determined where the blood was coming from [not menstrual], you know—it was (pause)—I was obviously really scared. You know cause you—I didn't really know much about IBD or anything like that. I had no idea why this was happening and what it was. I mean I think as human beings you know that you shouldn't be passing blood through your stool. So, I was really quite scared.

Participants also expressed fear of potentially needing more radical, invasive measures to control their disease. Susan expressed how scared she is that she might need surgery to manage her IBD in the future. She stated,

> It's like, I'm not sure how much strength I have (sigh) left sometimes, to keep going—and then, you know, what am I going to do if I go to the doctor, and he tells me after another colonoscopy that I have to have surgery? I think my husband will just die (begins crying heavily). Oh God. This is just really scary.

Avoidance. Participants reported that they began avoiding a number of outings or appointments, due to the concern that their symptoms would become unmanageable in public. John stated, "I worried that the second I would go to leave the house, I would be running back into the bathroom. Sometimes, I'd be like a block down the road, and I'd have to go back home and use the bathroom." Participants also reported their avoidance of anything that might exacerbate their symptoms, but that this sometimes meant avoiding eating because they did not want to feel any pain. Bob said,

> Eating became really complicated. I would eat and then had to go the bathroom right away. So, those things became associated in my mind, a kind of mental thing, like, 'look, maybe you don't want to eat because you will have to go to the bathroom,' type of thing. So I avoided situations where I might have to eat.

Participants were also given the BAI twice during the course of the study. Table 4. Illustrates the difference between anxiety levels when participants perceived their symptoms to be at their worst, compared to their levels of anxiety at the time of the interview.

Table 4.
Beck Anxiety Inventory Score Comparison: Worst Flare Versus Present Condition

Participant	**BAI Worst Flare**	**BAI Present**
Susan	27	21
Kelly	28	5
Joann	26	6
John	37*	5
Mary	50*	5
Bob	18	5

*Scores over 30 indicate severe anxiety

Stigma.

Every chronic illness includes their own unique, often cruel set of symptoms. Participants stated that the nature of the symptoms associated with IBD made them feel far more vulnerable to judgment because of how difficult it is to talk about bowel-related issues. All six participants reported concerns about how their illness would be received by society and the people around them.

Societal Norms/Symptoms. All six participants discussed their hesitancy to disclose their illness to people in their lives due to society's aversion to talking about digestive issues. Kelly said,

> I definitely think people will judge me if I tell them about my illness. People really don't like to hear about poop—it makes them really uncomfortable, actually. So, you feel differently with this illness, you feel like you should be embarrassed because of what's wrong with you. Even though it is nothing you can control.

Joann also discussed perceived societal judgment because of her symptoms, and the concern about how she would be viewed by people should they become aware of her symptoms. Joann discussed how she viewed sex differences in perceived stigma for the purpose of this study. Joann commented that she feels it is less acceptable for women to have bowel problems in our culture than it is for men. She stated,

> I’m aware of sort of this (pause) cultural stigma around bowel movements. I mean, I’m still so embarrassed sometimes when, you know, I’m just like having machine gun diarrhea in a public toilet and it’s just exploding. Or, if I’ve got really bad gas or something. I think a part of that embarrassment is—'cause, you know, women in our culture never fart or defecate (sarcasm, rolled eyes, laughed). I know, especially for women, there’s, um, this sort of expectation that you don’t have gas, and that your poop smells like roses, and just you know (laughs) all these—all these sorts of things. So, there’s definitely this perception from culture that this disease is gross, and that it makes women even more unappealing.

Bob also talked about how much information he chose to disclose to others about his illness, as he did not want to go into detail about the specifics of his disease. He stated,

> I don't tell many people that I have Crohn’s. And, it's more like if something is not going well, I say I just have indigestion and I gotta’ use the bathroom. Or, I don't want to eat a lot because I have indigestion. You figure out what is socially acceptable to say.

Mary was vehemently against sharing the details of her initial symptoms with anyone, as she reported she was too self-conscious to discuss what was wrong. She said,

> So I looked up blood in the toilet, and the first thing that pops up is hemorrhoids, right? And so, then I thought, ‘Fuck, I am not talking about this to anybody. This is mortifying. I have hemorrhoids, and I'm 22.’ I was not about to talk to anybody about this. Nope. Hell no. And, then they wanted to do a rectal exam—I pretty much sprinted out of the doctor’s office and refused to have it done. It was just too awful to have anyone know, (pause) and I wanted to deny it.

Invisible Versus Visible Illness. All six participants discussed how they believe societal stigma is also related to the invisibility of the disease. They reported that there are pros and cons to having an invisible chronic illness, as it enables them to keep some symptoms private, but that people sometimes then assume they are asymptomatic altogether. Kelly stated,

> Because people can’t see it, they will think you are healthy and fine. I did lose quite a bit of weight when I was in my worst flare, and people started to ask me about it then—or at least commented on the change. But, if I’m having a bad day now, no one knows unless I tell them, which is good and bad. On the really tough days, when you are doing your job, sometimes you wish people could know just how hard it is to function—let alone pretend like nothing is wrong. They would be shocked.

Bob also reported that people noticed his rapid weight loss during symptom onset, but that they didn't communicate their concern to him. He stated, "There were people after I was diagnosed that would tell me I looked thin, and they had noticed it, but that they didn't want to say anything to offend me." Joann also commented on the fact that people sometimes do not understand the need for special accommodations with this illness because they simply cannot see it, and cannot comprehend that someone who looks healthy might have a debilitating illness. She stated,

> When I am so bloated, I think people then perceive me as overweight (pause) when that's not really what is happening—when they just don't know what's going on because they can't see the other symptoms. They don't know why I'm bloating, they don't know why I'm wearing maternity jeans, and I often feel like they judge me when I need to park in handicapped spots. It makes you feel like no one gets it because it isn't a wound wrapped in a bandage.

Body Image/Physical Appearance. Participants indicated that the way in which they conceptualized their body image and appearance also changed while they experienced severe IBD symptoms. They reported feeling a distinct difference in how they viewed themselves, and how discouraging it was at times. Mary said, "I was so embarrassed by my body. And, in retrospect, I realize that I think I felt like if there was something wrong with me like this [UC], that was so gross, he [boyfriend] wouldn't care about me anymore. That's so messed up, but that is really how I felt." John and Susan reported that they have had to wear additional undergarments for protection against incontinence. John reported the negative impact this had on his body image, and said,

> Do I sometimes feel shy or uneasy with my body? Yeah, I mean why would a diaper affect my fucking confidence in life? That's not humiliating at all [said with thick sarcasm.]. This should be asked to people who aren't sick. How would you feel if you had to wear a diaper?

Joann also discussed that changes in her body impacted what clothes she could wear, which devastated her sense of self-confidence and how she viewed her body. She said,

> Sometimes, I have bloating so bad and that is when I have to wear maternity jeans. There is nothing sexy about gas and bloating and wearing maternity jeans. I'm aware of that, and it makes me feel betrayed by my body. It makes me feel like I am so unattractive and undesirable.

Susan discussed the concept of bargaining, and the fact that she would gladly experience other changes in her physical appearance if it meant she would be relieved of her IBD symptoms. For her, the concept of body image changed due to her experience with UC, and she now was much less concerned with how much she weighed, or how thin she was. She expressed, "If I could stop all this pain, and all this sickness, I would. I would even put back on ten or twenty or even *thirty* pounds just to make it stop. But that's just one of those trading with the devil things." For Kelly, however, body image was correlated with her athleticism and ability to engage in fitness-related activities. She reported that having IBD prevented her from working out, which altered her physical appearance.

> My body had always been athletic. I was a runner and have always been into fitness. When I couldn't work out (pause, sigh), it was so crushing for me. I got very thin and lost a ton of muscle because I just wasn't absorbing anything. I felt so weak at that time, which made me so angry with my body.

However, in contrast to the other participants, Bob stated that the impact of IBD on his body image was actually minimal. He stated that he was never overly concerned with how he looked, and that he didn't feel as though the disease made him any less physically attractive. He said, "I never considered myself to be a really good-looking person, or a ladies' man—or anything like that. So, body image was more like 'this is just how I am.' So, it didn't really change a whole lot of that for me."

Health

All six participants reported significant changes in their overall health as a result of IBD. They stated that it was very challenging to be confronted with physical and emotional limitations, when they had never experienced this as a 'healthy' person. Our participants identified that managing their overall health now meant dietary restrictions, change in physical activity, or dealing with additional medical concerns.

Diet Restrictions. Participants reported that the number of dietary restrictions that they now had to deal with was one of the most frustrating changes they experienced in disease adjustment. All six participants voiced the challenge of navigating a diet that was appropriate for IBD, which has resulted in significant restrictions as a result of their disease management. Mary stated, "I didn't ever think about my diet before. It was mainly about what was convenient. But, I feel like all I think about now is—what is my daily nutrient intake looking like, how am I getting all the stuff I need in?" The participants were encouraged by physicians to eat a more 'low residue diet,' as their digestive system was often unable to break down foods that were high in fiber. However, participants reported that this made eating fruits and vegetables incredibly difficult, which was a large proportion of the participants' diets prior to diagnosis. Kelly stated,

> I cannot tell you how much I love salads, and how much I have to resist the urge to eat them all the time. It is so unfair. But, I know, anytime I have a salad, it's not going to be a good outcome for my stomach—it's usually miserable.

Joann, a vegetarian, discussed the inability for her body to break down foods that were once her primary source of sustenance. She also addressed that giving up alcohol was difficult for her to do. She said,

> I still love apples, so I try to peel the apples now. This is because the skins are harder to break down, but I have lost so many foods I used to have all the time—lettuce, grapes, other fruits and vegetables. But, probably the most difficult thing, is that one of the medications I'm on reacts really strongly to alcohol. So, you are supposed to stop drinking altogether. I was never a big drinker before, but I miss just being able to have, like (pause) a glass of wine or a margarita. I still remember my last day of drinking was on a Thanksgiving holiday (laughs), which I needed because I had to deal with my family (laughs louder), and then I started taking that medication the next day.

Susan also said, “Oh, how I miss my beer so much. Just being able to come home at the end of the day (sigh), and have the option of drinking one would be so amazing. Just a nice, cold Corona while I put my feet up and kick back in the recliner. I cheat sometimes, because I just have to. Asking me to never drink again is fucking ridiculous. Not gonna’ happen.” For John, the dietary shift hit him extremely hard emotionally, and he said, “I no longer can eat the foods that used to bring me happiness. It really is the worst. And everyone else in my house can keep eating whatever they want, but I have to sit there and make a separate meal for myself.” Bob also discussed certain foods that he now has to avoid. He said,

> Roughage bothered me, so I had to go with softer foods. I had to go with more like drinking tea and bread, or something else soft and easy to digest. I got rid of milk products in general because they tended to cause trouble. But, sometimes I was only allowed to have liquids when my flare was really bad, which meant so much soup broth for me.

Additional Disease-related Complications. It is not uncommon for individuals with IBD to experience a series of other medical concerns after they have been diagnosed. All six participants in this study discussed the medical complications of having a compromised immune system, reactions to various medications, or extra-intestinal manifestations (i.e., other organs are impacted by the level of inflammation in the body with IBD, or malabsorption of nutrients affecting other body systems). Kelly stated that she noticed her immune system had definitely been impacted by her struggle with IBD. Not only did her immune system become more vulnerable to various contagions, it also impacted her body’s ability to recover when she did become ill. She said,

> I get sick with colds or the flu way more than I used to with UC. I mean, I know I work around kids and that doesn’t help, but I notice that it seems like I will get another cold right after I just got over the first one, or the colds will last a really long time—like a month.

John also commented that he is more susceptible to contracting viruses after his diagnosis, and also indicated that when he experienced periods of high stress, this only seemed to weaken his ability to fight off disease. John said, “I’m having a problem with my immune system—it is tough to fight off colds, but stress just makes me get sick so much faster. My immune system just gets hit so hard.” Men can experience complications related to erectile dysfunction or bladder control due to the severe inflammation in their intestines. Bob discussed how his IBD symptoms posed a deleterious threat to his bladder functioning. He reported that it was difficult for him to parse out his symptoms, as he was not sure whether or not he should attribute these problems to a side effect of CD, and stated,

> I started to have blood in my urine, and my concern was possible fissures, and thinking they could be connecting to other things in there, internally. And you're going, okay, ‘what if it's connecting to the wrong tube and dumping into the wrong place?’ So that was part of the concern. I'm being tested for this, but it could be related to my Crohn’s. So that was part of my thinking—what other problems do I have because of something related to Crohn’s.

Medication

All six of the participants discussed how their experience with various types of oral, rectal, or intravenous medications impacted their disease transition. They reported how much they struggled with side effects from the medication. Participants also provided insight into alternative methods they used to treat their IBD. Alternative methods of treating IBD were sought out by our participants when their prescribed medications did not suffice for symptom management, when the cost and accessibility of the prescribed medications became unrealistic, and when they began experiencing serious side effects from their medications.

Philosophy of Treatment Approaches. All six participants in this study shared varying views on the best way to approach the management of their symptoms, and how important it was for them to think about long-term care. The participants had different experiences with their attitudes towards the efficacy of the medication they were prescribed. For some participants, this was their first experience with prescribed medications that did not decrease symptom severity, which was a difficult cognitive shift based on their knowledge and experience with Western medicine. Susan said,

> When the new medicine came and I started taking three a day, it worked quickly. However, you never quite trust it. Ever. And you're always on guard—like I have, in my purse, all kinds of stuff in case I need it to manage symptoms because I never know when the other medication may stop working.

Joann also echoed this same sentiment when she opened up about her struggle in finding effective medications to control her symptoms. She said,

> I knew this [diagnosis] meant I was gonna have to take the medication for the rest of my life. The pain was pretty bad, and the symptoms were pretty bad, but I thought, if I could just take a, you know, a few pills a day for the rest of my life, and not live in that pain, that'd be okay. It's just—well, the medicine stopped working. So, I briefly went into remission, and then I was right back to where I started, or at least that's how it felt.

Due to the difficulty of finding 'traditional' medical treatment that was effective in symptom management, participants shared their exploration into alternative methods of disease control. For example, three of the six participants reported that medical marijuana was, in numerous ways, more effective at managing symptoms than previously prescribed medications. John stated that, "Marijuana completely saved me. When nothing else worked, and I was about to give up, I tried marijuana. It was amazing—the effect was so instant in helping the pain and inflammation. And, I could actually sleep!" John reported that he did not have health insurance due to the fact that it was difficult for him to work traditional hours, and that he had not regained enough strength after his most recent flare to engage in manually laborious tasks. Medical marijuana was the most accessible form of treatment for John, and he also relied on collecting samples of medication from the Centers for Gastroenterology when he felt he needed it. Kelly reported that she also received significant symptom reduction with the use of medical marijuana, which resulted in her taking a different approach to her care altogether. She said,

> I have really drifted to trying to manage my symptoms from a more holistic place. Part of that is cost of medicine, and part of that is that I really believe more natural treatments won't have as many side effects or potential complications like prescription drugs can. I put CBD oil in my water every day and my symptoms are more stable than they were on other medications. I feel so lucky to live in a place where I can access that [Colorado].

Side Effects. All six participants reported having significant negative side effects from medications they were prescribed throughout their disease adjustment. Prednisone was identified as one of the medications with the greatest, adverse side effects (all participants were prescribed Prednisone either during the onset of symptoms, or during the re-emergence of a flare). John stated, "I have been on and off prednisone with my UC, which is such a pain. I get cranky and moody on prednisone and it is hard for me to sleep. I will also use the Canasa suppositories if I am starting to see more blood in my stool. Never thought I would have to give myself those, but you'd do anything at times to make it better." Joann also discussed how difficult it has been for her to be on Prednisone for long periods of time. Prednisone contributed to a 50 pound weight gain for Joann, and she was recently told she was 'pre-diabetic.' She said,

> Steroids…oh boy, they're really a double-edged sword (pause) as I've now learned. I think they are so helpful—they've been so helpful for me [with symptom management], but I've had a lot of nasty side effects, and so, I get weight gain, major sleep disturbances, very vivid—very, very vivid dreams, sometimes I get night sweats so bad that I wake up and I've like soaked my pajamas—like soaked through. I have increased urination, so having to get up multiple times in the middle of the night to go to the bathroom also then contributes to the unrestful sleep…just a host of super unpleasant reactions.

Bob also discussed the impact of being on Prednisone. Bob was diagnosed with CD approximately 35 years ago, at a time when the medical field did not have some of the more advanced, specialized medications for symptom control. He stated that he wasn't aware of the negative, long-term side effects when he began taking the steroid.

> So the doctor said it was Crohn's disease, and he said, "We'll put you right on prednisone. It'll make you feel better." And in a couple days I'm eating all kinds of stuff because the inflammation goes down, which I thought was great at the time. But, Prednisone was the miracle drug with the long-term side-effects that they didn't really tell me about. I really believe my teeth are the way they are [damaged, stained] partially because of that. I was also really bloated. So, a lot of the weight was bloating from the medication. I also had the acne thing that you get—the pimples. Especially my back, it was covered with pimples pretty much all over.

John also stated that Prednisone was one of the first medications he was given in order to manage his IBD. He described his experience with the medication very similarly (almost verbatim) to Joann. John stated,

> I had tried a half dozen different types of pills, and um, and Prednisone was the only one that worked. But the problem, apparently, is Prednisone is a double-edged sword, and the other side of the blade is a lot sharper, you know, and when I started to see my doctor, she was just really adamant in making sure she didn't want me to be on Prednisone. She's just like (pause), she was very adamant in that.

Cost. We previously addressed the participants' feelings of loss in occupational identity as a result of being diagnosed with IBD. All six participants reported the effect that IBD has had on their earning potential, and the impact that it has had on their ability to access certain medications for disease management. Just as participants reported knowing little about IBD prior to diagnosis, they also reported how unprepared they were to hear the cost of disease management. John stated, "paying for medication was like paying a whole other rent." Susan detailed her experience when she said,

> And I said, it's never gonna go away, is it? And he [doctor] said, he just, you know how people don't answer, they just look at you—and, I said, what the hell are we gonna do? He said, well, you can take this budesonide, but it's a thousand dollars a month. I was in his office, and I just became hysterical. He said, 'there's nothing we can really do for you except this very expensive drug, so I'm

> giving you the website that we use from Canada. Some of our patients find that they can afford the medication that way, would you be open to that?' And I said, 'hell yes.' So, he gave me the names, and I've been getting those.

Kelly also talked about how difficult it has been for her to manage financial stress while trying to adhere to an appropriate treatment plan. She said,

> For me and my husband, finances are a huge source of stress. We aren't really saving much at the end of the month and we can sometimes only just squeak by to pay our bills with what we make now. The medications to treat this are so expensive. I get so much anxiety about whether or not I will need surgery at some point, and if that is something we could even afford to do. It kind of freaks me out if I really let myself think about it.

John also stated that, "it was like paying another rent to buy my medications." Bob has actually had a bowel resection surgery, and reported the difficulties in managing that financially. He said,

> But I do remember when I was having the surgeries done for the resection, the cost of that was some concern. When I finally went and had the resection done, I think I was mostly covered by insurance, but I had some things that were done out of—what do you call it? Out of area? Out of network? Yeah, that's it. Because I was out of network, there was at least one bill that never seemed to get covered that I thought should have been—and I didn't want to pay it directly. At the time, it was only a couple hundred dollars, but still, it seemed like a lot to me. And, it took me months to pay that off.

Social Support. All six participants reported that their disease adjustment was significantly impacted by the amount of social support they had around them. They reported that their illness sometimes precludes them from engaging in social activities, or having a high amount of energy during said activities. Participants stated that IBD is very difficult for people to understand, and that they often feel as though their symptoms are minimized by those that are supposed to be an essential part of their support network.

Family and Friends

All six participants reported that their relationships with family and friends changed as a result of their diagnosis of IBD. Five out of six participants endorsed “feeling other people do not understand you or are unsympathetic” on the SCL-90-R. All six participants reported feeling “self-conscious with others” on the SCL-90-R. Susan discussed her challenges in maintaining friendships, and stated, “I was really slowing down and that bothered me *a lot.* My friends were out walking, exercising, and I was beginning to get this *really strong* feeling of being left out.” Kelly also mentioned the growing distance she felt between her and her friends after her diagnosis. She stated,

> I have become so much more of an introvert since I was diagnosed. It takes a lot of energy to go out and do things now—definitely way more than it used to. Sometimes, it is just too much to go out with friends and try to have fun, if you don’t feel well, you don’t really have a good time anyway. Everyone just hates when you have to cancel or change plans. Friends can pull away very quickly when you start to have to deal with a chronic illness. They don’t get how much is involved.

Joann also stated how hurtful it has been for her when the people considered part of her support system have invalidated her experience and pain. She stated,

> You struggle sometimes with people—even family and friends—not believing how severe your pain is, or trying to tell you what your pain is like. And, it’s like ‘no, this is happening to my body and not yours.’ I’ve also felt judged the most by my sister, because when she first found out I had IBD, she said like ‘well at least now you’ll always be skinny.’ And, I remember (pause), I remember at the time, you know, I felt like I had just been completely annihilated by this diagnosis and I thought, ‘What the fuck?’ No one would choose this disease in order to be skinny. It was just so far off the mark of what I needed to hear in that moment.

John identified some of the positive changes that he has received from people in his social network, and how much this has helped him perceive his disease as manageable. He stated,

> I’m perceived as someone who’s sick, which means that um, well, now what I’ve also learned is that within my community, it means that I get extra support sometimes, and I get extra compassion.

Relationships with Medical Personnel. One of the most troubling findings as a result of this study, was how many negative experiences the participants reported having with physicians, specialists, and other medical personnel throughout their adjustment to IBD. All six participants reported having a negative encounter with individuals in the medical field during the course of their adjustment. They discussed feeling a sense of abandonment from their physicians, and stated it felt as though they were given a very serious diagnosis, and then were left to navigate the complexities of adjusting to it on their own. They reported that the relationship with their doctor significantly impacted how they perceived their illness, and their ability to treat it effectively. Susan stated,

> They [GI specialist] didn't check up on me or anything. I always have to be the one to call them. It's like, so, they just say, 'here, take all this medicine, and we don't care if you come back or not. Even though we know you won't get better, we're not willing to do anything for you.' You know? And I feel like, he was just spouting off the statistics—like, he [GI specialist] already knew there was nothing he could do for me. And if that's the case, I don't wanna hear that—because that just makes it so much worse.

Kelly discussed a time when she presented her symptoms to a gastroenterologist, who then dismissed her symptoms, resulting in a prolonged amount of time before she had the correct diagnosis and could begin treatment. She stated,

> The first GI doctor I went to see, told me he thought it [my symtoms] was just because I was so anxious. He referred me to a psychiatrist and basically didn't really test me for anything. I was pretty confused, because I didn't think my symptoms were normal, and it felt like something more serious. He just kind of dismissed me, which wasn't what I needed when I was scared and had no clue what was wrong. I was eventually able to see a different doctor—my current doctor—and she did a scope on me right away.

Joann recounted her first, diagnostic colonoscopy, and how traumatizing it was for her to go through. She stated that the challenge was due, in large part, to the lack of empathy and compassion conducted by the medical staff during the procedure. She said,

> Sweet Jesus…well, my first colonoscopy was absolutely *awful*. It was so, so *awful*. I had to—pretty quickly after I was diagnosed—I had to, let's call it 'fire her.' I had to move to another GI, so this wouldn't be an issue anymore. But, since being diagnosed, I've had even more awful experiences. I didn't know that was possible, but I have had them. That first time, though, it was just really, really bad. I mean, I just sobbed and sobbed and cried because I was just (pause) so hurt. They showed me no kindness, no decency, no respect.

John also stated his dissatisfaction with the level of care he received from his gastroenterologist. He stated,

> I was so helpless—I was so in need, and this doctor, who really literally wasn't doing anything for me, made me feel like he was this hero and was saving my life. I was like—just because you shoved a tube up my a** with a camera, and, and were able to explain to me what was going on inside of my intestines, doesn't mean that's where the help stops. He also told me I would never be able to heal, and that I needed to be prepared to just live as a sick person. I was so depressed after seeing him.

The participants reported that they also had very negative experiences while in the hospital or emergency rooms, and how much stress and feelings of defeat emerged from those experiences. Lack of communication and concern contributed to a particularly unexpected encounter for Bob while he was in the hospital. He said,

> The surgeon came into my room and said, 'Let me just look at your NG (nasal gastric) tube.' And then he didn't say anything. Then he unpinned it. And he just grabbed it and pulled it right out, 'there, you're done!' He didn't even tell me. Just yanked it out. And, I was like, 'what just happened?'

Joann also stated that she often feared going to the emergency room, as she did not want to be labeled a 'drug-seeker' by the providers there. She stated,

> You go to the ER, and they insinuate (cough) that you are perhaps drug-seeking. To me, that is just so offensive and so, so hurtful. You know, 'cause here you are in such physical—tremendous physical pain (pause) and you just want relief, but also I mean it's just so hurtful 'cause that's (pause), so not what I'm doing. You know? Like, I never would choose to have this to get high. Never. So, that insinuation of drug seeking and that sort of thing, really is just so hurtful and so offensive. They need to be way more careful with the way they judge people.

Identity Reconstruction

Biological

Symptom Stability. Achieving symptom stability was essential in aiding the participants' shift towards identity reconstruction. All six participants stated that they were able to feel as though they had more control over their illness once they were able to understand and manage symptom fluctuations more effectively. John said,

> So the flare lasted a few months, and that's probably around the time I started see a counselor. I also started doing alternative treatments to manage stress. And so, that, and I changed my diet—and these changes made it easier to predict my symptoms and when they might get bad again. I was able to do more things, and had a few periods of remission.

Kelly also discussed how much she benefitted from symptom reduction and decreased pain. She stated,

> My symptoms finally calmed down after a few months, and I feel like they have been steady since my last flare. I have good days and bad days, sure, but I know how to work around it a little better. I know what I need to give my body on a daily basis now so that I can stay healthy longer.

Joann also discussed how important it was to her to begin integrating changes into her life as quickly as possible to help her manage her condition. She said, "you get this diagnosis and you want to make sure that, right away, you do everything right. You know, 'cause I had this kind of mentality that what I did then, could maybe impact the course and trajectory of the illness altogether. So, I wanted to do things right." In order to achieve symptom stability, participants made drastic changes in the way in which they defined what it meant to be a 'healthy' person after they were diagnosed. Participants reported that they generated a new cognitive schema around their health and wellness after diagnosis. Kelly said,

> I had always thought about my health in terms of productivity and functioning, mostly. If I could do everything I needed to in my life, I was fine. I never really thought about it in a way of taking care of myself long-term, or needing to be

> careful with what medicine I took, and what foods I ate. That was new to me. Health meant something different now.

Physical Awareness. All six participants noted that they became far more aware of their bodies, and could better identify when their symptoms were starting to worsen as they adjusted to their IBD. Also of note, all six participants had to take a restroom break during the course of their interview, and commented on the fact that when they begin to feel pressure in their bowels, they don't hesitate to get to a bathroom now. They all stated that they first try to find the location of the bathrooms when they enter any building, so that they know where it is in case of an emergency. Joann stated,

> I'm getting better at listening to my body and (pause) especially in regards to pain I mean I remember the first—like in the beginning I—I was so worried that people were going to judge me for pain and think I wasn't being tough or wasn't being strong. Now, I'm to the point where it's like, 'well, fuck it. They don't know what's going on with my body, but I do. I know what's going on, and need to do what I need to do for my body.' So, I think in that way, this is a really good thing—like, for the first time in my life I'm actually listening to my body.

Bob also stated how important it has been for him to listen to his body in order to get the proper amount of rest that he needs. He also reported that he will adjust his diet for the day if he is aware that his symptoms might be more severe than usual. He stated,

> And so I'm controlling it [Crohn's disease] with how much I eat now, and also how I sleep, too. I should not diminish that. I sleep from 10 o'clock at night till 7:00 or 8:00 in the morning. Now, I do tend to wake up maybe 5:00 or 6:00 in the morning and go to the bathroom. And the thing I basically do every morning is go twice. I go once, go and lay down for an hour or so, and then go a second time. That's become a pretty good routine for me.

Susan stated that when she does experience physical discomfort, she will try to reflect and identify anything that she might have done differently recently that might have contributed to the pain. During one particularly, painful day, she reflected that, "I thought, what is going on? What am I doing? What's happening that could be causing this? And I thought it could be the coffee—

so we switched to less caffeine and that helped. We've also switched to dark chocolate which is filled with soy. But I think about my body now, and try to puzzle together what makes it feel worse."

Psychological

Return of Hope. All six participants in our study identified that they were able to experience some positive, psychological changes as a result of their disease experience. Five of the six participants identified that they didn't feel hope after their initial diagnosis, but were able to regain optimism after they had time to adjust to an altered lifestyle. Participants stated that they discovered a far deeper sense of strength and self-efficacy when they examined the amount of adversity they had overcome. Joann stated,

> I still see myself as someone who tries really hard to be a good person. The scientist piece has, unfortunately, diminished in its prominence just by virtue of what's going on in my life. But, I think that (pause) while it's diminished—diminished, not gone—a sense of a fighter has come and—and filled the hole. It is kind of like—not necessarily a warrior, but just someone who's fighting the battle, and not wanting to give up.

Mary discussed that she has learned a great deal about her mental health and wellness during her disease adjustment, as it was a major part of her ability to cope with having IBD. She reported the importance of attending to the psychological reactions to a diagnosis of IBD. She stated,

> I didn't realize how depressed I was, but the people around me knew I was really having a tough time. But it is a real thing, and that feeling of you can't pull yourself out of it, is real. I've [crosstalk] been there. I wish there was more information out there—one of the first things I always ask people after they share their IBD story, I'm like, 'Well, how did you get diagnosed? How are you feeling mentally about all of this? Where are you at psychologically?'

Acceptance is not Defeat. Five out of our six participants reported that when they learned to accept that this illness did not have a cure, and would require lifetime management, they were able to begin moving forward towards their identity reconstruction. Mary recognized the importance of accepting her illness, and stated,

> Because, I think there are two ways that you can deal with this. Choice A: you're miserable all the time, and you're unhappy. You're pissed off at this set of cards that life has given you. And, you don't seek any active treatment for what's going on in your head. And, you consume yourself with feelings of guilt, and then consume yourself with anxiety and depression over everything that you're dealing with. Or Option B: you can go and talk to somebody about it and you can see that it doesn't break you. I had to accept that this was my life now, and decided that I would still be able to experience so many wonderful things even if that meant working around this [UC]. And, that really helped me move forward.

John stated that, when he was first diagnosed, he kept trying to figure out how he could eliminate his disease completely. He expressed that he has now accepted certain truths about his healing potential, and that he has opened himself up to research and resources that have helped him understand disease management. He stated, "So right now, it's about me feeling better. It's not even about (pause)—not even about if can I get rid of this disease. It's about whether or not I can feel better." Joann reported that, through acceptance of her illness, she also gained a sense of empowerment in making her own medical decisions. She said,

> I realized that at the end of the day, I'm the one who lives in my body, so the health decisions I make are mine. I'm going to make them 'cause I (pause) I live in my body. So—while other people can have input—I have the final say. And I'm learning that it is okay to make my own choices. I have accepted that I will have to make tough choices with this illness. I have also been thinking about health from a really holistic place—really holistically. It isn't just medical and body, but like how am I (pause), how am I feeling emotionally, and spiritually, and, um, am I rested? So I view it a little more—much more comprehensively.

Increased Self-Worth. Four out of six participants reported that they also experienced a return of some of the self-worth they originally believed they lost. They reported that when they had a better understanding of the disease and how to manage it, they were able to collaboratively construct a treatment plan (either with or without a physician's assistance). They stated that they experienced a newfound confidence in themselves, and have learned that they are just people who happen to live with IBD—that they are not simply the disease. Mary stated,

> I don't wish this on anyone, but I just want people to understand this *can be* something that can be amazing for you, and, if you let it, something that can increase your life two, three and other phases that you didn't even think about before. You can't let yourself get to a point that makes you think that there's no hope or nothing gets better, because it does. You just have to frame your mind differently and think of it differently.

Bob discussed the growth that he has experienced in his confidence to manage his illness. He initially doubted whether or not he was capable of dealing with such a difficult disease, but stated, "I can control it with diet, exercise and using biofeedback when I can, which has helped me see that I have ability to handle this disease. I have more confidence in myself now that I can physically and mentally manage my symptoms." Joann also stated that she has been able to reach a place of stability, which has helped quell some of her negative, internal dialogue regarding her self-worth. She stated,

> I do have goals for the future and at the same time like, I do have (pause), I do feel at peace more so now than I have in a really long time. It is just kind of like, a—a type of contentment? So, I feel like I'm in a good spot between feeling at peace, like feeling content, but then also (pause) knowing I'm still working on things and still growing, too.

Social

Planning for Social Events/Travel. All six participants stated that they now plan differently for social events/functions, as they have learned what can happen when their symptoms involuntarily flare in public. In order to plan for social events, our participants reported using various strategies and techniques to enhance preparedness. Joann stated that she makes sure she has 'emergency medication' on hand should she need it, and said, "I keep a little pill case with me at all times so that I have the medications that I need. I've learned how to manage things more logistically—more about how to navigate everything." Bob stated that he has to manage a food schedule around his daily activities, as he can better predict the length of time between eating a meal, and needing to have a bowel movement. He stated,

> If I do eat, it is probably two to three hours later that I have to use the bathroom to have a bowel movement. I just (pause), I just plan my eating around what I will be doing for the day now, like waiting to eat until after I have finished a presentation so that I don't have to go in the middle of speaking. Or, when I travel, for example, I don't want to eat, because when you're on a plane, you don't know when you're going to get to the bathroom.

Mary said that planning and preparation are now part of her daily routine, and she reportedly asks herself each morning, "What preparations do I need? Where am I going? What am I doing? Do I need medication? Where are the bathrooms? Do I have a change of clothes and wipes with me?" Participants discussed that their travel plans can be completely usurped by a flare-up of their illness, but that they have learned how to keep going when it does. Joann once had a job interview in another state, but found herself in the hospital the evening she arrived due to the emergence of pain, diarrhea, and vomiting. She stated,

> It was just so bad, I threw up all over the bathroom, and was shitting everywhere and was just curled up in a fetal position. I told the people I was interviewing with that I had food poisoning and wouldn't be able to make the beginning of the interview—the breakfast and tour part. I didn't want them to know my diagnosis and have that automatically eliminate me from being hired. I ended up going to the emergency room, but rallied to do the interview the next day.

Boundary Setting. Five of the six participants in this study reported that they have become more comfortable setting healthy boundaries for themselves than they were in the beginning stages of their disease, but that it still isn't the easiest to communicate. Joann said,

> I feel like people think like 'well just get over it, just push yourself, like we're all tired, have some coffee.' But, this is not, 'have some coffee' fatigue. I mean this is just like ass dragging, constant fatigue—like, no matter how long you sleep for, you never feel rested. It is frustrating to explain this to people who can't understand why you aren't always up for a night on the town or a long hike on Saturday morning. It just requires SO much more effort and energy to do things with people, and they don't always have the patience to get that. I know rest is

> the most important treatment sometimes, so, now, I sometimes decline invitations so that I can take care of myself.

Bob also discussed how he decided to set boundaries for himself with the type of medications he was going use to treat his illness. He expressed that he 'took more ownership' over his treatment. He has also set a personal boundary of not having a GI specialist anymore, as he felt he wasn't improving based on the treatment plan they suggested. He said,

> I just sort of decided to do it myself. I was just like, I'm just going to try to get off of this Prednisone to see what happens. So I stopped it one day. I tried to get more sleep. I tried to control my diet. I tried to watch those kind of things, and I found I was able to operate without the Prednisone. Sure, my symptoms are still sometimes bad, but I just decided I didn't want to take it anymore. It has worked for me.

Interacting with 'Healthy' People. All six participants in this study talked about how they have to interact with 'healthy' people now, and how they try not to draw attention to their illness-related needs around others. Mary discussed a situation in which she was not quite sure how to react. She said,

> I remember (pause) we [her and fiancé] were out at dinner and he ordered a salad and asked if I (pause)—oh, also, we were on our first date—so, he asked if I wanted to order a salad, too. I was like, "Fuck. How the hell do I tell him about this on the first date?" And, I was like, "You know I can't. My digestive system makes it kind of hard for me to digest raw, leafy greens, but hopefully, I'll be able to have some soon. And, I had this moment where it was like, it's okay if he doesn't get it, but this is part of the package now. I knew he might not understand it as a 'healthy' person, but that it was part of me now.

Participants noted the positive impact of having the support of healthy people around them, who genuinely do want to understand the illness and how they can help in the management of it. Susan said, "I have gotten a lot of support. People always ask me, what can you eat? Where do you want to go if we go out to eat? I've definitely gotten some support, and they have to try to understand it. If they don't know, they won't (pause), they won't get what has to happen." Mary discussed how meaningful it was to her when she went on a second date with the aforementioned man, and he wanted to know more about her disease. She recounted,

> I remember on our second date he told me, he was like, "So, I went online and I Googled some stuff about ulcerative colitis and I have some questions for you if that's okay." He wanted to know how I managed it and how we could work dates and things around it. And, I wanted to cry it was so sweet.

Joann also noted the importance of acceptance and support from the healthy individuals who surrounded her. She realized,

> I have learned that I need more understanding and empathy from people instead of just physical support. Understanding is huge, because (pause) just knowing that people are not judging you in your experience and what you're going through, and that maybe they are in your corner, is *so huge*.

Bob stated that over the course of 35 years in battling his disease, that he has learned how to interact with healthy people over time, and that he can still engage in most activities that interest him. "I just know the tips and tricks of being around healthy people now. You just figure out how you exist as a chronically ill person (pause)—you keep it [Crohn's] under the radar, and just don't draw too much attention to it."

Post-Traumatic Growth

Five of the six participants in our study endorsed PTG as a result of their disease experience. The greatest areas of participant growth captured by the PTGI during this study include items targeted at possible areas of change, a change in priorities and life trajectory, positive changes in social relationships, identifying strength and self-efficacy, and conceptualizing life in a more spiritual way (Table 5). Interestingly, there was a clear difference in the way in which participants defined 'spiritual growth' in comparison to growth in 'religious faith.' Having a stronger religious faith was one of the areas that participants reported the least amount of positive growth, as well as developing areas of new interests/opportunities, and the ability to put forth additional energy to foster relationships. Results of the PTGI can be viewed in Table 5.

Positive Self-Growth

Strength/Resilience. Five of the six participants in the study described having positive experiences in recognizing the physical and emotional strength they developed throughout the course of their disease adjustment. For some, reflecting back on their worst IBD experiences, reminded them of the adversity they have overcome. Joann described a sense of empowerment in knowing more about her own strength. She stated,

> I now sometimes feel like a bad ass, ya know? Like (pause) knowing I can do hard things. I think about all the pain I've gone through, and I think about (pause)—I now think about emotional pain and physical pain in a way that says—'I'm strong…like, holy shit, I can take a lot. I can really handle a lot.' So, for me, that has been a good change.

Bob described the inner strength it took him to manage long hospital stays, and how he remained active to continue to improve his health. He stated he knew he had always been a driven person, but that this was a different type of perseverance.

> So I knew now, if I just sat around for a month in the hospital, I was going to be in really bad shape, right? Even before the surgery, I was doing exercises. In the hospital, I would [laughter] take the saline bottles and stuff and use them like weights, and I would walk around—there was a circle you could walk. I was focused on staying strong and active, and I wasn't going to let this get me down. I discovered my strength, and kept myself motivated by doing that.

John reported that his disease experience has helped him understand the power of his mind, and how he can use this newfound strength to help him manage his physical symptoms as well. He stated, "I think that I'm becoming a better person, really--even like, as long as I can maintain control of, of my mind. I've realized that I have the ability to change my disease experience with the power of thought. Sure doesn't cure it, but it helps."

Gratitude for Present Self. Five out of the six participants in our study expressed an appreciation for the way in which IBD changed their lives after they were able to reflect on what they had been through. Joann stated,

> So, I now see this more as like…I guess an invitation to grow in some of the personal kind of traits and qualities that I want. Like, I want to be patient, I want to be understanding, I want to be empathetic, I want to be sensitive to other people, and so this has kind of presented me the opportunity to grow in those things.

Kelly reported feeling more grateful for days when her symptoms were less difficult or painful to manage. She said, "I mean, ultimately I had a shift in perceptive. I am really, really grateful for good days, and, on bad days, I know it won't be pleasant, but that I can get through it now." Mary stated that she feels grateful for how much her experience with IBD has impacted the way she feels about herself. She said,

> And I don't ever see myself viewing my health the same way that I have. And that has been another kind of unexpected blessing to all of this. Because I think health-wise, I do have this autoimmune disease. But I think overall, I'm way more healthy than I was three, four years ago.

John reported that although his workload is not as intense as it once was, he is grateful for the fact that he can now work 2-3 days a week for a few hours. He has accepted the fact that he now has limitations, but is now able to focus on the positive areas of growth. He stated,

> And, you know, I said, I'll just try to work with that, but I-I remember that was the first time I felt some sense of empowerment again—I felt something empowering within myself when I started to go back to work. Even though it was like, yeah, three hours a day, it was still doing something.

It has been more difficult for Susan to find positive growth throughout her IBD experience, and she reported that she still feels she has had a significant reduction in quality of life based on her medical problems. She stated,

> My life is fulfilling sometimes on a good day, maybe, but not usually, no. If I write a good chapter, or if Rick comes home and he's real happy about something

> at work, and we sit and talk, or we do something that's fun together—and we just have a really good time. If you ask me then, I would say yes, but not (pause), not the majority of the time. And it's because of my health, it's not because of anything but that.

Knowledge about Health and Wellness. Participants also reported that they experienced growth in regards to their overall knowledge of health and wellness, and that they have become so much more enlightened about how to find balance between their illness and their health. Joann reported that she now feels far more capable of discussing her needs with the logistics required to manage IBD. She stated, "I've gotten better at navigating the system and so, that includes, like applying for financial aid at hospitals, payment plans, and even working with (pause) pharmaceutical manufacturers—because they have patient assistance programs—so working with them, to get my medication. Otherwise I couldn't have afforded it." Bob also stated that he reassessed health and wellness in his life after being diagnosed with IBD, and that he made positive behavioral changes in an effort to manage his illness with a little medical intervention as he could. He said,

> If you look at my transcript—volleyball, 17 times. Literally. Aerobics, half a dozen times. Every semester, if I needed one or two credits, that's what I threw in there instead to trying to find extra time to be active. I felt that was an important part of maintaining my health, and not stressing me more than I needed to be. That's what I did for years, and it slowed down my [PhD] program for finishing, but it allowed me to be what I considered 'healthy.' And, healthy in the way that I don't have to be on medications, I don't have to have colonoscopies, and I don't have to have doctors controlling my life.

Positive Social Growth.

Compassion for Others. Five out of our six participants reported growth in their ability to feel compassion for others as a result of their IBD. They reported that due to the extent of how much they suffered with their illness, that it provided them with a new perspective on how to treat and understand others who might also be in pain or battling a chronic illness. Susan said,

> But there’s so many people suffering out there, and I never, I never really understood physical suffering. Mental suffering, yes, but not physical. This is different. I, I feel really angry that people have to hurt this way, and be frightened, and sad…all those things.

Joann also stated that she has experienced a significant, positive shift in emotional perspective as a result of her disease experience. She said,

> I think also kind of how I’ve looked at it has shifted, at first it was more like ‘why me?’ I had already been through enough in my life and so didn’t need this—I didn’t deserve this. But now, the perspective that I’ve returned to is that I’m grateful for this opportunity. It’s a learning opportunity, and it helps me grow in patience, it helps me grow in understanding for other people, it helps me grow in empathy and so like those are—those are good things.

Value of Quality Relationships. Five out of our six participants reported significant growth in how much they now valued the quality of supportive relationships in their lives. They reported that they were able to recognize how important it was to have people around them who truly cared about their health and their experience.

> The two things that I took away from getting diagnosed with IBD is that the only two things that really matter in your life are the people you surround yourself with and your health. That's it. Because if you have those two things, you're doing pretty good. If you have people that you love and care about and that will be there for you, and you have good enough health to live life with them in a way that's good—live life in a way that's healthy and fun, that's all you really need to be happy.

For Joann, the quality of the relationships in her life also helped restore some of the faith that she questioned when first diagnosed with IBD. She stated that it was a powerful experience to see people reach out to help her. She stated,

> One thing that I’ve really grown in, and that I still (umm) am growing in, is seeing God as coming through for me (umm, pause)—like, through the people in my life. When people show up for me, and people are kind, and people help me, and people are patient, and all that—like people are supportive—it feels like (pause) God is acting through them. When others offer me compassion and love, I don’t feel as much like I’ve been sentenced to this, or deserted by God, (pause) but that God is still very much here and in this with me.

For John, he explained how the battle with his IBD has shaped his relationship with his romantic partner, and reported that he focuses on the ways in which this illness has brought them together. He stated,

> This is part of me changing as a person, and how I feel like I'm a better person, you know. Honestly, I feel like it just, the emotions just split wide open, and it's made my relationship with my partner change. Sex is more meaningful now when we have it because of what I have been through. It feels closer somehow.

For Susan, dealing with her IBD has helped her see a different, more caring side to her husband, and is grateful that she is able to see this part of him. She stated, "he has been really good. I mean, my husband is, you know, he's not the most sensitive man, but he has shown a lot of compassion I didn't even know he had."

Asking for Help. All six participants reported that their illness taught them how to ask for more help, and that they eventually realized that needing assistance was not weakness. For Susan, she reported that this might have been the only area of significant growth for her when she said,

> I have found that people, you know, certain people have been really sweet and helpful about this. That's a good thing. I've found out more about how people are (sighs) and want to help. But I can't say that there's anything else that's been you know, good about this.

John also discussed how he benefitted from talking to someone who was also struggling with IBD, as that connected him to another person who understood his symptoms and experience.

> I met someone else who had ulcerative colitis, and also had a back surgery, too. I think that the connection is the amount of the agonizing pain it brings you, without finding any relief at times. When someone else just understands that, it is so comforting. And, so, we ask each other for help when we need it—and sometimes that is just talking about it on the phone.

Bob also reported having the same experience when he was able to talk to others with IBD. He said, "I do go to groups or meetings where I feel like I can talk about Crohn's. It is nice to be able to learn from other people, and to also maybe help people with my own experiences."

Positive Disease Perception

Seeking Resources/Research. Five of the six participants reported feeling positive growth in their ability to manage their illness more effectively in the future. They reported that they sought out information about their disease so they could better understand it, and so that they could learn different ways in which to manage symptoms. Joann stated, "I do a lot of reading about this now, because this is ultimately my life. It's happening whether I want it to or not, so I figured I should be as informed as possible about it." John also stated that he has done his own research regarding IBD. He stated that he has 'looked into books on nutrition, and books that helped explain the mind-body connection and how stress influences the inflammation in the body." Bob decided to try biofeedback as a method of symptom reduction. He explained his process when he stated,

> I thought, well, biofeedback maybe can help with this, right? But I didn't know anything about how to do that. But I looked into buying little things that can give you biofeedback and stuff, and found a book called, *Self Analysis for Dummies*. It tells you this procedure of what I do on basically a daily basis to try to settle down my system and help me not get tense and stressed out.

Mary also identified how much she benefitted from talking to other individuals suffering from IBD. She stated that it helped her want to be involved in organizations that raised money for IBD research, and that she has met so many inspirational people through her activities.

> You can figure out there are a lot of other people that feel the same way you do. You can surround yourself with like minds, with people who have similar experiences as you. That's another really empowering thing about Team Challenge (IBD fundraising organization)—you meet all these other people who get it and all of this different stuff. And, again, I think there's power in the 'me too.' There's power in that camaraderie.

Turning Pain into Purpose. Five out of the six participants reported that after adjusting to their illness and integrating into their lifestyle, they were able to turn their negative experiences into something meaningful. Mary has become very involved in the Crohn's and Colitis Foundation of America (CCFA), and has even traveled to Ireland to run a half marathon that raised money for IBD research. She continued to talk about her fundraising goals, and how much it meant to her that her co-workers also chose to support her in this endeavor. She stated, "When I was raising money for Spin4 Crohn's and Colitis this past fall all of my co-workers donated. I signed up to do the marathon with Team Challenge a few months ago, and they all went in and were like, 'We're going to donate. We're going to do whatever you need us to do.' They're so supportive." Joann also discussed how much her pain has impacted her, and how much she has been able to learn from the experience. She said,

> When I think of my pain now, I think about what one of my favorite authors says, "that pain is like a traveling professor." So, you know, it's not pleasant, but I try to invite pain in and ask, "Okay, what do you have to teach me?

Table 5.
Post-traumatic growth experienced after Illness

PTGI Participant Cumulative Score on Measure Highest score: 105	**Additive scores across all 6 participants**
Highest PTG	
Possible areas of growth and change	25
I discovered that I am stronger than I was	25
I changed priorities about what is important in life	24
I discovered I am stronger than I thought I am	23
I learned a great deal about how wonderful people are	23
I established a new path for my life	22
I have a better understanding of spiritual matters	21
I have a greater sense of closeness with others	21
I know better that I handle difficulties	21
Medium Growth	
I have a greater appreciation for the value of my own life	20
I more clearly see that I can count on others in times of trouble	20
I learned a great deal about how wonderful people are	20
I am better willing to accept how things work out	19

I developed new interests	18
Least Growth	
I have a greater sense of self-reliance	17
I put more effort into relationships	17
New opportunities are available that wouldn’t have been there before	16
I am able to do better things with my life	15
I have a stronger religious faith	15
Individual Growth	
Participant scores on PTGI (105 top score)	
Mary	97
John	96
Kelly	79
Joann	63
Susan	51
Bob	32

DISCUSSION

Research Focus

The overarching purpose of this research study was to better understand the disease adjustment within the IBD population, and to examine any components of PTG based on their experiences. This researcher sought to understand what factors contributed to positive and negative experiences for our participants coping with IBD, and how this impacted their ability to move forward with their lives despite having a chronic illness. Classifying chronic illness as a traumatic experience is a relatively new concept, and it is starting to emerge in relevant research articles. There is recognition that chronic illnesses can be psychologically and physically traumatic to an individual struggling with disease adjustment (Hefferon, Grealy, & Mutrie, 2009). Few researchers have examined IBD from the perspective of trauma and potential growth, which was the aim of this study. The research team for the current study examined the various stages that individuals with IBD go through as a result of their diagnosis and ability to accept their illness. The PTGI was designed to measure positive growth for individuals who have experienced trauma, but it was not designed to originally assess trauma from the chronic illness expeirence (Tedeschi & Calhoun, 1996).

An individual’s preparedness for trauma was also a significant issue for our participants (Tedeschi & Calhoun, 1996). Our participants reported feeling shocked by their diagnosis, as they had never heard of the disease before, or they had always been a healthy person who hadn’t experienced significant medical concerns in their past. The study addressed the significant gap in IBD literature in terms of PTG. For the purpose of this study, we were able to generate a new model of adjustment for this particular illness. The use of narrative theory to approach this study contributed to the collection of individuaized data from participants who each had unique experiences with their journey in manging IBD. Previous examinations of PTG within the IBD population did not cover the scope of factors contributing to healthy adjustement to the disorder. By providing information in the Grief/Loss phase, as well as the Perception effect, a better understanding was gained of what contributed to more positive feelings of disease management, and the ability to find potential positive growth. Using the theories derived from the Transtheorectical Model of Change, we were able to confirm the importance of readiness to change. Individuals who had more negative experiences within the Perception Effect, struggled more to reach the stages of identity reconstruction and PTG. Including the Biopsychosocial model to conceptualize this illness, this allowed us to exame the extent to which the disease impacted individuals in numerous facets of their lives, incorporating the importance of psychological and social growth, as well as their biological health. It became clear in our findings that discussing the Grief/Loss phase and the Perception Effect, we were able to identify how many areas of the participant's life were impacted by IBD. The Perception Effect contributed greatly to motivation to change and reach the Identity Reconstruction phase. This is consistent with the Transtheoretical Model of Change, in that it addressed motivating factors associated in moving forward through the phases of PTG (King, Klinovski & Dubouloz, 2016). Individuals with greater negative perceptions of their illness struggled more to find the motivation to transition into a life that integrated their illness with their daily routine.

This study provided more disease-specific examples of PTG for individuals with IBD, and further elucidated the need to design more comprehensive models of disease adjustment. Within the context of this study, there was significant support for a model of IBDPTG. Each participant's experience was conceptualized using four stages: Grief/Loss, Percerption Effect, Identity Reconstruction, and PTG.

Grief/Loss

Each participant noted significant feelings of grief and loss when they were diagnosed with IBD. The onset of severe symptoms rapidly altered the ability of the participants to continue to engage in their normal, daily routines, which is consistent with other research findings (Palant et al., 2015). Participants described the difficulty of shifting from having an active personal and professional life, to essentially becoming prisoners in their own bodies (Palant et a., 2015; Paterson, 2001). Individuals reported feelings of a universal identity loss, as the onset of their illness made it incredibly challenging to maintain any semblance of their previous lifestyles. The participants in this study described the profound loss of functioning within the physical, personal sexual, occupational, and social domains of their lives (Kralik, Van Loon, & Visentin, 2006). They described the pervasive impact of their disease, and the level of disruption this caused in their daily activities. The sudden shift in ability proved jolting for our participants, especially if they had maintained a relatively healthy lifestyle and were diagnosed in their more formative years. Physically, participants were so impacted by this illness, they were often homebound due to the inability to function. This loss of functioning was closely associated with extreme fatigue, anemia from blood loss, frequency of trips to the bathroom, and overall nutrient absorption. Participants also experienced dramatic changes in their ability to work and provide for their families, which is a common issue for individuals with chronic illnesses. Individuals with chronic illnesses are often too sick to work when they are experiencing a flare-up of their disease symptoms, which can create great frustration for individuals who derive value and worth from their occupational identities.

Sexual functioning and intimacy also suffered as a result of severe IBD symptom flares, supporting research that discusses the negative impact chronic illnesses can have on romantic relationships. Issues pertaining to loss of interest in sexual pleasure, or difficulty with sexual functioning emerged for a number of reasons for the patients in our study. The three, female participants in our study who had male partners at the time of their symptom onset (and subsequent future flare-ups) worried about their sexual relationship with their spouses, often feeling a sense of guilt at the inability to provide their partner with what they perceived to be adequate sexual activity. Overall, female participants in this study reported more concern than male participants regarding body image and how the nature of their IBD symptoms made them feel undesirable to their partners from a sexual standpoint. These feelings of physical self-consciousness are closely related to the social stigma associated with bowel-related diseases. Participants also discussed feeling as though society views gastrointestinal disorders differently between females and males. Female participants in our study reported that they feel it is less acceptable for women to have issues with bowel movements, intestinal bleeding, frequent diarrhea, incontinence, and the potential of having a permanent surgery resulting in a form of an external ostomy to manage their symptoms. These participants were less likely to solicit social support from those around them than the participants who did not view the symptoms as negatively, as they feared they would be perceived as ‘dirty’ or ‘disgusting’ should they talk about their symptoms with friends and family. For our female participants, this significantly impacted how quickly they sought medical treatment for their physical symptoms, as they reported great embarrassment in the change in their digestive health. This also impacted how well female participants complied with treatment plans that involved the use of suppositories, prescribed enemas, or forms of surgical intervention that had the potential to alter their bodies in some negative way. Female participants intimated that they did not want their partners to view these types of treatments as deterrents in their sexual relationships. Our female participants also reported that, due to so much abdominal cramping, they could often not tolerate traditional intercourse as a result of the abdominal and rectal pain they were experiencing during flare-ups. The women in our study also discussed feeling as though their partners often wanted to support them, and were willing to change their expectations of sexual and physical functioning, but that they often felt helpless. Trying to find balance between being a romantic partner and a caregiver is a salient concern that arises for countless partners of individuals with chronic illnesses.

The participants in the study also identified what it was like to lose the ability to be as socially active as they once were, which contributed to feelings of isolation and depression. Due to limitations from symptoms, individuals with IBD can lose a sense of social identity because they no longer have the energy or physical ability to participate in a number of activities. Our participants felt as though people did not understand the severity of their symptoms and how debilitating they were (are). This invalidated the participants' physical and emotional struggle with their pain. Strong social support from friends is an essential component of coping with IBD, but it is often difficult to find people who are understanding and accommodating (Joachim, 2002). Findings of grief/loss were identified within the IBD population for the purpose of this study, and remained the first stage in the IBDPTG model.

Perception Effect

This study identified the importance of an individual's attitudes and beliefs regarding their ability to cope with negative changes in their lives. Literature on PTG discusses the positive impact of high levels of optimism and cognitive flexibility in disease adjustment (Prati & Pietrantoni, 2009). If optimism was conceptualized as an individual's belief that they will experience greater symptom reduction and management, even when symptoms are severe, the trait is identifiable as influential in overall disease perception (Cordova et al., 2007). Participants in our study were impacted by feelings of hopelessness, which contributed to higher levels of depression. In addition to feeling hopeless, participants in our study were impacted by the uncertainty and fear of symptom manifestation, which generated increased anxiety about the prognosis of the illness.

The extent to which the participants felt stigmatized by the norms of society and medical professionals created shame and embarrassment for our participants. It is not uncommon for individuals with IBD to feel as though they cannot share their experience with bowel-related symptoms, and our participants discussed the extent to which this contributed to their silence about their needs from others around them (Dur et al., 2004). Participants in this study also confirmed the importance of having a strong social network while they were experiencing their worst flare-ups. Acceptance, compassion, and empathy from others around them can create a completely different disease experience for individuals with IBD, as they are no longer spending limited resources of energy focusing on whether or not people will view them as inferior, or ‘gross’ because of their symptoms.

People with chronic illnesses also commonly feel negatively judged by the medical personnel helping them manage their illness, which was a significant factor in participant coping for the purpose of this study (Taft et al., 2009). Participants in this study viewed adverse experiences with doctors and other medical professionals as devastating to their belief that they could effectively manage their illness. The lack of support from these professionals, made it more difficult for our participants to feel supported, which made them less likely to seek help when they had disease-related concerns. The relationship with the medical professionals also impacted the ways in which our participants viewed prescribed medication. Participants in the study sought alternative methods of care after difficult experiences with people in the medical field. This supports findings that issues concerning medication compliance are linked to the relationship between patient and provider (Rubin & Cleveland, 2015). Research also suggests that the longer an individual has IBD, the more likely they are to use alternative treatment methods (Moser et al., 1996). The perception of accessibility of medications also impacted the way in which our participants coped with their IBD. The cost of prescription medications for IBD can be excessive, which also contributed to our participants feeling as though they couldn't afford to treat themselves. The perception effect is the second stage in the IBDPTG model, and there is strong evidence that patients can have vastly different disease experiences based on the way in which they feel they are being treated by others, their ability to develop self-efficacy and confidence in symptom management, and their ability to find a treatment plan with effective, affordable medications that do not include a tremendous amount of negative side effects (Gellad, 2011).

Identity Reconstruction

Significant changes occurred in the lifestyles of the participants in this study, consistent with those experiencing different chronic illnesses. Symptom stability and dietary management were identified as factors impacting identity reconstruction for our participants. The participants were more effectively able to integrate activities of disease management when their symptoms abated, and were more predictable. Participants identified that symptom management included increased planning for any activity or event, so that they did not feel stranded if they had an issue with their IBD symptoms while away from home. It also included the support of family and friends, and how much people were willing to help them with necessary accommodations.

Accommodation for IBD often includes access to different dietary options that are easier to digest (Massironi, 2013; Schneider, Jamieson & Fletcher, 2009). The study participants discussed the dietary sacrifices they have been forced to make as a result of their IBD, but also recognized that the alterations helped increase digestion and nutrient absorption (Sheikh, 2004). Personal acceptance of the illness, and increased self-efficacy in the ability to manage symptoms, included changes in diet, sleep, and exercise for our participants. Resuming activities once they reached symptom stability, gave participants greater confidence in their ability to live a meaningful life with a diagnosis of IBD. Participants approached health management from a different perspective during the identity reconstruction phase. They focused less on external, phenotypic presentations of themselves, and more on internal health, physical strength, and increased levels of functioning in their lives. Identity reconstruction is the third phase of the IBDPTG model, and encapsulates the extent to which an individual with IBD has integrated their disease management into their daily lives. Integration of healthy behavioral change can significantly enhance quality of life for individuals with IBD after their most severe symptoms (Shahar & Lerman, 2013).

Post-traumatic Growth

There were areas of positive change experienced by the participants in this study that were not fully captured by the PTGI. The accompanying qualitative data examining PTG provided clearer explanations for how and where this growth occurred in participants' lives, which is something the questionnaire cannot do, simply by design. The qualitative coding in this study identified three, major areas of PTG within the context of our study, including: positive personal growth, positive social growth and positive growth of hope for the future.

The emergence of PTG literature in chronic illness research continues to gain momentum, and this study examined the extent to which individuals with IBD could experience positive changes as a result of their illness experience (Linley & Joseph, 2004). Participants exhibited significant PTG in areas of self-efficacy and strength/resilience. Participants realized the depth of their capacity to handle adversity throughout their IBD disease adjustment. They were better able to recognize that they had enough strength to endure the pain and symptoms of IBD. Priorities and plans for future directions were also identified as areas of high PTG for the purpose of this study. Participants conceptualized meaning of life and purpose differently as a result of their disease experience, and focused more on the value of self-care, as well as the value of quality relationships and social support in their lives. PTG also occurred in increasing the amount of compassion and empathy that the participants were able to feel towards other individuals who also experience pain and suffering. Their journey with IBD provided them with a completely new understanding of what individuals with chronic pain and illnesses go through on a daily basis, and to be more cautious in judging someone for a functional impairment or deficit. As much as their experience with IBD impacted their ability to feel strong emotional connections with others in pain, it also taught them how to accept more help from the people around them. When individuals in our study were facing the initial loss of independence and identity, it was difficult for them to reach out to others for support. They reported that they realized they could not manage their illness without the help from others, and that it became easier to accept when they were also able to embrace their chronic illness lifestyle.

Spirituality was also an area of significant PTG for the participants in our study. However, this is one topic that we did not explore during this study. Participants in our study identified that they felt growth in spirituality, but did not endorse the same amount of growth when asked about religious faith. Chronic illness literature has identified the positive impact of religious faith for some patients trying to cope with a painful disease, but the participant's in our study questioned their religious beliefs and expressed feeling a type of betrayal from whomever they worshipped (Calhoun & Tedeschi, 2006). The participants questioned why they had to be diagnosed with their disease, and often sought for answers from religious faith and spirituality. Calhoun and colleagues (2006) suggest that there is a difference between spirituality and religion, in that religion is more of an institutionalized concept, whereas spirituality is better described by one searching for something sacred in their lives. Continuing to differentiate between the two concepts might be an area of future research within the IBD population, as our participants experienced high levels of spiritual growth, but expressed low levels of religious growth.

PTG was the fourth, and final stage of the IBDPTG model, and we collected abundant evidence that positive growth occurred in numerous ways for our participants. It was discovered that even though PTG is possible to reach in a collective sense, it is essential to understand that each individual will move through the IBDPTG model very differently based on the numerous factors examined in this study. The ideal goal would be to design a PTGI that is disease-specific to IBD. The model captured in this study illuminated differences in IBDPTG than that of other forms of trauma. In examining the patterns of experiences from the participants in this study, this researcher (or a future researcher) could generate items for an IBDPTGI. Initial questions could be studied through rigorous statistical testing to understand how reliable and valid the measure could be across a large sample size of individuals with IBD. Some examples of the disease-specific questions that could potentially be asked to generate a questionnaire for IBDPTG, include (based on the findings of this study):

1. I have learned a great deal about my body because of my illness.
2. I have learned more about how my physical health can impact my mental health.
3. I now understand that a multitude of treatment methods are available for my condition.
4. I have formed strong, positive relationships with the care team managing my case.
5. I now seek resources and information about my illness so that I can better understand it.
6. I am less frustrated at the need to make lifestyle changes because of my disease.
7. I feel better prepared to handle my symptoms should I experience a flare.
8. I better understand what type of social support I need to help me manage my illness.
9. I have a clearer understanding of how to manage my pain so that it is less of an impairment in daily functioning.
10. I have changed my perspective on what health and well-being looks like in my life.
11. I am better able to communicate appropriate information to others (friends, family, doctors) in order to meet my disease-specific needs.
12. I feel as though this illness has helped me become more spiritual and connected with the present.
13. I no longer view asking others for help as a sign of personal weakness.

These items are merely examples of questions that could be generated for the purpose of more understanding of PTG within the IBD population. Stanton and colleagues (2006) have discussed the need to examine PTG carefully, as it does ask the participant to engage in five complex states of processing, including 1) evaluating their current standing on a dimension (self-reliance, for example), 2) recalling their previous standing on the same dimension, 3) comparing their current and previous standings, 4) assessing the degree of change, and 5) determining how much of that change can be attributed to the traumatic event. Interestingly, Bob, the participant who has coped with IBD for 35 years, had the lowest score of growth on the PTGI. Bob's score could have potentially been lower than the other participants, as it might be difficult for him to recall the onset severity of his symptoms. If he could not recall an accurate measure of impairment, he may have underestimated the amount of growth that has actually occurred in his life. Similarly, Mary, who had the highest score on the PTGI, could have overestimated how severe her symptoms were at the time of their onset, potentially skewing the outcomes of PTG.

PRACTICAL IMPLICATIONS

Clinical Practice

Our study illustrated that PTG within the IBD population can be accomplished in numerous ways. However, it feels as though there are still barriers to areas of more positive growth that need to be addressed. Our participants resoundingly commented on how negative their experiences have been within various medical settings. There were significant feelings of abandonment and lack of empathy reported by our participants. In order to provide patients with IBD the greatest chance of progressing through the IBDPTG model, medical providers need to be adequately informed about the potential harm they are causing their patients when treating them. It is unlikely that providers intentionally hurt their patients, but there is a clear, negative impact nonetheless. Patients need to feel more supported by their providers. This support, as with any illness or medical case, needs to be individualized based on specific patient needs. Each patient has a completely different set of emotional and physical reactions to a diagnosis of IBD. It is essential to talk to the patient about any stressors that may be exacerbating their symptoms. While appointments are time-limited and providers need to see a high volume of patients each day, patients continue to feel as though they are a chart lost in the shuffle, and that the medical staff aren't concerned about their well-being. When giving a diagnosis of IBD, providers need to be sensitive about how they discuss the concept of an 'incurable' disease (Rubin & Cleveland, 2015). There is no cure that eliminates IBD completely, but there are a vast array of treatments that could greatly restore quality of life and functioning should the patients comply with the correct protocol (Seres et al., 2008). Unfortunately, as is the case with many chronic illnesses, it can sometimes be difficult to find the most effective treatment plan, and as such, the patient may need to try several different combinations of medications in order to find what best ameliorates their symptoms. The uncertainty about the effectiveness of medication can make patients feel even more anxiety and fear regarding symptom stability. However, if there is a steady flow of positive communication between provider and patient, the collaboration might result in higher rates of disease remission.

In order for medical providers to improve the ways in which they approach patient care, it is necessary that they understand the magnitude of impairment caused by IBD for their patient. It is recommended that physicians attend seminars on the psychosocial adjustment to IBD. Unfortunately, those kinds of training opportunities are limited, as there is a dearth of information about how to implement different clinical skills that might help patients with their IBD adjustment (Zoellner & Maercker, 2006). Providers could partner with organizations such as the Crohn's and Colitis Foundation of America (CCFA), and utilize the resources the organization provides about disease adjustment. CCFA also conducts training sessions for people who wish to start support groups in their area, and could potentially send representatives to speak to individual practices if the request is made.

While it is a unique approach to studying IBD disease adjustment, providers can also learn a tremendous amount about issues that patients struggle with in reading the comments made within IBD social media support groups (Antheunis, Tates & Nieboer, 2013). There are numerous support groups on Facebook, for example, where members provide candid feedback about their challenges with IBD. There was an increase in medical providers usage of Facebook from 10% to 67% between 2009 and 2011 (Antheunis et al., 2013). Social media has the potential to provide practitioners with information about biopsychosocial complications associated with IBD, as people share openly about the physical and mental impact of their illness. Members of these social media groups sometimes post photos of their disease experience, such as showing complications with their stomas, or discussing medication side effects and various treatment plans. Individuals also post demonstrational videos to help other people navigate the disease transitions, such as the most effective way to change an ostomy for them, and what unique methods people have had to come up with in order to manage their specific pouching system or set of symptoms. Medical professionals could use this information to provide patients with a number of different options of disease management that might not ever have occurred to the physician Antheunis et al., 2013). For example, some members have suggested that eating marshmallows about 10 minutes before changing the external pouching system helps their body to slow down motility to allow for a smoother application of the fresh pouching materials. There is no empirical evidence that this tactic will work for every individual learning how to manage a pouching system, but it gives them more options to keep trying to find what does work for them (that the options aren't all exhausted, and they can still hope). Naturally, appropriate boundaries would need to be kept by providers, and they should not select to follow a group on social media if they recognize one of their patients is also a member of the group (Antheunis et al., 2013).

Psychotherapy

It is highly recommended that patients seek additional psychological and emotional support as they try to manage their illness (Zoellner & Maercker, 2006). GI specialists and other providers need to refer more IBD patients to people who can manage the support that is necessary after medication and diagnoses are somewhat stabilized. Medical practices nationwide are starting to hire psychotherapists, health coaches, or social workers to attend to the psychosocial aspect of illness coping (von Wietersheim & Kessler, 2006). Having mental health providers available at the same practice where the patient either sees a primary care physician (PCP) or a specialist could make a tremendous difference in their willingness to talk about their emotional struggles with the disease (Bodenheimer, Wagner & Grumbach, 2002). The patients in these practices are familiar with the office and staff, they are familiar with their provider, and may tend to trust the mental health professional more due to the level of comfort they feel in the situation. If this is not an option for the practice, the patients need to be provided with referrals to the appropriate mental health provider. Based on the results of this study, and other studies identifying the strain IBD can have on romantic relationships, couple's therapy is also highly recommended for those impacted by the disease (Martire, Schulz, Helgeson, Small & Saghafi, 2010). It may also be beneficial for the patient to attend a support group for individuals with IBD, as that can be an excellent source of social connection, disease information, and personal acceptance. Suggested psychotherapy approaches include existential therapy, acceptance and commitment therapy (ACT), and dialectical behavioral therapy (DBT) (Zoellner & Maercker, 2006). These psychotherapy modalities work towards helping the patient understand their identity loss, can assist in learning tools of mindfulness and acceptance, and underscores the fact that it is possible for people to be able to feel both joy and pain—that they are not mutually exclusive (Calhoun & Tedeschi, 2006).

STRENGTHS AND LIMITATIONS

This study provided an in-depth examination of the phases involved in IBD disease adjustment. The model of IBDPTG is a new method of studying the patient experience for individuals with IBD. The current research on PTG within the IBD population is incredibly sparse, and this study further elucidated the factors involved in disease adjustment, and ultimately, what helps generate positive change within the person's life.

The research team for this study was not able to meet in-person to compare coding and data analysis. Google Chat provided the best alternative for the situation, but it is unclear whether meeting in-person would have impacted the selected domains and subthemes for the study. The research team was also comprised of four, Caucasian women in their late 20s-early 30s. Future researchers may want to increase the ethnic and sex diversity of the team, as it might provide different perspectives on illness adjustment, particularly in how chronic illnesses are perceived differently based on cultural norms, as well as differences in overall treatment philosophies. Additionally, this researcher's personal experiences with IBD could have impacted the results of the study, despite implementing steps to minimize bias.

Although small sample sizes are more common for qualitative studies, this study was only able to include six participants. Based on the consistency of domain identification during cross-analysis of the participant transcripts, it does not appear as though the reducing the sample size from eight participants to six would have had a significant effect on the outcome of this study. However, it is worth noting this as a limitation of the study based on the proposed number of participants. Our sample size included participants with a wide range of ages, but there was not enough diversity in ethnicity or socioeconomic status to identify how these difference in demographics might have altered participant responses. We also had a sample size that included four women and two men. While we were able to identify certain sex differences in perception of body image and appearance, we did not look at IBD disease adjustment from the standpoint of comparison between men and women (Bernklev et al., 2006). Research suggests that there are sex differences in coping with IBD, which focus more on change in identity roles, sexual functioning, and personal self-esteem and body image (Marcotte, Fortin, Potvin & Papillon, 2002). We also did not ask participants how long their flare lasted, as this might have also impacted their ability to cope with their symptoms. The duration of worst flare helps further examine the differences in coping strategies and impact on daily functioning as a result of time spent in a severe state.

This study was not able to use disease-specific questionnaires to assess the IBD patient experience. While the BDI-II, BAI, SCL-90-R, and PTGI provided meaningful data in the comparison of psychological functioning during greatest symptom severity, as opposed to the psychological functioning at the time of the interview, it is difficult to assess how much of the patient's depressive symptoms were already present at diagnosis, and what depressive symptoms might have emerged due to the medical condition. There may have been a contrast effect in participant responses based on their subjective interpretation of how severe their symptoms were at the time of their worst flare (i.e. they may have rated them more severe than they actually were based on their memory of the experience). Due to the potential contrast effect, the data might not reflect accurate mean differences between the participants' measures of anxiety, depression, and other potential psychopathology (Stanton, Bower & Low, 2006). We also could have used the Inflammatory Bowel Disease Questionnaire (IBDQ), a 32 item questionnaire that addresses various areas of functioning for individuals with IBD, to further assess symptom stability at the time of the interview (Guyatt et al., 1989). Using the IBDQ might have provided more objective data in regards to the participant's current IBD symptoms, which would have increased the reliability of the self-report from the participants. The IBDQ addresses 4 distinct subscales, which include bowel related symptoms (10 items), systemic function (5 items), social function (12 items), and emotional status (5 items) (Magalhaes, Castro, Carvalho, Moreira & Cotter, 2014).

FUTURE DIRECTIONS

While this model of IBDPTG is disease-specific, it could be used to inform researchers/medical providers working with a broad spectrum of chronic illnesses. This is one of the first studies to examine IBDPTG utilizing both quantitative and limited qualitative measures. This study produced evidence of PTG, and future research could continue to examine the specific subthemes identified based on participant interviews. Future research can also address the limitations of this study. Recruiting a more diverse research team is suggested for researchers, as well as increasing the diversity of the patient pool from which data were obtained. A slightly larger sample size may also provide more information about which negative experiences associated with their diagnosis prevented some individuals from experiencing PTG (Hill, 2012).

It would also be beneficial to examine the impact of age at diagnosis in considering PTG for individuals with IBD. For the purpose of our study, individuals had to be over the age of 18 to meet inclusion criteria, so this study did not include the child/adolescent demographic. There may be differences in PTG based on how early the individual had to implement lifestyle changes after diagnosis, as well as the level of social support they received from family members/friends. It is likely that children and adolescents experience different types of identity loss—as compared to those who received the diagnosis well into adulthood as a result of the age of disease onset (Mackner & Crandall, 2005; Olsson, 2003) Due to the need to manage their disease for a longer period of time than those diagnosed in adulthood, children and adolescents may also take a completely different approach to their treatment plan as a result of an early manifestation of their illness. Additionally, children and adolescents do not have as much autonomy in developing their treatment plan as adults who are diagnosed with IBD. As minors, parents are more in control of the decision-making process in their disease management. If parents of a child/adolescent cannot afford some of the prescribed medications (as we saw with our adult participants), the child/adolescent can do very little to try to find access to those specific medications, and are limited in alternative treatment approaches they might be able to try (such as medical marijuana, as was used by the participants in our study). Children and adolescents might be more focused on body image and appearance during that stage of life, which could create more issues of noncompliance with medications that change physical features, such as Prednisone. As mentioned previously, the side effects of Prednisone can contribute to weight gain, increased acne, bloating, swelling of the face, irritability and insomnia. While these side effects are not ideal in adulthood, they can be potentially be devastating to a child/adolescent that is seeking social acceptance. These children/adolescents may have a greater fear of stigma and negative judgment from their peers, which can increase anxiety, depression, and social withdrawal. This diagnosis may also limit the amount of activities/organizations in which the child/adolescent can participate, such as participation in some form of athletics, school functions/trips, and the ability to spend time with friends. However, while children/adolescents may be concerned about school attendance, they do not have the responsibility of providing their family with income. It is less probable that a family would be dependent on a child/adolescent to produce necessary income, therefore, it is doubtful that these individuals will experience a loss in occupational identity. Their interpretation of perceived disease management might produce different forms of PTG, or, perhaps, no PTG at all due to the severity of the individual's psychosocial struggle.

This study did not closely disseminate the sex differences between the ways in which men and women experienced PTG. Examining the specific subthemes within the larger model, may continue to elucidate why certain patients are able to reach PTG. Due to the fact that the participants all experienced such negative interactions with medical personnel during treatment, it is worth exploring the impact this relationship has on PTG in further research. Participants described that they did not feel as though they received quality care when their relationship with the medical professional was negative, regardless of whether they were giving an accurate diagnosis or prescribing the correct medications. Future research may want to examine IBDPTG by comparing individuals with IBD who have had positive and negative experiences with their providers. Research also suggests that SES is a potential factor in coping with trauma, and could be examined more thoroughly within the context of the IBDPTG (Stanton et al., 2006).

Due to the fact that the participants all experienced such negative interactions with medical personnel during treatment, it is worth exploring the impact this relationship has on PTG in further research. Participants described that they did not feel as though they received quality care when their relationship with the medical professional was negative, regardless of whether they were giving an accurate diagnosis or prescribing the correct medications. Future research may want to compare individuals with IBD who have had positive interactions with their medical providers, versus individuals who have had negative experience to identify potential differences in outcomes of PTG.

Future research may also want to focus on the ways in which individuals can broaden their social support network, as well as how easily others might be able to access that same type of support as well. Telehealth, or more online-based treatment services, are becoming more widely acceptable standards of care for people in rural locations who might not otherwise have access to treatment needs. Individuals within the chronic illness patient population may also experience significant hurdles in obtaining transportation to medical appointments. Limited transportation options are also compounded by the fact that these individuals may often need to take additional time off of work in order to make an appointment, which also impacts their income.

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APPENDIX A: INFORMED CONSENT

Consent to Participate in a Research Study

Colorado State University

TITLE OF STUDY: A Mixed Method Examination of Disease Adjustment for Individuals within the Inflammatory Bowel Disease Patient Population: A model for Post-traumatic Growth

PRINCIPAL INVESTIGATOR: Ernest Chavez, PhD, Psychology, ernest.chavez@colostate.edu

CO-PRINCIPAL INVESTIGATOR: Elise Bascom, Doctoral Candidate, ebascom@rams.colostate.edu

WHY AM I BEING INVITED TO TAKE PART IN THIS RESEARCH? You are being asked to participate in this research study because you have been diagnosed with either Crohn's Disease or Ulcerative colitis. Your experience with your illness can provide information about factors that contribute to more effective disease adjustment.

WHO IS DOING THE STUDY? This researcher will be obtaining consent from the participants of the study. This researcher designed the study and is a Co-PI with Ernest Chavez. Three undergraduate research assistants will help this researcher transcribe and code interviews as part of the data analysis required for the study. All members of this research team have been trained in appropriate ethical protocol for conducting research on human subjects.

WHAT IS THE PURPOSE OF THIS STUDY? The purpose of this study is to examine the distinct phases of disease adjustment that individuals experience upon diagnosis of Inflammatory

Bowel Disease (IBD). This study seeks to propose a model of post-traumatic growth that will better inform medical professionals about the various stages of disease transition, and how best to conceptualize and treat patients with this information.

WHERE IS THE STUDY GOING TO TAKE PLACE AND HOW LONG WILL IT LAST? This study will take place at the Centers for Gastroenterology or on campus at CSU. The study is expected to take approximately 90 minutes to complete.

WHAT WILL I BE ASKED TO DO? During this interview, you will be asked to fill out a variety of questionnaires, which include the Beck Depression Inventory (BDI), the Beck Anxiety Inventory (BAI), the Symptom Checklist-90 (SCL-90) and the Post-Traumatic Growth Inventory (PTGI). I will also be asking you questions pertaining to your illness. These questions will cover many aspects of your experience with IBD, including the physical, social, and psychological impact of coping with your disease. Your answers are completely confidential and will, at no time, be shared with anyone other than the research team involved in the study. Following completion of the questionnaires you will be asked to participate in a one hour interview. When the interview is complete, you will be asked to fill out several more questionnaires. The second round of questionnaires will be less time consuming than the first set. You are free to end the interview at any time, and can ask the researcher questions throughout the interview if you are unsure about how to answer a question. You can also decline to answer questions if you feel they are not relevant to your experience, or if they elicit too strong an emotion for you. If you are unable to read the consent form and the questionnaires, this researcher will read the content for you, making sure you fully understand the content and what you are signing up for.

ARE THERE REASONS WHY I SHOULD NOT TAKE PART IN THIS STUDY? You are not eligible to participate in this study if you are under the age of 18, are pregnant, do not speak English, and have not had your diagnosis for at least one year prior to the interview.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS? Participation in this study may elicit emotional feelings during the interview portion. Should this happen, this researcher will offer referrals at the end of the interview so that the participant will have the necessary support.

The following risk statement must be included on all consent forms: It is not possible to identify all potential risks in research procedures, but the researcher(s) have taken reasonable safeguards to minimize any known and potential, but unknown, risks.

ARE THERE ANY BENEFITS FROM TAKING PART IN THIS STUDY? Participation in this study will provide you with an opportunity to share your journey with inflammatory bowel disease. Sharing your story will provide you with an opportunity to contribute to empirical literature about how to better treat and understand patient experiences who are also coping with your illness.

DO I HAVE TO TAKE PART IN THE STUDY? Your participation in this research is voluntary. If you decide to participate in the study, you may withdraw your consent and stop participating at any time without penalty or loss of benefits to which you are otherwise entitled.

WHO WILL SEE THE INFORMATION THAT I GIVE? We will keep private all research records that identify you, to the extent allowed by law.

For this study, we will assign a code to your data (participant 1, participant 2, etc.) so that the only place your name will appear in our records is on the consent and in our data spreadsheet which links you to your code. Only the research team will have access to the link between you, your code, and your data. The only exceptions to this are if we are asked to share the research files for audit purposes with the CSU Institutional Review Board ethics committee, When we write about the study to share with other researchers, we will write about the combined information we have gathered. You will not be identified in these written materials. We may publish the results of this study; however, we will keep your name and other identifying information private.

WHAT IF I HAVE QUESTIONS? Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now. Later, if you have questions about the study, you can contact the investigator, Elise Bascom at ebascom@rams.colostate.edu. If you have any questions about your rights as a volunteer in this research, contact the CSU IRB at: RICRO_IRB@mail.colostate.edu; 970-491-1553. We will give you a copy of this consent form to take with you.

WHAT ELSE DO I NEED TO KNOW? Your interviews will be audio recorded for the purposes of this study. These audio recordings will be linked to your participant code and will remain confidential.

Do you consent to be audio taped during the duration of this study? Please circle one of the options presented:

I agree to be digitally recorded during this study: Yes

I do not agree to be digitally recorded for this study: No

Your signature acknowledges that you have read the information stated and willingly sign this consent form. Your signature also acknowledges that you have received, on the date signed, a copy of this document containing ___ pages.

____ _______________________

Signature of person agreeing to take part in the study Date

____

Printed name of person agreeing to take part in the study

____ _______________________

Name of person providing information to participant Date

____

Signature of Research Staff

APPENDIX B: DEMOGRAPHY SURVEY

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

We greatly value the time you have taken to participate in this study. For the purposes of this study, we need participants to fulfill certain requirements in order for their interview to be considered valid.

Please, verify that:

- You have a formal diagnosis of inflammatory bowel disease from a Gastroenterologist (preferably, a diagnosis that has been confirmed via colonoscopy).
- You received your diagnosis at least 1 year ago, and have been managing care during this timeframe.
- You must speak English, and you must over the age of 18.

In providing your signature on this line, you are stating that you understand and fulfill all inclusion requirements for this study. Your signature represents your voluntary participation in this study, and that you are free to leave at any point in time during the interview.

Signature of informed consent: ______________________ Date: __________________

I would like to ask you a few demographic questions, to better understand the context of your disease experience.

Demographic Information

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

Date of birth: _ _/ _ _ / _ _ **Age:** __ __

Sex/Gender Identity: ☐ Female ☐ Male ☐ Other (please, specify)________________

Is English your first language? Yes / No

What is your country of residence?

1. **United States**
2. **Canada**
3. **Other (please specify) ______________________________**

What is your ethnicity?

☐ **White/Caucasian**

☐ **Black/African American**

☐ **Hispanic**

☐ **Asian**

☐ **Native American**

☐ **Other ethnic group-______________________________**

What is your current employment status?

☐ Full time

☐ Part time

☐ Unemployed

☐ Student

☐ Retired

☐ Sick leave

☐ Homemaker

☐ Other ……………………..……..…(please specify)

What is your current level of income?

☐ Under $20,000

☐ $20,000-$29,999

☐ $30,000-$39,999

☐ $50,000-$59,999

☐ $60,000-$69,999

☐ $70,000-$79,999

☐ $40,000-$49,999

☐ Over $80,000

What is the highest level of education you completed?

☐ 8th grade Diploma

☐ High school Diploma/GED

☐ Associate’s Degree

☐ Bachelor’s Degree

☐ Master’s Degree

☐ Doctoral Degree

☐ Other……………….(please specify)

What is your marital status?

☐ Married

☐ Living together

☐ Single

☐ Dating/in a relationship

☐ Divorced

☐ Separated

☐ Widowed

How many children do you have?

a) No. of daughters: _____

b) No. of sons: _____

c) None

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

a) Depression

b) Anxiety

c) Other (please specify) ______________________________

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

Number of years since receiving diagnosis?(please specify) -

____

With which form of IBD have you been diagnosed:

a) Crohn's disease

b) Ulcerative Colitis

c) Diverticulitis

d) c) Other (please specify) ______________________________

Would you classify your disease as:

a) Mild
b) Moderate
c) Severe

Are you currently taking any medications? Yes / No

If yes, please describe your treatment regimen

……………………………………………………………

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

If Yes, which? ……………………………………….....

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

If Yes, how many? …………………….

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

Have any of your immediate/extended family members been formally diagnosed with IBD?

Yes / No

If Yes, who?....………………….

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

If Yes, what? ....

APPENDIX C: QUALITATIVE MEASURES

Beck Depression Inventory

This depression inventory can be self-scored. The scoring scale is at the end of the questionnaire. Please answer these questions as if you were in your worst flare-up. Try to remember to the best of your ability.

Question 1:

0 I do not feel sad.
1 I feel sad.
2 I am sad all the time and I can't snap out of it.
3 I am so sad and unhappy that I can't stand it.

Question 2:

0 I am not particularly discouraged about the future
1 I feel discouraged about the future.
2 I feel I have nothing to look forward to
3 I feel the future is hopeless and that things cannot improve

Question 3

0 I do not feel like a failure
1 I feel I have failed more than the average person
2 As I look back on my life, all I can see is a lot of failure
3 I feel I am a complete failure as a person

Question 4

0 I get as much satisfaction out of things as I used to
1 I don't enjoy things the way I used to
2 I don't get real satisfaction out of anything anymore
3 I am dissatisfied and bored with everything

Question 5

0 I don't feel particularly guilty
1 I feel guilty a good part of the time
2 I feel quite guilty most of the time
3 I feel guilty all of the time

Question 6

0 I don’t feel I am being punished
1 I feel I may be punished
2 I expect to be punished
3 I feel guilty all of the time

Question 7

0 I don’t feel disappointed in myself
1 I am disappointed in myself
2 I am disgusted with myself
3 I hate myself

Question 8

0 I don’t feel I am any worse than anyone else
1 I am critical of myself for my weaknesses or mistakes
2 I blame myself all the time for my faults
3 I blame myself for everything bad that happens

Question 9

0 I don’t have any thoughts of killing myself
1 I have thoughts of killing myself, but I would not carry them out
2 I blame myself all the time for my faults
3 I blame myself for everything bad that happens

Question 10

0 I don’t cry any more than usual
1 I cry now more than I used to
2 I cry all the time now
3 I used to be able to cry, but now, I can’t cry even if I want to

Question 11

0 I am no more irritated by things than I ever was
1 I am slightly more irritated now than usual
2 I am quite annoyed or irritated a good deal of the time
3 I feel irritated all the time

Question 12

0 I have not lost interest in other people

1 I am less interested in other people than I used to be
2 I have lost most of my interest in other people
3 I have lost all of my interest in other people

Question 13

0 I make decisions about as well as I ever could
1 I put off making decisions more than I used to
2 I have greater difficulty in making decisions than I used to
3 I can’t make decisions at all anymore

Question 14

0 I don’t feel that I look any worse than I used to
1 I am worried that I am looking old or unattractive
2 I feel there are permanent changes in my appearance that make me look unattractive
3 I believe that I look ugly

Question 15

0 I can work about as well as before
1 It takes extra effort to get started at doing something
2 I have to push myself very hard to do anything
3 I can’t do hard work at all

Question 16

0 I can sleep as well as usual
1 I don’t sleep as well as I used to
2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep
3 I wake up several hours earlier than I used to and cannot get back to sleep

Question 17

0 I don’t get more tired than usual
1 I get tired more easily than I used to
2 I get tired from doing almost anything
3 I am too tired to do anything

Question 18

0 My appetite is no worse than usual
1 My appetite is not as good as it used to be
2 My appetite is much worse now
3 I have no appetite at all anymore

Question 19

0 I haven't lost much weight, if any, lately
1 I have lost more than five pounds
2 I have lost more than ten pounds
3 I have lost more fifteen pounds

Question 20

0 I am no more worried about my health than usual
1 I am worried about physical problems like aches, pains, upset stomach, or constipation
2 I am very worried about physical problems and it's hard to think of much else
3 I am so worried about my physical problems that I cannot think of anything else

Question 21

0 I have not noticed any recent change in my interest in sex
1 I am less interested in sex than I used to be
2 I have almost no interest in sex
3 I have lost interest in sex completely

The Beck Anxiety Inventory

Below is a list of common symptoms of anxiety. Please, carefully read each item in the list. Please answer these questions as if you were in your worst flare-up. Try to remember to the best of your ability.

1. Numbness or tingling
    a. Not at all
    b. Mildly, but it didn't bother me much
    c. Moderately, it wasn't pleasant at times
    d. Severely, it bothered me a lot

2. Feeling hot
    a. Not at all
    b. Mildly, but it didn't bother me much
    c. Moderately, it wasn't pleasant at times
    d. Severely, it bothered me a lot

3. Wobbliness in legs
    a. Not at all
    b. Mildly, but it didn't bother me much
    c. Moderately, it wasn't pleasant at times
    d. Severely, it bothered me a lot

4. Unable to relax
    a. Not at all
    b. Mildly, but it didn't bother me much
    c. Moderately, it wasn't pleasant at times
    d. Severely, it bothered me a lot

5. Fear of worst happening
    a. Not at all
    b. Mildly, but it didn't bother me much
    c. Moderately, it wasn't pleasant at times
    d. Severely, it bothered me a lot

6. Dizzy or lightheaded
    a. Not at all
    b. Mildly, but it didn't bother me much
    c. Moderately, it wasn't pleasant at times
    d. Severely, it bothered me a lot

7. Heart pounding/racing
    a. Not at all
    b. Mildly, but it didn't bother me much
    c. Moderately, it wasn't pleasant at times

    d. Severely, it bothered me a lot

8. Unsteady
    a. Not at all
    b. Mildly, but it didn’t bother me much
    c. Moderately, it wasn’t pleasant at times
    d. Severely, it bothered me a lot

9. Terrified or afraid
    a. Not at all
    b. Mildly, but it didn’t bother me much
    c. Moderately, it wasn’t pleasant at times
    d. Severely, it bothered me a lot

10. Nervous
    a. Not at all
    b. Mildly, but it didn’t bother me much
    c. Moderately, it wasn’t pleasant at times
    d. Severely, it bothered me a lot

11. Feeling of choking
    a. Not at all
    b. Mildly, but it didn’t bother me much
    c. Moderately, it wasn’t pleasant at times
    d. Severely, it bothered me a lot

12. Hands trembling
    a. Not at all
    b. Mildly, but it didn’t bother me much
    c. Moderately, it wasn’t pleasant at times
    d. Severely, it bothered me a lot

13. Shaky/Unsteady
    a. Not at all
    b. Mildly, but it didn’t bother me much
    c. Moderately, it wasn’t pleasant at times
    d. Severely, it bothered me a lot

14. Fear of losing control
    a. Not at all
    b. Mildly, but it didn’t bother me much
    c. Moderately, it wasn’t pleasant at times
    d. Severely, it bothered me a lot

15. Difficulty in breathing
    a. Not at all

    b. Mildly, but it didn’t bother me much
    c. Moderately, it wasn’t pleasant at times
    d. Severely, it bothered me a lot

16. Fear of dying
    a. Not at all
    b. Mildly, but it didn’t bother me much
    c. Moderately, it wasn’t pleasant at times
    d. Severely, it bothered me a lot

17. Scared
    a. Not at all
    b. Mildly, but it didn’t bother me much
    c. Moderately, it wasn’t pleasant at times
    d. Severely, it bothered me a lot

18. Indigestion
    a. Not at all
    b. Mildly, but it didn’t bother me much
    c. Moderately, it wasn’t pleasant at times
    d. Severely, it bothered me a lot

19. Faint/lightheaded
    a. Not at all
    b. Mildly, but it didn’t bother me much
    c. Moderately, it wasn’t pleasant at times
    d. Severely, it bothered me a lot

20. Face flushed
    a. Not at all
    b. Mildly, but it didn’t bother me much
    c. Moderately, it wasn’t pleasant at times
    d. Severely, it bothered me a lot

21. Hot/cold sweats
    a. Not at all
    b. Mildly, but it didn’t bother me much
    c. Moderately, it wasn’t pleasant at times
    d. Severely, it bothered me a lot

The Symptoms Checklist-90-Revised.

Please answer these questions as if you were in your <u>worst flare-up</u>. Try to remember to the best of your ability.

Symptoms	Not at all	A little bit	Moderately	Quite a bit	Extremely
Headaches	0	1	2	3	4
Nervousness or shaking inside	0	1	2	3	4
Unwanted thoughts, words, or ideas that won't leave your mind	0	1	2	3	4
Faintness or dizziness	0	1	2	3	4
Loss of sexual interest or pleasure	0	1	2	3	4
Feeling critical of others	0	1	2	3	4
The idea that someone else can control your thoughts	0	1	2	3	4
Feeling others are to blame for most of your troubles	0	1	2	3	4
Trouble remembering things	0	1	2	3	4
Worried about sloppiness or carelessness	0	1	2	3	4
Feeling easily annoyed or irritated	0	1	2	3	4
Pains in heart or chest	0	1	2	3	4
Feeling afraid in open spaces or on the streets	0	1	2	3	4
Feeling low in energy or slowed down	0	1	2	3	4
Thoughts of ending your life	0	1	2	3	4
Hearing words that others do not hear	0	1	2	3	4
Trembling	0	1	2	3	4
Feeling that most people cannot be trusted	0	1	2	3	4
Poor appetite	0	1	2	3	4

Crying easily	0	1	2	3	4
Feeling shy or uneasy with the opposite sex	0	1	2	3	4
Feeling of being trapped or caught	0	1	2	3	4
Suddenly scared for no reason	0	1	2	3	4
Temper outbursts that you could not control	0	1	2	3	4
Feeling afraid to go out of your house alone	0	1	2	3	4
Blaming yourself for things	0	1	2	3	4
Pains in lower back	0	1	2	3	4
Feeling blocked in getting things done	0	1	2	3	4
Feeling lonely	0	1	2	3	4
Feeling blue	0	1	2	3	4
Worrying too much about things	0	1	2	3	4
Feeling no interest in things	0	1	2	3	4
Feeling fearful	0	1	2	3	4
Your feelings being easily hurt	0	1	2	3	4
Other people being aware of your private thoughts	0	1	2	3	4
Feeling others do not understand you or are unsympathetic	0	1	2	3	4
Feeling that people are unfriendly or dislike you	0	1	2	3	4
Having to do things very slowly to insure correctness	0	1	2	3	4
Heart pounding or racing	0	1	2	3	4
Nausea or upset stomach	0	1	2	3	4
Feeling inferior to others	0	1	2	3	4
Soreness of your muscles	0	1	2	3	4

Feeling that you are watched or talked about by others	0	1	2	3	4
Trouble falling asleep	0	1	2	3	4
Having to check and double-check what you do	0	1	2	3	4
Difficulty making decisions	0	1	2	3	4
Feeling afraid to travel on buses, subways, or trains	0	1	2	3	4
Trouble getting your breath	0	1	2	3	4
Hot or cold spells	0	1	2	3	4
Having to avoid certain things, places, or activities because they frighten you	0	1	2	3	4
Your mind going blank	0	1	2	3	4
Numbness or tingling in parts of your body	0	1	2	3	4
A lump in your throat	0	1	2	3	4
Feeling hopeless about the future	0	1	2	3	4
Trouble concentrating	0	1	2	3	4
Feeling weak in parts of your body	0	1	2	3	4
Trouble concentrating	0	1	2	3	4
Feeling weak in parts of your body	0	1	2	3	4
Feeling tense or keyed up	0	1	2	3	4
Heavy feelings in your arms or legs	0	1	2	3	4
Thoughts of death or dying	0	1	2	3	4
Overeating	0	1	2	3	4
Feeling uneasy when people are watching or talking about you	0	1	2	3	4
Having thoughts that are not your own	0	1	2	3	4

Having urges to beat, injure, or harm someone	0	1	2	3	4
Awakening in the early morning	0	1	2	3	4
Having to repeat the same actions such as touching, counting, wishing	0	1	2	3	4
Sleep that is restless or disturbed	0	1	2	3	4
Having urges to break or smash things	0	1	2	3	4
Having ideas or beliefs that others do not have	0	1	2	3	4
Feeling very self-conscious with others	0	1	2	3	4
Feeling uneasy in crowds, such as shopping or at a movie	0	1	2	3	4
Feeling everything is an effort	0	1	2	3	4
Spells of terror or panic	0	1	2	3	4
Feeling uncomfortable about eating or drinking in public	0	1	2	3	4
Getting into frequent arguments	0	1	2	3	4
Feeling nervous when you are left alone	0	1	2	3	4
Others not giving you proper credit for your achievements	0	1	2	3	4
Feeling lonely even when you are with people	0	1	2	3	4
Feeling so restless you couldn’t sit still	0	1	2	3	4
Feelings of worthlessness	0	1	2	3	4
Feeling that familiar things are strange or unreal	0	1	2	3	4
Shouting or throwing things	0	1	2	3	4

Feeling afraid you will faint in public	0	1	2	3	4
Feeling that people will take advantage of you if you let them	0	1	2	3	4
Having thoughts about sex that bother you a lot	0	1	2	3	4
The idea that you should be punished for your sins	0	1	2	3	4
Feeling pushed to get things done	0	1	2	3	4
The idea that something serious is wrong with your body	0	1	2	3	4
Never feeling close to another person	0	1	2	3	4
The idea that something is wrong with your mind	0	1	2	3	4

The Post-traumatic Growth Inventory

Indicate for each of the statements below the degree to which this change occurred in your life as a result of the crisis/disaster, using the following scale.

Possible Areas of Growth and Change	0	1	2	3	4	5
I changed my priorities about what is important in life.	0	1	2	3	4	5
I have a greater appreciation for the value of my own life	0	1	2	3	4	5
I developed new interests	0	1	2	3	4	5
I have a greater feeling of self-reliance	0	1	2	3	4	5
I have a better understanding of spiritual matters	0	1	2	3	4	5
I more clearly see that I can count on people in times of trouble	0	1	2	3	4	5
I established a new path for my life	0	1	2	3	4	5
I am better able to accept the way things work out	0	1	2	3	4	5
I can better appreciate each day	0	1	2	3	4	5
New opportunities are available which wouldn't have been otherwise	0	1	2	3	4	5
I have more compassion for others	0	1	2	3	4	5
I put more effort into my relationships	0	1	2	3	4	5
I am more likely to try to change things which need changing	0	1	2	3	4	5
I have a stronger religious faith	0	1	2	3	4	5
I discovered that I am stronger than I thought I was	0	1	2	3	4	5
I learned a great deal about how wonderful people are	0	1	2	3	4	5

I better accept needing others	0	1	2	3	4	5

APPENDIX D: INTERVIEW GUIDE:

Your participation in this study is greatly appreciated. It is important for you to remember that you are free to end the interview at any point in time if you wish to do so. Participation in this study is voluntary, and you are welcome to ask questions should you need clarification at any point in time. As this interview will be utilized for research purposes, it will be audio recorded, and later transcribed on a locked computer. To ensure your anonymity, these recordings will be deleted after the study has been completed.

Throughout the course of this interview, I will be asking you questions that pertain to your experience adjusting to IBD. These questions may elicit an emotional reaction, as they will cover topics that might be difficult for you to talk about. It is important that you share at your personal level of comfort.

1. Can you briefly describe your life before you developed IBD?
    a. Describe the activities that you engaged in on a daily/weekly basis?
        i. What was your occupation, if applicable? Did you consider yourself financially stable?
        ii. What were the hobbies you engaged in on a regular basis?
    b. Describe your social life and the people who you considered to be in your network of support.
        i. Describe your network of friends and family.
        ii. Did you have romantic relationships at this point in your life?
            1. How did you conceptualize intimacy at this time?
            2. If you were sexually active during this time, can you describe what role sexuality had in your relationship(s), as well as your own personal identity.
    c. How would you describe your body image and self-esteem during this time?
    d. What was your definition of health and wellness during this time?
    e. What would you have considered the most important components comprising your personal identity at this time?
        i. From what sources did you construct your conceptualization of self-actualization? Did you feel fulfilled by your life at this time?
2. Can you describe the onset of your IBD symptoms, the process you went through to receive your diagnosis from a Gastroenterologist, and the initial adjustment period you went through after you received your diagnosis?
    a. Please, describe your physical and mental health at this point in time.
        i. Did you experience psychological distress in conjunction with physical distress?

        ii. What did it mean to you to receive a diagnosis of an incurable disease at this time?
        i. What information did you possess about this disease prior to your diagnosis?
        ii. Did you feel as though you were experiencing a 'disruption' in your life as a result of your illness onset? Were you forced to eliminate activities from your life as a result of illness complications?
    b. What was your experience with medical professionals during this time?
        i. Describe your relationship with the Gastroenterologist who diagnosed you. What impact do you think this relationship had on your initial adjustment to your diagnosis?
        ii. Can you describe both positive and negative experiences you might have had with doctors, nurses, physicians' assistants, etc. during this time?
        iii. Did you have health insurance at the time of your diagnosis? If so, did you experience any struggle in receiving coverage for necessary procedures or medications?
        iv. If you did not have health insurance, what impact did your diagnosis have on your financial stability, if any?
    c. If you were in a romantic relationship at the time of your diagnosis, was there a shift in the dynamic between you and your partner that you feel you could attribute to issues stemming from your diagnosis?
        i. If you were sexually active at this time, were your intimate relations with a partner impacted by your symptoms?
        ii. If you were not in a romantic relationship at the time of diagnosis, were your feelings and approach to dating impacted at all? In what way?
    d. You described your body image and self-esteem before your diagnosis earlier in the interview. Did you experience any change in the way in which you conceptualized these parts of yourself?
    e. Again, how would you describe your personal identity at this time?
        i. Did you experience any change in self-actualization at this time?
3. Can you describe whether or not your experience with IBD was altered as you spent more time adjusting to the illness?
    a. About how long after your diagnosis did you begin to feel as though you were effectively managing your symptoms?
        i. What do you believe was most instrumental in helping you with symptom reduction, or perhaps, even a state of remission?
            1. Treatment plan (How did you generate a plan that was effective)
            2. What role do you believe social support had in helping you through the initial trauma of diagnosis? Medical professionals? Friends? Family? Romantic Partner?
            3. Do you believe that your attitude towards your diagnosis and illness integration impacted your adjustment to the disease?

        a. Can you describe what your attitude towards your illness was?
        b. Did your attitude towards your illness change over time? How would you describe it now?

ii. If you still do not feel as though you are effectively managing your disease, what do you believe to be the current barriers preventing this?

iii. Can you think of any positive or negative changes that have occurred in your life as a result of your disease adjustment?
    1. Do you feel as though you have experienced growth in any area of your life? If yes, which?
    2. Do you feel as though this disease has prevented you from progressing and growing in areas of your life that you would like to change? If yes, which?

iv. How do you conceptualize body image and self-esteem after having time to adjust to your diagnosis?
    1. Do you view health any differently?

v. If you are currently in a romantic relationship, how would you describe the dynamics of your relationship after more time to adjust, and manage, your symptoms?
    1. If you are sexually active in this relationship, how would you describe your experience with intimacy and sexuality after having time to adjust?
    2. If you are not currently in a romantic relationship could you describe whether or not your approach to finding a partner has changed throughout your adjustment to your illness?
    3. Has your illness experience deterred you from finding a partner? How? Why?

vi. Do you feel as though the way in which you describe your self-actualization and personal identity has changed as you have spent more time living with your illness? If yes, how?
    1. Can you describe the status of your occupational and personal roles?
    2. Would you describe your life as fulfilling? What do you feel provides the most meaning to you in your life?

APPENDIX E: RECRUITMENT FLYER

Research Participants Needed

A Qualitative Examination of Disease Adjustment for Individuals within the Inflammatory Bowel Disease Patient Population: A Model of Post-Traumatic Growth

WHAT:

- Want to participate a 60-75 minute interview regarding your individual adjustment to Inflammatory Bowel Disease (IBD)?

WHO:

- Are you at/over the age of 18?
- Has it been at least one year since you received your diagnosis of IBD?
- Have a diagnosis of IBD that was confirmed by a colonoscopy or gastroenterologist?
- Interviews will be scheduled at your convenience

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Principal Investigator:
Ernest Chavez, Ph.D.
CSU Counseling Psychology

Interviews will be conducted in fulfillment of a dissertation research study for:

Elise Bascom, M.S.

Colorado State University

Department of Counseling Psychology