

UNDERSTANDING MOMENTS OF ROMANTIC RELATIONSHIP TURBULENCE  
AS WOMEN MANAGE INFLAMMATORY BOWEL DISEASE

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### **Abstract**

**THESIS:** Understanding Moments of Romantic Relationship Turbulence as Women Manage Inflammatory Bowel Disease

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This study explored how women experience and negotiate romantic relationship turbulence related to managing IBD. This study used the Relational Turbulence Model as a framework for further understanding the ways uncertainty, intimacy and partner influence are experienced rather than testing their predictability. Three themes emerged from the 11 interviews conducted, themes include: Strategies and Phases of Disclosure, Experiencing Uncertainty, and Individual and Relational Identity. Themes were comprised of subthemes that all worked to answer the overlapping research questions driving this study. The overall findings suggest, first, that turbulent moments can be individually experienced. Additionally only two clear phases of disclosure occurred rather than multiple disclosures upon different life changes. Finally, women emphasized an accelerated sense of relational identity with their partner.

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## **Chapter One: Introduction**

### **Understanding Moments of Romantic Relationship Turbulence as Women Manage Inflammatory Bowel Disease**

Inflammatory Bowel Disease (IBD) is a term that broadly describes disease states of chronic or recurring immune responses to inflammation in the gastrointestinal tract. The two most common diseases are Ulcerative Colitis and Crohn's disease (Center for Disease Control and Prevention, 2014). Irritable Bowel Syndrome (IBS) and Celiac Disease are also common (Sutter Health, 2014). Each of these disease states is included under the term Inflammatory Bowel Disease and share similar symptoms. The Crohn's and Colitis foundation of America (CCFA) reported in 2014 that "approximately 1.6 million Americans currently have IBD," a growth of approximately 200,000 individuals since their last report in 2011 (Crohn's and Colitis foundation of America, 2014). They further state that one in 200 Americans suffer from IBD and "as many as 70,000 new cases of IBD are diagnosed in the United States each year" (Crohn's and Colitis foundation of America, 2014, p. 2). These numbers are growing and so is the need to understand the experiences of millions of Americans:

Although these numbers indicate an increase in cases of Inflammatory Bowel Disease (IBD)--a chronic autoimmune illness--they do not tell us about the people behind the statistics. Not only is there a growing number of people with IBD, there is a growing need to examine the IBD culture and its missing narratives. (Defenbaugh, 2007, p. i)

Mental health often impacts symptom experiences of IBD. Stress, anxiety and depression are significantly linked to exacerbation of the symptoms of this disease (Jerndal et al., 2010; Kearney, McDermott, Martinez & Simpson, 2011). Anxiety and depression can cause and be caused by symptom experiences or the illness alone. Research shows that the gut and the brain

are scientifically interconnected, meaning that symptoms experienced in the bowels are impacted by experiences of anxiety and depression (Mayer, 2011; Mayer, Tillisch & Bradesi, 2006). The physical symptoms of IBD are often times considered socially taboo, possibly contributing to the anxiety sufferers feel due to their illness. Individuals with IBD often experience frequent and painful bowel movements including constipation, diarrhea, abdominal pains, and sometimes inflammation. They may feel anxious when leaving the home, hoping they will be near a restroom if the sudden or immediate urge arises. Yet, it can also be embarrassing for individuals with IBD to use public restrooms. They may feel obtrusive to others when using stalls, due to bodily noises and groans of pain. Lifestyle change, such as diet changes, is also common for individuals with IBD. Certain foods will often escalate symptoms and inflammation. Due to the disease, individuals' overall quality of life may begin to diminish, and some might isolate themselves from social interactions. This could have adverse effects on their experiences of anxiety and depression.

For example, Voci and Cramer (2009) found that “The social undesirability associated with bowel habits along with the unpredictability of symptoms (e.g., a sudden urgent need to use the washroom) can cause significant anxiety and embarrassment and lead to social isolation” (p. 1169-1170). Individuals experience this anxiety and isolate themselves due to the perception that others hold or endorse stigmas about their condition. Stigma is a social belief that particular attributes are deviant and therefore shameful or disgraceful (An & McDermott, 2014). For example, compared to men, women consider bowel functions to be more shameful and in turn are more likely to keep their symptoms a secret ultimately resulting in physical, social, and emotional isolations (Voci & Cramer, 2009). This is important to note since research shows that women are more likely to meet criteria for IBD, seek treatment, and experience more damage to

their quality of life than men (Voci & Cramer, 2009). The social stigma and potential isolation associated with this condition can impact individuals' quality of life throughout their condition. It has become increasingly more important to understand the ever-evolving experiences of individuals with IBD.

This thesis aims to explore how women negotiate relationship turbulence while managing their IBD. I have given a brief overview of what the medical condition of IBD is and the growing number of diagnoses nationwide. In Chapter 2, I explain how IBD has garnered attention in popular culture, medicine, and psychology, as well as provide a discussion of what interpersonal communication scholars know about communication and illness. I review literature on disclosure and argue that it is time to move beyond understanding the initial IBD disclosure between partners, to understanding the long-term, ever-evolving effects of managing life with IBD. I conclude the chapter with a discussion of relationship turbulence and the specific research questions guiding my research project.

## Chapter Two: Literature Review

This chapter provides a framework and central argument for this study. I draw from The Relational Turbulence Model (Solomon et al., 2010), to identify the key constructs of interest in this research. Specifically, I am interested in how relationship turbulence as a result of IBD occurs in the relationship, the role uncertainty plays in these relationships, and how IBD may impact relationship intimacy as well as one's identity. As a foundation for this research, I turn to literature that explores how IBD is viewed in the various disciplines, what we currently know about communication and illness, and how illness impacts relationships.

IBD has garnered medical, psychological, and popular culture attention. The Crohn's and Colitis Foundation of America recently ran a campaign of public service advertisements in an effort to encourage people to learn more about the disease (Newman, 2013). They are not alone. Currently, there are a number of TV commercials and print advertisements for individuals with IBD, which ultimately may be changing perceptions and actions associated with the disease (An, 2008). Commercials and advertising campaigns have the ability to alter the rhetoric behind IBD along with the way our society and culture talk about the disease. Advertisements can promote ill individuals, as well as friends, family, and romantic partners, to seek more information. Increases in information seeking have the ability to reshape perceptions or stigmas (Ahn, Park, & Haley, 2014). Ahn et al. (2014) noted that rather than focusing on how consumers process one ad, it may be productive to allow individuals to gather health information from a variety of sources (e.g., television, print, and online), which reinforce one another, and can maximize the overall comprehension of information. For example, An (2008) found that direct-to-consumer advertisements for antidepressants increased individuals' perceptions of the prevalence of the disease and allowed them to reveal their symptoms and seek care. Similarly Murray, Lo, Pollack,

Donelan and Lee (2004) found that direct-to-consumer advertisements allowed lower socioeconomic classes to be more confident to schedule check-up's and disclose concerns to doctors. Yet Murray et al. (2004) importantly note that direct-to-consumer advertising has two goals: to provide information while simultaneously fulfilling a marketing goal. When consumers receive information from a biased third party, such as a pharmaceutical company interested in selling a product, the result can be wasted resources in the form of unnecessary, costly tests to determine if an individual really has the condition described in the advertisement. Commercials and advertisements for IBD may have similar effects on stigma and information seeking.

In addition to direct-to-consumer advertisement, popular magazines, news outlets, and online forums have addressed IBD. *Cosmopolitan* magazine, for example, highlighted the testimony of a woman living with Ulcerative Colitis and the impact the disease had on her relationship and communication with her partner (Ruderman, 2011). The story points to the troubling experiences of disclosure and symptoms. This story was also important because it allowed a number of young women, the magazine's general target audience and a large population of those being diagnosed each year, to identify with the story, seek information or support, and/or better understand the impact IBD can have on individuals and couples' lives. The growing number of recent diagnoses has led to increased news attention as well. CNN.com named 15 diseases doctors often get wrong; IBD, Celiac Disease, and IBS were among the diseases listed (MacMillan, 2014). Through these commercials, magazine articles and news stories, individuals with IBD may not feel so alone.

Another area of popular culture attention is the support that can be found in online forums. A number of online public forums exist (e.g., [girlswithguts.com](http://girlswithguts.com); [ibsgroup.org](http://ibsgroup.org); [ibstales.com](http://ibstales.com)) as a space for individuals to support one another and discuss the disease experience

such as symptoms, lifestyle challenges, and treatments. Online forums are a critical space for support given our social norm of not discussing bowel habits. Diener (2011) describes the challenge of discussing conditions in person, which highlights why online forums are a critical space for support. She states:

Dealing with erratic and foul bowel functions and fluids can be particularly challenging not only because of the physical pain that they cause but because of the stigma surrounding bodily fluids, more specifically poo. It seems as if there are no words that effectively describe excrement without making it seem overly medicalized or terribly vulgar. Despite the fact that defecation is a natural and universally shared human process, it is a source of disgust and private shame. Good people don't air their shit in public.

(Diener, 2011, p. 5)

These online spaces allow individuals to either identify themselves or remain anonymous. Anonymity is used strategically in online support groups when individuals face stigmas or illness related embarrassment (Rains, 2014). This online space allows individuals to voice their taboo narratives, and creates platforms that are critical for changing social views about the disease (Davis & Calitz, 2014). It provides a space to diminish isolation along with stigma and is a trend for those with IBD. When an individual experiences an illness that is stigmatized they may perceive that others see them as gross or disgusting, contributing to their anxiety. Popular culture attention has the ability to alter these stigmas (An, 2008).

Medical researchers and psychologists have also focused on the interconnected nature of stigma, anxiety, depression, and IBD symptoms (Jerndal et al., 2010; Kearney et al., 2011). Taft, Keefer, Leonhard and Nealon-Woods (2009) highlight that stigma is influenced by social and psychological factors and connect this stigma to health outcomes. They stated,

Perceived stigma was a significant predictor of increased anxiety and depression, as well as decreased self-esteem and self-efficacy. By increasing levels of depression and anxiety, perceived stigma may also compromise immune system functioning and lead to more frequent disease exacerbations.... A majority of IBD patients reported perceived stigmatization (Taft et al., 2009, p. 7-8)

The relationship between the gut and brain has created a need for psychotherapy (Mikocka-Walus, Gordon & Stewart, 2013). Anxiety can be caused by symptoms and in turn exacerbate them. Symptoms can cause distress and negatively impact quality of life (Banovic, Gilibert & Cosnes, 2010; Jaghult, Saboonchi, Johansson, Wredling & Kapraali, 2011; Koloski, Boyce, Jones & Talley, 2012; Lowe & McBride-Henry, 2012; Taft et al., 2009). It is because of the impact of the cycle of anxiety, depression, and symptoms that psychotherapy is used to help alleviate symptoms. IBD has been referred to as a psychosomatic condition (Gerson, 2002). A psychosomatic illness is “the sudden emergence of symptomatology without physiological explanation and without therapeutic relief” (Gerson, 2002, p. 382). It is important to note that symptoms are not the only explanation for individuals feeling stigmatized (Taft et al., 2009). Self-identity has also been identified as a central concept for individuals living with IBD (Taft et al., 2009). Finally, mood disorders have also been associated with IBD (Mykletun et al., 2010). As IBD emerges within our culture it is important to understand the medical, psychological, and media attention surrounding the condition and it is imperative to employ a communication lens in order to understand the impact this condition has on interpersonal relationships.

## Communication and Illness

Interpersonal communication scholars have explored specific disease states in order to understand how various health conditions impact individuals' lives beyond the physiological symptoms. Previous work on health in the field of communication has focused on mental illness (An, & McDermott, 2014; Knobloch & Delaney, 2012), HIV and AIDs (Brashers, Neidig & Goldsmith, 2004; Peterson, 2011; Horan et al., 2009; Smith, Ferrara & Witte, 2007), cancer (Heilferty, 2009; Horan et al., 2009; Miller & Caughlin, 2013; Weber & Solomon, 2008;), and Alzheimer's disease (Rhys & Schmidt-Renfree, 2000; Stone, 2013). Studies on illness and interpersonal communication have focused on identity (Charmaz, 1995; Charmaz, 1983; Kundrat & Nussbaum, 2003; Scott, 2006), social support (Brashers et al., 2004; Stone, 2013) and relationships (Brashers et al., 2003; Miller & Caughlin, 2013).

When individuals are adapting to their illness they experience different effects on their body, social identifications and self-definitions. Charmaz (1995) found that the effects of adapting to illness intersect between the body, identity and self. For example, Brashers et al. (2004) found that individuals living with HIV experienced a dilemma between reporting appropriate coping with the illness, and stating a need or desire for social support. Miller and Caughlin (2013) found that couples experienced challenges to their identities, how they saw themselves and their relationship in regard to illness. This work begins to highlight how individuals communicate about the multifaceted experience of illness. Interpersonal scholars have found that chronic illnesses pose unique challenges that impact communication processes. One communication concept particularly salient for this study is identity.

**Identity.** Illness, especially chronic illnesses such as IBD, can interfere with the daily routines of an individual's life. Individuals often will begin to see themselves differently upon

experiencing symptoms and receiving a diagnosis. Often, one's identity must be renegotiated after being diagnosed with an illness. Charmaz (1983) noted that when ill individuals experience less control over their lives and futures, they could lose their sense of self-identity. These changes in self-identity can influence their interpersonal interactions. In some cases, ill individuals will adapt to their new identities, and can begin to be open with others about their illness as well as how it impacts their life (Charmaz, 1995). Clarifying how the body, identity, and self intersect in illness, Charmaz (1995) offers that a method of negotiating life and identity with an illness is through adapting to it:

By adapting, I mean altering life and self to accommodate to physical losses and to reunify body and self accordingly. Adapting implies that the individual acknowledges impairment and alters life and self in socially and personally acceptable ways. Bodily limits and social circumstances often force adapting to loss. Adapting shades into acceptance. Thus, ill people adapt when they try to accommodate and flow with the experience of illness. (Charmaz, 1995, p. 657)

Ill individuals may not be the only ones adapting to illnesses; for example friends, relatives and romantic partners often make adjustments in order to maintain the relationship (Bute, Donovan-Kicken, & Martins, 2007). Solomon and Theiss (2011) note that as partners develop more intimacy with one another they tend to see one another as a part of their individual identity. Intimacy can be defined as the closeness and connectedness of individuals, establishing a bond and emotional tone in relationships (Knobloch & Solomon, 2004; Knobloch, Miller & Carpenter, 2007). Solomon et al. (2010) state, "As partners become more intimate, however, they allow each other to participate in previously autonomous routines. Eventually, everything from eating meals to visiting families can become dependent on a partner's behavior" (p. 120). Emotions

become shared and daily routines become integrated routines that require contributions from both partners for successful completion. Routine behaviors can also be referred to as rituals:

Couples engage in multiple rituals. They establish common ways to manage daily routines and tasks. They may divide up household chores of cooking, doing the dishes, and taking out the trash. They enjoy each other through idiosyncratic rituals that may include playful verbal banter, repeating favorite activities, or sharing memories. They engage in everyday talk, which includes specialized language. (Farrell, DiTunnariello & Pearson, 2014, p. 232)

The rituals and shared identities of developing relationships can be interrupted by illness. For example, Miller and Caughlin (2013) identified how couples share and negotiate identity throughout cancer treatment and survivorship. They demonstrated that identity challenges related to the condition are experienced as a couple.

Illness has been divided into two types within the literature: visible and invisible. Visible illness refers to illnesses that could be apparent before getting to know an individual (Kundrat & Nussbaum, 2003). Others can readily identify visible illness, which reduces individuals' options for disclosure (Joachim & Acorn, 2013). For example, illness that results in mobility impairment or assistance are often visible to others such as blindness or paraplegia. Invisible illness refers to any illness in which symptoms do not readily show to others on a day-to-day basis (Defenbaugh, 2013). Some chronic conditions include both invisible symptoms and visible symptoms, which often occur during disease set backs, complications, and flare-ups (Joachim & Acorn, 2013; Kundrat & Nussbaum, 2003). Since invisible illness is not always evident, individuals have more control over deciding to hide their disease or pass for healthy (Joachim & Acorn, 2013; Kundrat & Nussbaum, 2003; Myers, 2004). Invisible illness poses specific challenges to both individual

identity and identity as a couple because of the demand for disclosure. IBD is considered an invisible illness (Defenbaugh, 2013; Joachim & Acorn, 2003; Myers, 2004); therefore invisible illness will be the focus for the rest of this section. It is important to look at identity challenges related to invisible illnesses because individuals can be more strategic in their construction of illness as part of their identity. Kundrat and Nussbaum (2003) believe “that identity is constructed in interaction, and, through disclosure of an invisible illness, the ill individual’s identity changes” (p. 341). They further stated that invisible illness “often becomes apparent to a person only as a result of verbal disclosure by the invisibly ill individual” (p. 335).

Although invisibly ill individuals can often “pass” as healthy until they tell others about their condition, my study aims to explore beyond initial disclosure, when “passing” for completely healthy most likely cannot happen. It is also important to understand how “passing” may still occur after the initial disclosure and create a dilemma for ill individuals between disclosing an exacerbation of their condition or passing for healthy. After the initial disclosure, invisibly ill individuals often find themselves communicating more about their condition in order to validate their identity (Kundrat & Nussbaum, 2003). Because their symptoms do not readily show, the invisibly ill may feel the need to legitimize their identity as either healthy or suffering (Brashers et al., 2003; Defenbaugh, 2013). For example, concern for the ill individual is often relayed in the form of questions about the individual’s physical ability such as “Are you going to be all right?” and “Are you sure you can do this?” (Kundrat & Nussbaum, 2003, p. 340). Yet, if individuals view their condition to be worsening, they may choose not to disclose this fact to others. Greene et al. (2012) stated, “It may be especially difficult to tell others if a disease is progressing badly or is stigmatized. People might not want to share ‘depressing’ and/or identity threatening news with others and choose instead to protect others or themselves” (p. 365).

Beyond initial disclosure, invisibly ill individuals have a dilemma over protecting themselves and others from distress and must continue to contemplate further disclosure throughout their experience. The expectation of whether others will support stigmas related to illness or not will impact decisions to seek support and continue disclosure throughout their experience. Yet, disclosure must occur before they can be stigmatized. Whether or not others know of the individual's medical condition, the fear of rejection impacts an individual's decision to seek out support. It is possible that within romantic relationships, individuals may feel that their partner will endorse a stigma, which could impact experiences of intimacy.

### **How Illness Impacts Romantic Relationships**

In cases of chronic and invisible illnesses such as IBD, it is important to remember that the illness impacts the individual as well as those to whom they are closest (Defenbaugh, 2007, p. i). When individuals in a relationship become ill or choose to reveal an ill identity, they often experience uncertainty about their relationships. Brashers et al. (2003) found that individuals with HIV were uncertain about how others might respond to their HIV status, how to prevent social isolation, and how to maintain or create a relationship. Horan et al. (2009) explored the predicted relational outcomes when developing new relationships across different disease states. They found that HIV positive individuals had more negative predicted outcomes compared to cancer stricken and healthy individuals. It is highly possible that outcomes were more negative because HIV is transmittable.

Badr and Acitelli (2005) discuss the nature of dyadic adjustment that occurs during illness and suggest that relationship talk can be utilized as a tool to enhance partner communication throughout chronic illness. Hughes, Scholl and Walker (2005) explored health-related talk and marital satisfaction in couples with and without an ill partner. Their findings

suggested that communicating expectations for health-related talk, as well as expressing emotions and needs, promotes goal achievement, satisfaction, and avoids relational imbalance. Ill individual's increased needs may lead to the perception of imbalance which can result in decreases in closeness or intimacy. The increased needs of the ill individual may also lead them to feel like a burden to partners, increasing avoidant strategies. Similarly, Dillow, Dunleavy and Weber (2009) found that when individuals felt they were not getting what they deserved, they were less likely to talk about what was bothering them about the relationship. They also found that an increase in topic avoidance contributed to a decrease in relational closeness. Ill individuals may feel the need to weigh the costs associated with talking directly about the illness itself or symptoms of their condition. Yet, Dillow et al. (2009) found decreases in closeness when topics were avoided specifically out of self-protection.

Miller and Caughlin (2013) discuss the challenges of negotiating and redefining relationships throughout illness. They stated, "Even if a couple's satisfaction remains the same, the cancer experience can influence how couples see themselves, understand their relationship, and transition back to normal throughout survivorship" (p. 76). Further, Miller and Caughlin (2013) demonstrate that transitions of illness impact couples, at the individual and dyadic levels. They found that both individuals saw themselves to be a unit, yet defined their relationships in different ways (e.g. lovers, husband and wife, caregiver and care recipient). Invisible illness requires more disclosure, especially when seeking social support. Defenbaugh (2013) stated, "for those living with IBD their story may be familiar because they've likely created privacy boundaries and examined the benefits and challenges of disclosing time and time again" (p. 168). Research on illness and interpersonal communication has focused largely on the process of disclosure (i.e., revealing and concealing information). Yet, it is important to move beyond the

process and explore the effects of disclosure over time. Similarly, Badr and Acitelli (2005) highlight the need to examine the longitudinal effect of managing illnesses within relationships.

### **Interpersonal Relationships and Disclosure**

The processes of self-disclosure, including the concept of revealing and concealing information related to illness and health, have largely been studied within interpersonal relationships (Defenbaugh, 2013; Hesse & Rauscher, 2013; Miller 2009; Romo, 2011). Benefits of disclosure include preventing the suppression of painful thoughts, beginning sense-making and cognitive reappraisals as well as receiving social support (Lewis & Manusov, 2009).

Disclosure in close relationships can be attributed to levels of closeness and trust, access to social support, and obligations to the relationship or partner, which are all aspects of intimacy (Derlega, Winstead, Mathews & Braitman, 2008). Fear of losing respect and becoming rejected may prohibit individuals' from disclosing within close relationships (Derlega et al., 2008). In addition, individuals may choose to keep certain information private when deciding to disclose.

#### **Disclosure and privacy.**

Communication Privacy Management Theory provides a theoretical foundation for understanding the nature of privacy and the process of disclosure (Hesse & Rauscher, 2013). Individuals who value a higher level of privacy over their personal information make more careful decisions about when to disclose and with whom to disclose (Hesse & Rauscher, 2013). Individuals also use more indirect disclosure strategies when they perceive that others hold or endorse a stigma regarding their illness (An & McDermott, 2014). Diener (2011) stated,

The offensiveness and stigma surrounding bowel movements arguably makes it very difficult for those with IBD to be able to express their experiences and struggles with

illness. Talking about bowel movements with others, including medical professionals becomes difficult due to fear of being judged and shamed. (p.32)

Disclosures regarding taboo topics have been perceived as more threatening. Petronio and Martin's work in the mid 1980's produced conflicting results regarding the impact of the topic on disclosure decisions. In 1984, Petronio, Martin and Littlefield found that the topic did not impact disclosure decisions. Yet later in 1986, Petronio and Martin found that sexual topics, compared to achievement topics, were perceived as more threatening. Given the symptoms associated with IBD and the social taboo surrounding discussions of bowel functions, this topic is likely to impact disclosure decisions and predicted outcomes of disclosing. There is a need to explore repeated disclosure related to unpleasant taboo topics.

Past research supports that people selectively decide how, when and to whom they will disclose (Mathews, Derlega & Morrow, 2006). In addition, Petronio et al. (1984) found that sender and receiver traits significantly influenced decisions about when and with whom to disclose information. Women tend to disclose more frequently across a range of topics (Mathews et al., 2006). Petronio et al. (1984) discovered that women "find it more important than men do, that the receiver be discreet, trustworthy, sincere, liked, respected, a good listener, warm, and open" (p. 71). They also found that "it is important that [women] be accepted, be willing to disclose, be honest, frank, not feel anxious, or be provoked into giving information" (p. 71). Petronio et al. (1984) also suggest that their findings could be partially due to socialization and stigma of gender roles. Regardless of socialization, Petronio et al. (1984) found that emotion indeed impacted disclosure. Many scholars have studied individuals' decisions related to when and how to reveal or conceal information, yet few have examined the nature and impact emotions have on decisions to disclose information (Hesse & Rauscher, 2013). Individuals'

mood fluctuations can produce changes in the quality and reciprocity of self-disclosure (Forges, 2011). For example, positive moods promote daring and intimate disclosure strategies, while negative moods decrease intimacy yet improve self-monitoring and reciprocity of self-disclosure (Forges, 2011). It is important to understand the nature of mood fluctuations and disclosure because IBD is associated with mood disorders (Mykletun et al., 2010).

Kundrat and Nussbaum (2003) found that “the absence of disclosure [of invisible illness] may, in part, be a result of anxiety about possible relational consequences of such a significant revelation” (p. 335). Disclosing information to someone allows them some level of ownership and control over that information, which often calls for creating and maintaining privacy boundaries. Concealing information or engaging in “passing” behaviors is one way to manage invisible illness (Defenbaugh, 2013). The ability to engage in these passing behaviors to manage privacy boundaries provides a reason to extend beyond the initial disclosure stage. Hesse and Rauscher (2013) argue that future research needs to examine how privacy boundaries are negotiated in dating relationships with an ill partner.

#### **Disclosure decision making model.**

Greene (2009) created the Disclosure Decision Making Model (DD-MM) to better understand the process used when deciding to disclose information, specifically regarding illness. This model is designed to predict the likelihood of disclosure about nonphysical health information. Green et al. (2012) stated:

The selection of nonvisible health conditions allows for exploration of information management because the diagnosis must be intentionally shared, rather than focusing on conditions that are readily visible to others and not relevant for self-disclosure per se (although management of pain, stigma or treatment of such health conditions would be a

valuable area of study, this is very different from nonvisible diagnosis disclosure). (p. 364)

The model considers five factors when individuals decide to disclose illness: stigma, prognosis, symptoms, preparation, and relevance. Stigma is associated with receiving and sharing the diagnosis, and is the most studied of the five factors. Prognosis involves considering the future and nature of the disease (e.g., chronic, treatable), while symptoms are considered in terms of visibility and progression. The preparation factor focuses on if the diagnosis was anticipated (e.g., genetic), and relevancy refers to how the disease is transmitted (Greene et al., 2012). This model allows for exploration of the impact illness has on disclosure. The model highlights the facets of disclosure evoked by illness, and is a good starting point for understanding these facets beyond initial disclosure. The model further validates the importance of understanding how stigma impacts illness experiences.

In follow up work testing the model, Greene et al. (2012) found that sometimes individuals tested the possible outcomes of full disclosure by giving small amounts of information. They also found that the level of closeness and quality of the relationship between partners increased ill individuals' intentions to disclose, as well as their anticipation of a supportive response (Greene et al., 2012). Checton and Greene (2012) explored beyond initial stages of disclosure, looking at patterns of disclosure within relationships. Checton and Green examined the roles of prognosis and symptoms using Greene's Disclosure Decision Making Model. They found that uncertainty about the future encouraged breadth of topics, and disclosing a range of topics can decrease stress. Prior experience with the partner and disclosing the same information to others may affect the perceived ability to talk with that partner (Greene et al., 2012). Checton and Greene (2012) also found that individuals, who believed they had the ability

to talk with their partner about their condition, engaged in more in-depth talks and shared more intimate issues. Greene et al. (2012) noted that the anticipated responses from partners predicted increased depth of a current disclosure and the possibility of future disclosures. The work using DD-MM was important because it demonstrated the connection between illness experiences and disclosure decisions.

### **Relational influence on disclosure.**

Time spent together as a couple and the rituals that have developed throughout are found to increase levels of disclosure between partners. Indeed, Farrell et al. (2014) stated, “Rituals allow the couple to recall their relational history and to project their relational futures” (p. 232). Time spent together and secrets shared with one another can also enhance relational satisfaction (Farrell et al., 2014). Yet, couples can be reticent to disclose fearing their partner will react negatively to the information shared. Perceptions of the outcomes of disclosure are often more negative than the actual experience (Caughlin, Afifi, Carpenter-Theune & Miller, 2005). Manne et al. (2004) explored disclosure between breast cancer patients and their partners and found that perceptions of intimacy were related to partner responsiveness. They stated, “perceived partner responsiveness mediated the association between self-disclosure and perceived intimacy and between perceived partner disclosure and intimacy” (p. 596). Their findings demonstrate that partners play a key role in disclosure and intimacy.

It is important to employ a communication lens in the exploration of IBD in relationships because invisibly ill individuals often have to communicate more about their symptoms than visibly ill individuals. Throughout experiences of symptoms and distress, couples must negotiate their identities and daily rituals. The taboo nature of IBD can challenge boundaries and evoke feelings of embarrassment. Embarrassing situations within the context of relationships has not

been heavily explored (Petronio, Olson & Dollar, 1989). Individuals with IBD can often feel limited in life and embarrassed about their taboo symptoms (Diener, 2011). After chronically ill individuals adjust to their changing identity and are no longer embarrassed, it takes substantial support to move beyond the overall focus on the illness (Charmaz, 1995). Specifically in regard to IBD, Diener (2011) offers that allowing people to express the social conditions that challenge them could aid in their identity negotiation and illness experience. There is a clear need to explore communication over the long-term experiences of chronic illness. I aim to explore these ideas in this study.

While the previous work on disclosure provided critical information about how sensitive health information is initially revealed, I argue that scholars should now move beyond the initial stages of disclosure to understanding the long-term, ever-evolving experiences associated with managing a chronic illness, specifically IBD. Symptoms of IBD may bring about different relational challenges throughout the stages of the disease. Similarly, communication beyond the initial disclosure of illness is essential for understanding maintenance of physiological and relational wellbeing.

Finally, the physical nature of IBD can cause significant relational interference such as occupational and lifestyle challenges, preventing some individuals from working certain jobs and limiting leisure activities. Fatigue and sleep disturbance are also common among IBD patients (Cremonini et al., 2009; Cohen et al., 2013; Opheim, Fagermoen, Bernklev, Jelsness-Jorgensen & Moum, 2014; Ranjbaran et al., 2007). Sleep disturbance may cause interference between partners when sharing the same bed, or when negotiating sleeping in separate beds. IBD can also interfere with pregnancy (Crohn's and Colitis foundation of America, 2015), and is associated

with anxiety and mood disorders (Mykletun et al., 2010). Many of the symptoms of IBD can interfere with couples routines and the lifestyle of the partner in a number of ways.

This literature review establishes a significant need to understand the role of communication and possible relationship turbulence that may occur as a result of a female relational partner living with IBD. I argue that there is still more to be understood regarding disclosure, identity, intimacy and relational boundaries. The Relational Turbulence Model (Knobloch & Solomon, 2004) is used to frame this study in an effort to extend the current research beyond initial disclosure of a health condition to understand how health conditions are communicatively managed in romantic relationships. This study specifically aims to identify how the long-term management of illness can result in relationship turbulence as well as how turbulence is negotiated or managed. These management processes impact identity, disclosure, and relational intimacy.

### **Relational Turbulence Model**

Solomon, Weber, and Steuber (2010) argue that it is important to understand the underlying mechanisms within relationships, specifically relational uncertainty and partner interference. These shape and make communication significant to the development, decay, and the persistence or faltering of relationships (Solomon et al., 2010). Since its inception in 2004, the Relational Turbulence Model (RTM) is an evolving theoretical framework that “highlights how transitions require couples to establish or revisit the foundations of their intimacy in ways that can either create ongoing distress or promote relational well-being” (Solomon et al., 2010, p. 130).

*Transitions* are moments or experiences that create the potential for change in relationships. Transitions are also the process of moving from what is known to what is unknown

(Solomon et al., 2010). They often involve reorganizing identities, roles, actions and behaviors. Transitions are embedded within, and shaped by, social contexts (Solomon et al., 2010). RTM aims to understand how relationship qualities (i.e. uncertainty and interference) can impact transitions that may cause turbulence. As Solomon et al. (2010) state, “relationship qualities that surface during transitions might prompt individuals and their partners to forge new conceptions of themselves and their relationships” (p. 129). *Turbulence* has been defined as “the tumultuous experiences that might occur within relationships in response to a transition” (Solomon et al., 2010, pp. 117). Moments of turbulence are “amplified experiences within relationships, such as polarized cognitions, stronger emotions, and more extreme communication behavior” (Solomon et al., 2010, p. 120).

*Partner influence* can either facilitate or interfere with an individual’s goals and routines. Partner facilitation occurs when the influence of a partner increases the likelihood of accomplishing goals, while partner interference occurs when their influence disrupts routines and decreases the likelihood of achieving goals (Solomon et al., 2010). For some ill individuals, perceptions of partner interference are associated with fear, anger, irritation, and sadness about their condition (Solomon & Theiss, 2011). This means that emotions about the illness impact perceptions of partner interference, ultimately suggesting that the illness experience may impact perceptions of intimacy within romantic relationships. Partner interference has been linked to relational uncertainty (Knobloch et al., 2007). Relational uncertainty can also impact perceptions and behaviors and is a central concept of this model.

When *relational uncertainty* occurs, individuals may feel the need to alter their identity. Solomon et al. (2010) stated that “the altered identities that develop as people experience novel circumstances might contribute to the relationship doubts and disrupted patterns of

interdependence that sometimes follow from those changes” (pp. 129). Relational uncertainty was found to contribute to relational turbulence evoking negative emotions (Knobloch & Solomon, 2003). Relational uncertainty is consistent with judging partner irritations as severe, reacting to surprising events in an extreme manner, and engaging in topic avoidance, which can lead to decreases in sexual intimacy (Solomon et al., 2010). Theiss and Estlein (2014) found that communication about sexual intimacy was perceived as more threatening during experiences of relational uncertainty. Sexual intimacy can be considered a taboo topic at times, which may suggest that the taboo nature of topics associated with IBD may also be perceived as threatening during periods of uncertainty. Theiss and Estlein’s (2014) findings suggest that the taboo nature of IBD might impact relational uncertainty.

The model also examines whether or not communication promotes or undermines intimacy levels between partners (Solomon et al., 2010). *Intimacy* is one of the pivotal elements of the Relational Turbulence Model. The model suggests that intimacy both indicates relational development (Knobloch & Donovan-Kicken, 2006) and relates to the influence partners have over one another in the development of interdependence (Farrell et al., 2014; Knobloch & Solomon, 2004). Within the Relational Turbulence Model intimacy is divided into three levels, (low, moderate, and high) and partner influence and relational uncertainty are often associated with varying levels of intimacy.

The Relational Turbulence Model is still evolving and there is no clear measure of intimacy levels. Previous work employed a few different intimacy scales (e.g., Love Scales [Rubin, 1970; 1973]) or researcher-created instruments when trying to categorize participants. Research examining intimacy and relational turbulence demonstrates that low levels of intimacy encourage independent superficial patterns of relating, while high levels of intimacy encourage

interdependence, high levels of disclosure and mutual commitment (Knobloch & Donovan-Kicken, 2006; Porter, Keefe, Hurwitz & Faber, 2005). Low levels of intimacy are associated with partner interference, while high levels are associated with partner facilitation. Moderate levels of intimacy involve peaks in partner interference and turmoil (Knobloch & Solomon, 2004; Knobloch & Donovan-Kicken, 2006; Knobloch et al., 2007). Moderate levels of intimacy have produced interesting, and at times contradictory, findings.

For example, Theiss and Solomon (2006a) found that the nature of intimacy was unclear when analyzing communication about relational irritations. They found that depending on the context of the study, different intimacy effects were reported. Studies unrelated to conflict reported a preference for indirect communication at moderate levels of intimacy when responding to problematic events, including engaging in topic avoidance (Theiss & Solomon, 2006a). Similarly, Solomon (1997) found that moderate levels of intimacy produced more indirect strategies for dating requests, while findings focused on conflict found that more direct strategies were used at moderate levels of intimacy (Theiss & Solomon, 2006a). Theiss and Solomon (2006a) found that complaints were often expressed more at moderate levels of intimacy. The lack of consistent measures of intimacy within the Relational Turbulence Model leaves room for contradictory findings such as this. It is important to continue to establish the nature of intimacy in hopes that a fundamental measure of intimacy can be created. Scholars have called for future research on the Relational Turbulence Model to better understand the effect of intimacy in relationships (Theiss & Solomon, 2006b).

RTM has been a guiding framework in studies focused on appraisals of irritations within relationships (Theiss & Solomon, 2006a), perceptions of network support (Knobloch & Donovan-Kicken, 2006), experiences of negative emotions (Knobloch et al., 2007),

interdependence (Knobloch & Solomon, 2004; Knobloch & Theiss, 2010), jealousy (Theiss & Solomon, 2006b), hurt (Theiss, Knobloch, Checton & Magsamen-Conrad, 2009), communication about sexual intimacy (Theiss & Estlein, 2014), relationship talk (Knobloch & Theiss, 2011) and depression (Knobloch & Delaney, 2012). Scholars have called for more exploration into communication processes related to managing illness within relationships (Badr & Acitelli, 2005; Horan et al., 2009; Knobloch & Delaney, 2012; Miller & Caughlin, 2013). The onset of an illness can serve as a relational transition that results in turbulence. It is important to explore the constraints of an illness as moments of relational turbulence to understand how couples negotiate the nature of uncertainty, partner interference and intimacy overall. With the growing prevalence of individuals suffering from invisible illness, this is a critical area in need of study. Past research has examined the prevalence of turbulence at moderate levels of intimacy, and has given a significant amount of attention to the relationship between intimacy, uncertainty and partner interference. While it is important to understand when turbulence may occur, it is also important to understand how intimacy, uncertainty, and partner interference are experienced in the creation and negotiation of turbulence. I use the model and its concepts as a framework for understanding how romantic partners manage IBD, rather than testing the model's elements. My contribution to RTM is to understand how relational partners experience each concept to negotiate turbulence, with varying degrees of success.

### **Research Questions**

The overarching research question driving this study is:

How do women's experiences with IBD influence their romantic relationships?

Specifically:

RQ1: How do women share information regarding their illness at the beginning of the relationship and as the relationship develops?

RQ2: How do women negotiate periods of relationship turbulence, experience uncertainty during these periods, and how do these turbulent moments impact intimacy within their romantic relationships?

RQ3: How do women define and redefine their identities within their romantic relationships?

## **Chapter Three: Methods**

In this chapter I describe the research questions driving this study, participant recruitment, the study procedures, and data collection and analysis. I frame my study around the Relational Turbulence Model in an effort to expand research on the role of disclosure, uncertainty, and intimacy in moments of turbulence within relationships, specifically regarding illness. Further, in order to gain a rich and detailed understanding of the IBD experience, this study uses the qualitative method of narrative inquiry. The following methods section is modeled after Smith's (2013) doctoral dissertation methods, which explored marital intimacy after prostate cancer surgery. I used in-depth, semi-structured interviews to gather the data to answer the following research questions related to how women's experiences with IBD influence their romantic relationships?

RQ1: How do women share information regarding their illness at the beginning of the relationship and as the relationship develops?

RQ2: How do women negotiate periods of relationship turbulence, experience uncertainty during these periods, and how do these turbulent moments impact intimacy within their romantic relationships?

RQ3: How do women define and redefine their identities within their romantic relationships?

### **Narrative Inquiry**

According to Walter Fisher (1984) humans are storytelling animals. These stories are often referred to as narratives, which have been used to describe, in detail, the complex nature of human experiences. Researchers investigate narratives in order to understand individual experiences that may contribute to new knowledge. Narrative inquiry is a method born out of the

appreciation for exploring the depths of individuals' lived experiences and the information available within personal narratives. This study utilized narrative inquiry in an attempt to further understand the turbulent moments in relationships in regard to women's IBD experiences. Narrative inquiry allows researchers to "harvest the rich, intimate details of a personal story" (Smith, 2013, p. 46). Upon analysis, the details provided in narratives can reveal how an individual is constructing, organizing, or processing certain life experiences. The basic elements of a narrative are the selection, organization, and relationships between events (Bulow & Hyden, 2003).

Narratives have been used as a qualitative method in the study of illness and therapy. Narrative in the study of illness has served a number of different purposes including therapy and enhancing doctors' understandings of their patients' experiences (Franke, 2009; Hyden, 1997). Illness narratives have allowed health care professionals to better understand what the patient is experiencing. For example, gastroenterologists have used illness narratives to better understand the IBD experience for patients (Franke, 2009). The more the doctors and nurses know about their patient's experience, the more they can make informed decisions regarding treatment. Researchers studying chronic illness also used narrative inquiry to understand the life experiences and issues of identity resulting from chronic illness (Hyden, 1997). In the area of IBD, Defenbaugh (2011) explored personal narratives behind IBD identity, including performance; she weaved together individuals' narratives, and the reactions of others close to them. She attempted to open up a space for discussion of the private, often concealed, moments of an invisible illness. My project builds on Defenbaugh's work recognizing that relational experiences are likely to be expressed within narratives as well. Frank (1993) stated, "reflexively and sometimes prescriptively, illness narratives invoke change, based on understanding illness as

a moment at which change is especially possible” (p. 41). In other words, illness narratives have the potential to uncover the complex moments of change that may result from the illness experience itself.

I utilized narrative inquiry in this study to gain a rich understanding of how experiences of IBD may create turbulent moments and impact disclosure and intimacy within relationships. Smith (2013) used narrative inquiry to explore couples’ maintenance of marital intimacy after prostate cancer surgery. Through interviews, she “probed deeply into the personal stories of their interactions and their doubts, hopes, fears, and triumphs along this path of experience” (p. 46). Narrative inquiry allows individuals to openly discuss their experiences, as they have perceived them to occur. The goal of using this approach is to illuminate a new understanding of the complexities behind how individuals respond to illness and how they negotiate their illness and romantic relationships.

Narrative inquiry utilizes interviews as a primary source in data collection. Charmaz and Belgrave (2012) state, “obtaining rich interview data is crucial for developing robust theories” (p. 348). While the aim of this study is not to expand or develop a new theory, it is framed around the Relational Turbulence Model and narrative inquiry is well suited for answering these specific research questions. Interviewing is particularly helpful when detailed information is needed and focuses on a single or a few individuals (Smith, 2013; Tracy, 2010). Each interview is typically semi-structured and begins with a set of prepared questions, which fluctuate throughout the interview based on the individual’s narrative or discussion. The advantage behind this technique is that researchers have the ability to simultaneously gather and analyze data in order to ask more meaningful questions as the interview progresses. Bulow and Hyden (2003) noted that researchers should ask questions regarding the individual’s actions, obligations,

external barriers, and diminished possibilities in order to understand how an individual constructs the order of, and relationship between, events. The specific interview and data collection procedures for this study are discussed below.

### **Recruitment**

I aimed to recruit approximately 10-20 participants using network and volunteer sampling techniques; my recruitment procedures resulted in 11 participants overall. A campus-wide email was sent through the Ball State University Communication Center calling for participants. This initial recruitment email highlighted the purpose, procedures, and inclusion criteria for this study. I also posted the recruitment email on my Facebook page. Individuals who volunteered for the study were also asked to share the email containing my contact information (e.g. email, telephone) with other potential participants. Previous studies framed around the Relational Turbulence Model have employed similar networking methods (e.g., Owlett, 2014).

Participants responding with interest were sent a second email with further information regarding the project. This included the research questions, goals, study procedures and finally an informed consented agreement. This agreement ensured participant confidentiality by discussing the procedures for storing and protecting data, as well as the use of pseudonyms in transcriptions and print. Further, this agreement informed participants of their ability to opt out of the study or any particular questions at any time, without consequence. The informed consent document was emailed in advance to allow the participants time to read over the material and carefully consider all elements of the study before agreeing to participate. Participants were asked to sign a physical copy of the agreement before the interview. For interviews that were not in person, consent forms were printed by the participant, signed, scanned and emailed to me as a PDF document.

In the second email I also explained the basic interview procedures, including that a typical interview lasts about an hour and could be conducted via FaceTime, Skype or face-to-face in a location of their choosing. I offered a location of their choosing on Ball State University's campus and all interviews held face-to-face were on campus while others occurred through FaceTime and Skype. Participants were asked to read over the consent form and then reply to me with the date, time, and location or medium in which they would like to have the interview. Participant comfort was important for this study due to the taboo discussions that occurred. Allowing the participant to select the interview location and or medium allowed them to feel more comfortable to offer a more open and detailed discussion. One week after receiving the consent form, a follow up email was sent to participants that had not yet responded to set up an interview. The follow-up email thanked them for their interest and encouraged them to contact me for an interview.

### **Participants**

Altogether there were 11 participants in this study consisting of women ages 19-30, from the Midwestern United States, with a diagnosis of IBD. The inclusion criteria for this study were comprised of females with IBD, including Crohn's Disease, Colitis, Celiac Disease, and IBS. Women had to be over the age of 18, and be currently in a relationship, or have been in a relationship within the last two years and following their diagnosis of IBD. The criteria ensured that participants were able to provide specific narratives regarding the nature of their relational communication during turbulent moments as a result of their IBD. It is important to note that past relationships are just as important as current relationships when aiming to understand the rich nature of disclosure, uncertainty, and intimacy, and how turbulent moments may either result in the continuation or termination of the relationship. In an effort to obtain a full and

dynamic understanding of communication processes and relationship turbulence, this study did not exclude any participants based on sexual orientation. Exclusion criteria for this study included, women who were under the age of 18, or had not been in a relationship following their diagnosis. Although it is important to understand the initial development of relationships, this study focused on the impact of IBD on established romantic relationships, with a particular focus on the negotiation of relationship turbulence.

Nine participants were in a relationship at the time of the interview and two participants were single. Seven of the participants lived separate from their partners and spent occasional nights together and two of the participants were married and cohabitating. In terms of specific diagnosis five participants were diagnosed with Crohn's disease and six participants were diagnosed with IBS, two of these participants also mentioned being undiagnosed with a second condition (see Table 1). Ten participants identified themselves as white/Caucasian, and one participant identified as bi-racial, Mexican and white.

Table 1

*Descriptive Statistics of Participants*

Pseudonym	Age	IBD	Status
Rachel	19	Crohn's	Dating
Sue	19	Crohn's	Single
Emily	20	IBS	Dating
Karly	22	Crohn's	Dating
Paige	23	Stress Induced IBS	Dating
Renee	23	IBS	Dating
Molly	24	IBS	Dating
Adrian	28	IBS & Undiagnosed	Dating
Haley	28	IBS & Undiagnosed	Married
Michelle	29	Crohn's	Married
Taylor	30	Crohn's	Single

## Procedures

I confirmed the details for each interview following each participant's reply to the follow-up email. The confirmation for each interview was given to participants at least 48 hours before the scheduled interview. After the consent form was signed, and the interview was about to begin, I briefly reminded each participant of her ability to opt out of the study or questions she may feel uncomfortable answering, at any time without consequence. Each interview was semi-structured with a set of prepared, open-ended questions (See appendix A for a copy of the interview schedule). These questions were the framework for the interview and I asked follow-up questions based on the information shared by participants during the interview to allow for rich, detailed accounts of each participant's lived experiences.

The interview questions used in my study were modeled after the type of questions asked by Morman and Whitely (2012) while examining critical incidents. They asked "participants to share their brief narrative accounts of the most memorable aspects of an event or experience" (p. 25). The Critical Incident Technique is a method of investigating important moments in life, in which individuals are surrounded by circumstances affecting their futures (Morman & Whitely, 2012). I asked participants to give accounts they were comfortable sharing in which they experienced increased IBD symptoms that they felt impacted their romantic relationships. The identification of the critical incident related to their IBD served as means to ground participants' narratives in times of relationship turbulence related to the IBD. Participants were prompted to give accounts that were less focused on symptoms and more on the status of the relationship, relational communication, connectedness of partners, and other relationship experiences at that time. After the interview concluded, I thanked participants, and had a brief conversation about

any questions they might have had. I also informed them as to when they could expect to hear more regarding the final results of the study.

My role as a researcher in this study was a complete observer (Keyton, 2011). This approach required careful listening to participants while simultaneously analyzing data in order to ask more specific and personal questions. It is important to note the impact the researcher's demographics could have on how comfortable the participant feels discussing different topics. It was expected that participants would feel more comfortable talking with me because I am similar to them. I am a female in my mid-twenties from the Midwest, who also suffers from IBD. I have chosen to take the role of complete observer rather than participant observer in order to explore a multitude of experiences, and not direct the interview to narratives about experiences similar to my own. While my experience with the condition certainly informs the questions for the study and within the interviews, I am interested in the overall nature of communication processes within times of relationship turbulence that may also differ from my own experiences. Thus, it was unnecessary that I be a participant observer in this study. To ensure I accurately captured the information shared by participants in the study findings, I sent an executive summary of the findings to all the participants for their review. Their review and response served as my member check. All participants reported that the findings reported in this study were consistent with their experiences.

### **Data Collection**

Interviews ranged from 16-43 minutes in duration with the average interview lasting approximately 26 minutes. Each interview was audio recorded using my personal laptop as a recording device and the files were stored on my secure, password-protected computer. I transcribed each interview and assigned pseudonyms to the participants to maintain participant

confidentiality. During the interview and transcription process, I made notes and observations before the coding and analysis process began. All data including audio recordings, transcripts and notes were stored under lock and key. Data will be kept for one year after the close of the study.

### **Data Analysis**

Interviews were recorded, transcribed and coded using a systematic and repetitive coding process to determine the emergent and overarching themes. Data was analyzed using an iterative approach, which is “the reflexive process of consulting and re-consulting the data to identify the emerging concepts that progressively refine the focus of the inquiry” (Tracy, 2013, p. 184).

Iterative approaches allow data from within narratives to emerge through the processes of coding. After all of the interviews were transcribed, they were coded in cycles to identify themes and answer the research questions. Tracy (2013) noted the “primary cycle coding begins with an examination of the data and assigning words or phrases that capture their essence” (p.189).

During primary cycle coding, I examined the narratives to identify themes of illness and relational turbulence. “Primary cycle codes are usually, but not always, also first level codes. First-level codes focus on ‘what’ is present in the data. They are descriptive, showing the basic activities and processes in the data” (Tracy, 2013, p. 189). The primary cycle coding revealed 52 key experiences and reflections tied to specific participant words (e.g. annoying, honest, realize, rough, stressful) that were collapsed into first level codes. The reflections were listed and then grouped into categories based on their similarities or the discussion surrounding the reflection. This process resulted in 14, second-level level codes. Further coding cycles aimed to identify codes specifically related to how participants negotiated IBD within romantic relationships. A few examples of these second-level level codes included: understanding, guilt,

stress/anxiety/depression, secret/invisible and lifestyle changes. The next cycle of coding re-examined the 14 primary codes and collapsed them into six third-level level codes. This process was conducted by listing the concepts that were highlighted in the research questions. For example, the research questions ask about six different concepts (experiences with IBD, sharing illness information, turbulence, uncertainty, intimacy, identity), which were then listed out. Second-level level codes were then collapsed under the six broader third-level codes based on their relevance to each concept.

The third-level level codes were titled: experiences with IBD's influence on the relationship, sharing illness information, negotiating turbulence, experiencing uncertainty, the impact of turbulence on intimacy, and defining and redefining identity within the relationship. The final cycle of coding further examined each of the six third-level level codes and the overlapping codes were then collapsed into the final three overarching themes: *Strategies and Phases of Disclosure*, *Experiences of Relational Turbulence*, and *Individual and Relational Identities*. Participant narratives illustrated multiple themes at once as these themes overlapped to inform the research questions.

## **Chapter Summary**

In this chapter, I discussed the methodical framework for addressing the research questions and understanding how moments of turbulence are created and negotiated with regard to women's IBD experiences. The methodology presented in this chapter argued for the utility of exploring personal narratives to gather sound evidence and a deeper understanding of the intricate nature of negotiating relational turbulence resulting from illness. I delineated the data collection and analysis procedures that allowed me to answer the research questions guiding this study.

## Chapter Four: Results

I gathered data from 11 interview participants for this analysis. These interviews were semi-structured and focused on questions regarding women's relationships and how they managed their disease. The overarching research question driving this study is:

How do women's experiences with IBD influence their romantic relationships?

Specifically:

RQ1: How do women share information regarding their illness at the beginning of the relationship and as the relationship develops?

RQ2: How do women negotiate periods of relationship turbulence, experience uncertainty during these periods, and how do these turbulent moments impact intimacy within their romantic relationships?

RQ3: How do women define and redefine their identities within their romantic relationships?

How do women define and redefine their identities within their romantic relationships?

Data from the interviews highlighted three overarching themes – *Strategies and Phases of Disclosure*, *Experiences of Relational Turbulence*, and *Individual and Relational Identities* – composed of subthemes. I will begin by describing the overarching themes and then provide examples along with explanations of each subtheme.

### Themes

#### Strategies and Phases of Disclosure

There were two phases of disclosure that had an impact on the relationship, the initial disclosure and continued discussion.

**Initial disclosure.** Within the initial phase of disclosure individuals used three disclosure strategies: direct, indirect and concealment.

**Direct disclosure.** Direct disclosure of the diagnosis was the most common strategy used. Six out of the 11 participants directly disclosed having IBD to their partners. For these participants, this strategy of disclosure did not create turbulent moments or have a significant impact on the relationship. Each individual that used a direct disclosure strategy had a partner with some prior knowledge of chronic illness. Some partners had medical knowledge from their professions, while other partners had previous knowledge through experiences with family members with chronic illness. Ultimately, this prior experience gave partners some sense of understanding and made disclosure less threatening for the individual. For example, Adrian's partner had experienced chronic illness among the women in his family. She stated,

... Well, he grew up with a sister that has, that had, Cerebral Palsy and his mom [had] Multiple Sclerosis ... as bad as it is, he's just kind of used to it. So it was never a big thing um, so I told him you know, I have, you know, these issues....

Adrian went on to express that because her partner had witnessed more severe chronic illnesses, disclosure was not a big deal. Karly also felt comfortable directly disclosing to her partner due to his prior knowledge. She said,

Okay, so he's actually a medical student so, thankfully, like, he's not really a stranger to those kind of things. And so, I think when we were in those first phases of talking, I mentioned [having Crohn's] and he was like, "yeah I know a little bit about that." And he kind of was interested and asked me questions and didn't make me feel embarrassed about it.

Finally, Paige described that she did not know of her partner's prior experience until after her direct disclosure. She stated,

I just said...yeah, like this is something that's like, kind of stigmatizing slightly, just cause if I have to go away and I'm in the restroom for 20 minutes, I don't want you to be like "are you dead." Like no, my bowels are just like exploding, and I'm dying slowly so, it's fine.... So he's like, "oh that sucks.... Cause, he um, worked with mental patients, or children with mental disabilities, and stuff and so, he said that there were some kids, [that] had those kinds of issues and stuff too. And he's like, "yeah, no it like super sucks."

Paige's experience is unique to the other participants in two ways. First, she was not aware of her partner's prior knowledge of the disease before using the direct disclosure strategy. Second, her experience is unique in the sense that while she used direct disclosure, she acknowledged that a stigma surrounds IBD. This is interesting to note because Taft et al. (2008) found that individuals with IBD report a perceived stigma surrounding the disease, and An and McDermott (2014) maintain that indirect disclosure is typically used to avoid that stigmatization. Yet, the literature also suggests that prior experience with a partner can affect the perceived ability to communicate with that partner (Greene et al., 2012). Paige's prior communication with her partner may have contributed to her willingness to acknowledge the stigma of IBD with her partner. The prior experiences partners had with people with IBD or other chronic illnesses helped some of the participants to feel more comfortable being direct in their initial disclosures. For some women, however, strategies of disclosure were less direct.

***Indirect disclosure.*** Contrary to direct disclosure, four out of the 11 participants used indirect strategies of disclosure. Individuals using indirect disclosure strategies expressed

varying levels of uncertainty or discomfort with their diagnosis. For example, as Molly described her strategy for initial disclosure, she said,

I found out that I had it just a little bit before we started dating. Um, so when he asked me out on my first date I was like, “well, I need to just go somewhere like, with a gluten free option.” So it was really awkward for me because I still wasn’t comfortable with the diagnosis and I didn’t want to come across as someone who is um, stuck up or needs things a certain way. Because my personality is really laid back and again I just didn’t wanna like, believe that I had an issue.

Molly was uncertain about her disease and she chose an indirect strategy for disclosure by stating that she could not eat certain foods, yet left out why she could not eat those foods. Previous literature suggests that the fear of losing respect or being rejected can prohibit individuals’ from disclosing certain information in their relationships (Derlega et al., 2008). Study participants engaged in indirect disclosures by providing less threatening or minimal amounts of information. Individuals disclosed indirectly by stating that something was medically wrong and they were seeing a doctor rather than describing symptoms or offering details about the disease experience.

It appeared that some participants hoped or assumed that partners would come to realize the condition on their own as a method of indirect disclosure. Understanding these experiences are important for increasing understanding of what types of information were shared when using an indirect disclosure strategy. For example, Taylor’s use of indirect disclosure was unique. She said,

I never have had to have that conversation with a partner, to say, you know, this is my disease and I have this. It’s more, it came out because he worked with me and knew I was, you know, in and out and had something. And so, eventually we just, you know,

discussed what I had. But um, he was familiar with the fact that I had something going on.

Along these lines, indirect disclosure also occurred when partners experienced more symptom visibility and progression. It was assumed that the partner was aware that there was a medical problem through observation rather than disclosure. For example, Rachel said,

I think it's more of a gradual thing because it was like, a few months of me just like having the symptoms of it. So he knew something was going on and then, um, I went to the doctor a few times and when I found out for sure, I guess I just told him. And, um, I mean he was pretty supportive about it. Before then he didn't really like to talk about like poop and stuff, or anything, since it was a problem he didn't have an issues with it after that.

Rachel described using indirect disclosure strategies until she was officially diagnosed and was able to disclose her condition more directly. The specific diagnosis legitimized her experience and allowed her to feel more comfortable discussing her symptoms and experiences with her partner. At times, indirect strategies led to more direct disclosure, for example relaying information given by the doctor or eventually stating things directly after partners observed the participants' struggles.

In some cases, it appeared that being in the middle of the diagnosis process resulted in indirect disclosures to partners. Yet, overall, individuals uncertain about their condition, their partner, or the relationship utilized indirect strategies. For one participant, uncertainty resulted in concealing the diagnosis altogether.

**Concealment.** One participant, Sue, never disclosed her disease to her partner during their half-year long relationship. Sue described instances of symptoms arising and how she managed to avoid disclosure. She said,

It came up, you know, a couple times cause, you know, I'd have to go home very fast and he's like where'd you go? But uh, I never told him. It was just, uh, it was hard. It's hard for me to talk about, um, and he wasn't like the most, uh, understanding person so.... I'd usually say, "oh well I had to pick up my little brother from school," and I'd forgotten or, you know, "there's just an emergency at home" or, you know, whatever.... He was a little self-centered so he didn't pry that [sic] too much.

Sue described concealing information due to uncertainty about her partner's level of understanding and acceptance.

Perceived stigma and the individual's level of personal acceptance of the disease, had an impact on the strategies participants in this study used during the initial phase of disclosure (i.e. direct, indirect, on concealment). While most individuals that felt uncertain or that a stigma surrounded their disease chose an indirect strategy, Paige's uncertainty led her to a more direct strategy of disclosure. She even addressed a perceived stigma during her direct disclosure. For most participants, the perception of stigma increased uncertainty that was eventually either reduced or managed through disclosure strategies.

Finally, Taylor further described uncertainty surrounding the social pressure behind initial disclosure. She stated,

It is always a part of the dating scene where it was just like, sort of like, if you have a child and people are like, "are you gunna you know tell him that you have a child right

away? Are you gunna wait or like, what?" And that is what it felt like, that it is always sort of like this, this, secret and this thing I had to share....

While the strategies used for initial disclosure were indeed important to how participants shared illness information, the continued phase of disclosure or continued discussion seemed to have a larger impact on the relationship.

**Continued disclosure phase.** Often times the continued discussion of IBD will occur during a flare-up, in which participants' symptoms are most active, present, and often witnessed by their partner. It was not until symptoms were experienced in the presence of the partner that the continued and more detailed phase of disclosure occurred. For example, Michelle stated,

And I mean when you're not in a flare it's manageable, like you're normal. I eat normal stuff, granted dairy free pretty much all the time now, and every now and again I have to do gluten free. But, like, other than eating habits I mean, it's pretty normal when there's not a flare. When there's a flare it makes, it makes life rough and you have to learn to like work through it.

Kundrat and Nussbaum (2003) maintain that following initial disclosure invisibly ill individuals communicate more often about their illness. For example, Rachel said,

I guess at the beginning we talked about it more, like cause I had like stomach, my stomach hurt and obviously the diarrhea and stuff. So, we talked more specifically about it when, like, the symptoms were worse and stuff, but, um, since they're better it's just more of a casual thing.

Previous literature also suggests that ill individuals are not the only ones that must adapt to the illness (Bute et al., 2007; Defenbaugh, 2007). Individuals were able to test whether partners will

stay through tough times according to their willingness or abilities to adapt. For example, Adrian described,

I think that there are couples who are together for three or four years before they go through something like this. Before their relationship is tested. Before they see each other at their absolute worst. I had it six months in, my boyfriend saw me in a hospital, uh you know, going to the bathroom followed by periods where I couldn't go to the bathroom at all. Like, my stomach is swollen and I'm in pain um, nauseous, I'm sweating, like all the beautiful symptoms that come along with it. He saw me almost from the beginning and he still stayed. I don't, I don't know what experience could mirror that. This disease, as much as I hate it, as much as it sucks, gave me the opportunity to really test the waters early and find out, okay, is this guy a keeper or am I wasting my time?

Partners were able to learn more and adapt to the individual's lifestyle after this continued discussion.

In some cases, closeness, openness, and honesty were increased as a result of when participants experienced symptoms and shared information with their partners. For example, Paige described experiencing uncertainty as she shared more information with her partner. She stated,

I think it's gotten easier as we've been together longer 'cause definitely the first few times that we slept over, or whatever, that was scary as hell cause I was just like really nervous.... [Now] I'll say like, "oh wow, I just, my stomach was ripped out" and "I was just in there, in a lot of pain" or something, and he'll usually be like sympathetic to that, [and say] "oh that sucks."

Further, Renee explained how her symptom visibility impacted closeness and made her feel she could share more details during subsequent discussions about her diagnosis.

R: ...while I know my boyfriend would love me no matter what, I don't really need to give him that imagery when we're being intimate haha.

I: Do you think it would impact intimacy if you did give him more imagery or detail?

R: I think I did for a long time, but recently, on his birthday, I decided to have projectile vomiting and diarrhea at the same exact time and destroyed his bathroom at midnight on his birthday haha. So I'm starting to think, no, it would not affect it at all, he uh, went through that like a champ.

Participants expressed that after their initial disclosure, it became necessary to share more detailed or specific information regarding their symptom experiences and the impact of IBD. Partners' responses to continued discussions, for most individuals, were positive and for some unexpectedly so. This finding is important as it is in line with previous findings maintaining that perceptions of disclosure outcomes were more negative than actual experiences ended up being (Caughlin et al., 2005). When partners reacted positively, participants described increased feelings of closeness, openness and honesty.

Contrary to this, some women's continued disclosure resulted in distance, misunderstanding, and turbulence. For example, while frustrated with the doctors and inconclusive test results, Haley aimed to discuss her frustration with her partner. She said,

I am a stressful person, I have anxiety and my form of stress is sometimes sleepless nights. Like, I can't sleep. I kind of get that tight feeling in my chest and I wasn't feeling that so, I was like, I know I'm not stressed...and my husband was like, "I think, like,

you're kind of starting to come up with this stuff in your head" and I was like, "I can't have blood in my stool and that's in my head."

Haley further stated that soon after that interaction, she had more test results come back inconclusive to which she responded, "...I was like, there we go again, I'm just a crazy person, you know." Haley described her processes of trying to figure out what had caused her symptoms for the specific flare-up she was experiencing. When her partner insinuated that it might be in her head, it really challenged Haley to reappraise the situation. She stated,

...I just kind of shut down telling him anything that was going on with my body, I was like, then, if that's how I can deal with it, and we can mend this, I'll just stop talking about it and that's kind of what I did.

She decided that she did not want to continue to share illness information with her partner. She said,

...I did feel bad. I wouldn't tell him because I didn't want, I just [be]came very reserved, and I [be]came very almost protective of how I felt cause, I was like, well he doesn't understand, so.... I still sometimes don't tell him, you know, "oh there's blood again in my stool," like, I just don't like to talk about it, or like, "I don't feel well today" or like anything like that.

Haley and the two participants that were single during the interviews (Sue and Taylor), embraced their ability to be in control, own their illness information, and carefully decide what and when information would be disclosed. This is similar to what Greene et al. (2012) found regarding anticipated responses predicting the possibility for further disclosure.

## Experiences of Relational Turbulence

Participants experienced relational turbulence in varying degrees. Some participants identified their experiences as turbulent while others described these as times of uncertainty and self blame. Participants offered a definition for what turbulence meant to them to better explain their experience. Examples within the subthemes are discussed in detail below to better illustrate the findings.

**Defining turbulence.** Participants were asked to describe a time in which their IBD impacted their relationship and if they would describe that time as turbulent. Participants were given the descriptor words stressful, dramatic, and messy to describe turbulent moments. Some participants identified with these descriptions of turbulent moments while others did not.

Adrian and Rachel did not describe their experiences as turbulent. For example, Adrian described feeling uncertain about her relationship based on her past experiences, yet when her partner reacted differently, it led to a realization. She said,

I thought it was going to be dramatic just based on my previous experiences.... So, I don't think that it was necessarily like turbulent or dramatic. I think it was just more of a time of self-reflection for me and realization that not everybody's going to leave you just because you have a disease like this.

Karly described turbulence as, "...kind of that, discomfort and embarrassment...not turbulent but just, you know, a little uncomfortable." Similarly, Rachel expressed not feeling turbulence, yet she described the uncertainty she experienced with her partner and how it was easily reduced upon diagnosis. She said,

I guess at the beginning I didn't really tell him about it very much because I thought like, it was, he would be grossed out about it. But once he knew that, like, there was something wrong, he wanted to hear about it. Like, just to make sure everything's okay.

Rachel's perception that her partner accepted the taboo stigma surrounding IBD increased her level of uncertainty about disclosing her illness and she reported this was the most turbulent time in her relationship as it related to IBD. At times, turbulence was expressed as the individual's perception rather than a mutual experience. In other words, some individuals were unsure if the partner was aware of how they were feeling or if the feelings were mutual. To illustrate this idea, Paige hesitated to define her experience as turbulent because she was unsure of her partner's emotions or knowledge of the turbulence. She stated, "... it was more on me, where I was more stressed out about it." Michelle described how turbulence was an individual experience in a unique way. She said,

I mean it's pretty normal when there's not a flare, when there's a flare it makes, it makes life rough and you have to learn to like work through it. So that, I would say, is the more turbulent time.... And I think it's mostly me that makes it that way. Like it's not dramatic for him cause he's not experiencing it. So what he's getting is my feedback. So it's the feedback that I'm providing to him. And it's because I know that I need to calm down, but because I know I need to calm down, I'm freaking out because I don't feel calm.

While these individuals did not describe their experiences as directly or mutually turbulent, they did conceptualize turbulence in their own way.

The individuals that agreed with the definition of turbulence I provided in the interview also expressed how their experiences of turbulence made them feel. For example, in Emily's description of her experience of turbulence she stated, "...it just made me feel isolated on top of

already feeling disgusting....” Similarly, Haley described, “Oh it was more turbulent...you do start questioning yourself and, like I said, I [be]came so much more reserved and protective of my own body and how I felt.” Finally, for Sue, she stated, “Yeah, it was hard, it was, it was a challenge.... So yeah, I think it strained the relationship and it, it strained me. It was a challenge.” The extensions to the description offered, and altogether redefining turbulence, allowed for a more rich understanding of how turbulence was experienced and negotiated, specifically in regard to IBD.

**Negotiating turbulence.** From these results it appears that turbulence can affect only one relationship partner and does not necessarily need to be a shared experience. For others, turbulence does impact both relationship partners and requires relationship partners to work through or negotiate those moments. Turbulence was negotiated in a few different ways including using open communication with partners, partners offering reassurances, and engaging in avoidance or withdraw behaviors.

**Open communication.** Some of the women in this study discussed a sense of ease in negotiating turbulence by having open and honest discussions with their partners about what they were and were not able to do. For example, Adrian said,

I would say that I was just very honest about, these are, this is, what I’m feeling. These are the symptoms I’m experiencing right now. I don’t feel well. I don’t want to go out. I think the honesty was a strategy that I employed because I didn’t want to go out, force myself to go out and fake it and be miserable the whole night and then be resentful of him for dragging me out. It was right up front, “Colin, I don’t want to go out. I’m sorry if that disappoints you. I’ll make it up to you. Can we do XY and Z instead tonight?”...I’d say that just being honest and having open communication was perfect.

Adrian offered alternatives to her partner, which was similar to other's experiences. Participants that described having an open discussion to negotiate turbulence mentioned talking with their partner about what they were able to do instead and would come to a mutual agreement. For example, Renee described how she and her partner negotiated turbulence by agreeing to avoid being intimate during vacation. She stated,

We went on vacation to Santa Cruise and I tried to be really calm and meal plan for the vacation and made sure I knew my options and stuff. And, um, then the vacation time came and our plan was to drink, and usually, like, if I had wine or lite kind of spirits, I wouldn't have, as bad of a reaction. . . . And, um, it just went downhill from there. And we both just kind of agreed f\*\*k it, we're not going to have sex, we're just going to drink and eat all the food.

Open communication was one strategy for negotiating turbulence that appeared easy to manage for the individual and the partner.

***Partners offering assurances.*** Similarly, another way that turbulence was negotiated was through partners offering assuring statements to show women they were accepted. For example, Karly stated,

I'm not going to lie, I feel like he probably did a lot of the work [to negotiate turbulence], cause like just with comforting me and saying like, you know, "its not embarrassing", "I don't judge you for it", "I don't, you know, see it as an issue." Um, so, he was just very good about verbally, asserting that, you know, he didn't see it as problematic or embarrassing.

Additionally, in her interview, when prompted to discuss advice she would give other women with IBD, Karly stated,

I think probably just being open about it and about the disease just so it gives their partner the ability to understand where they're coming from, where the embarrassment might stem from, and kind of give their partner, like, the tools they need to help be supportive....

Similarly, all of the other participants mentioned openness and honesty as important factors as well.

**Avoidance.** For a few women in this study, turbulence was negotiated using avoidance. While avoidance at times can carry a negative connotation, two of the three women that utilized avoidance had a positive experience. For example, Michelle's partner would skirt discussions that might cause her stress so that they could avoid turbulent moments. She stated,

I don't know, he kind of like, he knows that stress makes it worse. So, I feel like if he thinks I'm going to get stressed then he just avoids telling me things, cause he thinks I'm just gonna stress out about them.

For Emily, avoidance occurred because she did not know if her partner was aware of how hurt she was and stated that she did not even realize at the time how much it affected her. She stated,

I think that after, after all that happened, I don't think he realized how impactful it was on me and I don't think I even realized it until I started talking about it. Because, like, of course I just kind of like blew it off, um, and so, like, I didn't really realize how impactful it was until of course I'm talking about it now.

Also, Haley engaged in avoidance with her partner by cutting off communication with him about her body or symptoms as a strategy for negotiating turbulence.

**Withdrawing.** Finally, for two of the participants in this study, turbulence was ultimately negotiated through withdrawing. Taylor and Sue both stated that a contributing factor to

terminating the relationship was the turbulence, yet it was not the sole reason for the break up. Withdrawing from the relationship altogether negotiated turbulence by terminating the relationship. Experiencing and negotiating turbulence contributed largely to the final theme examining how individual and relational identities were defined and redefined.

### **Individual and Relational Identities**

Through disclosures and negotiating turbulent moments, individuals were able to define and redefine their individual and relational identities. Participants provided glimpses of their individual identities within their relationships while managing IBD. Descriptions included feeling: self-conscious and awkward, independent, and invisible.

#### **Individual Identity.**

*Self-conscious and Awkward.* A few participants described feeling self-conscious about their disease. While this is not a direct form of identity expression, discussions surrounding participant's feelings of self-consciousness highlighted portions of the individual's identity. For example, Emily described feeling self-conscious and stated,

Now, I think it, it makes me feel like, awkward, because I don't really, I don't really do the things that other women do. I just, I've never really been [in a serious relationship] so I never really thought about [my disease] actually like being [less feminine] because, I wasn't in a relationship....

She further stated,

You feel ugly, like, so ugly...Um you know, at first it was like, I can't do anything about this, like, what am I supposed to do? Should I be in a romantic relationship if, like, all of this is happening to me? I mean, guys don't like when women are not womanly quote unquote.... If I have to release gas, I don't want anyone to see me. I don't want to be too

invasive. And so like, I think that will be a struggle throughout the whole thing, is just like, being more comfortable in my skin about it.... I don't really understand that, like how do you just, I don't know, how do you just live with a condition? Like can't I just take medicine and just be all better?

Emily described feeling self-conscious and questioning if she could manage her symptoms and a romantic relationship simultaneously. Adrian also described IBD making her feel awkward and frustrated that she will never be able to cure her condition with only medication.

***Independent.*** Haley described feeling self-conscious while also including independence as part of her identity. She stated,

I've been very self-conscious with it. I think more than I thought I was going to be. Like you know when you're bloated and you don't feel well? I don't wanna talk to anyone. Like, I kind of just am like don't talk to me. Don't look at me. Let me just sit here in my sweatpants and wallow in my self-pity.... Haha, I know that sounds so awful.... But, like, um, I wish I would handle it better some days.... There's also a sense of, I'm also not letting it hold me down, um, I have to keep going.... Um, but so, I think I am still managing how I feel.... I'm a very independent person. I didn't wanna look like, "oh I can't do anything without my boyfriend or fiancé", like, I can't go to the grocery store without somebody being with me....

While Haley mentioned feeling self-conscious, she also expressed that independence was part of her individual identity. Sue and Taylor also mention independence as an aspect of their identity.

For example, Taylor described,

I just liked to act like I didn't have the disease and then sort of deal with it. And now my approach is much different that, I um, talk about it and think about it and know I have it.

And I'm so glad that I'm healthy now but I realistically know it's just a part of me instead of trying to live extremely, you know, having this life pretending like I don't have this disease and then getting sick and having this drama and being really upset about it....

When I stepped back, and we did break up, it was great for me to see that I could do it on my own, independently. I realized after that, you know, was I settling for certain things in my relationship? ...Once I stepped back and I saw I could do it on my own and I went back to school and I worked, remotely, uh, it just was a really freeing feeling of like, well it's hard, but you can do it by yourself.

Taylor expressed her feelings of independence as part of her identity and how terminating her relationship allowed her to redefine her identity.

*Invisible illness.* Finally, Paige described her sense of identity with an invisible illness, she stated,

I do kind of think that having any form of IBD is an invisible identity because it is something that is very much a part of you. And you have to learn that it's part of you now, forever. And it can become part of your identity if you want, but, just, it's a daily struggle.

Other participants described invisible aspects of the illness as well, yet only two participants discussed invisibility directly. Most participants' discussions of identity pertained to when the disease was visible. Similarly, some participants discussed engaging in passing behaviors (Defenbaugh, 2013). For example, Taylor described,

I always felt like I had this secret that I wasn't sharing and that's okay, but it does feel odd when, like I would make up all these excuses. Like, when I'd go on dates [I'd say] like, I can't eat salad because of, you know, whatever. "I don't like this" or "I can't eat

this because I'm on a gluten free diet." I would just make up these really silly excuses.... I think that um, I definitely hid behind the fact that I, at the time, looked so healthy but it was really easy with sort of like this invisible illness for me to hide it, um, and I did. I definitely did. But then there was a time when I took Prednisone and gained weight and all the sudden it wasn't as hidden and I had to discuss it more.

Molly also described her use of passing behaviors,

...If, you know, we go out to restaurants, I think, I don't want to be like, "oh can you make sure that it's not with any bread?" or "Is there wheat in the ranch dressing?" And to ask questions like that, I think makes me sound snotty or snooty, and it's just not me. So I think that is something that I'm like, maybe that person like, they're not going to want to stay with someone that's like that.

Both women in these examples focused on their dietary habits when trying to pass for healthy. Taylor described the initial dating stages, while Molly described her experience one year into her relationship. Passing behaviors surrounding dietary choices could be due to the nature of the disease and the influence dietary habits have on later symptom experiences. Passing behaviors seemed to occur to avoid disclosure of IBD.

### **Relational identities.**

Participants were quick to move to discussions of relational identity and partner support when prompted to discuss individual identity. Relational identity refers to how participants saw themselves and their partners as a unit or couple. For example, Renee stated,

Just being diagnosed with it initially, I had a lot of depression and it was really hard. And I was like, in a cycle of denial of like, first I'd be angry, and then sad, and then I would plead with the heavens to like take it back, and then I would just cry. And him handling

that after only knowing me for like three months was pretty impressive and made me love him more and I think him being able to be there for me when he could, emotionally, made him more attached.

Relational identities were often times redefined during a flare-up, or increased symptoms; one way of establishing these relational identities was through partners offering support. Partners offered support through asking questions, seeking answers and holding participants accountable. Participants described their relational identity with a more mature outlook or understanding of their partner and relationship than before.

*Asking questions, seeking answers.* Partners were able to begin establishing a system of support for individuals by asking questions or researching to answer questions. Partners attempted to understand what individuals were experiencing as well as what participants needed in order to live comfortably during a flare-up or turbulent experiences. This is also in line with previous findings that information seeking had the ability to alter stigma and question asking was a way of showing concern for ill individuals (Ahn et al., 2014; Kundrat & Nussbaum, 2003). For example, Rachel explained that her partner continued to ask questions until he understood her diagnosis better. She said,

I think um, just because I went to doctor's visits, afterwards he would ask me how they went, um, so, I just like slowly told him about it after all those [visits] and most of the time if I didn't really say that much, he would ask more about it.

Similarly, Paige described when her partner did not know much about IBD and they had not yet discussed the disease in detail. She explained,

.... He'll kind of be like are you okay? I'm like I need to go to the bathroom for a little bit so just keep, like...watching a movie or something. So sometimes it's frustrating but um,

he asked me, “What is that like? Cause you look like you’re trying to like, hold something back”....

Renee expressed that her partner did research online to better understand what foods he could buy or make to accommodate her. She states,

My boyfriend got really into research about the kinds of foods that I could eat and stuff that he could actually make. And so, like, at his house we’ll have a couple snacks that are available at the grocery store near his place that I could really snack on and at my place I’ll have different stuff so I don’t eat too much of one.

Further, Adrian explained that question asking is a common way she and her partner show support,

...We both are very good about that, showing our support of one another, asking questions to learn more about what the other person is sharing. I think being, acting like you’re interested in the other person is just a great way to show support.

Michelle’s experience, on the other hand, is unique; she is married, and her husband is in the military. He was deployed during her past flare-up and during her interview Michelle discussed her partner’s reactions and responses to her symptoms when he was present. His first time being present while she was having a flare-up increased his concern and enactment of support. In her interview, Michelle was asked how she thought her partner would respond if he were to be deployed again while she experienced a flare-up. She stated,

...He would feel a need to call, like every single day to make sure I’m okay. Which he did anyway before, but I mean, like, he would go out of his way like, “are you okay?” Like the first thing he would ask is, “Are you okay? How’s your belly? Are you handling, are you managing everything?” Like he would be more concerned about me and so I

think that he would be, I think it would affect him more than it would affect me, cause he would be the one like freaking out that he wasn't here.

While her response was hypothetical, it still uncovered Michelle's perception that question asking can sometimes be understood as a method of support.

On the other hand, a lack of question asking also spoke to the degree or type of support individuals received from partners. For example, one participant was able to understand her lack of support better through the lack of question asking from her partner. Haley stated that her partner was questioning the illness before their wedding and further explained,

Yeah, he doesn't get emotional. He doesn't pry, like he doesn't ask, "Okay, so what are you feeling today? What's going on? Like, what have you done?" Sometimes he will say, "what did you eat today?" like, um, "well you could be stressed."

Haley's experience with the lack of question asking from her partner, along with her awareness that her partner was questioning the legitimacy of her illness altogether, left her feeling unsupported and reticent to communicate further about her illness.

Paige highlighted a potentially negative impact that question asking had on her perception of support. She described, "I think it's just really frustrating because sometimes, when like, [he asks], it feels like it's really on me and it's my fault." Paige discussed feeling that when her partner asked questions, at times, it resulted in negative feelings. Paige mentioned feeling like her symptoms were a burden to her partner and feeling guilty that she should be managing them better on her own. Partners used question asking and direct statements, not only to show support, but to hold individuals accountable for managing their disease.

***Accountability.*** Partners held individuals accountable for their eating behaviors or stress levels. Partners often were able to hold individuals accountable after they had gathered more

information about the disease and what particularly sparked a flare-up for the individual. Partners held individuals accountable for behaviors that may negatively affect the disease, therefore attempting to help individuals manage their IBD. Eating behaviors and stress levels often contribute to the progression of symptoms for individuals with IBD, which may account for why partners used this strategy to show support. To better illustrate partner accountability, Michelle expressed that her husband learned more when he finally witnessed her in a flare-up. She further described that her partner held her accountable because he wanted her to get better. She stated,

...He'll eventually learn the lifestyle and then he'll hold me accountable to it, like, what I have to do to get past this. So he's learning. He knows by, like, what I've said to him in the past and what we talked about when he was deployed last time. But, um, and it's different with him being actually here and experiencing it. I think he's like the kind who would just hold me accountable because he's been doing it now that he realizes what I can and can't eat and stuff like that.

Michelle articulated that when her husband was able to see her during a flare-up he learned what helped and hindered her symptoms and tried to hold her accountable and help her manage her disease. Further, Renee also described her experience with partner accountability. She stated,

.... In the beginning was like, when I found out I couldn't eat all these foods. I was like f\*\*k it I won't eat and he would be my, like, reminder to eat until I got into the habit of it.

Partner accountability was used as a method of support to help women manage their IBD.

Asking questions and partner accountability are systems of support used to contribute to a more mature understanding of their relationship.

***Mature understanding of the relationship.*** Individuals appeared to have a more mature understanding of their relationship, or stronger relational identity, following disclosure,

experiences of turbulence, and re-defining individual and relational identities,. Individuals were able to redefine their identity in the relationship with a more developed understanding of their partner's commitment or feelings for them. Individuals reflected on how they worked as a unit in the relationship. To unpack this idea a bit further, Taylor stated,

Well, I mean, I think you, with this disease, for me, and my relationship, you sort of move 10 steps faster than you would if you didn't have it. Because doctors, especially with me being a female were talking to me about things, like, if I want to get pregnant, when I would need to do that, just with the disease and the progression. And, you think ahead into the future a lot more with what the disease could do to impact not only you, but your relationship as well as kids. And we would not have talked about that, you know, a year or so into our relationship. That would be my guess, especially in my twenties at that time. So, I think it just pushes you forward a lot more than, uh, you would have been.

Similarly, Renee stated, "I think [IBD] definitely sped along the emotional connection." While, Adrian described,

He is just a damn good man, and he is just a catch, and I've learned that if we stay together, which, I sincerely hope we do, if we stay together until we are 90 and I have to wear diapers and I have false teeth, he's not going to bail just because I'm not as hot as I was when I was, you know, 26 or 27, when we started dating. So I think that, that just shows me that he's in it for the long haul and that he's not materialistic and he's not just concerned with how I look or those surface things.... I would say that [this experience] showed me that I am worthy of a relationship.

Similarly, Molly described,

I think I have been able to see my partner be more caring. Like, I really see, like, this caring aspect to him that like, makes me, just fall for him more and more. Um, just to realize, like, how caring and kind and generous he is so. I definitely think to that aspect, it's, you know, made us, or like made me, view him differently.... And just knowing that when I think of my future and I think of someone that I'd want to marry, like, I would want someone to have those aspects in a partner.

Many participants described knowing that their partner was someone they would like to marry based on their experience with managing IBD or negotiating turbulent moments. Michelle said, "...I was having a colonoscopy ... and he's just there, like, taking me to the bathroom, like, see, I know I'm going to marry you, if you're sitting in a hospital with me right now." She further described

...I get to see a side of him that I don't, I mean he's always really sweet and really caring and stuff like that ...but it seems like it's, he's more sensitive and more like, in tune to the fact that I need, I have certain needs now that have to be met a certain way. And he's going to have to do them that way or else things are just rough for me.

Michelle described here that her husband has supported her multiple times with her health and happiness in mind even before marriage. Similarly, Paige stated, "Yeah, but it just kind of taught me a lot of just, he's a really good supportive person and so that makes me feel like I won the lottery." Preceding examples from Taylor, Adrian and Molly illuminate a few of the ways women defined their relational identities. Participants described seeing a new side of their partners and thinking about future decisions and outcomes such as having children or getting married.

Haley stated that attempting to open up and disclose illness information again was still a work in progress, yet she also stated feeling that her marriage was in good standing. She said, "If this is literally the one thing we've ever really gotten into a knock down drag out in six years about, um, I just was hurt and I knew I could get over it, it just was gonna take some time.... I'm starting, still working through [my diagnosis] cause it is so new it's, it's hard for me to, it's still stressful. I still don't like to talk about it a lot, so that's where I know I should rely on my partner for that. I'm still, it's still, a work in progress."

In terms of relational identity, Haley highlights that one misunderstanding or turbulent patch in life is not enough to break-up her marriage. Finally, for individuals that were single at the time of the interview, they articulated what they would be looking for in a future partner such as the partner's level of maturity/selfishness or being understanding of lifestyle changes as the disease progresses.

### **Chapter Summary**

In this chapter, I discuss the themes that emerged from the interview data. Three key themes were presented in this chapter, with subthemes to increase understanding. Themes included phases of disclosure, experiences of relational turbulence, and individual and relational identities. There were two phases of disclosure, initial and continued. Initial disclosure consisted of three subthemes (e.g. direct, indirect, and concealment). Turbulence was defined in participant's own words and four subthemes were used to describe strategies participants used to negotiate turbulence (e.g. open communication, partners offering assurances, avoidance, and withdrawing). Finally, individual identity consisted of three subthemes (e.g. self-conscious and awkward, independent, and invisible illness), and relational identity consisted of three subthemes of partner support (e.g. asking questions/seeking answers, accountability, and mature

understanding of the relationship). The final chapter will discuss the overall findings and implications of these results.

## Chapter 5: Discussion

Scholars have highlighted a need to continue exploring communication processes related to illness management within relationships (Knobloch & Delaney, 2012; Miller & Caughlin, 2013); this study attempted to address that need. More specifically, I argued that it is important to understand the role of communication and turbulence for those managing IBD, particularly due to the growing numbers of individuals diagnosed each year. In this study I aimed to extend RTM and our understanding of turbulence by examining how a chronic illness, IBD, created turbulence in romantic relationships in order to further investigate how uncertainty, identity and intimacy are experienced. Additionally, this study explored beyond the initial disclosure of a health condition to see how that condition is communicatively managed within romantic relationships.

When I began this research study I expected that women would experience increased amounts of relational turbulence related to IBD. I expected narratives to be ripe with examples of turbulent moments as individuals managed symptom experiences along with their romantic relationships. I also knew there was the possibility that the women would experience minimal to no turbulence and would feel comfortable managing their disease and relationship. The findings suggest that turbulent moments in regard to IBD were not as clear or ubiquitous as I initially expected when I proposed the project. I expected to find clear discussions of turbulent moments experienced between both the individual and her partner, in regard to IBD. However, participants hesitated to identify moments as mutually turbulent and operationalized their lived experiences of turbulence in their own words. Although participants' expressions of turbulence were not always consistent with definitions of turbulence found in the literature, they did describe a response to a transition in the relationship. Participant operationalized turbulence to better fit

their lived experiences. For example, Solomon et al. (2010) maintain that moments of turbulence in relationships include “polarized cognitions, stronger emotions, and more extreme communication behavior” (pp. 120). It is clear that participants experienced turbulent moments, and were identifying different types of turbulent experiences. For example, Emily experienced polarized cognitions and strong emotions when her partner asked her to sleep in another room, she expressed feeling isolated and did not know if her partner was aware of her feelings. This example demonstrates that relationship turbulence is not always experienced as a couple. One relationship partner can experience turbulence that results in the re-evaluation of uncertainty, intimacy, and relational longevity. Researchers may be too narrow in their definitions to capture the true lived experience of turbulent moments related to illnesses. This study expanded our understanding of relationship turbulence through identifying different types of turbulence based on participants’ lived illness experiences. The use of RTM as a framework and narrative inquiry as a method of data collection for that framework allowed for an enhanced understanding of the complexities behind participants’ experiences in their romantic relationships and when managing IBD.

In this chapter I will discuss the key findings of this study, the theoretical implications, practical applications, limitations of this study and directions for future research. I will begin by discussing the key findings and how the themes worked together in order to answer the research questions. Then, I will discuss the theoretical implications this study has for the relational turbulence model as well as the practical applications of the results for personal experiences, interpersonal communication research, and health communication research. Finally, I will discuss the study limitations and provide directions for future research based on the findings.

## Key Findings

There were three key findings within this study focused on the following constructs: (a) turbulence related to IBD; (b) phases of disclosure; and (c) accelerated relational identity. While all of the results discussed in chapter four are significant to our understanding of the influence IBD can have on romantic relationships, these key findings combine themes in order to specifically address how the results work together to answer the overlapping research questions.

**Turbulence related to IBD.** The first key finding in this study is how romantic relational turbulence was experienced and negotiated as it related to IBD, and how that impacted the development of interdependence for managing the disease. Relational turbulence related to IBD was experienced by some of the participants while others hesitated to define moments as directly turbulent. Some participants described turbulent moments in their relationships in regard to the definition offered, while others described moments marked with individual experiences of turbulence and increased uncertainty.

Participants had to negotiate lifestyle changes necessary because of the disease, while also being fair to their partner's wants and needs. For example, changing routines, cancelling plans due to symptoms, and spending lots of time in the restroom increased turbulent times for some participants. Feelings of turbulence were not always mutual. It appeared when individuals felt turbulence related to IBD and the relationship, they were sometimes unsure of their partner's awareness of those feelings.

Turbulent moments occurred when individuals were uncertain and experienced symptom flare-ups. Turbulent moments described by participants contributed to their cycle of anxiety (Kearney et al., 2011; Jerndal et al., 2010); this means that it appeared that turbulent moments would arise upon an exacerbation of symptoms, resulting in anxiety and uncertainty, in turn

increasing or prolonging the flare-up. Being caught in this cycle of anxiety and disease exacerbation explains why individuals experienced increased feelings of uncertainty. Additionally, partner support for managing this cycle, such as offering assurances, helped individuals negotiate uncertainty and further manage the disease. Women saw open and honest communication as important for managing life with IBD. All of the participants expressed that partners offering support, and individuals being open and honest about symptoms or ability, were important factors in a relationship as it related to managing IBD and the relationship.

Turbulence was negotiated in different ways including using open communication with partners, partners offering reassurances, and engaging in avoidance or withdraw behaviors. A few participants experienced partner interference, yet for most of the participants, partner influence was predominately facilitative. It appeared that overall, partner facilitation and interference influenced uncertainty related to continued disclosure of IBD symptoms. Those that experienced partner interference accepted the definition of turbulence provided in the interview and used avoidance or withdraw strategies to negotiate turbulence. Women that experienced partner facilitation, on the other hand, reported personally experiencing turbulence but were uncertain about whether turbulent feelings were mutual. These women negotiated turbulence through open communication and were in relationships where partners offered assurances. Women negotiated turbulence in a number of ways with their partner, however, and often times those negotiations determined relational outcomes such as increased closeness or termination.

Although treated as separate discussions in chapter four, collectively the findings suggest that there is a link between negotiations of turbulence and reflections about the nature of the relationship. For example, when turbulence was negotiated through open communication and partner assurances, women reported mutually negotiating turbulence, using direct initial

disclosure and being satisfied with their partner and relationship overall. Similarly, women that used avoidance to negotiate turbulence mentioned they were satisfied with their partner as well, yet they also reported using indirect initial disclosure strategies and feeling uncertain about how their partner viewed the disease. Finally, those that withdrew in order to negotiate turbulence used concealment or indirect initial disclosure strategies and expressed not being fully satisfied in their relationships. The findings suggested that experiences and negotiations of turbulence, as a result of IBD, allowed individuals to have a more developed understanding of their current or future relational identities. Negotiations of turbulence influenced women's understanding, for better or worse, of the role their partner had in co-managing the disease. The relational turbulence model, as the theoretical framework for this study, provided an understanding of how relational partners experienced each concept of the model to negotiate turbulence, with varying degrees of success. This key finding highlights how women experienced and negotiated romantic relationship turbulence while managing IBD.

**Phases of disclosure.** The two phases of disclosure is the second key finding in this study. This finding is particularly interesting because there were only two clear phases of disclosure, initial and continued. This study aimed to extend the current research beyond initial disclosure of a health condition to understand how that condition was communicatively managed in ongoing romantic relationships. I expected to find multiple points of disclosure as new symptoms and lifestyle changes occurred. I found, however, that after revealing their conditions, the partners engaged in repeated conversations that helped individuals understand whether their partner accepted or rejected the disease. The continued phase of disclosure often occurred during symptom flare-ups, which in turn was also linked to moments of turbulence and uncertainty. Continued disclosure did not occur as distinct, major talks about the disease, rather the continued

phase was made up of normal conversations about IBD sharing details with partners regarding individual's disease experiences. This is in line with what Charmaz (1995) offered in terms of adapting to illness and redefining identity. Conversations related to IBD seemed to be viewed as discussions rather than disclosures. From this, it is gathered that the long-term, ever-evolving effects of managing life with IBD, do not involve multiple points of significant disclosure, and the two phases of disclosure expressed, influenced relational identity.

Further, I expected to find more discussions about the use of passing behaviors, yet participants only briefly discussed the invisible nature of their illness and the use of passing behaviors. It appeared that upon the continued phase of disclosure, most individuals terminated the use of these behaviors. Participants that were more certain about their disease, terminated the use of passing behaviors, while some women still uncertain about their disease engaged in these behaviors when in public. This suggests that feeling comfortable with the disease and the relationship can eliminate the use of passing behaviors.

The findings suggest that beyond initial disclosure, the continued phase of disclosure concerning IBD allowed individuals to understand their partner's role in helping them manage the disease. For example, those that stifled discussions or concealed information did not see their partner as having a positive role in managing the disease. Individuals that felt supported and comfortable were able to talk more freely to their partner during times of flare-ups and saw their partner as assisting in managing the disease.

Disclosure strategies appeared to be linked to reports of partner support for managing IBD. While treated as separate discussions in chapter four, looking at the results collectively there appears to be a link between direct disclosure and expressions of closeness, openness and honesty when sharing illness information in their relationship. Direct, initial disclosure was used

when individuals felt comfortable disclosing to their partner and when individuals were more certain about their partner's responses. On the other hand, concealment and indirect initial disclosures were used when individuals experienced uncertainty regarding the disease itself, partner reactions, or both.

**Accelerating relational identity.** The third key finding is accelerated relational identity. The findings suggest that rather than IBD having a negative influence on romantic relationships, instead it allowed individuals to have a more developed understanding of their partner and relationship. Through experiences with IBD, individuals were able to evaluate and reduce uncertainty regarding their relationship. Having IBD allowed individuals to test their partner's level of acceptance of the disease as well as the couple's ability to work through tough times. These experiences allowed individuals to move beyond surface level understandings of the relationship much earlier on. Moving beyond the surface level included having more serious discussions much sooner in the relationship due to disease progression or effects. Discussions included conversations about having children or breaking boundaries to discuss taboo topics.

Disclosure also allowed individuals to increase their understanding of relational identity. The findings suggest that the initial phase of disclosure allowed individuals to begin uncovering how their partner feels about their disease. Similarly, for most of the participants, the continued phase of disclosure allowed individuals to feel more comfortable discussing their disease and symptoms with their partner. Some women, however, stifled the continued phase of disclosure with their partner due to feeling uncertain about partners' responses or because the initial disclosure was not well received.

While the continued phase of disclosure predominately increased satisfaction, turbulent moments often occurred during this phase as well. Participants expressed that experiences and

negotiations of turbulence allowed individuals to understand their partner and their relationship much faster than couples that may not face challenges quite so early on in the relationship. It appeared that partner's responses and acts of support allowed women to decide if they could trust and be open with their partner. Women's experiences with IBD accelerated their construction of relational identity from the point of initial disclosure and throughout experiences and negotiations of turbulence.

In terms of relational identity, a majority of the participants grew closer to their partners and saw them to have a role in co-managing the disease. Initially, I aimed to understand how women defined and redefined their individual identity, yet participants were keen on discussing their relational identity. It appears that the true finding here is that relational identity was more directly and openly discussed than individual identity and women with IBD may place increased importance on their relational identity by establishing it early on.

Below, Table 2 charts out the overlapping themes and key findings that work to answer each specific research question. When looked at collectively, what we can glean from these key findings are the answers to these research questions overall. It appeared that turbulent moments related to IBD were evident, and through negotiations of turbulence and continued discussions of the illness, individuals felt an accelerated sense of relational identity. Negotiations of turbulent moments allowed women to understand the role their partner had in co-managing the disease. Negotiations further allowed women to redefine their individual and relational identities. For some women, partners appeared skeptical or uncomfortable with the condition, which led to women withholding illness information, feeling rejected, and ultimately negatively impacting their individual identity. For example Haley expressed feeling 'crazy,' because of her inconclusive test results and her partner's suggestion that her condition was all in her head.

However, most individuals engaged in continued disclosure and grew closer to their partner. These women were met with acceptance about their illness. Overall, experiences and negotiations of turbulence along with continued disclosure experiences, shifted individuals' feelings from two separate individuals to one strong unit, working together to co-manage the disease.

Table 2

*Answering the Research Questions Through Themes and Findings.*

RQ's	Themes	Key Findings
How do women's experiences with IBD influence their romantic relationships?	Phases & Strategies of Disclosure Experiences of Rel. Turbulence Individual and Rel. Identity	Turbulence & IBD Phases of Disclosure Accelerated Rel. Identity
How do women share information regarding their illness at the beginning of the relationship and as the relationship develops?	Phases and Stages of Disclosure	Phases of Disclosure Accelerated Rel. Identity
How do women negotiate periods of relationship turbulence, experience uncertainty during these periods, and how do these turbulent moments impact intimacy within their romantic relationships?	Experiences of Rel. Turbulence Individual and Rel. Identity	Phases of Disclosure Accelerated Rel. Identity
How do women define and redefine their identities within their romantic relationships?	Phases & Strategies of Disclosure Experiences of Rel. Turbulence Individual and Rel. Identity	Phases of Disclosure Accelerated Rel. Identity

## **Theoretical Implications**

My study extended RTM into qualitative research by focusing on how the model concepts were experienced rather than predicting specific relationships between model components. My study addressed scholars' previous call for more exploration into communication processes related to managing illness within relationships (Badr & Acitelli, 2005; Horan et al., 2009; Knobloch & Delaney, 2012; Miller & Caughlin, 2013). This study explored turbulence as a result of managing a health condition with the hopes that RTM would provide a framework for a more rich understanding of illness experiences, as well as illuminating how couples formed new concepts of identity (Solomon et al., 2010). RTM was a useful framework for understanding moments of turbulence illustrated in some of the women's narratives, though not all women embraced the concept of turbulence as defined by the model. For these couples, the relational turbulence model may not have been the best explanatory framework for understanding how women manage romantic relationships and IBD experiences. While RTM highlights transitions in relationships and the impact those have on intimacy, it appears that rather than examining turbulence, it may be more helpful to explore relational maintenance strategies. Previous literature has established five maintenance strategies: positivity, openness, assurances, networks, and sharing activities (Canary & Stafford, 1992). Similarly, the results of this study found that women with IBD negotiated turbulence through openness and partners offering assurances. Exploring relational maintenance strategies could enhance our understanding of how individuals communicatively manage both the unique times of symptom flare-ups and the mundane experiences of IBD.

## **Practical Applications**

There are practical applications of these findings regarding personal experiences, interpersonal communication and health communication. In terms of individuals' experiences these findings can help women understand the importance of taking ownership of their illness information and making strategic disclosure decisions to avoid the cycle of anxiety. For example, most women expressed feeling uncertain during flare-ups, when deciding if they should discuss their health with their partner, and during moments of turbulence, which could contribute to the cycle of anxiety and exacerbate symptoms. The findings suggest that using open communication and being honest with partners in the initial disclosure phase can reduce uncertainty and possibly avoid perpetuating the cycle. For example, most participants expressed that being open and honest during continued disclosure allowed partners to learn more about the disease, become more comfortable with the disease, and allowed them to take part in co-managing the disease. It is important for partners to know what specifically sparks a flare-up and causes stress for the individual in order to offer support and help individuals avoid behaviors that will perpetuate this cycle. This study also has implications for interpersonal communication research.

Understanding how turbulence is experienced is important for understanding the effects turbulence can have on an individual's relational and physiological health (Kearney et al., 2011; Jerndal et al., 2010). The findings from this study suggested that being open and honest with relational partners about illness experiences was the best way to negotiate turbulence and manage the disease. Being open and honest appeared to reduce uncertainty and anxiety, and helped to avoid the exacerbation of physical symptoms and decrease feelings of turbulence. Previous literature maintains that communicating expectations for health-related talk enhances partner communication while managing a chronic illness, and communicating about emotions

and needs promotes goal achievement and avoids relational imbalance (Hughes et al., 2005). In line with this research, some participants in this study used health-related talk as a tool during times of adjustment to both the disease and relationship. Health-related talk allowed couples to break down boundaries and carry on continued discussions regarding IBD. Interpersonal communication scholars can begin to utilize these findings to explore deeper into the nuances of co-managing illness in relationships. The findings suggest that the continued disclosure phase allowed individuals to break boundaries and could inform further exploration regarding how couples communicate about and throughout illness, to form stronger relational units.

Finally, this study has implications for health communication research, particularly, invisible illness. In line with previous research, invisible illness often was identified through verbal disclosure and following that initial disclosure women began talking more about the disease (Kundrat & Nussbaum, 2003). Health communication researchers can also utilize these findings to further understand how individuals communicatively manage disease experiences together. The findings are also important for understanding how individuals communicate about taboo topics related to an individual's health, including how and when they engage in passing behaviors.

### **Limitations and Directions for Future Research**

The results of the study must be viewed in light of study limitations. The first limitation is the sample size. While 11 participants allowed me to reach theoretical saturation, including more voices may have strengthened the soundness of the findings. The sample also consisted of predominately Caucasian women, with only one participant identifying as bi-racial. All women in this study discussed heterosexual relationships, yet participants were not asked to identify their sexual orientation. A more diverse sample may have influenced results and is certainly a

direction for future research. The second limitation focuses on the collection of data regarding individual identity. When I asked participants how they felt about IBD and what they had learned about themselves, individual identity was not always directly discussed. I believe adding more direct questions regarding identity specifically may have enhanced the findings. A third limitation is that, while this study was able to identify the ways individuals communicatively manage IBD, the long term, ever evolving effects of managing the disease were not quite as clear. Participants in the study were at different relational stages, yet a majority of the participants had been in their relationship for at least a year. Some participants were single and could speak to the long-term effects as it related to the length of their relationship, yet a longitudinal study may have gathered a more developed understanding of the true long-term, ever evolving effects. Similarly, using a retrospective interviewing technique may have uncovered more of the nuances behind these effects. Attending to these limitations is one step for future research to further understand the communication processes behind managing a chronic illness and a relationship.

Additionally, this study offers many directions for future research, first, researchers should include men in their sample population and should explore the relational maintenance strategies used while managing a chronic illness and romantic relationship. Further, research should continue to examine how individuals communicate their illness identity as well as negotiate discussions regarding invisible aspects of their illness. It may also be important to further explore the partner's perspective to understand how they attempt to communicate support and help co-manage IBD. The findings from this study identified different types of turbulent moments, and exploring partner perceptions further will allow for a more holistic understanding of how turbulence is experienced in regard to illness. Scholars should further examine how

experiences with chronic illness can accelerate feelings of commitment, satisfaction and trust, or result in ending the relationship. Gathering the partner's point of view would enhance understanding of turbulent experiences and negotiations. More specifically, conducting interviews with the couple together or both the individual and his/her partner separate would enhance further understanding of how invisible illness is co-managed in relationships. Finally, research should examine managing and negotiating moments of turbulence related to IBD, within family relationships. A number of participants mentioned during their interview that they discussed symptoms and experiences with their parents or siblings, with varying degrees of success. Individuals mentioned engaging in concealment and passing behaviors with family members due to a lack of understanding or to avoid feeling shamed by them. While discussions about communicatively managing family relationships were outside the scope of this study, they are important to consider for the future.

### **Conclusion**

The three key findings within this study were (a) turbulence related to IBD; (b) phases of disclosure; and (c) accelerated relational identity. Individuals operationalized turbulence and identified different types. This finding enhanced our understandings of how turbulent moments related to illness are experienced and negotiated. Initial and continued disclosures, allowed women to further understand their partner's role in co-managing the disease, for better or worse. Partner's co-management of the disease brought individuals closer together and helped create a stronger relational identity. A growing number of American's are being diagnosed with IBD each year (Crohn's and Colitis foundation of America, 2014). This study is important because it uncovered new understandings of experiences of romantic relationship turbulence related to managing IBD. Further, the findings from this study illustrated varying disclosure strategies and

ways relationship partners negotiated turbulence in order to grow closer together. This study attended to an underexplored area in the literature regarding communication processes related to managing illness in relationships. The findings suggested that when partners were more understanding of the disease, they took part in co-managing it by learning about the disease and offering support. Also, this study extended the relational turbulence model into qualitative research, uncovering new understandings of experiences of turbulent moments related to illness and relationships. While there were certainly limitations to this study, there are many more avenues for future research.

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**Appendix A**  
Interview Guide:

Hi \_\_\_\_\_, How are you doing? Thank you for joining me today!

I wanted to share with you a few quick reminders, you do not have to answer any questions that you do not want to answer and you can decide to withdraw from the study at any time! In order to be as accurate as possible with the information you share today, I will be audio recording the interview. Do not worry, the recordings will be typed out to review, using pseudonyms, and these will all be stored under lock and key, as well as on a secure password protected computer. This is just to be sure that none of your shared information is missed.

Do you have any questions before we get started?

**If yes: (answer any questions). The main thing I will need from you today is honesty; YOUR voice should be heard according to your true opinions, emotions, and experiences.**

**If No: The main thing I will need from you today is honesty; YOUR voice should be heard according to your true opinions, emotions, and experiences.**

**Begin Audio Recording**

**Interview Questions:**

**If you are ready, we will begin with a few easy questions,**

[Participant Characteristics]

What is your age?

How would you identify your race?

What is your diagnosis?

How long have you had this diagnosis?

Are you currently in a romantic relationship?

**If Yes: Use Script 1**

**If NO: Use Script 2**

**Script 1: Now the questions will require a bit more thought,**

**I want you to think about your romantic relationship for a minute:**

How would you describe the current status of your relationship?

Can you describe how support is enacted between you and your partner?

**Now, I want you to think about your Inflammatory Bowel Disease:**

How would you describe your level of control over managing this disease?

Can you describe the initial disclosure to your partner and how he/she responded?

How do you feel about your disease? How do you feel about your symptoms?

How do you think your partner feels about your disease and/or symptoms? Please Explain.

**Now, think about a time in your relationship in which your IBD really seemed to impact your relationship.**

Can you describe to me what happened?

Would you describe this as a relationship transition? For example, did you grow closer or further apart as a result of this situation? If not, is there another time where you feel your IBD was a key player in a relationship transition?

Was this an easy time or do you feel it was more turbulent, for example dramatic, continuously stressful or messy? How so?

How did IBD specifically, impact this transition?

Did you experience uncertainty at this time? Uncertainty about how you felt in the relationship or how your partner felt?

How did this situation impact the degree of closeness you experienced in your relationship?

Did this experience impact how you saw yourself or how you viewed your partner or even the relationship as a whole? If so, how so?

How did you and your partner overcome this situation? (i.e. what strategies did you use, what types of conversations did you have, did it help or hurt your relationship? How/why?)

What have you learned about yourself?

What have you learned from or about your partner through this?

Is there advice that might be interesting or helpful to share with other women, regarding the experiences you have had with IBD and your relationship?

Is there anything else you think might be helpful or interesting for this study or future research based on your experience?

*[End Script; refer to closing remarks]*

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**Script 2: Now the questions will require a bit more thought,**

How long has it been since your last relationship?

**Now, I want you to think about your Inflammatory Bowel Disease:**

How would you describe your level of control over managing this disease? Both currently and at the time of your relationship?

Can you describe the initial disclosure to your partner and how he/she responded?

How do you feel about your disease? How do you feel about your symptoms?

Did you feel this way when you were in your previous relationship? Has that changed? How?

How do you think your partner felt about your disease and/or symptoms? Please Explain.

**Now, think about a time in your previous relationship in which your IBD really seemed to impact your relationship.**

Can you describe to me what happened?

Would you describe this as a relationship transition? For example, did you grow closer or further apart as a result of this situation? If not, is there another time where you feel your IBD was a key player in a relationship transition?

Was this an easy time or do you feel it was more turbulent, for example dramatic, continuously stressful or messy? How so?

How did IBD specifically, impact this transition?

Did you experience uncertainty at this time? Uncertainty about how you felt in the relationship or how your partner felt?

How did this situation impact the degree of closeness you experienced in your relationship?

Did this experience impact how you saw yourself or how you viewed your partner or even the relationship as a whole? If so, how so?

How did you and your partner overcome this situation? (i.e. what strategies did you use, what types of conversations did you have, did it help or hurt your relationship? How/why?)

What have you learned about yourself?

What did you learned from or about your partner through this?

Is there advice that might be interesting or helpful to share with other women, regarding the experiences you have had with IBD and your relationship?

Is there anything else you think might be helpful or interesting for this study or future research based on your experience?

*[End Script; refer to closing remarks]*

**Thank you so much for your time today, I think we are done.**

**Do you have any questions for me?**

**If yes: (Answer all questions). If you have further questions feel free to contact me at any time!**

**If No: If you think of any questions please feel free to contact me in the future.**

**I have enjoyed our discussion and again would like to thank you for participating in this research. When the project is finished I will be more than happy to share a summary of the results with you. Have a great rest of your day! (If interview is in person, show participants the way out)**

**Turn off recoding device.**

**Label and Transfer Recorded Files to a Secure Computer**

**Transcribe Interviews**