

Crohn's Disease and the Young Adult Couple: An Interpretative Phenomenological Study

Ruth Nutting

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Erika L. Grafsky, Committee Chair

Fred P. Piercy

Paul Springer

Anisa Zvonkovic

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## **Abstract**

There are over 700,000 individuals living with Crohn's disease in the United States. Crohn's disease is a chronic inflammatory bowel illness that can have debilitating effects on individuals and their partners. There is ample literature on the various medical effects of Crohn's disease on the diagnosed individual but a dearth of literature on how Crohn's disease affects young adult individuals and their partners. This dissertation endeavors to fill this gap in the literature. Through Interpretative Phenomenological Analysis, this study explores how an individual's diagnosis of Crohn's disease is perceived to affect the couple relationship and young adult life-cycle transitions. From this study, healthcare providers can better understand how the numerous physical symptoms of Crohn's disease cause psychological and social implications for the diagnosed individual and partner. This understanding will allow healthcare providers to complete couple level clinical assessment and increase systemic interventions, promoting greater resilience among young adult couples.

# Crohn's Disease and the Young Adult Couple: An Interpretative Phenomenological Study

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## **General Audience Abstract**

Crohn's disease is a chronic illness that is currently affecting over 700,000 Americans, and is most often diagnosed in early adulthood. This disease frequently causes inflammation and irritation to any part of the gastrointestinal tract and most often affects the lower end of the small intestines. There are many studies that highlight the various medical effects of Crohn's disease on the diagnosed individual but there are few studies identifying how Crohn's disease affects young adult individuals and their partners. This study begins to fill this lack of understanding. Through interviewing young adult couples, this study explores how an individual's diagnosis of Crohn's disease is perceived to affect the couple relationship and young adult life-cycle transitions. From this study, healthcare providers can better understand how the physical symptoms of Crohn's disease cause psychological and social implications for diagnosed individuals and their partners. This understanding will allow healthcare providers to complete couple level clinical assessments and increase interventions that positively affect the diagnosed individuals and their partners, increasing more positive coping among young adult couples.

## **Dedication**

This dissertation is dedicated to the participating couples who made this all possible, and in loving memory of my sister, Rachel Nutting, who when on this earth, gave praise of my dedication to learning and knowledge.

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## **Chapter One**

### **Introduction**

Currently, there are more than 700,000 individuals diagnosed with Crohn's disease living in the United States (Crohn's & Colitis Foundation of America [CCFA], 2014), with peak prevalence being between ages 20 to 30 (Thomas, 2014). Crohn's disease is an inflammatory bowel disease (IBD) that chronically affects the gastrointestinal (GI) system (CCFA, 2014; Kunz, Greenley, & Howard, 2011; Mayo Foundation for Medical Education & Research [Mayo Clinic], 2014). Crohn's disease may cause inflammation and irritation of any part of the gastrointestinal tract and most often affects the end part of the small intestines, referred to as the ileum and the right side of the colon. The inflammation of Crohn's disease extends deep into the tissue of the affected part of the GI tract causing edema. Continuous inflammation frequently produces scar tissue that can lead to a stricture and possible bowel obstruction. A stricture is a narrowed passage that can slow the movement of food through the intestine causing pain and cramps. Another aspect of Crohn's disease can be diarrhea or frequent bowel movements, although many patients with Crohn's never experience this symptom (National Digestive Diseases Information Clearinghouse [NDDIC], 2014).

The specific cause of Crohn's disease is unknown. Crohn's disease is thought to potentially result from the body's immune system abnormally attacking common intestinal bacteria. This overreaction of the immune system is typically preceded by certain bacteria or viruses (CCFA, 2014; National Digestive Diseases Information Clearinghouse [NDDIC], 2014; WebMD, 2013). Crohn's disease has been genetically linked, as 20 to 25 percent of diagnosed individuals have a close relative who also has Crohn's disease (CCFA, 2014; NDDIC, 2014; WebMD, 2013; University of California San Francisco Medical Center [UCSF], 2015). Environmental factors, such as substances from food; microbes found in bacteria and viruses;

and cigarette smoke have also been shown to contribute to Crohn's disease by triggering an immune system response, an inflammatory cascade that once turned on does not stop and leads to damage of the intestines (CCFA, 2014; NDDIC, 2014; WebMD, 2013). Crohn's disease is more common in developed countries than undeveloped countries, is found more often in urban rather than rural areas, and is more common in northern climates than southern climates (CCFA, 2014; NDDIC, 2014; WebMD, 2013). Nonsteroidal anti-inflammatory drugs (Ananthakrishnan et al., 2012), antibiotics (Ko, Butcher, & Leong, 2012), and oral contraceptives (Hou, Abraham, & El-Serah, 2011) have shown to slightly increase the chance of developing Crohn's disease (NDDIC, 2014). Diet and stress can aggravate Crohn's disease but are not direct, independent causes (CCFA, 2014).

The onset of Crohn's disease is acute, however most patients have had the disease or symptoms for about 2 years before they are formally diagnosed. As with any acute illnesses, when individuals are first diagnosed with Crohn's disease, there is likely a state of disbelief (Rolland, 1990, 2003, 2004). Crohn's disease has an episodic course. Individuals experience periods when the disease flares and causes painful symptoms followed by extended periods of remission where individuals feel few, if any, physical symptoms (CCFA, 2014). An episodic course can place strain on individuals, as there is an uncertainty of knowing when their next Crohn's attack will be. Coping and future planning are often hindered by increased anxiety and ambiguity about the disease trajectory and how this trajectory will impact individuals' lives (Rolland, 1990, 2003, 2004).

When an acute flare up occurs, individuals can experience intense cramping, and their intestines begin rejecting the food that is in their systems (CCFA, 2014; Mayo Clinic, 2014; NDDC, 2014). This often leads to hospitalization in which high doses of corticosteroids are

given to decrease GI inflammation, as well as high doses of narcotics for the pain (CCFA, 2014; Mayo Clinic, 2014; NDDC, 2014). After being released from the hospital, individuals continue to take anti-inflammation medication, along with continued doses of corticosteroids (e.g. cortisone; hydrocortisone; prednisone) for a month or two. Common side effects of corticosteroids include weight gain, sleepless nights, and varying mood swings (Mayo Clinic, 2014).

Seventy percent of individuals living with Crohn's disease are unable to maintain control of the disease even by receiving immune system suppressor treatment to decrease GI inflammation (CCFA, 2014). Should immune-suppressive therapy fail, the only remaining option is surgery which involves reshaping of the intestines, or the removal of the affected area of the intestines (Mayo Clinic, 2014; Crohn's and Colitis UK [CCUK], 2014). Surgery takes several weeks of recovery time. Depending on how the surgery is performed, substantial scarring can form. Repeated surgeries can eventually lead to short bowel syndrome, which is when significant amounts of bowel have been removed. Increasingly, surgeries can be performed laparoscopically leaving small scars and decreasing recovery time. However, this type of surgery may not be available in all hospital settings, and may not be appropriate if abdominal surgery has already been completed or the exact location of the affected bowel does not allow laparoscopic approach (CCUK, 2014).

The numerous physical implications of Crohn's disease cause psychological repercussions for diagnosed individuals and their partners. Like all chronic illnesses, Crohn's disease has a component of ambiguous loss. Boss and Couden (2002) define ambiguous loss, in relation to Crohn's disease, as well as other diseases as, "a situation where a loved one is perceived as physically present while psychologically absent..." (p. 1352). Boss and Couden



(2002) go on to highlight that ambiguous loss is likely the most difficult loss as it produces the most stress.

When people are unable to obtain clarity about the status of a family member, they are often immobilized; decisions are put on hold; roles remain unclear; relationship boundaries are confusing; celebration and rituals are cancelled. Couples and families may remain immobilized until they are able to perceptually reconstruct the meaning of the ambiguity surrounding their loved one's absence or presence. The ill person too, experiences ambiguous loss. They are here, but no longer as they once were (p. 1352).

Understanding the impact of Crohn's disease on young adulthood is highly significant as peak prevalence of the disease is between ages 20 and 30, meaning young adults are most likely to be diagnosed. Young adulthood has unique tasks that Crohn's disease is likely to affect. These unique tasks may include beginning/finishing college, defining one's career, and forming deep relationships with others in order to establish stability and support when separating from one's family (Carter &McGoldrick, 2005).

The existing literature on Crohn's disease neglects to describe how Crohn's disease affects young adult life-cycle transitions and the couple relationship. As young adult couples solidify their relationships, they embark on a lifetime journey and begin defining themselves as a unit. The purpose of this study is to understand how Crohn's disease affects young adult life-cycle transitions and couple relationships.

### **Rational for Study**

Crohn's disease has biological, psychological, and social effects on the diagnosed individual and the partner. The majority of research that has been completed on the effects of Crohn's disease is from a biomedical lens that has been focused on the diagnosed individual.

Therefore, the first goal was to provide a rich understanding of how a partner's diagnosis of Crohn's disease is perceived to affect the couple relationship and young adult life-cycle transitions. Second, research is beginning to shed light on how chronic illnesses affect not only diagnosed patients but their partners as well. However, there is a dearth of literature on how the numerous physical symptoms of Crohn's disease cause psychological and social implications for diagnosed individuals and their partners. Third, there is no literature specific to Crohn's disease, which describes young adult couple-targeted interventions that have been most beneficial to couple functioning. Fourth, the only literature to date that focuses on Crohn's disease impacting couple systems centers on older couples. This study begins to fill the gap in the existing literature by focusing specifically on couple relationships and young adult life-cycle transitions. Fifth, this study provides insight for future researchers who are interested in studying the effects of chronic illness on young adult couple systems. Finally, this study gives healthcare providers a greater understanding of the effects of chronic illness, specifically Crohn's disease, on young adult couples. This understanding allows for more systemic clinical assessment and intervention.

### **Rationale for Qualitative Methods**

The ultimate purpose of qualitative research is to gain an in depth description of a phenomenon (Rossman & Rallis, 2012). More specifically, Creswell (2009) defines qualitative research as a way to explore and understand the meaning individuals or groups make of a social or human problem. This is completed by forming research questions, collecting data from a sample population that will provide the appropriate information of what is being studied, inductive data analysis that builds from initial codes to themes, and an interpretation of meaning from the data by the researcher (p. 4). In the views of many scholars, qualitative research has an

enormous amount to contribute to the fields of health, medicine, and public health (Meyrick, 2006).

Interpretative Phenomenological Analysis (IPA) is a recently developed qualitative approach that is committed to examining how people make sense of major life experiences (Smith, Flowers, & Larkin, 2009, p. 1). IPA has been an ideal approach in studies related to health, medicine, and public health. Smith et al. (2009) provide several reasons for the use of Interpretative Phenomenological Analysis. For example:

- IPA is concerned with exploring experience in its own terms.
- An IPA researcher is interested in looking in detail at how someone makes sense of a major transition in his/her life (e.g. diagnosis of a chronic illness).
- An IPA researcher is engaged in a double hermeneutic as the researcher is trying to make sense of the participant trying to make sense of what is happening to him/her.
- IPA studies have a small sample size of reasonably homogenous participants and the aim is to reveal something of the experience for each individual. As a part of the study, similarities and differences may be explored in detail between each case.

### **Statement of the Problem**

Diagnoses of Crohn's disease are increasing among young adults in the U.S. The available literature in this understudied area has mainly focused on biomedical aspects of Crohn's disease on the diagnosed individual. Given the increase in Crohn's disease among young adults, it was pertinent to conduct a study that explored how a partner's diagnosis of Crohn's disease is perceived to affect the couple relationship and young adult life-cycle transitions.

### **Research Questions**

The central research question of *how one partner's diagnosis of Crohn's disease is perceived to affect couple relationship satisfaction and young adult life-cycle transitions* guided this study.

This study also addressed the following sub-questions:

1. How do the numerous physical symptoms of Crohn's disease cause psychological and social implications for the diagnosed individual and partner?
2. What couple-targeted interventions, given by healthcare providers, have been most beneficial to the functioning of the couple system?
3. In what ways can healthcare providers better support couple level coping?

### **The Role and Background of the Researcher**

I am an individual who was diagnosed with Crohn's disease in young adulthood. I was diagnosed at the age of twenty-two. At this time, I was in a committed relationship with my partner, working full-time as a health information management technician at an acute care hospital, and taking a full-time caseload of undergraduate behavioral science courses. Upon diagnosis, I remember feeling angry at my body for "failing" me, and I was concerned how Crohn's disease would impact my job and my education. I was confident in my relationship, as I found my partner being supportive and available to me.

Over time, it became evident that my course of Crohn's disease was mild and, for the most part, I was able to maintain stable health by taking an anti-inflammatory medication. I was able to complete my undergraduate degree and my master's degree with few Crohn's disease related issues. During this time my long-term relationship ended. For the first time, I became self-conscious about having Crohn's disease as I began to date. I was concerned about how

potential partners would perceive me and questioned why someone would want to date me- as I had a disease.

When I started my master's program, I became more and more interested in the field of integrated healthcare. My previous experiences of working in the acute care hospital setting and having a personal diagnosis of Crohn's disease provided me the opportunity to witness the gaps in a pure biomedical approach to healthcare. I understood that patients, although receiving excellent physical care, were not being treated in a holistic biopsychosocial approach— psychological and social, as well as systemic needs were not being met. It was then that I decided to obtain my Ph.D. and pursue research in the area of medical family therapy.

As I began preparing for my dissertation, I reflected on my experiences of Crohn's disease, how slightly it had impacted my young adult life-cycle transitions, and how it often can have a greater impact on other young adults. In doing this, I realized the importance of completing research in this understudied area. Therefore, writing this dissertation was both professional and personal. As a young adult individual, living with Crohn's disease, I am able to highlight my personal experiences of chronic illness and how I have made sense of these experiences. I can more holistically understand the phenomenon of Crohn's disease on young adult couples' lives. As a behavioral health provider and researcher, I am aware of the benefits of integrated biopsychosocial healthcare and its occurring increase. My research gives healthcare providers a greater understanding of the impact of chronic illness on young adult couple systems in order for more effective biopsychosocial treatment.

My clinical experiences greatly influenced my desire to complete chronic illness-related research as well. Throughout my graduate programs, I worked with underserved populations in which individuals experienced an array of challenges. Although none of my previous internship

experiences focused specifically on healthcare, patients often presented with challenges stemming from chronic illness.

My committee at Virginia Tech supported my desire to conduct research and provide psychotherapy to patients facing chronic illness. I was incredibly blessed to complete my pre-doctoral internship and post-doctoral fellowship in the Department of General Internal Medicine at the University of Nebraska Medical Center as a behavioral health faculty member in training. In that position I was able to collaborate with medical residents, attendings, and other medical disciplines in order to meet the biopsychosocial needs of underserved populations facing the numerous stressors of chronic illness.

### **Outline of Dissertation**

This dissertation is divided into five chapters along with an appendix section. The first chapter provides an introduction about Crohn's disease and its physical effects on diagnosed individuals, the rationale for the study, the rationale for using qualitative research methods, the rationale for using Interpretative Phenomenological Analysis, statement of the problem, the research questions, and role and background of the researcher. Chapter two presents a comprehensive review of the literature. Chapter three describes the research methods including choice of sample sizes, selection of participants, forms of data collection, analysis of data, validation strategies used to increase validity and quality of the study, and potential ethical issues. The fourth chapter presents and defines the results of the line-by-line analysis of cases. Each case is described in great detail along with the themes that emerged from analysis. Themes are presented accompanied with quotes. Rich quotes representing differing perspectives from the results of the cross-analyses are also provided. Chapter five, the final chapter, discusses the results of the study, the implications for theory development, practice, public policy, future

research, strengths and limitations of the study, a conclusion, a section on lessons learned, as well as the references used in all the chapters of this dissertation. There is an appendix section that includes copies of the internal review board approvals from the University of Nebraska Medical Center and Virginia Tech, informed consent forms, interview structure, tables, figures, and selected entries from the researcher's reflective journals.

## Chapter Two

### Review of the Literature

This chapter is divided into four sections. The first section describes the phenomenon of chronic illness. In this section (a) ambiguity of chronic illness and (b) stigma of chronic illness are highlighted. The second section of this chapter focuses on chronic illness and its perceived effects on young adults, highlighting its impact on life-cycle transitions. The third section identifies the role gender plays in coping with chronic illness. The fourth section emphasizes systemic treatment of chronic illness by healthcare providers. Lastly, the fifth section presents a framework for promoting coping and resilience for individuals and families facing chronic illness.

#### Chronic Illness

Half of all American adults live with a chronic illness (Centers for Disease Control and Prevention [CDC], 2014). The term *chronic illness* refers to diseases in which there is no available cure to conditions that are incapable of being eradicated and are typically progressive (Royer, 1998). Chronic illness can pose some of life's greatest challenges (Levinson, 1986).

**Ambiguity of Chronic Illness.** Royer (1998), defines uncertainty as the inability to determine the meaning of events, and outcomes are not able to be accurately predicted. Uncertainty forms when (a) patients lack information about their diagnosis and prognosis; (b) predictions cannot be made in regards to the course of an illness; (c) there is ambiguity in recognizing the stage of an illness; (d) patients lack knowledge of treatment options. Uncertainty in regards to the outcome of illnesses is identified as the single greatest psychological stressor for individuals with life-threatening chronic illness (Boss & Couden, 2002; Koocher, 1984).



Boss and Couden (2002) further define uncertainty as “ambiguous loss”. They define ambiguous loss as “a situation where a loved one is perceived as physically present while psychologically absent, or physically absent but kept psychologically present because their status of dead or alive, dying or in remission remains unclear” (p. 1352). Boss and Couden (2002) agree that ambiguous loss is likely the most difficult loss, as it produces the most stress. They conclude that ambiguity creates a barrier between coping and resilience. These barriers can best be defined through the Family Stress Perspective. The Family Stress Perspective highlights the dimensions of barriers as: (a) ambiguity causes confusion; (b) prevents reorganization of family roles; (c) has no markers of loss; (d) causes individuals to question the fairness of life; and (e) causes physical and psychological exhaustion (Boss & Couden, 2002, p.1353).

Abrams (2001) writes that resolving ambiguous loss occurs when patients and their families recognize the illness, make sense of the illness, and accept the changes the illness has brought to the family system. If an illness is held in secrecy, the family system will not be able to resolve the ambiguous loss, because “it is engendered by the external situation and the role and boundary confusion within the actual family composition” (Abrams, 2001, p. 283). Secrecy around a chronic illness infers that shame is attached to the illness and often leaves the patient and family system in a state of confusion and disempowerment. When both patient and family members are able to make sense of the chronic illness and subsequent ambiguous loss, they become empowered which fosters coping and resiliency (Abrams, 2001).

**Stigma of Chronic Illness.** “Chronic illness and disability are often stigmatizing; intolerance, fear, and misunderstanding at one extreme, and well-meaning but humiliating and patronizing sympathy at the other, often greet the chronically ill in their everyday social lives” (Jennings, Callahan, & Caplan, 1988, p. 6). In America, achievement, health, and independence

are greatly valued. Illness creates dysfunction in our social system as achievement, health, and independence are interrupted (Thorne, McCormick, & Carty, 1997; Parsons, 1975). Chronically ill individuals are often expected to maintain pre-diagnosis roles, even at the expense of their health (Royer, 1998). When others learn that an individual has a chronic illness, they may be challenged in interacting and forming relationships with chronically ill individuals who have decreased or perceived decreased abilities. Because of these inferences, individuals often put distance between themselves and chronically ill individuals (Albrecht, Walker, & Levy, 1982). When individuals realize this treatment from others, they often feel discredited and withdraw from friends, families, and partners (Royer, 1998).

**Social Isolation.** “Lessened and impaired social contact and a sense of social isolation are among the more detrimental consequences of chronic illness” (Royer, 1998, p. 65). Social isolation is a state of loneliness due to decreased social relationships or reciprocal participation in social relationships. Strauss and Glaser (1975) identify two ways isolation occurs: (a) the ill individual withdraws from social contact due to symptoms, crises, treatment regimens, and loss of energy due to chronic illness, and (b) the ill person is avoided or abandoned by friends and relatives. With all chronic illnesses, short-term, long-term, or periodic, isolation is common.

Various factors compound in impaired social interaction and social isolation. An altered physical or emotional state, a decreased state of well-being, an altered self-concept, and potentially decreased finances affect long-standing relationships that were formed under different circumstances (Karlen, 2002; Knowles, Gass, & Macrae, 2013; Royer, 1998). Emotions also play a role in impaired social interaction and social isolation, as friends and family members may withdraw from chronically ill individuals in order to protect themselves from feelings of hopelessness and helplessness.

Social isolation is a consequence of many chronic illnesses (Royer, 1998), that can lead to poor psychological well-being. To counteract the effects of social isolation, it is beneficial for chronically ill individuals to reassess their expectations of themselves and their relationships, as well as overall life pursuits (Charmaz, 2006). These expectations, relationships, and pursuits may be very different than what patients envisioned for themselves pre-diagnosis, but are likely more obtainable and less psychologically distressing.

### **Chronic Illness and Its Impact on Young Adults**

Chronic illness diagnosed in young adulthood can be even more challenging than chronic illness diagnosed early in life or in later years due to numerous life-cycle transitions common in young adulthood (Maslow, Haydon, McRee, Ford, & Halpern, 2011). These life-cycle transitions, or tasks, may include starting to work, beginning/finishing postsecondary education and graduate programs, beginning careers, supporting oneself, and forming deep relationships—often through marriage (Carter & McGoldrick, 2005).

Young adults living with chronic illness diagnosed in childhood have similar rates of continuous employment and college completion as young adults living without chronic illness. However, young adults with recent diagnoses of chronic illness have much lower rates of continuous employment and college completion (Maslow, et al., 2011). There are numerous variables that increase these lower rates: (a) initial diagnoses may pose severe interruption in daily life with symptoms of illness requiring prolonged medical attention or hospitalization; (b) recently diagnosed young adults are likely to struggle more with transitioning into treatment regimens; (c) psychological and emotional well-being are more decreased at time of diagnosis (Eddington, Mullings, Fedele, Ryan, & Junghans, 2010; Maslow et al, 2011).

Due to lowered psychological and physical well-being, young adults with chronic illness often struggle in their interpersonal relationships (Eddington et al., 2010; Karlen, 2002; Knowles et al., 2013). Although chronic illness can bring a need for increased physical and emotional dependence, young adults are often embarrassed and resentful of this dependence at a time when, socially speaking, they should be healthy, vibrant, and well-achieving. These feelings of embarrassment and resentment can compound when young adults are partnered. Individuals may turn away from partners, as they become consumed with their illness (Royer, 1998). Individuals not in relationships may experience increased anxiety in relation to dating as they struggle with self-identity, fear of how a person of interest may respond to their disclosure, and find themselves undeserving of love now that they have a chronic illness (Karlen, 2002).

Chronic illness can impact young adults' plans for child bearing, as well. Young adult couples who have planned on bearing and raising children may worry about the uncertainty of their future due to the implications of the chronic illness on physical health and the unknown course of an illness. Partners can withdraw from one another as the diagnosed individuals process disappointment in themselves for becoming ill, are angered that child-bearing plans are potentially altered, and experience feelings of guilt about their chronic illness impacting their partners' hopes and dreams for children. Likewise, their partners may simultaneously withdraw as they struggle with guilt for feeling disappointed that child-bearing plans are potentially altered (Royer, 1998).

Chronic illness has been found to have an even greater impact on young adult couples than older adult couples. Berg and Upchurch (2007) identify that chronic illness poses lower distress to older adults due to a greater ability to regulate emotions, as their brains are fully matured (Geid et al, 1999). Likewise, older adult couples are typically more stable in their

relationship and are better prepared to meet life's challenges. Lastly, chronic illness is recognized as a part of older adult life and poses fewer challenges as older adults face fewer personal transitions.

### **Chronic Illness and Gender**

Chronic illness studies have primarily taken a position of gender neutrality in which gender inequity is not depicted as an issue (Thorne et al., 1997). This form of gender neutrality fails to identify the differences in which chronically ill individuals experience and respond to chronic illness. Additionally, this position omits how gender socialization and inequalities are associated with stress.

A small body of research indicates that chronically ill females and males respond differently to treatment adherence, social pressures, anxiety and depression, and social support (Berge, Patterson, Goetz, & Milla, 2007; Machio, 2016; Malmusi, Artazcoz, Benach, & Borrell, 2011). Berge et al., (2007) identify the differences between young adult genders in response to living with the chronic illness in a study completed on Cystic Fibrosis. In this study they identify females as being more likely to adhere to treatment regimens than males, and in order to adhere to treatment regimens females find support from a specific family member. Socially speaking, they report that males experience greater acceptance from others, while females experience greater social isolation. This is likely, in part, due to females physically experiencing more pain (McClish et al., 2008) and greater daily activity limitations (Malmusi et al., 2011) which can lead to decreased social interaction and acceptance from others. Anxiety and depression are also experienced differently. Males have higher rates of risk-taking behaviors, such as drinking, smoking, and drug use, while females have increased negative thought patterns, often related to poor body image. These reports indicate that males more often externalize feelings of anxiety

and depression, while females internalize these feelings. Lastly, females show greater interest in support groups than males. This may be due to female's experience of social isolation, as well as a greater tendency for females to obtain support from others. Berge et al., (2007) identify two similarities in males and females responses to chronic illness. Both genders are concerned with acquiring other chronic conditions, and both genders strength through an optimistic outlook on the future.

### **Systemic Treatment of Chronic Illness**

Research continues to highlight the need for greater attention to chronically ill individuals' partners' well-being as they are greatly impacted by chronic illness (Armour, 2005; Carmack Taylor et al., 2008; Lister, Fox, & Wilson, 2013; McLean, 2013; Pakenham & Samios, 2013). Up to 40% of partners have shown increased rates of anxiety (Janssens et al., 2006) and depression (Bogosian, Moss-Morris, Yardley, & Dennison, 2009; Nicholl, Lincoln, Francis, & Stephen, 2001). For example, Perrone, Gordon, and Tschopp (2006) found that caregivers of partners with multiple sclerosis (MS) reported lower marital satisfaction, decreased communication, and less satisfying physical intimacy than partners of individuals without chronic illness. Researchers have also found that patient and partner levels of distress and interpersonal functioning are very similar to one another in dyads coping with various chronic illnesses, including MS (Pakenham & Samius, 2013), lung cancer (Carmack Taylor et al., 2008), and HIV/AIDS (Fife, Scott, Fineberg, & Zwick, 2008; Pereira, Dattilio, Canavarro, & Narciso; 2011).

Couple and family therapists traditionally emphasize a family system approach to the treatment of chronic illness (Munichun, 1974; Rolland, 1994) in order for dyadic coping to occur. With systemic treatment, given by healthcare providers, couples can unite as a team and

prepare for the various transitions ahead; as they are informed about prognosis, treatment regimens, and long-term outcomes (Berg & Upchurch, 2007). Recently, there has been increased attention given to the positive impact of couple-targeted treatment by healthcare providers (e.g. physicians, behavioral health providers, case managers) (Carmack Taylor et al., 2008; Chambless, Miklowitz, & Shoham, 2012; Escobar et al., 2007; Fife, Scott, Fineberg, & Zwick, 2008; Lister et al., 2013; McLean, 2013; Pakenham & Samios, 2013; Pereira et al., 2011).

With increased emphasis on couple level coping, healthcare providers can incorporate *in the moment*, brief interventions in the consult room. Although couple oriented interventions related to chronic illness are increasing, many healthcare providers have not received training on how to intervene at the couple level (Canavarro & Dattilio, 2011). The following section highlights the Family Systems Health Model, a model formed to assist healthcare providers of all disciplines in supporting family systems through chronic illness. Although this model does not speak specifically to young adult couples, it is likely this model can be expanded upon and adapted to the young adult couple population.

**Family Systems-Illness Model.** John Rolland (1990, 1994, 2004) is the creator of the Family Systems-Illness Model, which is a framework to evaluate, formulate, and intervene in families in which a member has a chronic illness (Rolland, 1990, 1994, 2004). This model views the family in terms of the life-cycle process, in which family members are perceived to offer resources to the ill individual (Rolland, 1987a, 1990, 1994, 2004; Walsh 1996, 2003, 2004). Collaborating with Froma Walsh's (1996, 2003) work, Rolland provides an emphasis on *coping well* and *building resilience*. According to Rolland (1990, 2003, 2004), coping well and increasing resilience requires individuals and families to master four different areas: (a) fully

understanding how the trajectory of an illness will affect the family system includes understanding the pattern of physical and emotional demands over the course of the illness, as well as understanding illness-related developmental tasks; (b) viewing themselves as a functional unit; (c) appreciating the individual, couple, and family life-cycle helps to stay cognizant of the changing fit between demands of chronic illness and developmental issues for the family system and each individual member; and (d) comprehending the beliefs and multigenerational legacies that lead their conceptualization of meanings about health problems and the relationships they have with healthcare providers.

***Psychosocial types of illness.*** Rolland (1990, 2003, 2004) provides a rich schema of the relationship between the biological and psychosocial aspects of chronic illness which include (a) the onset (acute or gradual), (b) the course (constant, progressive, or episodic), (c) the outcome (extent to which the illness impacts an individual's life), (d) the incapacitation (extent of disability), and (e) the level of uncertainty (not knowing the trajectory of an illness). This schema encourages a more encompassing explanation of how chronic illness affects family units. Rolland (1990, 2003, 2004) stresses that chronic illnesses can be grouped in regards to biological similarities and differences as well as unique psychosocial demands to individuals and families.

***The phases of illness.*** The concept of time phases allows healthcare providers and individuals to view chronic illness as a continuous process in which landmarks, transitions, and changing demands occur. Three main phases occur: (a) crisis, (b) chronic, and (c) terminal. In each phase there is different individual and family functioning.

The *crisis* phase includes a symptomatic period before diagnosis and the initial period of adjustment and treatment regimen after diagnosis. This period is described as having a number of critical developmental tasks for individuals and families. These tasks include (a) creating a



meaning for the disorder which leads to mastery (i.e. control over the illness); (b) grieving the loss of the pre-illness identity, (c) acceptance of permanence of the illness; (d) undergoing crisis reorganization while developing flexibility in lieu of uncertainty and potential loss; (e) adjusting to illness-related symptoms and treatments; and (f) building alliances with healthcare providers (Rolland, 1990, 2003, 2004).

The *chronic* phase can be depicted by constancy, progression, or episodic change (Rolland, 1990, 2003, 2004). This is the day-to-day living with chronic illness. Individuals and families strive to avoid burnout, maintain autonomy, adapt altered long term goals, and sustain intimacy. During this phase emotions often fluctuate between feelings of mastery and incapability for both patients and their families. Patients often feel frustrated with themselves for increased dependence, and families often experience feelings fluctuating between survivor guilt and resentment for their lives being affected by the illness.

***Health beliefs.*** When patients are first given a diagnosis of chronic illness, they grapple with feelings of betrayal towards their bodies, as they now recognize themselves as being invulnerable, and often wonder what they have done to cause their bodies to betray them. The main developmental task for patients and families is to create meaning of the illness experiences which fosters a sense of mastery (Rolland, 1987a, 1994a, 1997, 1998, 2004; Wynne, Shields, & Sirkin, 1992). These meanings or beliefs serve as cognitive maps that guide decisions and actions among ambiguous situations for present and future functioning (Antonovsky & Souran, 1988; Rolland, 2004).

***Beliefs about normality.*** Family beliefs about what is normal and abnormal have great implications for adapting to chronic illness. Families who seek help from providers and other

resources gain increased resilience. Beliefs that pathologize outside support decrease positive coping and resilience (Rolland, 1990, 2003, 2004).

*Family's sense of mastery facing illness.* When defining mastery of a chronic illness, patient and family beliefs of mastery are based on internal control (individuals and families believe they can influence the outcome of their situation), external control by chance (outcomes are not influenced by patient or family behavior, or external control by powerful others (God or another force is in control of the illness and its course). Individual and family beliefs about mastery greatly influence their relationship to the illness and to healthcare providers (Rolland, 1990, 2003, 2004). When individuals and families believe they have little power over the course of their illness, they are less willing to cooperate with providers in following treatment regimens, and can often experience more frequent relapses.

*Family beliefs about the cause of an illness.* A family's beliefs about the cause of an illness are different than the beliefs about the outcomes of an illness. Some individuals and families might mistakenly view an illness as punishment (e.g. caused by unapproving behavior), blame a family member ("Your smoking made me sick!"), harbor feelings of injustice ("Why is this happening?"), place blame on genetics of one side of the family ("Runs on his side of the family"), view an illness as negligence (e.g. drinking), or feel that it is as simple as bad luck. These beliefs make it extremely difficult for individuals and families to adapt to the demands and changes brought on by chronic illness. Optimal family functioning involves understanding the limits of scientific knowledge, affirming competency, and incorporating biological and psychosocial healing techniques (Rolland, 1990, 2003, 2004).

## **Coping and Resilience**

When treating chronic illness through a systemic process, coping and resilience will be increased. Froma Walsh's Family Resilience Framework, drawn in part from other family resilience theorists (e.g. McCubbin, 1975, 1983, 1986, 1997; Patterson, 1988, 2002), has advanced a systemic view of resilience in ecological and developmental contexts (Walsh, 1996, 2003a, 2003, 2004). The key processes in this framework involve: (a) *Family Belief Systems*- meaning making, positive outlook, spirituality; (b) *Family Organizational Patterns*- flexibility, connectedness, social & economic resources; (c) *Communication/Problem Solving*- clarity, open emotional communication, collaborative problem solving (Walsh, 2003a). Walsh's framework has advanced research, intervention, and prevention.

**Family belief systems.** Family belief systems largely influence how families view crisis, suffering, and options. These systems organize family processes and approaches to crisis situations. Resilience is fostered through shared beliefs which increase options for solving problems, healing, and growth.

***Making meaning of adversity.*** In facing adversity, families do best when viewing a crisis as a challenge that is comprehensible, manageable, and meaningful. As families attempt to make sense of how things happen, clarity is gained, and the healing process can begin. The implementation of rituals can also assist patients and families in the process of grieving "what used to be" (Walsh, 2003). Buchbinder, Longhofer, and McCue (2009) highlight how incorporating coping rituals for expressing emotions, such as evening prayers, and family celebrations to highlight treatment milestones with symbolic meaning, provide stability and security for families in which a member has cancer.

***Positive outlook.*** "Hope is to the spirit what oxygen is to the lungs: It fuels energy and efforts to rise above adversity" (Walsh, 2003, p. 408). High-functioning families have been

shown to hold a more optimistic and hopeful view of life. It is important that patients and families feel that their strengths are affirmed in order to counter feelings of helplessness, failure, and blame. In countering feelings of helplessness, failure, and blame; it is beneficial for patients and families to language and to structure their circumstances in ways that bring meaning, understanding, and overall hope for increased positive functioning (Flaskas, McCarthy, & Sheehan, 2007). Resilience is reached by continuous confidence.

***Transcendence and spirituality.*** Families find strength and comfort through transcendent beliefs as these beliefs provide strength, comfort, and guidance in adversity (Walsh, 2003; Werner & Smith, 1992). Healthcare providers must be cognizant to assess for families' faith as faith can be inspirational. Studies have revealed that spirituality and its subcomponents: (a) peace, (b) meaning, and (c) faith, positively impact patient and family coping in the face of illness (Holt-Lunstad, Steffen, Sandberg, & Jensen, 2011; Whitford & Olver, 2012). Crisis and illness can be viewed as an experience for learning, transformation, and growth (Walsh, 2003).

**Organizational patterns.** As today's families are increasing in complexity, families must organize themselves in unique formations to meet various challenges. Resilience is bolstered through structure, connectedness, and social and economic resources in family organization.

***Flexibility: Bouncing forward.*** People, most often, measure pursuits by past, present, or future goals and or experiences (Charmaz, 2006). It is important that individuals and their families recognize the impact of chronic illness on individuals' overall well-being and abilities. Families experiencing health-related crises often cannot "bounce back" as "normal" has changed. Instead families must look forward in constructing a new "normality" (Walsh, 2003).

***Connectedness.*** Resilience is strengthened by family members displaying mutual support, collaboration, and commitment to succeeding through adversity. At the same time, it is important for family members to maintain individuality in order to not become overly dependent on one another. If family members become too dependent on one another, family systems will not adapt to their new circumstances as efficiently (Walsh, 2003). Danoff-Burg and Revenson (2000) highlight that support and collaboration change over the course of rheumatoid arthritis in response to changing treatment regimens, self-image, disability, pain, and symptoms. This is not only true for rheumatoid arthritis but of all chronic illnesses. The type of support offered by family members must fit the needs of patient and family at that time.

***Social and economic resources.*** Although it is common for patients and their families to withdraw from one-another and other inter-personal relationships, social networks are important sources of emotional and economic support. Involvement in community groups and social networks fosters greater resilience. When families face the challenges of chronic illness, financial resources can be depleted. Community groups and social networks can help relieve some of this stress (Walsh, 2003). As families find it challenging to reach out to others, especially during times of crisis, healthcare providers can play a large role in connecting families to further community resources (Shapiro, 2002).

***Communication and problem solving.*** Quality communication fosters resilience as it brings clarity to crisis situations, encourages emotional expression, and fosters collaborative problem solving.

***Clarity.*** Clarifying and sharing information about crisis and future expectations (such as course of an illness, treatment regimens, outcomes of an illness) with healthcare providers facilitates meaning making, authentic relating, and informed decision making (Amirkhan, 1994).

If families avoid discussing these matters, increased ambiguity can lead to blocked understanding, closeness, and mastery. Sharing in acknowledgement of the reality of circumstance and losses fosters healing and resilience (Walsh, 2003).

***Emotional expression.*** Open communication that occurs through mutual trust, empathy, and tolerance for differences, fosters a wide variety of emotions to be expressed in families (D'Ardenne, 2004). Allowing space for the emotions to be expressed is beneficial as family members process feelings and begin to heal at different paces. If feelings are suppressed, family members may become unable to move forward (Walsh, 2003).

***Collaborative problem solving.*** Family resilience is reached and maintained by collaborative problem solving and conflict management. Creative brainstorming leads families to new possibilities and opportunities for overcoming adversity and healing. For example, a young adult couple may initially be devastated to hear that they will have fertility complications due to chronic illness. However, in accepting new possibilities and opportunities, the couple can look to other options (e.g. assisted reproductive technologies, adoption) (Pasch & Christensen, 2000). In order to move forward, resilient families define goals and priorities and work towards achieving these goals (Walsh, 2003).

### **A Gap in the Literature**

The reviewed literature highlights the need for healthcare providers to treat chronic illness from a systemic perspective. Frameworks have also been provided to highlight how healthcare providers can evaluate, formulate, and intervene in families in which a member has a chronic illness (Rolland, 1990, 1994, 2004); as well as have an advanced systemic view of resilience in ecological and developmental contexts (Walsh, 1996, 2003a, 2003, 2004).

Examples of various chronic illnesses have been provided to give rich description to the above frameworks.

Young adulthood poses many unique transitions and challenges for individuals and their partners. Chronic illness adds another complex level to an already complex time. Although the provided frameworks are rich in value, they do not specifically address how healthcare providers can effectively promote systemic coping among young adult couples.

The goal of this study was to give healthcare providers a foundational understanding of the perceived effects of Crohn's disease on couple relationships and young adult life-cycle transitions. Findings identify what couple-targeted interventions provided by healthcare providers have been beneficial to couples; and, in turn, highlight further areas of needed healthcare provider systemic assessment and intervention.

### **Summary of Literature Review**

The scholarship on chronic illness presents opportunities for further research to those interested in the advancement of healthcare to young adult couples in the United States. The available studies on this understudied topic highlight themes and trends in the literature. These themes are (a) chronic illness is ever increasing and is impacting young adult couples more than ever before, (b) ambiguity of chronic illness makes it particularly stressful for couples to cope, (c) chronic illness psychologically and socially impacts both diagnosed individuals and their partners, (d) chronic illness impacts younger adult couples more greatly than older adult couples, (e) chronic illness is experienced differently between genders, (f) treatment of chronic illness is trending towards a systemic, family-strength approach. These themes and/or trends highlight the current discussions chronic illness researchers are having. Some of these themes, as well as other themes, emerged in the results of this study.

## **Theoretical Framework**

For the purposes of this study, the researcher viewed the impact of chronic illness from a systemic lens, incorporating John Rolland's *Family Systems-Illness Model*. As much attention was given to the partners of individuals with Crohn's disease, as was given to the diagnosed individuals. Young adult life-cycle transitions were conceptualized according to Carter and McGoldrick's (2005) family life-cycle framework. Lastly, coping and resilience were viewed from Froma Walsh's family resilience framework (Walsh, 1996, 2003a, 2003, 2004). As this study utilized Interpretative Phenomenological Analysis the researcher remained attuned to making meaning of how participants made meaning of how an individual's diagnosis of Crohn's disease affects couple relationship satisfaction and young adult life-cycle transitions.



## **Chapter Three**

### **Methodology**

#### **Overview**

I chose the research design for this project to understand *how one partner's diagnosis of Crohn's disease is perceived to affect young adult couple relationship satisfaction and life-cycle transitions*. The sub-questions *how do the numerous physical symptoms of Crohn's disease cause psychological and social implications for the diagnosed individual and partner; what couple-targeted interventions, given by healthcare providers, have been most beneficial to the functioning of the couple system; and in what ways can healthcare providers better support couple level coping* provided further understanding of how healthcare providers can support young adult couples in successfully sustaining their relationships and completing life-cycle transitions, regardless of chronic illness.

#### **Research Methods**

This study utilized Interpretative Phenomenological Analysis (IPA) for inquiry. Smith, Flowers, and Larkin (2009) define IPA as a qualitative research approach focusing on the examination of how people make sense of their major life experiences. It is phenomenological as it is concerned with exploring experience. IPA researchers are most interested in what happens when the everyday flow of lived experience takes on a new significance for people. IPA was used to gain further insight into how Crohn's disease impacts young adult couple relationship satisfaction and life-cycle transitions.

#### **Case selection.**

Table 1

*Purposive Sampling Criteria for Participating Diagnosed Patients*

- Aged 20-35.
- Patient diagnosed > than one year.
- Diagnosis occurred in current relationship.
- Cohabiting, engaged, or married.

In order to attain perspectives on the experiences of a specific phenomenon, this study used purposive sampling. Purposive sampling is a type of nonprobability sampling in which observed participants are chosen on the basis of which ones will be most representable—based on inclusion criteria (Babbie, 2011). As IPA is an idiographic approach, most concerned with understanding particular phenomena in particular contexts, sample sizes for studies are small. To capture and describe the central themes of how Crohn’s disease is perceived to affect couples in young adulthood, five young adult couples were recruited to participate. This sample size allowed for a detailed analysis of each case and then subsequent micro-analysis of similarities and differences across the cases (Smith et al., 2009). Each couple included one partner with a diagnosis of Crohn’s disease; this partner had been diagnosed while in the current relationship; and had the diagnosis for at least one year, such that the individual and partner were able to reflect on the perceived effects of Crohn’s disease on the couple system.

The couples were citizens of the United States and were of white race. The diagnosed patients were identified by gastroenterologists at the University of Nebraska Medicine Center. The patients were made aware of the purpose of the study and how their participation would add to the literature available for healthcare providers treating Crohn’s disease.

**Data collection.** Inclusion criteria included patients having a diagnosis of Crohn’s disease greater than one year, ranging between the ages of 20 and 35, and being with current partner at the time of diagnosis. The diagnosed patients were receiving treatment at the

Gastroenterology and Hepatology Clinic of the University of Nebraska Medical Center (UNMC). Gastroenterologists introduced the study to patients who met criteria. The gastroenterologists notified the researcher via the UNMC electronic medical record of patients who verbally agreed to participate. The researcher contacted these patients via telephone to schedule interviews.

Interviews were completed in-person or over Skype, this was dependent on convenience for participants. The in-person interviews were held in the behavioral health room at Nebraska Medicine Midtown Clinic. All interviews began with a structuring session in which the researcher focused on joining with couples; provided an overview of the study; and described what participation would encompass. Couples were able to ask questions about the study during this time. Participants were made aware of their anonymity and were asked to choose a pseudonym in order to maintain anonymity. They were assured of the confidentiality of all recordings, transcripts, and any other study related material.

During the structuring session, all in-person participants were given a consent form (Appendix B). As the researcher read the consent form, she stopped after each section to provide specific examples and to enquire if participants had any questions. When the researcher completed reading the consent form, the participants verified that they understood the purpose of the study was to understand how a diagnosis of Crohn's disease influences the experiences of partner relationship satisfaction for couples and affects young adult life-cycle transitions. The researcher also ensured that the information gained would support healthcare providers in recognizing the specific challenges to the couple system this disease poses, promote systemic interventions, and improve public health. A HIPAA form was also given to all participants (Appendix B). This form highlighted privacy and security rules, as well as participants' rights. Participants were informed of the freedom to withdraw from the research study at any time,

without any penalty, and reassured that all records would be destroyed upon withdrawing. All participants understood that the risks of this study were believed to be minimal; however, participants were informed that there was a potential to find some questions distressing as certain emotions could arise, and participants could experience heightened relationship problems, which were previously dormant or unacknowledged, due to the nature of interview questions. Participants were made aware that there was no guaranteed personal benefits to this study, though participants could find the interview experience beneficial in creating a space to talk about how Crohn's disease has affected their life-cycle transitions and relationship satisfaction. They were also informed that when the research became published they would have access to the publications.

For long distance participants, the informed consent and HIPAA form were e-mailed prior to completing the interview over Skype. Participants signed the consent and returned it via e-mail to the researcher before the interview. When completing the structuring session, via Skype, the researcher verbally provided an overview of what the participants agreed to through the consent process.

In addition to the purpose of the structuring session as described in a previous paragraph, the researcher also took the opportunity to state her positionality in relation to the study topic by briefly informing the participants of her Crohn's disease diagnosis and why she was interested in this study. She did not disclose her personal experiences of Crohn's disease as to not skew the participants' responses to later questions. The following is an example of how the researcher approached this disclosure: "As a young adult behavioral health provider, having Crohn's disease myself, I am interested in other young adults' experiences of Crohn's disease. What was initial diagnosis like for you? Have your hopes or dreams been altered due to Crohn's disease?"

How has the disease impacted your relationship?” Ample space was available for participants to ask any questions they might have had. Next, the researcher asked couples questions in regard to how Crohn’s disease had affected them as a couple. The questions (Appendix C) were: *How have you supported each other since the diagnosis of Crohn’s disease? How does your relationship now compare to your relationship before Crohn’s disease?* The themes from these questions were included in the final write-up. Near the end of the structuring session, basic background information was gathered from participants, including age, marital status, occupation, status of children, and length of Crohn’s disease diagnosis.

**Interviews.** After completing the structuring session and couple interview, the PI completed one-on-one interviews. These were completed in-person, or over Skype depending upon which was more convenient for participants. The in-person interviews were held in the behavioral health room at Nebraska Medicine Midtown Clinic. The interviews were recorded on two audio recorders. Two recording systems were used in case of equipment malfunction of one device. Before each interview the recording devices were tested in order to ensure they were functioning correctly. Extra batteries were available for the audio recording devices to ensure continuous recordings. Notes were taken in order to retain information gathered and to identify any content of interest (Lofland & Lofland, 1999; Groenewald, 2004).

Each partner of the couple system was interviewed individually for approximately 25-30 minutes. Interviews were completed individually in order to eliminate the potential of responses being compounded. Smith et al. (2009) identify the role of the interviewer as an active listener who engages in probing participants to learn more about the interesting or important things they are saying. In interviewing the individuals, the researcher focused on concrete, lived experiences in order to fully explore the phenomenon (Hein, 2013).

The specific interview structure is provided in Appendix C. The interview questions asked of the diagnosed individuals encompassed the themes of: *how Crohn's disease affected their biological, psychological, and social well-being; how Crohn's disease affected couples' young adult life-cycle transitions, how Crohn's disease affected overall relationship satisfaction; what couple-targeted interventions, given by healthcare providers, were most beneficial to the functioning of the couple system; and in what ways could healthcare providers better support couple level coping.* The questions asked to the partners of these individuals encompassed the themes of: *what it was like for them when their partner was diagnosed with Crohn's disease; how their partner's Crohn's disease affected their young adult couple life-cycle transitions; how Crohn's disease affected overall relationship satisfaction; what couple-targeted interventions, given by healthcare providers, were most beneficial to the functioning of the couple system; and in what ways could healthcare providers support couple level coping.*

**Reflective journal.** A reflective journal and field notes were kept during the interviews and data analysis. The journal allowed the researcher to describe her feelings and thoughts about conducting this area of research. According to Rossman and Rallis (2012) the use of a reflective journal adds rigor to qualitative inquiry as the investigator can record his/her reactions, assumptions, expectations, and biases about the research process. The field notes provided additional data for the analysis. Selections of the reflective journal are available in Appendix F and Appendix G.

**Data storing.** The researcher transcribed all interviews herself in order to become further acquainted with the data. All transcripts were kept in a Microsoft Word file. The Microsoft Word file was kept on the researcher's personal, password protected laptop, as well as on an encrypted flash drive.

A paper folder for each couple was labeled by the date of the interviews. This folder included each individual's consent form, as well as any research notes written during the interview sessions. The notes included observational notes, theoretical notes, methodological notes, and analytical memos (Groenewald, 2004). These files were locked in a file cabinet in a secured office at Nebraska Medicine Midtown Clinic.

**Analysis of the data.** This study employed Interpretative Phenomenological Analysis. The essence of IPA lies in its analytic focus, which directs attention towards the lived experience of a particular phenomenon and participants' attempts to make meaning of their experiences. IPA is a set of common processes and principles which are flexible (Smith et al., 2009). Smith (2007) describes IPA as an iterative and inductive cycle. Thus, the researcher conducted the following process:

***Reading and re-reading.*** The researcher began by immersing herself in the original data. This entailed listening to the audio-recording while transcribing. She then re-read the transcripts to reflect and record powerful recollections of interviewing, or initial, powerful, observations in her journal, to help bracket her thoughts. Repeated readings also allowed for a model of the interview structure to develop and for the researcher to gain an understanding of how narratives held sections of an interview together (Smith et al., 2009). For example, chronological accounts provided structure of an interview. However, within these chronological accounts, there was, at times, emphasis placed on specific life events (e.g. a participant explaining his experiences of being partnered to an individual with Crohn's disease moved from the perceived effects the disease has had on overall live-cycle transitions to the participant talking about specific thoughts and feelings concerning recent events preceding the interview). Reading and re-reading also allowed for the researcher to appreciate how rapport and trust built across an interview and

highlighted richer or more detailed sections or contradictions and paradoxes throughout the interview (Smith et al., 2009).

***Initial coding.*** The initial level of analysis was the most detailed and time consuming. This level of coding examined semantic content (i.e. meaning of content), and use of language on a highly exploratory level (Smith et al., 2009). The researcher strove to maintain an open mind as she noted areas of interest within the transcript. This process fostered further familiarity with the transcript and allowed the researcher to identify specific ways in which the participant talked about, understood, and thought about an issue (Smith et al., 2009). The aim of initial coding was to produce a comprehensive and detailed set of notes and comments on the data. The researcher focused on the process of engaging with the transcript as much as with the outcome (i.e. meaningful and legible comments that were used in the next step of analysis). There were descriptive core comments, which stayed close to the participant's explicit meaning (Smith et al., 2009). The participant described things that mattered to her/him (objects of concern, such as reactions to initial diagnosis, relationship changes following diagnosis, interruption of life-cycle transitions) and the meaning of those things for the participant (what those relationships, processes, etc. were like for the participant). From this, more interpretative noting formed as the researcher understood how and why each participant had these concerns. Interpretative noting developed by the researcher paying close attention to the language the participant used, thinking about the context of their concern (the world they experience), and identifying abstract concepts which helped to make sense of the patterns of meaning in their account.

Exploratory commenting was conducted in three discrete processes: (a) descriptive, (b) linguistic, and (c) conceptual, following the recommendations of Smith and Colleagues (2009):



- Descriptive comments focused on describing content of what the participant had said (these comments were in normal text).
- Linguistic comments focused on exploring the specific use of language by the participant (these comments were in italics).
- Conceptual comments focused on engaging at a more interrogative and conceptual level (these comments were underlined).

These discrete ways of completing exploratory commenting were combined on the same transcript as the links and connections between them were critical for the researcher to be able to immerse herself in the participant's life-world and engagement in deep data-analysis.

*Developing emergent themes.* Through comprehensive exploratory commenting, the data set grew substantially. Beyond the researcher having familiarity with the model of the interview itself, she also had an additional level of important, yet provisional, notes. This larger data set formed the focus of the next stage of analysis—development of emergent themes. An example of emergent theme formation is displayed in Table 2 (Appendix D).

In looking for emergent themes, the researcher focused on reducing the volume of detail (the transcript and initial codes) while focusing on maintaining complexity by mapping the interrelationships, connections, and patterns between exploratory notes. The initial codes became the focus, rather than the transcript. However, the exploratory commenting closely related to the original transcript (Smith et al., 2009).

Analyzing exploratory comments to identify emergent themes involved focus on discrete chunks of transcript, as well as recalling what was learned through the process of initial coding. The original whole of the interview became a set of parts as the analysis was conducted but came

together again, as a new whole, during the write-up. The resulting analysis was the product of both the researcher's and participants' collaborative efforts (Smith et al., 2009).

Transforming notes into themes involved an attempt to produce a concise statement of what was important in the various comments attached to a piece of transcript. Themes were expressed as phrases that spoke to the psychological essence of the piece and contained enough particularity to be grounded, as well as enough abstraction to be conceptual. The focus was to capture what was crucial at that point in the text. The themes reflected not only the participant's original words and thoughts but also the researcher's interpretations (Smith et al., 2009).

Table 2

*Selected Examples of Narratives, Exploratory Commenting, and Emergent Theme Formation*

Emergent Themes	Original Interview	Exploratory Commenting
Fear of the unknown	"It was good at first to say, 'Ok, I have this thing, and something is really going on here'. But, at the same time then you think about all the things down the line that you're going to have to deal with....it is not pleasant."	<u>When diagnosis is given there is an initial relief, followed by questioning what the future will be like. The unknown prognosis is unpleasant and can leave the patient feeling powerless.</u>
Admitting seriousness of symptoms meant, losing control.	"I would not want to admit to the nurses or other people what was going on. That gave me a sense of control, by not admitting to people what had just occurred".	By not admitting how severe his symptoms were to medical staff the patient created an illusion of control. <u>Was the patient scared to acknowledge the control his body had taken over him?</u>
Impact on career	"My work has been really accommodating and helpful, but I think that it could get to a point where if I got sick because of it, then I might have to think about a different career, or different area to work in the zoo, so that's had a pretty big impact."	<i>"I think that it could get to a point where if I got sick because of it, then I might have to think about a different career..." implies patient recognizes the impact Crohn's may have on her career.</i>
Psychological effects	"[Crohn's] wears on ya. Wondering if things will ever get better. Or, wondering 'why is this happening to me', 'why do I have this', and things like that."	<u>Struggling with the questions of "why" puts psychological strain on patient.</u>
Practically supportive	"I started farming the last three years. Farming was really good, this year it's	<i>"We just do what we gotta do to make it work. I'll probably get a real job</i>

through self-sacrifice.	not. So, now we don't know what we're doing. We're trying to figure that out. We buy private insurance. Prices are going up, and crop prices are going down. I mean, we just do what we gotta do to make it work. I'll probably get a real job again or something."	<i>again or something" infers self-sacrificing behavior. <u>Is partner self-sacrificing by giving up farming to get a job that will better support the financial costs of Crohn's?</u></i>
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*Note.* Descriptive comments: focused on describing the content of what the participant has said, the subject of the talk within the transcript (normal text). Linguistic comments: focused upon exploring the specific use of language by the participant (italic). Conceptual comments: focused on engaging at a more interrogative and conceptual level (underlined).

***Searching for connections across emergent themes.*** Once a set of themes was established within the transcript and ordered chronologically, in the order they were evidenced, the next step involved the development of mapping how the researcher thought the themes fit together (Smith et al., 2009). If themes arose that were not pertinent to the overall research question and scope, they were discussed in the write-up as all themes were critical to report. The researcher then focused on drawing together the emergent themes and produced a structure which allowed for attention to be given to the most interesting and important aspects of the participant's account (Smith et al., 2009).

To look for connections of themes, the researcher typed all themes into chronological order. In looking at the list, themes were moved around to form clusters of related themes. Some themes pulled other themes towards them.

***Moving to the next case.*** The next step involved moving to the next participant's transcript, and repeating the above process. The researcher strove to treat the next case individually. This involved bracketing the ideas emerging from the analysis of the prior case. In order to bracket, the researcher attempted to set aside the emerging themes from prior cases by journaling reflective thoughts in order to maintain an open mind. This was continued for each subsequent case (Smith et al., 2009).

**Looking for patterns across cases.** The next stage involved looking for patterns across cases. This included laying each emergent theme out on a large surface and looking across themes to find connections (Smith et al., 2009). The researcher asked herself questions like: ‘how does a theme in one case help illuminate a different case?’ and ‘which themes are most potent?’ This led to reconfiguring and relabeling of themes, which led to theoretical levels of analysis.

An emergent theme was considered a theme only if three or more quotes, from differing transcripts, formed the emergent theme. As you can see in Table 3 (Appendix D) the emergent theme ‘experience of diagnosis for partners’ only had two similar quotes, therefore in further analysis this emergent theme was combined with other emergent themes to form the theme ‘feelings of fear’.

Table 3

*Selected Examples of Emergent Theme Formation*

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**Experience of Diagnosis for Patients**

Inconclusive diagnosis (1a 6; 1b 80, 257; 2b, 109; 3b, 97; 4c 100; 5c 230, 240)

Symptoms confirming diagnosis (1a 11)

Diagnosis was shocking/frightening (1b 73; 3b 100)

**Experience of Diagnosis for Partners**

Diagnosis was scary for partner (1b 311; 3c 374; 4c 24)

Partner was naïve at diagnosis (3c 369)

**Support Given by Partners**

Partner is practically supportive (1a 13; 1b 185; 1c 336; 2a 7, 24; 3a 27; 3b 234; 3c 392; 4a 3; 5a 7)

Partner is emotionally supportive (1a, 17; 1b, 187; 1c, 336; 3a, 24; 3b, 234; 5a 6, 16; 5b 156)

Partner is self-sacrificing (2a 10, 16; 3a 21)

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*Note.* In parentheses number depicts what transcript quote was taken from. Letter identifies which part of transcript. (a) couple interview; (b) patient interview; (c) partner interview. Number following letter identifies line in transcript.

**Creation of Super-Ordinate Themes.** Once themes were completed, abstraction was used to identify patterns between themes and to develop a sense of ‘super-ordinate’ themes (Smith, et al., 2009). This involved putting like with like and developing a new name for the

cluster. For example, a series of themes around the impact of diagnosis: ‘depression’, ‘questioning personal value’, ‘guilt’, and ‘loss of self-esteem’ were grouped together under the super-ordinate theme title: ‘The Psychological Effects of Crohn’s Disease’. The super-ordinate theme then emerged at a higher level. Subsumption was also used if an emergent theme itself required status of super-ordinate (Smith et al., 2009). For example, ‘loss of power’ became a super-ordinate theme and brought together closely related themes including: ‘lack of control’, ‘frustration’, and ‘feelings of helplessness’.

In addition to abstraction and subsumption, polarization was used to examine for oppositional relationships in emergent themes between transcripts by focusing on differences rather than similarities (Smith et al., 2009). For example, set against the negative aspects of ‘strained relations’ there was another set of themes, which detailed the perceived positive effects of Crohn’s disease on couple relations. This polarization was found in one couple’s transcripts and is identified in Table 4 (Appendix D). This oppositional relationship offered a higher level organizing device for the researcher, but did not change the super-ordinate theme of ‘strained relations’ as this polarizing theme was only found in one couple’s transcripts.

Table 4

*Selected Example of Polarized Emergent Theme*

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**Perceived Positive Effects on Relationship**

<i>Howard:</i> I think it has [Crohn’s] made me mature faster than I would have before, which I think maturity is helpful in any relationship.	Line 150 (5b)
<i>Geneva:</i> I think it’s stronger [relationship]. We’ve grown up a lot in terms of having to deal with major stressors that come along with Crohn’s....I think it made us better at communication too. Because, you just have to talk about it. I think it has both made us a little more patient and understanding.	Line 42, 53, 340 (5c)

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*Note.* Line number depicts what line in transcript quote was taken from. Number and letter in parenthesis identifies which transcript and which part of transcript. (a) couple interview; (b) patient interview; (c) partner interview.

The final results of these processes are presented in Table 5 (Appendix D). In this table, themes were nested under super-ordinate themes, and each theme was illustrated by at least three quotes from participants.

Table 5

*Selected Examples of Narratives, Themes, and Super-Ordinate Theme Formation*

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**Experience of Diagnosis**

**Inconclusive diagnosis**

<i>Mary:</i> A lot of them (providers) were on the fence, ‘maybe you have Crohn’s maybe you don’t’. Then I had a fistula and they were for sure.	Lines 11, 80-82 (1a, b)
<i>Sarah:</i> I had struggled from the time I was 12 or 13, and had tests done and nobody could ever figure anything out. Part of me was relieved that something was actually going on, and I wasn’t just losing my mind...	Line 97-100 (3b)
<i>Annie:</i> Well, at first we really didn’t know what it was...the diagnosis was ambiguous.	Line 100 (4c)

**Feelings of fear**

<i>Mary:</i> I think it was a little bit of shock, and then a lot of disbelief and anxiety about what was going to happen.	Lines 73-76 (1b)
<i>Frank:</i> It was kind of a scary feeling. You could see it [fear] in her.	Line 311 (1c)
<i>Pete:</i> She was in the hospital for appendix problems or whatever, then they found Crohn’s. So, at first, it was just like questions, and we were young, so we didn’t know what to expect. We just, blindly went into it. It was scary.	Lines 371-378 (3c)

**Biopsychosocial Factors**

**Biological**

<i>Rose:</i> It hasn’t affected me very well. It’s made everything harder.	Line 188 (2b)
<i>Sarah:</i> I’ve been in pain for about three years, that’s probably the hardest because how I feel physically affects me emotionally, and spiritually.	Lines 133-135 (1b)
<i>Howard:</i> I felt like I was Jason Bourn, sitting in a restaurant, knowing where the restroom was.	Line 129 (5b)

**Psychological**

**Loss of power**

<i>Frank:</i> It’s terrible when you can’t help your partner when you know they need help.	Line 329 (1c)
<i>Sarah:</i> Pushing our wedding back was the first punch to the gut, of ‘this is completely dictating my life’.	Line 372 (3b)
<i>Howard:</i> I would not want to admit to the nurses or other people what was	Line 108 (5b)

going on. That also gave me a sense of control, by not admitting to people what had just occurred.

### ***Concern for the future***

*Frank:* It's the fear of the unknown. You don't know what the side effects of the infusions are going to do. You don't know what's going to happen. Line 492 (1c)

*Mike:* I worry about her health and our family...it's not curable, it's not fatal, but it leads to other things.

*Annie:* I was thinking about our future in a different way than I had in the past, wondering if it would be the same, or wondering if we'd be going through a lot of surgeries. Line 102 (4c)

*Geneva:* After multiple medication failures, and being on multiple immune-suppressant medications at one time, I was very worried about what the future would look like and what could be done to give him somewhat of a life back. Line 282 (5c)

### ***Mixed emotions***

*Mike:* We both exercise and eat right; sometimes I feel 110% and when she does not it isn't fair....You don't always want to feel bad for your spouse, so there's a little guilt. Lines 552, 774 (2c)

*Sarah:* I hate that I can't handle having a full time job and having my kids. I don't feel like I'm living up to the standards that I want to for wife and mom, that's really one of my biggest struggles. Lines 164, 190 (3b)

*Everett:* [Crohn's] wears on ya. Wondering if things will ever get better. or wondering "why is this happening to me", "why do I have this" and things like that. Line 44 (4b)

### **Social**

*Frank:* I'd say it's changed quite a bit just because of the dieting and the things that she's trying to do specifically....We pretty much don't go out to eat anymore. Line 37 (1c)

*Sarah:* People don't get it, and I don't expect them to I guess. But, sometimes it's easier just to not deal with it, and just stay in our little section, our little corner, on the farm, and be comfortable. Line 76 (3b)

*Howard:* I was 23 at the time of diagnosis. I think it helped me mature a lot faster. I had to think about things I could or could not do in life more, the consequences of my actions. I could not go out and stay up until 4 in the morning or be as carefree with friends or activities as I did before. Line 144 (5b)

### **Interference in Life-cycle Transitions**

#### **Childbearing halted/delayed**

*Rose:* I had been thinking about a third one, but taking heavy drugs while I'm pregnant would make me nervous. Line 300 (2b)

*Sarah:* My kids are my miracles. They are healthy and they are awesome, and absolutely the loves of my life. I always wonder had I been healthy, or had no issues maybe we would have had more, I don't know. Lines 181, 220 (3b)

*Geneva:* I think it delayed our decision to start a family. I know that I wanted him to be healthier before I even thought about having kids. Line 316 (5c)

### **Career struggles**

*Rose:* The place I was working is definitely not conducive to having to go to the bathroom a lot. I worked at this framing place and you're in one big room, you just can't get away from it. That had been my job. Line 232 (2b)

*Sarah:* I had a full time job. I hate that I can't handle it now. My biggest priority needs to be my kids, and I can't handle a full time job and my kids. Line 160 (3b)

*Geneva:* I, quite honestly, don't know how he got out of bed and went to work some days, but he fought through residency until he just couldn't anymore. Line 290 (5c)

### **Dependence on family of origin**

*Mary:* They have helped me financially with medical bills. Line 160 1(b)

*Sarah:* I can't imagine ever moving or not being as close to our families because they help us a ton. Line 200 (3b)

*Pete:* Financially we rely on our parents.... I don't know how we'd get through what we do if both of our families weren't around. Line 423 (3c)

*Annie:* I'm getting a lot of financial assistance... Line 134 (4c)

### **Relationship Satisfaction**

#### **Strained relations**

*Rose:* When I'm not feeling good, it makes it hard. He's a great dad and husband, but he does not know how to handle some of it. I don't know if he really understands how sick I can feel. Lines 88, 322, 341 (2b)

*Annie:* It's definitely put stress on our relationship. Especially when he wasn't doing well. There were definitely periods of time that we weren't doing well with each other. Line 154 (4c)

*Geneva:* When he first started developing symptoms, I don't think he felt well. I mean, there were other things going on but part of it was that he didn't feel well, and he was kind of snarky with me. I didn't have an answer for it, I couldn't get him to open up and talk about it...We did break up for about a month and a half. Line 336 (5c)



### **Practically and emotionally supportive**

- Frank:* I try to be there for her, a shoulder to cry on or whatever. Line 336 (1c)
- Rose:* When I'm sick, he drops everything and he takes care of everything. Line 10 (2a)
- Sarah:* It's not all financial; he's supporting me emotionally. He's been there for everything. He goes to my appointments. Lines 27, 231 (3a, b)
- Annie:* I've been the one to take care of a lot of the logistic pieces...obtaining medicines, calling insurance companies, and dealing with diet changes. Line 3 (4a)
- Howard:* [She's] practically supportive about the nuances of getting things done around the house, and paperwork, and logistics...all the daily grind activities that need to get done. Line 7 (5a)
- Howard:* [She's] always concerned, helpful...emotionally supportive. Line 6 (5a)

### **Team approach**

- Mike:* We are a little bit more of a team. Line 541 (2c)
- Pete:* She said, 'I'm not going to hate you if you want to leave, now is your chance before we sign on the dotted line'. And, I was like, 'no, we are in this together, and that doesn't change anything'. Line 380 (3c)
- Geneva:* I think we have grown closer, and our relationship is stronger. We are a much better team. We've supported each other with a lot of family stressors... Lines 374, 18 (5c, a)

### **Meaning making**

- Rose:* ...I'm coming to terms of having to deal with Crohn's forever. I'm trying to be positive about it, and know that I will feel better soon and maybe for a long time. I'm looking forward to that. Lines 172, 178 (2b)
- Sarah:* I've helped a lot of people with Crohn's and connected with them. I think maybe that's what I'm here for. To help people dealing with the same thing... Line 304 (3b)
- Everett:* I learned that things are the way they are, and all you can do is do your best to try to get by. Line 48 (4b)

### **Need for increased communication**

- Mary:* It probably would help if I talked to him more about it. He didn't even know when I was initially diagnosed. Line 206 (1b)
- Frank:* I don't know if she can have kids or not. I don't even know if she wants kids that much. Lines 377, 400 (1c)
- Rose:* I've wondered if it would help if he knew a little more. But I don't know, I don't want to say all these symptoms, so many of them are gross. [If I communicated more] maybe he would be more empathic. Lines 380, 402 (2b)
- Mike:* I think we have some communication issues; maybe we have for a long time... Line 472 (2c)

## Experiences of Healthcare System

### Individualistic approach

*Mary:* Having him there at an appointment would probably help him, but logistically I make appointments when they are good for my schedule, not necessarily his. Line 242 (1b)

*Frank:* I'll get the brief after the doctor. It's always strictly about what's happened. As far as them attending to me, I see no reason for them to. Lines 460, 472 (1c)

*Pete:* I don't know if we've ever really gotten direction or support or anything relationship wise from any of the doctors, or anything. They're doing their job, as far as I can see. I don't look to them for advice on anything other than what's going on with her. Lines 466, 478 (3c)

*Annie:* We have had little to no support as a couple. Line 168 (4c)

### Personal agency

*Mary:* I constantly think, 'what can I do to help the situation?'. Trying to decide what the best thing to do is taxing. Getting it under control is frustrating too. Lines 117, 266 (1b)

*Rose:* I know that I'm having some emotional problems and things, and it is affecting my relationship, but I've just tried to look online about that stuff and I'm starting to see a therapist. Line 462 (2b)

*Sarah:* Crohn's is life-long. If you don't speak up and explain to your doctors where you are physically and emotionally, they can't treat you better. It was really from my own findings that I figured out what was going on, and that "ok, I'm not just going to die from this"... Lines 278, 120 (3b)

### Insurance and financial challenges

*Rose:* My medicine isn't helping me much, but that's because I'm not even on the right thing. Line 64 (2a)

*Mike:* It's tedious getting different types of medicines. Line 54 (2a)

*Pete:* I worked, what we call, a "real" job, so I had insurance. We could afford to pay for all the medical expenses and now I farm, and we can't afford it. Line 14 (3a)

## Needed Healthcare Improvements

### Increased psychosocial assessment training

*Rose:* They're not trained to talk to you about how you're feeling about things. So, I don't usually share. I don't go down that road. If it was a part of treatment, I would. Lines 414, 428, 442 (2b)

*Annie:* I think that the behavioral aspect of the disease definitely needs to be addressed more than it was. Doctors don't necessarily listen to emotions and feelings. They just talk about diagnosis and treatment, and then are out the door. I really think it would have Line 196 (4c)

been easier had we had that support from the beginning.

*Geneva:* It would have been helpful to even have resources available.

Lines 390, 401 (5c)

I think having the information and being able to distribute it is a powerful thing. That wouldn't take much time from the physicians or nursing staff.

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*Note.* Line number depicts what line in transcript quote was taken from. Number and letter in parenthesis identifies which transcript and which part of transcript. (a) couple interview; (b) patient interview; (c) partner interview.

**Trustworthiness and Quality.** Yardley (2000) presented four broad principles for assessing the quality of qualitative health research. Yardley's principles offer a variety of ways to establish quality. These principles can be applied to different theoretical orientations of qualitative research (Smith et al., 2009). Therefore, the researcher implemented Yardley's principles for trustworthiness and quality as they are relevant to IPA.

***Sensitivity to context.*** To ensure a high quality research study, the researcher demonstrated sensitivity to context (Yardley, 2000). This sensitivity began in the structuring session as the researcher joined and built rapport with participants. Sensitivity to context was demonstrated through an appreciation for the interactional nature of the data collection within the interview setting. The researcher paid close attention to the interview process—showing empathy, putting participants at ease by recognizing interactional difficulties, and negotiating the intricate power-play between research expert and experiential expert. Sensitivity to context during data analysis occurred by the researcher providing immersive and disciplined attention to making sense of how participants made sense of the unfolding accounts and what could be learned from them (Smith et al., 2007; Yardley, 2000).

Sensitivity to context is also demonstrated throughout the written report of the findings. The findings chapter highlights verbatim extracts from the participants' transcripts to support the conclusions made, to allow for participants to have a voice in the project, and to provide the ability for the reader to check the interpretations made. Claims made by the researcher are

appropriate to the sample being analyzed and offered cautiously (Smith et al., 2007; Yardley, 2000).

The researcher also shows sensitivity to context through an awareness of the existing literature related to chronic illness. Relevant substantive literature is used to help orient the study and findings. The discussion also includes a dialogue with literature not found referenced in the introduction to the study, as this is customary in IPA (Smith et al., 2007; Yardley, 2000).

***Commitment and rigor.*** Rigor refers to the thoroughness of the study—the appropriateness of the sample to the research question, the quality of the interview, as well as the completeness of the analysis (Smith et al., 2007; Yardley, 2000). The sample was selected carefully to match the research questions and to be reasonably homogenous. The researcher conducted thorough interviews in order to demonstrate rigor, as well as commitment (Smith et al., 2007; Yardley, 2000). In conducting in-depth IPA interviews, the researcher displayed personal commitment in ensuring participants were comfortable throughout the interview process. The researcher also attended closely to what participants described in order to remain attuned to the interview process.

Data analysis was conducted thoroughly and systematically with researcher engagement with the data. The analysis was sufficiently interpretative, as the researcher went beyond a simple description of what there was to an interpretation of what it meant (Smith et al., 2007; Yardley, 2000). The researcher was cognizant of telling the reader something important about individual participants, as well as something important about the themes they shared. In the results section, each theme is supported with quotes from participants. The researcher strove to show respect to participants and the data throughout the entire research process (Smith, 2007; Yardley, 2000).

When the data analysis and an initial write-up were completed, the researcher provided the write-up to the research participants. Participants, who responded ( $n = 4$ ), reported that the write-up captured their experiences of Crohn's disease. No changes were made to the analysis or write-up.

***Transparency and coherence.*** Transparency represents how clearly the stages of the research process are described in the write-up of the study. The researcher enhanced transparency by describing how participants were selected, how the interview was structured and conducted, and what steps were used in the analysis. Tables were included in the appendix to detail each of these features (Smith et al., 2007; Yardley, 2000). As this was an IPA study, the phenomenological and hermeneutic sensibility was apparent in the write-up. The write-up also highlighted IPA as an inherently interpretative activity. The reader was made aware that they are positioned as attempting to make sense of the researcher trying to make sense of the participants' experiences (Smith et al., 2007; Yardley, 2000).

In order to ensure coherence, the researcher read the drafts of the write-up carefully and intentionally put herself in the stance of an outside reader. The researcher carefully drafted and re-drafted the write-up. As the writing was re-drafted the analysis became clearer. The final write-up represents a testament to the process of IPA (Smith et al., 2007; Yardley, 2000).

***Impact and importance.*** The final test of the trustworthiness and quality of qualitative research is whether or not the reader finds the final write-up of the study to be interesting, important, and useful. By following the above principles, the researcher aspired to create a valuable contribution to the literature.

***The independent audit.*** In addition to Yardley's (2000) quality criteria, an independent audit was completed (Smith et al., 2009). An independent audit was a powerful way for ensuring

validity in this study. The researcher's pre-doctoral internship/post-doctoral fellowship supervisor, Dr. Jennifer Harsh, conducted mini audits of the researcher's work; for example, she looked at the first interview transcript annotated with the researcher's initial codes. Dr. Harsh checked that the annotations had validity in relation to the text being examined and the approach being employed. She also conducted audits of three additional transcripts throughout the research process. In addition, Dr. Harsh offered an occasional note on what she thought was interesting or important throughout the transcript (Smith et al., 2009).

### **Ethical Considerations**

All of the participants were treated in accordance to the ethical guidelines of the University of Nebraska Medical Center and Virginia Tech Institutional Review Boards (IRBs) (Appendix A) and the American Association for Marriage and Family Therapists (AAMFT). There were several factors that lead to this research study having a potential for minimal risk to participants. First, patients diagnosed with Crohn's disease and their partners were interviewed and discussed personal information in relevance to the perceived effects of Crohn's disease. There was a potential that participants would feel uncomfortable speaking about their experiences or explaining personal information about the couple system. Second, as this study dealt with Crohn's disease, a chronic illness, participants were potentially triggered while reflecting and discussing the initial diagnosis and the adjustment to Crohn's. Third, there was a potential for participants to feel pressured to answer all the questions designed for the interview as the researcher held a position of power. Fourth, and perhaps most significantly, participants could have experienced heightened relationship problems, which were previously dormant or unacknowledged, due to the nature of interview questions.

These considerations were incorporated during the research design stage and throughout

data collection, data analysis, and write-up. All cautions were taken to ensure participants felt safe and comfortable during the entire research project. The structuring session specifically allowed for rapport building with participants and provided opportunity to emphasize that participants had the freedom to withdraw from the study at any time. During the interview process, individuals were reminded that their identity would be kept confidential, but as this is an Interpretative Phenomenological Analysis, the sample size would be smaller and participants could potentially identify their partners' responses in the draft and final write-up. Participants were also assured that if there was distress at any time, and they wished for resources of support, appropriate referrals would be provided. No participants reported any distress.

## Chapter Four

### Findings & Discussion

The purpose of this study was to understand how one partner's diagnosis of Crohn's disease is perceived to affect young adult couple relationship satisfaction and life-cycle transitions. As a reader, you are positioned as attempting to make sense of the researcher making sense of the participants' experiences (Smith et al., 2007; Yardley, 2000). The findings presented in this chapter are not linear. Rather, they are organized to emphasize the relational aspects of Crohn's disease, followed by the related healthcare aspects. This chapter is divided into eight sections. These sections include participant demographics, interview process, results, implications, limitations, future research, and lessons learned. There is a conclusion provided at the end.

#### Participant Demographics

The participants in this study ranged in age from 28 to 40. All participants were of white race. Relationship duration ranged from 2.5 years to 14 years. Three couples were married; two couples were cohabitating. Length of diagnosis ranged between 1.5 years to 13 years. Three of the diagnosed individuals were female, two were male. A summary of participant demographics is displayed in Table 6 (Appendix D).

Table 6

#### *Participant Demographics*

<b>Couple Pseudonyms</b>	<b>Gender</b>	<b>Age</b>	<b>Race</b>	<b>Relationship Status</b>	<b>Diagnosis</b>
Mary (Diagnosed)	Female	34	White	Cohabitating	Diagnosed- 2013 (Dating since 2013, now cohabitating)
Frank (Partner)	Male	35	White		
Rose (Diagnosed)	Female	35	White	Married	Diagnosed- 2012 (Dating since 2005, now married)
Mike (Partner)	Male	40	White		
Sarah (Diagnosed)	Female	32	White	Married	Diagnosed- 2002 (Dating since 2001, now married)



Pete (Partner)	Male	35	White		married)
Everett (Diagnosed)	Male	29	White	Cohabiting	Diagnosed- 2013 (Dating since 2000, now cohabiting)
Annie (Partner)	Female	28	White		
Howard (Diagnosed)	Male	34	White	Married	Diagnosed- 2005 (Dating since 2002, now married)
Geneva (Partner)	Female	33	White		

## Interview Process

Couples were initially interviewed together. In completing the initial couple interviews, participants presented hesitant to speak openly in regards to the two questions asked. The diagnosed individuals were able to readily describe how they felt supported by their partners, while the undiagnosed partners were unsure how the diagnosed partner was supporting them. This was represented by an undiagnosed partner asking, “How do you support me?” Some couple systems were reserved when sharing how their relationship has changed. However, when interviewed individually these participants reported openly about this and other questions. All participants appeared relieved to verbalize their experiences with Crohn’s disease.

## Results

During both the couple and individual interviews, participants described the impact of the diagnosis and how Crohn’s disease affected them in multiple ways across various aspects of their lives. These descriptions from separate interviews were presented together in order to provide a rich understanding of the perceived effects on the couple system. Overall, the diagnosis and biopsychosocial well-being appeared central to how the couple system experienced their relationship, life-cycle transitions, and the healthcare system. Figure 1 (Appendix E) provides a representation of how the experience of one partner’s diagnosis of Crohn’s disease affects the couple system. Each area of the figure is represented throughout this chapter.

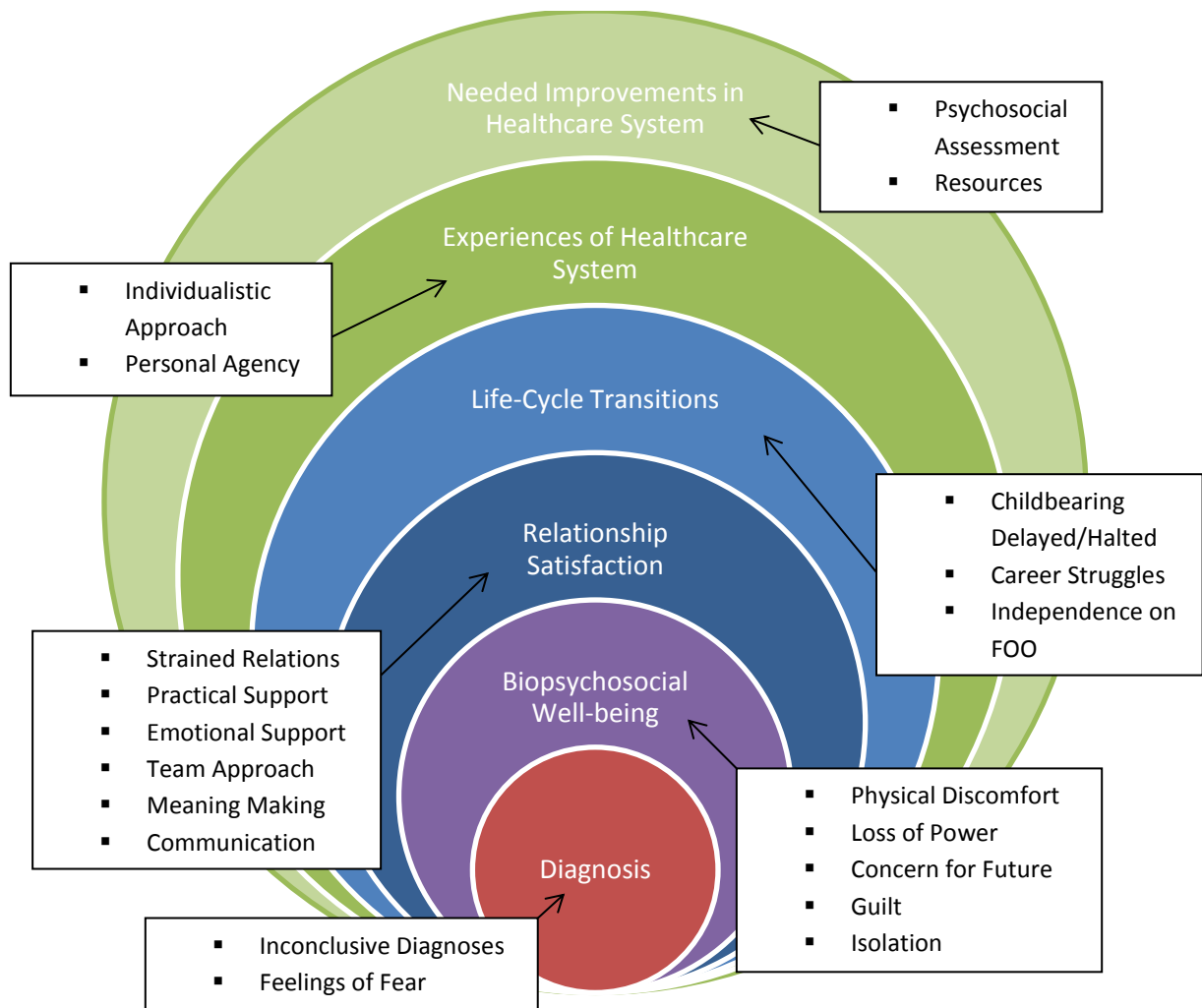


Figure 1. Representation of overall experiences of Crohn's disease among couples.

**Couples' Experiences of Diagnosis. "I think it was a little bit of shock and then a lot of disbelief and anxiety about what was going to happen."**

Couples described the diagnosis process as drawn out and inconclusive for sometimes years. When a conclusive diagnosis was given, couples often felt an initial sense of relief, as they were affirmed something was physically wrong with the diagnosed individual. Followed by this initial relief, couples were shaken by feelings of anxiety and disbelief as the reality of Crohn's disease set in.

**Inconclusive diagnosis.** Several couples experienced the physical symptoms of Crohn's for years, without diagnosis. These years were spent living in physical pain for patients and psychological frustration for patients and partners as healthcare providers were unable to give a diagnosis. Patients eventually began to question whether their symptoms were in their heads. When a diagnosis of Crohn's was finally given, couples felt an initial sense of relief.

Mary, a 34 year old woman, experienced frustration with her healthcare providers as she experienced various symptoms of Crohn's that went undiagnosed for an extended period of time. She recounted her experience of a significant Crohn's symptom leading to a conclusive diagnosis, by stating "A lot of them [providers] were on the fence, 'maybe you have Crohn's, maybe you don't'. Then I had a fistula, and they were for sure".

Sarah, a 32 year old woman, had a similar experience. She was relieved when her physical symptoms were confirmed; she no longer feared it was all in her head. Sarah described struggling with symptoms for almost ten years before being given an official diagnosis, "I had struggled from the time I was 12 or 13, and had tests done; nobody could ever figure anything out. Part of me was relieved that something was actually going on, and I wasn't just losing my mind..."

Geneva the 33 year old partner of Howard, described her relief when Howard was finally given a correct diagnosis:

I think it was a relief, at first, to have answers. I was worried, but at the same time relieved to have an answer to what was causing the symptoms, at least it felt like there was some sort of a treatment plan—like, we had an answer.

Years of misdiagnoses cause significant distress to couples which in turn affect life-cycle transitions. With a conclusive diagnosis, couples feel relief as symptoms are now understood

and treatable. In the minds of couples, a diagnosis implies better symptom management, improved physical and psychological well-being, and, perhaps, a cure.

**Feelings of fear.** Couples reported feelings of fear, disbelief, and overall shock following the initial relief of diagnosis. This time was described as “scary”. There was a sense of “fear” in the air. These feelings of fear were greatly associated with future thinking and wondering what was to come.

Mary mentioned feelings of “shock” and “disbelief” about what was going to happen as she thought about her and her partner’s future. She was aware of the physical difficulties Crohn’s could potentially pose, and this thought caused anxiety. Pete, the 32 year old partner of Sarah, described a sense of shock and naiveté of future complications when Sarah was diagnosed, “She was in the hospital for appendix problems, then they found Crohn’s. So, at first, it was just like questions, and we were young, so we didn’t know what to expect. We just, blindly went into it. It was scary.”

These two experiences of diagnosis differ in that Mary was aware of possible symptoms, while Pete and Sarah were “young” and “didn’t know what to expect”. Although the level of understanding of Crohn’s was different for these couples, the fear appears equal between knowing and not-knowing.

**Discussion.** The themes of inconclusive diagnosis and fear are in-line with the theme of ambiguity of chronic illness depicted in the literature review. Ambiguity refers to the inability to determine the meaning of events and to accurately predict outcomes (Royer, 1998). From couples’ reports, it is clear that inconclusive diagnoses create a sense of not knowing. Due to sometimes extensive periods of inconclusive diagnoses, patients begin questioning their mental well-being, as there are no explanations for the symptoms they are experiencing. When

inconclusive diagnoses become conclusive, couples experience an initial sense of relief, quickly followed by a sense of fear and concern due to the reality of the disease and the now ambiguous future.

**Biopsychosocial Effects. “It’s made *everything* harder.”**

Couples reported significant, perceived effects on their biological, psychological, and social well-being. On several different accounts, patients described the biological symptoms being responsible for decreased psychological and social well-being. Like patients, partners are also affected psychologically and socially due to the numerous challenges they face alongside the patients.

**Biological.** The physical symptoms of Crohn’s make everything *harder*. Not only are patients experiencing physical discomfort, but the physical symptoms cause patients to be on constant alert to their bodies and their environments. Mary described her physical symptoms as “annoying” and “always there”, by stating, “I have to go to the bathroom multiple times a day, and sometimes it’s urgent. I usually have rectal pain after I go to the bathroom, so that’s annoying and always there”. Howard referenced the fictional undercover agent, Jason Bourne, to describe his urgency of previous physical symptoms, “I felt like I was Jason Bourne, sitting in a restaurant, knowing where the restroom was”.

Rose and Sarah described the physical symptoms as “hard”. For example, Rose reported, “It [Crohn’s] hasn’t affected me very well. It’s made everything harder”. Sarah stated, “I’ve been in pain for about three years. That’s probably the hardest because how I feel physically affects me emotionally and spiritually”.

From these descriptions it is clear that the biological symptoms of Crohn’s negatively impact the psychological well-being of patients. As biopsychosocial aspects are interrelated,

decreased psychological and social well-being are likely to increase the biological symptoms. This circular pattern can become even more disabling to patients.

**Psychological.** Loss of power, concern for the future, and mixed emotions are psychological symptoms prevalent for couples as they struggle with a sense of decreased power. Whether it's feeling powerless about the physical symptoms being experienced or feeling powerless with the inability to make a significant other feel better, couples are faced with challenges never experienced before. These challenges are beyond their control, and lead to frustration.

**Loss of power.** Mary depicted being haunted by the fact that she has Crohn's, as she stated, "It's disturbing knowing it's [Crohn's] there, and that it hasn't gone away is frustrating". Mary's partner, Frank also experiences a loss of power as he described the terrible feeling of powerlessness when "you can't help your partner when you know they need help". Howard's physical symptoms of Crohn's disease stripped him from a personal sense of power. He recalled:

I remember passing blood all over the bathroom in the hospital. Blood was everywhere. That sense of control, for the first time was gone. I had never experienced anything like that in my life, and it horrified me to feel so helpless.

Geneva identified how challenging it was for her to see Howard suffer with these physical symptoms, "It was hard to see somebody you love in that much pain, and suffering. It was hard".

Although these experiences vary in type and degree, they describe an overall lack of control. Mary's and Howard's experiences are as diagnosed individuals who perceive the physical and psychological effects of Crohn's first hand. Frank and Geneva feel the second hand

frustration of not being able to alleviate the physical symptoms for their partners. These examples highlight the systemic effects of Crohn's.

*Concern for the future.* Like many chronic illnesses, Crohn's disease has an episodic course with periods of remission. With knowledge of the long-term effects of Crohn's and the side-effects of treatments, couples often find themselves wondering about the future. More partners expressed concern for the long-term effects of Crohn's than patients.

Rose was the only patient who reported thinking about the future. She articulated future thoughts as "not pleasant" in relation to thinking about what she may experience in upcoming years. Mike, her partner, reported spending a great deal of time thinking about their nuclear family's future by stating, "I worry about her health and our family...it's not curable, it's not fatal, but it leads to other things". From this statement it is clear that Mike understands the potential implications for their entire family's well-being. Frank identified, "fearing the unknown. You don't know what the side effects of the infusions are going to do; you don't know what's going to happen". Geneva likewise identified the fears that arose for her when Howard was not responding well to differing medications:

The hardest part was when his symptoms continued to flare....When Remicade started to fail for him I was very worried about what the future would look like and what could be done to give Howard somewhat of a life back.

The partners' reports of fear of the unknown appear to identify that their sense of security and control over the future is compromised. As they are not personally diagnosed with the disease, their sense of lack of power may be even greater than the patients' because patients have greater involvement in their treatment.

**Mixed emotions.** Crohn's disease increases mixed emotions for couples. Patients reported personal psychological battles as well as guilt for not being able to fulfill the expectations they had once set for themselves, which in turn led to feeling insufficient. Partners expressed mixed emotions including guilt for being "healthy" and for "feeling bad" for their significant other.

Everett highlighted the psychological battle he endures by stating, "Crohn's wears on ya. Wondering if things will ever get better, or wondering 'why is this happening to me?'" Sarah described her psychological decline being due to not meeting her personal standards, by stating:

I hate that I can't handle having a full time job and having my kids. I don't feel like I'm living up to the standards that I want to for wife and mom, that's really one of my biggest struggles.

Mike was forthcoming in describing the psychological challenges that he experiences when he stated, "We both exercise and eat right; sometimes I feel 110% and when she does not, it isn't fair....You don't always want to feel bad for your spouse, so there's a little guilt". Mike described a sense of guilt for both physically "feeling well", and for "feeling bad" that Rose does not feel well. Similarly, Frank "feels bad" for Mary, and the biological and psychological struggles she is facing. Annie reported "[Crohn's] has brought on sadness, and anxiety, and trepidation. We've been through happiness too. Pretty much any emotion that you can think of we've probably felt it at some point or another".

It is clear that Crohn's psychologically wears on couples and decreases the ability for patients to meet the expectations they have for themselves. These expectations may be physically related, or role related. As partners observe these struggles, they often feel sadness



for their spouses which in turn leads to guilt for feeling this way, as well as for not experiencing the physical symptoms.

**Social.** Couples described a sense of social isolation caused by Crohn's disease.

Logistically speaking, couples are not able to easily go out for dining, as stringent diets are being followed. A lack of understanding and empathy from others also adds to couples withdrawing from social settings.

Mary and Frank have greatly decreased the amount of socializing they do as Mary is on a "crazy" diet in an attempt to have better control over her Crohn's. Frank reported the change in activities when saying, "It's changed quite a bit because of the dieting....We pretty much don't go out to eat anymore". Although Mary and Frank have lost socialization they report the quality of their time together improving, so that it all "evens out". Sarah expressed her frustration of others by stating, "People don't get it, and I don't expect them to, I guess. But, sometimes it's easier just to not deal with it, and just stay in our little section, our little corner, on the farm, and be comfortable". Her use of "I guess" implies that part of her does wish people would understand the impact of Crohn's in her life, and what she experiences. Perhaps, if others were able to understand Sarah and her partner's situation more, they would not feel the need to isolate themselves.

Social isolation can lead to decreased psychological well-being, as couples are not spending time with others they care about. Also, by decreasing socialization, couples may experience a lack of resources found through community connection. If others were more understanding and sensitive to the experiences and needs of others couples would likely feel less of a need to withdraw.

**Discussion.** The biological effects of Crohn’s disease make everything harder as patients become keenly aware of the alerted states of their bodies, and often suffer in pain from symptoms. These effects cause increased psychological turmoil to patients and partners. Couples long for control and a sense of certainty that Crohn’s steals from them. Ambiguity ranges from the day-to-day wondering of how the patient will feel and what the patient will be able to accomplish, to future physical and psychological well-being of patients and their families’ years beyond. Couple systems experience mixed emotions, as patients often feel guilt about not being able to fulfill previous roles, and partners experience guilt for being “healthy” and for “feeling bad” for the patients.

Stigmatization is an experience felt in the social context as participants reported that others do not understand how patients’ previous behaviors could now have consequences. These feelings of frustration specifically cause female patients and their partners to withdraw from social connections, as it is easier to live in *their own world*. This finding is in line with previously reviewed literature that highlighted chronic illness as stigmatizing (Albrecht et al., 1982; Jennings, Callahan, & Caplan, 1988), and that identified chronically ill females as tending to experience greater isolation than males (Berge et al., 2007) due to often increased pain and limited activity (Malmusi et al., 2011).

**Relationship Satisfaction. “When I’m sick he drops everything, and he takes care of everything.”**

Couples depicted six themes of how they were functioning post-diagnosis. They reported Crohn’s disease causes relational strain at times. Partners are monumental in decreasing this strain by being both practically and emotionally supportive. Couples also learn to cope with the strain by forming a team approach and move forward by making meaning of the disease in their

lives. Overall, communication was reported as the greatest area of need for improvement within couple functioning.

**Strained relations.** The physical symptoms of Crohn's disease were reported as being the greatest cause of relational stress. This relational stress was reported primarily by partners; only one patient alluded to strained relations. Perhaps this is due to partners being able to recognize the changes in relational patterns more fully, as they are not physically battling the effects of Crohn's.

Rose described the strain she experiences with Mike, "When I'm not feeling good, it makes it hard. He's a great dad and husband, but he does not know how to handle some of it. I don't know if he really understands how sick I can feel." Mike admittedly stated, "There are some blurps here and there". Annie was open about a decrease in sexual functioning, with the increases in Everett's flares:

It's definitely put stress on our relationship, especially when he wasn't doing well.

We've experienced some difficulties with sexuality. It was the stress that was put on our relationship that caused me to withdraw. In that sense, we were in this fight or flight situation with his health; my brain just wasn't going to the sexuality piece.

According to Geneva, Howard was so overwhelmed with his initial symptoms that they broke up while dating:

When he first started developing symptoms, I don't think he felt well. I mean there were other things going on but part of it was that he didn't feel well, and he was kind of snarky with me. I didn't have an answer for it, I couldn't get him to open up and talk about it....We broke up for about a month and a half.

The perceived effects of Crohn's cause couples to pull away from one another. The physical symptoms of Crohn's are described as spurring psychological stress leading to relational strain. It is clear, from these excerpts, that Crohn's disease has a systemic effect.

**Practically and emotionally supportive partners.** Partners fulfill roles of providers and caretakers, in order to maintain a sense of normalcy, and to remain psychologically strong. Pete articulated this in stating:

I try to not let myself be affected, because I'm the provider, I try to be strong, and pay the bills, make the kids get along, and help her when she needs help. I don't take the time to sit and think about it.

Sarah was quick to clarify, "It's not all financial; he's [Pete's] supporting me emotionally. He's been there for everything—he goes to my appointments." Mary indicated that her partner, Frank is "sensitive" to her situation. Frank described this as, "trying to be there for her, a shoulder to cry on." Howard described Geneva as, "practically supportive about the nuances of getting things done around the house, and paperwork, and logistics...all the daily grind activities that need to get done." As well as, "she's always concerned, helpful."

As these excerpts illustrate, partners find value in providing practical support. Although they cannot take away the physical symptoms of Crohn's they can be supportive in taking care of daily tasks and alleviate a degree of stress. Patients clarified that not only are their partners being practically supportive, but emotionally supportive, as well. By these clarifications it is evident that patients find great value in emotional support. Likewise, it is important to partners to remain emotionally available and sensitive to the diagnosed individual.

**Team approach.** Couples have taken a team approach in dealing with Crohn's. Crohn's has become the norm. They cope together to face the associated challenges.

Sarah and Pete provided a clear description of this when referring back to Sarah's initial diagnosis during their engagement. Sarah stated:

We were engaged when I got diagnosed, so it's been our normal. There's never been a question of how are we going to do it. We took our vows, and it's 'better or worse, sickness and health', and we live that.

Pete confirmed this when he reported, "She [Sarah] said, 'I'm not going to hate you if you want to leave, now is your chance before we sign on the dotted line.' I was like, 'no, we are in this together, and that doesn't change anything.'" Geneva even alluded to Crohn's as having perceived, long term, positive effects on her and Howard's relationship. She stated, "I think we have grown closer, and our relationship is stronger. We are a much better team."

These couples demonstrate a commitment to one another through sickness and health. Rather than allowing the stressors of the disease to deteriorate their relationships, they have accepted what they cannot change, and they have learned to cope as a team through the trials they experience.

**Meaning making.** Couples reported that coming to terms with Crohn's and making the best of it allowed them to move forward with their lives. Everett alluded to this by stating, "I've learned that things are the way they are, and all you can do is your best to try to get by." Some participants have been able to come to a state of hope about their future. Rose highlighted this in reporting, "I'm coming to terms of having to deal with Crohn's forever. I'm trying to be positive about it, and know that I will feel better soon and maybe for a long time. I'm looking forward to that." Sarah has been able to get to a state of finding meaning and value through her experiences of living with Crohn's disease. She reported this by saying, "I've helped a lot of people with

Crohn's and connected with them. I think maybe that's what I'm here for. To help people dealing with the same thing..."

Accepting and making meaning out of Crohn's had been empowering. Couples reported a state of fear for the future at initial diagnosis. As time has gone by, these same couples have been able to accept the presence of Crohn's, while moving forward with their lives.

**Need for increased communication.** Couples reported a lack of communication in reference to Crohn's disease. This lack of communication often began at the initial diagnosis. For some couples, it continues as patients are often uncomfortable sharing the full symptoms of Crohn's due to feelings of embarrassment.

Mary recognized that, "it probably would help" if she talked to Frank more, as he "didn't even know" when she was initially diagnosed. Rose provided her account of embarrassment by stating, "I've wondered if it would help if he [partner] knew a little more. But I don't know, I don't want to say all these symptoms, so many of them are gross. [If I communicated more] maybe he would be more empathic." Mike is aware of their lack of communication as he stated, "I think we have some communication issues. Maybe we have for a long time."

Although partners have reported functioning as a team, it is clear, by these descriptions, that patients do not fully disclose the symptoms they are experiencing. Level of comfort appears to have a significant influence on whether patients self-disclose to their partners. Symptoms that are perceived to be "gross" are kept private due to embarrassment.

**Discussion.** Similar to the reviewed literature on chronic illness, relationship satisfaction is altered by Crohn's disease (Eddington et al., 2010; Karlen, 2002; Knowles et al., 2013; Royer, 1998). This is evident by participants' experiences. The most significant period of strained relations is during initial diagnoses and uncontrolled flares. During these times, patients are not

only dealing with new diagnoses and uncertainty of their futures but also feelings of embarrassment in regard to the symptoms they are experiencing. This embarrassment causes patients to pull away from their partners in order to protect themselves from feeling more shame. Royer (1998) reported this as a normal phenomenon for young adults facing chronic illness.

Couples learn to cope with Crohn's by taking a team approach. Partners provide a role of caregivers for patients. This caregiving is practical, as well as emotional. In the reviewed literature, it is clear that the role of caregiver has a negative effect on partners as they often experience emotional and physical withdrawal, as well as caregiver fatigue. These experiences increase partners' chances of developing anxiety and depression by 40% (Janssens et al., 2006; Bogosian et al., 2009; Nicholl et al., 2001). The partners of this study did not identify increased anxiety or depression. However, partners did report experiencing a decrease in emotional and physical intimacy, specifically during times of Crohn's flares. If these periods of decreased emotional and physical intimacy are to continue, partners may experience anxiety and/or depression.

Although couples experience times of increased relational strain, they reported that overall, Crohn's disease encourages greater teamwork. The diagnosed individual and partners specifically reported high levels of commitment in regards to physical, psychological, and social challenges. Patients diagnosed prior to marriage reported their partners being consistently supportive and choosing to follow through with marriage regardless of a lifetime affected by chronic illness.

Froma Walsh (1996, 2003) emphasizes that in order for couples to *cope well* with chronic illness it is salient that they make meaning of chronic illness in their lives. This includes understanding the physical and emotional demands of an illness, viewing themselves as a

functional unit, appreciating life-cycle transitions and the effects chronic illness has on these transitions, and lastly, comprehending familial beliefs about illness and how these beliefs play a role in their functioning (Walsh, 1996, 2003). Meaning making for the individuals in this study first meant accepting their lives being affected by Crohn's disease; learning how to manage the disease, as well as daily responsibilities; and finding a new identity that incorporates Crohn's disease. These tasks, of meaning making, have allowed patients to be in a state of function, rather than dysfunction.

Couples also recognize the need for increased communication, and are working towards this, if they have not already achieved this. Decreased communication was identified in regard to the physical symptoms of Crohn's disease and the impact on patients' physical well-being. Patients identified that the greatest lack of communication was in regard to symptoms, as the symptoms of Crohn's are experienced as embarrassing. However, patients recognize that if they are more honest about their physical symptoms, partners will be more understanding of patients' physical restrictions and needs. Decreased communication between young adult partners is common and can be even more common with the presence of chronic illness (Royer, 1998). As young adults' identities are still forming, they can experience increased anxiety in regard to how their partners will respond to their symptoms, which in turn leads to decreased communication (Karlen, 2002). As stated in the literature (Eddington, et al., 2010; Maslow et al., 2011), young adulthood is a unique time in which couples face many challenges and transitions. Crohn's disease adds another layer of complexity to already complex lives.

**Interference in Life-Cycle Transitions. “We were supposed to get married in May and she was in the hospital, so we cancelled our wedding and we got married in November. She told me to run away then.”**



Couples described three common areas in which they felt Crohn's has affected their young adult life-cycle transitions. These areas included childbearing, career, and increased dependence on family of origin. The effects on life-cycle transitions are experienced and viewed differently among couples. Some couples pursued reproduction, while others choose to not reproduce. All couples have experienced negative effects on their careers. Some of these negative effects have led to changes in career, while other couples have not let the disease influence a career change.

**Childbearing halted/delayed.** The diagnosed female participants that chose to have children did so with concern from their healthcare providers. Significantly, the women who bore these children referred to the childbearing years as the "good" years in terms of feeling well and having few Crohn's related symptoms. Both Rose and Sarah have two healthy children, each wanting a third, but have chosen not to conceive in an effort to not put themselves or the fetus at risk. Rose articulated this by stating, "I had been thinking about a third one, but taking heavy drugs while I'm pregnant would make me nervous." Sarah is thankful for her two children and wonders about a third, "My kids are my miracles. They are healthy and they are awesome, and absolutely the loves of my life. I always wonder had I been healthy, or had no issues, maybe we would have had more, I don't know."

It is clear that having children is important enough for these patients to go against healthcare provider advice, to a limit. Participants were aware of "pushing their luck", and stopped after having two children. Mary takes a somewhat different approach as she fears her child experiencing what she has. "I wouldn't want my kid to go through the things I'm going through...I'm leaning more toward adoption." Mary still plans to fulfill her desire of being mother, but it will occur without a personal pregnancy.

Howard, being a male, did not have to worry about the effects of his medications on a fetus. However, the physical symptom of Crohn's caused him and Geneva to delay having children. Howard stated, "I had to have surgery my third year of fellowship. I was becoming chronically anemic from blood loss. Once I recovered from that, and the bleeding stopped, I think that made both of us psychologically ready to have children." Geneva iterated this when she reported, "It [Crohn's] delayed our decision to start a family. I wanted him to be healthier before I even thought about having kids."

The physical symptoms of Crohn's cause childrearing to be postponed or decreased, regardless of gender. Likewise, the idea of having an "unhealthy" partner as a parent deters partners from a typical trajectory of having children. Patients and partners want to be as healthy as possible when fulfilling their roles as parents.

**Career struggles.** Two female participants have experienced their careers being affected in similar ways. Rose and Sarah have been unable to return to their jobs after they each bore their second child, as they are not able to physically handle the demands of caring for their children and working.

Rose identified that her former job is no longer conducive to her current physical needs. "The place I was working is definitely not conducive to having to go to the bathroom a lot. I worked at this framing place, and you're in one big room. You just can't get away from it." Sarah spoke of the turmoil she feels not being able to work and raise her children, "I had a full time job. I hate that I can't handle it now. My biggest priority needs to be my kids, and I can't handle a full time job and my kids."

Like Rose and Sarah, Everett and Howard have experienced living with the physical symptoms of Crohn's while fulfilling professional roles. Remarkably, they have somehow

“muddled through” balancing symptoms with work life. Howard described this as, “I somehow muddled through medical school, and was able to do everything I needed to do, despite pretty bad IBD.” Everett likewise stated, “It [Crohn’s] slowed me down a little bit because my job is physically demanding, but we just worked around it and things are better now”.

What is different between the female scenarios and the male scenarios is the element of caring for children. Everett and his partner Annie do not have any children, and when Howard was experiencing his severe symptoms he and Geneva did not have children. It appears that the added role of parenting, specifically for mothers, leads to decreased ability to fulfill professional roles. This is likely compounded with mothers traditionally having the primary role in caregiving.

Although the partners of these patients do not experience the physical effects of Crohn’s disease, Pete described the potential of giving up his love for farming in order to get a “real” job to better handle the financial burden of Crohn’s. The two other partners reported no perceived effect on their careers, other than occasional “sleepless” nights, when they are in the ER with their significant other.

It is clear that career is important to all couples. Rose and Sarah have prioritized motherhood, but there is a sense of frustration not being able to physically handle a career as well. Everett and Howard have pushed through severe symptoms of Crohn’s in order to maintain and complete career goals. Pete is poised with the challenge of giving up a job he loves to find a job that will provide more support for his wife’s financial burden of Crohn’s.

**Dependence on family of origin.** Couples reported their families providing both financial and childcare assistance. Couples Rose and Mike and Sarah and Pete mentioned that they live close to their parents, and rely heavily on them to care for their children when they are

in the ER for a Crohn's flare. Mary and Frank as well as Everett and Annie have experienced only financial assistance, as they do not have children at this time.

Rose stated, "I have become dependent on Mike [her husband] or my parents taking care of the kids...." Sarah highlighted her appreciation of family by stating, "I can't imagine ever moving or not being as close to our families because they help us a ton." Her partner, Pete, reported similarly, "Financially, we rely on our parents....I don't know how we'd get through what we do if both of our families weren't around." Likewise, Annie articulated, "[We're] getting a lot of financial assistance...so, I would say [we're] still financially dependent on my parents."

From the difference in reporting between couples with children and the couples without, logistical family assistance, such as childcare, is of greater need when children are present. Regardless of children, there is a theme of needing financial assistance among participating couples, indicating that there are significant healthcare costs related to Crohn's.

**Discussion.** Chronic illness diagnosed in young adulthood is often more challenging than chronic illness diagnosed in earlier or later life (Maslow et al., 2011). The participants of this study identified Crohn's disease as impacting childbearing, career, and family relations. In regard to childbearing, mothers diagnosed with Crohn's disease identified feeling blessed with the children they were able to successfully bear, as healthcare providers had warned them about the risk of pregnancies. Each mother identified longing for a third child but deferred due to the increased risk of complications. For male participants, childbearing was and/or is delayed until symptoms reside, and these male participants were/are healthy enough to be involved fathers. Delaying childbearing was commonly evidenced in the literature. Royer (1998) identified partners potentially withdrawing from one another as chronically ill individuals often acquire a

sense of guilt for presumably disappointing their partners' hopes by altering childbearing. Sense of guilt for altered childbearing was not apparent in this study.

Although sense of guilt for altered childbearing was not found in this study, mothers reported a sense of guilt for not being able to physically handle the demands of motherhood and careers. This was reported by two mothers who are unable to return to their places of work after having children. Due to the physical symptoms they experience from Crohn's they are no longer able to manage the demands of work and children. This likely greatly impacts their sense of accomplishment and self-identity. One of these mothers has been diagnosed for a short time, and both mothers experience their symptoms being poorly controlled. This is a common phenomenon among the chronically ill as young adults with recent diagnoses have much lower rates of continuous employment (Maslow et al., 2011). The male participants also reported struggling through pain and other various symptoms. However, they are able to maintain their jobs and reach professional goals. What is different for these men is that they do not have children. It appears that the addition of children, specifically when one is primary caretaker, compounds the ability to maintain intended careers.

Most of the couples identified increased dependence on family of origin. This dependence was reported as financial as well as logistical, such as childcare. Couples implied a sense of gratefulness for the assistance their parents could provide. In completing a literature review to understand this concept further, there was a paucity of literature. Therefore, further research should be completed to understand how relationships with family of origin can serve as a positive support in sustaining functioning.

**Experience of Healthcare System. "I don't know if we've ever really gotten direction or support or anything relationship wise from any of the doctors...."**

Healthcare providers were reported to focus primarily on the diagnosis. As this is often the normal approach, some couples reported being satisfied. Couples take responsibility for getting their psychological and relational needs met outside of the doctor's office, as these topics were not discussed in treatment. The greatest frustration reported were insurance plans making it difficult to get needed medications, and insurance premiums making insurance difficult to afford.

**Individualistic approach.** Partners reported that healthcare providers focus on the effects of Crohn's almost entirely for the patient alone. Some partners expect nothing different, while others wish for healthcare providers to include them more.

Frank reported his experience as "getting the brief" after the appointment, and then went on to state, "I see no reason for them [healthcare providers] to attend to me." Pete responded similarly to Frank in stating, "I don't know if we've ever really gotten direction or support or anything relationship-wise from any of the doctors. They're doing their job as far as I can see. I don't look to them for advice on anything other than what's going on with her."

As healthcare provider support and intervention are often focused solely on the patient it seems that these partners have accepted this as appropriate care. However, partners Annie and Geneva have different opinions, as they emphasized feeling left out of the treatment process. Annie identified, "Not being married really puts a strain on communication with physicians.... That has been very, very challenging....I never really feel that I am respected in the eyes of the doctors as being Everett's partner." Geneva feels similarly, "I have so much respect for all of his treaters, but of course they were paying attention to his symptoms of pain and anemia. 'How are you doing with this, how are coping as a couple.' I don't remember that ever coming up".

In the first paragraph, we understand that Frank and Pete have no expectations of healthcare providers attending to them by incorporating them into the treatment process. Perhaps

this is due to Frank and Pete not recognizing the role they play in patients' over-all well-being, and the role Crohn's plays in couple well-being. Annie and Geneva, on the other hand, seem to recognize the systemic effects of Crohn's disease and what it means to cope as a couple. It is their hope to be more included.

**Personal agency.** Patients reported taking considerable effort in bettering their physical and psychological well-being. Doing this seems to provide a sense of control over a disempowering disease. Mary alluded to this as she reported, "I constantly think, 'what can I do to help the situation?'" Sarah reported learning to advocate for her greater well-being:

Crohn's is life-long. If you don't speak up and explain to your doctors where you are physically and emotionally, they can't treat you better. It was really from my own findings that I figured out what was going on, and that, 'Ok, I'm not just going to die from this'.

Rose reported looking for further resources in order to have her emotional and relational needs met. She stated, "I know that I'm having some emotional problems and things, and it is affecting my relationship, but I've just tried to look online about that stuff. I'm starting to see a therapist."

These accounts demonstrate a sense of personal agency. This personal agency supports positive coping. If healthcare providers were to assess for psychological well-being, patients could experience more applicable interventions and further behavioral and psychological resources.

**Insurance and financial challenges.** Crohn's disease is expensive, and insurance coverage is challenging. Patients struggle to get needed medication as these medications are sometimes denied by their insurance companies. Rose addressed this by reporting, "My medicine isn't helping me much, but that's because I'm not even on the right thing." She is not

on the right medication, as her insurance will not pay for a biologic until all other forms of medication are tried, regardless of her provider noting that Remicade, a biologic, is needed. One partner's career change has led to not being able to afford the financial demands of Crohn's. Pete stated, "I worked what we call a "real" job, so I had insurance. We could afford to pay for all the medical expenses. Now I farm, and we can't afford it".

With not being on needed medications, patients continue to experience debilitating symptoms of Crohn's disease. Beyond medication complications, the rising cost of insurance premiums adds to couples' stress. This increased stress has perceived negative effects on relationship satisfaction, as previously noted.

**Discussion.** The literature review provided an in-depth exploration of the need for healthcare providers to incorporate a systemic approach to treatment in order to meet the biopsychosocial needs of patients and their partners. This need was not as evident in the analysis process. Rather, couples reported themes of expecting an individualistic approach to healthcare and feeling a sense of personal agency. The analyzed information demonstrates that couples are comfortable with their historical experiences of the healthcare system. This does not mean that an individualistic approach is better; it means that couples are comfortable with what they know. In addition, couples noted an increased need for healthcare providers to attend to greater psychosocial assessment.

The majority of patients reported that they attend Crohn's related appointments without their partners. This was implied as being due to logistical ease; partners are most often working or providing care for children. One couple reported attending all Crohn's related visits together; however, this couple has to drive three hours for care and so turn these trips into "getaways". When patients were questioned as to whether or not they would find value in their partners



attending their appointments they identified that it would likely be helpful but logistically challenging. Overall, female participants reported finding value in partner inclusion, while male participants inferred that healthcare providers had no reason to include partners. This divide in findings implies that female participants have a greater perception of the effects of chronic illness on the whole couple system. It is likely that gender roles also play a role in this discrepancy as males are generally socialized for greater levels of independence and individuality. These discrepancies continue to flourish in the healthcare setting (Celik, Lagro-Janssen, Widdershoven, & Abma, 2011; Verdonk, Benschop, de Haes, & Lagro-Janssen, 2009).

One area of particular interest is the overall sense of personal agency patients indicated. Rather than placing expectations on healthcare providers for physical and psychological support, patients expressed personally seeking out literature and finding support groups in order to fully understand how to make the best of their situation physically and mentally. This finding of personal agency is a perceived strength as patients clearly take responsibility in learning to manage Crohn's disease. However, if one is not successful in attaining a sense of independence, self-control, and personal responsibility, he/she may internalize this as failure and experience shame (Delmar, Boje, Dylmer, Forup, Jakobsen, Moller, Sonder, & Pederson, 2006). It is important for healthcare providers to distribute resources to couples in order to promote positive personal agency and biopsychosocial coping.

The theme of health maintenance organization (HMO) and financial challenges was not expected prior to completing this study. In retrospect, this theme is not uncommon in any way. Rather, the researcher did not account for how HMO policies could interfere with patients getting needed treatment and their overall health-related outcomes. Patients reported experiencing severe symptoms of Crohn's disease, sometimes for years, as HMOs would not

relinquish payment for biologics until all other medications had been trialed. Other participants reported that they may need to make a career change as premiums keep rising and they can no longer afford to be self-employed. The findings from this unexpected theme are preliminary as this study did not specifically address this area. However, this finding is a glimpse of another area of needed research.

**Needed Improvements to Healthcare System. “They’re not trained to talk to you about how you’re feeling about things. So, I don’t usually share. I don’t go down that road. If it was part of treatment, I would.”**

**Increased psychosocial assessment training.** Couples expressed their frustration with healthcare providers’ lack of attention to psychosocial well-being. Although frustrated with this lack of attention, couples understand that healthcare providers are not trained to attend to the psychosocial needs of couples. Partners reported that if providers were trained to take a minute or two to assess for psychosocial well-being, understood appropriate community resources, and provided handouts identifying these resources, the psychosocial needs would be attended to.

This scenario is demonstrated by Annie when she stated:

I think that the behavioral aspect of the disease needs to be addressed more than it is. Doctors don’t necessarily listen to emotions and feelings....They don’t tell you, ‘this is what you’re going to be dealing with, and you might have troubles with communication and sexuality’...you really have to live it, and seek it out. I really think it would have been easier had we had that support from the beginning.

Geneva similarly stated:

It would have been helpful to even have resources available. I think having the information and being able to distribute it is a powerful thing. That wouldn’t take

much time from the physicians or nursing staff.

Howard has the perspective of not only being a Crohn's patient, but a gastroenterologist, as well. From his personal and professional experience, he identified, "I don't think it's something [psychosocial well-being] that most providers, for better or worse, ask everybody with IBD."

These excerpts demonstrate the lack of healthcare providers' attention to the psychosocial effects of Crohn's disease during medical appointments. Participants suggested that providers need training as to how to briefly address psychosocial well-being, and that they need an understanding of the resources available. Providing this information to couples is empowering, and will improve all aspects of couples' well-being as they are holistically supported with the related stressors of Crohn's. A discussion of how healthcare providers can implement brief psychosocial assessments is provided in the following implications section.

### **Implications**

In the literature review, John Rolland's Family System's-Illness Model, along with Froma Walsh's Family Resilience Framework, were provided as effective mechanisms for healthcare providers to collaboratively assess and intervene in family systems in which a member has a chronic illness. To iterate, these frameworks are effective as they both view chronic illness within the life-cycle process (Rolland, 1987a, 1990, 1994, 2004; Walsh 1996, 2003, 2004). In addition, Rolland's model incorporates an understanding of the psychosocial typologies of illness, the phases of illness, and how family health beliefs play a role in overall systemic coping. Froma Walsh's resilience framework expands upon these understandings to an advanced systemic view of resilience in developmental and ecological contexts. Her framework also incorporates family belief systems, as well as family organization and communication

patterns. The findings from this study support the use of these frameworks as these frameworks provide a collaborative and systemic approach that can target relationship satisfaction and life-cycle transitions related to chronic illness stressors.

Collaborative and systemic treatment of chronic illness is invaluable in promoting positive health-related outcomes for both patients and partners. Although participants noted being comfortable with the individualistic approach to healthcare, they also identified a need for community resources that target couple functioning. In order for couples to be provided with accurate resources, as well as couple level interventions, it is pertinent that healthcare providers are able to complete systemic assessments of chronic illness. The following section, *practice*, provides a guide on how healthcare providers can incorporate tenets from Rolland's and Walsh's frameworks in a brief- oriented, solution focused format that targets assessment and intervention at the couple level.

**Practice.** Traditionally, couple and family therapists have emphasized a systemic approach to treating chronic illness (Minuchin, 1974; Rolland, 1994). It has not been until recent years that healthcare providers have also begun to recognize this need. This recognition by healthcare providers is essential as over half of U.S. adults live with a chronic illness (CDC, 2014).

There are various approaches that can be utilized by healthcare providers to assess for and implement psychosocial interventions. Some of these approaches include Motivational Interviewing, Solution Focused Therapy, Collaborative Goal Setting, and Cognitive Behavioral Therapy. For this study's purpose, I chose to depict the following framework to provide a brief-oriented, systemic approach for healthcare providers to more fully assess and implement needed psychosocial interventions.

Solution Focused Therapy (SFT) is a strength-oriented, patient-centered model that can be used by healthcare providers, and has been validated as being effective in the healthcare field (Stermensky & Brown, 2014). Figure 2 (Appendix E) provides an outline of what solution focused assessment looks like within the healthcare system.

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| <p>I. Addressing past successes</p> <ul style="list-style-type: none"><li>- Supporting couples in solution focused thinking and increasing their overall confidence.</li></ul> <p>II. Promoting behavior change</p> <ul style="list-style-type: none"><li>- Addressing what has worked well in the past.</li></ul> <p>III. Assessing emotional difficulties</p> <ul style="list-style-type: none"><li>- Clarifying what has helped them feel less down.</li></ul> <p>IV. Creating strategies</p> <ul style="list-style-type: none"><li>- Providing couple level interventions.</li></ul> |
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*Figure 2.* Outline of solution focused assessment.

Using the information gathered through this solution focused assessment healthcare providers are then able to collaboratively set systemic goals with couples. Figure 3 (Appendix E) is an outline of what the process of collaborative, systemic goal setting could look like.

<p><i>Our goal is:</i> _____</p> <p><i>We will:</i> _____</p> <p><i>When:</i> _____</p> <p><i>We will do this first:</i> _____</p> <p><i>Challenges that may arise:</i> _____</p> <p><i>We will handle them by:</i> _____</p> <p><i>We will reward ourselves when:</i> _____</p> <p><i>Our reward will be:</i> _____</p>
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*Figure 3.* Outline of collaborative, systemic goal setting. Adapted from “Brief Interventions in Primary Care”, by P. Khatri and K. Mays, 2011, [PowerPoint slides]. Retrieved from [http://www.integration.samhsa.gov/Brief\\_Intervention\\_in\\_PC,\\_pdf.pdf](http://www.integration.samhsa.gov/Brief_Intervention_in_PC,_pdf.pdf). Copyright 2011 by the Substance Abuse and Mental Health Services Administration.

By collaboratively addressing a specific health-related goal, a detailed plan of chosen behavior change is created. This plan highlights what the couple will do differently, when this new behavior will occur, and what action will be taken first. Challenges to this new behavior are identified in order for the couple to process how these challenges will be overcome. Lastly, a reward is established when an identified marker is obtained. Utilizing these two outlines provides an easily utilized framework.

Healthcare providers can complete the above framework within 10-15 minutes, during medical encounters. Although a seemingly simple approach, brief, systemic interventions have crucial health-related outcomes. Through utilizing brief, systemic interventions patients and their partners have improved psychosocial well-being as adherence to treatment is improved and

positive health behavior changes are maintained (Canavarro & Dattilio, 2011; Lister et al., 2013; McLean, 2013; Pakenham & Samios, 2013).

Not only is this framework valuable in healthcare settings, but traditional couple and family therapists can employ it, as well. Incorporating this framework to assess for how Crohn's disease and other chronic illness may be affecting the biopsychosocial well-being of couples is important in traditional settings, especially as couples with chronic illness may be seeking further support in this setting. Beyond utilizing this framework, it is necessary for traditional therapists to keep authorized communication with couples' healthcare providers in an effort to further appropriate treatment related goals.

**Public Policy.** Within the past couple of years, healthcare systems have taken on the Quadruple Aim. The Quadruple Aim stems from the precursor, the Triple Aim. Don Borwick and his colleagues first introduced the Triple Aim to enhance patient experience, improve population health, and reduce cost (Bodenheimer & Sinsky, 2014). Although this approach has been optimized throughout the healthcare system, it has increased provider burnout. In recognizing increased provider burnout the Quadruple Aim emerged, with the additional task of decreasing provider burnout (Bodenhemier & Sinsky).

It is paramount that healthcare providers continue to increase biopsychosocial, systemic treatment. With a systemic approach to healthcare, treatment adherence increases (Martire, Lustig, Schulz, Miller, & Helgeson, 2004; Stephens, Rook, Franks, Khan, & Ilda, 2010); with increased treatment adherence health-related outcomes improve (Chambless et al., 2012), which lead to decreased healthcare utilization, decreased provider burnout (Hojat, Louis, Markham, Wender, Rabinowitz, & Gonnella, 2011), and improve overall population health. The brief,

systemic assessment and intervention framework this study has indicated is a valuable approach healthcare providers can incorporate to support in the efforts of maintaining the Quadruple Aim.

### **Limitations**

There are several limitations to this study. The first limitation is that this study focused specifically on the effects of Crohn's disease on young adult couple systems. This was, in part, to draw attention to an under-studied disease and to examine the perceived effects on relationship satisfaction and life-cycle transitions. The second limitation is sample size. Five couples (i.e. 10 individuals) participated in this study. This sample size was appropriate for an IPA study, as saturation was attained through commitment to a detailed level of analysis and reporting, the individual cases provided were rich in meaning, and thorough organization was kept throughout the study process. In addition, similar instances were found over and over in participants' experiences which provided for empirical confidence. That being said, a larger sample size would allow for increased saturation with findings that could be applicable to more couples with one partner diagnosed with Crohn's disease. Third, the sample of participating couples was homogenous in race, socio-economic status, and location. The findings of this study can only be transferred to other white, middle class, couples living in the Midwest. Further research is needed in order to know if these findings are applicable for couples from other races, ethnic and cultural backgrounds, socio-economic statuses, and locations.

### **Future Research**

Further research incorporating young adult couples with differing diseases would provide a broader understanding of the similarities and differences experienced from varying diseases. Similar experiences among illnesses would provide for greater transferability of findings. Likewise, completing a longitudinal study would provide information on how couples experience chronic illness affecting all life-cycle transitions.



In completing this study, an unexpected theme emerged identifying how HMOs can cause barriers to appropriate treatment. Further research is needed in order to more fully understand the negative effects of HMO policies on patients' and partners' well-being. Based on these findings, efforts can be made to change current policies in order to assist healthcare providers' efforts to prescribe needed biologic interventions.

The integrated approach to healthcare is spreading throughout the United States. Awareness has been brought to the need of incorporating family systems in treating chronic illness, specifically in primary care settings. There has not been a framework specifically utilized by healthcare providers to complete brief, systemic-level assessment and intervention. The researcher of this study provided a framework that incorporates SFT and systemic-level goal setting. Research is needed to validate the benefits for both patients and healthcare providers in utilizing this framework.

### **Lessons Learned**

Precise inclusion criteria led to challenging recruiting efforts. Several willing couples were unable to participate in this study as they did not meet the inclusion criteria of being together at diagnosis. Finding couples in which the patient was diagnosed in the current relationship felt nearly impossible as relationship status changed often. Had this not been an inclusion criteria the sample size would have been approximately ten couples.

Organization is a must. As you move from initial coding, to developing emergent themes, to forming connections across emergent themes, and then creating super-ordinate themes keeping and on-going trail of notations is essential. This trail of notations and development of themes supports the findings.

Interpretative Phenomenological Analysis is intense, as well as rewarding. Making meaning of how others make meaning is no simple task. Emerging yourself in others' life experiences is an enthralling process as you watch patterns and themes unveil. It is an incredible and humbling opportunity to be allowed by others to share in their experiences.

### **Conclusion**

Crohn's disease greatly affects relationship satisfaction and life-cycle transitions for young adult couples. Couples learn to make meaning of this disease and join together in coping. Healthcare providers can better assist this coping by providing brief, systemic assessment and interventions. It is my hope that this study will encourage service providers to offer appropriately targeted support so that couples in which one partner has a diagnosis of Crohn's disease can thrive and experience biopsychosocial satisfaction.

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Appendix A

IRB Approval



NEBRASKA'S HEALTH SCIENCE CENTER

Office of Regulatory Affairs (ORA)  
Institutional Review Board (IRB)

September 2, 2015

Ruth Nutting, Ph.D.  
Internal Medicine-General Medicine  
UNMC – 8100

**IRB # 440-15-EP**

**TITLE OF PROTOCOL: Crohn's Disease and the Young Couple: An Interpretative Phenomenological Study**

**DATE OF EXPEDITED REVIEW: August 4, 2015**

**DATE OF FINAL APPROVAL AND RELEASE: September 2, 2015**

**VALID UNTIL: August 4, 2016**

**CLASSIFICATION OF RISK: Minimal**

**EXPEDITED CATEGORY OF REVIEW: 45 CFR 46.110; 21 CFR 56.110, Categories 6 and 7**

The IRB has completed its review of the above-titled research protocol. The IRB has determined you are in compliance with HHS Regulations (45 CFR 46), applicable FDA Regulations (21 CFR 50, 56) and the Organization's HRPP policies. Furthermore, the IRB is satisfied you have provided adequate safeguards for protecting the rights and welfare of the subjects to be involved in this study. This letter constitutes official notification of final approval and release of your project by the IRB. You are authorized to implement this study as of the above date of final approval. The following items were reviewed and approved by the IRB:

- Psychotherapy Referral List
- Interview Structure
- Recruitment Instructions
- Adult Consent Form IRB Version 1

Please be advised that only the IRB approved and stamped consent form can be used to make copies to enroll subjects. Also, at the time of consent all subjects must be given a copy of *The Rights of Research Subjects* and "What Do I Need to Know" forms.

The IRB wishes to remind you that the principal investigator (PI) is ultimately responsible for ensuring that this research is conducted in full compliance with the protocol, applicable Federal Regulations, and Organizational policies.

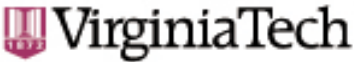
Finally, under the provisions of this institution's Federal Wide Assurance (FWA00002939), the PI is directly responsible for submitting to the IRB any proposed change in the research or the consent form. In addition, any adverse events, unanticipated problems involving risk to the subject or others, noncompliance, and complaints must be promptly reported to the IRB in accordance with HRPP policies.

This project is subject to periodic review and surveillance by the IRB and, as part of the Board's surveillance, the IRB may request periodic progress reports. For projects which continue beyond one year, it is the responsibility of the PI to initiate a request to the IRB for continuing review and update of the research project.

On behalf of the IRB,

Signed on: 2015-09-02 13:33:00.000

Academic and Research Services Building 3000 / 987830 Nebraska Medical Center / Omaha, NE 68198-7830  
402-559-6463 / FAX: 402-559-3300 / Email: [irbora@unmc.edu](mailto:irbora@unmc.edu) / <http://www.unmc.edu/irb>



**Office of Research Compliance**  
Institutional Review Board  
North End Center, Suite 4120, Virginia  
Tech  
300 Turner Street NW  
Blacksburg, Virginia 24061  
540/231-4606 Fax 540/231-0959  
email irb@vt.edu  
website <http://www.irb.vt.edu>

**MEMORANDUM**

**DATE:** September 3, 2015  
**TO:** Erika L Graftsky, Ruth Nutting  
**FROM:** Virginia Tech Institutional Review Board (FWA00000572, expires July 29, 2020)  
**PROTOCOL TITLE:** Crohn's Disease and the Young Couple: An Interpretative Phenomological Study  
**IRB NUMBER:** 15-639

Effective September 3, 2015, the Virginia Tech Institution Review Board (IRB) Chair, David M Moore, approved the New Application request for the above-mentioned research protocol. This approval provides permission to begin the human subject activities outlined in the IRB-approved protocol and supporting documents.

Plans to deviate from the approved protocol and/or supporting documents must be submitted to the IRB as an amendment request and approved by the IRB prior to the implementation of any changes, regardless of how minor, except where necessary to eliminate apparent immediate hazards to the subjects. Report within 5 business days to the IRB any injuries or other unanticipated or adverse events involving risks or harms to human research subjects or others.

All investigators (listed above) are required to comply with the researcher requirements outlined at: <http://www.irb.vt.edu/pages/responsibilities.htm>

(Please review responsibilities before the commencement of your research.)

**PROTOCOL INFORMATION:**

Approved As: **Expedited, under 45 CFR 46.110 category(ies) 6,7**  
Protocol Approval Date: **September 3, 2015**  
Protocol Expiration Date: **September 2, 2016**  
Continuing Review Due Date\*: **August 19, 2016**

\*Date a Continuing Review application is due to the IRB office if human subject activities covered under this protocol, including data analysis, are to continue beyond the Protocol Expiration Date.

**FEDERALLY FUNDED RESEARCH REQUIREMENTS:**

Per federal regulations, 45 CFR 46.103(f), the IRB is required to compare all federally funded grant proposals/work statements to the IRB protocol(s) which cover the human research activities included in the proposal / work statement before funds are released. Note that this requirement does not apply to Exempt and Interim IRB protocols, or grants for which VT is not the primary awardee. The table on the following page indicates whether grant proposals are related to this IRB protocol, and which of the listed proposals, if any, have been compared to this IRB protocol, if required.

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*An equal opportunity, affirmative action institution*



Date\* OSP Number Sponsor Grant Comparison Conducted?

\* Date this proposal number was compared, assessed as not requiring comparison, or comparison information was revised.

If this IRB protocol is to cover any other grant proposals, please contact the IRB office (irbadmin@vt.edu) immediately.

## Appendix B

### Informed Consent



IRB PROTOCOL # 440-15-EP

Page 1 of 6

### ADULT CONSENT - SOCIAL SCIENCE AND BEHAVIORAL

#### Crohn's Disease and the Young Couple

#### Title of this Research Study

Crohn's Disease and the Young Couple: An Interpretative Phenomenological Study

#### Invitation

You are invited to take part in this research study. You have a copy of the following, which is meant to help you decide whether or not to take part:

- Informed consent form
- "What Do I need to Know Before Being in a Research Study?"
- The Rights of Research Subjects

#### Why are you being asked to be in this research study?

You are being asked to participate in this study because you are between the ages of 20-35, and are either an individual diagnosed with Crohn's disease or are a partner of an individual with a diagnosis of Crohn's disease.

#### What is the reason for doing this research study?

Diagnoses of Crohn's disease are increasing among young adults in the U.S. The available literature in this understudied area has mainly focused on biomedical aspects of Crohn's disease on the diagnosed individual. Given the increase in Crohn's disease among young adults, it is pertinent to conduct a study that explores how a partner's diagnosis of Crohn's disease is perceived to affect the couple relationship and young adult life-cycle transitions.

This research is designed to (1) to provide an understanding of how a partner's diagnosis of Crohn's disease affects the couple relationship and young adult life-cycle transitions; (2) increase understanding of how the physical symptoms of Crohn's disease cause psychological and emotional implications for couples; (3) highlight what young adult couple targeted interventions have been most beneficial for couple functioning, and what areas of support are needed.

#### What will be done during this research study?

**Interviews.** You will be asked to complete a one-on-one, in-person interview. Each partner of the couple system will be interviewed individually for approximately forty-five minutes. The interviews will be recorded on an audio recorder, as well as recorded and transcribed by Dragon Transcription Software. Two recording systems will be used in case of equipment malfunction of one device. Notes will also be taken in order to retain information gathered. All audio-recordings and notes will be destroyed at the completion of the study.

**Analysis of the data.** This study will follow Interpretative Phenomenological Analysis (IPA). The essence of IPA lies in its analytic focus, which directs attention towards participants attempts to make meaning of their experiences. The principal investigator (PI) will review all transcripts in order to capture all relevant themes of your experiences of Crohn's disease. Upon completing the analysis, and the draft write-up of findings, the PI will have you review the draft write-up in an effort to verify the accuracy of the findings. If you feel any changes need to be made the PI will make these changes and, once these changes are made, will have you verify them. When the final write-up is completed and published the publications will be available to you.

**What are the possible risks of being in this research study?**

There are several factors that lead to this research study having a potential for risk to you:

(1) You will be interviewed and will discuss personal information in relevance to your perceived effects of Crohn's disease. There is a potential that you may feel uncomfortable speaking about your experiences or explaining personal information about the couple system.

(2) As this study deals with Crohn's disease, a chronic illness, you may be emotionally reactive while reflecting and discussing the initial diagnosis and the adjustment to the disease.

(3) There is a potential for you to feel pressure to answer all the questions designed for the interview.

(4) You may experience heightened relationship problems, which were previously dormant or unacknowledged, due to the nature of interview questions.

**What are the possible benefits to you?**

You may benefit by feeling heard and affirmed when discussing your experiences of Crohn's disease. This may be the first opportunity you will have to express the effects of Crohn's disease on your relationship and young adult life-cycle transitions. If the investigator identifies a need and interest, you will be provided referrals to further resources (i.e. therapeutic services), that could potentially benefit your individual and couple well-being. However, you may not get any benefit from being in this research

**What are the possible benefits to other people?**

The goal of this study is to give healthcare providers a foundational understanding of the effects of Crohn's disease on couple relationships and young adult life-cycle transitions. Findings will identify what couple-targeted interventions, provided by healthcare providers, have been beneficial to couples, and in turn highlight further areas of needed healthcare provider intervention. As the areas of needed interventions are highlighted, there is strong potential for applicable interventions to increase-filling this gap. This increase in interventions may be beneficial for young-adult couples seeking health-related care for chronic illness.

**What are the alternatives to being in this research study?**

Instead of being in this research study you can choose not to participate.

**What will being in this research study cost you?**

There is no cost to you to be in this research study.

**Will you be paid for being in this research study?**

You will not be paid to be in this research study directly. Rather, in recognition for your time, ten dollars will be donated to the Crohn's and Colitis Foundation of America. This donation will be explained during the structuring session of the interviews. You will determine whether you would like the donation made anonymously or in your name.

**What should you do if you have a problem during this research study?**

Your welfare is the major concern of every member of the research team. If you have a problem as a direct result of being in this study, you should immediately contact one of the people listed at the end of this consent form. If needed, appropriate psychotherapy referrals will be provided to you for further follow-up to ensure well-being.

**How will information about you be protected?**

All necessary steps will be taken to protect your privacy and the confidentiality of your study data. Patients identity will be protected by use of pseudonyms. All electronic records will be kept on an encrypted and password protected laptop. Audio records and paper material will be in a locked environment at all times.

**Who will have access to information about you?**

By signing this consent form, you are allowing the research team to have access to your research data. The research team includes the investigators listed on this consent form and other personnel involved in this specific study at UNMC.

Your research data will be used only for the purpose(s) described in the section "What is the reason for doing this research study?"

You are also allowing the research team to share your research data, as necessary, with other people or groups listed below:

- The UNMC Institutional Review Board (IRB)
- Institutional officials designated by the UNMC IRB
- Federal law requires that your information may be shared with these groups:
  - The HHS Office for Human Research Protections (OHRP)

You are authorizing us to use and disclose your research data for as long as the research study is being conducted. You may cancel your authorization for further collection of research data for use in this research at any time by contacting the principal investigator in writing. However, the information which is included in the research data obtained to date may still be used. If you cancel this authorization, you will no longer be able to participate in this research.

**How will results of the research be made available to you during and after the study is finished?**

The results of the analyses will be provided to you, for your feedback. The final write-up will be made available to you. The information from this study may be published in scientific journals or presented at scientific meetings, but your identity will be kept strictly confidential.

If you want the results of the study, contact the Principal Investigator at the phone number given at the end of this form or by writing to the Principal Investigator at the following address: *139 S. 40th St. Omaha, NE 68131*

**What will happen if you decide not to be in this research study or decide to stop participating once you start?**

You can decide not to be in this research study, or you can stop being in this research study (withdraw) at any time before, during, or after the research begins. Deciding not to be in this research study or deciding to withdraw will not affect your relationship with the investigator or UNMC. You will not lose any benefits to which you are entitled.

**Will you be given any important information during the study?**

You will be informed promptly if the research team gets any new information during this research study that may affect whether you would want to continue being in the study.

**What should you do if you have any questions about the study**

You have been given a copy of "What Do I Need to Know Before Being in a Research Study?" If you have any questions at any time about this study, you should contact the Principal Investigator or any of the study personnel listed on this consent form or any other documents that you have been given.

**What are your rights as a research participant?**

You have rights as a research subject. These rights have been explained in this consent form and in The Rights of Research Subjects that you have been given. If you have any questions concerning your rights or complaints about the research, you can contact any of the following:

- The investigator or other study personnel
- Institutional Review Board (IRB)
  - Telephone: (402) 559-6463
  - Email: IRBORA@unmc.edu
  - Mail: UNMC Institutional Review Board, 987830 Nebraska Medical Center, Omaha, NE 68198-7830
- Research Subject Advocate
  - Telephone: (402) 559-6941
  - Email: unmcrsa@unmc.edu

**Documentation of informed consent**

You are freely making a decision whether to be in this research study. Signing this form means that:

- You have read and understood this consent form.
- You have had the consent form explained to you.
- You have been given a copy of The Rights of Research Subjects
- You have had your questions answered.
- You have decided to be in the research study.
- If you have any questions during the study, you have been directed to talk to one of the investigators listed below on this consent form.
- You will be given a signed and dated copy of this consent form to keep.

Signature of Subject \_\_\_\_\_

Date \_\_\_\_\_

My signature certifies that all the elements of informed consent described on this consent form have been explained fully to the subject. In my judgment, the

participant possesses the legal capacity to give informed consent to participate in this research and is voluntarily and knowingly giving informed consent to participate.

Signature of Person Obtaining Consent \_\_\_\_\_  
Date \_\_\_\_\_

**Authorized Study Personnel**

**Principal**

\* Nutting, Ruth  
phone: 402-595-3939  
alt #: 402-595-3939  
degree: PhD

## What Do I Need To Know Before Being In A Research Study?

You have been invited to be in a **research study**. Research studies are also called "research surveys", "research questionnaires" or "scientific protocols." **Research** is an organized plan designed to get new knowledge about health, disease, behaviors, attitudes and interactions of, among and between individuals, groups and cultures. The people who are in the research are called **research subjects**. The **investigator** is the person who is running the research study. You will get information from the investigator and the research team, and then you will be asked to give your **consent** to be in the research.

**This sheet will help you think of questions to ask the investigator or his/her staff. You should know all these answers before you decide about being in the research.**

What is the **purpose** of the research? Why is the investigator doing the research?

What are the **risks** of the research? What bad things could happen?

What are the possible **benefits** of the research? How might this help me?

**How is the research different** than what will happen if I'm not in the research?

Will being in the research **cost** me anything extra?

Do I have to be in this research study? How will it affect my status at the institution if I say **no**?

Can I **stop** being in the research once I've started? How?

Who will look at my **records**?

How do I reach the investigator if I have more **questions**?

Who do I call if I have questions about being a **research subject**?

**Make sure all your questions are answered before you decide whether or not to be in this research.**



## **THE RIGHTS OF RESEARCH SUBJECTS AS A RESEARCH SUBJECT YOU HAVE THE RIGHT**

**\_ to be told everything you need to know about the research before you are asked to decide whether or not to take part in the research study.** The research will be explained to you in a way that assures you understand enough to decide whether or not to take part.

**\_ to freely decide whether or not to take part in the research.**

**\_ to decide not to be in the research, or to stop participating in the research at any time.** This will not affect your medical care or your relationship with the investigator or the Nebraska Medical Center. Your doctor will still take care of you.

**\_ to ask questions about the research at any time.** The investigator will answer your questions honestly and completely.

**\_ to know that your safety and welfare will always come first.** The investigator will display the highest possible degree of skill and care throughout this research. Any risks or discomforts will be minimized as much as possible.

**\_ to privacy and confidentiality.** The investigator will treat information about you carefully, and will respect your privacy.

**\_to keep all the legal rights you have now.** You are not giving up any of your legal rights by taking part in this research study.

**\_ to be treated with dignity and respect at all times**

**The Institutional Review Board is responsible for assuring that your rights and welfare are protected. If you have any questions about your rights, contact the Institutional Review Board at (402) 559-6463.**

## Appendix C

### Interview Structure

#### *Structuring Session: Couple Level Questions*

1. How have you supported each other since the diagnosis of Crohn's disease?
2. How does your relationship now compare to your relationship before Crohn's disease?

#### *Diagnosed Individual*

1. Describe what it was like for you being diagnosed with Crohn's disease (e.g. what were your initial thoughts and feelings; how did you respond to doctors and family members)?
2. Describe biological, psychological, social symptoms you have experienced due to Crohn's disease.

2a. How have these affected you?

3. In what ways do you feel Crohn's disease has affected your young adulthood life-cycle transitions? (examples provided below)

3a. How has it interfered with you completing your college/graduate education?

3b. How has it interfered with your career goals?

3c. How has it affected your ability to establish independence from your family?

3d. How has it affected the possibility of having children?

4. Describe how your relationship with your partner has been affected as a result of Crohn's disease (e.g. have you and your partner grown closer or more distant; do you interact differently; how has your partner been a source of support or stress for you as a result of your diagnosis).

5. What couple-targeted interventions (e.g. communication skills, goal setting), if any, given by doctors or other medical staff (e.g. behavioral health providers) have been most beneficial to your relationship?

6. In what ways can doctors and other medical staff better support you and your partner?

#### *Partner*

1. Describe what you experienced when your partner was diagnosed with Crohn's disease (e.g. what were your initial thoughts and feelings; how did you respond to your partner).

2. Describe how your partner's diagnosis affects your psychological well-being.
3. In what ways has having a partner with Crohn's disease affected your young adulthood transitions?
  - 3a. How has it interfered with you completing your post-secondary education?
  - 3b. How it interfered with your career goals?
  - 3c. How has it affected your ability to establish independence from your family?
  - 3d. How has it affected the possibility of having children?
4. Describe how your relationship has been affected as a result of Crohn's disease (e.g. have you and your partner grown closer or more distant; do you interact with one another differently).
5. What couple-targeted interventions (e.g. communication skills, goal setting), if any, given by doctors or other medical staff (e.g. behavioral health providers) have been most beneficial to the functioning of your couple system?
6. In what ways can doctors and other medical staff better support you and your partner?

## Appendix D

### Tables

Table 1

*Purposive Sampling Criteria for Participating Diagnosed Patients*

- Aged 20-35.
- Patient diagnosed > than one year.
- Diagnosis occurred in current relationship.
- Cohabiting, engaged, or married.

Table 2

*Selected Examples of Narratives, Exploratory Commenting, and Emergent Theme Formation*

Emergent Themes	Original Interview	Exploratory Commenting
Fear of the unknown	“It was good at first to say, ‘Ok, I have this thing, and something is really going on here’. But, at the same time then you think about all the things down the line that you’re going to have to deal with....it is not pleasant.”	<u>When diagnosis is given there is an initial relief, followed by questioning what the future will be like. The unknown prognosis is unpleasant and can leave the patient feeling powerless.</u>
Admitting seriousness of symptoms meant, losing control.	“I would not want to admit to the nurses or other people what was going on. That gave me a sense of control, by not admitting to people what had just occurred”.	By not admitting how severe his symptoms were to medical staff the patient created an illusion of control. <u>Was the patient scared to acknowledge the control his body had taken over him?</u>
Impact on career	“My work has been really accommodating and helpful, but I think that it could get to a point where if I got sick because of it, then I might have to think about a different career, or different area to work in the zoo, so that’s had a pretty big impact.”	<i>“I think that it could get to a point where if I got sick because of it, then I might have to think about a different career...” implies patient recognizes the impact Crohn’s may have on her career.</i>
Psychological effects	“[Crohn’s] wears on ya. Wondering if things will ever get better. Or, wondering ‘why is this happening to me’, ‘why do I have this’, and things like that.”	<u>Struggling with the questions of “why” puts psychological strain on patient.</u>
Practically supportive through self-sacrifice.	“I started farming the last three years. Farming was really good, this year it’s not. So, now we don’t know what we’re doing. We’re trying to figure that out. We buy private insurance. Prices are going up, and crop prices are going down. I mean, we just do what we gotta do to make it work. I’ll probably get a real job again or something.”	<i>“We just do what we gotta do to make it work. I’ll probably get a real job again or something” infers self-sacrificing behavior. <u>Is partner self-sacrificing by giving up farming to get a job that will better support the financial costs of Crohn’s?</u></i>

*Note.* Descriptive comments: focused on describing the content of what the participant has said, the subject of the talk within the transcript (normal text). Linguistic comments: focused upon exploring the specific use of language by the participant (italic). Conceptual comments: focused on engaging at a more interrogative and conceptual level (underlined).

Table 3

*Selected Examples of Emergent Theme Formation*

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**Experience of Diagnosis for Patients**

Inconclusive diagnosis (1a 6; 1b 80, 257; 2b, 109; 3b, 97; 4c 100; 5c 230, 240)

Symptoms confirming diagnosis (1a 11)

Diagnosis was shocking/frightening (1b 73; 3b 100)

**Experience of Diagnosis for Partners**

Diagnosis was scary for partner (1b 311; 3c 374; 4c 24)

Partner was naïve at diagnosis (3c 369)

**Support Given by Partners**

Partner is practically supportive (1a 13; 1b 185; 1c 336; 2a 7, 24; 3a 27; 3b 234; 3c 392; 4a 3; 5a 7)

Partner is emotionally supportive (1a, 17; 1b, 187; 1c, 336; 3a, 24; 3b, 234; 5a 6, 16; 5b 156)

Partner is self-sacrificing (2a 10, 16; 3a 21)

---

*Note.* In parentheses number depicts what transcript quote was taken from. Letter identifies which part of transcript. (a) couple interview; (b) patient interview; (c) partner interview. Number following letter identifies line in transcript.

Table 4

*Selected Example of Polarized Emergent Theme*

---

**Perceived Positive Effects on Relationship**

*Howard:* I think it has [Crohn's] made me mature faster than I would have before, which I think maturity is helpful in any relationship.

Line 150 (5b)

*Geneva:* I think it's stronger [relationship]. We've grown up a lot in terms of having to deal with major stressors that come along with Crohn's...I think it made us better at communication too. Because, you just have to talk about it. I think it has both made us a little more patient and understanding.

Line 42, 53, 340 (5c)

---

*Note.* Line number depicts what line in transcript quote was taken from. Number and letter in parenthesis identifies which transcript and which part of transcript. (a) couple interview; (b) patient interview; (c) partner interview.

Table 5

*Selected Examples of Narratives, Themes, and Super-Ordinate Theme Formation*

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**Experience of Diagnosis**

**Inconclusive diagnosis**

*Mary:* A lot of them (providers) were on the fence, ‘maybe you have Crohn’s maybe you don’t’. Then I had a fistula and they were for sure. Lines 11, 80-82 (1a, b)

*Sarah:* I had struggled from the time I was 12 or 13, and had tests done and nobody could ever figure anything out. Part of me was relieved that something was actually going on, and I wasn’t just losing my mind... Line 97-100 (3b)

*Annie:* Well, at first we really didn’t know what it was...the diagnosis was ambiguous. Line 100 (4c)

**Feelings of fear**

*Mary:* I think it was a little bit of shock, and then a lot of disbelief and anxiety about what was going to happen. Lines 73-76 (1b)

*Frank:* It was kind of a scary feeling. You could see it [fear] in her. Line 311 (1c)

*Pete:* She was in the hospital for appendix problems or whatever, then they found Crohn’s. So, at first, it was just like questions, and we were young, so we didn’t know what to expect. We just, blindly went into it. It was scary. Lines 371-378 (3c)

**Biopsychosocial Factors**

**Biological**

*Rose:* It hasn’t affected me very well. It’s made everything harder. Line 188 (2b)

*Sarah:* I’ve been in pain for about three years, that’s probably the hardest because how I feel physically affects me emotionally, and spiritually. Lines 133-135 (1b)

*Howard:* I felt like I was Jason Bourn, sitting in a restaurant, knowing where the restroom was. Line 129 (5b)

**Psychological**

***Loss of power***

*Frank:* It’s terrible when you can’t help your partner when you know they need help. Line 329 (1c)

*Sarah:* Pushing our wedding back was the first punch to the gut, of ‘this is completely dictating my life’. Line 372 (3b)

*Howard:* I would not want to admit to the nurses or other people what was going on. That also gave me a sense of control, by not admitting to people what had just occurred. Line 108 (5b)

***Concern for the future***

*Frank:* It’s the fear of the unknown. You don’t know what the side effects of the infusions are going to do. You don’t know what’s going to happen. Line 492 (1c)



*Mike:* I worry about her health and our family...it's not curable, it's not fatal, but it leads to other things.

*Annie:* I was thinking about our future in a different way than I had in the past, wondering if it would be the same, or wondering if we'd be going through a lot of surgeries.

*Geneva:* After multiple medication failures, and being on multiple immune-suppressant medications at one time, I was very worried about what the future would look like and what could be done to give him somewhat of a life back.

Line 102 (4c)

Line 282 (5c)

### ***Mixed emotions***

*Mike:* We both exercise and eat right; sometimes I feel 110% and when she does not it isn't fair....You don't always want to feel bad for your spouse, so there's a little guilt.

*Sarah:* I hate that I can't handle having a full time job and having my kids. I don't feel like I'm living up to the standards that I want to for wife and mom, that's really one of my biggest struggles.

*Everett:* [Crohn's] wears on ya. Wondering if things will ever get better. or wondering "why is this happening to me", "why do I have this" and things like that.

Lines 552, 774 (2c)

Lines 164, 190 (3b)

Line 44 (4b)

### **Social**

*Frank:* I'd say it's changed quite a bit just because of the dieting and the things that she's trying to do specifically....We pretty much don't go out to eat anymore.

*Sarah:* People don't get it, and I don't expect them to I guess. But, sometimes it's easier just to not deal with it, and just stay in our little section, our little corner, on the farm, and be comfortable.

*Howard:* I was 23 at the time of diagnosis. I think it helped me mature a lot faster. I had to think about things I could or could not do in life more, the consequences of my actions. I could not go out and stay up until 4 in the morning or be as carefree with friends or activities as I did before.

Line 37 (1c)

Line 76 (3b)

Line 144 (5b)

### **Interference in Life-cycle Transitions**

#### **Childbearing halted/delayed**

*Rose:* I had been thinking about a third one, but taking heavy drugs while I'm pregnant would make me nervous.

*Sarah:* My kids are my miracles. They are healthy and they are awesome, and absolutely the loves of my life. I always wonder had I been healthy, or had no issues maybe we would have had more, I don't know.

*Geneva:* I think it delayed our decision to start a family. I know that I wanted him to be healthier before I even

Line 300 (2b)

Lines 181, 220 (3b)

Line 316 (5c)

thought about having kids.

### **Career struggles**

*Rose:* The place I was working is definitely not conducive to having to go to the bathroom a lot. I worked at this framing place and you're in one big room, you just can't get away from it. That had been my job. Line 232 (2b)

*Sarah:* I had a full time job. I hate that I can't handle it now. My biggest priority needs to be my kids, and I can't handle a full time job and my kids. Line 160 (3b)

*Geneva:* I, quite honestly, don't know how he got out of bed and went to work some days, but he fought through residency until he just couldn't anymore. Line 290 (5c)

### **Dependence on family of origin**

*Mary:* They have helped me financially with medical bills. Line 160 1(b)

*Sarah:* I can't imagine ever moving or not being as close to our families because they help us a ton. Line 200 (3b)

*Pete:* Financially we rely on our parents.... I don't know how we'd get through what we do if both of our families weren't around Line 423 (3c)

*Annie:* I'm getting a lot of financial assistance... Line 134 (4c)

### **Relationship Satisfaction**

#### **Strained relations**

*Rose:* When I'm not feeling good, it makes it hard. Lines 88, 322, 341 (2b)  
He's a great dad and husband, but he does not know how to handle some of it. I don't know if he really understands how sick I can feel.

*Annie:* It's definitely put stress on our relationship. Especially when he wasn't doing well. There were definitely periods of time that we weren't doing well with each other. Line 154 (4c)

*Geneva:* When he first started developing symptoms, I don't think he felt well. I mean, there were other things going on but part of it was that he didn't feel well, and he was kind of snarky with me. I didn't have an answer for it, I couldn't get him to open up and talk about it....We did break up for about a month and a half. Line 336 (5c)

#### **Practically and emotionally supportive**

*Frank:* I try to be there for her, a shoulder to cry on or whatever. Line 336 (1c)

*Rose:* When I'm sick, he drops everything and he takes care of everything. Line 10 (2a)

*Sarah:* It's not all financial; he's supporting me emotionally. He's been there for everything. He goes to my appointments. Lines 27, 231 (3a, b)

*Annie:* I've been the one to take care of a lot of the logistic pieces...obtaining medicines, calling insurance companies, and dealing with diet changes. Line 3 (4a)

<i>Howard:</i> [She's] practically supportive about the nuances of getting things done around the house, and paperwork, and logistics...all the daily grind activities that need to get done.	Line 7 (5a)
<i>Howard:</i> [She's] always concerned, helpful...emotionally supportive.	Line 6 (5a)
<b>Team approach</b>	
<i>Mike:</i> We are a little bit more of a team.	Line 541 (2c)
<i>Pete:</i> She said, 'I'm not going to hate you if you want to leave, now is your chance before we sign on the dotted line'. And, I was like, 'no, we are in this together, and that doesn't change anything'.	Line 380 (3c)
<i>Geneva:</i> I think we have grown closer, and our relationship is stronger. We are a much better team. We've supported each other with a lot of family stressors...	Lines 374, 18 (5c, a)
<b>Meaning making</b>	
<i>Rose:</i> ...I'm coming to terms of having to deal with Crohn's forever. I'm trying to be positive about it, and know that I will feel better soon and maybe for a long time. I'm looking forward to that.	Lines 172, 178 (2b)
<i>Sarah:</i> I've helped a lot of people with Crohn's and connected with them. I think maybe that's what I'm here for. To help people dealing with the same thing...	Line 304 (3b)
<i>Everett:</i> I learned that things are the way they are, and all you can do is do your best to try to get by.	Line 48 (4b)
<b>Need for increased communication</b>	
<i>Mary:</i> It probably would help if I talked to him more about it. He didn't even know when I was initially diagnosed.	Line 206 (1b)
<i>Frank:</i> I don't know if she can have kids or not. I don't even know if she wants kids that much.	Lines 377, 400 (1c)
<i>Rose:</i> I've wondered if it would help if he knew a little more. But I don't know, I don't want to say all these symptoms, so many of them are gross. [If I communicated more] maybe he would be more empathic.	Lines 380, 402 (2b)
<i>Mike:</i> I think we have some communication issues; maybe we have for a long time...	Line 472 (2c)
<b>Experiences of Healthcare System</b>	
<b>Individualistic approach</b>	
<i>Mary:</i> Having him there at an appointment would probably help him, but logistically I make appointments when they are good for my schedule, not necessarily his.	Line 242 (1b)
<i>Frank:</i> I'll get the brief after the doctor. It's always strictly about	Lines 460, 472 (1c)

what's happened. As far as them attending to me, I see no reason for them to.

*Pete:* I don't know if we've ever really gotten direction or support or anything relationship wise from any of the doctors, Lines 466, 478 (3c)

or anything. They're doing their job, as far as I can see. I don't look to them for advice on anything other than what's going on with her.

*Annie:* We have had little to no support as a couple. Line 168 (4c)

### **Personal agency**

*Mary:* I constantly think, 'what can I do to help the situation?'. Trying to decide what the best thing to do is taxing. Getting it under control is frustrating too. Lines 117, 266 (1b)

*Rose:* I know that I'm having some emotional problems and things, and it is affecting my relationship, but I've just tried to look online about that stuff and I'm starting to see a therapist. Line 462 (2b)

*Sarah:* Crohn's is life-long. If you don't speak up and explain to your doctors where you are physically and emotionally, they can't treat you better. It was really from my own findings that I figured out what was going on, and that "ok, I'm not just going to die from this"... Lines 278, 120 (3b)

### **Insurance and financial challenges**

*Rose:* My medicine isn't helping me much, but that's because I'm not even on the right thing. Line 64 (2a)

*Mike:* It's tedious getting different types of medicines. Line 54 (2a)

*Pete:* I worked, what we call, a "real" job, so I had insurance. We could afford to pay for all the medical expenses and now I farm, and we can't afford it. Line 14 (3a)

### **Needed Healthcare Improvements**

#### **Increased psychosocial assessment training**

*Rose:* They're not trained to talk to you about how you're feeling about things. So, I don't usually share. I don't go down that road. If it was a part of treatment, I would. Lines 414, 428, 442 (2b)

*Annie:* I think that the behavioral aspect of the disease definitely needs to be addressed more than it was. Doctors don't necessarily listen to emotions and feelings. They just talk about diagnosis and treatment, and then are out the door. I really think it would have been easier had we had that support from the beginning. Line 196 (4c)

*Geneva:* It would have been helpful to even have resources available. Lines 390, 401 (5c)  
I think having the information and being able to distribute it is a powerful thing. That wouldn't take much time from the physicians or nursing staff.

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*Note.* Line number depicts what line in transcript quote was taken from. Number and letter in parenthesis identifies which transcript and which part of transcript. (a) couple interview; (b) patient interview; (c) partner interview.

Table 6

*Participant Demographics*

<b>Couple Pseudonyms</b>	<b>Gender</b>	<b>Age</b>	<b>Race</b>	<b>Relationship Status</b>	<b>Diagnosis</b>
Mary (Diagnosed)	Female	34	White	Cohabiting	Diagnosed- 2013 (Dating since 2013, now cohabitating)
Frank (Partner)	Male	35	White		
Rose (Diagnosed)	Female	35	White	Married	Diagnosed- 2012 (Dating since 2005, now married)
Mike (Partner)	Male	40	White		
Sarah (Diagnosed)	Female	32	White	Married	Diagnosed- 2002 (Dating since 2001, now married)
Pete (Partner)	Male	35	White		
Everett (Diagnosed)	Male	29	White	Cohabiting	Diagnosed- 2013 (Dating since 2000, now cohabitating)
Annie (Partner)	Female	28	White		
Howard (Diagnosed)	Male	34	White	Married	Diagnosed- 2005 (Dating since 2002, now married)
Geneva (Partner)	Female	33	White		

# Appendix E

## Figures

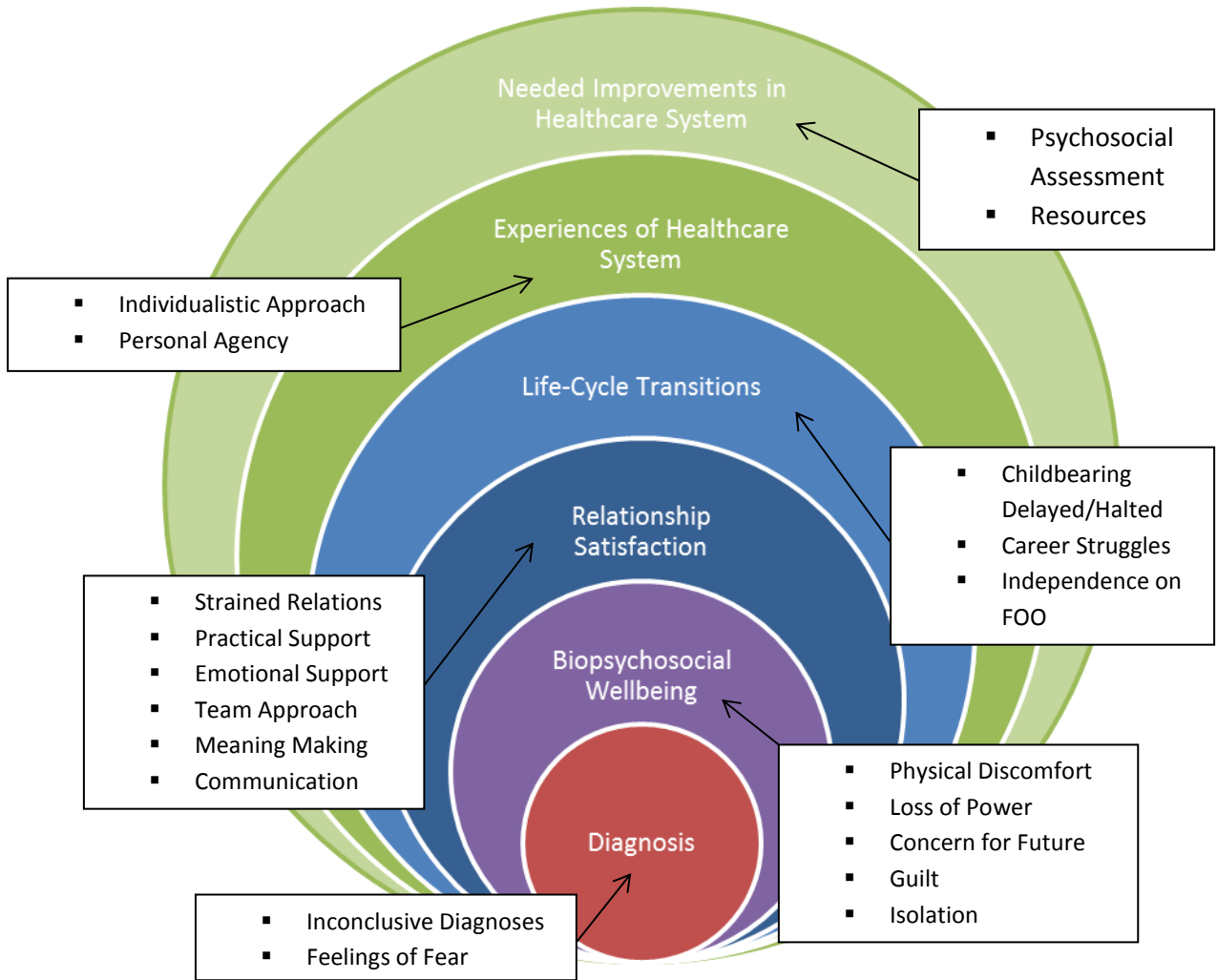


Figure 1. Representation of overall experiences of Crohn's disease among couples.

I. Addressing past successes

- Supporting couples in solution focused thinking and increasing their overall confidence.

II. Promoting behavior change

- Addressing what has worked well in the past.

III. Assessing emotional difficulties

- Clarifying what has helped them feel less down.

IV. Creating strategies

- Providing couple level interventions.

*Figure 2.* Outline of solution focused assessment.

*Our goal is:* \_\_\_\_\_

*We will:* \_\_\_\_\_

*When:* \_\_\_\_\_

*We will do this first:* \_\_\_\_\_

*Challenges that may arise:* \_\_\_\_\_

*We will handle them by:* \_\_\_\_\_

*We will reward ourselves when:* \_\_\_\_\_

*Our reward will be:* \_\_\_\_\_

*Figure 3.* Outline of collaborative, systemic goal setting. Adapted from “Brief Interventions in Primary Care”, by P. Khatri and K. Mays, 2011, [PowerPoint slides]. Retrieved from [http://www.integration.samhsa.gov/Brief\\_Intervention\\_in\\_PC,\\_pdf.pdf](http://www.integration.samhsa.gov/Brief_Intervention_in_PC,_pdf.pdf). C. Copyright 2011 by the Substance Abuse and Mental Health Services Administration.



## Appendix F

### Selected Entries from Interview Reflections

#### 10/12/15- Interview #1

This was my first interview that I completed for my dissertation. Overall, I think it went well. There are a couple areas I feel I could improve upon including getting each page of the consent initialed and describing what couple oriented interventions would look like in the healthcare setting.

When completing the interview with the patient, I was struck by the evident emotions. Crohn's disease has greatly impacted the couple's overall well-being. What I also found interesting was how the couple has stopped pursuing goals and has not realigned goals in regard to what is conducive with Crohn's disease.

Lastly, it was clear there was a break-down in communication. The patient's partner lacked knowledge of what Crohn's disease could potentially interfere with and what each other's goals were. He was not aware of the long-term physical effects of Crohn's disease.

#### 11/20/15-Interview #2

This was my second interview that I have completed. I really enjoyed this interview. It seems like each interview gets more and more comfortable. One thing I've noticed is that many patients have symptoms of Crohn's disease much worse than me. I feel for them, and I hope I never experience what they are experiencing.

With this couple it was clear that a lot has been left unsaid, much like with the first couple. The patient feels embarrassment about what some of her symptoms are and stated that she does not let her partner know about all the symptoms she is experiencing. She also stated that if her partner did attend her doctor's appointments she may not be as open. I found this interesting. Her partner mentioned that he would like to attend the regular appointments as he would like to learn more.

#### 11/30/2015-Interview #3

This couple is a team! They have faced this illness together. They attend each appointment together, and they feel that being together in sickness and health is what they promised one another. This couple reported becoming closer through experiencing Crohn's disease. What was unique about this couple is how they both reported that they feel responsible for positive coping and that they have not expected support in this through providers. The patient did mention that she could have been more supported during initial diagnosis by healthcare providers.

2/22/16- Interview #4

It has been a while since I have interviewed. I was both excited and nervous to interview. This was also my first Skype interview, so that was different. This interview went well. The couple was friendly, and the interview process was comfortable. What was reported is in line with current findings.

6/5/16- Interview #5

Phew, finally completed another interview! This interview was unique in that the diagnosed partner is also a gastroenterologist. He had the perspective of not only patient but also provider. For this patient, control was the biggest factor he held on to through initial diagnosis. He was able to “muddle” through med school and complete his residency. I found it interesting how this patient felt that his partner had been included in his medical treatment/plans. However, his partner reported feeling very differently. The patient did identify that healthcare providers do not typically attend to the psychosocial needs of patients with IBD.

## Appendix G

### Selected Entries from Write-Up Reflections

2/5/16

I'm exhausted. For the past couple of weeks I've been working 14 hour days between my fellowship and dissertation in order to meet tonight's dissertation deadline, not including steady weekend dissertating. I have officially just submitted three transcripts which include the original interview, exploratory commenting, emergent themes, themes of abstraction, and super-ordinate themes. As well as a first draft write up! This whole process has been incredibly detailed, as well as captivating. I feel like I know the participating couples personally as I've immersed myself in their transcripts over and over again. I'm looking forward for Erika's feedback. For now, it's a much needed break on the slopes of Colorado!

3/30/16

Ok, Erika's feedback came in. Her first comments, "This is a great...seriously excellent...first draft of your findings". Yes! I've been on the right track. There are some revisions to be made, but Erika is impressed! This is truly an amazing and empowering feeling! I've got this!

8/7/16

It's got to be close to midnight, and I am lying in bed with sheer excitement! My dissertation is coming together!! Can it be true? Maybe I should hold my breath because something is sure to happen, and this dream will surely be over. But no, it *is* happening! Yes, I still need to complete one more interview, but my analysis is complete thus far, and I'm now updating my methods section and changing the proposal from future to past tense. AMAZING! I just know this last interview will come together, and the final chapter will be written with ease. Erika has already told me that my analysis is in on point (with some needed changes of course). She's going to be pleased with the attention I have paid to her suggestions and with my further analysis. Please God, let her be pleased!

8/10/16

It's happening again. My eyes are welling up as I think about everything others have done for me and how this dissertation, my Phd, would not be possible without the care and consideration of others in supporting my efforts. I still cannot fathom how hard Dr. Young has worked to provide participants for me. Out of all of my recruitment initiatives all participants have come from UNMC. AMAZING!!

8/29/16

Tonight I submitted all 120 plus pages of my dissertation to Erika. It feels great. In that submission I also included a timeline in order to meet a defense date of late October. Erika agrees that this is a doable timeline! This feels amazing! There is still much work to be done, revisions, etc., but it's drawing close. I can just feel that PhD!

9/9/16

My committee is accepting my sample size, as they agree I have met saturation!!! I literally have small revisions remaining and I'm sending this dissertation back to Erika for one more read through, and any additional changes, then it will be sent to my committee for review and to participating couples for member checking!!! Best of all, we are setting a defense date!!! I'm praying all committee members agree on a defense date of 10/20 so I can celebrate that night at the VT vs. Miami home football game!!