ABSTRACT

LEGRAND, ERIN TRADO. Understanding How Irritable Bowel Disease Affects Full-Time Employees at a Community College in North Carolina. (Under the direction of committee chair Dr. James Bartlett, II.)

The fields of Adult Education and Higher Education serve not only to educate students, but also as employers for many faculty and staff. All too often, employees are treated homogenously and little thought is given to employees who face the trials of coping with a chronic illness. Employees with chronic illness face marginalization in the workplace due to their disease. There is a need to increase awareness of this marginalization and to fully understand the experiences of chronically ill employees. The focus of this research is to explore the experiences of employees with Irritable Bowel Disease (IBD) at a community college in the western region of North Carolina. This study employs a qualitative research design that uses an in-depth phenomenological methodology to determine the essence of what it means to be an employee with IBD at a particular community college in the western region of North Carolina. The three study participants were a purposeful sample of full-time employees at a community college who have received an official diagnosis of IBD, Ulcerative Colitis or Crohn’s Disease. The experiences of these individuals were captured through the participant’s written accounts, semi-structured interviews, and the researcher’s field notes. The study found that the participants desired better understanding on behalf of the institution and their coworkers to decrease the sense of isolation that accompanies being a chronically ill employee. Suggestions were made to institute formalized policies that would allow for a common understanding of the resources and support provided for chronically ill employees and would serve as a tool for institution wide understanding of how chronic illnesses impact the workplace.
Understanding how Irritable Bowel Disease Affects Full-Time Employees at a Community College in North Carolina

by

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DEDICATION

I dedicate this dissertation to my parents, Tony and Donna, for the unconditional love, support, and confidence that they have shown me throughout my life. You have always been my biggest fans and have taught me to believe in myself. I am grateful to have such wonderful parents and am blessed to be your daughter. Also, to my husband, Ryan, who lovingly provides support, encouragement, and dedication to help me achieve my goals. You have helped me manage a wonderful balance between family, career, and education and provided needed reassurance when I felt like I was taking too much time away from our family. Finally, I dedicate this document to my two sons, Owen and Ethan. The two of you have shown me that my heart can hold more love than I could have ever imagined. I love you both to the moon and back, and all around the world, billions of times.
BIOGRAPHY

Erin Trado LeGrand of Denver, North Carolina graduated from St. Stephens High School in 2002. She followed in her parents and grandfather’s footsteps and attended the University of North Carolina at Chapel Hill where she earned a Bachelor’s degree in Psychology in 2006. She then attended North Carolina State University and earned a Master’s in Public Administration in 2008. Erin began working part-time with the North Carolina Community College System in December of 2008, she became a full-time Human Resources Development Instructor in January of 2009. Erin quickly fell in love with the community college atmosphere and knew that she wanted a career within this setting. In August of 2009, Erin began NCSU’s Charlotte based cohort in pursuit of a Doctorate of Education in Adult and Community College Education.

At the time of completing this dissertation, Erin is serving as the Quality Enhancement Plan Director and the Institutional Researcher at a North Carolina community college. Erin is the daughter of Tony and Donna Trado and is married to Ryan LeGrand. She has two sons, Owen and Ethan.
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CHAPTER I: Introduction

Chronic disease affects about 133 million Americans, which can lead to decreased attendance in school, lower education levels, and difficulty obtaining and maintaining employment which all result in economic and social disadvantages (Beatty & Joffe, 2006; Perrin, Bloom, & Gortmaker, 2007; Munir, Leka, and Griffiths, 2005; Albrecht, 1992; & Wendell, 1996). According to the United States Center for Disease Control and Prevention (2005), approximately one-fourth of Americans have limitations in daily living caused by a chronic disease. Perrin, Bloom, & Gortmaker (2007) showed that children and college students are becoming increasingly affected by chronic illnesses. Although these increases in numbers have attributed to an increase in healthcare and insurance costs, many colleges and universities have yet to realize the significance and importance of this trend with respect to its implications on the traditional college format (Royster and Marshall, 2008).

More than one in every 10 Americans is faced with chronic, disabling conditions that cause major limitations in activity (Centers for Disease Control, 2002) Individuals with chronic diseases account for about 44% of disabled individuals over the age of 14. In addition, many chronic illnesses are invisible to others, which in turn creates a situation in which others are not unaware that the individual has an illness (Clair, Beatty, and MacLean, 2005; Edelman, Schuyler, & White, 1998). Due to the nature of unseen chronic illnesses, employees will often assume that employers do not provide support during times of flare-ups because the disease is not visible (Clair, Beatty, and MacLean, 2005). It is imperative that university addresses ways to retain students with chronic diseases, as well as, employers
address ways to retain individuals with chronic diseases and not let these individuals fall between the cracks because of invisible illnesses.

There is at least one section within the Americans with Disabilities Act (ADA) that refers specifically to individuals with health-related disabilities. The ADA and the Rehabilitation Act of 1973, mainly section 504, states that a person with a health related illness may be considered disabled if the illness limits one or more life activities including breathing, feeling, walking, or self-care (Americans with Disabilities Act of 1973). This act helps to ensure equal treatment for individuals with chronic health-related illnesses.

**Chronic Illness**

There are many ways to define chronic illness, however “In the broadest sense, a health-related illness affects the individual for at least three months and is likely to continue in the future” (Edelman et. al., 1998, p. 2). A chronic illness may also be referred to as a chronic health condition because of the fact that it undermines the health of the individual. It is possible for a chronic illness to become a disability when it substantially limits the person’s major life activities. Some examples of chronic illnesses include asthma, sickle cell disease, cancer, arthritis, Crohn’s disease, and many others (Edelman et. al., 1998; Sorensen, Olsen, & Binder, 1996).

**Irritable Bowel Disease**

This study will focus on the impact of two specific chronic illnesses, Crohn’s Disease (CD) and Ulcerative Colitis (UC), which are together known as Irritable Bowel Disease (IBD). The Crohn’s and Colitis Foundation of America (CCFA) defined CD as “a chronic (ongoing) disorder that causes inflammation of the digestive or gastrointestinal (GI) tract.
Although it can involve any area of the GI tract from the mouth to the anus, it most commonly affects the small intestine and/or colon.” CCFA defined UC as an abnormal response to the body’s immune system in which the colon becomes inflamed develops ulcers that produce puss or mucous. Mayberry, Probert, Srivastava, Rhodes, Mayberry (1991) add that Crohn’s disease “can begin at any age but often starts during the teens or early 20s when people are trying to complete their education or first enter in regular employment” (p. 312). Taking into account the fact that CD and UC often begin in young adulthood, it is important to examine how IBD will impact patients’ education and their roles in the workforce.

All chronic diseases have a tremendous impact on the individual. However, IBD has a unique affect in that its onset often occurs when the patient is pursuing secondary education or just beginning a career. With this inopportune timing, patient’s life-plans are often altered which can lead to devastating effects on the individual’s level of degree attainment and career outlook Jung, 2003. All too often very capable and talented individuals, who have much to offer the workforce, find themselves too consumed with managing a chronic disease that they remove themselves from the educational system or workforce all together (Beatty, 2004). Once removed from the workforce, these individuals often seek permanent disability claims and never again reenter the workforce to a significant degree (Beatty and Joffe, 2006).

**Statement of Problem**

Chronic illness in the workplace has been shown to lead to marginalization of chronically ill employees. This marginalization then leads to inaccurate stereotypes of employees with chronic diseases and forces responses from these individuals (Major and O’Brien, 2005). Chronically ill individuals usually respond negatively to these identity
threats in that they leave the workforce. This exiting of the workforce then leads to a decrease in income and decreased economic and social involvement (Perrin, Bloom, & Gortmaker, 2007; Albrecht, 1992; & Wendell, 1996). In the current literature (put some references here), authors do not agree on a set definition for disability. However, the United Nations and the ADA definitions share some commonalities in that they define disability as something that restricts the ability of a person to perform the activities of daily living in ways that result in economic and social disadvantages (Albrecht, 1992; Wendell, 1996). “While chronic illnesses, such as rheumatoid arthritis and encephalomyelitis, do not fit the more taken for granted understanding of disability – usually because they are less visible or invisible – they still comply with the criteria” listed above (Jung, 2002, p.178).

Chronic illnesses have a dramatic impact on labor force participation (Munir, Leka, and Griffiths, 2005). However, the symptoms of these illnesses are often invisible and organizations might be unaware of critically ill employees in the workplace (Beatty and Joffe, 2006). Beatty and Joffe (2006) stated that “48 percent of the population lives with some kind of chronic condition, and of these people, 60 percent of them work in some capacity.” (p.182) It is imperative that the needs of employees with chronic illnesses are considered in order for a productive work environment to be available. If chronically ill employees leave the workforce, there will be a large gap in talent and resources that have to be filled. Thus, if perceptions of employees with IBD in the workplace are not addressed, then employees may be chronically under-employed due to lowered career expectations caused by balancing health issues with their career (Beatty, 2004) and the fact it is such a hidden disease.
Statement of Purpose

The purpose of this phenomenology is to determine the essence of what it is to be an employee with IBD at a community college in the western region of North Carolina. The author of this study will attempt to gain a full understanding of the phenomenon of being an employee with IBD at a community college in the western region of North Carolina. At this point in the research, IBD patients will be defined as individuals who have been diagnosed with CD or UC. Ultimately this paper calls will examine the essence of what it is to be an employee with IBD at a community college and what supports could be created to provide additional support for this population of employees that will benefit the workforce.

Theoretical Framework

Theoretical frameworks help researchers to frame their study in an effort to guide research questions and create clear connections with the existing literature on the topic. Literature from many disciplines can be applied to educational research, thus a vast amount of theories are available for guiding research studies. The following two theories will be compared and contrasted, a model of stigma-induced identity threat and a self-disclosure model, which could be used to study chronic illness in the workplace. The most useful framework for examining how chronically ill employees are marginalized in the workplace will then be identified. Finally, a review of the Cognitive Flexibility Theory will be provided as a model of how individuals maneuver through a complex domain. This final theory is presented to ensure that the study does not assume, prior to data analysis, that the participants are marginalized in the workplace.
A Model of Stigma-Induced Identity Threat

Crocker and Major (1989) hypothesized that stigmatization threatens an individual’s self-esteem which can lead to an uncertainty as to whether they are being stigmatized due to their personal or social identity. Steele, Spencer, and Aronson (2002) thought that it was possible for individuals to feel threatened by being a member of a devalued social group if they receive social cues that indicate that the group to which they belong is devalued. Major and O’Brien (2005) developed a model that integrates identity threat models of stigma with transactional models of stress and coping. Major and O’Brien’s Stigma-Induced Identity Threat Model (Figure 1) “assumes that possessing a consensually devalued social identity (stigma) increases one’s exposure to potentially stressful (identity-threatening) situations” (p. 398).

The Stigma-Induced Identity Threat Model contains six inputs that impact outcomes of stigma. These six inputs are: collective representations, situational cues, personal characteristics, identity threat appraisals, nonvolitional responses, and volitional responses. Individual’s appraisals of the significance of situations that impact their well-being are affected by collective representations, box A, immediate situations cues, box B, personal characteristics, box C, identity threat, and box D, occurs when an individual is met by a stigma-relevant stressor that is perceived to be able to harm their social identity in a way in which the individual has no means with which to cope. In this model identity threat has two types of responses, nonvolitional and volitional, boxes E and F, respectively. Nonvolitional responses are those that are involuntary, such as anxiety. Volitional responses are voluntary
responses, such as coping efforts. The responses to the identity threat then have impact on outcomes such as self-esteem, academic achievement, and health (Major and O’Brien, 2005).

Figure 1. Stigma-induced identity threat model

**Collective Representations**

It has been shown that through experiences and exposure to the dominant culture, members of stigmatized groups are made aware of cultural views of their stigmatized status within society (Crocker, 1999; Steele, 1997). Steele (1997) found that in general all members of a culture are aware of the status of stigmatized groups and the stereotypes that are produced even if they do not support the opinion of the overall society. Major and O’Brien (2005) state that “Collective representations can affect the behavior of the stigmatized in the absence of obvious forms of discriminatory behavior on the part of others, and even when no other person is present in the immediate situation” (p. 399).
Situational Cues

Situational cues, such as stereotypes can make individuals aware of marginalization of themselves as an individual or as a group. However, some individuals place themselves in within a marginalized group when society would not have done so (Major, Quinton, McCoy, 2002). It has been seen that “A variety of personal, situational, and structural factors determine whether people perceive themselves as targets of prejudice” (Major and O’Brien, 2005, p. 400).

Personal Characteristics

Individual characteristics are capable of influencing how situations are perceived. Each individual sees every situation differently, thus his or her appraisal of the situation will be unique. Some individuals are more sensitive to being stigmatized than others. These individuals are more likely to see themselves as victims than individuals who are not as highly sensitive to stigmatization (Major and O’Brien, 2005).

Identity Threat Appraisals

Smith (1991) showed that individuals appraise events for their well being. The outcome of the appraisal process has a direct effect on the individual’s cognitive, behavioral, and physiological responses to the event. Stigma-induced identity threat occurs when an event is seen to be harmful to the individual’s well being, beyond the extent to which they are able to control the outcomes of that event (Major and O’Brien, 2005).

Nonvolitional Responses

Spencer, Steele, Quinn (1999) showed that anxiety is a possible involuntary response to identity threat. In addition, arousal and increased blood pressure have been shown
responses to threats against an individual’s well being (Ben-Zeev, Fein, Inzlicht, 2004; Blascovich, Spencer, Quinn, Steele, 2001). As shown in the study, not all responses, especially nonvolitional responses to identity threat are able to be self-reported by an individual.

**Volitional Responses**

There are several strategies for coping with identity threat appraisals. Major and O’Brien (2005) noted the following coping strategies: blaming discrimination versus blaming the self, disengagement versus striving, and group identification versus disidentification. Each of these coping strategies is unique to the individual and to the situation. Individuals do not have to respond to differing identity threats in the same manner.

**Outcomes of Stigmatization**

One of the outcomes of stigmatization that is mentioned by Major and O’Brien (2005) is that of an impact on health. It has been shown that members of stigmatized groups suffer from a greater risk of depression, hypertension, heart disease, and stroke than do nonstigmatized individuals (Krieger, 1990; McEwen, 2000). These health issues are of major concern when considering that they can be brought on by threats to an individual’s identity.

Overall the stigma-induced identity threat model presented by Major and O’Brien (2005) has shown how individual’s responses to identity threat are impacted by collective representations, situational cues, and personal characteristics. The individual’s reaction, either voluntary or involuntary, then goes to produce outcomes to the identity threat.
Model of Disclosure

Derlega, Metts, Petronio, and Margulis (1993) helped to define disclosure as the process of revealing authentic and intimate information to others. Fisher’s (1984) expanded definition states that disclosure is “verbal behavior through which individuals truthfully, sincerely, and intentionally communicate novel, ordinarily private information about themselves to one or more addressees” (p. 278). Beatty (2004) adds that an individual’s actions are also capable of disclosing relevant information about an individual. Among these actions are taking medications, missing work, and asking for alternate work assignments.

Jourard (1971) found that individual factors were the main predictors of disclosure where as Ragins and Cornwall (2001) argued that social and environmental factors were the main predictors of disclosure. Beatty (2004) provides a general model of disclosure (Figure 2) that is taken from a combination of the literature on disclosure, combining Jourard’s and Ragins and Cornwall’s points of view (p.16). The general model of disclosure that is presented by Beatty (2004) shows disclosure being influenced by individual factors and/or contextual factors. Then, individual outcomes and/or social outcomes are a result of an individual disclosing some piece of information.

![General model of disclosure](image)

Figure 2. General model of disclosure
**Individual Factors**

Beatty (2004) argues that one of the antecedents to individual disclosing of information is a sense of identity and that disclosure is related to a sense of self. The second antecedent that Beatty mentions is an individual’s perception of stigma, or potential risk that is taken by disclosing information.

**Contextual Factors**

Miller and Read (1987) showed that contextual factors influence how individuals determine the risk/reward potential of disclosing information and that potential influences the individual’s disclosure behavior. Individuals consider their environment prior to disclosing any information that could be harmful to their image (Royer, 1998).

**Outcomes of Disclosure**

Tardy (2000) found that reduced stress and improved well-being are associated with disclosure. However, this does not take into account the negative impact that disclosure can have on work related responsibilities. An individual can be impacted by negative outcomes from disclosure if the environment is not supportive of what they are disclosing.

Overall, the general model of disclosure provides vague guidelines for what initiates an individual to disclose personal information and how that disclosure impacts their life. Essentially, an individual can choose to disclose information due to individual or external factors. The result of the disclosure can have individual or social outcomes that can be either positive or negative.
Comparing Stigma-Induced Identity Threat and Disclosure Theory

Both of the Stigma-Induced Identity Threat theory and the Model of Disclosure theory were presented to discuss stigma as a portion of the model. The model of Stigma-Induced Identity Threat presented by Major and O’Brien (2005) used stigma to guide the entire model and were seeking to determine what outcomes come about from an individual being stigmatized. However, Beatty (2004) simply used stigma as a portion of her model in determining what leads individuals to disclose personal information and what types of outcomes are possible from such disclosure.

Major and O’Brien’s model of Stigma-Induced Identity Threat was much more detailed in how it related to the literature and how individuals could be impacted. This model provides a much more solid framework for creating a research study examining how stigma is dealt with in the workplace. Based on the level of detail in the model of Stigma-Induced Identity Threat and the ability to apply it to future research, it would be a better choice to use in examining how employees with chronic illness are stigmatized in the workforce.

Cognitive Flexibility Theory

Cognitive Flexibility Theory, developed by Spiro, Coulson, Feltovich, and Anderson (1988), examines how individuals learn or maneuver through complex domains or situations. Spiro, et al. define cognitive flexibility as a term that examines the way that individuals are flexible in their thinking within a situation in which one must quickly adapt in order to succeed in that particular experience. Spiro, et al. (1988) make the following statement:
“Cognitive flexibility is dependent on having a diversified repertoire of ways of thinking about a conceptual topic.” (p. 548)

Cognitive Flexibility Theory, grounded in constructivist theory, emphasizes that individuals must have the opportunity to develop their own representations of the subject or experience in order to learn (Spiro, et al., 1998). In addition to having the opportunity to engage in the subject matter, Cognitive Flexibility Theory also emphasizes the need to present complex information in the form of multiple examples in order to avoid overgeneralization of the subject matter. Furthermore, cognitive flexibility addresses how individuals categorize data in order to recall information previously gained from one experience and transfer the pertinent and relevant material for use in another experience. Spiro, et al. (1988) make the following statement concerning cognitive flexibility:

Cognitive flexibility involves the *selective* use of knowledge to *adaptively fit* the needs for understanding and decision making in a particular situation; the potential for maximally adaptive *knowledge assembly* depends on having available as full a representation of complexity to draw upon as possible. (p.548)

The seven themes or conditions to Cognitive Flexibility Theory are as follows:

1. Avoidance of oversimplification and overregularization
2. Multiple representations
3. Centrality of cases
4. Conceptual knowledge as knowledge in use
5. Schema assembly (from rigidity to flexibility)
6. Noncompartmentalization of concepts and cases (multiple interconnectedness)
7. Active participation, tutorial guidance, and adjunct support for the management of complexity. (Spiro, et al. 1988)

These seven themes or conditions lay the groundwork for transitioning individuals from rigid to more flexible thinking processes. Spiro, et al. (1988) claim:

Central to the cultivation of cognitive flexibility are the approaches to learning, instruction, and knowledge representation that (a) allow an important role for multiple representations, (b) view learning as the multidirectional and multiperspectival “criss-crossing of cases and concepts that make up complex domains’ “landscapes…” (c) foster the ability to assemble diverse knowledge sources to adaptively fit the needs of a particular knowledge application situation (rather than search for a precompiled schema that fits the situation). (p. 556)

Overall, the Cognitive Flexibility Theory provides a framework for helping learners and individuals to navigate through complex domains through the use of multiple representations of cases and the prevention of oversimplification of the situation. Cognitive Flexibility Theory calls for an individual’s increased ability to apply previously learned concepts to new situations and experiences by recognizing the interconnectedness of different experiences.

For this study, the employer, specifically the human resource office, would benefit most from the ideas and concepts presented in the Cognitive Flexibility Theory. It is easy for a human resource representative to treat all employees with IBD or chronic illness the same, especially if the institution has very few employees with IBD. Cognitive Flexibility Theory says that the human resource representative would be more likely to generalize and simplify the situation based on their experience with a small number of individuals affected by IBD.
In reality, two employees with IBD can have two drastically different disease states which lead to completely different accommodations that are needed. Cognitive Flexibility Theory will help the employer to develop a more complete view of an employee with IBD and will help to prevent overgeneralization and simplification so that they chronically ill employee can receive the most effective accommodations possible.

**Conceptual Framework**

The conceptual framework for shows a graphic image that depicts the relationship between the experiences of all employees who have IBD and the experiences of three employees with IBD at Catawba Valley Community College.

![Conceptual framework of employees' experiences with IBD](image)

Figure 3. Conceptual framework of employees' experiences with IBD
Research Questions

The overarching research questions for this study are:

1. What is the essence of the experience of employees with IBD at a community college in western North Carolina?
2. What does the essence of the experience of employees with IBD at a community college in western North Carolina mean?

Significance of the Study

Employees suffering from chronic medical conditions, such as IBD, are forced to manage difficult situations and to carefully balance work with their ongoing medical needs. For many employees, managing their illnesses means time away from work for treatments and regularly scheduled doctor appointments in addition to the time that they take to deal with flare-ups from the disease. Considering that employees with chronic illnesses are a vital part of the workforce (Beatty and Joffe, 2006) it is important to identify the resources that will help chronically ill individuals to thrive at work.

Not only should employers consider the needs of their chronically ill employees, the ADA, section 504 legally binds them to do so. Community colleges, much like other employers, need to become more aware of the impact of invisible illnesses on their employees, thus their institutions, so that they can become increasingly capable of identifying and mitigating challenges for chronically ill employees.

This study seeks to add to the small literature base concerning the impacts of chronic illness on employees in workplaces of higher education. The results of this study have potential implications for both employees and employers. Chronically ill employees will
come to the realization that they are not the only ones fighting a battle to maintain their health while serving as a productive employee for the organization in which they work. Employers will become more aware of the marginalization of chronically ill employees in the workplace and could revise or create policies to minimalize such unequal treatment.

This study will impact theory by expanding upon Major and O’Brien’s (2005) Stigma-induced Identity Threat Model by identifying more personal characteristics with which chronically ill employees characterize themselves. In addition, nonvolitional and volitional responses and outcomes to those responses that are specific to chronically ill employees in the higher education arena will become apparent.

The results of this study will draw attention to a marginalized section of society. Chronically ill employees constitute roughly 60 percent of the workforce (Joffe, 2006). These employees are often times marginalized within the organization due to their disease. Through exposure, this study will allow for more equal treatment of chronically ill employees. In addition this study hopes to serve as a motivator for employees with IBD to formally disclose their disease diagnosis. This formal disclosure will open lines of communication between the chronically ill employee and the employer.

**Limitations**

This phenomenology is limited to a. individuals with IBD, thus the participants must be diagnosed with either Crohn’s Disease or Ulcerative Colitis. The methodology for the study is limited to qualitative design due to the low number of employees at CVCC with IBD. The results of this study will be limited to the information that the participants reveal.
during the interviews with the researcher. The power to detect any themes across the interview responses is limited to the participants’ responses themselves.

**Delimitations**

This study is delimited to a. employees at Catawba Valley Community College b. individuals with IBD. Employees of CVCC who do not have IBD will not be considered for this study. The study is delimited to individuals who are interviewed as a part of the study. All individuals with IBD are not included in this study, although they may benefit from the results. It is not possible to generalize the results of this study to all individuals with IBD, only the individuals in this study. Finally, this study is delimited to the time frame in which the interviews take place.

**Definition of Terms**

*Chronic Illness.* “A health-related illness affects the individual for at least three months and is likely to continue in the future” (Edelman et. al., 1998).

*Disability.* Something that restricts the ability of a person to perform the activities of daily living in ways that result in economic and social disadvantages (Albrecht 1992; Wendell 1996).

*Irritable Bowel Disease (IBD).* Individuals diagnosed with Crohn’s Disease or Ulcerative Colitis (Crohn’s and Colitis Foundation of America).
CHAPTER II: Review of Literature

Introduction

Chapter Two provides a review of relevant literature concerning chronic illness. This chapter begins by discussing the effects that chronic illness has on adult and higher education. A transition is made to view higher education as a workplace followed by a discussion of the impacts of chronic illness on the workplace.

Very little research exists concerning how chronic diseases impact employees in the workplace. This literature review seeks to provide a robust review of how chronic illness impacts individuals’ lives leading up to and during the stages of employment. Literature addressing how chronic illnesses impact the fields of adult education and higher education is presented to build a case that chronic illness does not begin affecting individuals when they begin working. A parallel can be drawn between the impacts that chronic illness has on an individual as a student to the same individual as an employee. In addition to the parallel that exists between chronically ill students and chronically ill employees, education also serves as an employer to chronically ill faculty and staff. Thus, it is critical to consider how higher education addresses the impact of chronic illness on both students and employees to gain a better understanding of the types of marginalization that exist for both populations.

Impact on Adult and Higher Education

Chronic illnesses can have a varying impact on an individual’s tenure in higher education. The impact will range from very minimal to nearly devastating; it depends on the disease, disease course, and duration of periods of remission versus flares (Royster and Marshall, 2008). The Individuals with Disabilities Education Act (IDEA) and Amendments
to the Rehabilitation Act of 1973, especially section 504, indicate that for individuals with disabilities must be provided accommodations in elementary and secondary schools. This entitlement to accommodations disappears in the post-secondary arena and students must identify themselves as disabled in order to receive any accommodations (Eldeman et al., 1998).

Success and retention rates of students with chronic disabilities are greatly impacted by the amount of support that they receive for health-related educational needs. (Royster and Marshall, 2008). Students with chronic diseases need ongoing accommodations that take into account the unpredictable nature of their chronic conditions (Royster and Marshall, 2008). However, many traditional college and university programs do not offer students these accommodations because they are either unaware that the student needs the accommodations or they do not have the knowledge and resources to properly advise and retain individuals with such needs (Royster and Marshall, 2008).

The most common disabilities encountered during the educational process are usually learning disabilities and physical disabilities (Edelman et al., 1998). This is because learning disabilities and physical disabilities are more common and are perceived as more important than disabilities caused by chronic illnesses. For this reason, many debates and policies exist on accommodating individuals with more visible disabilities. One such definition and policy was established by the Individuals with Disabilities Education Act (IDEA) which states "a disorder in one or more basic physiological processes such as memory or auditory perception and one or more difficulties in learning specifically identified as listening, thinking, speaking, writing, spelling, reading and mathematical calculations" (Taymans, Swanson,
Gregg, Hock, & Gerber, 2009, pg. 5). However, this definition provided by IDEA only applies to students K-12 and not to specific populations of students like adults, but it focuses on learning disabilities.

Royster and Marshall (2008) stated, “in the fall of 2000, U.S. four-year colleges enrolled nearly 10,000 students with health-related disabilities, which included conditions such as severe allergies, cystic fibrosis, cancer, lupus, or multiple sclerosis” (p. 120). Furthermore, it was shown that 15% of all students with disabilities enrolled in four-year institutions as first-time and full-time students (American Council on Education, 2001). The reported 15% of all students is merely an estimate because health-disabilities must be self-reported and are not visible. Although the statistic might be underestimated, Anderson (2004) showed that about one-fourth of individuals with chronic conditions have daily activity limitations.

Many students choose not to identify themselves as having a disability; thusly they are not counted as a part of the disabled population (Royster and Marshall, 2008). When a student with a recognized health-disability chooses not to report the disability, they forfeit many opportunities to gain help with managing specific problems such as an inability to qualify for some financial aid options, unpredicted relapses, and the invisibility of their illness. Jung (2003) pointed out that the needs of students with chronic illnesses are often times overlooked by disability staffs because they are not familiar with the coming and going of symptoms or with the unpredictable relapses. Thus, when a student does not disclose that they have a chronic illness, the repercussions of having to miss class during a relapse or flare is much greater than if they were able to properly prepare and set policies before the missed
time. The National Council on Disability (2003) indicated that students with disabilities often experience difficulties attaining a postsecondary degree and the lack of self-reporting just compounds this already dismal statistic.

As students with chronic medical-illnesses move away from home to enter the world of post-secondary education, it is necessary that they ensure that they can receive proper medical attention in the event of a flare. In addition, many students need ongoing treatments including, infusions, breathing treatments, dialysis, etc. (Eldeman et.al.,1998). It is important that the students verify that these treatments are available to them in their new environment. If students do not have these resources available then they will either have to travel to a location that provides the necessary treatments or would be at an increased likelihood of suffering from symptom flare-ups. Both of these options would require time away from school that could be detrimental to the student’s successful completion of a post-secondary degree.

Jung (2003) indicated that students with chronic illnesses do not simply need a one-time accommodation to fulfill their needs, instead, they need to continually negotiate and adapt the arranged accommodations depending on the state of their illness. Part of the reason that students with chronic illnesses do not get the appropriate accommodations is because they have little understanding of the disease themselves, thus they do not wish to describe its impacts to school officials (Edelman et. al., 1998). In addition, the students do not know how their postsecondary institution will be able to help them accommodate their needs. “This lack of information and inability to develop coping strategies in postsecondary settings often results in students dropping out of the educational program before they can acquire a degree.
or other credentials for employment” (Edelman et. al., 1998, p.2). Jung (2002) finds this to be an unfortunate finding because education leads to better jobs and more professional employment. Higher levels of employment can then lead to better health care funding which is a crucial aspect for individuals with chronic illnesses (Jung, 2003).

When students with chronic illnesses are consistently led to drop out of higher education for an extended period of time they become a marginalized section of our society (Royster and Marshall, 2008). Not only does the time out of school impact the student’s chances of successfully completing a post-secondary degree, it also impacts their ability to obtain a higher level position of employment that can better help pay for the costs of having a chronic illness (Jung, 2003).

The previous section discussed the impacts of chronic illness on adult and higher education from the perspective of the student. However, these fields also serve as areas of employment. Faculty and staff with chronic illnesses rely on working for institutions that are able to adapt to their medical needs. Without the institution’s willingness to set policies that allow the employee to manage his/her disease, the employee could be forced to resign from his/her position. Considering chronic illness’ impact on such vital members of society, it is imperative to examine how this marginalization from early in the academic process affects chronically ill employees’ ability to enter into the workforce and maintain employment.

**Chronic Illness impact on the Workplace**

In the current literature, authors do not agree on a set definition for disability. However, the United Nations and The American Disabilities Act definitions share some commonalities in that they define disability as something that restricts the ability of a person
to perform the activities of daily living in ways that result in economic and social disadvantages (Albrecht 1992; Wendell 1996). “While chronic illnesses, such as rheumatoid arthritis and encephalomyelitis, do not fit the more taken for granted understanding of disability – usually because they are less visible or invisible – they still comply with the criteria” listed above (Jung, 2002, p.178).

Chronic illnesses have a dramatic impact on labor force participation (Munir, Leka, and Griffiths, 2005). However, the symptoms of these illnesses are often invisible and organizations might be unaware of critically ill employees in the workplace (Beatty and Joffe, 2006). Beatty and Joffe (2006) stated that “48 percent of the population lives with some kind of chronic condition, and of these people, 60 percent of them work in some capacity.” (p.182) It is imperative that the needs of employees with chronic illnesses are considered in order for a productive work environment to be available. If chronically ill employees leave the workforce, there will be a large gap in talent and resources that have to be filled. Thus, if perceptions of employees with IBD in the workplace are not addressed, then employees may be chronically under-employed due to lowered career expectations caused by balancing health issues with their career. (Beatty, 2004)

Employees suffering from chronic medical conditions, such as IBD are forced to manage difficult situations and to carefully balance work with their ongoing medical needs. For many employees managing their illnesses means time away from work for treatments and regularly scheduled doctor appointments. This does not even factor the time that they need to take to deal with “flare-ups” from the disease. Considering that employees with
chronic illnesses are a vital part of the workforce (Beatty and Joffe, 2006) it is important to identify the resources that will help chronically ill individuals to thrive at work.

Galanti (1991) defined culture as encompassing learned beliefs and behaviors that are shared by a group and influence how an individual perceives and shapes his or her own world. Turner (1996) stated that cultural beliefs and behaviors tend to influence a person’s perception of disease etiology, illness, and disease labels. Cultural beliefs about chronic illnesses make it easy for individuals with chronic diseases to become a marginalized section of society. Because of the role culture plays in influencing a person’s perception segments of the population that differ from the norm, it is important that students with chronic illnesses not be marginalized.

McElroy and Townsend (1989) recognized that diseases have complex etiologies that involve social, biological, and environmental factors. Stigma is a factor that pertains to the social realm. Markel (1992) found that stigma stems from when an illness becomes a socially or culturally devalued condition that marginalizes individuals and discredits or disqualifies them from full social participation.

**Advocacy Role**

This study aims to provide an avenue for the community college to access and evaluate the literature presented to recognize the full spectrum of chronic illness as a disability, pertinent to the ADA Section 504. As previously discussed, not all chronic illnesses present themselves outwardly. Employees with these invisible chronic illnesses, such as IBD, should be treated with the same level of compassion and understanding as employees diagnosed with more visible diseases such as depression, anxiety, heart disease.
For an employee with IBD, a flare-up of symptoms can lead to an increased amount of time spent away from the workplace. This can often time be attributed to severe pain, nausea, diarrhea, and/or necessary medical treatments and doctor’s appointments. It is imperative that employers take into consideration the needs of employees with IBD so that they will maintain legal compliance with the ADA, which protects any employee with a disability due to a chronic illness.

It is imperative to consider this literature when exploring how employees are affected by chronic illness. With the implications shown through this review of literature it becomes evident that individuals with chronic illnesses are important facets to our society and economy. Thus, considerations must be made as to how the illnesses these individuals face impact their lives as successful employees. In addition, it is crucial that chronically ill employees formally report their disease diagnosis to their employer to establish a line of communication between the two parties concerning the needs and concerns of both the employer and the employee.
CHAPTER III: Methods

Introduction

Chapter three provides an overview of the research methodology that was used in this study. The study is a qualitative phenomenology. The chapter begins with a discussion of why phenomenology is the best methodology for this study. Furthermore, the chapter covers establishing an Epoche, sampling, data collection procedures, informed consent, data storing procedures, and data analysis procedures.

This study is a qualitative research design; specifically the study will employ the phenomenological method to understand the experiences of full-time employees with IBD in a community college in North Carolina. Moustakas (1994) supports that the phenomenological research method seeks to fully understand participant’s experiences with a certain phenomenon. The study takes place in a moderately sized community college in the western part of North Carolina.

Phenomenological research is one qualitative technique that helps to reach the essence of an individual’s (the participant’s) experience with a particular phenomenon. Creswell (2009) defined phenomenological research as “a strategy of inquiry in which the researcher identifies the essence of human experience about a phenomenon as described by participants” (p. 13).

Moustakas (1994) stated, “the empirical phenomenological approach involves a return to experience in order to obtain comprehensive descriptions that provide the basis for a reflective structural analysis that portrays the essences of the experience” (p.13). Welman
and Kruger (1999) added “the phenomenologists are concerned with understanding social and psychological phenomena from the perspectives of people involved.” (p.189)

This section will outline the methodology to conduct a phenomenological study to understand the experiences of employees with chronic illness and how that illness impacts their careers. Moustakas (1994) continues to state that “The aim is to determine what an experience means for the persons who have had the experience and are able to provide a comprehensive description of it” (p.13). Ultimately, this study seeks to determine the essence of what it is like to be an employee with IBD at a particular community college in the western region of North Carolina.

**Phenomenological Methodology**

**Epoche**

Prior to beginning a phenomenological study, the researcher must first reach a place of freedom from all suppositions, known as the Epoche. (Husserl, 1931) Moustakas (1994) stated that

The challenge of the Epoche is to be transparent to ourselves, to allow whatever is before us in consciousness to disclose itself so that we may see with new eyes in a naive and completely open manner. Thus, in the process of being transparent in the viewing of things, we also become transparent to ourselves. (p.86)

The researcher is not to take a position in the Epoche; everything should have equal value. Thus, no judgments should be made concerning the subject matter or the participants. After completing the Epoche, the researcher may then begin the phenomenological research,
starting with expressing concern for the ethical constraints of conducting a study with human participants.

*Researcher’s perspective.* I have was diagnosed with Crohn’s Disease in December of 2002, two days after returning home for Christmas break, after completing the first semester of my freshman year at the University of North Carolina at Chapel Hill. The timing of my diagnosis could not have been planned at a more convenient time or location. During my second night home from college, I was prompted to seek professional medical help by a relatively sudden onset of extreme pain in the lower right side of my abdomen. I was promptly examined in the Emergency Room in my home town and received a barium enema for diagnostic purposes. Initially, the physicians working on my case thought that I might have appendicitis, but one of my test results was indicating that appendicitis was not the cause of my pain. A local gastroenterologist was requested to consult on my case at which point I was diagnosed with Crohn’s Disease, a disease of which I had never before heard.

My CD diagnosis was different from many individuals diagnosed with CD in that I was correctly diagnosed the first time that I sought medical attention for my symptoms. Many individuals diagnosed with IBD, Crohn’s Disease or Ulcerative Colitis, endure years of symptoms and sometimes incorrect diagnose before they are diagnosed and treated for the correct illness. Although, looking back on some of my previous, prior to diagnosis, illnesses, I feel that at least a couple of the times I felt that I had a stomach virus could have actually been the beginnings of CD symptoms. However, the illnesses and symptoms that occurred prior to my diagnosis with CD were never severe or persistent enough to seek medical
attention. Fortunately, I did not have to endure years of agonizing symptoms and wondering why unnecessary or improper treatments were not alleviating my pain.

**Course of treatment.** During Christmas break, I began treatment for my Crohn’s Disease. At the time, my course of treatment was out-patient, intervenious infusions of Infliximab (Remicade) every eight weeks. My class schedule for the spring semester of my freshman year was conducive to my treatment schedule in that I only had two morning classes on Fridays which allowed me to leave immediately following my 9:00 AM class and travel the two and a half hours home for my infusion therapy.

This maintenance therapy allowed me to stay in remission until the spring semester of my junior year (2005). I began having many typical CD symptoms including abdominal pain after eating, weight loss, and eventually, constant vomiting after eating. I attended the Emergency Room twice during this flare-up of symptoms, being sent home both times after hydration and monitoring. Eventually, during the summer of 2005, I was able to schedule an appointment with a leading gastroenterologist at the University of North Carolina GI Clinic. After examination, I was immediately scheduled for an endoscopy, to be performed that afternoon, and was scheduled to meet with a surgeon the following morning. Immediately following my appointment with the surgeon, I was admitted to the hospital to undergo a small bowel resection. The surgeon removed the 12-inch long infected section of my small bowel and performed an appendectomy due to fistulas that were dangerously close to penetrating my appendix. Following surgery, I was instructed to continue treatment with Remicade to prevent symptoms from returning. Once again, the timing of the unbearable symptoms was perfect. During the summer of 2005, I was volunteering as an undergraduate
research assistant and was not enrolled in any summer classes. This allowed me to take two weeks to have surgery and recover before I returned to the research lab. Once again, I experienced a relief from Crohn’s Disease symptoms so the disease did not impact the remainder of my undergraduate or master level studies.

Transition from student to employee. Immediately after completing my final semester of my master’s degree course work, December 2007, I began working part time in the continuing education division of the community college located in my home town. I worked with two different departments and averaged between 28 to 34 hours of work per week. It was during my time working for these two departments that I fell in love with the community college system and was determined to retain full time employment at a community college in the western region of North Carolina. I continued working as a part time employee for these two departments for a year while applying for full time positions at surrounding colleges. In January of 2009 I became a full time employee of one of the departments with which I was working part time. My supervisor was aware of my CD diagnosis as I had regular appointments with my gastroenterologist and was still undergoing Remicade maintenance therapy. Thus, my supervisor was made aware of the reasons for my frequent doctor’s appointments.

It was not until late in the spring of 2009 that I started to once again experience symptoms of a CD flare. Many of my coworkers were also aware of my diagnosis and tried to show support when possible. However, I try to minimize the impact that CD has on my life and my lifestyle, so usually only those individuals who are closest to me know if I am having any impacts of CD. It is not until my symptoms become overbearing that I let others
know what I am facing. In May of 2009 I was referred to a colorectal surgeon who performed surgery on an anorectal fistula as well as a stricture dilation because my CD had spread.

The surgeon indicated that the disease progression was worse than my symptoms led him to believe and that I would probably have a longer recovery than expected. I expected to take sick leave for the day of the procedure (a Friday) and return the following Monday. However, the pain from the procedure was still too great, and I ended up using sick leave for the entire week following the surgery. This was the first time since being diagnosed with CD that my disease had an impact on my commitments (in this case, employment and depletion of sick leave hours). During this time of symptom and disease progression, referral to a new surgeon, diagnosis, surgery, recovery, and post-operation follow-up appointments I was fortunate to have a supportive supervisor who made accommodations and assisted in finding substitutes for my classes which alleviated some of the pressure that was placed on me due to my absence from work. Once again, my coworkers tried to be supportive, but no one really understood what I was going though, as they knew very little about my disease. Also, CD symptoms can be very embarrassing, so I did not elaborate on my symptoms or feelings.

Through my experiences and gaining friendships at this community college, I have discovered three other employees who have also been diagnosed with IBD. For a period of about two and a half years my office was located directly across from one of these individuals who happened to also be diagnosed with CD. I found great comfort in talking with this coworker, especially in times of symptoms flares like the May 2009 flare that was previously discussed. During the time that I was located in close proximity to this individual,
I was able to form a bond with someone who truly understood what I was going through. This allowed me to feel a little less isolated and reassured me that I was not the only one who was battling this invisible disease.

I have since moved offices multiple times and have changed departments. In my new position and location on campus, fewer people around me know of my diagnosis which, at times, leads me back to that feeling of being alone and like no one fully understands what I face on a daily basis. This feeling and my experience as an employee with CD is what drives my interest in this research study. I want to know what other employees, like me, diagnosed with IBD experience within this work environment. I realize that my intimately personal relationship to this subject matter could impact my ability to truly ‘hear’ what the study participants are saying. But, I am well aware that everyone has their own story to tell that is based in their own experiences and their own perspectives.

**Advantages and disadvantages of the researcher’s perspective.** One advantage that I have serving as the researcher for this study and also as an employee with IBD at this community college is that I have experienced many of the same symptoms, feelings, and procedures that I asked the study participants to speak about. My ability to empathize with the participants could have allowed the participants to feel less vulnerable in discussing oftentimes embarrassing IBD symptoms. Two disadvantages to my dual role are, one, that the participants might feel as though information that they provided me could more easily be leaked to the college than if I was not an employee at the same college, thus increasing the reluctance to provide full disclosure. The second disadvantage of my CD diagnosis and employment at the same college may have been that the participants were not as explicit in
explaining their viewpoints as they would have been with someone who either did not have an IBD diagnosis or was not an employee at the same institution. It was imperative that prior to each interview and analysis session that I engaged in the Epoche in order to suspend my biases and perspectives so that I could fully focus on the participants themselves. The following section will provide further details of my process for engaging in the Epoche.

**Engaging in the Epoche.** Moustakas (1994) states that “Everything referring to others, their perceptions, preferences, judgments, feelings must be set aside in achieving the Epoche” (p.88) I allowed myself 30 minutes prior to each interview to focus fully on the individual with whom I would be speaking. I would read the written account that they had provided and try to free my mind of any prior judgments, preconceived notions, expectations, or biases. I allowed myself to enter a state of being fully receptive to what the interview participant would tell me so that I could hear the story from their point of view, it was being told, instead of clouded with my own feelings and accounts of similar situations. I engaged in the process of achieving the Epoche prior to each interview, prior to writing field notes, and prior to analyzing the data.

**Sampling**

Prior to conducting any research, the researcher must first determine the sample of the population to be studied and in which manner the sample of participants will be identified. The following will provide a discussion of the sampling techniques that were used in this study. Followed by, a description of the methods for data gathering, informed consent, data storing, and data analysis.
Welman and Kruger (1999) consider purposeful sampling to be the most important type of non-probability sampling, to identify primary participants. Kruger (1988) stated that purposeful sampling should be used when the researcher is looking for those who “have had experiences relating to the phenomenon to be researched” (p. 150). For the purpose of this study, the interviewees will serve as the primary unit of analysis (Bless & Higson-Smith, 2000).

For a study focused on employees with chronic illness and its impact on their careers, individuals with chronic illness within the local community college will be surveyed. Boyd (2001) recommends two to 10 participants to reach saturation, thus three chronically ill individuals have been identified to participate in the research project. Each of these individuals has been officially diagnosed, by a physician, with a form of Irritable Bowel Disease (IBD). More specifically the participants have either Crohn’s Disease or Ulcerative Colitis.

**Participant recruitment.** The researcher first discussed the study with potential participants in person to assess his/her willingness to participate in the study. After the initial discussion detailing the requirements of the study, individuals who were interested in participating in the study were sent a formal recruitment e-mail (Appendix C). The email outlined the voluntary nature of participation in this study. All of the potential subjects chose to participate in the study and were asked to select a time for an interview. The Informed Consent form was attached to the recruitment e-mail.

**Participants.** The participants in this study were three employees from a community college in the western region of North Carolina. The researcher has a working relationship
with each of the participants, thus informally discussed participation in this study with each of the individuals prior to a formal invitation to participate in the study. Table 1 shows the demographic information that was collected from each participant. The study consisted of two female participants and one male, two participants were diagnosed with Crohn’s Disease while one participant had Ulcerative Colitis, and two participants were staff members while one was faculty.

Table 1

Demographic data for participants

<table>
<thead>
<tr>
<th>Participant Number</th>
<th>Gender</th>
<th>IBD Diagnosis</th>
<th>Number of years diagnosed</th>
<th>Employment Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant: 010</td>
<td>Female</td>
<td>Ulcerative Colitis</td>
<td>15 years</td>
<td>Staff</td>
</tr>
<tr>
<td>Participant: 020</td>
<td>Male</td>
<td>Crohn’s Disease</td>
<td>27 years</td>
<td>Staff</td>
</tr>
<tr>
<td>Participant: 030</td>
<td>Female</td>
<td>Crohn’s Disease</td>
<td>11 years</td>
<td>Faculty</td>
</tr>
</tbody>
</table>

Data-gathering methods

The central phenomena focused on for this research study is how chronic illness impacts employees’ careers. The central research question that guided the study is: What is the essence of being an employee with IBD at a community college in the western region of North Carolina? Upon agreement to participate in the study, the study participants were
asked to submit a brief written account of what it is like to be an employee with IBD at this community college. This account was used as a source of baseline information for the researcher prior to the in person interview. A semi-structured interview was used to gain a better understanding of the experiences of the employees. In order to fully understand an individual’s experiences, it is important to access their feelings, opinions, and knowledge of the experience. Merriam (1998) and Patton (1990) state that the interview process is appropriate for determining what is in a participant’s mind and when we are not able to observe behaviors that help us to determine how he or she interprets the world in which they live. Bailey (1996) stated that the “informal interview is a conscious attempt by the researcher to find out more information about the setting of the person” (p. 72). The interviews sought to determine how the participants “think and feel in the most direct ways” (Bentz & Shapiro, 1998, p.96) about how chronic illness impacts the participant’s careers.

The study participants participated in an in-depth semi-structured interview which combined life-history interviewing and focused interviewing until the topic was saturated, or when no new perspectives were introduced on the topic (Seidman, 1991). Open-ended questions were asked to allow the participant to reconstruct his or her experience. Structured interview questions were used to collect demographic data (Merriam, 1998). The interviews strictly followed ethical standards and each participant was made aware that his or her participation in the study is voluntary. Appendix A shows the interview questionnaire.

Informed Consent

North Carolina State University requires that any research study applies with the Institutional Review Board (IRB) prior to the researcher recruiting participants for the study.
The IRB states that individuals who participate in a research study must sign an informed consent agreement before the study begins. The informed consent must release information pertaining to the following: knowledge that the individual is participating in a research study, the duration of the study, the purpose of the research, the procedures of the research, potential risks and benefits of the research, the voluntary nature of the research, the right of the participant to stop at any time during the research study, the terms of confidentiality of the research and the researchers conflicts of interest, if any exist. (http://research.ncsu.edu/sparcs/compliance/irb/irb-forms/)

The informed consent form is to be explained to subjects at the beginning of each interview. Any participant who does not agree to sign an informed consent form will not be allowed to participate and will be excluded from the study.

Data-storing methods

With the permission of the interviewees, each of the interviews was audio-recorded. For the purpose of confidentiality, each interview was assigned a code so that no identifying information will be linked to the audio-recording. As soon as possible, following each interview, the interview was listened to and notes were made accordingly. Key words, phrases and statements were transcribed “in order to allow the voices of research participants/informants to speak” (Groenewald, 2004, p.14)

Lofland & Lofland (1999) state that field notes are imperative in qualitative research to help retain the gathered data. Morgan (1997) argues that field notes are “part of the analysis rather than the data collection” (p.57-58). Field notes should include information regarding the participants of the interview, where the interview occurred, what happened, etc.
Lofland & Lofland (1999) feel that field notes should not be written any later than the morning following the interview. Bailey (1996) argues that “luck, feelings, timing, whimsy and art” should be included in field notes (p. xiii). In the process of writing field notes the researcher must try to be free of biases and must prevent premature collection into groups of data.

Finally, a full transcription of each interview, taken from the audio recordings, was transcribed by the researcher. This transcription was identified by the assigned subject identification code and allowed the researcher to easily break down themes from the interviews to determine the essence of the participants’ experiences.

The study related data is kept in a password protected file within a password protected account on the researcher’s personal computer. The recordings were labeled by the subject identification number, so no identifying information was recorded besides the sound of the participant’s voice. When not in use, all printed documents (ex: transcripts and participant’s written accounts) are kept in a locked drawer to which only the researcher will have a key.

Data Analysis


1. Using a phenomenological approach, obtain a full description of your own experience from the phenomenon.

2. From the verbatim transcript of your experience complete the following steps:


39
a. Consider each statement with respect to significance for description of the experience.

b. Record all relevant statements.

c. List each nonrepetitive, nonoverlapping statement. These are the invariant horizons or meaning units of the experience.

d. Relate and cluster the invariant meaning units into themes.

e. Synthesize the invariant meaning units and themes into a description of the textures of the experience. Include verbatim examples.

f. Reflect on your own textural description. Through imaginative variation, construct a description of the structures of your experience.

g. Construct a textural-structural description of the meanings and essences of your experience (p.122).
3. From the verbatim transcript of the experience of each of the other co-researchers, [study participants] complete the above steps, a through g.

4. From the individual textural-structural descriptions of all co-researchers’ experiences, construct a composite textural-structural description of the meanings and essences of the experience, integrating all individual textural-structural descriptions into a universal description of the experience representing the group as a whole. (p.122)
The final step in conducting a phenomenological research study is to summarize the study. Moustakas (1994) states that it is necessary for the researcher to summarize the entire study and consider possible limitations to the results. As a part of this summarization, the researchers is to return to the literature review to distinguish the findings from prior research (Moustakas, 1994). In addition, the researcher must conclude the study with suggestions for a future study and a summary of how the presented research will impact social meaning and personal and professional values (Moustakas, 1994).

Chapter Three provided a methodological outline for conducting a phenomenological study concerning how IBD impacts full-time employee’s careers at a North Carolina community college. Discussions on creating Epoche, informed consent, participant sampling, data storage, data analysis and study summarization constitute the bulk of the information described. Considering that this paper provides a prescription to follow the data analysis and study summarization sections do not incorporate chronic illness in the workplace because no data has been collected to analyze or summarize. The methods section will guide the author’s research study seeking to understand the essence of how IBD impacts full-time employees at a Community College in North Carolina.
CHAPTER IV: Presentation of Data

Introduction

Chapter four presents the data that was collected as a part of this phenomenological research study. The chapter begins with a discussion of horizonalization, followed by a description of the horizon statements and resulting themes from the study. Individual textural and structural descriptions are provided through the use of verbatim examples of participant’s responses which are then presented as unified or composite textural and structural descriptions of the phenomenon of what it is like to be an employee with IBD at a particular community college in the western part of North Carolina. This chapter concludes with answering the study’s research question through providing a synthesis of meaning and the essences of the phenomenon being researched. It must be noted that pseudonyms are used for study participants to maintain participant confidentiality.

Horizontalization

For a phenomenological study, horizonalization is the term used to refer to data reduction. This process helps the researcher to identify which of the participant’s statements are meaningful and relevant to the study and which are not in terms of creating a common experience of the phenomenon that is being researched. The process of horizonalizing begins with the researcher reading the entire interview transcript to extract significant statements, horizions, that are related to the phenomenon that is being studied. In this stage of the analysis process, it is essential for each of the participant’s statements to have equal weight. After horizons are constructed, any statements that are irrelevant to the topic are deleted which leaves only “nonrepetitive and nonoverlapping” (Moustakas, 1994, p.122) statements.
to be clustered into themes. Moustakas (1994) states that “Horizons are unlimited. We can never exhaust completely our experience of things no matter how many times we reconsider them or view them” (p. 95). I used the process of horizontalization with each of the participant’s written accounts, interview transcripts, and field notes. Through this process I uncovered 47 relevant, nonrepetative, and nonoverlapping horizon statements which, upon clustering into meaning units resulted six overarching in themes. The themes that are most salient in the individual textural descriptions are; (1) reliable restroom access, (2) desire increased coworker awareness and education, and (3) a desire for formalized policies at this institutional level. The themes that were revealed from the individual structural descriptions are, (1) worry and anticipation, (2) feeling of isolation, and (3) external stress. These horizons and themes are further described in the following paragraphs.

**Individual Descriptions**

This section uses the horizons and themes from each participant’s transcripts to create the individual textural and structural descriptions of the phenomenon. Individual textural descriptions offer an explanation as to how the experience is perceived from the participant’s view point. Moustakas (1994) states that “the individual structural description provides a vivid account of the underlying dynamics of the experience, the themes and qualities that account for ‘how’ feelings and thoughts” connected with the phenomenon of chronically ill employees are aroused, “what conditions evoke the phenomenon” (p. 135).

**Carroll**

Carroll is a dedicated staff member at this community college where she has been employed for 12 years. All of the positions that she has held at this college have been funded
through grant positions. The uncertain time frame of grants has a tendency to lead to an increased amount of job related stress when the funding periods near their end. Carroll was diagnosed with Ulcerative Colitis about 15 years ago and has had one major flare of symptoms in the past year. As a result of the severity of the symptoms that she experienced, Carroll has been absent from work for three days since June.

Before receiving a correct diagnosis, Carroll was not initially diagnosed with Ulcerative Colitis and was instead treated with antibiotics that did alleviate her symptoms. Carroll indicated that she suffered from UC symptoms for 3-4 years before she received a proper diagnosis. However, Carroll remained positive when referring to her struggles with diagnosis and with her job security. (This was demonstrated by her positive attitude towards working with UC.

**Individual textural description.** The experience of serving as an employee with UC at this community college is simply a fact of life for Carroll. When she first began working at the college she had a small number of direct coworkers, none of whom were aware of what IBD or UC are and the implications that these diseases have on a person or their work.

I have been diagnosed with irritable bowel and ulcerative colitis for some time now. During this time, I have had several flares that have been horrible. On the initial flare, I lost weight, hair, felt very weak and was getting very little nutrition from any food I ate. For a little more than a week I had to remain at home and in bed a lot of the time. Of course for a longer period of time, I was back at work making the very frequent trips to the bathroom and attempting to find some nutrition that would stay with me. I learned that very few of my co-workers understood the disease so I did
proceed to educate them as well as sending web links to them in email. Once they understood how the disease affects a person, they were very supportive and always patient and understanding (Carroll, personal communication, September 13, 2013). When asked if her coworker’s were receptive to being “educated” on IBD and UC, Carroll responded with the following statement: “Yes, yes, very much so. Because I was also going through the hair loss at that point in time, so they were seeing visible signs that something was wrong” (Carroll, personal communication, September 13, 2013). This was a point where the disease for Carroll went from being a hidden issue to a visible one.

I found Carroll to be a reliable, hardworking, and self-aware individual which carried over into how she conducts herself as an employee. Carroll described herself as “conscientious, dedicated, loyal, and hard driven” (Carroll, personal communication, September 13, 2013). She stated that she is harder on herself than other people are on her. She does not feel as if she allows her UC diagnosis to impede her dedication to her job, but does acknowledge that there are times when she must deal with symptoms at the moment and which have the ability to interfere with some of her timeliness.

Now, on occasion, I have had a delay of getting here at 8:00, but most of the time when that happens, I text [my supervisor] to let her know that I’m running late. Now, like I said, she is very aware of my disease, so she knows what that means when I say that I’m running late, because for the most part I am always here by 8:00. In a different environment I might not be getting that kind of patience, but here I do (Carroll, personal communication, September 13, 2013).
When asked about obstacles to work life, Carroll responded “just being near a bathroom” (personal communication, September 13, 2013) as a concern. She indicated that it is important to always “feel secure and know that it [the bathroom] is one that you can go into and it is relatively clean.” (Carroll, personal communication, September 13, 2013) Carroll adds that seat covers, which are provided in the college’s restrooms, give her a piece of mind about the cleanliness of the facility and help to make an uncomfortable situation a little more bearable.

Carroll mentioned that her office is located between two bathrooms that she is comfortable using. The closer bathroom is a little less private, but is perfectly acceptable in emergency situations.

Carroll indicates that it would be beneficial if the college instituted a formal process for “disclosure” of chronic illness and a policy for handling common issues that might arise for employees with chronic illnesses. Carroll stated the following when asked about officially disclosing her illness to college personnel: “If there is an official process to tell that, to do that, I don’t know about it. And, I have not ever discussed it with them. I don’t think that they have asked and I don’t offer that information to them.” (Carroll, personal communication, September 13, 2013) When questioned if the college has appropriate policies in place for chronically ill employees, Carroll responded that she didn’t know the college’s policy, if they had one. Later in the interview, Carroll indicated that if she could change one thing about being an employee with IBD at this community college, it would be an increase amount of information that can be provided to coworkers about balancing employment responsibilities and symptoms of chronic illness. Carroll stated the following:
I think it might be a good thing if we had a periodic email or a webpage we could go to about chronic illnesses and that would include things like high blood pressure, just a whole variety of things. I think that it would be good to have that information so that if we ever do have to talk to coworkers or supervisors they can go there. (Carroll, personal communication, September 13, 2013)

Carroll is grateful for the years that she has been an employee with this community college and is thankful for the support that she has received from her direct supervisor and coworkers. She understands that she might not have had the same type of support that she has experienced in another area of the college or with another employer.

**Individual structural description.** The structures that permeate Carroll’s experience as an employee with IBD at this community college are expressed in her relation to her relationships with others, her sense of responsibility, and her ability to conform to a new sense of normal to cope with stressful situations.

Regarding Carroll’s relationships with others, she indicates that she receives a great deal of empathy from her direct supervisor and her coworkers.

I think my friends and co-workers now have a good understanding of the effects of the disease and are very respectful about their concerns for me and others. Most of us have some sort of health issue that we must deal with from time to time and the more kindness, respect, and compassion we can reflect to our co-workers, the better our working environment becomes. I am a firm believer in the Golden Rule and apply it as often as I can. For the most part, I feel that I have been treated very well
when dealing with my illness. (Carroll, personal communication, September 13, 2013)

Furthermore, Carroll speaks about the move from isolation to a feeling of connectedness when she realizes that some of her coworkers are also coping with IBD in the workplace:

I have realized that there are other people who are dealing with Crohn’s and Ulcerative Colitis, and Irritable Bowel, and other things. Once I learned that, I think that made me feel, and I don’t wish disease on anybody. But, I think it made me feel like I was not a fish out of water. There were other people in the same boat so they have an even better understanding of what you’re going through which makes it a little easier to deal with. Because if you see somebody that you know and if you have it you can look at somebody and just know whether they are having a bad day or not. (Carroll, personal communication, September 13, 2013)

Carroll wrote the following in her written account about the relationships between other coworkers with IBD:

Also, I have learned there are several folks that work here that have the same or similar type issues with irritable bowel, ulcerative colitis, Crohn’s disease, etc. When we are having a bad time/flare and pass each other in the hallway, we have the opportunity to say something supportive to each other which I think helps tremendously. While not wishing anyone this crazy illness, it is good to know we are not alone in this battle. (Carroll, personal communication, September 13, 2013)
Carroll’s sense of responsibility is a force that is driven by her personality and permeates her work performance. Carroll views it as her responsibility to educate her coworkers about the invisible disease that she faces on a daily basis. Carroll stated the following about educating her coworkers:

…at that particular point in time they did not understand what Irritable Bowel or Ulcerative Colitis was about so, I took it upon myself to explain it to them and I also sent them some web links so they could get additional information if they needed it. (Carroll, personal communication, September 13, 2013)

The ability for Carroll to adapt and identify a new level of normalcy is evident when she states; “Having always been of the mind that I never had bowel movements in a public restroom prior to this disease, irritable bowel/UC has changed that”. (Carroll, personal communication, September 13, 2013) Carroll provides an example of her flexibility has allowed her to continue working with an unexpected, potential student while managing disease symptoms:

Occasionally, I will have somebody come in that is just a walk in, somebody that I am not expecting, and I have been able to work with them ok. Umm, and I am trying to think you know during that time that I have an episode where I have had to excuse myself. And, I think that I have had that happened a couple of times. And, each time that I did. I said, “You’re going to have to excuse me for just a couple of minutes. I’ll be right back.” Generally, I have some type of paperwork that they need to fill out anyway and I give them the paperwork to work on while I am gone. (Carroll, personal communication, September 13, 2013)
In addition, Carroll’s ability to adapt to life’s circumstances has allowed her to more easily manage the stress that she feels working in a grant funded position. She indicated that she had to place her faith in God in order to handle the uncertainty of her employment status because the increased amount of worry and stress in which she was engaged was what triggered her most recent flare-up of UC symptoms.

William

William is a hard working staff member at this community college. William spends most of his time working with local companies to determine ways in which the college can better serve the needs of their current and potential employees. William was diagnosed with Crohn’s Disease in 1986 but had symptoms since the early 1970s.

William has had one flare-up of disease symptoms in the past year that has lasted approximately nine months. During the nine months of disease symptoms, William indicated that he has only been absent from work three days due to his disease and each of those days missed were for a medical procedure such as a colonoscopy. William mentioned that he attends work even if he is feeling bad.

*Individual textural description.* William’s experiences as an employee with CD at this community college seem to be in a constant fluctuation, depending on the amount of support that he receives from his immediate supervisor and/or his coworkers for a given situation. When asked what his main obstacle to everyday life is, William replied with the following statement:

Making sure that a bathroom is within a mile of you... That’s a good concern down here in this place. There is only one men’s restroom and when it fills up with classes
I’m going to be running to another building, because you know, you can’t wait.

(William, personal communication, October 1, 2013)

Furthermore, William added that there is only one male restroom in his building. He indicated that at first, the minimal number of restrooms was not a major problem, because very few students used the facility. However, the number of classes that are using the building is increasing and is expected to continue increasing until the building is filled to capacity every day. William indicated that he has a real concern with his ability to quickly access a restroom when the building is filled to capacity; “…but if something happens [restroom emergency], I’m going to be in the car, going to be out of here really quick.”

(William, personal communication, October 1, 2013)

In his written account, William provides the reader with a glimpse into what it is like to live with Crohn’s Disease on a daily basis and a rationale for the emergent need for reliable and proximate restroom facilities:

For the most part, the day to day bouts of having to rush to the bathroom are the most difficult scenarios to deal with since bathrooms could be occupied and you have little time to get to the next bathroom. In addition, you may be in a meeting or out talking to a customer when the situation arises and many times you have little or no time to get to a facility. Bathroom facilities numbering more than one are always welcome due to the urgent nature of the situation. (William, personal communication, October 1, 2013)

William described himself as a “dedicated” employee who gives “110” percent. When discussing his job performance and describing himself as an employee, I got the since
that William did not feel as though he was measuring up to the standards to which he holds himself. He indicated that although he gives 110 percent of himself, it is not what it used to be. William stated that “I don’t feel like I am doing nearly as well as I used to… Yeah, I’m getting it done, but I am struggling to get it done. That’s the best way to put it.” (William, personal communication, October 1, 2013)

William indicated that he was not aware of any policies that exist at the college for dealing with chronically ill employees. Further, he suggested that some type of policy should exist that would provide an institutional level of understanding of what chronically ill individuals face and what types of accommodations they might require. William made the following statement about creating an institutional policy that pertains to chronically ill employees: “I’m not looking for shoulders to cry on, but a little understanding of what I am going through and why I do have to leave meetings, why I have to do this, why I have to do that…” (William, personal communication, October 1, 2013)

**Individual structural description.** The structures that permeate William’s experience as an employee with IBD at this community college are expressed in relation to his worry and anticipation about limited restroom access, his sense of isolation, and external sources of stress.

William addressed the worry and anticipation that is often associated with IBD in his following statement: “Is it going to hit you? When is it going to hit you? Please don’t hit me. It’s kind of waiting, anticipating. (William, personal communication, October 1, 2013)

Living with an invisible illness can lead to feelings of isolation due to the lack of awareness or understanding from individuals who are expected to provide support. William
commented “I feel like I am on an island by myself.” (William, personal communication, October 1, 2013) He provided further elaboration with the following about experiencing a lack of support as an employee with IBD:

There are moments that uh, I think there is a lack of understanding and some people don’t know what you’ve got, but you don’t get the respect you should. Even in your own group. I just don’t feel like they fully understand how bad this junk is. So, yes… There are times I feel like I don’t get the support that I would like to have, but that’s life. (William, personal communication, October 1, 2013)

In his written account, William shows the reader how isolating IBD can be:

My current position at the community college is just another chapter of living with this miserable disease. I work with a number of different people inside and outside the community college office environment each day. The fact is that most people know nothing about the disease and therefore don’t understand the pain and embarrassing situations you go through every day. (William, personal communication, October 1, 2013)

The pressure that William places upon himself is mentioned in the textural description of his account of what it is like to be an employee with IBD at this community college, but feels as though an undue amount of stress is placed on him at times when he feels the worst. William stated the following:

Uh, Just the fact that they will push… they know that I am having a bad, bad round of something or that I am really sick, but you’re going to have to get this done, this done, and this done. And they know I’m in bad shape. But, it comes, what’s more
important? To get the business or my health, and obviously it is to get the business. (William, personal communication, October 1, 2013)

Elyse

Elyse has been a faculty member with this community college for 19 years. During her tenure, she has been promoted to coordinator and eventually a department head position. Elyse was diagnosed with Crohn’s Disease in 2002, roughly eight years after beginning employment with the college. Over the past year, Elyse has experienced two flare-ups of CD symptoms but has not missed any days of work due to CD. Elyse has been fortunate in that the times in which she has had to be hospitalized for treatment have coincided with college closings such as Christmas break. Elyse enjoys her job with the college and commented that she to be in the classroom with students and seeing them learn. Through my conversations with Elyse, it became very evident that she has an intense passion for her field and for being a part of introducing and guiding students into her field of study.

Individual textural description. Elyse’s experience as an employee with IBD at this community college is rather volatile, she enjoys her career and working with students and engaging in the learning process, but she does not feel as if she receives the level support or empathy that she deserves from the college as a whole.

The main obstacle that Elyse faces in everyday life is simply being close to a restroom, especially after eating. Elyse feels fortunate that although much of her day is spent in a structured environment within the classroom, 9:00 A.M. – 1:00 P.M., she is physically located “right around the corner” from the restroom. In the case of an emergency, Elyse is able to briefly excuse herself from the classroom without mandating a break for the students.
in the class. Elyse indicated that she does receive some empathy from her direct supervisor and is confident that she would not have any issue with her taking emergent restroom breaks during class time.

Although, Elyse mentions feeling some level of empathy on a one-on-one basis, she is quick to say that she does not feel empathy or support from an institutional level. She perceives that there could be some discrimination, but has not experienced any first hand. When asked to describe what it is like to be an employee with IBD at this community college, Elyse responded: “I don’t want anybody to know, how about that?” (personal communication, October 7, 2013) Elyse’s perceived discrimination could be a result of how she feels the college would describe her as an employee. On one hand, Elyse describes herself as a “loyal… reliable, dependable, and creative” (personal communication, October 7, 2013) employee. However, she feels as if certain people at the college would describe her as a “problem”. Elyse refuted this notion, saying “I’m not a problem, but I think they would describe me as such.” (personal communication, October 7, 2013) Elyse indicated that college policies that specifically address chronically ill employees would be beneficial to the college and its employees.

**Individual structural description.** The structures that permeate Elyse’s experience as an employee with IBD at this community college are expressed in her relation to unnecessary stress from work, lack of empathy and uninformed coworkers, and the lack of a contingency plan for her absence.

Elyse addresses unnecessary stress from work several times, during the interview and in her written account, in relation to obstacles that she perceives as an employee with IBD at
this community college. She stated that “Anytime I get upset it goes to my gut.” (Elyse, personal communication, October 7, 2013) Moreover, Elyse stated that she would decrease the level of stress imposed by the college if she could change one thing about being an employee with IBD at this community college. She made the following comment about the amount of “unnecessary” stress within her work environment:

They need to quit changing things constantly, constantly, constantly. It gives you a sense of instability. There is no stability. So, when you are fearful of your job every other day, you can’t stay calm. And, that’s the big thing with this disease; you need not to have a lot of stress. And even the people who know that you shouldn’t have a lot of stress are willing to give you stress. (Elyse, personal communication, October 7, 2013)

Uninformed coworkers leads to a lack of empathy: Elyse indicated that she feels that there should be more empathy from the institution and coworkers in general. She commented “I mean there’s probably a bunch of us who have problems. But, nobody knows. And if they do know, they don’t really care.” (Elyse, personal communication, October 7, 2013) Elyse further commented that she does not feel as if the college would “bend over backwards for somebody who is ill”. When asked if she had officially informed the college’s personnel department of her diagnosis, Elyse responded: “I don’t know about that. It could be good, it could be bad… I just don’t know.” (personal communication, October 7, 2013)

Finally, Elyse indicates that the lack of a support structure, contingency plan, leaves her feeling as if she is not allowed to or able to be sick because there is no one to take her
place. In her written account, Elyse provides the following description of a lack of available back-up plans:

I am fortunate in that we do have sick leave available but it is very hard to be sick when you are in a position such as mine. I tend to just come to work and get through it rather than take off and rest. (personal communication, October 7, 2013)

During the interview, Elyse expressed the following concern with respect to the lack of a contingency plan for who will cover her workload if she is sick:

In the position I’m in, I don’t really have the luxury of taking off sick…Who is going to cover for me? There is not anybody…It’s me and [direct report], and he’s new. And [direct supervisor] is my supervisor and she is swamped. Yeah, you can’t really be sick. Luckily I’m not too sick to make it through the day. (personal communication, October 7, 2013)

The only time that Elyse indicated that she felt as if she had “luck” or fortune on her side was with respect to her ability to stay healthy which allows her to minimize her absences due CD and decrease the amount of stress with having to be away from her position. Elyse conveys a sense of frustration with the college in that she feels that an undue amount of stress is placed on her for unnecessary reasons. She indicates that she does not feel as if she has a stable work environment which leads to an increased amount of work related and personal stress which have an impact on her disease symptoms.

The previous section of Chapter 4 begins the phenomenological narrative with a discussion of the individual elements that provide a depiction of each participant’s experience as an employee with IBD at this community college. The following section will
combine common themes from the individual textural and structural descriptions to create a unified version of each that will express the common elements and experiences of the group of participants with respect to the phenomenon.

**Composite Descriptions**

**Composite Textural Description**

The invariant meanings and themes of each participant must be evaluated to create a composite textural description that depicts the experiences of the group as a whole. The individual textural descriptions reveal the following themes: (1) reliable restroom access, (2) desire for increased coworker awareness and education, and (3) a desire for formalized policies at this institutional level. These three themes are used to create the following composite textural description of that depicts the experiences of the group as a whole as employees with IBD at this community college.

The experience of being an employee with IBD at this community college is dynamic; it that although the research participants indicated that they did not feel as if they had been intentionally mistreated, they did expressed a desire for more support or understanding from the college. Each of the research participants provided a description of a reality that is daunting for many individuals to imagine.

Although the need for reliable restroom access was mentioned as the largest obstacle to everyday life for the participants, they also conveyed an attitude of “this is my life.” In other words, the need for reliable restroom access in the workplace, although very real and pertinent to their situation, is an obstacle that all of the participants must constantly face whether at work or in life outside of the workplace. This is simply a fact of life for the
participants. However, the desire for increased coworker awareness and education of how chronic illnesses, especially IBD, impact the workplace is a wish that stems from a yearning for the ability to connect and relate to their non-chronically ill coworkers on a deeper level.

All of the participants realize that individuals who have not been diagnosed with IBD will never fully understand its impacts on the career or personal life of those with an IBD diagnosis. Nor, would they wish the disease on anyone simply for increased awareness of the situation, but the participants did identify a need and desire to be more fully understood when it comes to the ways in which they have to cope with and manage their IBD in the workplace.

IBD brings with it a host of challenges for allowing un-impacted persons to fully understand the impacts of the disease. Oftentimes it is difficult for a diagnosed individual to communicate their fears and concerns with individuals who are not aware of the trials that accompany and IBD diagnosis because of the private and unappealing symptoms of the disease itself. In other cases, undiagnosed individuals try to minimalize the severity of the impact of the disease on a person’s life because everyone knows what it is like to have a bathroom emergency. But, for individuals with IBD, the emergent nature is not a one in a while occurrence or something that happens as a result of the flu or a stomach bug; it is an everyday fact of life. “Emergencies” happen after almost every meal. What is normal, when it comes to restroom necessities, for individuals facing IBD is abnormal for the average population. In many cases, individuals who are not impacted by IBD would use sick time for the same symptoms that many IBD patients experience on a daily basis.
The participants of this study do not wish for more affected individuals, they simply want their struggles to be understood and respected. A mechanism that could result in an increased level of awareness and understanding from coworkers could be made at an institutional level in the form of policies for managing the needs of chronically ill employees. An institutional policy addressing the needs of chronically ill employees would alleviate some of the participants' awareness and understanding concerns by providing a structure in which they are able to begin conversations with coworkers. This framework that could be created would help to pave the way to an increased sense of understanding that these participants so desperately seek.

**Composite Structural Description**

The themes that were revealed from the individual structural descriptions are, (1) worry and anticipation, (2) feeling of isolation, and (3) external stress. The composite structural definition provides an understanding of how the research participants, as a group, experience the phenomenon of being an employee with IBD at this community college. (Moustakas, 1994)

Living as an employee with IBD at this community college is filled with feelings of worry, anticipation, and isolation. For the participants in this study, it is the inevitability of having to face oneself as being different from the rest of their coworkers. The workplace is a location where most individuals, including the participants of this study, spend the majority of their waking hours. At times, the sense of otherness and isolation form the norm of everyone that surrounds you can be daunting. The level of sympathy that is felt does not minimize the amount of worrying about being different or having to anticipate every step to
access a restroom that leads to the feeling of isolation for the participants. Day in and day out, employees with IBD are pervasively attuned to the fact that their fears and worries are not understood by the vast majority of the individuals with which they spend much of their day. This realization simply perpetuates the feelings of worry, anticipation, and isolation that are already so predominant in the participant’s lives.

The internal feelings, mentioned above are a source of internal stress for employees managing IBD at this community college, but the external pressures that are placed on the individuals, by the college, lead to another level of anxiety for the participants. Stress is a known cause of symptom flare-ups for IBD patients. So, the external, work related stress is yet another source of worry and anticipation for the participants. Not only do the participants worry about efficiently and effectively carrying out their duties, but they also want to excel in every task they accept. The participants do not use their illnesses as an excuse for mediocre performances. So, when further external pressures are applied, the stress levels become too overwhelming and can lead to an increase of IBD symptoms which simply perpetuates the cyclical nature of the sources of stress for these individuals.

**Synthesis and the Essence of Being an Employee with IBD at a North Carolina Community College**

The final step in analyzing the results of a phenomenological study is to synthesize the composite textural and composite structural descriptions and to determine the essence of the phenomenon. In reference to determining the essence of a particular phenomenon, Moustakas (1994) states the following:
The essences of any experience are never totally exhausted. The fundamental textural-structural synthesis represents the essences at a particular time and place from the vantage point of an individual researcher following an exhaustive imaginative and reflective study of the phenomenon. (p. 100)

This section will integrate the texture and structure to create a more complete understanding of the essences of what it is to be an employee with IBD at this community college.

The experience of being an employee with IBD at this community college is riddled with a desire for more: more understanding on the part of coworkers, more awareness of the impacts of the disease, more policies related to chronically ill employees, more relief from anxiety and worry, and more of a sense of inclusion. Participants revealed a sincere sense of isolation that stems from coworkers lack of understanding of what they face on a daily basis and a worry that the manifestation of disease symptoms are simply not considered.

The participants express a desire for coworkers to have a better understanding of their conditions, but do not know the appropriate ways to educate those around them due to the lack of institutional support in terms of policies relating to chronically ill employees. The participants report that they feel “isolated” as if they are on an “island.” These reports expressed internal feelings of perceived isolation. None of the participants revealed that they were physically isolated or separated from their coworkers due to their disease. The feelings of loneliness are exacerbated by the feelings worry and anticipation that are associated with IBD.

In essence, the desire for being better understood by coworkers permeates the lives of the participants in this study. The feelings of isolation seem to dominate the way in which
the participants view the workplace and their need for an increase in awareness of the daily impacts of managing IBD in this community college.

**Summary**

Chapter 4 presents the data that was collected as a part of this phenomenological study. Further, this chapter completes the process for analyzing phenomenological data as presented by Moustakas (1994). The process for completing the analysis of data followed the following steps: horizontalization, clustering horizon statements into themes, developing individual textural descriptions, developing individual structural descriptions, combining the individual descriptions into composite textural descriptions and composite structural descriptions, and finally synthesizing the textural and structural descriptions to determine the essences of the experience of being an employee with IBD at this community college.

Through the data analysis process, it was determined that the participants in this study desired better understanding on the part of their coworkers and employers, less of a feeling of isolation, increased support, and increased awareness of what obstacles they have to face on a daily basis. Each of the participants also mentioned the desire for increased institutional support terms of the creation of policies that address the needs of chronically ill employees. The desire for increased support and understanding infiltrates the participants’ interviews.
CHAPTER V: Summary, Implications, and Outcomes

Introduction

Chapter 5 serves as the concluding chapter for this dissertation. The chapter provides an overview of the conducted phenomenological study, followed by a section that provides a comparison between the results of the study and the literature that was presented in Chapter 1. Then, the future research section is followed by the limitations and implications of the presented study. This chapter and this study will conclude with a personal statement from the researcher.

Overview of the Study

Understanding How Irritable Bowel Disease Affects Full-Time Employees at a Community College in North Carolina is an investigation into the phenomenon of how employees with IBD at a community college in the western region of North Carolina experience the workplace. The purpose of this phenomenology is to examine in depth the phenomenon of how employees with IBD experience the community college environment. The participant’s written responses and verbatim interview transcripts were thoroughly examined to answer the following research questions: What is the essence of the experience of employees with IBD at a community college in western North Carolina? and What does the essence of the experience of employees with IBD at a community college in western North Carolina mean? Phenomenology was best suited for this study because it provides an opportunity to hear the voices of the individuals who experience the unique phenomenon of being an employee with IBD at a western North Carolina community college. van Manen
(1990) states makes the following statement with respect to the value of a phenomenological study:

Phenomenology does not offer us the possibility of effective theory with which we can now explain and/or control the world, but rather it offers us the possibility of plausible insights that bring us in more direct contact with the word. (p. 9)

The data of this phenomenological study were gathered from written accounts, in depth interviews, field notes of three participants who were selected using purposeful sampling method. The study participants were required to have an official IBD diagnosis, from a physician and be a full-time employee at the community college that was selected as part of the study.

The analysis of the qualitative data revealed the following as the essence of the experiences of employees with IBD at a community college in the western part of North Carolina: the desire for being better understood by coworkers permeates the lives of the participants in this study. The feelings of isolation seem to dominate the way in which the participants view the workplace and their need for an increase in awareness of the daily impacts of managing IBD in this community college.

**Comparison to the Literature**

The study’s findings that the participants desire for a better understanding from coworkers and the feelings of isolation are supported by Major and O’Brien’s (2005) Stigma-induced identity threat model (Figure 5) that was reviewed in Chapter 1.
The overall essence of the participants’ experiences with being an employee with IBD in this community college provided evidence of each of the seven pieces of the Stigma-induced identity threat model: collective representations, situational cues, personal characteristics, identity threat appraisals, nonvolitional responses, volitional responses, and outcomes.

The participants showed that they were aware of the stigmatization and stereotypes of IBD in the workplace. The following statements from the participants’ interviews provide examples of collective representations, situational cues, and personal characteristics of the study’s participants:

- “Because people look at you like what is wrong with her?” (Carroll, personal communication, September 13, 2013)
- “I think there is a lack of understanding and some people don’t know what you’ve got, but you don’t get the respect you should.” (William, personal communication, October 1, 2013)
• “There are occasions where things are said to me that I wish were not.”
  (William, personal communication, October 1, 2013)
• “I think they would describe me as a problem.” (Elyse, personal communication, October 7, 2013)

These inputs are used by the participants to make an identity threat appraisal of the situation in which they find themselves. Elyse made the following two statements that eluded to her appraisal of an identity threat: “I think there could be [discrimination], yeah.” (personal communication, October 7, 2013) and “I don’t know about that [officially telling the human resource department]. It could be good, it could be bad… I just don’t know.” (personal communication, October 7, 2013). The participants mentioned nonvolitional responses such as being treated for anxiety and volitional responses such as educating coworkers on the symptoms and implications of IBD. Lastly, the outcomes associated with this study showed that the participants feel a sense of isolation from their coworkers and a desire for better understanding of how IBD impacts their work lives.

Future Research

The findings from this study provide evidence for the need for future research focused on the experiences of employees with chronic illness in the workplace. Based on the results and conclusions of this study, a mixed methods study is proposed.

First, the future research should examine quantitatively examine the differences between institutions with and without specific policies for chronically ill employees. After an initial assessment of and categorization of institutions with policies and without polices for chronically ill employees, it would be beneficial to employ qualitative method to
understand the experiences of a sample of employees with chronic illnesses at each of these types of institutions. The study could be expanded by using the same qualitative techniques to gain a better understanding of the employers and coworkers at each type of institution. Evaluating data from employers and coworkers would provide a more complete view of the work environment.

In addition, this future research should be conducted two fold. Once with employees who have been diagnosed with IBD and once with employees who have simply been diagnosed with a chronic illness. It is impossible to determine whether the thoughts, feelings, emotions, and experiences that are provided in the results of this study are limited to employees with IBD or if there are commonalities among all chronically ill employees.

Limitations

This study, like most studies is limited to the time and resources available at the time that is was conducted. The major study limitations are: participant access, time of data collection, and the researcher’s interpretation and synthesis of the qualitative data.

Access

Participants were invited based on the researcher’s personal knowledge of the individual’s IBD diagnosis. It is possible that there are more full-time employees at this particular community college with an official IBD diagnosis. In addition, access was limited due to the nature of the study’s population. There is a tendency for nondisclosure among critically ill employees which would result in limited knowledge of the possibility for study participants (Kruger, 1988).
Time

The research design used a one-time interview with a submitted oral interview. All of the interviews took place between September 13, 2013 and October 7, 2013 which limited the results to the timeframe of the study. It is possible that the experiences of the individual participants could have been different if they had been approached at a different time. In addition, the results of the study are limited to the amount of time that was spent interviewing each research participant (Moustakas, 1994).

Researcher Interpretation

Although the researcher took a great amount of effort in achieving an Epoche prior to each interview and each session of data analysis, the research is still limited to the researcher’s interpretation of the written accounts and the verbatim transcripts. The researcher provided exact quotes from the participants in order to allow their point of view to be more transparent. However, the researcher had to draw conclusions about statements and classify statements into themes in order to determine the overall essence of the experience of being an employee with IBD at this community college (Moustakas, 1994).

Implications

As previously stated in this study, roughly 48 percent of the population lives with a chronic condition and 60 percent of these individuals are employed to some degree (Beatty and Joffe, 2006). With these staggering statistics, it is evident that chronic illnesses have a dramatic impact on labor force participation (Munir, Leka, & Griffiths, 2005). The primary implications of this study are in seen in the workplace, the community college workplace,
and for individuals struggling with balancing the maintenance of IBD symptoms and full-time employment.

**Implications for the workplace**

The results of this study have implications in the workplace for both employees and employers. Although employers did not serve as participants in this study, the results call for an increased awareness and understanding from coworkers of employees with IBD. One of the suggestions for increasing coworker and institutional awareness of how IBD and chronic illnesses impact chronically ill employees is the creation of a policy that addresses the needs of employees that battle chronic illnesses. Each one of the three participants in this study discussed the need for policies that address the needs of chronically ill employees. The participants indicated that formalized policies would allow for employer and coworker’s increased awareness of the struggles that chronically ill employees face. In addition, the participants indicated that formalized institutional policies would allow for a starting point for disease disclosure.

From the employer’s viewpoint, instituting policies for chronically ill employees could be easily abused by such employees. Employees could claim to need more time or accommodations than are truly required for their disease state. Specifically for employees with IBD, the disease pattern follows periods of remission and flare-ups, an employee could require substantial accommodations during time of a flare and not need any during a period of remission while still taking advantage of the accommodations that were provided during a time of increased symptoms. Upon implementing policies, employers and employees would have to work together to ensure that policies are fair to both parties.
Implications for the community college workplace

The results of this study provide the community college with an opportunity to engage in educating its employees on how chronic illnesses impact not only their coworkers, but also their students. These individuals with invisible chronic illnesses are often overlooked and not provided with the support that is truly needed (Beatty and Joffe, 2005). With an increase in coworker and instructor awareness, through education, it is possible that these individuals would feel more comfortable in disclosing their illnesses and seek the support necessary to allow for maximum fulfillment of their potential (Major and O’Brien, 2005).

Just like other workplaces, employees and students with IBD should be protected by policies that allow for appropriate accommodations during periods of increased disease symptoms. In order for employees and students to benefit from such policies, they must formally disclose their diagnosis to human resources and/or the office that presides over student disabilities. Without this formal disclosure, the college has no way of knowing that any accommodations are necessary, thus the students and employees will continue to function under the college’s general policies and procedures that protect all employees.

Implications for individuals with IBD

An implication for employees with IBD is that they realize that they are not alone in their struggles and that other employees also deal with managing IBD or other chronic illnesses in the same work environment. During the course of the study, Carroll made the following statement in reference to finding other coworkers with IBD:
I have realized that there are other people who are dealing with Crohn’s and Ulcerative Colitis, and Irritable Bowel, and other things. Once I learned that, I think that made me feel, and I don’t wish disease on anybody. But, I think it made me feel like I was not a fish out of water. There were other people in the same boat so they have an even better understanding of what you’re going through which makes it a little easier to deal with. (personal communication, September 13, 2013)

The results of this study provide implications in the workplace, the community college workplace, and chronically ill individuals. Increasing coworker awareness through policies and institution wide education would provide support for chronically ill employees and students.

**Personal Statement and Closing Remarks**

This phenomenological study of employees with IBD in the workplace attempted to ascertain the essence of the experiences, beliefs, feelings, and interpretations of the employees with IBD a community college in the western part of North Carolina. I am hopeful that the analysis of data, the results and the implications of this study have provided a thorough and accurate account of the participant’s experiences. Ultimately, I am thankful for the opportunity to conduct a study that is personal to me which helped me to manage my own feelings of isolation and a desire for increased understanding from my coworkers. I am optimistic that the results of this study will prove to increase the awareness of the needs of employees with IBD.
REFERENCES


Americans with Disabilities Act, 42 U.S.C.§ 12101 et seq. Retrieved from:

http://www.eeoc.gov/policy.


http://www.heath.gwu.edu/files/active/0/college_freshen_w_disabilities.pdf


Seidman, I.E. (1991). *Interviewing as qualitative research: A guide for researchers in*


APPENDICES
Appendix A

Institutional Review Board Approval Letter

From: Deb Paxton, IRB Administrator
North Carolina State University
Institutional Review Board

Date: July 13, 2013

Title: Understanding How Irritable Bowel Disease Affects Full-Time Employees at a Community College in North Carolina

IRB#: 3371

Dear Erin,

The project listed above has been reviewed by the NC State Institutional Review Board for the Use of Human Subjects in Research, and is approved for one year. This protocol will expire on July 15, 2014 and will need continuing review before that date.

NOTE:

1. You must use the attached consent forms which have the approval and expiration dates of your study.

2. This board complies with requirements found in Title 45 part 46 of The Code of Federal Regulations. For NCSU the Assurance Number is: FWA00003429.

3. Any changes to the protocol and supporting documents must be submitted and approved by the IRB prior to implementation.

4. If any unanticipated problems occur, they must be reported to the IRB office within 5 business days by completing and submitting the unanticipated problem form on the IRB website.

5. Your approval for this study lasts for one year from the review date. If your study extends beyond that time, including data analysis, you must obtain continuing review from the IRB.

Sincerely,

Deb Paxton
NC State IRB
APPENDIX B

Informed Consent Document

North Carolina State University
INFORMED CONSENT FORM for RESEARCH

Consent form is valid from July 15, 2013 through July 15, 2014

Title: Understanding How Irritable Bowel Disease Affects Full-Time Employees at a Community College in North Carolina

Principal Investigator: Erin Trado LeGrand
Faculty Sponsor: Dr. James Bartlett

What are some general things you should know about research studies?
You are being asked to take part in a research study. Your participation in this study is voluntary. You have the right to be a part of this study, to choose not to participate or to stop participating at any time without penalty. The purpose of research studies is to gain a better understanding of a certain topic or issue. You are not guaranteed any personal benefits from being in a study. Research studies also may pose risks to those that participate. In this consent form you will find specific details about the research in which you are being asked to participate. If you do not understand something in this form it is your right to ask the researcher for clarification or more information. A copy of this consent form will be provided to you. If at any time you have questions about your participation, do not hesitate to contact the researcher(s) named above.

What is the purpose of this study?
The purpose of this study is to explore how employees’, with a particular chronic illness, careers are impacted by health-related issues. Ultimately the researcher would like to determine the essence of what it is to be an employee with a specific chronic illness at a community college in Western North Carolina. This research will explore the following: how perceptions applied to employees’ careers with a chronic illness are impacted by health-related issues, what life is like as an employee with a chronic illness at this community college, the positive impacts of additional support for employees with a chronic illness, ways to increase coworkers awareness, and ways to help chronically ill employees to realize that they are not alone.

What will happen if you take part in the study?
If you agree to participate in this study, you will be asked to provide the researcher with a written account of an example of what it is like to be an employee with a chronic illness at
this community college. This portion of the study should take you 30 minutes to one hour to complete. In addition, you will be asked to participate in an in depth, audio recorded individual interview. Structured interview questions will be used to collect demographic data. Open-ended questions will be asked to allow you to reconstruct your own experience. The interview will take approximately 1-2 hours to complete. The interview will take place at a private location that you select and is mutually agreed upon by the participant and the researcher. The total time amount of your time that is expected for you to complete this study is 1½ hours to 3 hours.

**Risks**
The potential risks for subjects participating in this research study are emotional distress brought on by talking about his/her chronic illness and/or his/her experiences as an employee with Irritable Bowel Disease. Most of the interview questions are open-ended, so the participant will be able to avoid topics that are too difficult to discuss. A participant is allowed to refuse to answer any of the questions and allowed to withdrawal from the study at any point, without penalty.

There is also a risk to confidentiality if audio recordings are lost, someone could identify the participant’s voice and will have knowledge of the answers that are given to the interview questions which are of a personal nature. If someone were to gain access to the audio recordings of the interviews and is able to identify the individual through voice recognition, then that person would become aware that the individual is diagnosed with a particular chronic illness and would have access to how the chronic illness impacts the participant’s work environment. The audio recordings will be kept in a password protected file within a password protected account on the researcher’s personal computer. The recordings will be labeled by the subject identification number, so no identifying information will be recorded besides the sound of the participant’s voice and the information they choose to share. When not in use, all study related documents will be locked in a file cabinet to which only the researcher will have a key. Participant stories may be recognized in reports about the research, even though identities will be protected.

**Benefits**
The participants will realize that they are not alone in managing a chronic illness and employment. In addition, potential indirect benefits are an increase in awareness of chronically ill employees in the workplace, an increase in accommodations made for critically ill employees in the workplace, a decrease in marginalization experienced by chronically ill employees in the workplace.

**Confidentiality**
The information in the study records will be kept confidential to the full extent allowed by law. Data will be stored securely in a password protected file within a password protected account on the researcher’s personal computer. No other individuals will have access to the personal account or file. The
recordings will be labeled by the subject identification number, so no identifying information will be recorded besides the sound of the participant’s voice. When not in use, all study related documents will be locked in a drawer to which only the researcher will have a key. All study related data, including: participant’s written accounts, transcripts, field notes, audio recordings, researcher’s notes, etc. (except those that are part of the final copy of the researcher’s dissertation) will be destroyed 3 years after the final submission of the researcher’s dissertation. No reference will be made in oral or written reports which could link you to the study.

Compensation
You will not receive anything for participating.

What if you are an employee of this college?
Participation in this study is not a requirement of your employment, and your participation or lack thereof, will not affect your job.

What if you feel that you need to discuss your feelings with a professional counselor?
If you feel that you need to discuss your feelings with a professional counselor, The Counseling Group, Inc. is available to offer individual/personalized counseling sessions. To schedule an appointment, please call <TELEPHONE NUMBER>. The Hickory office is located at <ADDRESS>.

What if you have questions about this study?
If you have questions at any time about the study or the procedures, you may contact the researcher, Erin T. LeGrand, at <ADDRESS>, or <TELEPHONE NUMBER>.

What if you have questions about your rights as a research participant?
If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Deb Paxton, Regulatory Compliance Administrator, Box 7514, NCSU Campus (919/515-4514).

Consent To Participate
“I have read and understand the above information. I have received a copy of this form. I agree to participate in this study with the understanding that I may choose not to participate or to stop participating at any time without penalty or loss of benefits to which I am otherwise entitled.”

Subject's signature__________________________ Date __________________

Investigator's signature__________________________ Date __________________
APPENDIX C

Recruitment E-mail sent to Proposed Participants

Dear XXXX,

Hope you are all well. As you are aware, I am a doctoral candidate in Adult and Community College Education at NC State University. I am working on my dissertation for which I am trying to determine the essence of being an employee with a particular chronic illness at a western North Carolina Community College. I am working closely with my dissertation chair, Dr. James Bartlett, for guidance on this study.

You have been chosen to participate in this study because of your diagnosis with a chronic disease and your employment status with a North Carolina Community College. I would appreciate it if you would be willing to participate in an in-depth interview that will last approximately one to two hours. With your permission, the interview will be audio recorded. During the course of the interview, you will be asked to discuss your diagnosis, to indicate your feelings as a chronically ill employee at this community college, your perceptions of how your co-workers view you, how content you are with your work environment, to discuss your treatment as an employee with a chronic illness at this community college, etc.

If you choose to participate in this study, please complete the following Doodle link to schedule an interview.

Doodle link

Once we have settled on a mutually agreeable date and time for the interview, I will contact your via email to determine a meeting location.

In addition to the scheduled in-depth interview, I ask that you prepare a written account of an example of what it is like to be an employee with IBD at this community college. Please bring a printed copy (for the researcher) of this account to with you to the interview. This portion of the study should take approximately 30 minutes to one hour to complete. The total duration of time that you will spend as part of this study will be 1½ hours to 3 hours.

Please see the attached copy of the Informed Consent form.

I truly appreciate your help in advance!

Thank you,
Erin LeGrand
APPENDIX D

Interview Questionnaire

1. Participant Number
   ____________________________________________________________

2. Date/Time of interview
   ____________________________________________________________

3. Start time
   ____________________________________________________________

4. End time
   ____________________________________________________________

5. Gender
   ____________________________________________________________

6. IBD Diagnosis (Crohn’s Disease or Ulcerative Colitis)
   ____________________________________________________________

7. Number of years Diagnosed with IBD
   ____________________________________________________________

8. Number of flare-ups in the past year
   ____________________________________________________________

9. Number of days missed due to IBD in the past year
   ____________________________________________________________

10. Number of Hospitalizations in the past year
    ____________________________________________________________
11. Faculty or Staff

12. Tell me about your diagnosis.

13. What are some of the obstacles to everyday life?

14. What are some of the obstacles to work life?

15. What is an average day like on your job?
   a. Prompts: What are your duties? Do you sit most of the day? Do you have scheduled breaks or a more flexible schedule?

16. How would you describe yourself as an employee?
   a. Prompts: Are you reliable? Are you punctual? Do you get along well with others? Are you effective at accomplishing tasks? Are you efficient at accomplishing tasks?

17. Please describe for me what it was like to be an employee with IBD at this community college?
   a. Prompts: Do you feel like you are treated fairly by your supervisors, peers, subordinates, students? Is there empathy in the workplace between you and your supervisor? Do you think that there should be empathy? Do you enjoy your job? DO you think that it is important to enjoy your job?

18. Do you think that this community college has the appropriate policies in place for employees dealing with chronic illnesses? Why or why not?

19. If you could change one thing about being an employee at this community college with IBD, what would it be?
20. Do you have anything to add to this interview about your experiences as an employee with IBD at this community college?

21. Do you have anything that you wish to add to or clarify for your written account?
R: Tell me about your diagnosis.

P: I have always been real careful about making sure that everything works like it should, but I started having some issues going on and it was like… I’m trying to remember back what it was. I had constant diarrhea and there was blood involved. And then, after a period of time, I finally was convinced that I needed to go to the doctor, because anything that I was trying to do wasn’t helping. And the blood started becoming more and I could see infection looking stuff, and I was like, mmm, it’s probably time for me to go. So, I did go to the doctor and they gave me at that particular point in time, they gave me an antibiotic because they weren’t really sure what exactly was going on. That did help some, but it didn’t clear it up like it should. So, I was scheduled to go back for a recheck and they decided to go ahead and do a colonoscopy. And um, that is when they found it. And the doctor said, well, now that we know what it is, we know how to treat it. So, they began giving me steroids for a while to get me cleared away. And um, I was not hospitalized, but I was told to stay at home until I… but I actually went through a time where I actually lost hair because my nutrition, my food was not staying in my body long enough for me to get the nutrition.

R: How long did you go with undiagnosed symptoms prior to diagnosis?

P: Probably 3-4 years. I was really trying not to pay it a lot of attention. Because, I am one of those people that if I can take an Imodium to handle it, then I will. But, I have learned that that is not the best way to handle it.
R: What type of medication are you on now?

P: I am taking sulfasalazine and I also have some problems with reflux so I am also taking Nexium. I also have the possibility for Barrett’s disease, but I have not been diagnosed yet.

R: What are some of the obstacles to everyday life?

P: Always having to know where the bathroom is. (laughs). To make sure I feel secure and know that it is one that you can go into and it is relatively clean. Fortunately, at my workplace, we do have seat covers, and that does help tremendously. That and in addition to that, you know if on the weekend you want to go out to eat with your family and then go to the movies afterword, that does not work if you are having a flare. You have to go to the movies first and then go out to eat and then go straight home, because you are pretty soon going to have an episode in the bathroom.

R: Right, go eat somewhere close. What are some of the obstacles to work life?

P: Well, for the most part. Um, you know, just being near a bathroom. Where my office is located, I am in between two, and one is a little more private than the other. So, I tend to use the more private one for the most part. But there have been occasions where I didn’t think that I could make that walk fast enough, so I would use the other one. And, um, fortunately I have a boss who is very understanding and knows about my condition. And I can say to her, “I’m going to be gone for a little bit” and she understands what that means.

R: Are there obstacles to dealing with coworkers?
P: Well, sometimes we like to go out to eat for lunch and on those occasions, if I am having a flare, or a particularly bad... well I can’t always say that it is just when I am having a flare… she will always ask, the person that I generally go to lunch with, she will always say: is your stomach up for blah, blah, blah? And, we like Mexican food, we love Mexican food and there are days where I have to say that it might not be a good day for me to go do that or I might just be able to go get a cheese quesadilla and it will be ok.

R: What is an average day like on your job?

P: A normal day?

R: Yes.

P: Generally, I come in and usually check my email, take care of anything like that. And then my particular job is working with people that come in and I talk with them about new fast track training for them. For the most part, I am talking to people with all backgrounds. It could be somebody looking for a Six Sigma class or somebody looking for a certified production class. I’m talking to people from a variety of backgrounds. For the most part, most of them will have an appointment with me, so I pretty much know a day ahead of time what people I will be working with. And I can review there information and have a clue what I am going to be working with that day and I will try to get somewhat prepared prior to their appointment. Occasionally, I will have somebody come in that is just a walk in, somebody that I am not expecting, and I have been able to work with them ok. Umm, and I am trying to think you know during that time that I have an episode where I have had to excuse myself. And, I think that I have had that happened a couple of times. And, each time that I did. I said, “You’re going to have to excuse me for
just a couple of minutes. I’ll be right back.” Generally, I have some type of paperwork that they need to fill out anyway and I give them the paperwork to work on while I am gone.

R: And the meetings are typically one-on-one?

P: Yes.

P: And I will also notify Jane, across the hall from me and let her know that there is somebody in my office working on some paperwork and I will be right back. And, she always knows what I am talking about.

R: Do you have scheduled breaks or more flexible?

P: More flexible. And that is by choice. I mean, they allow us to take a break, I just don’t.

R: How would you describe yourself as an employee?

P: Um, Conscientious, dedicated, loyal, hard driven. I’m harder on myself than other people.

Don’t they call that Type 1 personality or something?

R: So, definitely punctual?

P: Yes.

R: Does your diagnosis ever get in the way of your punctuality or do you ever feel like you are not measuring up?

P: Now, on occasion, I have had a delay of getting here at 8:00, but most of the time when that happens, I text Jane to let her know that I’m running late. Now, like I said, she is very aware of my disease, so she knows what that means when I say that I’m running late, because for the most part I am always here by 8:00. In a different environment I might not be getting that kind of patience, but here I do.
R: Do you feel like your disease is ever a burden at work in accomplishing tasks that you need to get done?

P: Not really, um, I’m trying to think… Well, most recently, that episode that I had most recently, that was kind of hard because I was also taking Prednisone to deal with it and thank God for patient coworkers, that is all I can say. Because, I think personality wise I was very careful to try to control my point to a point where I didn’t let myself get crazy, crazy. Probably, um, that could have interfered, but it didn’t.

R: Please describe for me what it was like to be an employee with IBD at this community college?

P: At this community college, um, I have been here for almost 12 years and during my entire time of employment I cannot think of any time that things…. Things went well for the most part. I had to educate my coworkers. When I originally began here I had more coworkers and I had about 5, and at that particular point in time they did not understand what Irritable Bowel or Ulcerative Colitis was about, so, I took it upon myself to explain it to them and I also sent them some web links so they could get additional information if they needed it. And, once they understood what it was about. It was a situation of oh, we understand what is going on. It’s kind of like, I guess, it um, I guess you could compare it to when we have our periods and we get real weird and crazy; if it’s another woman, they understand. Well, in this case, if people know what is going on then they tend to understand. If they don’t know what is going on, if you try to keep it on the down low then I think that is when you are going to run into problems. Because people look at you like what is wrong with her. You know, like: she is going to the bathroom all the time.
R: Do you think, were your coworkers initially pretty receptive to being educated?

P: Yes, yes, very much so. Because I was also going through the hair loss at that point in time, so they were seeing visible signs that something was wrong.

R: Do you enjoy your job?

P: I do, very much. I’m getting ready to lose it.

R: From what you have been saying, I’m hearing that there is a lot of empathy from your supervisor.

P: Absolutely, yes.

R: And would you say from your coworkers as well at least the ones that have been educated?

P: Yes, I would. Another thing about coworkers, I think that once people kind of know what is going on. I have realized that there are other people who are dealing with Crohn’s and Ulcerative Colitis, and Irritable Bowel, and other things. Once I learned that, I think that made me feel, and I don’t wish disease on anybody. But, I think it made me feel like I was not a fish out of water. There were other people in the same boat so they have an even better understanding of what you’re going through which makes it a little easier to deal with. Because if you see somebody that you know and if you have it you can look at somebody and just know whether they are having a bad day or not. I can see one male coworker in the hallway and tell almost immediately that he is not doing well. And, I look at him and go “uh-oh” and he goes “yeah, I know, it’s terrible isn’t it?” and I will go “Yeah” and we will have a little bit of a conversation and some encouraging talk. But, they moved him now, so he is in another building.
R: Have you officially, is there an official process to tell the school HR or whoever?

P: If there is an official process to tell that, to do that, I don’t know about it. And, I have not ever discussed it with them. I don’t think that they have asked and I don’t offer that information to them. But, there is another medication that I take when I have a little bit of a flare that I forgot to mention to you, Hyoscyamine ER. Now, what this one does, and he told me is that I can use it anytime I felt the need to. What that one does is it kind of slows things down, so anytime I eat a meal if you feel like you need to, if you feel like you are really going to have to rush to the bathroom. You can take that medication and after that first time you won’t have to be going back several times.

R: Oh, cool!

P: So, its pretty good. And as I said, I just got that with this most recent episode.

R: Does it cause constipation?

P: No, it just slows that process down between your stomach and the lower part of the intestines because that is where my Ulcerative Colitis resides.

R: Has your UC spread over the years?

P: They haven’t told me that it has. It may have and I just don’t know it. But, I do have a colonoscopy about once every other year.

R: And your work is pretty receptive to letting you off for those treatments?

P: Right, I have sick time, so I use my sick time if I have to be off for those kinds of procedures.

R: Do you think that this community college has the appropriate policies are in place for employees dealing with chronic illnesses? Why or why not?
P: I don’t really know what their policy is if there is a specific one. But, I have always been able to use sick time when I needed it without feeling that I was going to be punished for doing so.

R: *Were the three days that you took off, were they in a row, for this most recent flare?*

P: For this most recent flare, they were not in a row. Well, I take that back. There were two days in a row and then the single day was maybe the 7-8 day of the flare or somewhere around there. When you think you feel better and then all of a sudden you don’t.

R: *If you could change one thing about being an employee at this community college with IBD, what would it be?*

P: One thing?

R: *Or, it could be more than one thing.*

P: Well, let’s see. You know, I don’t know… I think it might be a good thing if we had a periodic email or a webpage we could go to about chronic illnesses and that would include things like high blood pressure, just a whole variety of things. I think that it would be good to have that information so that if we ever do have to talk to coworkers or supervisors they can go there.

R: *Would you possibly suggest linking policies, if there are any that would relate to that disease?*

P: Yes, yes. I think that would be great.

R: *Do you have anything to add to this interview about your experiences as an employee with IBD at this community college?*

P: I don’t think so. I think that we have pretty much covered everything.
R: Do you have anything that you wish to add to or clarify for your written account?

P: No.

*** After thought, participant asked to record this section as well.***

P: Erin, I wanted to add something that I forgot to tell you in the earlier talking points. That one thing is that my employment has been based on grants ever since I have been at this college, which is almost 12 years. Most recently we found out that the grant that is supporting me right now is going to be cut in less than half of the amount of money which means that it will only support one position. Well, that means that I am going to be unemployed. And um, because of that, I started worrying about it and got it on my mind and started thinking about the fact that I am an older person and will I be able to find employment and will I be able to make this work to move on and that kind of thing. When I finally realized that I had made myself sick and ended up with this UC flare and had the Prednisone to get me through it. I set down and I did some real soul searching and finally realized that I needed hand my problem over to God to get a handle on it and get it off my plate so that I could feel better. And, I did that and I think from this point forward I am going to, um, do my dead level best to make it a point to when something concerns me to that point to try not to worry about it because I know that was my trigger for this flare. I know that.
APPENDIX F

Participant 020: Interview Transcript

R: Tell me about your diagnosis.

P: My diagnosis, which part?

R: All.

P: Oh my gosh, we need to schedule a day to cover that. Started in 1986, I was in Texas, nearly bled to death, got a transfusion. Came back here and got a transfusion here. They didn’t find it right away. Finally a doctor in Morganton did a scope and he came back to talk to me and told me that I have Crohn’s and I started cheering. And um, that is where the whole thing started. Since then I have been in the hospital, I’m guessing, maybe 10 times for blockages, for bleeding. It used to be every two years that I would have a flare.

R: When did it slow down?

P: Let’s see, probably about 2002 or 2003, where I wasn’t going every two years.

R: What are some of the obstacles to everyday life?

P: Making sure that a bathroom is within a mile of you.

R: Or closer.

P: That’s a good concern down here in this place. There is only one men’s restroom and when it fills up with classes I’m going to be running to another building, because you know, you can’t wait.

R: So, there aren’t any faculty/staff bathrooms?

P: None. You have one bathroom in the back that is it. That is a concern. Because right now we have, today we are going to have 50 people come in here in just a little while from all
over the western part of NC. I’m going to be in the meeting, but if something happens,
I’m going to be in the car, going to be out of here really quick.

R: How often do you have that many classes?
P: Right now, we don’t. It has just started. The intent is to fill this place up.

R: Daily?
P: Yes. That is very concerning.

R: I’m assuming the bathrooms meet requirements.
P: Yes. I asked myself early on. Because I figured if it was for a restaurant that it would
meet requirements. But, they did take one out. The one in the middle one was a family
bathroom that they turned into a janitor’s closet.

R: That more focused on work life, any other obstacles to home life or out and about
life?
P: Out and about, it is still a concern. It doesn’t happen as much as it used to… when you go
out to eat and 30, 10, 15 minutes later it is like “Oh My God!” Fortunately I haven’t had
as bad a problem with that as I used to. It is not as problematic. Used to, it was
automatic. It used to be as soon as I got through [eating] I had to run. Outside, that is my
biggest problem. And going to sporting events is always worrisome. And I go to A LOT.
It is always “Is it going to hit you?” “When is it going to hit you?” “Please don’t hit me.”
It’s kind of waiting, anticipating.

R: What is an average day like on your job?
P: Average day, in terms of the…?

R: Sitting, standing, travel?
P: I do a lot of sitting. I go on spurts where I do traveling to other sites, industrial sites and businesses. Mostly, and unfortunately sitting.

R: I am going to add as an obstacle to work life printer as well.

P: That one I am really worried about because of what is going on with my legs.

R: So, when you go to off-site work environments, are there typically readily available bathrooms?

P: Not always, but most of the time. Most is a good operative word. Most of the time. It’s the travel in between that if it hits me, it can be a concern, which it has, I’ve been going to a site and been like uh-oh I have to stop somewhere.

R: Do you have scheduled breaks or a more flexible schedule?

P: Not really. I, well, I flex. I stay all their hours and then later or earlier. So, yeah, I guess I do. To a point, I’m not saying I have a flexible schedule, ‘cause I don’t. I still have to be here 8:00 - 5:00.

R: Right. But you don’t have to take a break at 10 o’clock?

P: No, no.

R: How would you describe yourself as an employee?

P: Uh, dedicated. I give it 110, but whatever 110 is with me because it’s not 110 anymore.

But I attempt to give it 110. I attempt to do that. I am conscientious about my job. I don’t feel like I am doing nearly as well as I used to.

R: I would definitely say that you are reliable and very punctual.

P: I try to be.

R: So, you feel like you are not accomplishing as much as you used to because of…
P: Yes, I do feel that, because of the problems I’m having.

**R: How long has that been going on?...these 9 months?**

P: Yeah, it actually started in December so I guess it is 10 months now. Yes, a very definite, 

Yes. It got worse and it has gotten a little better, moving offices.

**R: That’s right after I left you just need to be near my office again.**

P: That’s what did it. I know it. I got so upset that we were apart.

**R: Do you feel like you are less efficient or, do you still get everything done, but it is just taking longer or more steps?**

P: Yeah, I’m getting it done, but I am struggling to get it done. That’s the best way to put it.

**R: Please describe for me what it was like to be an employee with IBD at this community college?**

P: There are moments that uh, I think there is a lack of understanding and some people don’t know what you’ve got, but you don’t get the respect you should. Even in your own group. I just don’t feel like they fully understand how bad this junk is. So, yes… There are times I feel like I don’t get the support that I would like to have, but that’s life.

**R: Can you give an example of that?**

P: There are some examples that I would like to give, but I better not. Uh, Just the fact that they will push… they know that I am having a bad, bad round of something or that I am really sick, but you’re going to have to get this done, this done, and this done. And they know I’m in bad shape. But, it comes, what’s more important? To get the business or my health, and obviously it is to get the business. That’s the best way to put it. A little indirect. I’m beating around the bush.
R: Is that all the time?

P: Not all the time, not all the time, some of the time.

R: Do you think there is any empathy?

P: Yeah, a little, yeah, a little. I hear it, but I don’t feel it, you know what I mean?

R: Is that mainly from coworkers?

P: My boss.

R: That’s good, at least.

P: Yeah, and my coworkers, do too.

R: Is where you hear it?

P: Yeah, I mean, yeah. Not from all, but there are a couple of them that I think genuinely care.

R: Do you enjoy your job?

P: You, you’re going to get me fired.

R: I’m not. Nobody is going to know it’s you.

P: They have turned this job into a sales type job and I am NOT and do NOT enjoy and do not like to be a salesman.

R: Got yah.

P: Does that answer your question?

R: Got it.

P: Other than that, I enjoy going into industries and businesses and this and that, but not as a used car salesman.
R: Do you think that this community college has the appropriate policies are in place for employees dealing with chronic illnesses? Why or why not?

P: I don’t know of any policies, so I guess the answer would be no, unless there are any policies that I am not aware of.

R: Do you think there should be policies?

P: Um, yeah, some type of policy. I don’t know how you would handle it. I think there should be something. I’m not looking for sympathy. I’m not looking for shoulders to cry on, but a little understanding of what I am going through and why I do have to leave meetings, why I have to do this, why I have to do that, something to address that. Not a pity party.

R: Right, most policies usually are not.

P: Right.

R: If you could change one thing about being an employee at this community college with IBD, what would it be?

P: Private bathrooms.

R: Wouldn’t that be wonderful?

P: I know that is a stupid one, but it would be good. I don’t know. Although, a bathroom would be good. I don’t know. I don’t really know. I mean, they’re not doing anything drastically bad to me. With the exception of bathroom limitations. That is my biggest issue.

R: So, you have worked outside of this college.

P: Yes.

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R: So, is it a drastically different working environment here than it is that you have experienced outside?

P: Yeah, oh yeah.

R: In relation to dealing with Crohn’s.

P: Yeah.

R: Really?

P: Yeah, it is. In the outside environment, in industry, uh, if you have Crohn’s, great, I need you to go to Honduras today. I need that done by tomorrow. The pressure, believe it or not is a whole lot worse than this. In terms of getting things done. On one hand. On the other hand, the way it was in outside industry, or for me anyway, with a salary position. It was, I could be out for up to six months and get paid, no questions asked. Those policies have changed since I left, but um, I could say I need to be out for six months and they would say go ahead, do you what you need to do. And when you got back, you would be covered up, but still. So, I mean, I was out one time two months, two straight months.

R: And you got paid.

P: Oh yeah, I got paid straight through, 100%.

R: Even though you didn’t have sick leave to cover the entire thing?

P: They didn’t give you sick leave. If you were salaried. It used to be that you could be out six months a year. Like I said, that rule has changed, since I worked there. Like I said I used it for two months.

R: Right.
P: We didn’t have sick leave. There was no such thing. They do now, the way they have structured it. But, we didn’t. It was just, go out, take care of yourself. So, to me it was a lot better in that respect.

R: Right.

P: I didn’t have to worry about income or anything else.

R: While you were there?

P: While I was there, it was different, yeah. Unless something happened. Yeah. There was a lot of pressure. Long hours, 70-80 hours per week and a lot of pressure. But I liked it.

R: Where would you prefer to work?

P: You’re going to get me fired.

R: I’m not.

P: Industry.

R: Do you have anything to add to this interview about your experiences as an employee with IBD at this community college?

P: No, overall, I can’t say that I have been mistreated or anything. It is just that I have to deal with it. There are occasions where things are said to me that I wish were not. I wish I could share with you. One about three months ago.

R: But, it’s not usually from your boss?

P: No comment.

R: Do you have any support network here?

P: Not really, if I did I wouldn’t know… I don’t look for support. I feel like I am on an island by myself. I just kind of do.
R: Do you have anything that you wish to add to or clarify for your written account?

P: I would like to, but I can’t. Not really.
R: Tell me about your diagnosis.

P: Ok, um. I got diagnosed in 2002, following an episode of having a recurrent bladder infection. I got sick in February of that year, and went to the doctor, was diagnosed with a bladder infection, got put on antibiotics, went through a round of antibiotics. And then, I got sick again. So, I got diagnosed with H. Pylori and so they put me on a round of antibiotics for that, and I got better, that was in about May or June. Then I got sick again in September and it was a bladder infection supposedly, and they gave me a round of antibiotics and I didn’t get better, and they gave me a shot of Rocephin and I didn’t get better, and they gave me another shot of Rocephin and I didn’t get better, and so I um was having a lot of abdominal pain, a lot of lower abdominal pain and so they sent me to a specialist. To a surgeon to see if it was appendicitis and it turned out to be Crohn’s. So, I got the diagnosis of Crohn’s in October and then I was referred to a Gastroenterologist. And um, he put me on a bunch of anti-inflammatory meds and some steroids and told me if I spiked a fever let him know, and I did. So, that’s when I had to go have exploratory surgery. He was going to remove my ileocecal junction they ended up taking 14 inches of small bowel.

R: Thinking it was exploratory surgery?

P: Well, they sent me to a surgeon thinking it would be exploratory surgery, but he wanted to remove the ileocecal junction after he did the um, barium enema and all that, he saw fistulas in there and so he wanted to take that section, but when he got in there he took
way more than that. So, that was on December 4th I had that surgery, December 4th of 2002.

R: So do you know if your subtype is fistulizing Crohn’s Disease?

P: I tell you what, when I moved to Hickory, this is the first time that I have lived anywhere for over 4 years, in my life. Because, I was raised as a GI brat, then I went to college, my dad retired when I was a senior in high school, and then I went to college, and then I moved to Texas, and then I moved to Florida, and then I moved back to Texas, and then I moved to California, and then I moved here. So, I had never lived anywhere long enough, to have a doctor long enough to have a chronic illness diagnosed. So, I have probably had this, Crohn’s, all this time that it has been called irritable bowel, since I was in my late 20s. Or maybe even in my teens. Because when I was in my teens I had a break out of some kind in my mouth. That was a bunch of sores and my lip swelled inside out, and I couldn’t eat and I lost 25 pounds over two months and they didn’t know what was wrong with me. And I was taking all kinds of drugs and Nystatin swishing around in my mouth, and all this stuff. And now, in retrospect, looking back, that might have been the start of something, but who knows. Because I never, like I said, I was never under the same physician’s care long enough to be diagnosed with anything. So, I’ve had really problems, off and on, off and on, off and on, all my life. But, I’ve never had anything like that when I got really sick. I was sick. I was dying, I mean, I thought I was dying I was hurting so bad. It was bad. So, I haven’t had anything like that ever since. Even when I had this flare up when I had to go to the ER, it was just that I couldn’t keep anything down. I was vomiting, and diarrhea, and vomiting and diarrhea all at the same time, and I was getting
dehydrated. So, I knew that if I could just hang on long enough that I would be alright, but I couldn’t. So, I had to go get some IV fluid and they gave me Dilaudid, which was wonderful. And, I was like, “Oh, Thank you Lord.” And I was fine after that. So, that’s the only time that I had to go to the ER, because I was dehydrated.

R: So, you didn’t have any major stenosis at that point?

P: They did all kinds of x-rays, abdominal x-rays and all that kind of stuff and everything looked fine. I haven’t had any problem at all since my surgery.

R: Really?

P: None. I switched to eating a better diet; only organic meat, no pork, very little processed foods, a lot of fruits and vegetables and I take a lot of supplements. I also got diagnosed with depression and so I started taking medication for depression and anxiety and I think all that combined has just calmed me down enough that every bit of my nerves aren’t going to my gut. And, I’m just taking better care of myself. So, I haven’t had any more problems. So, I call myself the cure of the knife. You know, maybe the surgery got all the bad parts and nothing has come back.

R: Right…

P: That’s what I’m thinking.

R: Have you had?....

P: I had a colposcopy when I turned 50, and that was 7 years ago and they didn’t find a polyp, nothing. My gut was completely clean. They went through there, went all the way up to my anastomosis and everything was perfect. So, I haven’t had another one because it was good.
R: Were they able to get past your anastomosis?

P: He didn’t go that far, he went up to it and everything was fine. So, I need to go back after 10 year, I guess, when I’m 60. But, then there’s a debate on if you even need to go when you’re 60 if you didn’t have any polyps or stuff like that when you did your one when you were 50 years old. So, I don’t know if I’ll do it or not because the prep for that liked to kill me. Just cleaning out my gut like that, really seriously, it’s painful. And, totally unnecessary if there’s nothing wrong. That’s my opinion. So, I don’t know, when I’m 60 I’ll think about it, going to get another one but that will probably be the only one. So, unless I have another problem. And, I will never have another Barium enema as long as I live. I was so sick when they did that and I was hurting already. You know, because it was prior to my surgery and it was so bad. I really think that that’s…. I won’t ever do that again, and I’ll just tell them, “No!” And thank God, the girl who was doing my x-ray was so good. She stayed right in there with me and switched the films out while somebody else took them so that she didn’t have to go back and forth. So, it was really quick, but still… I think that was bad, I was just sweating… whew, anyway.

R: What are some of the obstacles to everyday life?

P: I just have to make sure that I’m close to a bathroom… after I eat, particularly after I eat. That’s really the only big one. Then I have to be careful about if I eat out. I have to make up my mind that it’s ok to be sick for that day. If I decide that I want to have a hotdog or I want to have pizza, certain things that I shouldn’t eat that I just love to eat. So, if we have like a pot luck something like that, I have to be really careful about that. Making myself be really picky about what I eat.
**R: Do you have any major trigger foods?**

P: Just hotdogs, bad. Popcorn. That popcorn is what caused that deal. I went to the movies the night before that and saw that Eat, Live, Pray thing. And I ate a thing of popcorn because I hadn’t eaten dinner, so I was hungry. Oh my God. And, I didn’t realize that popcorn will do that. I can eat a little bit of popcorn, but I can’t eat a big tub of popcorn.

**R: And, I do better if I eat a meal before I eat popcorn.**

P: Yeah, if I’ve had something else, but I hadn’t had anything. The only other thing that I’ve had trouble with, and it was the same thing… I ate a bunch of pistachios on an empty stomach, not realizing that they would do me that way and they just about killed me. But I was ok. I mean, I made it through that. I went and laid on the couch and sweated, and hew, hew, and drank Sprite. So yeah, nuts and popcorn, things like that, seedy little food.

**R: What are some of the obstacles to work life?**

P: Just stress, I mean really, you know. Anytime I get upset it goes to my gut. And, because of everything that has happened around here. It’s just stressful to even come in. I hate that because I used to love my job. And, I still love my job. When I can be in the classroom and be just with students and be… but with all the other stuff surrounding that…

**R: What is an average day like on your job?**

P: I come in and turn on my computer, check my email, and get my books ready to go to class and go to class, all within the first hour of getting here. I get here and I’m in class within an hour. And, then I teach um, some days I have a lunch break, some days I don’t. Then I get done between 1 and 2 o’clock each day and then I go in my office and prepare
for the next day, do any administrative stuff I need to do, go to any meetings I need to go to, anything like that. It’s a lot. A lot to do. Here lately, there’s a lot more than normal.

R: *So, do you primarily have scheduled breaks when you are in the classroom?*

P: Yes. But you know what, I am fortunate now, because I have a bathroom right around the corner. So, I can just tell my students, “Sorry, I have to go the restroom, I’ll be right back.” So, it’s not a problem anymore. It used to be a problem that I would have to actually have to have a break and time to go all the way down the hall and around the corner and to the restroom and stuff. But, I’m really luck now.

R: *How long have you been close to the restroom?*

P: Since I moved up there in 2010. And it’s a private bathroom too, which is nice.

R: *And you’re able to just leave the classroom?*

P: Yeah.

R: *Have you ever had problems in meetings?*

P: I try to always make sure that I go before I get there, that kind of stuff. But, I wouldn’t hesitate to just get up and leave either.

R: *And you wouldn’t think that would cause any problems?*

P: No. I haven’t had any problems as far as that goes around here. If I have something I just get up and go and come back. If somebody says something, “what was the matter?” I just tell them that I have Crohn’s and they say “Ok, no problem.” So, I’ve had to just tell people flat out, my bowels just can’t wait for you, sorry.

R: *Have you officially told HR?*
P: No. I thought about when all this stuff was going on with my job, that I should tell them but I didn’t. Because I didn’t know… I don’t know about that. It could be good, it could be bad… I just don’t know.

**R: Have you ever run up against any type of discrimination?**

P: No, but I want to avoid that so much.

**R: So you think it could be.**

P: I don’t know, is that a protected class?

**R: Yes.**

P: Because my mother told me that “You need to tell them, that they need to back off, that you have Crohn’s.” I don’t think that will help, Mom. So, I don’t know. No, I haven’t ever told officially. I think Jane knew I had it because she was just working here when I took off to go have my surgery. I had disability, so I could get some… You know, I had Aflac. So, I filed for that. You know, they only gave me $800 for having a bowel resection. Terds. It wasn’t worth $800, I can tell you that.

**R: Do you perceive that there could be some…?**

P: I think there could be, yeah. But, then I’m paranoid, but not without reason.

**R: How would you describe yourself as an employee?**

P: Loyal, I’ve stayed here a long time. I think they would describe me as a problem. I’m not a problem, but I think they would describe me as such.

**R: Everyone, or just direct supervisors?**

P: Just certain people. I really like what I do. I really like watching students learn and seeing them get it, that kind of thing. What kind of employee am I? Reliable, dependable,
creative… if I can’t figure out one way to do it, I’ll figure out another way. You know that kind of thing.

R: Do you feel that you are effective at accomplishing tasks?

P: Yes. I’m a get it done kind of person.

R: And efficient?

P: Yes.

R: Do you feel that Crohn’s ever gets in the way of your efficiency or effectiveness?

P: No, I don’t think so.

R: Please describe for me what it was like to be an employee with IBD at this community college?

P: What do I think it’s like to have IBD here? I don’t want anybody to know, how about that? **R: How many people would you say do know?**

P: The people in my division who were here when I had my surgery know. Just because after my surgery I was crazy and I was showing everybody my huge scar and what they did to me. I don’t know why… Why do people do that if they have a big surgery, they show everybody their scar. So, some people know, but I don’t like announce it. And like Sarah knew, because she shared an office with me. So, since I have this flatulation problem, I thought it best for her to know. I told her there might be some of that going on occasionally, so she knew I had it because we shared an office for a while. But, a lot of people that knew are gone. My direct bosses, Gial knows.

R: So, your direct supervisor does know?

P: Yes.
R: But, your students don’t?

P: My second year does now, yeah they know now. Because I said something in class about when I had my bowel resection. They were like… you had a bowel resection? And I said, yeah, I have Crohn’s disease. So, they do know. The second years know.

R: Do any of your subordinates know?

P: This new guy just started, Jason. And I think Jason may know that I had surgery back then because he was a student. I don’t remember if that was when… I think I had my surgery after he graduated, but I think he knows about that. But, I haven’t really talked to him about it. So, maybe.

R: Do you think that there is empathy in your workplace between you and your supervisor with relation to Crohn’s?

P: Yeah, I think so. I think so, yes. I would say, yes. I know when we had our site visit, I was really sick and I went ahead and came to work and she was like, you didn’t have to come. I was like we’re having accreditation, I have to come. So, yeah, I think she…

R: Do you think that there should be more empathy or less empathy?

P: More.

R: On the part of your supervisor or just in general from the school?

P: In general. I mean there’s probably a bunch of us who have problems. But, nobody knows. Andy if they do know, they don’t really care and that kind of thing. And like I said in my narrative, in the position I’m in, I don’t really have the luxury of taking off sick.

R: Right.
P: Who is going to cover for me? There is not anybody…It’s me and Jason, and he’s new. And Gail is my supervisor and she is swamped. Yeah, you can’t really be sick. Luckily I’m not too sick to make it through the day.

R: So, more backups in general?

P: A way to, yeah, a backup would be good.

R: Do you think that this community college has the appropriate policies are in place for employees dealing with chronic illnesses? Why or why not?

P: I’m not aware of any policies for chronic illnesses.

R: Do you think there should be?

P: Probably so, it wouldn’t be a bad idea.

R: If you could change one thing about being an employee at this community college with IBD, what would it be?

P: Less stress, they need to quit changing things constantly, constantly, constantly. It gives you a since of instability. There is no stability. So, when you are fearful of your job every other day, you can’t stay calm. And, that’s the big thing with this disease; you need not to have a lot of stress. And even the people who know that you shouldn’t have a lot of stress are willing to give you stress. So…

R: So, it’s a lot of undue stress?

P: Yes, very much so. Unnecessary, exactly.

R: Do you have anything to add to this interview about your experiences as an employee with IBD at this community college?

P: Nope. I think I’m pretty lucky.
R: What do you mean by that?

P: Well, I’ve just been lucky. It’s just been luck, really. That I haven’t been sick a lot, that I have been able to stay healthy.

R: Do you think that this community college would have worked with you?

P: No, no. I don’t get the impression that they’re going to bed over backwards for somebody who is ill. No. But, I could be wrong, maybe they would. I just don’t think so. I wouldn’t want to try, let’s say.

R: Do you have anything that you wish to add to or clarify for your written account?

P: Nope, I think it looks good.