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Inflammatory Bowel Disease & Social (In)Visibility: An Interpretive Study of Food Choice, Self-Blame and Coping in Women Living with IBD

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Inflammatory Bowel Disease & Social (In)Visibility: An Interpretive Study of Food Choice,
Self-blame, and Coping in Women Living with IBD

by

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A dissertation submitted in partial fulfillment
of the requirements for the degree of
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ABSTRACT

This dissertation is an interpretive project that uses autoethnography and qualitative interview methods to understand the role Inflammatory Bowel Disease (IBD) plays in women's quality of life and interpersonal relationships. It focuses on the impacts on patients of dietary changes and how food choice serves to make this ordinarily "invisible" illness visible to others, leading to unwanted exposure. Using Erving Goffman's stigma theory and its extensions in studies of chronic illness, I demonstrate that IBD is characterized by layers of stigma because it creates situations in which patients are forced to disclose their illness even if they are not ready to do so. These stigmas are compounded when the patient is seen as bringing the illness on herself by voluntarily eating foods that deviate from traditional definitions of "healthy" eating. This study shows the need for further investigation of the discourses surrounding healthy eating. The findings also show the problems inherent in IBD treatment models which assume that patients should practice rigorous self-management. It argues for changes in how doctors or patient providers communicate with their IBD patients so that dietary changes as a part of self-management are presented in more compassionate and patient-centered ways.

CHAPTER 1:

INTRODUCTION AND LITERATURE REVIEW

Inflammatory Bowel Disease is an illness characterized by chronic inflammation of the digestive track that affects about 1.6 million Americans (Crohn's & Colitis Foundation, 2021). Its symptoms include diarrhea, rectal bleeding, abdominal pain, fatigue, reduced appetite, weight loss, joint pain, and occasional vomiting. The condition is characterized not only by chronic pain but also by day-to-day physical and emotional uncertainty due to the unpredictable onset of symptoms such as diarrhea and vomiting. While the exact origin of IBD remains unknown, the most likely cause is thought to be an immune system malfunction (Mayo Clinic, n.d.; Crohn's & Colitis Foundation, 2021). Because there is no cure for IBD, patients are treated with medication to target the inflammation which may cause symptoms. However, to manage the illness and remain in remission, they are also typically tasked with changing their diet along with medication. Food choice is thought to be integral to IBD patients' maintenance of their physical health.

A central characteristic of IBD is fluctuation between relapse and remission. However, as challenging as the management of physical symptoms is, patients also face unique impacts on their quality of life due to the socially sensitive and embarrassing nature of the illness. Many patients fear the consequences of exposing the condition. Ongoing tensions between openness with others and concealing the illness add to the emotional burden of IBD.

I was diagnosed with Crohn's Disease at 23. I had been experiencing symptoms for about a year before a diagnosis was reached. These symptoms included severe joint pain, diarrhea,

vomiting, lack of an appetite, and weight loss. These symptoms progressively increased as the months went on. They started with joint pain that eventually spread, then included diarrhea, then vomiting, and then loss of appetite. Throughout the process, I was losing weight. Through numerous doctor's visits, lab work, and guesses at diagnoses, there seemed to be no light at the end of the tunnel, only uncertainty. It was not until my first colonoscopy that a diagnosis was reached.

The precise cause of my illness was unclear. I have a distant relative with Crohn's Disease, but that person is my only diagnosed family member, and I did not have other known risk factors such as a history of smoking or of abusing anti-inflammatory medications. My doctor explained the disease as a process of my immune system attacking my digestive tract with too many antibodies; this was evident in my blood work that showed an excess amount of white blood cells. However, because of the uncertain cause, it was difficult for me at the time to make sense of the illness in the context of my everyday life. I sensed that others would perceive IBD as grotesque¹ because it involves specific socially taboo bodily functions, in particular a lack of bowel control. I struggled with whether to disclose my illness to others and with how to describe the nature of my sickness or explain why I could not participate in certain events. This was especially difficult because my IBD is normally not visible, and I did not always appear to be sick. In short, I had trouble storying my illness to myself and others in the first couple of years, especially given the lack of a clear cause. And, beyond just the causes of IBD, I felt immense daily uncertainty surrounding the possible occurrence of flare-ups and having the illness inadvertently exposed. I found that trying to navigate social interactions with my friends, family,

¹ Grotesque is used here to convey the felt experience of IBD patients. I use this term to indicate that the responses that IBD patients receive in the context of their interpersonal relationships create the feeling that the illness is grotesque in nature, a feeling which becomes internalized.

and co-workers involved significant “communication work” (Head et al., 2021) to maintain my privacy while acknowledging the reality of the condition.

Treatment of my IBD included medication, although it took a few months to find the right drugs. I had been put on steroids periodically throughout the process of finding a diagnosis, which did work but had terrible side effects. It was not until my third hospital visit that I was put on a Crohn’s medication that helped with my joint pain. I was put on two more medications following my colonoscopy that were meant to regulate my bowels. In addition, my doctor recommended a new diet – one without foods high in fiber like vegetables and some fruits. Suddenly, eating took on new meanings. Choosing the “right” foods daily became a constant focus and an unwelcome reminder of the illness. Food had always been a source of pleasure because of the many family traditions we had surrounding food. I had learned to cherish my Nonna’s recipes for homemade pasta and sauce, roasted potatoes, green beans, broccoli, and tomato salad and her ways of cooking many different types of foods. The idea of needing to change or avoid those dishes completely was disturbing. Once I was diagnosed, food choice and diet management were among the most important practices that I engaged in as a patient with IBD. My eating also brought unwelcome visibility and shaped other’s perceptions of me in unexpected ways. Interactions focusing on my eating as healthy or unhealthy, good for me or not good for me, became an unavoidable part of managing the illness.

Understanding IBD as an Illness Identity

This dissertation aims to shed light on an aspect of a chronic illness that is poorly understood, specifically, food choice, and the role it plays in IBD sufferers’ performance of self. It draws on my own personal narrative along with analyses of in-depth narratives of other women living with IBD. This qualitative approach allows access to the embodied experience of

IBD, including not only its debilitating symptoms but also day-to-day eating routines and how they are disrupted by IBD. In this study, I explore the impact of those disruptions on IBD sufferers' sense of self and their relationships.

Communication researchers along with those in related fields have been influential in demonstrating the role of communication in constructing illness identities. Martin (2016) describes how social interaction influences someone's identity. With a focus on altercasting (putting others into defined roles based on perception of them as helpless or sick), Martin (2016) highlights how communication constructs illness identities. While Martin claims that identities are formed through social interaction, she notes that the ways persons are alter-cast by others are not necessarily accepted by the individuals themselves (in this case, the patients). In her study of Parkinson's Disease, she found "several participants reported resisting and renegotiating the way that others seem to perceive them" (p. 316). The patients wanted to distance themselves from the illness and not let it define them. Charmaz & Rosenfeld (2006) describe this process as it relates to mortification when the body does not behave as it is meant to. In those instances, "losing trust in [the] body, the person also loses trust in [their] ability to continue the relationship as before" (Charmaz & Rosenfeld, 2006). The patient then struggles with maintaining their identity because of the loss of trust in their own body. For patients with IBD and other stigmatized conditions, much of their daily communication centers on managing disclosure to others in ways that allow them to maintain a positive identity. This includes a particular focus both on how they conceal *and* how they disclose their illness, including the language they use and decisions about whom to disclose to (Charmaz, 2002; Charmaz & Rosenfeld, 2006; Defenbaugh, 2013; Thompson, 2013).

An additional focus of communication scholarship is on how we talk about illness more broadly by identifying socio-cultural discourses that define what it means to be healthy and by

seeing how they can function to shape individuals' sensemaking about their illness experiences. These larger conversations surrounding illness and what it means to look or be sick can affect patients in ways that call their authenticity into question when their appearance does not conform to normative expectations. In the context of this project, a discourse perspective also includes investigations of discourses that define "healthy eating" or "healthy food" and how they can constrain and enable individuals' food choices, sometimes contributing to individuals' well-being but also to their distress (Mudry, 2009; Shugart, 2016). When an individual appears to violate societal expectations for healthy eating, it can have significant consequences for individuals' identities and close relationships.

To summarize, the ways in which we communicate about an illness affects how it is viewed and the identities and emotions of individuals experiencing chronic illness. Although research is beginning to emerge on the specific effects of IBD on patients' sense of self and their relationships, these impacts are still not well understood.

In the remainder of this chapter, I first provide an overview of the medical context of IBD. I then turn to the conceptual foundations of the study by reviewing several areas of research. First, I consider research on chronic illness as it has been informed by dramaturgical perspectives on illness identities and Goffman's stigma theory. These frameworks have been especially helpful in analyzing the social interactions between patients and others and how they can be threatening to a patient's "face" or desired self-image. As part of this, I introduce Charmaz and Rosenfeld's (2006) concept of the "looking glass self" to consider how the unique features of IBD as a so-called bathroom disease lead to heightened concerns over bodily control which can damage patients' sense of self. I also review literature on how chronically ill patients

control information and keep their conditions “invisible” through careful decisions about self-disclosure.

An additional area of relevant literature explores macro-level cultural discourses of healthy eating. Healthy eating discourses are pervasive and can affect everyday interaction at a micro level, especially if an individual’s food choices trigger social judgements from others. Together, these bodies of research help to clarify the communicative context of IBD. Following the review of these areas, I present the symbolic interactionist and sensemaking perspectives that guide my approach to this study. Finally, I detail the rationale for this project, the research questions it addresses, and then give an overview of the contents of the remaining chapters.

The Medical and Social Context of IBD

To begin to understand the impacts of IBD on patients’ lived experience, it is important to consider the medical aspects of this complex condition. By detailing some of what is known about the medical aspects of IBD, including its causes, symptoms and diagnostic complexities, and its treatments, I seek to give important context that will ground the research participants’ accounts of their illness experience.

One distinguishing feature of IBD compared to other illnesses is that the diagnosis process tends to be long-term and uncertain because the illness encompasses two types of disease: Crohn’s Disease and Ulcerative Colitis (Mayo Clinic, n.d.; Crohn’s & Colitis, 2020; Crohn’s & Colitis Foundation, 2021; Barsed et al., 2016). While the two diseases are similar in their symptoms, they are different in the way in which the inflammation affects the digestive tract. For Crohn’s Disease, inflammation can reach deeper layers within the digestive tract, whereas with Ulcerative Colitis, the inflammation occurs mostly along the superficial lining of the digestive tract and contains sores (ulcers) throughout. While this seems straightforward, the

diseases are so similar that in some cases the diagnosis is ambiguous. For example, my doctor was torn between both because I was exhibiting symptoms of both, had severe inflammation along my digestive tract that affected the deeper layers, and had ulcers throughout my digestive tract and esophagus. He eventually labeled it Crohn's Disease while recognizing the overlapping nature of my illness.

Without management, IBD can flare at any time increasing the amount of uncertainty that patients feel. Several treatment options are available for those who live with either form of IBD. Most medical treatments include medication that suppresses the immune system, in the form of biologics, or antibiotics (Mayo Clinic, n.d.; Crohn's & Colitis, 2020; Crohn's & Colitis Foundation, 2021) along with anti-diarrheal medication, pain relievers, and vitamins depending on the severity of the illness. Changes in diet to include less spicy or high-fiber foods, fewer dairy products, eating smaller meals, and drinking plenty of liquids (Crohn's & Colitis Foundation, 2021) are also recommended. When these treatments do not work, surgery may be recommended to remove a portion of or all the lower digestive tract.

Dramaturgical Perspectives on a Hidden Disability

IBD is one of several "hidden disabilities" along with conditions such as fibromyalgia/chronic fatigue syndrome, HIV, and learning disabilities (Graham, 2009; Gallagher et al., 2012; Couzens et al., 2015). Like these, IBD can fall under the category of hidden disabilities because it is not readily visible on the body unlike someone in a wheelchair for example. The symptoms of IBD are intermittent and normally occur out of public view. Studies of hidden disabilities from a dramaturgical perspective reveal some of the communicative work involved in navigating social interactions involving an illness identity such as IBD (Dibley et al., 2018). This work makes use of Goffman's theory of impression management (1959) which

builds on the metaphor of social interaction as a theatrical performance. For example, research by Martin (2016) on Parkinson's patients uses a dramaturgical approach to understand how worsening symptoms such as tremors and slurred speech can present threats to a patient's identity. If the patient fails to perform as a "competent adult," their public presentation of self is undermined. Martin (2016) found that Parkinson's patients respond to identity threats by attempting to "pass" without giving off signs of illness for as long as possible but once they feel their symptoms begin to show, they may disclose their illness selectively. In so doing, they hope that "others will attribute *future* identity-threatening symptoms to the disease rather than to a personal failing" (Martin, 2016). Another example is Charmaz & Rosenfeld's (2006) research on chronic illness, which argues that patients will work towards changing the negative image that others have of them because of their illness to maintain their presentation of self and identity. Similar to Martin (2016), the authors find that patients attempt to conceal the illness symptoms to avoid damaging their presented identity (Charmaz & Rosenfeld, 2006).

Using notions of "front stage" and "back stage," Goffman's (1959) model sees people as actors who attempt to manage the impression they make in social interactions. In a front stage context, behavior is visible to an audience and concerns itself with how one might present oneself in socially acceptable ways, whereas backstage behavior would be what people do not want others to see or hear about themselves.

Stigma theory, a further development of Goffman's dramaturgical framework, has influenced research into the social and emotional impacts of IBD. Goffman (2006/1968) describes stigma as "bodily signs designed to expose something unusual and bad about the moral status of the signifier" (p. 131). Social actors evaluate individuals in social settings according to normative expectations for the larger social world. When we place these normative expectations

on people, we impose a potential virtual social identity to make sense of their behaviors. The problem arises when actors exhibit something unusual or outside of the normal, causing others to reject them from full social acceptance (Goffman, 2006). In the case of IBD, the possibility of stigma stems from the specific nature of the medical condition. As, Trachter and colleagues (2002) explain, symptoms of a flare-up such as diarrhea and flatulence are regarded in American society as private acts and when they occur in public, leave individuals open for ridicule. Moreover, this ridicule can lead to feelings of rejection and loneliness (Barned et al., 2016). Because of this pain and exposure, boundaries are created by the IBD patient so to not expose themselves to stigmatizing messages (Kralik et al., 2004), boundaries such as when to disclose and to whom to conceal the illness. Privacy boundaries are also created through performative strategies such as wearing makeup, dressing up, trying to limit number of bathroom trips, and paying close attention to prevent unintentional disclosures (Defenbaugh, 2013). Charmaz and Rosenfeld's (2006) research on the body's role in chronic illness is helpful in explaining the stigmatizing nature of IBD. In particular, they discuss bodily control as an issue for people with disabilities. Loss of control over physical movement or internal digestive processes or even the size of the body threatens the presentation of a "morally and technically competent self" (p.42).

To avoid stigmatization, individuals engage in face-work, according to Goffman (1959). That is, we conceal or downplay certain aspects of ourselves to save face or maintain a desired self-image. Goffman's framework has allowed researchers to see how people whose bodies are compromised by chronic illness try to control information and manage their identities, as evidenced in the previously cited research by Martin, Charmaz, and others. For individuals with hidden disabilities, successfully concealing our illness/disability or "passing" as normal within our social groups, is how we avoid embarrassment (Goffman, 1955). Goffman (1959) further

describes how preserving face is a collective effort as we not only protect our own positive face but attempt to protect others' face with what he calls civil inattention. By tactfully not paying attention to certain behavior (behavior that is normally meant to be backstage) such as burping or flatulence, we allow others to save face. In certain situations, the rituals of civil inattention are disregarded and occasionally, people will direct their attention to and acknowledge behavior that breaches norms of bodily acceptability as when someone falls or faints and others come to their aid. While successful face-work can save us from embarrassment there may be times when the condition is revealed and our identities are discredited, i.e., we are "outed" and must deal with the social consequences.

Goffman's framework explains why a condition like IBD might lead a person to withdraw from social situations or act in ways to conceal the illness from others. As Thompson (2013) discusses in his ethnographic study of an IBD support group, our bodies are symbolically differentiated into two parts or selves: the private and the public. We reserve the private for bodily functions that are necessary to sustain life but are, in a social sense, considered polluting or even revolting such as tears, sweat, urine, feces, blood, among others (Thompson, 2013). Normally, these secretions do not enter our public performance of the self but if they do, we face the stigma attached to them as our private bodily functions are publicly exposed. Even in the focus groups with IBD patients that Thompson (2013) conducted, the participants did not address their IBD specifically, which was an indication of the power of these normative rules of behavior. Instead, they used euphemisms to avoid addressing the private bodily functions that they experience often. In this way, they continue their performance of self by showing their front stage to the group members even though they all understood and lived with IBD.

IBD patients can pass as non-disabled in most social interactions because the illness is hidden, but that does not mean that they are relieved of stigma. While most hidden disabilities mean that the person will not automatically experience enacted stigma in which others actively exclude or discriminate against the stigmatized person, these individuals may receive little understanding or support unless the illness or disability is explained, creating the potential for unwanted exposure (Cavet, 2000). Cavet (2000)'s study of school children living with IBD found that because the children's illness is hidden there is typically more need for clear communication about the illness to the teachers and staff. However, some of the students in the study revealed that there was occasionally a lack of belief that the child had the illness due to its invisibility, which resulted in more stigmatizing. Additionally, because the causes of IBD are uncertain, individuals living with IBD "may feel particularly reluctant to draw attention to their condition, since they are unable to meet some of society's basic expectations" regarding what it means to be sick (Cavet, 2000, p.154), causing patients to further conceal their illness to avoid stigmatization.

Stigma theory is an important framework in the literature on IBD because stigma influences many aspects of IBD sufferers' experiences and adjustment to their condition. Health communication researcher Nicole Defenbaugh (2008/2013) uses Goffman to describe the stigma associated with IBD both in a patient/doctor setting and in interpersonal settings. Using innovative approaches such as autoethnography to describe her experience, she explains how symptoms, feelings, and issues tend to be overlooked or ignored in medical settings, leading the IBD patient to feel unheard and, at times, abandoned (Defenbaugh, 2008). She also describes the lengths that she goes through to conceal her illness when going out of her home by putting on makeup and dressing nicely to conceal any notion that she might be sick (Defenbaugh, 2013).

Defenbaugh shows how these issues affect women in particular ways as they are subject to powerful cultural pressures to meet conventional beauty ideals to be thin, able-bodied, and physically attractive (McKay et al., 2018; Trinidad et al., 2019). Female IBD patients often experience their bodies as a source of distress because of weight fluctuations, bloating, and other effects of the condition and its treatments (Trachter et al., 2002). The unpredictable nature of IBD symptoms create an added burden of shame for women who may fear they will be viewed as unfeminine (Trachter et al., 2002).

Defenbaugh also explores the bathroom as a significant space for women patients. Writing in the first person, she reflects on how its walls offer her privacy that allows her to conceal not only the bodily functions but also her use of makeup to conceal her pale, gaunt face. She focuses primarily on strategies of self-presentation to avoid unwanted attention. In spite of these practices, Defenbaugh (2013) describes how people can visibly see the number of times she goes into the bathroom so that her behavior becomes a source of unwanted attention and stigma. In this sense, the bathroom becomes part of the IBD patient's front stage performance.

Another line of research on stigma and chronic illness reveals how the symptoms of IBD might cause a person to "internalize" stigma, that is, come to believe the stereotypes held by others are deserved or true (Muse et al., 2021). Posing the question, how and when do changes in appearance and bodily capacities affect a person's self-image, Charmaz and Rosenfeld (2006) develop Cooley's model of the "looking glass self" which proposes that as we imagine what others think about us and how they judge us, we begin to internalize that perceived judgment and turn it in on ourselves in the form of pride or shame (Quist-Adade, 2018). Charmaz and Rosenfeld's (2006) concept of the "looking glass body" emphasizes the physical body's role in this process. They suggest that the compromised or ill body becomes a looking glass in which

we imagine how others see us, including the character judgements they may make. In particular, they discuss bodily control as an issue for people with disabilities. Loss of control, over physical movement or internal digestive processes or even the size of the body, threatens the presentation of a “morally and technically competent self” (p. 42).

These theoretical extensions help to clarify the stigmatizing nature of IBD. Rather than situating stigma as static attribute, communication scholars such as Martin (2016), Defenbaugh (2008; 2013), and others conceptualize stigma as both communicatively constructed as well as a source of shame. Social interactions in which patients are treated by others as an ill or physically incompetent person can lead them question their own self-worth. Furthermore, an important but less well-known contribution of stigma theory is to shed light on the food-related interactions of IBD patients since food choice is a way of measuring the extent of a person’s rationality and self-control. When a person’s food choices are perceived as risky or unhealthy, they open themselves to a process of “volitional stigma” (Easter, 2012) in which others make character judgements based on the perception that the illness is the result of their voluntary choices. The theme of illness and personal responsibility will be explored further in Chapter 4.

Difficult Conversations: Navigating Self-Disclosure

IBD patients may choose to manage their illness by “passing” as a person without IBD, but there comes a time when the IBD patient may choose to reveal their illness, for example if symptoms progress and are becoming harder to conceal. Yet, disclosure of IBD can dismantle the face-work and impression management that the IBD patient has done. Therefore, patients must make complicated decisions about how, when, and to whom to disclose. Carter et al. (2020) explains that there is risk in disclosure because negative disclosure experiences can lead to stigma, social judgement, and isolation. Kaushansky et al. (2016) and Carter et al. (2020) both

give insight into the considerations that guide decisions to disclose. To begin, Carter et al. (2020) distinguishes between revelatory/forced disclosure, when a person is forced to explain their condition regardless of their preparedness or willingness, and protective/preventative disclosure where the patient purposely discloses their condition to have some control over the social consequences. Barned et al. (2016) also includes spontaneous disclosure that is more emotion-based and includes feelings of shock about the diagnosis.

These types of disclosure give a broad picture of how and why disclosure happens. But what about to whom? Barned et al. (2016) created a flow chart that details how children living with IBD navigate this process, including such questions as: Do I trust the person I want to disclose to? Are there benefits to disclosing? Am I well informed about my IBD? Is the person someone I have known for a long time? How severe is my IBD? Has my behavior or appearance changed? Will I be judged or teased? Unfortunately, for those who experience revelatory/forced disclosure (Carter et al., 2020), do not have the time to move through these questions before making an informed decision. Kaushansky et al. (2016) interviewed young adults and children and found factors similar to Barned's (2016) and furthermore that patients distinguished between different categories of others, including family, friends, romantic partners, social media, and work supervisors. The authors and others have found that patients placed special importance on the anticipated responses. In a study of how IBD affects children in school, Gordon (2012) found that parents' and children's decisions to disclose were contingent upon the anticipated responses of teachers and peers to ensure fair treatment or acceptance. If they were likely to be viewed differently, they would avoid disclosing and continue their face-work (Goffman, 1955). Some patients may find they have incorrectly anticipated responses and their fears of being rejected or seen differently were fulfilled (Carter et al. 2020). Even so, some participants did experience

unexpected support from friends and family post-disclosure and found that it strengthened their relationships.

Specifically, for women, studies have shown the important role of trust between friends in female patients' readiness to disclose (Trachter et al., 2002). Because of the nature of IBD, women in particular may feel a sense of shame that decreases "both body and sexual self-image" (p. 415; see also Trindade et al., 2002). This shame can lead to increased psychological and emotional burdens and heighten the need for trust and closeness between their significant others and friends before disclosure (Trachter et al., 2002). While choosing when to disclose to others is difficult and worrisome, women report that it can lead to greater intimacy and can reduce anxiety (Trachter et al., 2002).

These insights about disclosure have important methodological implications for this project because they point to the importance of trust in enabling participants with IBD to open up about the impacts of their condition. My experience sharing my illness history with participants and the benefits I felt in the process of this sharing fit with Defenbaugh's (2013) point about the importance of social support when it comes someone with the same condition.

Food Choice as a Challenge to Constructing Positive Identities

Across disciplines there has been a blossoming of literature on the role of food choices in individuals' construction of their cultural and social identities. This work shows how food communicates values, class, and cultural background and helps individuals construct the type of person they strive to be (Bisogni et al., 2002; Harter et al., 2005; Lupton, 1996; Olsson et al., 2009; Wiggins, 2004). One result of this research has been to bring a critical perspective to the meanings that people attach to "healthy eating" and the identity of the "healthy eater." For example, Shugart (2016) and Mudry (2009) problematize the models of healthy eating promoted

by medical authorities and food industries. Their studies of the cultural meanings and politics of food and eating practices show how a person's food choices can create a context for social judgement and criticism by others. Mudry's (2009) book, *Measured Meals*, focuses on the language used to describe the food pyramid and what it communicates about healthy eating in the United States context. She argues that the food pyramid reframes healthy eating in ways that lead to attempts to control American eating and discusses the subsequent consequences when someone deviates from the food pyramid. Shugart's (2016) *Heavy: The Obesity Crisis in Cultural Context*, focuses on different narratives of obesity in terms of their cultural, environmental, and other implications to highlight how food and obesity have become stigmatized. With a focus on the failure of neoliberalism, she argues that each narrative about obesity has a center of authenticity (real or imagined) that goes against neoliberal ideals about individualism and becomes an extension of our cultural identity.

Their work helps to explain the scrutiny that we tend to place on people who deviate from the healthy food pyramid or eat foods that society has deemed "bad" for their health. A guiding model in cultural understandings of healthy eating is the food pyramid. The food pyramid is a diagram that details what foods and in which quantities are best for our physical health. Designed to make healthy eating easier, the bottom of pyramid represents what should be eaten frequently and tapers to the top with what should be eaten sparingly. At a societal level, the food pyramid has become an influential guide for Americans to quantify their eating habits and adhere to nutritional experts' definition of a correct diet (Mudry, 2009; Shugart, 2016). Even though the food pyramid is a highly generic set of recommendations, it is widely looked to as a source of advice (Wiggins, 2004). According to Shugart (2016), the food pyramid is the number one reference point for lay persons' assumptions about diets and for their understandings of obesity.

Using the food pyramid as a guide, with its emphasis on grains, vegetables, and low-fat proteins at the bottom of the pyramid, a person's discipline and self-control is assessed according to the foods that they are eating and in what quantity (Lupton, 1996; Mudry, 2009; Shugart, 2016). Eating mostly "bad" foods, typically those high in sugar, fat contents, and more processed foods, is seen as indicating a lack of discipline and self-control, even of laziness (Mudry, 2009; Shugart, 2016). In general, it is expected that we can and should regulate our eating. Thus, individuals perceived as violating the guidelines are vulnerable to being labelled as immoral because they lack the character strength necessary to maintain their good health or what is considered a disciplined and "civilized" body (Lupton, 1996; Mudry, 2009; Shugart, 2016). For women, this problem is compounded by the gendered basis of healthy eating norms. Women are expected to be "champions" of healthy eating and especially of light food items like salads and vegetables, a factor which is thought to contribute to women's often problematic relationship with food (Peel et al., 2005).

In addition to the food pyramid, two diet related narratives impact social judgements of healthy eating with specific consequences for chronically ill individuals. The first is the discourse of quantification in which individuals are expected to monitor the number of food groups they consume to maintain a healthy weight (Mudry, 2009). Mudry (2009) claims that using quantifiable language to describe healthy diets fails because it simply relies upon "numbers, amounts, degrees, or standards to create knowledge" (p. 9) without considering individual preferences. Furthermore, the discourse of quantification assumes a specific type of body (Wiggins, 2004), one that is not burdened by IBD. This places chronically ill individuals into a bind. Mudry (2009) demonstrates that the food pyramid imposes expectations associated with each food category on individuals. While it might be an effective guide for limiting calories,

chronically ill individuals cannot subscribe to the same quantification rules, especially when they cannot eat certain food groups. For example, the food pyramid suggests that individuals should be eating 3-5 servings of vegetables each day as part of a healthy diet (Mudry, 2009), which some chronically ill individuals, such as myself, are not able to do. The problem with the discourse of quantification is that it certifies a reality that may not be true for many individuals.

A second narrative, outlined by Shugart (2016) that relates to the experience of IBD patients, extends the discourse of quantification by labeling foods as “good” and “bad.” In focusing on self-regulation as a means to fight obesity Shugart (2016) examines how diets identify foods as “good” or “bad.” Those individuals who cannot stay on track by removing the bad foods from their diet or eating them in moderation as the discourse of quantification would suggest, are seen as unhealthy, lacking discipline, and implicitly as immoral and even “unclean” (Shugart, 2016). This narrative is problematic for those living with chronic illnesses including IBD, who cannot eat “good” or “healthy” foods as specified in healthy eating discourse and are having to renegotiate their relationship to food. Ironically, chronically ill individuals’ food choices in social situations open them to be seen as lacking in discipline, which in reality, they are practicing. IBD patients tend to refer to food in categories of “safe” and “unsafe” foods: in other words, foods that will prevent a flare and foods that could cause a flare. Thus, in the process of learning about their illness and which foods work and which do not, the IBD patient is simultaneously practicing discipline and self-control. However, the food pyramid and other healthy eating discourse does not account for bodies that cannot eat a certain food group for whatever reason (Wiggins, 2004). My own case is a good example of disciplined experimentation. My doctor told me that I could experiment with some vegetables after going into remission, but he emphasized staying away from dark greens and salads. Once in remission,

I tried eating carrots, mushrooms, broccoli, sweet potatoes, and others and I would jot down my reaction to each and either cross it off the list or leave it on. Unfortunately, most of the vegetables I tried caused my Crohn's to flare. Because of that, I only experimented with those foods when I was at home and had no plans for the next few days.

For chronically ill people, the possibility of stigma arises when illness-specific diets or visible food choices necessary to maintaining health are perceived by others as unhealthy. One of the few studies exploring the links between food choices and stigma is research by Olsson and colleagues (2009) on adolescents with Celiac Disease. In their study, they focus on how adolescents living with Celiac Disease navigated unwanted disclosure and exposure when gluten free options were not available. Some participants in this study had to verbally request food to be gluten free when out in public making, thus an invisible illness visible. Additionally, the adolescents described how sometimes the school lunches would get mixed up and they would have to go into the kitchen to describe what they needed to the kitchen staff. This would occur even if the kitchen staff was supposed to be aware of the student's condition. Some of the participants said that the kitchen staff would tell them that it is just too hard to remember that they have Celiac Disease which caused repeated and unwanted disclosure. This resulted in more stigma for the student in different contexts. Similar to Olsson et al. (2009), I address how food choices expose IBD individuals because of change in diet or amount of food eaten and the resulting surveillance of food choices. Additionally, I describe how those food choices can lead to a flare and resulting blame from themselves and others. In exploring the intersections of food, blame by self and others, and stigma, I nuance the IBD experience both interpersonally and intrapersonally.

Conceptual Foundations: Symbolic Interactionism and Narrative Sensemaking

Perspectives

Studies of the cultural meanings of food suggest that food can be an area of conflicting messages for IBD patients and a site of struggle between macro-level narratives and individual needs. My own experience has shown me that these larger cultural narratives concerning food, “health,” and “healthy eating” often enter everyday interpersonal conversations and impact the day-to-day workings of patients’ lives. However, rather than seeing patients as simply reacting to these received messages, this dissertation shares the perspective of communication scholars Vanderford, Jenk, and Sharf (1997) who argue for viewing patients as “active interpreters, managers and creators of their health and illness” (p.14). My project is grounded in a symbolic interactionist perspective emphasizing the process through which meanings are created in face-to-face conversation between patients and their friends, family, and significant others (Quist-Adade, 2018). As people construct and negotiate complex understandings food, eating, and health through social interactions, symbolic interactionism assumes that they employ elements of creativity in how they conduct themselves. This can include resisting dominant understandings, not only of so-called healthy eating, but of what it means to be a “good patient” who practices “responsible” self-management of their chronic illness (Kendall, 2011).

Despite the strain on chronically ill patients’ well-being cause by the stigmatizing nature of their conditions, symbolic interactionism also offers ways of thinking about how patients are resilient to the challenges they face through narrative coping processes that can allow them to thrive (Lee & Pool, 2005). In contrast to psychological views, interactionism emphasizes narrative as a way of coping with traumatic experience (Waskul & Vannini, 1997). According to Frank (2013), illnesses can be a unique “call” for stories. Stories are a means to “repair the

damage that illness has done to the ill person's sense of where [they are] in life, and where [they] may be going" (p. 53). When people organize their lives in narrative form, they often reorganize experiences into a sequence in which one event is presented as leading to our "caus[ing]" another (Weick, 1995, p.128). Thus, as Bruner (1991) argues, we come to understand changing reality through stories because "narrative organizes the structure of human experience" (p. 21). Not only does the construction of illness stories help the ill person reimagine their lives, but hearing these stories provides us as audience members an opportunity to witness other people's stories and to understand how they construct reality after a diagnosis (Harter, 2009). Through the analysis of stories, researchers can gain a processual view of how chronically ill individuals "construct meanings about self and subjective existence" (Charmaz, 2002, p. 306).

In this project, narrative frameworks guided my approach in several ways. First, sharing my own story of living with Crohn's Disease in the dissertation enabled me to achieve a richer understanding of my experience and to show in more concrete ways how identities are organized, changed, and shaped through illness. I also took a narrative approach to data gathering by structuring the interviews around open-ended questions to allow participants as much as possible to follow their own sense of direction in telling their stories. Lastly, I devoted a portion of the analysis to applying Frank's (2013) narrative model of illness as "chaos," "restitution," and "quest" narratives to get a preliminary understanding of how participants made sense of their illness history.

Summary and Research Questions

IBD offers a complex and intriguing context in which to explore how patients make sense of and communicate about their changed relationships to food. Informed by symbolic interactionist perspectives on illness as a socially enacted identity and of chronically ill

individuals as active sense-makers who are both constrained by and resistant to dominant narratives of health, this study explores the following questions:

- 1) How do IB patients negotiate tensions between “concealing” and “revealing” as their food choices become publicly visible, and what are the relational consequences of illness exposure?
- 2) How do IBD patients make sense of notion of personal responsibility and self-control embodied in diet-based treatment programs?
- 3) What forms of communicative coping do IBD patients adopt in response to the physical and social challenges of the illness?

In the following chapters I first offer a description of methods used in conducting the research. In Chapter 3, I analyze how participants describe their diet and food choices and how they navigate these choices in public settings when questions arise. In Chapter 4, I analyze how participants assume personal responsibility for managing their illness through diet treatment and how they make sense of flares when they eat something outside of their recommended diet treatment. Additionally, I address how participants negotiate outsiders’ perspectives on their food choices that are perceived as leading to flare-ups. In Chapter 5, I explore different types of coping strategies with particular focus on communicative forms of coping to make sense of their illness during flares and remission. In addition to humor and strategies of normalizing one’s appearance, I highlight Frank’s (2013) model of the chaos, quest, and restitution narratives with participant examples to demonstrate how participants story their illness as a form of sensemaking in responses to crisis. Finally, the conclusion presents a summary and discussion of the project’s contribution to communication along with limitations and directions for future research.

CHAPTER TWO: RESEARCH METHODS

Prologue

As I began the research for this project, I was trying to be vigilant about my health. I was watching what I was eating, managing my stress, and taking my medication as prescribed. Then towards the second half of the interview process, I began a flare. My medication had been on back order at the pharmacy for a few weeks and it finally completely wore off. The constant need to run to the bathroom, pain in my stomach, and fatigue made holding the interviews difficult during the end of June. I knew that should an emergency arise during the interviews that my interviewees would be the most understanding. Given that they dealt with similar situations daily, I did not feel like I had to hide that I was experiencing. I typically opened up with them about the flare I was in around the middle of the interview, after we had gotten to know each other, and the participant had shared their illness story.

At this particular point in the interview process, I was conducting seven interviews in one week, many more than I had done earlier. While the flare started a few weeks before, this week it had gotten worse probably because of the number of interviews and the resulting strain on my body. I realized that in pushing myself to stay on track I had overestimated my capabilities. Because I was working from home and had regular access to a bathroom, I didn't think I had to worry about accidents, so I pushed myself that week to do more than my body was able and that weekend, I felt it: the pain, urgency, fatigue, and loss of appetite, all more intensely than I had in

a few years. This flare was going on a month, and I was in the thick of it. I knew my body needed rest and time to relax so it could heal as much as possible without the medication.

The next week, I went to Illinois to visit family and took some time off from interviewing and transcribing. This break was much needed, and I came back feeling less fatigued; the pain lessened a bit. Still under the effects of the flare, I knew that without that week of time away from work, my body would be in a much worse state and less manageable.

Although I documented these events in my journal, it wasn't until later, when the flare was over, that I could really begin to make sense of what I felt and the impact my condition had on the interviews. Once I was back on my medication, I could feel my body ready to push forward again although I am still aware of the occasional urgency and need to watch my diet.

In retrospect, I recognized that the flare influenced the way I conducted and engaged in the interviews. While these conversations were still fruitful and meaningful, I was less engaged, energized, and focused than earlier and I struggled to be objective. Although it is always hard for a researcher to compartmentalize their illness, especially a chronic illness such as Crohn's, as long as I was feeling well, it could become part of the background as my research identity moves to the foreground. But during that last week of interviewing, the illness was ever-present. Because of this, during sections of the interview that focused on flares and pain I was more attentive than others. I was distracted by my sharp pains in my abdomen and failed to hear certain parts that were not related directly to flares. While I tried to focus and listen to each response carefully, I was distracted by my illness and failed to listen to their whole story.

Rationale for Research Method

In what follows, I explain the qualitative methods used in this study, in particular qualitative interviewing and autoethnography, and the reasons for these choices. From there, I

discuss the recruitment of participants, the procedures for interviewing, and my process for analyzing the interviews.

A variety of research methods have been used to study illness experiences. Broadly, the goals of this project are to understand how chronically ill patients make sense of and manage a stigmatized medical condition, and more specifically to uncover the meanings of food choices for their relationships and their coping processes. This project used a qualitative interpretive approach to guide data gathering and analysis. An interpretivist approach complements the symbolic interactionist orientation of the study because it assumes that knowledge and beliefs about illness are constructed in and through communication and interaction. According to Tracy (2013) interpretivist research attempts to gain access to social realities from participants' standpoints and uses methods that offer a deep and empathic understanding of human actions and feelings. From an interpretive perspective, qualitative interviews position the interviewee as actively involved in meaning making (Holstein & Gubrium, 1995), and thus are well-suited to understanding people's illness experience. I recognized that while I was not directly observing them in public dealing with IBD issues, I was instead observing their reactions to their IBD experiences as they described them to me through stories of their struggles.

A hallmark of qualitative methods is their focus on context-specific situations to better understand human behavior (Tracy, 2013). In so doing, the qualitative researcher gains a better appreciation for rules and meanings of behavior in everyday social settings (Tracy, 2013). By studying a specific context, "qualitative researchers examine people's actions (local performances) and the structures (informal guidelines and formal rules) that encourage, shape, and constrain such actions" (Tracy, 2013, p. 22). From this viewpoint, qualitative researchers recognize that people's actions are contingent upon the context that they are in and the social

norms or rules that regulate behavior. This is particularly helpful in studying the ways IBD patients navigate various contexts from public outings with friends and family to workplace settings; across all of these, their IBD is ever-present and poses risks that an individual's behavior may deviate from social norms, leading to experiences of stigmatization.

Qualitative approaches can also give insights into how chronically ill individuals navigate unequal power relationships, in particular those which are grounded in the institutional roles of doctors and patients. Research on patient-provider communication shows how patients' voices can be disregarded or downplayed in medical decision making (see for example Bylund, 2005). Although not the specific focus of this project, several participants described interactions in which their doctors dismissed their food-related concerns or experiences. Finally, qualitative approaches can also reveal how patients' understandings of their illness are shaped by larger societal structures that are assumed to be normal and natural, as reflected for example in discourses of "healthy food" that circulate in society and give meaning to individuals' behavior (Bisogni et al., 2002).

As a woman with IBD, my personal perspective has strongly influenced the design of the project. I chose to interview other women living with IBD because I wanted to learn about their experiences. IBD is an isolating illness. Patients struggle with finding people that they can talk to who will truly understand what is happening to their body both physically and socially. In thinking about a choice of research format, I wanted, if possible, to create the possibility for new insights to emerge for myself and my participants. I foresaw the possibility that their experience and the meaning they would generate might be different from mine, but I hoped that bringing together diverse perspectives could create a more complex picture of the illness.

I also wanted my project to include my voice as it relates to the IBD experience and the interview process, and so I chose to include autoethnographic components along with my findings. Autoethnography is a personal style of writing in which researchers examine their own lives. It is marked by vulnerability, emotion, and a high degree of self-reflexivity (Tracy, 2013). As Bochner and Ellis (2016) explain, autoethnography is also a way of “connecting the personal to the cultural” (p.65) to see how the events we experience are shaped by wider cultural meanings. By incorporating autoethnography into this project, I attempt to convey an understanding of the embodied nature of this illness and how, as a so-called bathroom disease, the experience is situated in and influenced by social interactions. I began this chapter with an autoethnographic account of conducting and analyzing interviews during a flare because I wanted to convey the illness’ physical impacts and unpredictability.

Although there are a few “standard” methodological formulas, autoethnographic research usually involves immersion into one’s memories, recalling, for example, episodes of illness flare-ups and recall of the emotions experienced (Bochner & Ellis, 2016). As part of my introspective process, I recalled episodes in which IBD interrupted my work or social experiences and disrupted my daily physical functioning. I also recalled conversations and interactions that I had with significant others such as friends, family members, and doctors and how these influenced decisions about whether to disclose and how disclosure was sometimes forced on my unexpectedly. I recalled how I coped with accidents caused by the illness. Even though this writing is emotionally difficult, I try to write the most honest account possible, also recognizing that I am interpreting past events from my current vantage point and that I may not report experiences completely accurately. I rewrote some of the autoethnographic pieces after

interviews because I found that in recounting these stories to my participants, I was able to remember new details.

This study integrates interview findings with autoethnography so that my own story can provide an interpretive context for the interview data. Similar to how Berry (2016) included reflexive interludes in his study of youth bullying, I include a reflexive piece at the beginning of each chapter which is intended to illustrate some of the themes found through the analysis.

Research Procedures

Recruitment of Participants

I received notice that my study was exempt from IRB approval on March 8th, 2021, and shortly after, I began to reach out through personal networks and word of mouth to find participants for the study. To qualify for the study, participants were required to be women between the ages of 18 and 40 living with a form of IBD (Crohn's Disease or Ulcerative Colitis) who have been diagnosed or have experienced symptoms for at least 1 year. Probably because of the nature of this illness, and because recruitment was occurring at a time when people were also struggling with many impacts of the pandemic, I found the population hard to access. I spent more than a month trying find individuals through my personal networks and word of mouth. When my initial efforts were not successful, I put an announcement on social media, including Facebook and Reddit. I believe that being transparent about being a member of this community myself may have allowed the participants to feel comfortable to come forward. In the original post, I did not mention my health status, but as women approached me, I discussed my diagnosis and the length of time I have been diagnosed before they committed to participate. Eventually I did find fifteen participants through Facebook and Reddit, although it took some time for the participants to reach out to me. Two participants were encouraged to reach out and participate in

this study from a significant other or family member who saw the posts. Of the fifteen participants three were from outside of the U.S., two in Scotland and one in Germany. Additionally, the range of time since diagnosis was broad, from a year and a half to 28 years. This is because one of my participants was diagnosed at 6 months old with Crohn's while most others were diagnosed as adolescents or young adults.

Because this study was done during the latter half of the pandemic, thirteen of the interviews were held over Zoom between June and July of 2021 and two were conducted over email. Zoom includes a built-in audio recording tool, as well as an auto-captioning tool that made transcription of the interviews easier. I downloaded the video captions and formatted them into transcripts, then re-listened to the recordings to check for accuracy. The Zoom interviews lasted an average of about 80 minutes, with the shortest being 56 minutes and the longest being 90 minutes. Following the interviews, I recorded journal entries about my experience during the interview, noting my impressions and reactions to the conversation, and outstanding questions that I used to go back and review the transcripts.

In two cases, participants had prolonged scheduling issues and we eventually decided to conduct their interviews by email. I recognize that the email format creates a different form of data because the participants have more time to review the questions and think about how they would like to respond. There was also no way for me to respond to nonverbal feedback or gauge their immediate reactions to my questions or stories. While both of those participants were equally vulnerable and worked through stories with me in similar ways to participants I met with over Zoom, I cannot overlook the differences in the nature of responses obtained in email interviews versus face-to-face interviews.

Each interview began with a review of the study goals, and I also confirmed participants' consent. Similar to Thompson (2013), I conducted the interviews in a semi-structured way, where I drew from a series of questions or topics while giving the participant flexibility in how to reply. The interview was organized into three parts with the first part focusing on illness history, the second on dietary changes and the impact of these on the participant's quality of life, and the third on strategies for coping with the illness. Some of the questions I asked to guide the interview included: When did you begin to experience your symptoms leading to the diagnosis and what was that like? What have been some of the impacts of the illness on your life day-to-day? Did your diet change? If so, what was that like? (see full interview guide in Appendix A). It is important to note that many of the questions elicited stories and anecdotes that captured significant moments in the person's illness experience such as illness crises, flare-ups leading to public accidents, or episodes of concealing or revealing the illness. We learned from each other through sharing our stories. A question like "When did you first experience symptoms?" seemed to open up a natural dialogue between myself and the participants which sometimes prompted me to share pieces of my story. Dunn (2019) follows a similar interviewing process in which she asks open ended questions and draws from her own experience to encourage conversation. Using Dunn's piece as a model, I tried to create spaces in which the participants felt comfortable engaging in conversation with me, and their stories gave me the opportunity to ask more questions beyond the list I started with. Usually, as the interview progressed, a level of trust was established and I felt I could ask more probing questions like, "Do you find yourself 'self-blaming' because of a food choice that resulted in a flare?"

The participants occasionally asked me questions such as type of medication I am on, if I experienced accidents, what my diet is, among others. This back-and-forth conversation created

a dialogue that felt natural, energized, and easy to maintain. Furthermore, because many responses were given in story form, I found that during the analysis process, I could easily recall the interview conversations and review my journal entries more efficiently to find notes on critical points. In Chapter 5, I report on a preliminary analysis of these illness stories as examples of communicative coping.

Compassionate Interviewing. Ellis (2017) explains that compassionate research involves using kindness and showing love and care towards the individuals being interviewed. Additionally, compassionate interviewing focuses how the researcher orients compassionately toward themselves as well as to the interviews and interviewees (Ellis, 2017). In these types of interviews, the participants collaborate with the interviewer through reciprocal sharing and participate together in the meaning-making process. Both the researcher and participants are working together in conversation to think more deeply about personal experiences as they relate to more universal human experience. I observed something of this process when the participants recounted stories and anecdotes to me. Occasionally, the conversation created a space in which they would recognize why they may have behaved one way versus another, for example in deciding to disclose their illness. In those moments, we reflected together on their motivations and connected their experiences to larger, normative structures such as norms of professionalism in the workplace. In this way, we became partners in the research process with each of us gaining a new perspective on a past experience.

The deep listening that distinguishes compassionate interviewing from more mainstream interviewing approaches in which the researcher tries to maintain more emotional detachment means that data-gathering is an active process for both the researcher and participants and does not always end when the interview ends. When the interviews were over, some of the

participants kept a line of communication open with me and we continue to discuss our experience with IBD.

One justification for compassionate interviewing is that it rests on egalitarian values as the researcher tries to create a more collaborative research relationship by sharing their own vulnerabilities with interviewees. At the same time, it can lead a researcher to lose some critical distance from the material, which can complicate the process of analysis and interpretation. These challenges will be addressed in a later part of the chapter.

Analysis of Interviews

After completing the interviews and journal entries, I conducted a thematic analysis of the interviews. Broadly, “thematic analysis is a method for identifying, analyzing and reporting patterns (themes)” that occur across participant responses (Braun & Clarke, 2006, p.79).

Thematic analysis is an inductive approach, that is, a process of coding which tries to stay close to the data as much as possible not to allow patterns to emerge. However, although I tried to stay close to participants meanings, I also used certain sensitizing concepts to guide my interpretation. Sensitizing concepts are ideas or theories drawn from former scholarship that serve as jumping off points. They offer frameworks through which researchers see and organize the research problem (Tracy, 2013). Key sensitizing concepts in this analysis came from literature on hidden disabilities, in particular Goffman’s concepts of facework and passing. In addition, I used concepts of health accountability and self-blame from the literature on the self-management of chronic illness. Sensemaking was another important concept that guided the analysis.

After all the interviews were transcribed and journal entries were written, I began the analysis by reading through each interview multiple times to familiarize myself with the data. As

a second step, I began a process of what Tracy (2013) call “primary cycle” or first-level coding to capture the data broadly by pointing out recurring phrases, ideas, and words. Here, I noted specific words and phrases, including words related to foods (e.g., “fatty foods,” “unsafe foods”) and emotion words such as “struggle,” “guilty,” and “regret” to name a few. I also noted specific words the participants used in talking about their bodies and symptoms such as references to IBD “attacking” the body and being “in” or “out” of control of one’s body.

On the third reading, I began to make interpretations and tease out themes within the interviews while referring back to the sensitizing concepts. During this process, my advisor and I would meet to review at least one interview and to see how individual codes might be combined to reveal broader themes. The goal in this stage of the process is to show patterns across all the interviews in the semantic content of the data (Braun & Clarke, 2006). In the final stage of analysis, I began to make interpretations (Tracy, 2013) guided by the research questions and the sensitizing concepts to explain the patterns I observed. This interpretive stage allowed me to theorize the broader implications by identifying what Braun and Clarke (2006) refer to as “assumptions...and ideologies,” (p. 84), such as ideologies of patient responsibility and self-management.

In presenting my findings, I have tried to present rich descriptions that nuance the many layers that accompany an IBD diagnosis and its management. Throughout the findings, I feature participants’ voices by including quoted excerpts as exemplars. These passages provide important contextual details and I hope will also enable the reader to better understand how the interpretations were arrived at.

Ethical Concerns and Research Reflexivity

In the interviews, it felt natural for me to orient myself as a collaborator and member of the IBD community. Because both the participants and I are living with IBD, I felt we could build trust throughout our shared experiences and stories. Even if our stories and experiences were not exactly the same, I anticipated similarities in managing exposure, shame, and the stigmatizing nature of the disease. However, while sharing similarities can be a way of building rapport, they can also cause complications in gathering and interpreting interview material. A shared illness experience requires that the researcher be reflexive about how her identity may have influenced the process. Reflexivity is especially important in the context of compassionate interviewing because the researcher is active in the interview process through conversation and storytelling. The researcher must work to understand how their involvement might be influencing the research findings because of the personal effect(s) that the participants are having on them (Ellis, 2017).

According to Hertz (1997), reflexivity is a kind of self-awareness by the researcher that they are an active participant in the research process. Reflexivity requires that the researcher think about how their own unacknowledged assumptions shape the research process. It includes some awareness that how participants respond to questions is influenced by their perceptions of the researcher. Reflexivity is especially important in the study of illness and other sensitive topics, especially if the researcher decides to disclose that they are a fellow-sufferer. Probst (2016) discusses the benefits and the costs of researcher disclosure of personal information. By describing what it is like to fill a participant's role during the research process, Probst (2016) explains that the researcher gains "an appreciation for mutuality, reflexivity, co-construction, and respect for both the knowledge and vulnerability of interviewees" (31). This appreciation can be

applied when the researcher shifts out of the participant role and into the researcher role to truly understand the position that the participants are in. On the other hand, some disadvantages of occupying both spaces are a loss of safety, differences between researcher and participant's stories, and cultural differences (Probst, 2016). Probst (2016) explains that when occupying a participant role as a researcher, the comfort and safety of the research position is blurred, and the researcher becomes vulnerable. Additionally, the researcher needs to understand that their story is not a perfect mirror of the participants' stories, and she needs to address the differences that arise based on the experience itself as well as cultural contexts that shape experiences (Probst, 2016). In this study, I found that I did come to appreciate the vulnerability that the participants displayed as well as their hand in the co-construction of the data. However, the sense of losing the safety net of being a more distanced researcher did allow me to be more vulnerable than expected in ways that blurred the line of researcher and participant. That is, I may have shared aspects of myself and my illness that influenced the participants to give responses that were similar to mine. I also needed to remember that my experiences as a middle-class woman in the US are culturally based while a few of my participants lived in different countries so their experiences would not exactly line up with mine. Through a process of reflexivity, I tried to work through these disadvantages to imagine how my behavior and identity might have influenced the findings of the study. Yet I also found more appreciation for the co-construction of themes and data that I and the participants had a hand in creating.

This chapter has described the procedures used in this interpretive study to address the following questions:

- 1) How do IBD patients negotiate tensions between “concealing” and “revealing” as their food choices become publicly visible, and what are the relational consequences of illness exposure?
- 2) How do IBD patients make sense of notions of personal responsibility and self-control embodied in diet-based treatment programs?
- 3) What forms of communicative coping do IBD patients adopt in response to the physical and social challenges of the illness?

In Chapter 3, I address the first question by exploring the impact of dietary restrictions on IBD patients’ daily lives, in particular on their public visibility and social interactions. In Chapter 4, I look at the processes of sensemaking as participants connect their food choice to episodes of relapse and remission. In Chapter 5, I explore different kinds of coping revealed in participants’ accounts, including problem-focused coping and forms of communicative coping including normalizing appearances and storying illness. In Chapter 6, I summarize significant findings and discuss the contributions of this study to our understanding of how chronic illness and its treatment impact patients’ sense of self-and interpersonal relationships. I also consider some implications of the findings for the practice of medical care.

CHAPTER THREE:
NAVIGATING CONSTRAINTS IN FOOD CHOICE IN PRIVATE AND PUBLIC
SPACES

Prologue

Beep.... beep.... beep.... beep. I have been staring at an open refrigerator for over five minutes. Luckily, our fridge is new and alerts us via a beeping noise when it is open for too long. I sigh and shut the fridge. There's nothing in there I can eat. Or that I want to eat. At this rate, I'll be malnourished before I have another flare-up.

I was diagnosed with Crohn's Disease three weeks ago. I was told my diet needed to significantly change so my body could heal and remain in remission. Before my illness I had prided myself on eating many different things and enjoying each food group. I loved trying new things and experimenting in the kitchen with different types of vegetables in stir-fries or new health foods such as flax seed and granola. When I learned that fruits or vegetables high in fiber were no longer safe foods for me to eat, I felt like I was losing part of who I was to stay in remission. I kept reminiscing about all the Sundays of my childhood spent at my Nonna's house learning her recipes, even the delicious goat stews that took hours simmering on the stove, made with vegetables from her garden. There was nothing quite like the farm-to-table freshness of her many different salads (lettuce, tomato, and orange to name a few), green beans, and homemade tomato sauce for pasta. I wondered how, with an (almost) entire food group eliminated from my meals, I would be able to continue enjoying her recipes.

I found myself at a crossroads in terms of how much to change my diet and how much to try to retain a sense of normal and familiar. I told myself I could still experiment in the kitchen and make Nonna's recipes or my own, that I just needed someone else to try the foods I couldn't. I could do that with my mom, dad, and sister. They already knew what I was going through and were very supportive of the changes I had to make. I could be open with them about my new diet, but I didn't want to tell anyone else besides my immediate family.

It wasn't until my first public outing with some friends about two months after my diagnosis that I felt the full impact of these changes. I was happy to be out again, spending time with my friends. On this particular day, I was with Carrie, my best friend since kindergarten. Carrie is a highly health-conscious person who exercises daily, counts her calories, works for a fitness and nutrition center. She would always ask me to come exercise with her and then make two green smoothies with protein powder afterwards for both of us for lunch. Up until this meeting, we had not exercised together in a year.

Carrie and I were eating out with a few other friends at a local bar. Tucked away in a corner table surrounded by bustling waiters, people eating and drinking, and loud music in the background, we waited for our order of drinks to come before placing our entrée orders, and chatted about how our families were, what we have been up to, and what our plans were for the weekend.

Distracted by our small talk, I didn't think twice about what to order when the waiter came. I just knew I needed to order food that fit my new diet – no vegetables and high in protein. So, I ordered a French dip sandwich with fries – just bread, meat, cheese, and fries. Right after the waiter left, I was caught by surprise when Carrie asked, in a tone laced with judgement,

“Why didn’t you order a side of broccoli, or get a salad instead of the sandwich? It would have made it more balanced.”

My friends (who had all ordered a vegetable on the side or just a salad) stopped talking, stared at me, and waited for my response. In this moment, I realized that the most visible sign of my illness was my food choices. Of course, my trips to the bathroom would be noticeable, especially if I was running there every 15 minutes, but the walls of the bathroom provided some privacy. No one knew what went on in there. The bathroom or stall walls concealed when I was experiencing rough bowel movements. But there is no anonymity with food. People could hear and see my food choices and those who knew me well would question those choices.

Not knowing what to say, I looked around the table at my friends and then back to Carrie. Finally, I just stuttered, “I...I...I just didn’t want any today.”

No one spoke and I could sense how uncomfortable the others were discussing my choice considering Carrie’s opinions on healthy eating, so before Carrie could say anything else, I just changed the subject by asking, “So, what are everyone’s plans for the weekend, again?”

Later, I reflected that I could have brushed off their questions with an attitude of not caring about my health, or I could have made a comment about having good metabolism. Not entirely a lie, but not entirely the truth. I do have a high metabolism, but my recent weight loss came mainly from 5-6 bowel movements an hour and constant involuntary vomiting. I managed to avoid any more conversation about my food choices during that lunch, but as time went on, my friends became more curious about my diet as we spent more and more time together.

I saw Carrie about once every week after that and she continued commenting about how my gaunt, pale skin must be related to my food choices. She couldn’t reconcile how I could eat so many carbs and proteins, barely work out, and still be as skinny and frail as I was. She and my

other friends pushed for an explanation, but I was embarrassed. The accidents, frequent bowel movements, and vomiting that I endured were difficult to discuss. But eventually I had had enough. I told them that I had Crohn's, a bathroom disease, and all it entailed.

After this disclosure, my friendship with Carrie and the others was never the same. Being forced to talk about the subject, to tell them I felt fine, felt good, felt hungry, was exhausting. But revealing my diagnosis did not bring the understanding I was hoping for. Repeating myself and rehashing my diagnosis was becoming more emotional labor than I was ready for. I longed for a better sense of normalcy with my friends. When they scrunched their noses at the grotesqueness of my illness, I tried to understand their perspective. Maybe they didn't know how else to deal with my illness. Maybe this was the only way they could cope with it. We did not talk about my illness any more even though I wanted to clear the air.

After this disclosure, my friendships were never the same. Carrie and I drifted apart slowly. Once I moved to Florida, the drift became more permanent. We stayed in touch as much as possible with our conflicting schedules and long-distance friendship, but it was never the same after the diagnosis. Carrie would still be a bridesmaid at my wedding, but there is an unspoken subject that lingers over us when we are together. She has been my best friend for years and I can't help but try to understand how difficult it must have been for her to understand my illness and subsequent changes. I wish we could reopen the conversation so we can find our way back to how our friendship used to be.

Introduction

In writing this narrative, I have tried to bring awareness to some of the changes in the way the self and the body are experienced following an IBD diagnosis. My food preferences and my love of cooking and eating were deeply rooted in my family background and my place in the

family as a daughter and granddaughter. After being diagnosed with Crohn's, I was forced to make different choices about food. Managing my diet was among the most important practices that I engaged in as a patient. The changes required in my eating, both alone and with others, contributed to my sense of loss and vulnerability.

This chapter addresses a common theme that surfaced across the interviews, which is the participants' changed relationship to food following diagnosis. Although most IBD patients lack visible symptoms, this normally invisible condition becomes visible to others when the patient's eating appears to violate normative expectations (Olsson et al., 2009). Managing these interactions is even more difficult when a patient is also struggling internally to redefine the meaning of "healthy" food considering their medical requirements. Before digging in to examine the social consequences of dietary changes, I begin by offering some observations about the interview process, especially the variations I noticed in how responsive participants were to my questions. Following this discussion, I take up a central theme, which is how participants were constrained by the need to find foods that were safe and how they both accepted and resisted these constraints. A second theme concerns the social impacts of food choices, including the way in which food choice serves to invite questions from others, in some cases inadvertently exposing the condition.

The Interview Process

As I reflected on my interviews with my participants, I was initially struck by the variation in their stories and in the different meanings they attached to food and diet. These differences were partly because each woman's illness followed a unique course and entailed individualized treatments in which dietary changes played a more or less significant role. I also noticed differences in the conversational process that added to their uniqueness. There were moments in

the interview process where a certain question would resonate especially well with a particular participant. Even though the interviews were conducted over Zoom, it was still possible to sense when a question triggered the participants' interest and enthusiasm. For example, I shared with one participant, Kat, a brief version of the problems I had with Carrie around my diet and asked if she had ever felt anything similar. She responded with a jumble of words and phrases: "Yeah! Like 100%, like, yeah! That's like, yeah so, it's also connected with, similar to you, for me it's a private thing. . ." Kat then went on to describe the difficulty she had concealing her treatment during her family's Christmas dinner. Reading Kat's body language and tone of voice, I could tell that the visibility of her food choices was a central and emotionally important issue. But when I shared the same story with MacKenzie, she responded much more briefly, "Yep. And I feel like I was pretty lucky after I got diagnosed. . . I was on prednisone so I could basically just ignore it."

Some participants were more expansive on some topics than other topics. When I noticed a participant launching into a story or spontaneous reflections, I felt that it was necessary to stay with the topic by listening, following up with more questions and sometimes sharing something about my own experience. This is where the interviews became more narrative, less structured, and took on a back-and-forth quality between me and the participant. The interview questions were designed to be open-ended so that each participant could follow their own sense of direction in telling her story. This process worked well because it allowed me to completely submerge myself in the unfolding stories without focusing too narrowly on what I hoped to find.

The interviews followed a sequence beginning with several questions to get a picture of the participant's medical history and current situation. I would then shift the conversation to issues surrounding food choice by asking participants about whether their diet had changed after

their diagnosis, and if so, how? The participants would describe any diet changes or if they tried changing their diets even before diagnosis. As part of this, I would often share a story about how my diet changed. The participants would sometimes have questions for me so that an organic conversation surrounding food choice and related issues would follow. Discussing stories that centered around food, the participants and I were able to think more deeply about food choices (or lack thereof) and their emotional impacts. There would be some instances where I would have to steer the conversation to focus on food as a site of exposure, but typically the participant would bring up a story containing those themes, and I would ask more questions to get further details.

Rethinking the Meaning of Healthy Eating

For IBD patients, the terms “healthy” and “unhealthy” are not particularly useful in guiding their food choices and yet the interviews show that they are still constrained by the dominant understandings of healthy eating. Many participants, as well as I, myself, tend to label food as “safe” and “unsafe” rather than healthy or unhealthy. In this way, we identify what our bodies can tolerate to avoid relapse. Over time, the result of learning to distinguish foods that are safe is that IBD patients must rethink assumptions that were developed in early childhood about what we socially deem to be healthy eating.

Given the importance of diet in the management of IBD, it was interesting that many of the participants at first downplayed having to modify their food choices or diet. When I did bring up the topic of food, about half of the participants deemphasized their diet changes whereas others wanted to talk in more detail about their relationship with food and asked me questions as it relates to my diet. The participants who were most vocal on the topic of food, indicated that food was tied to their identity in ways that complicated their IBD experience. There were also

some participants who downplayed their food choices not because they didn't have stories and opinions but because of its contentious nature; they found food to be a source of frustration and a topic they did not enjoy discussing.

As Ruth commented:

I just find it so distressing the topic of food. And like I said I don't want to look for the food that's gonna make myself feel better because if I am in flare, nothing's gonna make me feel well... my point is if my intestines are going to do things that don't make sense, why would I try to make it make sense?

When Ruth discussed her diet, she focused more on her moral and ethical positions about being vegan than the impacts of food choices on her IBD.

Another participant, Janice, was matter of fact about changes in her diet, saying "I'm not sacrificing much because my diet was kind of like clean beforehand anyways." Interestingly, when I first asked her about changes to her diet, Janice responded that "I think I have medication more to thank than diet honestly." But then she went on to mention the specific impacts of a Mediterranean diet on her IBD:

I will say that there are some foods that have been helping my stomach and are safe to digest like avocados and fatty foods, like salmon, have been helping a lot. And when I was in the middle of a flare those were the only foods that I could eat. Like foods like avocado and salmon and high fat foods were really good for me.

Here, Janice shows a high degree of conscious attention to food. She refers to specific foods (avocados) and categories ("fatty foods") to explain her understanding of the foods she found helpful, that she "could eat," that are "good for me." Learning about the effects of specific foods and what foods are "safe to digest" as she puts it, is similar to a process of scientific investigation

carried out systematically over time. When she was diagnosed a year ago, Janice had already been changing her diet regularly:

I was, I have gone through so many diet changes. I was vegetarian, well I was vegan last year and then I went vegetarian and so now I have just incorporated fish into my diet.

We see here that Janice was already oriented to the health benefits of a “clean” (vegan) diet. She had experienced several shifts in her eating, from vegan to vegetarian to pescatarian. Although food choice and diet were central to her identity, she did not seem to experience IBD-related dietary changes as a disruption the way other participants did. According to Lupton (1996), veganism and vegetarianism often entail moral and ethical commitments so in that sense, Janice’s mention of these diets might speak to the importance of food to her identity as a whole.

Similar to Janice, other participants discussed the importance of sticking to “safe” foods or not eating foods they “can’t eat” to make sure they did not trigger a flare up. It is important to note that “safe” foods were a relative judgement depending on how the body reacts; participants varied in their definitions of what was safe. For example, Marie discussed foods that she cannot eat and what might happen if she does.

Especially recently the list of the foods I can’t eat are growing so like right now I think I just like randomly I just can’t eat eggs or anything that has eggs in it and it’s really bad if I do. I’m sick for like a few days and it’s stressful to go out.

Marie, in her early thirties, has been living with IBD and dietary constraints for almost 20 years. Like Janice and others, she needs to keep track of the foods she can and cannot eat and has been committed to learning through a process of trial and error what is safe and unsafe for her. She recalls that when she was younger, her parents exerted control over her food choices which created problems when she became sick:

At that point I was so sick. I wasn't eating much anyway when I was younger. My parents were still more in control of my diet. I guess the biggest thing is they just used to be really big into, "we made this for dinner, you eat it." And once they realized that that could cause some issues if I can't eat it. And if I couldn't eat it, I was allowed to make something else, and it became more of a control that way. But as I got a little bit older and got more control over what I could eat and stuff, I would pick and choose what I wanted to eat. Of course, my current GI doctor doesn't believe that food choices matter.

Marie details how difficult it was navigating her IBD, and the lack of control she had when she was younger. Once her parents finally realized that certain foods were making her IBD worse they were willing to give her a bit more control and allow her to make something different for dinner from the rest of the family. Marie's account gives a picture of the messages about food she was exposed to as a child and the need for her to find ways to navigate them. In her childhood environment, food choice was considered a family matter with options dictated by her parents. Even after her diagnosis, food was a site of disagreement as her parents failed at first to understand the role of diet in preventing symptoms. She also mentions the continuing disagreement with her doctor, who dismisses the importance of diet. I asked her if she agreed with her doctor that food doesn't affect IBD:

No not at all. Absolutely not. One of the first things that started happening when I was really young was that I could not eat onions. And then that has just grown steadily since then and if I am in a flare-up, I can eat very little things and if I do it hurts my stomach. It upsets my stomach you know. I have to run to the bathroom. Like I understand where he's coming from like if it is an inflammation thing it is not so much what you eat it is just the fact that you are eating. But when you are in like less of a flare or a bit more in

remission, I think that if you talk to anyone with IBD they will be like yeah, I can't eat these things.

Marie explains here how she might be able to understand what her GI doctor means by food not having an impact on IBD if symptoms are due to underlying inflammation rather than specific foods, but this medical explanation runs counter to her experience. To challenge his position, she cites other patients as authorities: "if you talk to anyone with IBD...." These patients, like her, have learned through many years of trial and error what they can and cannot eat. As she mentioned, the list of foods that she cannot eat has grown since she was younger, so it is hard for her to separate food choices from her IBD.

Through trial and error, patients learn what they can tolerate. In this way, they are evaluating their food choices according to the occurrence of symptoms rather than to their actual preferences. Unfortunately, this is the reality for many IBD patients. In my experience, there is always the worry that I might cause my IBD to flare so I focus on what I know it can tolerate regardless of whether I enjoy it.

There were many participants like Janice and Marie who discuss how trial and error has helped them learn which foods work for them and which do not. Some types of food categories can be further nuanced for a particular patient. For example, Samantha, who is in her early thirties and has been living with IBD for 12 years, has become acutely aware of what her body can tolerate. She learned that her body might not be able to eat everything in a certain food category, such as cheese: "And it's weird. I've noticed that if I eat like fresh mozzarella cheese, like that's all it is. There's nothing to it. It doesn't upset my stomach at all. I can eat that."

Samantha went on to list the types of ethnic foods she can and cannot tolerate:

I can't eat Indian food. I will go full-fledged into a flare and my stomach will just buckle on me. The spices is what it is and I can't eat it. But other spices I'm fine with. Like if I eat Mexican food or Chinese food it is okay but definitely any dairy stuff or spicy foods. I have to be careful with red meat. If I eat any of it, I have to be really careful because it is just really hard for my body to digest it. So, things like that and any processed foods.

Samantha knows that her choices have consequences; she is highly aware of how severely she is affected by different ethnic food categories and her comments give a sense of the burden she faces in choosing foods and restaurants that won't cause her symptoms to flare.

Like Samantha and Marie, other participants described the process of learning through trial and error what is safe and unsafe. Khloe is in her late twenties and has lived with IBD for 14 years. She talked about experimenting with food and its physical effects as well as why she is still hesitant towards some foods:

So, like after I had stopped eating everything and it was like so we are going to try one thing at a time. So, for like a long time I would eat like rice, and I would eat grilled chicken, and I would eat that and bagels, and those were like my foods. And it was slowly like okay, let's see if we can try...hamburger meat. I don't know if that is something that I can have. Like can I have, you know, dairy? Which I found out I am lactose intolerant so that was off the list and so it was definitely like well let's try this and see how it goes and never try it again and there's certain foods like even now like years and years later that I still have hesitancy towards because I have tried it before, and it went really, really bad.

Here, Khloe details her growing understanding of how different foods affected her. She even highlights how the physical effects of some food trials have lingered in her body years later,

making her still hesitant to try them. Khloe's comments fit with previous research which found that adults managing Type I diabetes are constantly "listening to their bodies" and monitoring glucose levels as they search for a reliable pattern in their responses to various foods and medication (Price, 1993). Similarly, Khloe refers to certain foods as "her foods" and as having a "list." When diabetes patients cannot discern a reliable pattern of responses, they may have to settle for a self-management program that is "good enough" but not satisfactory (Price, 1993). In Khloe's account the distinction between safe and unsafe food overshadows any considerations of personal preference and it gives a sense of her constant vigilance about the possible effects.

Further meanings of safe and unsafe surfaced later in Khloe's interview when she described having to explain her food choices to a co-worker:

She [co-worker] made a comment about how I eat a lot of like fast food type things – because I know what foods are safe in that context. And she made a comment about, "I never see you eat like salad." And I'm like, "cause salad will make me so sick," and she's like, "that doesn't make sense to me." I was like, "okay well, yeah, because that's something that's hard for your body to process. It's not like healthy and unhealthy food, it's what is hard for our body to process and eat," and so like I am not going to be bringing a salad to work and I am not going to have fresh veggies for a snack 'cause I can't do that.

Here, Khloe describes having to justify her food choices by describing to a co-worker how salad affects her. When her co-worker expresses confusion about why salad would be harmful, Khloe offers the information that salad is "hard to process," contradicting the common understanding of salad as healthy food by describing its impact on digestion. At this point in our interview, Khloe expressed how uncomfortable those conversations are for her and how she feels responsible for

educating others on her illness. Not only is she attempting to challenge her co-worker's negative evaluation, but she is navigating the conversation in a work setting, causing her to feel particularly exposed:

And so, my coworkers are always talking about diets and like weight gain and stuff. And like healthy food is really hard to find when you have Crohn's because like my diet when I am sick defaults to white carbs, that's what safe. And they don't like understand that. Because safe foods and healthy foods are not the same thing.

Khloe details the difficulty of explaining to others the difference between safe foods and "normal" healthy foods. Her story illustrates how the dominant discourse of nutrition as described by Mudry (2006) seeps into everyday life and shapes the way individuals think about what it means to eat healthy. But the example also illustrates a point made by Wiggins (2004) in his analysis of family mealtime conversations, that it is through our interpersonal conversations that we create an understanding of what it means to eat healthily. While medical authorities' definitions are influential, local interactions are where we collectively construct and debate meanings of healthy eating (Wiggins, 2004). For Khloe's coworker, as for many people, food can be clearly and simply categorized as bad or good; something that looks like fast food is categorically bad while salad is good. Our day-to-day conversations not only reflect those larger narratives that Mudry (2006) discusses but sometimes they also serve to foster and maintain those narratives.

In addition, Khloe's excerpt shows the subsequent consequences of eating "unhealthily" in public spaces. It gives a sense of the communicative labor (Head et al., 2011) involved in trying to make it easier for others to understand why a person with IBD has to eat what she eats. In so

doing, she is not only exposed as someone living with IBD but carries the burden of normalizing her behavior to others.

Noelle, another participant, echoed Khloe's about the social consequences.

Like right now I am eating mush. It is pretty much just baby food all of the time. And they definitely want an explanation. It's not a judgement thing but I find that like going out with friends and family isn't as fun as it used to be because I am usually very limited in what I can eat, and you know I can't drink with my friends. I can't really participate as much as I would like to.

Noelle has only been living with IBD for 3 years. Like Khloe, she describes social situations that require her to discuss her unusual food choices. She makes a point of saying that her social group "want[s] an explanation" for what she is eating. Although she comments that this is not "a judgement thing," it impacts her desire to participate in her social group.

Food as a Site of Social Exclusion and Accountability

Many participants discussed how their atypical diets impact their participation in social life. A clear theme running through the interviews is how their specialized needs for their food choices leads to experiences of social exclusion or lack of desire to participate, as it did for Noelle.

Kim, who has been living with IBD for 14 years, also feels as though she cannot join in outings with her family because of having a Celiac diagnosis on top of her IBD diagnosis:

I can't go out to eat anymore. There's cross contamination everywhere. Like I have to go to very specialized restaurants. And that to me is like very upsetting because it becomes, not only is this, like I need something to eat, but this is my social outlet. I love going to restaurants. I love trying new food and that's severely inhibited.

Eating out is a space for her to bond with her family and, as she puts it, her social outlet. However, she perceives that she is primarily responsible for navigating her dietary constraints and that her family does not feel the need to accommodate her. Given her needs to go to “very specialized restaurants,” Kim implies that the restaurants her family typically chooses will not always align with her dietary needs. The only exception is her mother who does try to find appropriate restaurants for her.

Other participants reported similar experiences to Kim’s. Cutting out certain foods, prompted feelings of missing the food *and* of feeling left out. Jackie, who has lived with IBD for 10 years, notes that managing her diet is more stressful than any other part of her IBD in part because it impacts her social life. Jackie was not as concerned with missing foods that she loved but instead struggled with feelings of isolation which she connects to not being able to explain her diet to others:

. . . Then when I was not on Remicade anymore and I did like an elimination diet and so that was kind of hard and I sort of like made chicken broth and added foods in. And that was a pain ‘cause I was feeling more isolated because I didn’t want to go anywhere with food situations. But I think, like with my good friends or people who did care about me, you know, they wanted to keep up so they’d say, like “what can you eat or what can’t you eat?” And so, it’s like you said, you can’t just be, “I’m vegan” or “I can’t have dairy” so it’s like I think that was kind of the hard part because it is so individualized because there’s not a simple way to summarize it.

Jackie’s comment shows that food and socializing are linked in complex ways. To begin with, her goal of finding a reliable pattern of safe foods through systematic elimination makes it hard to eat out. But Jackie also details how she did have some support from good friends who tried to

accommodate her needs by asking “what can you eat?” She recognizes that the of nature of her diet may not be as understandable to others as it is for someone who says they are a vegan or lactose intolerant. She lacks a vocabulary for describing her diet that her friends can relate to. At this point in our interview, I could tell from her tone that Jackie was feeling how frustrating it had been to have to explain to others what foods she can and cannot eat.

Another participant, Audrey, who has been living with IBD for 13 years also reflected on the importance of food in social gatherings, saying “[Food] offers comfort and enjoyment as well as something for people to gather around in normal social settings or celebrations...I think if consuming food was solely about nutrition others might have less to say about what foods we choose to eat or not to eat.” As someone who has often had to consider the impacts of her choices on others’ views of her, Audrey seems to be saying that food is symbolically important as an expression of individual and group identity, and these meanings are the basis of norms of appropriate eating.

In addition to adjusting to new dietary limits, participants also had to negotiate new social situations that centered on their food choices. To explore this theme in greater depth, it is important to understand that all participants shared a feeling that any changes to their bodies associated with their IBD including weight loss, the occurrence of accidents, or bathroom trips when others were present, were visible to others. On top of these, food choice also created occasions of increased visibility and heightened participants’ awareness of their presentation of self (Charmaz & Rosenfeld, 2006; Goffman, 1955). Eleven of fifteen participants felt that their food choices had been observed in public settings, including the workplace, restaurants, and family gatherings. In many of these moments, participants found that their food choices were being openly questioned or had become a point of concern that required an explanation. Like

Mudry (2009) and Shugart (2016), Wiggins (2004) notes that the body is the ultimate authority on what healthy eating is and that not all bodies fit neatly within larger healthy eating discourse. We define the meanings of healthy eating both in the way our bodies react and through social interactions. It is in our everyday conversations where cultural models of healthy eating are reinforced but also where generic advice that doesn't fit individual needs is challenged.

Navigating Disclosure

In situations where an IBD person's food choices are being called into question, the person can find themselves having to justify their food choices based on what they have determined as healthy eating for their body. In contrast to the obvious physical symptoms of illness like weight gain or frequent bathroom trips, food choice allows for the possibility of what Olsson and her colleagues (2009) call discretionary disclosure, in which an individual evaluates situational needs to decide how much information to disclose (p. 977). The need to respond to these questions from others creates a dilemma because the responses from others to the disclosure can vary widely from positive and supportive to negative. Thus, in these moments, individuals may choose to rely on face-work (Goffman, 1955) in the form of "passing," specifically concealing potentially stigmatizing information and keeping their backstage hidden from view. As Olsson and her colleagues observe, the decision to pass as normal carries risks of discovery that make even ordinary situations highly stressful. Furthermore, situations can arise (such as a flare or unexpected symptom) in which the patient loses discretion, and the illness must be disclosed.

In those moments when IBD patients feel pressured to disclose their illness in public settings they need to find ways avoid or lessen the disapproval. Marie offered an example showing how questions from others can surface unexpectedly during social gatherings, requiring

her to manage the situation by communicating the impact that her food choices have on her body:

...Like one time a speaker was coming in and I wanted to meet with him and we went out to like a bunch of the students...get together and have lunch with him and talk...And like one I was stressed out because we have to go and like eat and well if I eat now then I'm going to have to go to the bathroom halfway through his talk but then everyone else is eating so you kind of feel like you have to...So I was like well okay well I order the French fries and I'll just eat French fries. And the speaker commented on my food choice which was I thought was quite rude and he was like, "well if you just eat these, you're going to gain weight..." Which was odd because he was a Celiac so I pointed out to him that it wasn't his business and that I had colitis which is similar to Celiac in a way that he would understand. And in which case he sort of like back pedaled.

Here, we get a glimpse into the internal struggle that IBD patients have when trying to decide whether to pass as normal and how that decision is tied to choices about what and when to eat in a public setting ("If I eat now, then I'm going to have to go to the bathroom halfway through. . ."). We also see Marie receiving direct criticism in a large gathering from a new professional acquaintance. In response, Marie first pushes back, telling him it "wasn't his business" and then disclosing the information that she has Crohn's. While she did not tell me how she knew he had Celiac Disease, she does explain that she used that as a way to explain her illness "in a way that he would understand." Because the two illnesses are so similar, she doesn't feel the need to give additional details. We can see here how the speaker, not knowing that she chooses French fries to prevent symptoms, makes Marie accountable for her food choices. He offers an implied criticism of French fries as an unhealthy choice, going so far as to point out the possible side effect of

weight gain, (which is something that women are likely to be concerned with). If we assume that the definition of “healthy” versus “unhealthy” food is socially constructed (Wiggins, 2004), we see that Marie could have taken this as an opportunity to openly challenged the idea that French fries are necessarily unhealthy. Instead, she responds defensively by claiming her choice is a private matter and then disclosing her illness. This seems to have been an effective impression management strategy that causes the visitor to back off.

Marie was not sure initially if she should eat at all because she did not want to have to leave to go to the bathroom during the speaker’s speech but felt like she had to because everyone else was eating. Here, the combination of social pressures of feeling the need to eat because everyone else is and the questions about her food choice from the speaker left her exposed.

Marie detailed this exposure further:

But the annoying thing with that is I don’t care about informing him but then there’s like all of my peers from my work group that I don’t think it is any of their business to know and now I have to like disclose in front of all of them and so I think that is frustrating.

Marie notes here that she never planned on telling her peers in her work group about her IBD. But because of the questions from the speaker, she had to give a public explanation that included the entire group.

Through Marie’s story, we see that IBD and food choice are interlinked and a point of struggle when trying to navigate relationships, future plans, and group participation. To avoid the visibility that a flare might create, many of the participants focused on eating only what was safe for them, even if that meant needing to explain their food habits to their coworkers. Even though uncomfortable, some of the conversations were necessary to preserve positive face as we saw with Marie.

Noelle also felt compelled to give an explanation at work that exposed her condition: I feel like you know, at work I bring all of my own food and people see me eating and I get those like squeeze pouches of baby food. Like they are small, and they are delicious, and I love them, but I had a co-worker one time, he's like, Noelle why are you eating baby food? Like literally my infant child eats those. And I was like well 'cause I can't digest my foods and so this is my go-to.

Here, Noelle describes how her food choices were questioned. When her face is threatened by being compared to an infant, she responded, not by talking about the food itself (which she describes to me in the interview as "small" and "delicious") but by explaining that her body cannot digest certain foods. Here again, the workplace becomes a site of exposure during mealtimes.

The workplace is not the only place the IBD body can be exposed through food choice. Jackie describes how unnerving social gatherings can be. She talks about how she tries to avoid social gatherings so she does not have to ask for food modifications which would make her IBD visible.

...Like you said, food is a social thing and it's like an illness that wouldn't really be noticeable to other people or at least not visible...[food] really like puts it out there when you can't eat something, and you have to ask questions or ask for modifications with the food. Or like when you go to someone's house, and you can't eat the food that they are offering, and it feels like it's rude even though it's not and so you try to over explain and then you know, it's just kind of, yeah.

Here, Jackie talks about how uncomfortable going to restaurants or someone's house is because of the food modifications she needs. This excerpt illustrates another aspect of the impression

management she performs. She worries that the request for food modifications might be heard, not as evidence of a careless attitude toward eating or as childishness but as rudeness. Jackie is stuck in a bind in these situations. In order to manage her dietary needs and maintain her public face of politeness she feels she must “over explain” and disclose more than she wants to. Jackie weighs the different types of tradeoffs between wellness and privacy in these social situations and struggles to find the right balance.

Social pressures dictate to Jackie what choices she has if she wants her IBD to remain invisible. But if she is exposed, she notes how uncomfortable it can be. Forber-Pratt et al. (2020) discusses the difficulty of coming to terms with a disability whether visible or invisible and notes that while individuals come to accept their disability, they need to acknowledge the potential negative views of others’ acceptance and the frustration that accompanies it in social situations. Jackie explains what it feels like to have to explain yourself in these situations.

It’s like you’re apologizing so you are trying to offer this explanation and it’s just like you have to end up saying a lot more than what you would have wanted to. And I think that’s really the most frustrating thing about diet...it becomes like something that you want to avoid.

Jackie details nicely what is frustrating about food choice when living with IBD, particularly how a patient feels that they must say more than necessary, and therefore just ends up wanting to avoid those situations entirely. In these instances, Jackie finds herself over-explaining to achieve acceptance and move beyond the frustration (Forber-Pratt, 2020).

Another participant, Gretchen, had to address questions about the appearance of her body after making diet changes due to her IBD before she decided to adopt a pescatarian diet. Gretchen has been living with IBD for about 11 years. She talks about using exclusion diets to

find what is safe for her, but she notes that she found herself having to explain the diets to combat any negative comments about her body.

Like when I did those exclusion diets, like there was a time where I was only just eating chicken breasts, olive oil, and I forget what else. And people were like, oh are you anorexic? And I was like no, I just can't eat anything. I'm not allowed to. So, it just so happens to work for my body or at least what I can tell.

Gretchen describes here that people were commenting on her body being too thin. This reference to anorexia may explain why in her response Gretchen talks about her body in a way that connotes a separation of the physical body from the self. Like the comment Marie received about French fries and weight gain, Gretchen's questioners also link her food choice to norms of female appearance and body size. However, anorexia is a psychiatric disorder which is highly stigmatized. The question, "oh are you anorexic?" is a direct threat to Gretchen's positive face. To counter the idea that she might be anorexic she says she is "not allowed" to eat certain foods implying that her choices are being made for her by some other(s). Her final point, "it happens to work for my body," emphasizes that food choice is beyond her control because of the direct effect of food on her body.

Finding Agency in the Chaos

The previous excerpts show how IBD patients are constrained in their food choices, living with the constant fear that certain foods will prove to be unsafe for them. What emerges from these accounts is a picture of women who are constantly accommodating their food choices to their illness. Additionally, they are exposed to questions and critiques of their eating habits from their social circles, which can make IBD patients feel as though they are continually doing something wrong.

Because of the nature of IBD, many patients do not have much agency when it comes to what they can and cannot eat, adding one more layer to the suffering of the IBD patient. However, while this lack of agency is important for understanding patients' experience, it does not capture the full picture. Several participants gave examples of trying to take control of the situation by choosing foods according to personal preferences rather than medical needs. These examples were notable because they illustrate how participants reframe eating unsafe food as a choice and act of personal agency.

Gretchen, for example, talks about having found a vegetarian diet with occasional fish as something that works. She is highly conscious of how her body reacts to different foods and yet she comments that she most likely will still eat what she wants, saying, "Everybody is, like, 'you shouldn't eat spicy food.' But I will never stop eating spicy foods." Gretchen demonstrates a form of agency by this choice, possibly because she has her IBD under control enough that she can eat unsafe "spicy" foods while maintaining her condition in a way she can live with.

Other participants felt similarly in wanting to take back some control through their food choices, as in the following example from Noelle. She explained that she finds the most agency with her food choices when she is in flare, saying, "I also have this bad habit of, if I am already flaring up, that, well, I am already feeling like crap anyways so might as well eat fun things." She reasons that since she is in a flare it doesn't matter if she eats the "fun" foods, so she does it anyway.

Additionally, participants demonstrated agency through their ethical choices about food. For example, Ruth explained that right after she was diagnosed with IBD she made the decision to become vegetarian, because, as she says, "it was something I believed in and something I was

passionate about...” Later on in her IBD journey, she decided to go fully vegan, and she gave more of the context for making those choices, as well as describing the physical consequences:

My phrasing, when I found out I had this disease in my stomach and it was supposed to be related to food, was, and I still say this to my friends, “well you know what, I don’t negotiate with terrorists.” And my intestines are a terrorist...So there’s no, I mean really...there’s no cure and there’s no cause. And there’s no foods that we *know* are good or bad, and yet we’re supposed to find what works for us!...But my point is if my intestines are going to do things that don’t make sense, why would I try to make it make sense?

Ruth demonstrates her agency by eating what she thinks is beneficial to everyone (animals included) regardless of how her IBD responds. A vegetarian turned vegan, she argues that what she eats matters more for the animals involved than it does for her own well-being. Later in the interview she talks about her commitment to being vegan even if eating meat were a cure for IBD:

And let’s just say [the cure is] beef, you know, filet mignon and beef broth. Let’s just say that’s the cure...or not that that’s the cure but that it works for some people. Well in my opinion... it doesn’t work for the cow so it’s, like, I just don’t.

Ruth is passionate about her commitment to veganism. As she says, she doesn’t think it is fair to the cow for her to eat red meat just because her body can tolerate that better than vegetables. Her outlook on food goes beyond what is safe for her body, to include what is best for the whole planet.

Ruth’s comment is also revealing because she, like other participants, used metaphorical terms to talk about the struggle with an illness that seems to control her choices and body.

Calling her intestines “terrorists” and saying she refuses “to negotiate” with them makes a strong statement about what she will and will not accept, regardless of how her actions affect her body. I heard other participants use terms that characterized their illness as a battle or attack. Kim described herself as “being so upset that my own body is attacking itself and I don’t know what to do.” This language conveys an idea of the ill body as something separate from the whole self, as uncontrollable, and of the person as being at war with a body that attacks back. Kim becomes upset because she has no course of action to manage the attack. It is as if she is losing the battle.

This separation of body and self is not a new way of describing illness. People living with eating disorders feel alienated and frequently speak in a way that separates themselves from their bodies (Lupton, 1996). But when Ruth says, “my intestines are terrorists,” she is expressing frustration with a specific aspect of IBD, the occurrence of flares seemingly out of nowhere, regardless of the foods she eats or medication she takes. In Ruth’s case the terrorist metaphor allows her to see herself as taking charge and fighting back. It enables her to make sense of an unpredictable illness as she tries to find a sense of normalcy (Buzzanell, 2010). The narrative theorist, Arthur Frank (2013), sheds some light on the use of these expressions, explaining that in situations in which an ill person has a clear cure or solution, the fight to become healthy again does not seem unattainable (Frank, 2013). For those ill patients, metaphors of war and battle suggest that a winning chance is possible. However, IBD patients have no cure. They are left to deal with the illness each day with the hope that it might be a good day. Lacking a cure, they must redefine winning to mean reaching remission rather than returning to their previous health before the diagnosis. As shown in Ruth’s example, metaphors of the body as an enemy and the illness as a war allow IBD patients a way to frame their illness to make sense of its continuity and difficulty.

Conclusion

Through these stories, we can see what is at stake for IBD patients as they struggle to cope with dietary restrictions. In order to achieve remission from symptoms, patients learn to listen to their bodies to identify “safe” and “unsafe” foods. But food has many other meanings beyond its role in medical treatment, as a source of emotional comfort, a social outlet, and even a platform for enacting social change. And these symbolic aspects contribute to the social pressures felt by IBD patients over whether to participate or withdraw from social life.

These accounts also show how these women deal with unexpected questions that can lead them to disclose their illness unwillingly. In these moments, when the back stage is made visible (Goffman, 1959), patients try to preserve face by engaging in the work of educating others about a condition that is not well understood. In spite of the medical and social constraints of IBD, we also see how patients strive to find a degree of agency in their food choices so that the illness does not completely dictate their diets.

The next chapter will delve deeper into the issue of agency by looking at how participants make of an illness in which relapse and remission can happen unexpectedly. It explores how careful self-management practices can create a bind for women who may take responsibility for relapses, leading to experiences of self-blame.

CHAPTER FOUR:

SELF-BLAMING AND STIGMA IN NARRATIVES OF ILLNESS MANAGEMENT

Prologue

Today is a big day. I have finally come out of my first Crohn's flare. I have finally reached remission. Or something that feels like remission. These thoughts roll through my mind as I think about my family's dinner plans tonight. We aren't celebrating anything important. We just want a nice outing together on a mid-summer's night. We decided on Hibachi for tonight's dinner. Nothing too fancy. I look forward to watching the chef cook in front of us and eating the meal he prepares, especially the veggies. Finally, to be able to sit in a restaurant and have a meal without running to the bathroom sent chills down my spine.

But as I think about what food I would the chef would prepare I worry about whether any of them could trigger another flare. After being so focused on cutting out high fiber foods, mostly vegetables, from my diet, I wonder if I can eat some vegetables now that I have reached remission. There is always the fear in the back of my mind that a flare will come back. I don't think giving in to a few vegetables would hurt. It's only some mushrooms, zucchini, and onions. I miss those so much. For one night, it shouldn't hurt.

On the drive to the restaurant, I keep worrying. The fear of being sick again is enough to make me continue to play it safe. But I miss vegetables. I tell myself that the resulting flare won't matter because the next day is Sunday and I can deal with anything that came of it. And, if I only eat a little bit, the flare shouldn't be too bad. But what do I know? This is my first taste of remission. I guess I won't learn what works without trial and error. Is it worth it though?

When we sat down at the restaurant, I decided that it didn't matter, and I was going to eat the veggies regardless, even if only a couple. I wouldn't be having the full Hibachi experience without eating everything. I keep these thoughts to myself.

I look eagerly at the chef chopping up veggies, searing the chicken and steak, and tossing cooked shrimp in guests' mouths. I'm checked out of the conversation my parents and sister are having, finally feeling a sense of normalcy. As soon as the veggies hit my plate, I fork a zucchini, onion, and mushroom into my mouth. In that moment, I feel like myself again. No restrictions, no stomach aches, no worries.

That moment is fleeting. Immediately, I hear my sister gasp, "Jess! What are you doing?! You can't eat that!" She jolts me back to reality and I look at her with contempt. Why is she policing my food choices? And, why is she questioning my choices in public, for all to hear? It's not as if what I eat will make her stomach hurt.

Throughout our childhoods I have always been the "cool" older sister, she the "bratty" younger sister. We've had had a back-and-forth relationship for most of our lives, bickering, fighting verbally and physically, with the typical sibling hatred for each other. Even so, we always stood up for each other. It was one of those I'm-the-only-one-that-gets-to-mess-with-her types of relationships for both of us. Later, things changed for the better. We became much closer because we were both dating and looking to each other for advice and guidance. She came to me more than I came to her, which was flattering. As time went on, we shifted from being bickering siblings to best friends. Now, she looks out for my best interests in every facet of my life just as I do for her. She was even my maid of honor at my wedding

But now, questions about her reaction fill my mind. Maybe she is just worried about me. Maybe she doesn't want me to be sick again. I don't think she meant to sound harsh and cold;

I'm sure this was coming from a place of care and love. But why is she being so direct and loud? Why is this a conversation that needs to happen at the table instead of as a side conversation or later when we leave the restaurant?

With questions running through my head, I respond quietly, "I am out of a flare, and I want it."

At this point, the other guests on the other side of the table are staring as my sister's outburst catches their attention. Unaware of them, she looks at me, saying sternly, "Fine, make yourself sick. I don't care. But don't come crying to me tomorrow when you are in too much pain to move. It'll be your fault." Her statement feels so harsh. Even if it comes from a place a love and concern, I struggled with (resentment?) over how public the scene is and how defeated I felt.

My parents didn't say anything. They just let the moment pass as they and my sister and parents went back to eating their food. I tried to eat but the guilt of thinking about eating another vegetable on my plate put my stomach in knots. Even if my sister's outburst came from a place of worry, even if her intentions were not to surveil my food but to express her concern, I felt criticized. I ate a few more bites of the steak and left the rest. I thought I had regained control of my diet and was no longer restricted from my Crohn's, but in that moment, I realized that I wasn't just battling the illness and my own fears and thoughts, but also other people's worries, thoughts, and opinions.

Introduction

As discussed in the previous chapter, struggles with finding agency and bearing responsibility go hand in hand in patients' experiences of IBD. Many of the participants' stories centered around a loss of control over the body and IBD symptoms as well as control over

private information. Some participants spoke directly about losing control or seeking more control. In these instances, IBD was layered with other issues that they were experiencing. For example, Samantha describes how she was going through many things outside of her control: “My mental [state], I was anxious, I was depressed, I was tired. It was just an influx of things I couldn’t control.” Khloe describes how she feels isolated without anyone to understand her lack of control: “Like I don’t think there’s, like outside of this illness, other adult people can’t understand that situation, there’s no explaining that this is something that I cannot physically control.” Kim describes how she tried to regain control of ordinary things that were taken from her such as having access to a bathroom: “...To have my ability to get to a bathroom be dependent on somebody else was very upsetting and that is what made me shift my diet to be like, well I am just not going to eat in the morning. Because if I don’t have anything in my stomach to get my digestive tract going, then maybe I will be okay just to get some of that control back.”

From the patient’s perspective, IBD is defined by the physical processes of remitting and relapsing which can create ongoing uncertainty in daily life. However, IBD treatment depends on some assumption of patients having agency (Easter, 2012) which is referred to in the chronic illness literature as “self-management.” Self-management has been described as “behaviours and strategies undertaken by an individual in order to maintain or improve health and control illness” (Aduluv et al., 2010, p. 94). Further, self-management can include many different aspects such as the “management of negative emotions, consultation with health-care providers, managing symptoms, taking prescribed medication or managing a diet” (Aduluv et al., 2010, p. 94). The concept of self-management emphasizes the patient’s role in taking charge of their own health by working with their doctors to learn about diet, medication, and coping techniques to reduce

stress. Patients and their doctors assume that self-management is a key factor in reducing pain and gaining a degree of control over chronic illness, which may also slow its progress (Auduly et al., 2010). Yet, even when patients comply with doctors' recommendations and take responsibility for careful food choices, regular medication, and the development of coping techniques, IBD remains unpredictable and often "uncontrollable." In these situations when self-management practices are ineffective, they can become a source of stress for the participants.

In this chapter, I will examine participants' stories of self-management to understand how they make sense of the unpredictable course of the condition. These stories are especially revealing of how they internalize responsibility for the illness in the context of food choice, as well as how others interpret and critique those choices. Stories about their practical efforts to live with the illness work as a sensemaking tool for IBD patients by juxtaposing events and actions to imply motives and causes (Greenhalgh et al., 2011). Narrative scholars have found that stories are a useful tool for sensemaking by putting into perspective the impacts of a crisis (Bruner, 1991; Frank, 2013; Greenhalgh et al., 2011). Furthermore, in Greenhalgh and colleagues' (2011) work on diabetes, they found that in sharing stories with one another, patients exchanged information about self-management challenges, some of them applicable to IBD patients such as knowledge, diet, exercise, medication, and attending check-ups. Each of these challenges are framed within a storyline to better make sense of the illness for the patient and for others in their lives. For IBD patients the central challenge of self-management is gut health.

This chapter begins by examining some of the tensions experienced by patients who follow self-management goals, and in the process, come to blame themselves and their behavior as the cause of their flare-ups. Next, I turn to the impacts on patients of blame from others in the form

of advice-giving and criticism, and then discuss how these processes lead others to attribute patients' food choices in ways that further stigmatize them.

Dilemmas of Self-management

The analysis of participants' stories showed that IBD patients need to develop food-related knowledge to cope practically with their illness. Given that no one standardized diet works for all IBD patients, a specific form of participants' self-management was to develop detailed understanding of the effects of different foods. Such knowledge was developed through a process of careful risk assessment followed by trial and error. One participant, Mackenzie, nicely detailed this process of weighing risks when she said,

I have always struggled with corn. Every time I decide to like when I was feeling good, do I wanna risk it? Like I love corn but is it worth it?

Mackenzie illustrates here the internal questioning that IBD patients experience around food when deciding what to eat and if it is okay to give into those cravings. A bit later she gives another example, saying "I miss being able to have beer. Like beer was setting me off so bad. And I was like, I love beer. I would love to just have like a single beer and not feel awful for the next two days." Mackenzie's comments reflect her belief that a recurrence of symptoms is the direct outcome of eating or drinking specific foods, a belief echoed by Samantha. Samantha's doctor advised her "'Don't eat fast food or anything like that. It's not good for you.' So, I have actually been doing that for a very long time. And the years that I don't do that, I pay for it." In these excerpts, both Mackenzie and Samantha construct themselves as directly responsible for their symptoms and their health.

Like Samantha and Mackenzie, Kat described trying to control her flares as much as possible through careful management of her diet. She uses the word "struggle" in this excerpt

and throughout the interview, indicating the pressures that self-management goals can create.

Becoming visibly emotional with tears welling up in her eyes, she says:

...So, it's only supposed to be a diet for a short term to bring everything down and into remission. Like bring flare down. So that was like, yeah so since then the diet was fantastic, but it's been a struggle because I feel like if I don't do that it's my fault.

Studies of how chronically ill patients make sense of their condition show that individuals vary in how much personal responsibility they assume for their illness (Auduly et al. 2010). Those who heavily internalize responsibility tend to invest themselves in following a comprehensive program of self-management. While this approach can be beneficial in relieving symptoms, this type of thinking reinforces patients' feelings of accountability, so when the disease worsens or a flare occurs, they may blame themselves. The accounts of Kat and other participants suggest that in attempting to manage their symptoms through food choices, medication, and coping techniques, they may experience internal conflict around their level of self-discipline.

In my experience, feeling of guilt and self-blaming were a big part of any flare that I had. I believed that because of my food choices, I was making myself sick. Given my history, I thought it important to introduce this topic directly in the interviews to understand how the practice of self-managing might lead IBD patients to doubt themselves and even question their self-worth. In approaching this subject, I asked questions about whether participants ever felt that a flare had arisen from certain food choices and if so, what they felt in those situations. Similar to my experience, many of the participants offered stories of flares accompanied by feelings of regret and guilt even if they did not immediately label them as self-blaming. Other participants brought up the issue of self-blame without any prompting because they saw it as such a salient aspect of IBD. Often participants explained these incidents by talking about how food was more

than just physical nourishment. Because food was tied to cultural traditions and interpersonal relations, they felt that they were missing out on fully experiencing those things because of what they could not eat. In those moments, they justified eating the “unsafe” food as a source of comfort and sign of normality.

One participant, Samantha, immediately nodded her head when I addressed self-blaming and gave a recent example of celebrating her birthday.

Oh, all of the time [referring to whether or not she self-blames]. I shouldn't have done it. Great example we celebrated my birthday this past Saturday.... We went to a winery because for years I've always loved going to wineries.... So, I was like for one day I am going to go out and I'm going to have fun and I am going to do a wine tasting and it's going to be fine. And I'm not fine. I am still paying for it. I am still hurting, and I am still exhausted, and I am still running to the restroom every 5 minutes.... And in my head, I am like, “This is why I don't do that. This is the exact reason as to why I don't drink, and I don't eat like crap” And I was like, “Why do I keep doing this to myself?”

Another participant, Noelle, talked about why she gives in to certain cravings. In particular, she loves potato chips and crunchy, salty, food.

Like I know it is going to make me feel bad, but in the moment, it doesn't matter to me and afterwards I feel really bad and I'm like “You idiot. You did this to yourself.”

Noelle notes here that she knows that she will end up in a flare after giving in to a craving, but in the moment, none of that matters. For Noelle and Samantha, prior history with certain foods leads them to attribute the cause of their relapses to specific choices. The language they use (“Why do I keep doing this to myself?” and “You did this to yourself”) suggest a build-up of strong feelings of self-judgement for their lack of appropriate self-management.

In contrast, Rose did not seem to experience regret or guilt when she gave in to these cravings:

So, I have been very, very naughty and we have been having pizza like once a week.... And maybe we will have pasta Bolognese. But I will always have it when I know that I am not working the next day and I can just be like fuck it and can just lay in bed or I am working but it is a part of my job when I don't have to be on the phones with the boys... Yeah, it is just that extra way of controlling it.

With her joking reference to being “naughty,” Rose makes light of choosing to enjoy foods likely to cause symptoms. However, she spends time and effort planning when to eat those meals so that she is not experiencing a flare during work. Rose is not alone in this practice. Several participants described planning schedules to be able to give in to cravings. Kralik and her coauthors (2003) discuss this form of self-management at length: how patients attempt to maintain control and create order through carefully planning their schedules and setting boundaries to avoid exposure and disorder. Scheduling time to accommodate food cravings is a unique way in which patients find agency with their IBD.

Several factors can potentially contribute to positive or negative self-management for chronically ill patients. Audulv et al. (2010) claims that emotional distress, limited economic resources, and physical limitations create barriers to self-management, whereas individual health beliefs and knowledge, self-efficacy, and social support have been found to facilitate self-management.

In reviewing the interview recordings and transcripts, I noticed that most participants tended to frame their illness through ideas of self-management and personal responsibility in ways that lead them to feel guilt and to see themselves as the sole cause of their flares. There

always seemed to be instances where the participant felt that they should have done something differently or they knew, or should have known and used, better illness management techniques. As Voth and Sirois (2009) discuss, self-blaming arises from a patient's belief that they have intentionally done something to worsen their symptoms and define responsibility as directly related to the patient's control over the illness. Drawing on a distinction first proposed by Janoff-Bulman (1979), the authors argue that patients tend to identify the source of their problems in controlling their illness as either characterological or behavioral (Voth & Sirois, 2009). Characterological self-blame is the belief that one's character or disposition is the reason for struggles with self-management, while behavioral self-blame attributes these problems to specific behaviors (Voth & Sirois, 2009). Because character, unlike behavior, is assumed to be fixed, characterological blame implies less agency on the part of the individual. This distinction, although presented in psychological terms centered on the individual, is helpful for understanding the deep frustration evident in some of the stories over patients' inability to manage their illness. For example, several participants, including Khloe, spoke about the difficulty of managing stress levels as well as diet to prevent flares.

So, like right now I am in [a flare] and I feel like I immediately was like, I let myself get stressed out. I shouldn't have started grad school. I should have known that that was going to cause me to have a flare up...Or I should have taken more days off or I should have taken vacation time or whatever it is. Immediately you are like, there must have been something I could have done to stop this from happening.

Khloe's comment about "let[ting] myself get stressed out" focuses on her perceived failure to regulate negative emotions.

Kim echoes Khloe's thoughts and focuses on how her stress levels can get out of her control and cause a flare. On top of Kim's IBD, she has also developed a skin condition that looks similar to blisters and may be a symptom of Celiac Disease as well. For Kim, this skin condition has been going on for about a year or so and she has received medication for it, but the skin condition reappears after the medication wears off. This diagnosis creates another layer of self-management for Kim in terms of diet and managing symptoms, leading her to feel even more emotional pressure:

...So, it is like this constant reminder of, like, you kinda let this happen because you have been so stressed, and you didn't take care of your health and now you have another disease that you are going to have to manage for the rest of your life. So, it is just like a very defeating feeling for sure.

Kim explains how she feels like she has put herself in a flare. Once she realizes that she was not paying attention to her stress levels, Kim starts to question her abilities to manage her illness: "was I not paying attention to my stress level? Did I just assume that because it wasn't high that it was gone?" Her comments suggest the self-fulfilling nature of attempting to manage stress in the sense that blaming events on one's own actions or weaknesses in controlling stress contributes to additional stress (Voth & Sirois, 2009).

Overall, these examples of blaming the self for an inability to manage stress show how patients assign causality to events in their lives as a way to manage and predict their illness. A vivid illustration is the link Khloe makes between her current flare and her earlier decision to start graduate school, implying that she should have predicted the increased stress levels ("I let myself get stressed out. I shouldn't have started grad school. I should have known...").

Another participant, Jackie, describes how she assumed she was at fault when finding out that she needed to have a colectomy:

It was obviously a lot to process, and I noticed at first like, and a lot of it was, a lot of the questions I was asking my doctors at first was like, I felt responsible somehow. Like I had done some something wrong or I had failed or is it because I did this, or you know like yeah, about food, about medication, about what I did or didn't notice. Like yeah, with wanting to be in control comes with this sense of responsibility and guilt and I think that's interesting and probably in different ways a common experience for people with IBD.

We see here that Jackie initially tended to blame herself for “failing,” that is for reaching the point of needing a surgery. She is aware of herself as striving to be in control as much as possible, but knows that ultimately, she is not. Further, she goes on to describe how she tried to use diet to control the illness:

Like with food, that definitely became a thing. I felt like that was the way that I could definitely control what I was putting into my body, and it was my responsibility for how I was going to manage my health.

In these excerpts Jackie suggests that feelings of guilt and responsibility are something that comes with IBD. She is especially reflective about how she and other IBD patients assign meaning to their illness experience. These meanings become a guide for future behavior as patients attempt to restore coherence to the disruption, for example by carefully abiding by dietary limitations.

Health communication scholars Sharf and Vanderford (2003) are among those who argue that creating narratives about our lives can help us make sense of our realities. Illness narratives,

specifically, “make use of familiar elements with which we have learned to shape our perceptions of the world” (Sharf & Vanderford, 2003, p. 15). Elements such as people, location, emotions, thoughts, context, actions, among others help patients to make sense of how the illness is affecting them and what their role is in the story (Sharf & Vanderford, 2003). Drawing on Arntson and Droge’s 1987 work, Sharf and Vanderford (2003) claim that these narratives allow patients to do four things: “[1] make sense of health and disease, [2] assert control in the midst of physical and psychological losses, [3] transform their identities and social roles as a result of altered health and disease, and [4] make decisions about their health” (p. 16). For chronic illness patients, using narratives as form of sensemaking allows them to fit the illness into their identity and take responsibility for the decisions that they make about their own health. Furthermore, Sharf and Vanderford (2003) claim that illness narratives shape patients’ perceptions of control and restore it when the perception of control has been taken away.

Jackie centers her chronic illness story around surgery and symptoms and, in turn, centers her behavior as the possible cause for surgery. These interpretations can prompt feelings of regret and even guilt. However, researchers have found that participants who have strong support systems and extensive knowledge about their illness were better equipped to manage the resulting self-blame or guilt in their narratives (Voth & Sirois, 2009).

Food Choice as an Occasion for Criticism and Advice-giving

Participants offered various examples of criticism and unsolicited advice from others concerning their self-management practices. These episodes, which involved doctors, friends, and family members, varied in their emotional tone and in the meanings, they were seen as conveying. Khloe described how frustrating it was when her doctors were openly critical: “Sometimes from my doctor like, ‘you weren’t taking your medication, so I am not surprised that

you are having a flare.’ And it’s like that’s not helpful to me right now. I just need someone to listen to me.” The doctor seems to see her as a noncompliant patient (Donovan & Blake, 1992) and he offers his criticism as necessary medical advice whereas Khloe is looking for an expression of caring and support. When my sister criticized my food choices, her tone came across overbearing, blunt, accusatory, and loud even though her intentions were out of care for my well-being. In those moments, I felt shocked, although I would try to respond to her in a quieter tone and let her know calmly that it is not her job to police my food choices regardless of her good intentions. Moments like I experienced with my sister and Khloe with her doctor demonstrate the sensitivity needed in giving advice to a patient for her to feel supported rather than policed.

Many participants experienced their food choices being surveilled. Marie’s description of having her food choices evaluated by her friends was similar to my experience in that her friends were very direct in questioning her judgement:

My friends are stricter than me. Like sometimes I’ll be out and be like I’m going to get nachos and my friends will be like “if you eat dairy, you will be sick later” and I’m just like, “I don’t care I want nachos” and then they are seeing you order that, but I want to. Marie recognizes that these comments are meant as a form of honest advice. Not only do they not want her to be sick, but their advice can be heard as a relational message affirming that her well-being is important enough to them to risk causing offense (Tracy & Robles, 2013). However, her account shows how advice that is not meant as derogatory can be felt that way, especially when it turns into joking or teasing. Marie went on to describe her friends’ reaction, “But, you know at most they will just make fun of me later like ‘oh well you shouldn’t have gotten the nachos’ (said in a soft sing-song voice). Which is fine and I’ll be like whatever just

make me tea and leave me alone.” Marie avoids an argument with her friends by pretending she is not offended but the effect of the whole interaction seems to make her feel even more isolated. Another participant, Jocelyn, worries about her coworkers’ judgment: “Like for instance if I eat something I shouldn’t at work, I wonder if others think to themselves, “Well, she shouldn’t have eaten that or whatever.” Like Marie, she chooses not to make an issue of their comments, but rather, “just blow it off and not worry about what they think or say.”

In contrast to my experience and Marie’s, in which criticism was expressed directly, Kat described how her family, specifically her grandmother, was more indirect in her comments. For example, her parents might briefly comment on her choice of food, saying “...’oh you had chicken, is that fine?’ So, they are not too much concerned about it and that’s fine.” However, Kat’s grandmother remarked to her:

‘Oh, I didn’t know that you were allowed that, or I didn’t think you were able to eat that.’

And it just becomes, it’s just too difficult to explain like, having it [IBD].

Although the comment is tactful on the surface, Kat hears it as blaming because it makes an ordinary event (her eating) into something problematic (Tracy & Robles, 2013), thus requiring her to give an explanation that allows her to save face.

Goffman and later communication scholars such as Martin (2016) and Goldsmith and Fitch (1997) have discussed how issues of identity and face can be at stake in episodes of advice-giving and criticism. Any input, whether it is implied or stated directly, can be heard as threatening the receiver’s face, especially if the comment is heard as implying a lack of knowledge or competence. As Goldsmith and Fitch (1997) explain, advice-giving even if it is meant as support, can have unintended effects if it is heard as a boundary violation, thus increasing receivers’ distress or creating resistance. Additionally, theories of interpersonal

communication emphasize the relational sensitivity of criticism as the same message will be heard differently depending on who the participants are and the history of their relationship (Tracy & Robles, 2013). This point is, again, illustrated in Kat's interview when she describes receiving a series of comments and questions from her grandmother that over time have caused her to become guarded: "I think my grandma may have questioned something along those lines like, 'oh like how do you think you got this?'" Kat senses disapproval in this question because it implies that she herself is responsible for having IBD. Because of these day-to-day challenges to her self-image, Kat, along with many of the participants, is careful with who she invites into that part of her life to avoid increased tension in her relationships.

In one particularly traumatic episode when Kat and her grandmother were on an airplane, she tried to keep her grandmother from knowing that she was having an accident in the middle of the flight. As her grandmother slept beside her, Kat got up and rushed to the toilet but fainted while waiting in the queue. When she came to on the floor of the plane, she "knew that I needed to go to the toilet, like it was going to come out soon...and then I said...I need to go to the toilet. And they still kept me down...So, thankfully, the flight attendant helped me, and I had hand luggage and all of my clothes was in that so thankfully like she went to get it and I just said to her, 'Please don't wake my grandma. She's asleep.' I don't want her to worry ever, and I would never have told her anyway. But I was specific by saying, 'Please don't wake my grandma.'" In this moment she was not concerned with complete strangers like the flight attendant helping her or seeing the accident, nor was she focused on her physical condition as much as she was on how her grandmother (someone who "doesn't understand") might react.

Beyond internalizing stigma from others, participants described moments when participants felt blame from others. These were scenarios where people would directly blame

them for a food choice or surveilling other decisions they made. I have also experienced blaming from others because of my food choices, specifically from my sister as described in the opening narrative. While participants described this blaming as subtle and not meant in a derogatory way, they felt that it was unnecessary because of the amount of self-blaming or regret they were already experiencing. Participants' accounts of self-management show that dietary regulation is one of the ways IBD patients "create order, discipline and control in their lives" (Kralik et al., 2003, p. 260). But these practices also carry costs, especially when the added policing of food choices by others adds to the stigma that the participants have already felt and internalized.

Self-Blaming and Implications of the Looking Glass-Self

As I read and re-read the interviews, I gained a better understanding of how deeply internalized the stigma of IBD can be and how the stigmatizing interactions surrounding IBD differ from those of some other illnesses. The idea that patients see themselves reflected in others' responses to them (Charmaz & Rosenfeld, 2006) is a powerful lens of understanding how they feel about themselves and their bodies. This is especially complicated for those living with IBD because their bodies are always in flux between remission and flares, leading to the constant threat of exposure of the illness.

The threat of exposure is even more salient when we consider the role of food choice. When others are aware of the consequences of certain food choices on the bodies of IBD sufferers, their responses (e.g., "you shouldn't eat that" or "I didn't know you could eat that") address the individual's perceived lack of proper self-management. Easter's (2012) concept of volitional stigma is helpful for understanding how others' framings of the illness in relation to self-management ideals are communicated in ways that reinforce a sufferer's feelings of responsibility and of self-blame. Easter (2012) considers how genetics play a role in stigma for

those living with an eating disorder. The possibility that genetics plays a role in eating disorders means that the condition can be viewed in less stigmatizing ways “because eating disorder stigma centers on personal responsibility, rather than dangerousness or unpredictability” (p. 1408). Easter (2012) goes on to describe two kinds of stigma associated with eating disorders that can be transferred to other forms of illness (both physical and mental): 1) labeling a condition as a “mental illness” and, 2) trivialization. For this project, both of those types of stigma are important but trivialization is of utmost concern. This type of stigma denies the seriousness of the illness and connects the illness to behavioral choices instead of physiological causes; here, the idea that the illness arises from the patient’s choice is a reason to discount its seriousness. Therefore, if the person is choosing to skip medication doses or eat foods that aggravate the illness, their behavior is assumed to be the cause of symptoms, and the illness is therefore perceived as less serious. Here is where we can see volitional stigma in action according to Easter (2012). Volitional stigma describes the illness not as “something one *is* or *has*, but . . . something one *does*” (p. 1410).

This concept can be applied to those living with IBD. While patients cannot control the fact that they have IBD, they still have some agency over their choices. Even during a relapse when it feels to a patient like they are losing control, family and friends may choose to place the source of the problem on patient’s behavior rather than the condition, which can compound the stigma. For example, Gretchen describes people questioning her appearance when she was going through exclusion diets: “. . .like there was a time where I was only just eating chicken breasts, olive oil, and I forget what else. And people were like, ‘oh are you anorexic?’ And I was like no, I just can’t eat anything. I’m not allowed to.” Kat shared similar experiences: “. . .So I was measuring some stuff for what I was eating and then there’s the question of ‘why are you

measuring that' and then they start labelling, but they don't say anything but I'm thinking in my mind they think I've got an eating disorder which just adds just a massive amount of stress." Eating disorders become conflated with IBD when a patient does not offer an explanation of their food choices, which as Kat says adds to the felt stigma.

When I asked Kat whether she had ever felt that someone saw her as faking her illness she offered a powerful example of how an illness can be delegitimized that centered on her grandmother. Her grandmother's friend's daughter had been diagnosed with a severe case of ulcerative colitis and had lost a lot of weight. Kat explained that

She [grandmother] was talking about it and it was almost like a comparison [to Kat]. "Oh, but she is really sick!" and I think at one point she said, "but you don't look sick." And part of you thinks, "you don't see me every day. Do you want me to tell you every time I go to the toilet?"

This example illustrates the subtle way in which volitional stigma can be enacted and it also shows the burden of performing "credibility work," in which patients must convince others, either doctors or relatives, that they are truly sick. If others suspect a patient is "crying wolf," the patient is faced with persuading them that her health concerns are legitimate (Head et al., 2021). Thompson and Duerringer (2020) argue that this type of communicative labor is especially demanding for those patients "whose suffering may be the greatest and for those who are already doing a great deal of credibility work to appear as convincing witnesses of their own health" (p 17). Credibility work is also associated with gender and other social identities, as women face added barriers in trying to be viewed as legitimately sick (Head et al., 2021)

Credibility work is under-addressed in IBD research. Given the socially stigmatized and "shameful" nature of symptoms like diarrhea and vomiting, performing the role of legitimate

patient creates an additional bind for IBD patients because those symptoms are normally concealed. As Kat says, in her imagined dialogue with her grandmother, “Do you want me to tell you every time I go to the toilet?” IBD patients who are struggling to conceal the physical signs of illness, the severity of the illness is discounted. These pressures add to those she already feels because others might question her food choice and then blame her (directly or not) or try to label her with an eating disorder. Another participant, Jackie, who went through surgery for her advanced IBD, offered a reason for why others might apply volitional stigma to a patient. She suggests it is because others want to think that the person has control.

I think that kind of control is not only an issue for the person with the disease but the people around them want to believe that the person with the disease is in more control than they think they are because then they think that, “well it won’t happen to me cause I can choose things instead of it just being that you are kind of at the mercy of whatever is going to happen with your body”...

She perceives that people want to avoid the idea of having an illness whose cause is unknown and whose symptoms involve so much unpredictability. They prefer to see the illness as something that can be avoided through careful choices and self-management.

Jackie highlights how self-management assumptions and goals, summarized in the idea of poor self-control, play in to the looking-glass phenomenon. This is something that Charmaz and Rosenfeld (2006) discuss in length. They argue that when our public performance of self fails to match the person we consider ourselves as being, we internalize the negative feedback we get from other people; thus, the looking glass-self is realized. Jackie describes IBD patients as being “at the mercy of whatever is going to happen with your body,” highlighting the helplessness that she and others experience both in relation to their symptoms and in relation to others’ views of

them. She recalls that she began to feel that “it was my responsibility for how I was going to manage my health . . . [Food choice] was a lot internal but *I think we also kind of get that message from the people around us or just like in general* so that’s confusing.” Messages of blame or shame from others implying poor judgement, lack of will power or noncompliance are both pervasive and “confusing,” leading patients to internalize these negative perspectives.

Participants described their self-blame as something that they did not even think about consciously; it just happened based on judgement or criticism that they had received. Each participant struggled with stigma regarding their food choices, regardless of whether or not they experienced a flare. As several of them emphasized, the illness can flare regardless of a patient’s self-management techniques, including techniques for managing stress as well as diet. Many participants recognized that no matter how rigorously they managed their diet or stress, a flare could still happen. Regret or blame usually followed an unexpected flare-up because most of the participants attributed relapses to their seemingly poor self-management. Thus, participants used self-management as a way to frame and make sense of both the lows and highs of their illness. It was not surprising, that when I brought up self-blaming during the interviews, some participants immediately nodded their heads and said something along the lines of “well it’s just part of the illness.” They had a better understanding of how to address their self-blame and cope, a topic that will be detailed further in the next chapter. We can see how management, blaming, food, flares, and stress layer on top of each other to create an emotionally difficult situation for IBD patients.

Conclusion: Self-blaming: A Normal Part of IBD?

This chapter further nuanced the connection between food and agency for IBD sufferers by exploring practices of dietary self-management and how they can lead patients to patterns of

self-blaming, especially after eating “unsafe” foods. The chapter demonstrated that many participants felt that self-blaming is a normal part of IBD, that it just comes with the territory. Viewed through a sensemaking lens, self-blaming may be a way of regaining a sense of control by viewing one’s symptoms as explainable. The chapter also analyzed instances of unsolicited advice that patients receive from friends and family about their food choices. It shows how the looking glass-self becomes realized for patients when others attribute symptoms to patients’ voluntary behavior, unintentionally compounding feelings of stigmatization and self-blame. In the next chapter I turn from a focus on constraints to an analysis of coping mechanisms. I discuss some of the ways that patients find communication strategies for constructing a new, more empowering normal.

CHAPTER FIVE: COPING COMMUNICATIVELY WITH IBD

Prologue

It's Thanksgiving. I have been going back and forth to doctors and residents for the past 3 months describing, in detail, my stomach and joint pain and my frequent bowel movements. In between each appointment, I have given what seem to be liters of blood to find the culprit causing me to feel this way. But still no news from the doctor or his resident. I'm in pain from my back, legs, and stomach and can barely eat or drink. I'm pale, cheeks sunken, gaunt.

Despite all of this, I decide to go on a family vacation to Siesta Key, Florida to be with family, enjoy some sunshine, and get away from the cold suburbs of Chicago. My spirits are up, and I am relieved to get a break from work and classes and take my mind off my uncontrollable body. At the condo, I decide to go out to the balcony and admire the view of the icy blue waves washing up on the white sand beach as the sun rises in shades of yellow, orange, and pink. I pour a bowl of cheerios for breakfast hoping that they stay in my stomach and so far, they seem to be. The white sand beach [maybe sandy beach? to vary it from earlier sentence] with waves lapping up is calling my name and I just hope my body behaves.

“Jess, almost ready?” Dad asks.

“Yeah! I want to get a good spot on the beach!” Julianna quips.

“Almost! Just got to put on my bathing suit and put up my hair,” I reply as I walk to the bathroom.

Mom chimes in with “Well hurry up! Everything is packed and ready to go!”

I have my bathing suit on and am trying to put up my hair when I feel my stomach gurgle. Here we go. I'm worried those cheerios are ready to come back up. But no, I think it's just gas, so I relax my body to release it. Instead of gas, a load of shit empties into my bathing suit bottoms. I cry and cry and cry. I feel like a child who hasn't been potty trained and must retrain my body. I carefully take off my bathing suit bottoms and set them in the tub. Cleaning myself off as best as I can, I put on shorts and run out of the bathroom in tears and choke out, "Go to the beach without me!"

"What? Why?" mom questions, surprised.

I feel so small, defeated, and embarrassed that I don't want to tell them the truth. Their worried faces aren't making matters easier for me. I'm embarrassed to say anything, but I do.

"Because I shit myself! And I didn't even feel it!" I continue to cry and cry and cry. I don't know what to do and I feel like a child. I'm scared because my body betrays me in ways that I don't or can't understand. Their eyes are wide open with mouths agape, no one says anything. I watch my parents exchange glances and my sister's eyes glued to my face. Finally, my mom says calmly,

"Honey, it's okay."

"We're here for you" Julianna says.

My dad tries to come over and hug me, but I shrug away. I feel dirty, like shit is running out of me constantly and there's no cleaning it up. My family just lets me cry. I can see pity in their faces along with worry and it doesn't make me feel any better.

"Sweetie, why don't you just quickly wash your bottoms. We'll wait for you," mom says.

So, I did. All the while thinking in the back of my mind that it could happen again but in a public place. *What will I do if this happens on the beach? In front of strangers? How will I*

explain myself or deal with it? Unsure of what my parents and sister are discussing, I can only imagine that they are thinking about how to handle this situation when I come out. Eventually, when I have cleaned myself up and emerge from the bathroom, they all act like nothing happened and we continue to the beach. Maybe they want to save me from more embarrassment. I feel broken and lost. We don't know why this has happened but I'm worried that my body will revolt again. My stomach still hurts and so does my back and legs, but I endure it silently. I endure it for the family. I endure it to enjoy the beautiful white sand beach and cool water. I endure it so I can regain some normalcy in my life. It was just an accident. But my body betrayed me.

This accident was a turning point in my journey with Crohn's. For the rest of this trip and even to this day, my parents and sister have kept a careful watch over me. Because my family chose to ignore the incident even while treating me like a porcelain doll, I didn't feel like I could bring it up again or work through it. Instead, I tried to cope with it on my own through journaling. Still undiagnosed, I felt as if I had lost all control. The embarrassment and stress that accompanied this moment has stayed with me. Because my parents and sister lived through it with me, we experienced it together, yet we coped differently. While I wanted to move on quickly from the experience and forget about it, they wanted to keep bringing it up to prevent it from happening again. Treating me as if I would break, they brought up questions like "Honey, should you eat that? Remember what happened" or "What if you have another accident?". These questions were always accompanied by looks of pity and widened eyes if I chose the opposite of what they expected. Their way of coping was trying to keep me on track.

Outside of my parents and sister, no one knew of my symptoms and what was going on at that time. I relied heavily upon them for support and guidance through the process of coming to a diagnosis. Even if their support was not exactly the support I needed or wanted, just having them there to talk to and listen helped me these uncertain times and gave me a foundation for learning how to cope with future flares post-diagnosis. Without their support, I would not have been able to be as open about my illness as I am now. By not treating me differently or belittling me for accidents, I felt that I could find similar support in other relationships. I knew that once I decided to find a partner and settle down, they would need to be kind and supportive when issues of my illness came up because this illness is not going away. I am lucky to have found that now. Because my family has learned about the illness and its effects with me, I know that they will understand. although indirectly. the pain, struggles, and uncertainties that I face.

Introduction

The previous two chapters focused on the tensions facing women with IBD whose food choices are evaluated according to prevalent understanding of healthy eating. I have also explored the relational consequences of food choices, in particular the dynamics of blaming by self and others when eating deviates from medical authorities' recommendations. By showing how day-to-day eating routines are disrupted by IBD and how disrupted eating affects social relationships, participants' stories give a detailed picture of the impact of IBD on quality of life. As the symbolic interactionist framework emphasizes, the meanings that IBD sufferers make of their symptoms and experiences form the basis for how they act toward their illness and its limitations (Charmaz, 2006), in other words, for their coping.

Coping has been defined in many ways but is broadly understood as actions that seek to lessen the physical and emotional burden that is linked to stressful life events, such as chronic

illness (McCombie, 2013). The interviews revealed that coping among the participants was constant and fluid, a necessary component of living with IBD. Transitioning in and out of remission, managing flares and the accompanying self-blame, and dealing with unexpected disclosure of the illness seem to be a daily battle. Many participants found themselves especially challenged when coming out of flare because they were not sure how long remission would last or what exactly they could do to sustain it. Furthermore, because IBD can be an “invisible” illness (Charmaz & Rosenfeld, 2006), participants felt as if their condition was invalidated by others. They described having to explain their behavior or appearance when people questioned how they could “look well” or “not sick” while still living with the unpredictability of IBD.

Given the personal content of the interviews and the feelings of sadness and frustration shared by the participants, it seemed natural that our conversations would transition to a discussion of coping. It came up both as part of my interview questions when I asked participants questions like, “how do you cope with accidental disclosure?” or “have you found outlets for coping?” but was also mentioned spontaneously. There were times throughout the interviews when the participants would bring up coping on their own and even ask me for my advice regarding coping with such a fluctuating chronic illness. These moments increased my awareness of my dual role as a researcher and IBD sufferer. I found in these moments that the participants were more open about their guilt and shame because they saw me as a member of the IBD community who could relate to their experiences. From my perspective, being able to talk to someone who has experienced a flare, or who recognizes the impulse to self-blame helped me feel validated. I no longer felt so alone with the illness. And the participants mirrored this response. Many talked about how nice it was to talk about the illness without having to over-explain; there was an implicit understanding of the illness and its consequences. After reflecting

on the interviews, I realized that just talking about the illness with women who are also living with was helpful to me because of our shared understanding of the illness.

This chapter focuses on how IBD patients cope with the everyday chronic concerns of their illness. To do so, I first explore moments in the interviews where the participants are describing their individualized coping techniques. However, the sensemaking perspective that guides this dissertation invites critical reflection on the communicative processes underlying coping techniques. One form of communicative coping is storytelling, in which we recount our experience with illness, however turbulent, and try to find positive moments to foreground. Other forms of communicative coping that emerged from the interviews included normalizing appearances, storytelling, humor, and relational support, among others.

Types of Coping

From a biomedical perspective coping has been described as a continuum ranging from adaptive to maladaptive depending on how it affects a patient's health outcomes and quality of life (McCombie et al., 2013). Participants used similar language when they spoke of coping well or poorly. For some participants, coping itself was a source of self-blame. For example, Audrey described herself as “defiant and angry” early in her illness and “trying to be as normal as possible and do[ing] the same things everyone else was.” She describes how coping by ignoring the flares made them much worse, leading to discussion with her doctor of possible surgery. Eventually Audrey found more effective strategies. In particular, she cites medical cannabis as the reason for her two-year remission. Lainey also described using marijuana to help calm and relax her.

Along with marijuana, participants described other forms of what McCombie et al. (2013) refer to as “problem-focused coping” to lessen their symptoms, such as working out. Ruth

describes going to the gym as “mak[ing] me feel really good in life” and how “having my muscles stretch and strain and grow through strength training you know just gives me peace of mind.” This helps Ruth ease her stress and, in turn, manage flares better. Ruth’s approach focuses on solving the problem of relieving symptoms to find a sense of greater well-being.

Samantha echoes the importance of exercise, explaining: “...so my disease is now very active in my rectum, so whenever I am not having a bad day, I get on the bike, and I just do a ride.” Samantha also describes going outside, reading, changing her diet, and meditation as ways to relax. Her approach illustrates what McCombie et al. (2013) call “emotion-focused” coping. Beyond physical workouts, Samantha discusses meditating, changing her diet, and going outside to help her cope with her IBD. In emotion-focused coping, the patient attempts to reduce any emotional turmoil they are experiencing due to the illness (McCombie et al., 2013). This is more than just eliminating the problem, instead focusing on ways to handle the emotional stress that accompanies a flare or disclosure, for example. Here, Samantha talks about finding ways to breathe and relax so that she feels like she has control over some parts of the illness: “...if I don’t have the energy, I’ll do a meditation. So, I’ll sit there and just breathe.” With an illness that is so unpredictable, it is difficult to manage symptoms even with medication, so doing meditations, taking a ride on her peloton, or changing her diet helps Samantha to cope by making her feel like she is more in control.

Another form of problem-focused coping to address symptoms involves accessing health-related online message boards such as Reddit for advice and information. Kim attributed the improvement of her symptoms to learning how to track her eating more effectively, which was the result of information she gathered online. The virtual community of IBD sufferers was an unexpected source of support for her:

Hearing more about what foods are triggering for other people and...just knowing that other people are going through this. Like hearing success stories. Like I saw one post a couple of weeks back and [it talked about] ‘I just went in and got a colonoscopy done and my GI was like, it looks like I never even had ulcerative colitis because I just managed it so well.’ So those types of things where it might be completely unachievable goal for most people but knowing that you can have that with this lifelong disease where it is like I can get into a good remission. It is possible.

These comments are an example of “cybercoping” as described by Kim and Lee (2014).

Accessing information can be a coping mechanism when it provides a sense of reassurance and connects individuals to “fellow problem solvers” (Kim & Lee, 2014, p. 778). Beyond providing practical information, Kim is inspired by others’ stories that show that remission is possible. She wishes that she had known about this virtual community when she was first diagnosed.

Coping with an (In)visible Illness

The previous examples show participants coping with illness through intentional forms of self-management that extend beyond diet. Using medical marijuana, engaging in physical exercise, and accessing online communities are some of the ways IBD sufferers try to reduce pain and gain control of their illness. But the interviews also revealed other kinds of coping that were aimed at managing threats to identity and psychosocial difficulties that arise with a stigmatized condition. Three forms of communicative coping that emerged from the interviews are normalizing appearances, humor, and re-storying illness.

Normalizing Appearances

The body’s appearance is central to the experience of IBD and to the social and identity processes involved in its management. There were many points in the interviews where

participants described strategies for maintaining a normal appearance, knowing that once their condition became known, their lives would need to be reorganized around their public and “deviant” identity (Kelly, 1996). With a seemingly invisible illness such as IBD, at times when accidents occur in public or the lesions appear on the body during a flare, the unusualness of the bodily display can make them object of powerful stigmatization. Because of this, many participants felt that they needed to hide their illness.

Defenbaugh (2013) recounts the many ways women can conceal a chronic illness such as IBD, including using make-up, adopting a professional dress code, and putting on a performance of wellness in relational moments. However, when I asked participants whether they tried to hide the illness through their dress, many responded that they did not make a serious effort to change their physical appearance. As Kat said, “And when you just don’t feel good you just want to be in comfortable clothes...I would just wear more baggy and more comfortable clothes.” Kat explains that she does not feel like she must dress a certain way to hide the illness and would rather just be comfortable. On the other hand, some participants did mention instances in which they went out of their way to hide their illness, giving forceful accounts of the work that went into normalizing their appearance. The follow analysis focuses on one such account because it shows the many decisions that go into the effort to maintain a desired front as a person who is not sick and the tensions that arise from that performance. Samantha offered a highly detailed picture of how she concealed her IBD at work.

I guess it’s just with time that I have learned how to sneak away or dodge out of something really quickly or have different phrases of, “Oh I just have to go check on something really quick. I’ll be right back...” Or I have my own office so I can close the door if I am having terrible symptoms or I am not feeling well, and cry it out and open

the door when I am ready...I guess I come in every morning to my job with a huge smile on my face and upbeat personality because I have told myself over the years that I am never going to let my illness affect me when I am at work or in my personal life...And so that upbeat kind of attitude really deflects from people thinking, oh she's sick.

Samantha details the phrases that she uses along with the layout of the offices and her closed door to provide concealment from her co-workers. Significantly, she adopts the demeanor and attitude of a "well" person so that she does not draw unnecessary attention. She then gives more examples of how her dress helps her conceal her IBD, saying,

I am going to show up in heels every day, slacks, a dress, my hair is going to be done, my makeup is going to be done. My makeup is gonna be perfect because I am going to get up at five in the morning and make sure that you don't know [about the illness]. And I feel terrible. I mean there have been days where I pull out of my driveway and my husband is like, "Don't go to work." I put on my makeup, I did my hair, I put on the outfit, I'm going to work. I might cry on the way to work, but no one knows by the time I step in that door. Because the way that I look, looks like I just woke up and came to work that day.

Further, Samantha describes doing these things not only to conceal, but as a way for her to cope with her illness and find stability:

Every day I would wake up and put makeup on and I would get dressed and that was my thing. My hair is naturally very curly, and I would just leave it down and I can't do that. I would make sure that I looked good so that I could start feeling better.

Samantha describes doing her making and getting dressed up as her "thing," a routine that makes her feel better. On one hand, her behavior can be viewed as an attempt to conform to gendered

expectations by adhering to a middle-class, able-bodied, and stereotypically feminine appearance. By normalizing her appearance, she reinforces the stereotype that women need to be presentable and attractive and cannot appear ill. Instead of focusing on reaching remission and having a physically “good” day, the goal of this type of coping is to maintain an outward feminine appearance that is unbothered by illness (Kendrick, 2008). Feminist scholars such as Kendrick (2008) offer a perspective on this philosophy of “look good, feel better” as it is marketed to female cancer patients and especially how it emphasizes hiding the illness as much as possible to present an outward appearance of femininity. Kendrick points to the beauty and makeover workshops in which cancer patients are taught the “look good, feel better” philosophy which centers on hiding hair loss, body scarring, and other signs of illness. These workshops assume that patients are in heterosexual relationships, with workshop leaders’ remarks focusing on how patients’ husbands will appreciate their use of makeup and a breast prosthesis. Kendrick (2008) critiques these practices for normalizing heterosexual femininity and reinforcing stereotypes for what it means to be feminine even while sick.

Beyond illustrating the “look good, feel better” philosophy, Samantha’s attitude can also be seen as an example of what Hay (2010) refers to as the John Wayne Syndrome. Based on her research with chronically ill patients in the U.S., Hay (2010) argues that chronically ill people continue to force work-based productivity as a way to avoid shame or guilt. Strategies to hide the illness by “pushing through” at work come from U.S. based expectation of productivity which then “coalesces into a cultural model that I call the ‘John Wayne Model’ [after the iconic actor in Western movies] – a purposeful indexing of the image of disease as something to be wrestled into submission” (Hay, 2010, p. 260). By hiding the illness and maintaining their productivity, chronically ill individuals may be trying to reclaim their agency and especially with an invisible

illness, this is motivation may be even stronger. Patients living with invisible illnesses appear healthy, so any lack of productivity comes into question with others needing evidence to prove that the fatigue, stomach aches, or joint pain is in fact real (Hay, 2010). Because of this, many chronically ill patients want to continue to lead a “normal” life of productivity to avoid pity or punishment. Seen in this light, Samantha was focusing on finding ways to be productive to force the illness “into submission” while creating an outward appearance of strong femininity.

However, while there are valid criticisms of the “look good, feel better” philosophy and John Wayne Model for their emphasis on concealing illness, it is important to recognize that Samantha was using these tools to regain agency without concern for the cultural narratives at stake. For her, taking care of her appearance was an effective strategy for coping with her illness. In other words, Samantha’s effort to make herself look good led, in turn, to improved emotional outlook, which helped her conceal her illness even more. As she says, “I might cry on the way to work, but no one knows by the time I step in that door. Because the way that I look, looks like I just woke up and came to work that day.”

This ability to appear ordinary was empowering for her during times of great physical struggle. Samantha was focused on not drawing attention to her body so falling into the cultural narratives of maintaining a heterosexual, feminine body and being continuously productive helped her remain in the shadows and cope with her IBD.

Humor

Humor is an important element of interpersonal communication between IBD sufferers and others. Disability scholars Bingham and Green (2018) note that humor can “encourage, even force, others to view an aspect of the human experience from a perspective with which they may not be personally familiar or to consider sides of an issue to which they usually stand in

opposition” (p. 2). Because IBD can be perceived as grotesque and serious in nature, especially during flares, many participants found that joking about it not only helped them make light of a serious situation, but humor could open a space for the discussion of taboo topics, especially with friends and significant others.

Marie describes conversations with her friends about going on long road trips together: “They are like ‘How long is it going to take us to get from this place to this place’ and they are like ‘It’s about a 3-hour drive and if we stop for Marie’s bathroom breaks maybe it will be about 5 hours.’” Her friends use humor to lessen the seriousness of her flares and frequent bathroom trips. Marie talks about how this makes her “. . . feel better because you know, in your mind you are like, ‘Oh shit, I have to go on this drive with people, what if I don’t feel well’ and having them like acknowledge the fact that they are totally okay with that just totally removes the stress from the situation.” Her friends use humor to show their acceptance of her and the illness.

Gretchen and Rose had similar experiences to Marie. Gretchen explains how she and her siblings have used humor throughout their lives to handle difficult situations so when she was diagnosed, humor felt like a natural coping technique: “Me and my sister have an older brother, so we always have...joked around...It made it easier for me to make a joke about [IBD] instead of feeling so different...So, it was just easier to make jokes about all of this stuff.” Gretchen fell into humor because it was a natural coping technique that she was used to. She explains that humor became the vehicle for her to feel less different despite having IBD.

Similar to both Marie and Gretchen, Rose explains that humor is how she has coped with many different traumatic events in her life. From relationship trauma, IBD, childhood trauma, to other illnesses, Rose describes how, with co-workers, friends, and her boyfriend, she always makes light of the situation and tries to find the positive, for example when she and her boyfriend

discuss her frequent bathroom trips: “Like I will come out of the toilet and come back to bed, and I’ll be like, ‘I had diarrhea’ and he will be like, ‘did you poop on the floor?’ And we just make jokes about everything which makes things a lot easier for me.” Humor has enabled Rose to cope through multiple traumas but in the context of chronic illness, it allows patients to describe IBD scenarios that are ordinarily taboo, like going to the bathroom, and enables friends and family to respond with ease and understanding. Rose explains that laughter is fundamental to coming out of serious or traumatic situations, posing the question: “If you cannot laugh, what can you do?”

Even further, humor can work as a tool to help others understand IBD better. Marie, Gretchen, and Rose have all described how humor helps them feel less different. In social situations with friends and family, humor gives space for understanding and acceptance. Rose described how using humor allows her to show others that she is okay with her IBD, which can open up more serious conversations about what it entails: “Yeah [joking] helps them understand and see that I am okay, and it opens up a conversation about [IBD] which I think is really necessary.” Humor as a gateway for discussions about IBD can help to lessen stigma and create more awareness of the everyday battles that an IBD patient faces.

Storying Illness

In addition to the practices of humor and normalizing appearances, another kind of coping process is found in participants’ illness narratives, particularly in the way they structure their stories of becoming ill. Early in the interviews I asked each participant to tell the story of their illness onset and diagnosis and they responded by providing a sketch of their illness history. Several of these accounts were especially detailed and they shed light on the ways in which IBD sufferers attempt to restore a sense of order to a chaotic experience (Bruner, 1991; Weick, 1995).

Additionally, storytelling works as a form of emotion-focused coping (McCombie et al., 2013) and allows IBD patients the chance of working through and constructing meaning retrospectively and in some cases, finding positive outcomes in their interpretations of events.

Using Frank's typology (2013) as a guide, I will describe how IBD patients illustrate each of the three main types of storying: restitution, chaos, and quest. Most participants showed a mixture of the narrative types. However, IBD patients do not necessarily move through these three types in a continuous or linear way. Depending on the course of their illness, patients may settle on one narrative form whereas others may cycle between different forms. An IBD patient who is experience a flare going on many months, may story their illness as a chaos narrative for a longer period of time than someone who reached remission sooner and find it difficult to resolve events into a quest narrative. The following discussion is based on participants' accounts of their early illness and diagnosis. The analysis is preliminary; since I was not able to conduct interviews at different points in time, I use their illness stories mainly as snapshots, focusing on the structure and sequencing of events at the time of the interview to see how each of the narrative types of chaos, restitution, and quest are reflected in the accounts of their illness.

Restitution. Frank (2013) describes restitution as a narrative organized around the theme of restoring oneself to one's normal, healthy state. Restitution is "the most general storyline that can be recognized underlying the plot and tensions of particular stories" (p. 75). While Frank (2013) claims that the chronically ill rarely use this narrative since recovery is technically not achievable, it still occurs. Some IBD patients can find lasting remission and thus are able to frame their illness as finding restitution despite lacking a permanent cure. Among the participants, Gretchen illustrates this narrative most clearly because she describes how she found relief from symptoms by finding medication that worked.

Gretchen describes how she experimented with different medications throughout the beginning of her illness and emphasizes the difficulty of finding one that worked:

And then I had a colonoscopy...so I started taking Asacol. Didn't really see much improvement from that... [The doctor] started doing...the enemas with like local...steroids and that didn't really do a lot for me. And [the doctor] was like "I don't get it." ...And so, I had to do like two sigmoidoscopies...and after...the second one she was like "You know you just need to go on steroids."

Starting to re-story her illness, she explains that by working with the doctors, she was able to get on steroids and better manage the illness. While Gretchen now occasionally deals with minor flares, she explains that after going through this, she has reached a point where she can manage her illness much better than in the beginning:

After [the steroids], I had pretty tremendous improvement and then...I had been taking Lialda...I think that was probably like ten years ago and I haven't really looked back. Like steroids were an absolute game changer...I mean it's not perfect by any means, but it is much better than it was ten years ago.

Although she is still living with IBD, she is no longer having the strenuous flares of ten years ago. She has gained some distance from the symptoms and, as she says, hasn't "looked back." Gretchen described her illness through a restitution narrative that starts with the embodiment of the illness and continues with the discovery of a remedy that allowed her to move on and focus on other important issues for her. Later parts of her narrative describe her changes to vegetarian and pescatarian diets. Her focus now is on the impact that she is making: "pull[ing] back from meat consumption [to have] more of an impact on our environment and on climate change."

Chaos. Frank (2013) describes the chaos narrative as lacking order or coherence. Told as the narrator experiences the events and without a clear sequence, it is the opposite of the restitution narrative in that narrators lack a sense of control. All IBD patients experience chaos to some degree during their illness. Because IBD fluctuates between flares and remission, the uncertainty feeds the chaos narrative especially during flares. Many of the participants evoked chaos narratives when describing their flares, especially the feeling of being out of control or without hope. However, one story, Jackie's, stood out the most vividly as a chaos narrative.

The time of the interview was shortly after Jackie's colectomy when she was coming out of a major flare and still feeling the impact of losing control of her body. Because of this history, the way she recounted her past flares leading up to her current one illustrated the chaos narrative well. Jackie recalls how she feels entering into a flare: "As soon as I saw any blood I was like 'Oh everything's going to spiral out of control.' I would think it was going to be really severe." In storying her flare at the beginning like this, she creates a scenario for chaos. Describing another flare, she again stresses the overwhelming nature of the physical symptoms: "I just had, like cramping and pain and then...I...saw blood and I was immediately like I need to take time off of work..." Again, she leans into the chaos narrative when a flare starts to present itself. Jackie goes on to describe how her experience leading up to her surgery was full of inconsistencies, inconvenience, and an overall lack of coherence:

I was having fevers pretty consistently and I was just asking questions about it and [my doctors] told me to go to the ER so I could have a CT scan and blood work done and I was like, this is really inconvenient...Then they told me they were going to admit me and I was like "Well I have a presentation tomorrow night, it's virtual, will I still be able to do

it?” And they were like “No, you’re really sick.” And then...everything was just really bad, and I had a colonoscopy in the hospital like the next day.

This moment was only a few weeks before our virtual interview and Jackie was still working through extent of the flare. She was told after the colonoscopy that she needed a colectomy and this event affected how she made sense of this particular flare. At the beginning she thought to herself:

This is just another flare. I’m going to get through it and it just like kept getting worse and I didn’t even really notice how bad it was...Just over three weeks ago I had the surgery and so it’s like huge...It just feels like, I don’t know.”

Jackie’s story illustrates the chaos narrative by highlighting her emotional uncertainty. During the interview, she was still trying to make sense of what happened and what it meant for her future. Even so, she describes how, through this process, she becomes an expert on her health, and yet feels it is not enough, given the ongoing nature of the condition:

I guess how I would sum that up would be like you get really used to it and you kind of become an expert more than anyone else but at the same time everything is always changing...But also it’s just like each flare is also so individual from the last time and so it just can be really hard cause you’re constantly having to adjust and you know that isn’t something that is ever going to go away and not be a thing.

In Jackie’s account of her illness there is no clear sequence that describes becoming an expert or even how she is changing and adjusting. Because each flare is different and can happen at any time, living in the chaos narrative for IBD patients is more common than not. In this situation, Jackie is still living within a flare that hopefully is solved by the colectomy, but her condition still keeps her within the chaos narrative because of its constant fluctuation. Jackie’s scenario is

particularly interesting because of the recency of her severe flare, but chaos narratives can occur in the stories of any IBD patient as they navigate the fluctuating nature of the illness.

Quest. Frank (2013) describes this narrative as focusing on the idea that some learning can be gained from the illness. Through this plot, the narrator searches for some use for the illness. In other words, what benefits came from this illness experience? Living with a chronic illness can make it difficult to find the good in the illness story but for those actively seeking a sense of how to live with their illness, the creation of a quest narrative can show the individual finding a purpose. The quest narrative is different from the restitution and chaos narratives by foregrounding and “speak[ing] from the ill person’s perspective and [thus] hold[ing] chaos at bay” (Frank, 2013, p. 115). Unlike Jackie and other IBD patients who are still constructing their stories around the chaos narrative, Rose focuses her illness experience on what can be done going forward rather than on the difficulty of managing flares.

Besides IBD, Rose has other illnesses along with partner abuse and childhood trauma and she uses the quest narrative to reframe these experiences. Instead of living in the traumatic, uncontrollable moments, she emphasizes the lessons learned from those experiences. She sees the alternative paths that IBD and other traumas have opened up for her, saying “Everything does happen for a reason...Because if I hadn’t been broken up with or been in that horrible situation I wouldn’t have been as appreciative as I am for Daniel [current partner] ...” Her focus on the future and believing that everything happens for a reason allows her to think beyond difficult situations and find hope. Most importantly, she explains the benefits gained from an IBD diagnosis:

I lived a really shitty lifestyle. I was like drinking, smoking, on a bunch of meds, fights, just really bad stuff. If I hadn’t started getting sick, I would probably either have a child

about 5 or 6 or I wouldn't be present. So, me getting sick gave me a different path...Having an illness like this really, really, really makes you appreciate every second that you are on the planet.

Finally, Rose expresses a strong sense of purpose in her description of how she helps other patients talk about the illness. She sees herself as a resource, sharing advice about managing disclosure (“Be open...Or write a letter to the people that you want to tell...Be as open as you can be.”). She is active on Reddit, sharing her story in the hope that it will help others help themselves. She even becomes an advocate on Reddit: “Whenever I comment on a Reddit post or anything like that...I will always say ‘Hey my DM’s [direct messages] are open if you want to talk about this more, or vent, or ask questions.’...And people have taken me up on that.” As shown in the narrative, she sees herself as having unique expertise; she has turned her illness experience into something that can be used to help others.

Out of all the participants, Rose seemed to be the most hopeful participant despite her many illnesses and traumatic experiences. She described her IBD experience through the lens of appreciation and learning and wanted to use her experience and knowledge to lessen stigma and facilitate learning.

These three narratives show some of the ways in which IBD patient story their illness. Frank's (2013) model is helpful in revealing the differences in patients' sensemaking. While many of them may find themselves stuck in the chaos narrative, others are able to see themselves somewhat restored to their pre-illness condition by achieving remission. Finally, there are some who are at a point of accepting the changes brought on by the illness and even find ways of drawing new insights that can be shared with others, as shown in Rose's story. Each way the illness is storied allows the patient to cope with the stage of the illness they are in.

Conclusion

This chapter focused on some of the ways IBD patients cope with the physical and emotional impacts of symptoms. By using marijuana, exercise, and online support, some patients found what works best for them to achieve symptom relief and relaxation. However, to handle the stigma, uncertainty, and emotional burden of IBD, patients made use of other approaches aimed at reframing the illness to bring more positive understandings including humor, managing appearances and re-storying the illness experience. In my own experience with IBD and from the interviews, I have learned that there is no right way to cope. Each patient needs to find their own path to remission. The strategy of normalizing appearances shows that some patients prefer to push the boundaries that have been imposed on them by appearing and acting like persons who are well. However, concealing the physical signs of illness may not work for others. Their stories show how some patients can reach more empowering interpretations of their illness. Listening to the stories of my participants helped me find solidarity with others and learn that I am not alone with this illness.

In the next chapter, I close this project with a review of the themes that emerged from the interviews, advice to IBD patients, and future directions for communication research on IBD. I will also discuss the limitations of this study as well as reflecting on my experience and times in which my IBD interrupted the interview process.

CHAPTER 6:

CONCLUSION

This project aimed to better understand IBD from a patient perspective in terms of tensions around dietary change and food choice. While there is extensive research that discusses IBD as a stigmatized condition, there has been very little study of the role of food in contributing to the stigmatizing of IBD patients. This project has filled that gap and addresses how food choice, as part of medical treatment, carries its own stigma. By focusing on food as a site of illness exposure, I explored how IBD becomes socially visible and the resulting impacts on patients' quality of life and relationships.

The literature review provided an overview of research on IBD as a hidden disability. Previous research on hidden disabilities focuses on the ways in which individuals attempt to navigate social situations without giving off signs of their illness to prevent stigma or embarrassment. For the IBD body, concealing the illness is especially challenging, as shown in Defenbaugh's (2013) study of the bathroom as a site of both privacy and exposure for those living with IBD. Thompson (2013) highlighted the polluting nature of bodily secretions such as sweat, urine, feces, and tears along with the powerful social norms that discourage acknowledgement of IBD symptoms, especially in public spaces. These pieces are crucial to better understand stigma surrounding IBD, but they do not address how food choice serves as a site of exposure for those living with IBD, a gap which led me to this research.

Medical literature on patients' self-management of IBD does discuss the role of food in treating the illness, but this literature does not consider how our food choices are policed by

others according to cultural models of “healthy” eating. By exploring the processes through which food choices are surveilled and questioned, we can understand how our food choices impact the construction of patient identities. Because food is typically at the center of social gatherings, the IBD body may be exposed through the types of food a patient chooses to eat, so that accounting for those choices becomes an unavoidable part of managing the illness.

To better understand patient perspectives IBD, I conducted interviews with 15 women along with autoethnographic writing as my primary methods. The semi-structured interviews gave the participants a sense of direction but also allowed them space to freely share stories and experiences. In these interviews, I moved between the roles of researcher and participant because of my personal experience with IBD. The reflexive pauses throughout the analysis chapters gave a glimpse into the stories that I shared with participants and also served to frame the chapters.

My theoretical approach was guided by symbolic interactionism because it offers a way of thinking about how patients negotiate meanings of food, eating and health as they attempt to cope with illness. I used Goffman’s dramaturgical framework along with sense-making theories from Bruner and Weick to guide my analyses. Goffman’s (1995/1959) theory calls attention to the ways in which patients maintain a distinction between their “backstage” lives and “front stage” performances and how individuals use facework strategies to maintain the front stage identity and avoid stigma. Narrative perspectives such as Bruner’s (1991), Frank’s (2013), and Weick’s (1995) offered a way of understanding how IBD sufferers attempt to cope with illness and restore a sense of order to a chaotic experience, in particular by using stories to construct causal connections to make sense of disruptions to reality.

Summary of Findings

The first analysis chapter addressed the question: How do IBD patients negotiate tensions between “concealing” and “revealing” as their food choices become publicly visible, and what are the relational consequences of illness exposure?

This chapter focused on the use of food as a way to treat IBD and the disruptions in daily life caused by the need to find “safe” rather than “healthy” food choices. Because there is not a standard diet for IBD, patients need to use trial and error on an individual basis to discover what foods are safe or unsafe which leads them to evaluate their food choices according to the occurrence of symptoms rather than to their preferences.

Furthermore, unlike some other conditions like Celiac Disease, IBD patients lack a clear vocabulary for explaining diet changes or food choices. When they are questioned, they struggle with finding the right way to explain why certain foods are safe. These become teachable moments for the individuals asking the patient about their food choices, but they involve communicative labor for patients who must make the effort to normalize their behavior to others. This chapter offers a glimpse into the internal struggle that IBD patients have when trying to decide whether to attempt to “pass” as normal or to disclose the illness, and how that decision is tied to choices about what and when to eat in a public setting.

The second analysis chapter addresses the question: How do IBD patients make sense of notions of personal responsibility and self-control embodied in diet-based treatment programs? The self-management model used in IBD treatment emphasizes patients’ role in taking responsibility for their health. These findings suggest that this model creates expectations of patients’ personal responsibility, which then lead them to feel guilty when they feel they have not been disciplined enough, as well as inviting criticism from others. including doctors who see the

patient as non-compliant if they are not following the food treatment plan. When others attribute the patient's illness to their own volition, stigma are compounded as the patient is seen as bringing the illness on themselves since they ate the "wrong" thing. These findings show the power of discourse surrounding definitions of the "good patient," which insist on the patient adhering to the treatment plan regardless of how difficult is to maintain.

The third analysis chapter addressed the question: What forms of communicative coping do IBD patients adopt in response to the physical and social challenges of the illness?

This chapter highlighted the different forms of coping that patient engaged in, including problem-focused symptom relief through marijuana and exercise and emotion-focused coping through normalizing appearances, humor, and storytelling. Certain forms of communicative coping allowed the patient to restore a sense of normalcy by "looking good" to feel better and to avoid stigma. Whereas feminist research critiques medical treatment that encourages women to perform in ways that conceal their illness for the sake of others, the results of this analysis suggest that normalizing one's appearance can be experienced as empowering to these patients.

Implications for Communication

This project contributes to communication theories in three ways: by challenging the discourse surrounding healthy food and showing some of the impacts of this discourse on interpersonal relationships; by adding to our understanding of stigma and hidden disabilities; and by expanding theories of patient self-empowerment.

First, this project asks communication scholars to recognize and rethink the discourse surrounding healthy food and how it shows up in day-to-day conversations. One outcome of the study is to show the various situations in which IBD patients must defend themselves with a unique form of communication that centers around defending their food choices. The analysis

shows the communicative labor for patients in having to explain their food choices or why they are not feeling well because of a food choice. To maintain positive face, patients must frequently respond to others' questions by defining what healthy eating looks like for them in terms like "safe" and "unsafe" foods, which tends to prompt even more questions, requiring more communicative labor on their part. This "communication work" as explained by Head et al. (2021) places added stress on the patient because it leads to the possibility of overexplaining and disclosing more personal information than desired as a face-saving measure. Furthermore, in showing the widespread impact of healthy eating discourse, these findings are potentially important to critical health communication scholarship. As Wiggins (2004) discusses, healthy food talk or advice is typically framed as a set of universal guidelines. In this way, the talk is generalized and fails to include bodies that do not fit the universal standard for healthy eating, thus creating spaces for stigma. This analysis extends that work by showing the problems patients have in finding an available language different from the cultural model to describe their eating practices and thus it shows the difficulty patients have in challenging macro-level discourses.

A second contribution of this project is to add to stigma theory by showing how stigma can be multi-layered. Stigmatizing interactions are different and more complicated for IBD patients because IBD, while primarily an invisible illness, involves symptoms that expose patients' backstage activities. In addition, "bad" food choices are also stigmatized, an aspect of stigma that is not typically seen with other illnesses or disabilities. Because IBD is understood to be a bathroom disease (Thompson, 2013), the stigmatizing effects are inherent in any reference to the condition, but when coupled with seemingly poor food choices, the IBD patient is faced with doubly stigmatizing messages. Furthermore, patients' illness status is sometimes doubted by

others. Appearing to be well, they must often work to convince others that they are truly sick, which may require disclosing details of the illness. All of these aspects of stigma create unique communicative burdens for patients that impact their quality of life and relationships.

Finally, this research shows the importance of gathering patients' perspectives to expand our understanding of forms of self-empowerment. Several participants gave examples of trying to take control of their illness by choosing foods according to personal preferences rather than medical needs. These examples illustrate how participants can reframe eating as an act of personal agency, for example, by scheduling time to accommodate food cravings. Furthermore, some patients can find agency in the way they story their illness to highlight their sense of achievement in overcoming obstacles. As shown in Rose's example, it is possible for some IBD patients to find benefits in the illness experience, as when Rose expresses a strong sense of purpose in being able to help other patients.

I would also like to point out the methodological contributions of this study in showing the importance of the researcher's role as an "insider" to the illness community when researching stigmatized conditions. As I discovered through my research, the sensitivity nature of IBD symptoms makes this particular population hard to reach for research purposes. Because of the multi-layered stigma surrounding IBD and food, and frustration with dietary treatment that didn't always work, some participants found it difficult to begin to talk about food. Many of the participants needed to build a level of trust with me before sharing their stories. They explained to me that they find support with close friends and family but even then, those people do not understand the extent of what they are experiencing. The participants described feeling relieved when they hear of someone going through the same symptoms as they are, on Reddit for example.

Using autoethnography throughout this project carried unique risks as well as benefits. On one hand, it carried risks of being re-stigmatized as I and the participants relived moments in of embarrassment and shame. On the other hand, it allowed me to connect even more with the participants because I made clear with them that my stories were also being incorporated. This built more trust between us by showing them that I was willing to be vulnerable alongside them. In my narrative about vacationing in Florida and having an accident, I was particularly vulnerable. I initially had trouble engaging with that memory and putting myself back in that moment. This vulnerability came not only from reliving the accident itself but also searching for more support and guidance from my family than I received. In that moment, I did not want to expose my body to the public world for fear of another accident happening, while my family acknowledged the accident, they chose to continue on with the day's plans to make it seem as normal as possible. This form of support lacked what I really needed: understanding of the fear of reoccurrence. Including this story as well as the others allowed me to complexify the issues that I was discussing with the participants by highlighting the vulnerability that comes with IBD and the experience of others' reactions as neither entirely positive nor negative but both/and. Furthermore, I believe that the participants were able to resonate more with my stories because of our similar experiences and the details I shared.

As an insider to this group, I connected with the participants in ways that someone without IBD could not. This high level of trust and empathy was needed to help them be open and honest about their IBD experience. Because I am a member of the IBD community, there was a level of understanding that was built into the interviews. Even so, the participants still felt that they had to maintain facework during the interviews to present a healthy body even though we were discussing their IBD. I also found myself engaging in facework, especially during

moments in the interview process where I found myself in a flare. It was interesting to see these facework techniques such as dressing professionally and maintaining high energy to hide the illness we were openly discussing. The dynamics that I observed concerning researcher roles and community membership may be of interest to others engaged in research on chronic illness.

Implications for Practical Action

These findings show the importance of strengthening patient support by creating more opportunities for dialogue about the illness. When people hear that I have Crohn's disease, I can see the proverbial wall go up because it is not an illness that people are comfortable talking about. I find myself over-explaining the illness and what it means for me and my body in ways that are not needed. I also find myself trying to hide my illness, so I do not have to broach the difficult subject. As a researcher, I saw this happening with my participants and the communicative implications this had for relationships. The way in which the participants discussed the illness with me is different from how they have described the illness to friends or family who do not have experience with it.

We need to create more spaces for patients to be open and honest about their experiences. Trust and empathy for IBD patients is important for them to communicate what they need and want. Without a high level of trust, it is more difficult for IBD patients to be open about their illness experiences. Hearing the participants explain how easy it felt to talk to me because of my IBD experiences was heartwarming because I, too, felt like someone finally understood what I was experiencing and what it meant interpersonally. We connected and supported each other as we shared stories that each of us related to. The interviews created a safe space in those moments for the participants and myself. When I say "safe space," I am referring to an interpersonal moment based on shared experiences where a person can openly and honestly

discuss their identity, whatever that may be. This space is free of stigma and judgement. As Thompson's (2013) study of IBD support groups showed, patients do not necessarily drop their defensive strategies, even among a group of fellow IBD sufferers. It may be necessary that dialogue first be created among pairs of individuals through a peer mentoring program or something similar before participating in a larger group. For the IBD patient, it is imperative that one feel free to openly discuss their illness without fear of needing to save face (Goffman, 1955) or over-explain. They can just "be." Whether in pairs or larger groups, however, these safe spaces, do not always occur as they did in these interviews.

I asked participants what advice they would offer to newly diagnosed patients and several of them emphasized the value of being open with others, as crystallized in Noelle's response:

I think just being open about it and not being ashamed of it even though it can be really embarrassing a lot. I think those are good strategies and just like getting comfortable with your body and being able to openly discuss your symptoms especially with your medical providers. Because when I was first diagnosed, I was very shy about it. I didn't want to share the whole story just 'cause I thought it was gross and now it's, nothing is off of the table, and I get better quality medical care because I am not afraid to share anything.

Acknowledging how embarrassing IBD can be, Noelle recognizes that the more open she is about her symptoms, especially with doctors, the better she can advocate for herself.

If doctors understand that IBD patients need a space of understanding and empathy, they can do more to direct patients to support groups or online spaces that can help patients feel less isolated. Doctors can play a larger and important role in implementing support systems that can be part of the patients' treatment plan to facilitate open communication and reduce isolation. When I was diagnosed, this was not part of a treatment plan for me. I was told that I could go out and find

support groups, but I was not given access to any that the doctors' office might have already had. Additionally, my doctors did not say that these support groups were integral to my treatment. I believe that if some supportive experiences were offered as part of the treatment plan, I would have coped better with the illness that was out of control at the time of diagnosis.

Another implication for improving patient care stems from the different ways doctors and patients talk about the illness. In my interviews, many participants used words like "fight," "struggle," and "battle" to describe what they are experiencing with IBD. When we think of IBD as a battle we start to look at the illness from a patient perspective. The patients end up facing a double bind because the more they internalize the "good patient mentality" and practice rigorous self-management the more they are constrained. This can then lead them to have a harder time coping or being resilient by feeling paralyzed by the treatment model or expectations. Furthermore, it constrains their ability to make sense of the illness themselves especially when they are being held accountable by others including family members and doctors.

Research on chronic illness has found that medical providers' assumptions about self-management programs, and their ways of presenting it to patients, can sometimes be counterproductive for patients' health. Self-management-based treatment tends to view patients' individual practices as the reason for health improvements and failures: "When consumers experience poor health, there is an assumption that they have not practiced 'good' self-management, resulting in them being labelled irresponsible, or worse, as a burden" (Kendal et al., 2011, p. 93). The results of my analysis show that the unpredictable nature of flare-ups carries a lot of weight in how patients interpret their illness. Knowing this, medical providers could be encouraged to present self-management recommendations in more patient-centered ways that acknowledge the uncertainty of relapse. Patients may be less likely to blame

themselves if they understand that rigorous self-management will not necessarily improve their quality of life.

Finally, beyond specific changes in treatment approaches such as the implementation of support groups, communication scholarship can contribute to our understanding of how we as a society talk about IBD and healthy eating. The rhetoric that we use to discuss IBD contributes to the inherent stigma that it carries. By routinely calling IBD a “bathroom disease,” we come to associate the person who has IBD with the bathroom, a place where we conceal bodily functions that are not meant to be seen publicly. When IBD is labelled a bathroom disease, the person’s identity gets defined in relation to all of the bodily functions that happen in the bathroom, contributing to felt stigma. Furthermore, accidents that IBD patients experience reinforce this stigma. The patient cannot always conceal their bodily functions in the bathroom and thus when accidents happen, they tend to be seen as out of control or incompetent. To change these assumptions, we as a society can reduce the taboo by fostering environments where there is greater inherent understanding about IBD and its unpredictability. Moreover, with healthy food discourse, we create expectations that many people cannot live up to. This is not just limited to IBD sufferers. By either expanding the food pyramid to recognize different types of dietary requirements or even eliminating expert recommendations that connect food to conditions of health and illness we can start on a path that is more inclusive of all types of bodies. Furthermore, recognizing that what someone eats should not be up for debate or discussion is a good step in the right direction to alleviate stigma around healthy eating.

With small initial steps, we can begin to remake beliefs and language related to IBD and, in turn, break some of the silence surrounding this invisible illness. By creating spaces and

relationships where IBD does not have to be concealed but can be discussed in accepting ways as part of the treatment plan, it may be possible to better support patients in their sensemaking.

Limitations & Future Directions

Although this study has brought new insights to our understanding of the impacts of dietary change on patients dealing with chronic illness, it is not without limitations. First, the study was limited to the experiences of women between the ages of 18-40. IBD patients are a hard-to-reach population and while the sample of 15 meets the standards of most qualitative studies, especially those conducted with hard-to-reach populations, it does not include the experiences of other people such as men, nonbinary, trans, elderly, or children. Their experiences may be similar in certain ways to the participants in this study, but those experiences may also be different and would provide a more well-rounded view of the of the social and emotional impact of IBD. Future research could also be expanded to include other related illnesses, especially those in which diet is part of treatment. This study focused on Ulcerative Colitis and Crohn's disease and while these are the two main diseases under IBD, there are illnesses derived from each that fall under IBD such as Pancolitis. Those illnesses are similar to Ulcerative Colitis and Crohn's but entail minor differences that could be led to different physical and social impacts. This would also allow the researcher to further nuance the nature of stigma associated with IBD.

Second, this study focused on how we communicate about IBD from a patient perspective. While this was an important and necessary starting point, it would be interesting to include the voices of those who are indirectly affected by the illness such as family members, friends, and partners. This would allow for a more detailed description of the effects of IBD on interpersonal relationships and how those indirectly affected by IBD respond and attempt to help the patient. Their accounts of a family member's illness would also give us a better

understanding of how our communication which may be intended as supportive, works unintentionally to stigmatize those living with chronic illness.

With the acknowledgement of these limitations, this study may open the door to other communication researchers interested in understanding chronic illness. The specificity of this study helps us better understand how women are affected by IBD in their relationships beyond the physical ailments. This study also gave a variety of experiences of IBD from those living with it for many years to those that have only been living with it for a couple of years. As a whole, this project provided insights into the many different faces of IBD and how it affects communication, relationships, and the body.

Going forward, communication research should focus on rewriting the language we use to talk about chronic and other illnesses. Our communication not only shapes our reality but creates experiences of exclusion and marginalization for ill people that cause them to conceal the illness or hide from others. With more research, we can increase public awareness of the interpersonal dynamics surrounding stigmatized illness and begin to shift the way we interact with chronically ill toward ways that are more accepting and less ostracizing.

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APPENDIX A

Starting Interview Questions

1. When were you diagnosed with IBD? How many years have you been in remission?
2. How often are your flare-ups?
3. How do you cope?
4. Do you find that telling stories about your illness is helpful? In what ways is it? Or in what ways is it not?
5. When you were first diagnosed, what was your approach to talking about your illness to friends, family, or a significant other?
6. Did you try to keep your diagnosis private? If so, what steps did you take to ensure your privacy?
7. Were there moments where you felt forced to disclose your illness? If so, please describe them (i.e., what happened, how did it make you feel, did you have to justify anything).
8. In those moments, what was the cause of your disclosure?
9. How has your diet changed? Did you have to cut anything out or start including anything specific? If so, how was that transition?
10. If your diet did change due to the diagnosis, did you experience judgement or more questions around the foods you were eating from friends, family, or a significant other? If so, please describe the experience (i.e., what happened, how did it make you feel).
11. What is/was your biggest concern with this illness when communicating with family, friends, and a significant other? How have you or how do you plan to cope with this concern?
12. What is something that you have gained from this diagnosis, if anything? Was this illness a blessing in disguise? If so, how?

APPENDIX B

Call for Participants

Hello friends! I am currently working on a research study (study # 002078) here at the University of South Florida. The purpose of this research study is to better understand how communication plays a role in shaping identities and relationships after an Inflammatory Bowel Disease (IBD) diagnosis and the role food plays in exposure of an IBD diagnosis. IBD consists of Crohn's Disease and Ulcerative Colitis. I am most concerned with situations in which we are exposed as living with IBD and how those exposures affect identities and relationships with family, friends, and significant others. I am also curious as to what exposes us a living with IBD.

To explore this, I am looking for women that have been diagnosed with a form of IBD (either Crohn's Disease or Ulcerative Colitis) and are between 18-40 years of age. For the research study, I would meet with the participants for anywhere from 45 minutes to 2 hours for a one-time interview during the duration of the study. The meetings will be held virtually via Skype or Zoom depending on the participant's preference. Participants may benefit in terms of support for their illness through the interview and from the principal investigator (Jessica Lolli). Participants will also be directed to resources for support should they choose to do so. There is no compensation for participating in this study.

If you know of anyone who may be interested in participating in this study, please have them direct message or email Jessica Lolli. My email is jlolli@usf.edu.



APPENDIX C

Script for Obtaining Verbal Informed Consent

Information to Consider Before Taking Part in this Research Study

Title: Impact of food communication on IBD patient's identity formation and relationships post-diagnosis

Study # 002078

Overview: You are being asked to take part in a research study. The information in this document should help you to decide if you would like to participate. The sections in this Overview provide the basic information about the study. More detailed information is provided in the remainder of the document.

Study Staff: This study is being led by Jessica Lolli who is a Graduate Assistant at/in the University of South Florida. This person is called the Principal Investigator. She is being guided in this research by Dr. Jane Jorgenson. Other approved research staff may act on behalf of the Principal Investigator.

Study Details: This study is being conducted at virtually via Skype or Zoom and is supported by the University of South Florida. The purpose of the study is to understand how food works as a site for exposing the IBD body communicatively. The purpose of this study is to find out how the IBD body is exposed and if food choice plays a role in exposure. The research process will include a 45 minute to 2-hour one-time interview conducted virtually via Skype or Zoom in which the principal investigator will ask questions related to the participant's IBD experience post-diagnosis. The interviews will be recorded. There will be a short 5 question demographic questionnaire for the participant to answer. This is a qualitative study, and a summary of the results will be shared with participants. The results will either be shared verbally via Skype or Zoom with the participants or via email.

Participants: You are being asked to take part because you have been diagnosed with one form of IBD (Crohn's Disease or Ulcerative Colitis). We want to understand how an IBD diagnosis affect a person's relationships and identity formation.

Voluntary Participation: Your participation is voluntary. You do not have to participate and may stop your participation at any time. There will be no penalties or loss of benefits or opportunities if you do not participate or decide to stop once you start. Your decision to participate or not to participate will not affect your job status, employment record, employee evaluations, or advancement opportunities. Your decision to participate or not to participate will not affect your student status, course grade, recommendations, or access to future courses or training opportunities.

Benefits, Compensation, and Risk: We do not know if you will receive any benefit from your participation. There is no cost to participate. You will not be compensated for your participation. This research is considered minimal risk. Minimal risk means that study risks

are the same as the risks you face in daily life.

Confidentiality: Even if we publish the findings from this study, we will keep your study information private and confidential. Anyone with the authority to look at your records must keep them confidential.

We will do our best to keep your records private and confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Certain people may need to see your study records. The only people who will be allowed to see these records are: the Principle Investigator, the Advising Professor, and The University of South Florida Institutional Review Board (IRB).

If you have any questions, concerns or complaints about this study, call Jessica Lolli at 708-522-3213. If you have questions about your rights, complaints, or issues as a person taking part in this study, call the USF IRB at (813) 974-5638 or contact the IRB by email at RSCH-IRB@usf.edu.

Would you like to participate in this study?