I Am Relieved to Discover My Symptoms Are Normal for My Condition: An Analysis of Two Irritable Bowel Syndrome Support Communities

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LOYOLA UNIVERSITY CHICAGO

“I AM RELIEVED TO DISCOVER MY SYMPTOMS ARE NORMAL FOR MY CONDITION”: AN ANALYSIS OF TWO IRRITABLE BOWEL SYNDROME SUPPORT COMMUNITIES

A THESIS SUBMITTED TO THE FACULTY OF THE GRADUATE SCHOOL IN CANDIDACY FOR THE DEGREE OF MASTER OF ARTS

PROGRAM IN WOMEN’S STUDIES AND GENDER STUDIES

BY ERIN HVIZDAK

CHICAGO, IL

MAY 2013
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ACKNOWLEDGMENTS

First and foremost, I would like to thank Dr. Prudence Moylan and Dr. Anne Figert for agreeing to guide me through this thesis process and for being so patient with me as I completed it. Your courses and conversations have been incredibly influential on my thinking and you both challenged me to see the world in ways that I could not have imagined when I first started this degree.

I want to thank my mom and dad for being so supportive and open-minded, trusting me to make the right decisions, and teaching me to always approach life with a critical eye. You two become more awesome each year that you don’t have kids to worry about. Mark, you’ve become one of my best friends (I would also like to note here that I am now officially winning in the degree count), and Mary, I am more than thrilled that you are now part of the family. Michael, you are my favorite and you always will be.

Timothy Lynch, I have no idea how you had the will to stick around through all of this. Thank you for all of the patience you have shown and the sacrifices you have made to ensure that I could continue, and in some cases complete, all of the weird paths I have wandered onto in the last couple of years. You’ve built up enough credits to last a lifetime, or at least until your dissertation is finished.

I would like to thank all of those that I have met in this graduate program for providing such an engaging, supportive atmosphere in which to pursue my research. Particularly, I would like to thank Katie Filous, Bernadette Raspante, Lorena Ornelas,
and Kristen Black for helping me through this process in a variety of ways.

Janet Olson, thank you for being so patient and encouraging, for always thinking of me when new opportunities arise, and generally for being a great friend. Someday, when I am a rich and famous archivist, I will think of a way to repay you for everything. Women at the Evanston History Center that also deserve special note are Lady History Solver Jenny Thompson, Erin Hughes, Karen Alvarez, Kris Hartzell, and Lori Osborne.

I could not have gotten this far without the support and friendship of Susan Hanf, Lindsey Hammond, Jonathan Waldrop, and Allison Neely. I am so lucky and sometimes in disbelief that I have all of you in my life. Elizabeth Buchanan, I would not be where I am right now had it not been for you (and your awesome family).

Last but certainly not least, thank you to everyone that took the time to respond to my survey and questionnaire. Your responses have not only influenced me academically, but have also helped me to understand myself better as a person living with the symptoms and diagnosis of IBS. I hope that this study is only one in many more to come from around the world that attempt to make all voices heard in this illness.
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ABSTRACT

Symptoms of Irritable Bowel Syndrome (IBS), a “medically unexplained illness,” are present in up to 20% of the United States population. Individuals experiencing symptoms of IBS often report that physicians dismiss their experiential and embodied knowledge, leading to a sense of isolation and frustration. Many of these individuals attempt to diminish isolation and also exchange their knowledge in a community setting. In order to enable a more complete understanding of IBS, a survey about community participation was sent to members of a large online support group for IBS located on Facebook, with 81 completed surveys received. Further, an open-ended questionnaire was conducted with a local meet-up group for IBS, with three individuals responding.

Community participants seek both informational and emotional support. Both similarities and differences between members re-embody and validate the participant’s unique IBS experience, thus increasing well-being. Experiential knowledge was in some cases trusted more than other types. Both men and women seek informational and emotional support, but do so at different points in community participation. Differences between the global and local communities include the local community’s ability to provide more specific information and contribute to a more embodied experience. While the focus of this study includes the voices of individuals experiencing IBS symptoms, it also demonstrates the need to bring other perspectives into the conversation, particularly those of men and also the experiential knowledge of physicians.
CHAPTER ONE

INTRODUCTION

While written within the context of a women’s and gender studies graduate program, this thesis is not about “women” or “gender” but rather uses feminist theory to examine power dynamics and contested knowledge in the case of a “medically unexplained illness.” While women are diagnosed with these illnesses at higher rates than men, diagnoses are not just “given” or bestowed from the doctor, rather they are produced through ongoing dialogue between the doctor and the individual experiencing symptoms, and these individuals utilizing their agency to seek answers to their embodied pain. We have come to expect that modern medicine should help us when we are in pain and suffering. It should provide answers to illness etiology, and it should provide treatment for our symptoms. Physicians are trained to know our bodies better than we know them ourselves, but do they?

I sought out to “prove” that women were the victims of a corrupt, patriarchal, capitalist medical system. As a woman that had been diagnosed with Irritable Bowel Syndrome (IBS), a “medically unexplained illness” that often leaves those diagnosed feeling helpless and in a constant search for answers, I was speaking from a place of anger at the lack of information and support I was receiving from physicians. After finding a physician who took her time with me and actually asked what was going on in my life, I finally “accepted” my diagnosis of IBS. Yet I still felt confused, as there is no
definitive cause or cure for IBS. Like many others, I was basically sent on my way. I was told to eat healthier and somehow “discover” and then avoid my triggers, reduce my stress, and exercise more. I knew people in my life that seemed to experience more stress, eat unhealthy food, and exercise less, and yet they seemed unscathed. At the risk of sounding like a cliché, I had to ask, “why me?”

Women comprise 66-75% of those diagnosed, with seemingly no explanation. When I entered a women’s and gender studies graduate program, I wanted to prove the conspiracy against women, that they were being given unexplained diagnoses to take away their power and defer their unhappiness in an already broken social system, to keep them buying products in a capitalist system that preys on desperate individuals. I quickly discovered that to study women as “victims” actually denies their agency and hands power to the medical establishment that I was trying to prove “wrong.” The power of the IBS individual\(^1\) is alive in medicine, but it is hidden in studies that focus on “expert”

\(^1\)After a discussion with my thesis committee, I struggled with the use of the word “patient,” which I originally used throughout this work. This is a contentious term that implies that the individual is passively suffering, while I am trying to demonstrate patient agency. Further, not all IBS “patients” interact with physicians or suffer throughout their entire illness experience, and not everyone that joins communities for IBS has been diagnosed. I tried out a number of different phrases and words. For example, I thought I had settled on “ill individual,” but then considered who exactly was defining the individual as “ill” (the individual, the physician, or society), and thought about whom exactly was “ill” in this situation (particularly as I claim that physicians are trying to fix the broken individual when there should be more attention paid to the broken system). I also considered using the phrase “individual experiencing symptoms of IBS,” but this also implied passivity. Passivity is also implied in “individual with IBS,” and also many diagnosed individuals experience symptoms that do not fall into the “normal” range of this medical category. The phrase “individual that is defined as ill by either themselves or society and also experiences symptoms that mirror what is commonly considered IBS by the medical system” was entirely too long and awkward, although it does more accurately reflect the message I would like to convey. I have settled on the term of “IBS individual” to mean “one who associates him or herself with the medical diagnosis of IBS,” whether through symptoms, or a diagnosis, or both. This seemed most accurate in light of the fact that all of the individuals that are in the communities of my study joined an IBS-specific community, regardless of diagnosis. It is still a very awkward phrase and does not differentiate those that have been diagnosed from those that have not, and in some cases I have kept the word “patient” when it most accurately reflects the literature being discussed. This only highlights the need to re-examine our terminology and ask how our common use of active/passive language replicates these dominant/subordinate relationships.
interpretations of the illness. The feminist standpoint which I am utilizing does not only ask questions about gender, rather, it also seeks to reveal subjugated knowledges and thus power imbalances and inequalities in this dominant/subordinate relationship.

Foucault defines “subjugated knowledges” as “historical contents that have been buried and disguised in a functionalist coherence or formal systemization” (Foucault, 1980, p. 81). They are a “whole set of knowledges that have been disqualified as inadequate to their task or insufficiently elaborated” (Foucault, 1980, p. 82) and are “particular, local, regional…incapable of unanimity” (Foucault, 1980, p. 82). Haraway (1988) similarly explains that science has used a “god-trick” in its claimed objectivity by “gazing” at its objects of study from a disembodied distance. Science claims that this distant viewpoint produces the most objective knowledge, as it homogenizes diverse bodies into single theories that seemingly apply to all. Yet, Haraway (1988) argues that science provides only a partial perspective because it does not allow its objects of study to participate; rather, their voices are subjugated in the creation of formal categories and systems of science. These “objects” of study have an even stronger claim to objectivity as they have experienced the dominant system as a marginalized person, which the experts cannot claim (Harding, 1991). This embodied location holds individuals accountable for the knowledge claims they are making.

The embodied knowledge of IBS individuals is subjugated in the medical system, as made apparent in the conflict between their knowledge and physician knowledge in IBS. Physicians not only hold but are also constrained by power, as the medical system acts under the claim that it has all the answers to bodily pain. Both IBS individuals and physicians want the same thing from the medical system, and that is to make people feel
better. But in an uncertain, “unexplained” illness such as IBS, each side is left feeling frustrated at the lack of answers. Physicians act as the gatekeeper to diagnoses and many forms of treatment, and due to the dominant/subordinate relationship produced by the professionalization of medicine, embodied knowledge of the individual experiencing symptoms is rendered invalid, suppressed, and subjugated. In order to become well, the IBS individual must stay silent and become compliant, and align rather than integrate their knowledge with medicine. IBS individuals want to become well, but they do not so easily dismiss their own knowledge in the process. Neither side holds a complete truth, and neither side has the final answer, especially highlighted in a medically unexplained illness. Without the perspective of every person affected by medically unexplained illness, we cannot reach a more “objective” understanding of IBS. Until all sides begin to work together on solutions, all sides will remain dissatisfied.

One site in which IBS individuals exchange their experiential and embodied knowledge is in a community setting. Communities for IBS individuals can be created by professionals, corporations, or lay individuals, and can reveal where knowledge of the IBS individual is most often subjugated and conflicts occur in the medical interaction. In order to make visible these subjugated knowledges and thus enrich general knowledge of the IBS illness experience, I have chosen IBS communities as my sites of study. My research questions were exploratory. First, I asked, “Why do individuals that have been diagnosed with or experience symptoms of IBS join and participate in communities related to their health?” Second, I asked, “What do participants read, share, and gain from these communities?” Lastly, I asked, “How does community participation affect relationships with family, friends, and physicians?” I chose both a large online group and
a smaller, local meet-up group that meets online, in person, and over the phone, and I pursued mixed methods. A survey with qualitative and quantitative questions was sent to the online community, while open-ended qualitative questionnaires were pursued with the smaller local community. The benefits, limitations, and ethics of each will be explained further in my section on methodology.

My research comes from a feminist standpoint as I seek to demonstrate the value of IBS individuals’ embodied knowledge in healthcare decision-making. As so little research has been done on IBS communities and on IBS from the perspective of those that believe they are experiencing symptoms, this was one way to gain access to and make visible this knowledge in order to set a research agenda for future study. Chapter two begins with a look into “expert” perspectives of IBS, and then moves into a literature review on sites of contested knowledge in IBS, IBS individuals’ definitions of a supportive medical encounter, and the current state of health communities, including those for IBS. Chapter three provides a background of my communities of study, methodology, ethics, limitations and an explanation of my data analysis. Chapter four presents my results and discussion, while chapter five outlines my conclusions and possible directions for future study. My findings indicate that community participants derive relief and thus increased well-being through the embodied experiences of others, as it re-embodies their own experience. While there are few answers in a medically unexplained illness, the disembodied gaze of medicine creates overarching formal diagnostic and treatment categories that are supposed to apply to everyone, allowing physicians to maintain the power to determine if someone is “ill.” IBS individuals often deviate from these categories, and this separation of the mind and body in Western
medicine leads them to feel abnormal, isolated, and thus both question themselves and their physicians. Diverse perspectives found in these communities dismantle the detached “objective” gaze of medicine and physicians and demonstrate that no one holds all of the answers. Through this experience, they do not wish to dispute physician knowledge or directly challenge the authority of medicine, but rather challenge that it is the only authority. While the focus of this study is on IBS individuals’ voices and knowledge, it demonstrates the need to also bring physicians into this conversation. Particularly as global communications increase and IBS individuals have access to many systems of knowledge, integrating the embodied knowledge of IBS individuals and admitting uncertainty may actually increase rather than decreased physician credibility and authority and improve the medical interaction.
CHAPTER TWO
LITERATURE REVIEW AND THEORY

Irritable Bowel Syndrome

IBS has existed in various manifestations and with different names in the medical literature for over 100 years, and possibly as early as 1554 (Mendelson, 1897, p. 145). An earlier version of this illness was “Mucous Colitis,” as its diagnosis relied on the visible presence of mucous during defecation. This presence is still considered an indication or symptom of IBS, though it is not required for diagnosis. An 1895 medical work indicates that the “long continuance of the disease, the absence of fever, and the exciting role played by neurasthenia and the emotions serve to distinguish the disease from diseases of an organic basis” (Lockwood, 1895, p. 488; see also Osler, 1892). Slightly later works encourage the medical community to find a more organic cause, pointing to new medical technologies and increasing knowledge of bacteriology (Massachusetts Medical Society, 1912, p. 115; Harrower, 1919). Jordan (1932) later expanded the diagnosis to one of the “irritable” or “unstable” colon, given only with the presence of pain in the upper abdomen and not necessarily with the presence of mucous, thus closely matching what is used today. During the 1930s and 1940s, treatment options such as sulfonamides and antibiotics, and in the 1950s ACTH and adrenal steroids, further indicate a growing acceptance that this might be of biological origin and thus can be treated with a biological or medicinal agent (Kirsner, 2001). No biological marker has yet been determined to
indicate the presence of the syndrome, but medical terminology is utilized in diagnosis and treatment to make this “medically unexplained” illness a “medical” concern.

Medically unexplained illnesses are vast and include fibromyalgia, chronic fatigue syndrome, multiple chemical sensitivity, and many more that may or may not yet have an actual name. These illnesses are often considered psychosomatic, or produced primarily through a psychological disturbance. IBS first appeared in ICD-9 (International Classification of Diseases), and is now classified in ICD-10 as 564.1 under “Functional digestive disorders not elsewhere classified.” Its classification as “functional” indicates that while a part of the body feels ill or abnormal, there appears to be nothing physically wrong, and the individual is still “functional” (World Health Organization, 2010).

According to Jones (2004), Osler’s (1892) link between IBS and the psyche remained popular until Adrian Manning created a set of diagnostic criteria in 1978, based on a survey completed by 32 IBS individuals referred to gastrointestinal clinics (Manning, Thompson, Heaton, & Morris, 1978). The authors found that four of the fifteen symptoms tested for were significantly more prevalent in individuals that had been diagnosed with IBS: Abdominal distention, pain relief with bowel movement, frequent stools with the onset of pain, and looser stools with the onset of pain. Currently, individuals are diagnosed with IBS if they meet the symptoms listed in one of several diagnostic criteria (Manning, Rome I, Rome II, and Rome III). Lea, Hopkins, Hastleton, Houghton, and Whorwell (2004) find that many physicians do not strictly follow these sets of criteria, do not know about them, or may utilize different sets, leading to a lack of uniformity in diagnosis (see also Mearin et al., 2001). The latest set of criteria, Rome III, was written in 2006 and has three criteria, only two of which must be present on an
ongoing basis for three months, within the last six months before diagnosis:
Improvement of pain with defecation, symptom onset associated with a change in frequency of stool, and symptom onset associated with a change in form of stool (Drossman, 2006). IBS symptoms include constipation or diarrhea or both, abdominal bloating with or without distention, nausea, abdominal pain and cramping, sensations of gas or fullness (Lee, Mayer, Schmulson, Chang, & Baliboff, 2001), and heartburn (Cain et al., 2009). Symptoms also extend beyond those of an “irritable bowel” to include chronic visceral and musculoskeletal pain (for example, headaches, backaches, joint pain) (Lee et al., 2001), fatigue and tiredness (Voci & Cramer, 2009), and psychological disturbances including depression and anxiety (Cain et al., 2009). The opinion of professionals that it currently affects up to 20% of the population (diagnosed or not) of the United States (Lacy et al., 2007; Talley & Koloski, 2000), coupled with an ever-widening set of “criteria,” may suggest increased medical surveillance of our daily lives.

Current medical explanations of the etiology of IBS point to both biological and psychological factors. Biological explanations of its onset include a post-infectious reaction (Dupont, 2007), varied gut transit time (Deiteren et al., 2010), and basic food intolerance (but not allergies, as visible markers exist for these) (Jones, McLaughlan, Shorthouse, Workman, & Hunter, 1982). Though biological explanations may be utilized, it is crucial that IBS not be confused with an Inflammatory Bowel Disease (IBD) such as Crohn’s, as these have biomedical markers such as visible inflammation of the intestines, while IBS does not. Psychological explanations for this illness include general stress, overwork, or environmental stress, in addition to a found high prevalence of individuals with IBS that were subject to trauma or abuse as a child (Levy, Olden, Naliboff, Bradley,
Researchers have recently linked the biological and psychological by positing a disrupted brain-gut axis in IBS individuals, whereby psychosocial factors stimulate neuroimmune and neuroendocrine reactions that produce gastrointestinal symptoms (Mulak & Bonaz, 2004).

“Triggers” of symptoms differ from overall origin. The etiological origin of the illness is when symptoms first began and why, and is the turning point from a “healthy” to a “sick” body. Triggers are ongoing life events that make bodily symptoms worse or return. In chronic illness, the individual is always sick, but may only feel symptoms when they interact with these triggers. Even triggers, however, can be unpredictable and inconsistent. Casiday, Hungin, Cornford, de Wit, and Blell’s (2009) interview study with 51 primary care “patients” with IBS indicated that these individuals are more interested in determining triggers than finding the underlying origin of IBS, emphasizing the need to address individual lives and needs.

Depending on the type of criteria used, between 9-20% of individuals in the United States have either been diagnosed with or experience symptoms of IBS, and it constitutes up to 28% of all referrals in gastrointestinal clinics (Lacy et al., 2007; Talley & Koloski, 2000). In the United States, women are diagnosed at a rate of 2:1 or 3:1 to men, depending on the type of criteria used (Drossman et al., 1993; Heitkemper & Jarrett, 2008; Longstreth & Wolde-Tsadik, 1993), and these numbers have remained constant since at least 1892 (Lockwood, 1895; Osler, 1892; White, Cobb, & Jones, 1939). The current medical literature uses assumed gender roles to explain both why women experience symptoms and are diagnosed more often in the United States. These two phenomena are not synonymous, as men may simply seek treatment less often while
suffering at higher rates in silence (Verbrugge, 1995). For example, Voci and Cramer (2009) claim that those with agentic (generally masculine) personalities tend to have “increased self-esteem, greater perceived control,” and utilize “active coping strategies” (p. 1175), leading to a more positive body image and greater control over IBS symptoms, while communal (generally feminine) personalities typically hold a negative view of their body in relation to the disease and a greater perceived lack of control, leading to more doctor visits. Toner and Akman (2000) cite body image issues, as flatulence and abdominal bloating may prove a greater embarrassment to women than men, while women’s need to remain “agreeable” with others also leads her to attempt treatments that she is not comfortable with or do not work just to please her physician. Ali, Richardson, and Toner (1998) explain that symptoms may be exacerbated by the stress of others ignoring or trivializing abdominal pain, the stress of the caretaking role, and also the stress that a woman may feel when seeking care for herself, as she is stepping out of the expected caretaker role. These assertions produce a psychologization of women’s health issues, blaming women’s thoughts and actions rather than a biological cause (Lorentzen, 2008, p. 68). Furthermore, it homogenizes women into a single category that seemingly have identical relationships to caretaking and gender roles and thus all deal with the stresses of these roles under the heading of IBS. As Horton-Salway (2002) indicates, “If patients can be construed as recognizable types to whom doctors can attribute a psychological diagnosis, this avoids having to say that their diagnoses are uncertain” (p. 417). Attaching the IBS label to a particular group makes diagnosis appear more “objective,” as it ignores individual context (Horton-Salway, 2002), allowing the physician to maintain authority in an illness that cannot be explained.
Few studies address other demographics. Studies on IBS and race in the United States demonstrate a similar prevalence between White and African-American populations, with a slightly lower prevalence in the Hispanic population (Drossman, Camilleri, Mayer, & Whitehead, 2002). These numbers are difficult to ascertain with certainty, however, as differences in cultural approaches to symptom reporting or access to healthcare can have a profound influence on diagnosis (Zuckerman, Guerra, Drossman, Foland, & Gregory, 1996). Over half of individuals diagnosed experience symptom onset before the age of 35 (Johns Hopkins Medicine, Gastroenterology & Hepatology, 2013). Large-scale studies of the IBS population reveal that prevalence of IBS increases with a decrease in income (Andrews et al., 2005; Brandt et al., 2009) and a decrease in education (Andrews et al., 2005). At minimum, the findings indicate that while there is a found “prevalence” of IBS in particular demographic groups, it is extremely diverse in reach and affected by cultural and socioeconomic factors.

Further, this illness is not only prevalent in the United States, as it has been diagnosed around the world with varying rates and with a diverse array of symptoms depending on geographic locale. Gerson and Gerson (2010) for example studied Mexico City, Montreal, London, Bari (Italy), Beersheva (Israel), Kolkata (India), and Beijing, while Heitkemper and Jarrett (2008) indicate that men are diagnosed more often than women in Sri Lanka, India, Iran, and Korea. Bockus, Bank, and Wilkinson (1928) long ago described the illness as one of “civilization,” while Gwee (2007) updated this theory by noting that newly developed countries in Asia are seeing a rise in IBS rates, calling it a product of “colonization.” The variance in rates, demographics (particularly related to gender), and symptoms of those diagnosed with IBS between countries further
demonstrates that cultural and socioeconomic factors likely impact diagnosis (World Gastroenterology Organisation, 2009).

**IBS as Contested Illness**

Until this point, I have provided findings from medical and clinical research on IBS. But there is another side to this story, and that is the side of IBS individuals and their embodied, experiential knowledge. This does not always arise from clinical drug trials, medical studies, or visits to the physician, but rather through the everyday experience of living with a chronic illness. The majority of the literature on IBS is from the expert perspective, focusing on either the biological aspects of the illness, or the psychological aspects as they impact IBS. The experts, while “studying” IBS individuals, are actually talking about themselves. Few studies examine the impact of IBS on psychosocial well-being, or the illness within diverse lives and circumstances. For example, only one study approaches IBS and gender role in cultural context. Lu, Chen, Chen, and Ou’s (2009) interview study of 12 Taiwanese women diagnosed with IBS focuses on the link between the women’s experience with IBS and cultural expectations of femininity, and how each individual woman manages her illness. They write: “Contrasting with the biomedical explanatory model, which in previous IBS-related studies have emphasized the patients’ physical-psychological burdens and their reactive health-seeking behavior” (Lu, Chen, Chen, & Ou, 2009, p. 47), the women in their study recognized the gap in physician knowledge and set about to manage the illness on their own, “including the building of support networks and applying alternative therapies” (Lu, Chen, Chen, & Ou, 2009, p. 47). Drossman’s (1998) proposed “biopsychosocial” approach to IBS suggests that physicians should look at the whole lives of IBS
individuals and integrate the psychological with the biological and social, but he posits that IBS arises out of how these individuals react to particular situations rather than examining what might be wrong with the situations. Medical and clinical studies on IBS turn the “patient” into an object of study by naturalizing their sometimes marginalized position in present social systems and then studying how they react to particular controls. Examining the historical context of these roles, the stresses they produce, and the symptoms that ensue may demonstrate diversity in the illness experience and thus dismantle the objectivity and authority of science and medicine, situating its agenda. Davis (1988) writes that scientific medicine “channel[s] women’s dissatisfaction with their lives into safer paths and teach[es] them to look to men for a solution to their problems” (p. 346). Medicine keeps trying to address the outcome of particular conditions that a marginalized individual may experience, but as long as these conditions continue, these outcomes will also continue.

Paying attention to the situatedness of each individual would expose the situatedness of medicine and physicians, diminishing their authoritative positions over our bodies. As explained by Harding (1991):

Starting thought from women’s lives increases the objectivity of the results of research by bringing scientific observation and the perception of the need for explanation to bear on assumptions and practices that appear natural or unremarkable from the perspective of the lives of men in the dominant groups. (p. 150)

Starting from the voices of IBS individuals, listening to their truth claims, and honoring them as valid begins to make “strange” and “unfamiliar” (Harding, 1991, p. 150) the naturalness of their condition, of their stress, of their position, and of medicine. Both medical and IBS individuals’ voices are crucial to more fully understanding the illness
and thus the needs of those that experience its symptoms. Yet, only a small portion of the literature attempts to understand the IBS individual’s perspective of IBS. I do not want to solely blame researchers or medical practitioners for the lack of literature. As explained later, IBS individuals largely deny psychosocial explanations of their illness, so perhaps participating in these studies perpetuates the idea that these symptoms are psychosomatic. These choices should be examined as they may reveal much about the social constraints of the illness. The literature on these individuals’ perspectives is centered in nursing, a traditionally female-intensive, “caring” profession. While it might be difficult to find participants for these types of studies, the fact that the literature resides here provides a clue into who is more actively pursuing and valuing these perspectives.

Emerging from these few studies are themes of frustration, abandonment, and isolation in the diagnostic and treatment process. Increased IBS individual well-being is connected to a feeling of partnership and empathy from physicians. These studies emphasize that IBS individuals do not always accept physician or medical knowledge, and as such, IBS can be considered a “contested illness.” A contested illness is an “illness that is dismissed as illegitimate – framed as ‘difficult,’ psychosomatic, or even non-existent – by researchers, health practitioners, and policy-makers operating within conventional paradigms of knowledge” (Moss & Teghtsoonian, 2008, p. 7). For these illnesses and even those that are “proven,” physicians, activists, or those that generally consider themselves ill may contest “the etiology, diagnosis, symptomology, and treatment of illness” (Moss & Teghtsoonian, 2008, p. 7). Thus, power and resistance come from all involved in the illness. Dhaliwal and Hunt’s (2004) literature review revealed “a disparity between patient and GP perceptions regarding the nature, severity,
consequences and etiology of IBS, value of dietary advice and diagnostic criteria in the primary care setting, leading patients to perceive this interaction as one of dissatisfaction” (p. 1164; see also Dixon-Woods & Critchley, 2000). IBS individuals feel frustrated because their experiential knowledge conflicts with the biomedical and experiential knowledge of their physician, and their voices are not being heard.

Diagnosis itself provides both advantages and disadvantages. Håkanson, Sahlberg-Blom, and Ternestedt (2010) found that for individuals that have experienced a diagnosis of IBS, the diagnosis provided “a kind of legitimacy in relation to health care providers. It also meant that they could start to trust their own illness experiences” (p. 1125). Being part of a diagnostic group legitimizes and re-embodies the illness and allows access to treatment, permission to take days off to heal, and garners sympathy from others, allowing these individuals to move through the “sick role” (Parsons, 1951). Meadows, Lackner, and Belic’s (1997) study participants expressed frustration at the length of time it took to be diagnosed with IBS, and felt it was because physicians did not care enough to follow through. But without a cause or cure, McCormick et al. (2012) describe an IBS diagnosis as “a map and a compass to start the journey of life with a chronic GI condition” (p. 28). Although helping IBS individuals “move on,” it can cause even further confusion, feelings of hopelessness, or stigma. Indeed, it could now be taken less seriously, as the diagnosis signals that the tests and doctor visits are “supposed” to stop (Whitehead, 2006). Through the professionalization of medicine, it is expected that physicians can treat our pains (Ehrenreich & English, 1978), and indeed, participation in medicine allows one to gain access to these resources that move an individual through the sick role. A diagnosis gives the symptoms a name, re-embodies the illness, and provides
a link in the treatment formula, but this becomes complicated in a chronic, “unexplained” illness with no single treatment. IBS falls under medicine’s jurisdiction because it encompasses physical pain, but it is yet “unexplained,” so all sides come to their own conclusions. To more fully understand the illness experience and thus address IBS individuals’ needs, it is important that all sides are heard and valued. It is clear from the literature that this is not always the case for IBS.

Sites of Contested Knowledge

IBS individuals are dissatisfied with the information and education given to them by their physicians. Håkanson et al.’s (2010) study of nine IBS individuals revealed that most felt their encounters with medical professionals were unsupportive and led to feelings of “humiliation, insignificance, and abandonment” (p. 1116). Halpert et al.’s (2008) study of the educational preferences of 29 IBS individuals indicates that those dissatisfied with received education found that it provided too little information (60%) or was too general or broad (50%). Further complicating matters, the “heterogeneous nature of the signs/symptoms between those affected” (Fletcher, Schneider, Van Ravenswaay, & Leon, 2008b, p. 279) means that each must learn to manage individually, so overarching medical categories produced through the disembodied gaze often do not apply. IBS individuals are not simply frustrated at the lack of information; rather, they come into the diagnostic and treatment process with their own experiential knowledge seeking validation, and are frustrated at the challenge they receive from their physician (Kennedy, Robinson, & Rogers, 2003, p. 307). They accept that physicians make mistakes or do not know everything (Lorentzen, 2008), but are more likely to react with resistance when their needs and knowledge are challenged.
Psychological Contestation

IBS individual and physician knowledge particularly conflict in the psychologization of symptoms. IBS individuals largely eschew psychological explanations of IBS etiology, while physicians and even family and friends may follow this theory. As expressed by a participant in Meadows et al.’s (1997) study: “Nervous stomach was the biggest one I got. I was just told I was full of shit. ‘That’s the way you are – deal with it.’ That’s basically the attitude I got for many years” (p. 163). One participant expressed in Stenner, Dancey, and Watts’s (2000) study: “I wish the people who write about IBS being a mental problem could taste the physical pain of it – then perhaps they’d change their minds” (p. 445). This “psychological issue” causes very real physical pain. Psychological illness or stress is often delegitimized by society as the fault of the IBS individual, as if they are doing it to themselves, or are too weak to handle life’s concerns (Taft, Keefer, Artz, Bratten, & Jones, 2011). IBS individuals rarely cite stress from working too hard at a job or in family life as a cause of the symptoms, rather “working hard” is used to offset allegations that they are “faking” it or doing this to themselves; they worked hard before without symptoms, so the two cannot possibly be related (Soderlund & Malterud, 2005). Håkanson et al. (2009) cite “an impressive determination not to let the illness take over, for example, by refusing to take sick leave or by modifying their activities, which can be understood as an expression of inner strength” (p. 37). However, working when ill is not simply “impressive determination,” but also a struggle to prove strength and legitimacy in a society that stigmatizes both mental and medically unexplained illness. “Feelings of anger, frustration or humiliation will arise if the sufferers are made to feel to blame for what they are going through”
Physicians do not “know” the psychological and thus are quick to attach this explanation to physical symptoms that they cannot explain, to preserve authority in the lack of an explanation (Davis, 1988; Horton-Salway, 2002; Soderlund & Malterud, 2005; Werner, Isaksen, & Malterud, 2004; Whitehead, 2006). Thorne, Nyhlin, & Paterson’s (2000) study of the medical interaction in chronic illness (specifically Type I Diabetes and Environmental Sensitivities) similarly reveals that “patient” knowledge is subjugated in favor of physician control, especially in these types of illnesses where needs are ongoing. Physicians may see individuals actively asserting control over their treatment as calling into question their authority, even if this is not what they are trying to do. IBS individuals that reject the claim that IBS is caused by stress or anxiety, or ask for more tests and treatment, may be seen as difficult or non-compliant. However, they are living in a system that stigmatizes mental illness and delegitimizes the physical symptoms of those with mental health issues. They want their physical symptoms taken seriously so that they can get the help that they need.

The literature on IBS individuals’ perspectives reveals, however, that a majority of these individuals do believe that stress plays some role in IBS onset and symptom aggravation (Bertram, Kurland, Lydick, Locke, & Yawn, 2001; Corney & Stanton, 1990; Lacy et al., 2007; Meadows et al., 1997; Wainwright, Russell, & Yiannakou, 2011). Stenner et al.’s (2000) 60 completed open-ended surveys revealed seven “types” of IBS individuals that all relate differently to the psychologization of symptoms. While stress management might alleviate symptoms (and some of these individuals may want this), one-size-fits-all education does not work due to each individual’s complicated and unique relationship with mental health. IBS individuals accept that psychology impacts
symptoms, but clearly deny that their physical symptoms are “all in their heads.” A separation of the mind and body in Western medicine has perpetuated this idea; if medicine cannot explain it, the IBS individual must be making it up. Joining the mind and body back together may allow for more complete healing and less of a challenge from IBS individuals to the idea that the psychological does have an impact. More fully embracing psychological stress rather than denying or working hard to prove a different etiology can also begin to unravel the systems and social constraints that keep these stresses in place. This can also begin to unravel the claimed truth and authority of medicine. Medicine acknowledging stress as a cause of symptoms may appear to do just this, but it seeks instead to fix a broken person, not a broken system.

**Biological Contestation**

IBS individuals instead point to a biological etiology that may be met with contention by their physicians. They most often cite diet and food intake as a cause of symptoms (El-Salhy, Lillebo, Reinemo, Salmelid, & Hausken, 2010; Fletcher & Schneider, 2006; Jarrett, Visser, & Heitkemper, 2001; Kennedy et al., 2003; Meadows et al., 1997; Schneider & Fletcher, 2008). They reported a number of diet strategies to reduce IBS symptoms, including refusing, adding, or spacing foods, or not eating at all (Jarrett et al., 2001), or using constipation or anti-diarrheal medication (Bertram et al., 2001; Rønnevig, Vandvik, & Bergbom, 2009; Schneider & Fletcher, 2008). While food intake is the “choice” of the individual, they cite social situations that make it difficult to refuse. They will strategically stay home or leave events early if food is served in order to avoid having to refuse the food or having an embarrassing reaction, or they will take over-the-counter medication in order to participate (Fletcher, Jamieson, Schneider, &
Harry, 2008a; Schneider & Fletcher, 2008; Vidali, 2010). It may not “cure” symptoms, but allows them to participate better in day-to-day living in the short term. Without a long-term solution, this is all they can do until one is found.

Control over diet is one of the primary ways in which IBS individuals exercise agency in their illness treatment (Kennedy et al., 2003), and indeed, achieving “control” was a common theme in some studies from the IBS individual perspective (McCormick et al., 2012; Rønnevig et al., 2009; ). This demonstrates that IBS individuals are not simply “victims” of the medical system, rather, they actively construct their illness and use experiential knowledge to find what individually works best for them regardless of physician or medical knowledge. Further, as explained in Wainwright et al. (2011), some of the study subjects felt “blamed and judged by suggestions that they were not eating the right foods and exercising” (p. 1649). They avoid self-blame for symptoms due to food consumption by separating the mind from the body and citing the unpredictability of bodily processes. Their body is out of control but their mind is not, so rational choices regarding food prove the legitimacy and existence of the symptoms. This demonstrates the split between the mind and the body that is so pervasive in Western medicine, and both patients and physicians have internalized this idea. From both the IBS individual and the physician perspective, the mind is controlling bodily symptoms; for IBS individuals, the mind can rationally control the unpredictable bodily symptoms through food intake, while for physicians, the mind’s “illness” causes psychosomatic pain. In each case, the mind and body are separate entities, and the mind has control over the body. Seeking ways to re-integrate the two, or at the very least recognizing that physicians and IBS
individuals are essentially coming to the same conclusions, may effectively reduce this conflict in the medical interaction.

Participants in these studies were frustrated at being given a “deal with it” attitude from their physicians. In Jamieson, Fletcher and Schneider’s (2007) study of eight undergraduate females, one woman expressed regarding diet: “He’s like, ‘You have to try things and see what works for you and what doesn’t,’ and I was just like ‘Ok, but, do you not care?’ like I didn’t really get it” (p. 156). One participant in Casiday et al.’s (2009) study stated: “I said its food related and he said don’t be so stupid what do you think you are talking about; I just turned round and said I’m the one that is suffering” (p. 44). Despite the claims of their study participants, Jamieson et al. (2007) still assert that, “Whether diet plays a role in the pathogenesis of either IBD or IBS remains unclear” (p. 159). While IBS individuals suspect based on their experiential knowledge that diet is to blame, other medical studies “prove” that a diet connection is “unproven.” Words used to describe diet control and use of over-the-counter medicine include negative, inappropriate, offending, and adverse (Fletcher et al., 2008a; Schneider, Jamieson, & Fletcher, 2009). Physicians contest “patient” knowledge of the biological because this means that their own knowledge (or lack thereof) is being called into question. It is up to the IBS individuals to become more comfortable with their illness, to change their eating habits to those that are “healthier,” to feel more normal in being abnormal, to feel less stressed when they are subject to social stigma from refusing food.

Biomedicine prioritizes feeling physically well over feeling socially well, while diet control by IBS individuals as limited by social context creates “non-compliant patients” engaging in “inappropriate” behaviors. IBS individuals must align themselves
with medical standards of healthy living in order to be compliant and thus gain access
to resources that help them to heal. However, these standards do not always work or
apply, especially in a medically unexplained illness with such diverse symptoms and
experiences, so IBS individuals seek out their own, “non-compliant” strategies that may
actually work, but also bar them from full medical participation. Acknowledging that diet
behavior is *context-specific* would dismantle medicine’s ability to produce “objective,”
authoritative knowledge that asserts that diet is not to blame. I do not want to encourage
these so-called “negative” behaviors, which have very real consequences, and I do not
want to demonize physicians or medical researchers as cruel or clueless. There is a
wealth of medical literature exploring the link between IBS and diet, some proposing
food elimination diets or tests for food sensitivities (Drisko, Bischoff, Hall, & McCallum,
2006; Gibson & Shepherd, 2005; Jones et al., 1982; Marcason, 2012). Yet IBS
individuals still cite frustration that their claims are “unproven” and dismissed by
medicine. When IBS individuals’ strategies of control are rendered “unproven” by
medicine, these individuals feel challenged, frustrated, and let down by a system that they
feel is supposed to help and guide them. The most beneficial approach is when physicians
work together with the IBS individual to incorporate many truths and acknowledge
uncertainties in the search for solutions.

**Supportive Encounters**

Despite challenges and conflicts between different knowledge systems, many
individuals wish to incorporate medicine into their own health practices rather than
completely step out of it (Ehrenreich & English, 1978; Riessman, 1983; Ryan & Grace,
2001). Physicians and others in the medical profession are currently gatekeepers to many
forms of treatment and to the legitimacy that comes through diagnosis, so they are valuable in a number of ways. Individuals participate strategically in medicine to obtain their needs and wants. We constantly engage with medical power, question it, and resist it. Power comes from all sides and is not top down. As explained by Lorentzen (2008):

> If medical power relations may be accurately understood to function in this way, through truth claims participants advance and resist, then the production of an uncontested medicalized reality cannot be assumed to be the only possible outcome of doctor–patient interaction. Consequently, the outcome of medical power relations cannot be conceived of as predetermined, that is, as only producing passive, compliant bodies. (p. 56)

When an “ill” individual’s truth-claims are challenged, resistance occurs, and how they deal with this resistance will vary from person to person depending on the outcome they are seeking (Davis, 1988). This struggle is also produced through the media, our education, our race, class, gender, our jobs, our friends, and our families. To draw broad inspiration from Foucault (1980), power comes from everywhere and all sides.

Some of the studies from the expert perspective propose that IBS individuals simply need more education. Halpert et al. (2007) proposes: “[T]he role of the teacher is to facilitate learning by first identifying the gaps, confusions, and errors in patients’ conceptions, and then using appropriate strategies to negotiate the status of the patients’ conceptions relative to those of medicine” (p. 37; see also Lacy et al., 2007, p. 1335). Kennedy et al. (2003) constructed a guidebook for IBS, incorporating IBS individuals’ stories and knowledge as a response to “most medical information, which tends to reflect what clinicians want patients to be told or what they think patients may want to know” (p. 304). One-size-fits-all education designed by medical professionals encourages “patient” compliance (Stimson, 1974) and the idea that scientific medicine is the only truth in the
illness experience. Although IBS individuals do want more education (Bertram et al., 2001; Halpert et al., 2006; Halpert et al., 2007), traditional education will continue to be ineffective as long as only a biomedical model is utilized (Kennedy et al., 2003, p. 304).

Rather, IBS individuals want their physician be a partner and a team member. Halpert et al. (2006) found in their study of 29 IBS individuals that 69% found the doctor to be the most reliable source of information, with health educators (27.6%) and other health professionals (31%) following. The majority, 82%, wanted this information presented to them by the doctor in person. Halpert et al.’s (2008) survey of 1242 IBS “patients” (85% women, 39 years mean age) indicated that educational media preferences were nearly identical between the doctor (68%) and the Internet (62%). Casiday et al.’s (2009) interviews with 51 IBS individuals revealed that most spoke very highly of their general practitioner and acknowledged that they were doing the best that they could. Both Meadows et al. (1997) and Håkanson et al.’s (2010) study participants reported a number of factors that make the medical interaction feel supportive. IBS individuals value “teamwork” in terms of “attending to what works for the patient, working together on diet and medications, discussing exercise programs, and working together on planning stress reduction exercises” (Meadows et al., 1997, p. 165). IBS individuals are okay with a physician’s lack of understanding or knowledge as long as it becomes a “mutual search” (Meadows, et al., 1997, p. 165) for answers, but a lack of teamwork causes them to pursue their own path. Håkanson et al.’s (2010) study found that IBS individuals desired an interest in and acknowledgement of their lives over only medical information, stating, “Jennifer believed that this physician’s interest in her lived experience of illness was the key to trust, rather than whether or not he had adequate knowledge about IBS”
This study also found that patients felt more supported when going to a specialist clinic. As one participant reported, “It’s so nice to be here. Here it doesn’t feel like I need to defend myself” (Håkanson et al., 2010, p. 1122). Likely, physicians here not only had more knowledge of the newest treatments or theories, but also more knowledge and acceptance of the fact that this is all very uncertain. All of these studies indicate that IBS individuals respect the authority of the physician and see their knowledge as valuable, but also want their physician to act as a team member and to respect and integrate their knowledge.

An acceptance of uncertainty can open up the floor for many voices to be a part of the conversation, however, this also makes room for competing ideas that may lessen medical authority. As Foucault (1994) states, the “individual” gets in the way of purported medical objectivity:

If one wishes to know the illness from which he is suffering, one must subtract the individual, with his particular qualities: ‘The author of nature,’ said Zimmerman, ‘has fixed the course of most diseases through immutable laws that one soon discovers if the course of the disease is not interrupted or disturbed by the patient’; at this level the individual was merely a negative element, the accident of the disease, which, for it and in it, is most alien to its essence. (p. 14)

IBS individuals do sometimes come into contact with physicians that are supportive, so the physician cannot simply be faulted for being “unsupportive.” Rather, the physician is also caught up in the linear cause and effect model of the biomedical system, and as such, dealing with a lack of information in a medically unexplained illness may be frustrating, especially when they are expected to provide a definitive answer. IBS individuals may feel this frustration and become confused at the number of different options or solutions that become apparent when reading information about or encountering others with IBS.
Allowing for uncertainty may actually lend more credibility to the physician in the end, as patients no longer “expect” to be cured and may feel as if they have a voice and thus more control over their own courses of treatment.

**Health Communities**

Internet Health Communities

One place that IBS individuals may produce, utilize, gain, or share their embodied, experiential knowledge is within a community setting. Lorentzen (2008) explains that through the Internet in particular, individuals can now more easily create communities with others that experience the same or similar illnesses and symptoms, and turn to a plethora of medical information formerly only accessible to professionals. The Internet has diffused medical knowledge and expertise, and opened up new avenues for truth claims, information gathering, and thus potentials for resistance. It is global, dynamic, and can be updated by nearly anyone at anytime, making all users a potential creator. As Barker (2008) states, “The process of understanding one’s embodied distress has been transformed from an essentially private affair between doctor and patient to an increasingly public accomplishment among sufferers in cyberspace” (p. 21; see also Conrad & Stults, 2010). No longer do these individuals rely on the top-down dissemination of information, rather they can now piece together information into a narrative as they see fit, on their own time (Hardey, 1999). Individuals can share their autobiography to inspire others with the illness, or raise money for various causes (Gillett, 2003). Internet communities further embrace and allow for diverse perspectives that the institutionalization of activism cannot provide (Gillett, 2003). Individuals can come together regardless of their identity, which is especially useful for those that cannot
leave due to disability, and can anonymously ask embarrassing questions (Conrad & Stults, 2010; Hardey, 1999). Overall, communities have “psychosocial benefits including improvements in coping ability, a sense of empowerment and increased psychological well-being” (Malik & Coulson, 2010, p. 142), and can increase participant self-esteem even offline (Veretilo & Billick, 2012).

Studies on Facebook groups demonstrate the diversity in Internet health communities. For example, De la Torre-Díez, Díaz-Pernas, and Antón-Rodríguez’s (2012) study of breast cancer, diabetes, and colorectal cancer groups on Facebook found that overall, the groups focused mainly on preventing diseases (18.02%) and providing support (17.92%) (see also Bender, Jimenez-Marroquin, & Jadad, 2011). Within groups, needs of participants vary. Coulson, Buchanan, and Aubeeluck’s (2007) content analysis of posts to an online discussion board for Huntington’s disease indicated that the posts offered informational (56.2%), emotional (51.9%), network (48.4%), and esteem support (21.7%), with some actually offering tangible assistance (9.8%). Mo and Coulson’s (2008) analysis of an online HIV/AIDS support group came to similar results. My research focuses on support communities, but as the literature indicates, online communities exist for a multitude of purposes, not only to strictly provide “support.”

In addition to enabling participants to gather diverse perspectives and information, online communities can “permit individuals to normalize their conditions by creating a community of ‘sameness’” (Copelton & Giuseppina, 2009, p. 625). They can mobilize a large number of individuals to legitimize and reify their symptoms in order to push for medicalization (Barker, 2008; Fair, 2010), or participants may even use this information to self-diagnose (Copelton & Giuseppina, 2009). Greene, Choudhry,
Kilabuk, and Shrank (2011) found in their study of posts to an online diabetes board that many participants argued that they needed tighter physician control of their unique activities and symptoms. Physicians may fear that these communities signal the de-professionalization of medicine and the dismantling of their expertise (Hardey, 1999), but studies show that Internet information is merely a supplement (Conrad & Stults, 2010; Nettleton, Burrows, & O’Malley, 2005). Nettleton et al. (2005) note “rhetorics of reliability” that individuals use to assess a site, such as linking it to a professional organization or physician. Silence, Briggs, Harris, and Fishwick’s (2007) later study found a shift where users deemed sites more credible when they provided personalized and empathetic information; in other words, they trusted more embodied information. This shift indicates an “increased value being placed on personal, first hand experience…[and] a desire for people to test out ideas regarding their health and to seek a broad range of opinions and advice before deciding on a course of action” (Silence et al., 2007, p. 403). Expert sites mirror the monolithic, authoritative knowledge of physicians by which individuals feel their own knowledge is being suppressed.

These communities may present a number of drawbacks. For example, the “self-governance” gained through these communities can turn into “medical dominance” (Fox, Ward, & O’Rourke, 2005, p. 1307). Fox et al.’s (2005) examination of posts to an online discussion board about obesity found that participants utilize a biomedical model of obesity as the condition to overcome, rather than relying on their own models, so “becoming an expert patient was normative, as opposed to a radical process” (p. 1307). The authors question why, within this model, physicians would feel threatened. Barker’s (2008) study of fibromyalgia discussion boards paints a similar picture, as individuals are
verifying their symptoms with one another and discussing how to obtain “physician compliance” in order to better participate in medicine. Medicalizing one’s symptoms opens access to resources, but may also serve to mask potential inequalities in this access. Individuals should be able to be compliant participants in biomedicine without experiencing the inequalities present in medical dominance. Drawbacks further include that these communities are often open and anonymous, so dangerous information could be read and utilized without verification (Coulson, 2005; Malik & Coulson, 2010). Further, one may not be able to participate or have full access to resources unless they are diagnosed (Vayreda & Antaki, 2009), cliques could form within the community and potentially exclude individuals (Malik & Coulson, 2010), and particular types of comments (i.e., complaints) may be censored or bar certain individuals (Peterson, 2009). Negative comments can also have the effect of producing feelings of anxiety in the reader, as they may be reliving tragic experiences (Peterson, 2009), though this also may have the benefit of preparing individuals for procedures involved with the illness (Malik & Coulson, 2010). Online support groups also have the potential to be addictive, hindering offline social participation (Malik & Coulson, 2010).

IBS Communities

Just a few years ago, communities surrounding the diagnosis of IBS were almost non-existent (Meadows et al., 1997), but have since proliferated online, in person, and even through hospitals and clinics. Support groups help IBS individuals “realize they are not alone” (Schneider & Fletcher, 2008, p. 146), and focus group study participants found participation itself therapeutic (Bertram et al., 2001, p. 525; see also Kennedy et al., 2003). McCormick et al. (2012) found:
Given the often taboo topics discussed, participants seemed grateful for the opportunity to ‘let it all out’ among others that could relate. As one participant put it: “It’s great to meet other people who have gone through what I have gone through. You know what I mean? I’m not alone. Yes you’ve got people online, but actually to physically see somebody in a room, it makes me feel like, ‘God, I’m okay.’” (p. 33)

Some of the studies on IBS used IBS communities to recruit participants (Dancey & Backhouse, 1993; Stenner et al., 2000; Taft et al., 2011), but none included the role of the community in their studies. While the literature mentions in passing the benefits of support group participation for individuals with IBS, only three published studies have been carried out with this population, and only one with an online support group. Payne and Blanchard’s (1995) comparative study of individualized cognitive therapy, an in-person self-help support group, and symptom-monitoring found that cognitive therapy improved both gastrointestinal symptoms and stress and anxiety significantly over support group therapy, but that the 34, mostly female participants still reported satisfaction with support group therapy and would suggest it to others. A later study by Blanchard et al. (2007) compared group-based cognitive therapy, a psychoeducational support group, and intensive daily symptom monitoring between 180 participants, finding that the cognitive therapy and support group provided a significant reduction in symptoms over the individual monitoring of symptoms. Coulson’s (2005) study examined discussion board posts to a large online community devoted to IBS. His analysis of 572 messages revealed that participants most often provided “informational support,” specifically in the areas of “symptom interpretation, illness management, and interaction with health care professionals” (Coulson, 2005, p. 582). While emotional, network, and esteem support were also present, the prevalence of informational support
(in some cases, highly technical information) served both a learning and support function (Coulson, 2005, p. 583). He notes that informational support is more useful when an individual feels he or she can control the situation, while emotional support may be more prevalent when the participant is experiencing a distressing situation.

While IBS symptoms and overall struggles mirror those of other medically unexplained illnesses, the illness is unique in that it has an added layer of stigma because it directly impacts the bowels. This makes the formation of these communities even more relevant and important to understand, as they may have a significant impact on the isolation of the IBS experience. Further, because individuals are turning to these communities despite the fact that physicians are available, these communities shed light on sites of conflict in the medical interaction in IBS, the existence of many different knowledge systems in medicine, and the potential negative consequences to the IBS individual experience when all of these systems are not considered. The mere existence of communities highlights the fact that medicine is incomplete in its ability to increase well-being. More studies on communities would also add to the sparse studies on IBS from the IBS individual perspective, which largely utilize females in their populations. Homogenous study groups (largely white and female) provide the illusion of more “authoritative” knowledge, upholding medical objectivity because “diversity” in experience does not interfere. The literature in this area would benefit from more diverse, global perspectives in both the researchers and the study populations.

The majority of studies on online health communities perform content analyses of discussion board posts. This is useful for understanding the interactions between participants and the “public” side of the illness. It answers questions of how users present
themselves to other community participants, and what types of conversations are happening in these spaces. These spaces are sites of a sort of naturalistic communication, and as such, “help build knowledge related to the construction, negotiation, and maintenance of human social practices and structures…the Internet mediates – and in some ways moderates – interactions and the possible outcomes of these interactions at the dyadic, group, and cultural level” (Markham, 2004, p. 97). What they are missing, however, are the users’ experiences beyond these posts, such as how these communities interact with their everyday lives or what they gain from interacting in these communities. They also do not allow the participants to consciously participate in research. A few notable exceptions combine content analyses with interviews (Kgatitswe, 2012; Marel, 2012), which “allowed the women to reflect on their experiences while using their own words to construct and tell their stories; as done on the on-line forums” (Kgatitswe, 2012, p. 30). As explained below, my study did not include a content analysis of an online community’s discussion board. Rather, a survey and open-ended questionnaire were conducted with two IBS communities to gain participants’ first-hand perspectives and to compliment or contradict “public” behavior online. These communities are one way to obtain access to subjugated knowledge so that the IBS illness experience can be more fully understood.
CHAPTER THREE

METHODOLOGY

Communities of Study

Two communities were included for study. The first was a Facebook group devoted to IBS that is associated with a larger online IBS community not on Facebook. The second was a local IBS community that meets in person, over the phone, and online via a discussion board and through newsletters. Loyola University Chicago Lakeside’s Institutional Review Board approved all human subjects research under project #772.

Facebook Community

After an unsuccessful attempt to receive responses to a survey posted in the “Research Studies” section of a large online IBS community, the creator and moderator indicated that the Facebook page associated with the site was more active and might garner more responses. The original site was chosen specifically for its size and prominence, as it is the largest online community for those affected by IBS, with over 50,000 active participants. Facebook, a social networking website created in 2004, now has over 1 billion users as of October 2012, with over half of those users logging in daily (Associated Press, 2012). The site allows participants to create a personal profile, link to

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1 I have chosen to use the word “participant” rather than “member” to more accurately reflect each individual’s agency, and also because community existence depends on the action of these individuals. Not all “participate” in the traditional sense of contributing information, however, I feel that reading information also counts as participating. This is especially true as the number of times a message is viewed on the larger online IBS site is visible to all participants (so more views could drive more traffic to that post), and the moderator of the Facebook group can gather viewing statistics, thus possibly driving content creation. Further, not all that participate are actually official “members” of the community.
others by becoming their “Friend,” and share public and private messages and multimedia. Participants can “Like” anything a friend has posted, or any product, organization, or service that has a Facebook page. Liking these groups allows access to their resources, updates from the groups’ moderators, and interaction with others in these groups. In most cases, what an individual “Likes” is visible to anyone that the participant is connected to. Facebook’s popularity, dynamic and interactive nature, and ability to bring many people together in one space yet allow for diversity makes it a necessary site of study to determine how individuals interact with it in the illness experience.

I edited the original survey to fit the larger IBS site’s associated Facebook page and made it shorter and more quantitative in the hope that this would encourage individuals to respond. The site moderator posted my message about the study with a link to an Opino survey containing 16 questions. Because the site administrator posted the study, it reached all participants of the group (at the time these participants numbered over 4000, but have now reached over 5000). The message appeared in the participants’ “newsfeed,” which is updated by the second. From this announcement, 81 surveys were completed while 32 were incomplete and thus removed from the dataset (as this was taken to mean a “withdrawal”). The recruitment statement was only posted once, which is a limitation. This 2% response rate does not represent the whole population of IBS community participants, but provides a starting point for further study.

I am offering this study as a way to begin conversations on how to understand the role of the health community and discover sites of contested knowledge in IBS. A selection bias exists in the sample, as I distributed the final survey to the Facebook page based on convenience, availability, and a high probability of getting a large number of
completed surveys. Those that chose to participate in the survey actually read their newsfeed, are active participants, and had the time to complete it, so a self-selecting bias occurred when only a few people chose to take part.

**Survey Research as Feminist Research**

Surveys have a number of limitations, particularly in feminist research. Quantitative data is aggregated and does not pay attention to each individual’s unique background. Qualitative methodologies may provide richer data that pay closer attention to socioeconomic context and allow the researcher to better identify the situatedness of each respondent. Surveys also run the risk of generalizing responses to the larger population. These individuals are potentially the agenda-setters for the community, but this presents a self-selecting bias. Survey methods further consist of an order and preset questions and categories determined by the researcher, and do not allow the respondent to obtain clarification or dispute the topic (Westmarland, 2001). Peplau and Conrad (1998) indicate, “quantitative data may diminish the psychological richness of human experience by focusing on overt behavior or by restricting responses to preset categories” (p. 388). Such flaws in my own survey construction will be noted during the data reporting.

Feminist research, however, does not necessarily depend on the method; rather, it depends on the aims and purpose of the research. Harding (1987) states, “it is not by looking at research methods that one will be able to identify the distinctive features of the best feminist research” (p. 3). Westmarland’s (2001) literature review reveals a number of benefits to quantitative research. It can reveal large-scale trends that would have taken too long to discover qualitatively and that can have an immediate impact on policy. Researchers can also gather more sensitive responses that may not have come out in
personalized qualitative research, due to the anonymity of surveys. Thus, numbers can have a powerful effect on changing overall systems in a (relatively) rapid manner. Chafetz (2004) explains in her defense of positivism that discovering “patterned behaviors and processes” (p. 328), while initially homogenizing individuals into single groups, can shed light on social constraints and thus where we may operate to help individuals free themselves from these constraints.

A “feminist standpoint” (Harding, 1987) is “characterized (amongst other elements) as emphasizing the importance of reflexivity; that research should be woman-empowering and should take women’s accounts seriously; and that it should focus around the notion that ‘the personal is political’” (Griffin & Phoenix, 1994, p. 289). However, “feminist research need not be defined in terms of a primary (or sole) concern with gender relations or women’s experiences” (Griffin & Phoenix, 1994, p. 293). My research comes from a feminist standpoint as I am studying dominant/subordinate relationships in medicine and bringing subjugated IBS individuals’ knowledge to the forefront. My anonymous survey was one way to gain access to this knowledge. Thus, my study holds the dual purpose of shedding light on IBS communities and also more generally making subjugated knowledge visible. My combined survey and interview methods were chosen to determine larger patterns in the respondents and to identify what populations need to be included as part of ongoing conversations.

**Ethics of Internet Research**

My survey was also an ethical way of conducting research in an online environment. Much research on online communities uses discussion posts without the knowledge or agreement of the participants. Many researchers that study online boards,
forums, blogs, and other online media consider these writings “public” and thus outside of the realm of informed consent. Indeed, what constitutes “public” and “private” online has not been settled, nor may it ever be. Ess and The Association of Internet Researchers Ethics Working Committee (AoIR) (2002) released guidelines to help researchers determine if the data they are collecting from these sites are indeed available for public use or are considered “human subjects” research, and thus if the “subjects” need to be notified and consent to their participation. These guidelines still require much individual researcher interpretation, and consider the size of the group, whether or not these boards are password protected, and the sensitivity of the information.

The presence of thousands of participants in the community studied and the fact that these conversations can be read by those that are not “members” may indicate that participants should expect a lessened level of privacy in their conversations. However, this assumes a high level of information and technology literacy on the part of the participant, which I feel cannot be done due to their diversity. Further, the conversational “forum” may lead individuals to expect a higher level of privacy (Ess & The Association of Internet Researchers Ethics Working Committee, 2002). Moreno, Fost, and Christakis (2008) remind us that even though users may understand that their writings are public, this differs from awareness that they are being used for research purposes. Hudson and Bruckman (2004) experienced hostility at high rates in online chatrooms when they made their presence known, but this diminished when the size of the group increased. While informed consent would be impossible to obtain in all cases, this highlights the idea that online researchers may be enrolling participants against their wishes.
Using a survey to collect data was an opportunity for individuals to select themselves to be a part of the research. While survey research has a selection bias, choosing even several hundred electronic messages to examine is also extremely selective based on the billions in existence. Survey research can provide a view into how participants see themselves and their activity online versus what they are actually doing online, shedding light on both public and private experiences of illness. My survey indeed provided space for qualitative answers and “other” in the quantitative responses to account for diversity. In the quantitative data, the voices I am hoping to make visible are coming through only by way of my voice in the question-and-answer construction. This is a limitation of my research, but I hope these patterns can be used to inform future studies on IBS individuals’ voices and perspectives. Gender, race, and ethnicity were kept open-ended, providing both advantages and disadvantages as explained in the results. Choosing not to pursue discussion board research without participant knowledge was my way of more fully respecting the individual. Even though I feel that subjugated knowledge is crucial to healthcare decision-making, I should not expect that each individual will want to offer this information or will see the value in it. Thus, their permission for me to use their knowledge was essential in my aims. I have also chosen not to directly name the Facebook group or local meet-up community as another way to respect privacy, and have chosen pseudonyms for the local community participants.

Local Meet-up Community

To supplement my survey data, I sent an open-ended questionnaire comprised of 17 questions to participants of a local IBS meet-up group that meets over the phone and in person, and has a password-protected online discussion board. The creator and
facilitator of this organization sent my recruitment statement to their email list, which has approximately 50 participants. Three individuals agreed to participate in this study, two of which completed the questionnaire via email, while one completed the questionnaire over the phone in a structured interview. For privacy purposes, their names have been changed. The questionnaire closely mirrored the survey given to the Facebook group. These results provided richer qualitative data to enhance the survey results and provided a site of comparison to the online group. I did not follow up with the interview/questionnaire participants, which was a limitation of my research. Both of these communities were chosen specifically because lay people that have experience with IBS created them, rather than medical professionals or a corporation.

Data analysis

Quantitative survey data will be reported through descriptive statistics. These quantitative data were also analyzed by gender and are reported below. Qualitative data from both the survey responses and the questionnaire responses were coded as the data were read. No pre-determined categories were created, although as with any researcher, I went into the survey with pre-conceived notions about what might emerge based on my reading of the literature and own experiences, assumptions, and feelings about IBS and communities. Codes were sometimes guided using the language of the participants, but sometimes I used my own interpretations and voice to code and analyze the data, which is a limit within feminist research. However, directly asking questions about the community experience allows participants to consciously answer these specific questions in their own words, rather than me trying to decipher the answers to these questions through their discussion board posts without their knowledge.
I found myself recoding, moving the responses, and seeing connections between “different” codes, so it became a cyclical process as I began linking codes together into arguments or theories. Additionally, some of the responses fit into more than one code. Qualitative responses are reported exactly how they were received and are not edited, so that readers of this thesis may critically engage with my interpretations or draw their own interpretations from their reading. Research is messy and contains power from all sides, including the power to respond, the power to interpret, and the power to publish. I do not want this study to be final and thus do not feel that my results are final. The more interpretations given of IBS, the more we will see similar patterns emerge in a diversity of contexts and experiences.
CHAPTER FOUR
RESULTS AND DISCUSSION

Facebook Community Survey

Connectedness and Embodied/Disembodied Information

Participants initially came to the Facebook community for both informational and emotional support. When asked, “Why did you seek out this community?” the most common responses were to learn how others cope with their IBS (79%), find more information about IBS in general (70.3%), connect with other individuals with IBS (64.2%), read information about new available treatments (54.3%), and read about the latest medical research (44.4%) [Table 1]. Participants were able to choose more than one response. Thus, reasons for joining the community are evenly divided between wanting to read general information, medical information, and about treatments for IBS, and connecting with and learning how others cope.

When asked, “What type of information do you MOST OFTEN read on the Facebook page?” and “What type of information do you MOST OFTEN share with others?” (with participants told they could select up to three), most indicated that they read (58%) and share (44.4%) information and advice on how to cope with symptoms, while 53.1% read and 45.7% share personal stories or narratives. These stories might also include different types of treatments or technical medical information, although 30.9% separately indicated that they also read the latest medical studies (6.2% share), 29.6%
read about new available treatments (6.2% share), and 29.6% read information regarding the cause of IBS (6.2% share) [Table 2] [Table 3].

Table 1. Facebook Community: Reasons Participants Initially Joined the Community

<table>
<thead>
<tr>
<th>Response</th>
<th>Male (n=13)</th>
<th>Female (n=67)</th>
<th>Total (n=81)</th>
</tr>
</thead>
<tbody>
<tr>
<td>To find more information about IBS in general</td>
<td>9 (69.2%)</td>
<td>47 (70.1%)</td>
<td>57 (70.3%)</td>
</tr>
<tr>
<td>To find out about IBS treatments</td>
<td>9 (69.2%)</td>
<td>35 (52.2%)</td>
<td>44 (54.3%)</td>
</tr>
<tr>
<td>To connect with other individuals with IBS</td>
<td>8 (61.5%)</td>
<td>43 (64.1%)</td>
<td>52 (64.2%)</td>
</tr>
<tr>
<td>To share my IBS story with others</td>
<td>7 (53.8%)</td>
<td>15 (22.4%)</td>
<td>23 (28.4%)</td>
</tr>
<tr>
<td>To give advice to others</td>
<td>7 (53.8%)</td>
<td>17 (25.4%)</td>
<td>24 (29.6%)</td>
</tr>
<tr>
<td>To learn how other people cope with IBS</td>
<td>9 (69.2%)</td>
<td>55 (82.1%)</td>
<td>64 (79%)</td>
</tr>
<tr>
<td>To learn how to talk to my doctor about IBS</td>
<td>2 (15.4%)</td>
<td>7 (10.4%)</td>
<td>9 (11.1%)</td>
</tr>
<tr>
<td>To learn how to talk to my family and friends about IBS</td>
<td>4 (30.8%)</td>
<td>9 (13.4%)</td>
<td>14 (17.3%)</td>
</tr>
<tr>
<td>To learn about the latest medical research on IBS</td>
<td>6 (46.2%)</td>
<td>30 (44.8%)</td>
<td>36 (44.4%)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (7.7%)</td>
<td>2 (3%)</td>
<td>3 (3.7%)</td>
</tr>
</tbody>
</table>

Table 2. Facebook Community: Type of Information Most Often Read

<table>
<thead>
<tr>
<th>Response</th>
<th>Male (n=13)</th>
<th>Female (n=67)</th>
<th>Total (n=81)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recently published medical studies on any topic of IBS</td>
<td>4 (30.8%)</td>
<td>21 (31.3%)</td>
<td>25 (30.9%)</td>
</tr>
<tr>
<td>Information and advice on how to talk to your physician or health care provider</td>
<td>0 (0%)</td>
<td>5 (7.5%)</td>
<td>5 (6.2%)</td>
</tr>
<tr>
<td>Personal stories or narratives of your life and experience with IBS</td>
<td>7 (53.8%)</td>
<td>36 (53.7%)</td>
<td>43 (53.1%)</td>
</tr>
<tr>
<td>Information on the cause of IBS</td>
<td>2 (15.4%)</td>
<td>21 (31.3%)</td>
<td>24 (29.6%)</td>
</tr>
<tr>
<td>New available treatments</td>
<td>0 (0%)</td>
<td>24 (35.8%)</td>
<td>24 (29.6%)</td>
</tr>
<tr>
<td>Research studies in which you can participate</td>
<td>2 (15.4%)</td>
<td>4 (6%)</td>
<td>6 (7.4%)</td>
</tr>
<tr>
<td>Information and advice on how to cope with symptoms</td>
<td>5 (38.5%)</td>
<td>42 (62.7%)</td>
<td>47 (58%)</td>
</tr>
<tr>
<td>I do not read the messages on the page</td>
<td>2 (15.4%)</td>
<td>1 (1.5%)</td>
<td>3 (3.7%)</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>1 (7.7%)</td>
<td>3 (4.5%)</td>
<td>4 (4.9%)</td>
</tr>
</tbody>
</table>
Table 3. Facebook Community: Type of Information Most Often Shared

<table>
<thead>
<tr>
<th>Response</th>
<th>Male (n=13)</th>
<th>Female (n=67)</th>
<th>Total (n=81)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recently published medical studies on any topic of IBS</td>
<td>1 (7.7%)</td>
<td>4 (6%)</td>
<td>5 (6.2%)</td>
</tr>
<tr>
<td>Information and advice on how to talk to your physician or health care provider</td>
<td>0 (0%)</td>
<td>1 (1.5%)</td>
<td>1 (1.2%)</td>
</tr>
<tr>
<td>Personal stories or narratives of your life and experience with IBS</td>
<td>7 (53.8%)</td>
<td>30 (44.8%)</td>
<td>37 (45.7%)</td>
</tr>
<tr>
<td>Information on the cause of IBS</td>
<td>1 (7.7%)</td>
<td>3 (4.5%)</td>
<td>5 (6.2%)</td>
</tr>
<tr>
<td>New available treatments</td>
<td>0 (0%)</td>
<td>1 (1.5%)</td>
<td>1 (1.2%)</td>
</tr>
<tr>
<td>Research studies in which you can participate</td>
<td>0 (0%)</td>
<td>1 (1.5%)</td>
<td>1 (1.2%)</td>
</tr>
<tr>
<td>Information and advice on how to cope with symptoms</td>
<td>4 (30.8%)</td>
<td>32 (47.8%)</td>
<td>36 (44.4%)</td>
</tr>
<tr>
<td>Information and advice on how to talk to your family and friends</td>
<td>1 (7.7%)</td>
<td>5 (7.5%)</td>
<td>6 (7.4%)</td>
</tr>
<tr>
<td>I do not share information on the page</td>
<td>4 (30.8%)</td>
<td>23 (34.3%)</td>
<td>27 (33.3%)</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>0 (0%)</td>
<td>1 (1.5%)</td>
<td>1 (1.2%)</td>
</tr>
</tbody>
</table>

Participants are seeking to integrate disembodied medical information with information produced through the embodied experience. The community helps them to more fully embody and thus accept their diagnosis and learn how to move forward with it, rather than step out of it. They realize that disembodied, “objective” medical information is valuable to learning more about the illness experience, but they are also seeking to ground this information in the real, embodied experiences of others. Finding others with the same or similar symptoms as one’s self can provide a sense of relief (Bertram et al., 2001; Blanchard et al., 2007; Kennedy et al., 2003; McCormick et al., 2012). Individuals overwhelmingly indicated a connection to others on the board based on these symptoms and this suffering. However, most did not note that fellow participants experienced the exact same symptoms, rather only that there are others that suffer as they do, demonstrating a shared suffering experience. For example, one
participant noted they “Liked” the page because: “Although its a bit of a 'catch 22' knowing that others go through similar discomforts as me, I still find comfort in that” (Female, 26-30, “White”). Another participant gained: “Confidence and a better insight into ibs also learnt that I am not alone and I don't have to suffer in silence” (Female, 36-40, “British”). Yet another stated: “I liked it to give me comfort and support to deal with the IBS on a daily basis, knowing others out there also suffer as I do” (Female, 46-50, “Australian”). This is only a very small sample of the many responses that reflected this sentiment. Some even felt better because others were worse off, for example: “I remember reading stories of how people cope with traveling with IBS and thinking to myself that I really thought I had it bad, but some people have a lot worse problems than myself” (Female, 26-30, “White”).

A diagnosis should indicate that there are others out there like the participant, yet something is making them feel abnormal, so they seek information that helps them to fit better into this diagnostic category. Medicine’s propensity to create overarching, “objective” frameworks can make an individual feel even more isolated when their experience deviates from what is “normal.” For example, if fiber is recommended as a treatment but exacerbates symptoms, individuals may feel frightened. One participant indicated that she had gained through her participation:

[A]n understanding of what others go through and that it is a lot similar to what i go through. a lot of times i thought that the doctors were wrong and that i don't have ibs but after hearing others talk about it i can see that i do and can focus on managing my symptoms instead of worrying about what else might be wrong with me. (Female, 31-35, “Caucasian”)

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1 Gender, race, and ethnicity were kept open-ended, as explained in the next section. I have provided each participant’s identity exactly as they have expressed it.
Another participant cited: “I am relieved to discover my symptoms are normal for my condition” (Female, 36-40, “Welsh and British”). When asked, “At what point did you find this Facebook page?” 90.1% of the respondents came to the community after diagnosis, while 3.7% came prior to diagnosis and 6.2% have not been diagnosed. The participants, while diagnosed with IBS, were feeling something different than what their physicians told them they were “supposed” to. When asked on a scale of 1-5 (with 5 being “strongly agree”) if “My participation in this community has increased my sense of well-being and comfort with having IBS,” the mean answer was 3.53 (N/A was not included in final percentages) [Table 4]. The diversity of experiences and information found and accepted in the community means less of a struggle for IBS individuals to have their own voices heard, so they can move forward with accepting and coping with their illness rather than “worrying about what else might be wrong with me.”

Diversity in information and experiences might be overwhelming, but it can also be positive as it demonstrates the variety of experiences that reside within this illness. When hearing only medical information or perspectives, IBS individuals join the disconnected medical gaze to look upon their own body, which may not conform or comply with the “objective” medical viewpoint. The diversity in experience and information may demonstrate to the individual that there is no real “normal,” and that there are multiple ways to approach and treat each unique illness. The embodied experience of others helps to reconnect the mind and the body, and in some cases, the respondents indicated that they trusted this embodied information even more so (Sillence et al., 2007), as one respondent stated: “Nobody knows what you are going through unless they have it too —my family and friends have no clue” (Female, 46-50, “White”).
Table 4. Facebook Community: Participation in Community Has Increased Well-Being

<table>
<thead>
<tr>
<th>Response</th>
<th>Male (n=13)</th>
<th>Female (n=67)</th>
<th>Total (n=81)</th>
</tr>
</thead>
<tbody>
<tr>
<td>N/A</td>
<td>1 (7.7%)</td>
<td>5 (7.5%)</td>
<td>6 (7.4%)</td>
</tr>
<tr>
<td>1 (Strongly Disagree)</td>
<td>1 (8.3%)</td>
<td>1 (1.6%)</td>
<td>2 (2.7%)</td>
</tr>
<tr>
<td>2 (Disagree)</td>
<td>2 (16.7%)</td>
<td>7 (11.3%)</td>
<td>9 (12%)</td>
</tr>
<tr>
<td>3 (Neither Agree nor Disagree)</td>
<td>0 (0%)</td>
<td>26 (41.9%)</td>
<td>26 (34.7%)</td>
</tr>
<tr>
<td>4 (Agree)</td>
<td>6 (50%)</td>
<td>16 (25.8%)</td>
<td>23 (30.7%)</td>
</tr>
<tr>
<td>5 (Strongly Agree)</td>
<td>3 (25%)</td>
<td>12 (19.4%)</td>
<td>15 (20%)</td>
</tr>
<tr>
<td>MEDIAN</td>
<td>4</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>MEAN</td>
<td>3.66</td>
<td>3.5</td>
<td>3.53</td>
</tr>
</tbody>
</table>

The number of individuals that share medical or treatment information is considerably low compared to the number reading this information [Table 2, Table 3]. Such information could be coming from commercial users with an interest in sales, not the well-being of the participants (Greene et al., 2011; Coulson, 2005), and so could be potentially dangerous. An outside perspective might see the sharing of highly technical information as troubling and potentially harmful, but when done within the context of personal stories or narratives, participants might not see it this way. They have tried treatments that either did or did not work for them, so the embodied information is verified to the community participant. For example, one participant liked the page because: “Although my symptoms have improved since I was diagnosed, I still have bad days where I find it difficult to manage and the information about what helps others is useful. I also want to help others with what I have learnt in my experience with IBS” (Female, 21-25, “White Australian”). Continuing to seek “technical” medical information outside of the physician’s office may indicate that participants are also trying to find
information that fits their unique reactions or symptoms that do not fit the “normal”
IBS experience. They may actually feel validated, and not confused, by the diversity of
information available, as it helps them understand that there is rarely one “normal.” If
physicians emphasized the uncertainty and heterogeneity of the illness upfront during
diagnosis, it may actually provide comfort rather than confusion. When told that their
symptoms are not real, when tests reveal nothing, when treatments do not work, and
when family, friends, and co-workers wonder why they are not getting better, IBS
individuals are left in a constant, frustrating, exhausting search for any evidence of its
etiology in hopes that a cure or treatment can be found. Finding others that experience the
same “normalizes” particular aspects. As one respondent noted: “I have liked the page.
This is because I believe that by ‘normalizing’ my condition I will be better able to cope
with an attack, and will cause myself less stress and anxiety when away from my safety
zone” (Female, 26-30, “Caucasian”).

Yet, this “normalization” can mask inequalities or questions about the status of
this illness once medicalization is achieved (Barker, 2008). Normalizing symptoms or
treatments could also isolate individuals, or even just re-use the biomedical framework
(Fox et al., 2005). These communities help their participants to move forward with
treatment and coping, but the diagnosis of the “medically unexplained” may still not be
given serious merit amongst the diagnosed individual’s circles (work, family, friends) or
even the public. The constant quest to be taken seriously in the first place may hinder the
ability to raise awareness or be an activist for this illness. One respondent noted: “I liked
the page because it's a community. IBS is a very solitary issue; there are no parades or
walks like for other disorders (even non-life-threatening ones). No one wants to hear
about your bowels. I can speak freely on the page” (Female, 26-30, “Caucasian (75%)/Native American (25%)”).

Until this illness is fully accepted as “legitimate,” these individuals will likely be stuck in the loop of continually trying to prove themselves as individuals in need of help. Pushing so hard for legitimacy through participation in the medical diagnosis, and to have their voices heard in the medical community, may mask the lack of attention that is being paid to solving these conflicts between the IBS individual and physician, the lack of studies from the IBS individual perspective, and the comparative lack of research diverted to these medically unexplained illnesses. In fact, raising public or even medical awareness of IBS does not seem to be a central factor in this community. Participants are raising awareness for themselves, amongst their family and friends, but not necessarily in a public setting. One of only two related responses reads:

It has a lot of information about IBS and day to day living, and I suspect there are many out there who have it that are too "embarrassed" to discuss it, so if by my liking the page a friend may see it and get the assistance they need to be open about it. (Female, 41-45, “White…Predominantly English/Irish”)

IBS individuals may think that they are being compliant in actively gathering knowledge, as their own knowledge and the knowledge of others can build “certainty” in this illness. However, this runs counter to what medicine wants and expects out of its “patients,” which is to accept medicine as the authority and stay silent. Social support communities, then, may serve dual functions. While physicians want “patients” to be more “active participants” (Schneider & Fletcher, 2008), they want them to do so on the terms of biomedicine (Halpert et al., 2007; Kennedy et al., 2003; Lacy et al., 2007). Thus, communities may frustrate this relationship, as participants are gaining information,
experiences, and knowledge that dismantle medicine as the only truth. Participants
draw on both embodied experiences of others and disembodied medical information to
insert themselves into the general knowledge on IBS, and are likely left confused or
frustrated when physicians dismiss this attempt at participation.

Participation in Medicine

Treatment Information

Community participants want to better participate in medicine and wish to utilize
their own knowledge and experiences, and the experiences of others, to do so. This is
apparent in the frequent quantitative and qualitative responses that mention treatment for
IBS. In the quantitative responses, 54.4% first came to the community to read about new
treatments, 29.6% still read about new available treatments, and only 6.2% claim to share
this information. As an example, one participant cited they had found information on:
“Calcium supplements as treatment, low FODMAP diet, many others” (Male, 41-45,
White/European). Another participant stated that they shared: “Personal stories, personal
remedies like the use of peppermint or medications prescribed by a physician like Bentyl
are my most shared topics on FB page” (Female, 26-30, “White, Italian”). Another
participant “Liked” the page because:

I was looking for alternatives to help my self. I know ibs can not be cured but I
don't want to mask the problems with western medicine and not be in control. I
want to use natural alternatives to help with at least some of my issues. (Female,
36-40, “Spanish and Native American (Pueblo Indian)"

Another gained a “greater understanding about how to deal - I would probably still be in
lots of pain and having issues if someone hadn't suggested trying a gluten-free diet”
(Female, 41-45, “Caucasian”). Despite the high number of respondents that indicated
“treatment” in their qualitative responses across the survey, only two qualitative responses mention anything about tests. One indicates that they want more information on tests, while one indicates that their doctor will not give them the tests that they want in order to obtain a diagnosis of IBS.

All of these data indicate that community participants are seeking ways to better move forward with their diagnosis, not necessarily directly contest it through further testing. This acceptance likely occurred after participation in the community and not upon initiation, as well-being increased after time was spent here [Table 4]. Overall, participants are still seeking to incorporate the “biological” into their treatment, whether prescribed by a physician or not (probiotics, peppermint, Bentyl). Individuals are either sharing this information altruistically so others can benefit, or they could be sharing this information to validate their decisions and embodied experience (Greene et al., 2011). This highly personalized information cannot be found in a physician’s office, especially as medical studies homogenize participants and create normative frameworks for IBS.

Treatment responses often mentioned diet, which corresponds with the literature indicating that IBS individuals most often believe diet is to blame for symptoms (El-Salhy et al., 2010; Fletcher & Schneider, 2006; Jarrett et al., 2001; Kennedy et al., 2003; Meadows et al., 1997; Schneider & Fletcher, 2008). Diet is so specific to each person and may involve many false starts before finding the one that fits, so normative medical studies used by physicians often do not apply to each individual, causing frustration. Particularly, the FODMAP (Fermentable Oligo-, Di and Mono-saccharides, And Polyols) diet came up often in responses. This diet is based on the theory that “excessive delivery of highly fermentable but poorly absorbed short-chain carbohydrates and polyols…to the
distal small intestinal and proximal colonic lumen is a dietary factor underlying susceptibility to Crohn’s disease” (Gibson & Shepherd, 2005, p. 1401). This has since been extended to IBS, where sensitivity to one or more of these carbohydrates or polyols (oligosaccharides, polyols, free fructose, and lactose) is determined in the IBS individual and then food from these categories is eliminated from the diet (Marcason, 2012). This is a “formulaic” diet, yet still accounts for diversity as there are several categories of the diet into which one might fit. FODMAP affirms what individuals have been suspecting all along, that diet is to blame and each person is different, and it is being supported by biomedicine, which may act as a layer of legitimacy to their experiential knowledge.

In all qualitative responses in my survey, stress and anxiety are only specifically mentioned once, although many indicate that they share generally how to “cope.” No one cited psychological therapy as a treatment they read or shared, and no one mentioned psychological medication, rather they express how they cope with the stress or anxiety that the IBS is causing. That respondents did not volunteer information about stress reduction as a treatment for IBS is in line with the literature that admitting a psychological origin delegitimizes the illness (Håkanson et al., 2009; Stenner et al., 2000; Taft et al., 2011). In line with Lacy et al.’s (2007) study, “only a small number recommended counseling to alleviate symptoms. This apparent disconnect may reflect patient reliance on medications, lack of information about the benefits of counseling or inability to find an appropriate mental health professional” (p. 1334). Rather than recommending a different course of treatment (counseling) than what IBS individuals want (medication), physicians should critically examine why they want medicine or biological treatments. Eschewing the psychological is a strategy utilized by the IBS
individual to be *more compliant* in the medical system, thus giving them wider access to medical resources. The avoidance of discussion regarding psychological treatment also calls into question whether or not this community experience truly re-embodies the IBS experience. While participants feel “normal” again regarding their symptoms and suffering because others feel as they do, this community of sameness may just be reifying IBS individual beliefs that this is indeed a biological illness and should be treated as such. Continuing this separation of the mind and the body may bar access to obtaining the resources necessary for fully coping with the illness.

**Medical Interaction**

Although these data may indicate that IBS individuals want to better participate in medicine, gaining information on how to interact with physicians was a low priority when participants joined the community [Table 1], and continues to be a low priority in what they read and share [Table 2, Table 3]. Only 11.1% came to the community to learn how to talk to a doctor, 6.2% read information on how to talk to one’s doctor about IBS, and 1.2% share information on how to talk to one’s doctor. Participants also did not overwhelmingly indicate, “My participation in this community has improved my ability to talk with my physician about IBS.” On a scale of 1 to 5, with 5 meaning that they strongly agree, the mean was 3 (N/A was not included in final percentages) [Table 5]. Physicians are only mentioned five times in all qualitative responses to my survey. Two participants wanted general information about experiences with doctors. Two contested their physician’s lack of diagnosis, for example, one indicated: “My current doctor does not understand IBS and he will not give me the diagnosis. He is a doctor at a free clinic. When I had more $$, my previous physician did give me the title but had no testings”
(Female, 26-30, “White, Italian”). Another wanted to be taken more seriously, as they stated that they shared: “Mostly about how frustrating it is to talk to doctors who either don't believe that IBS is an actual condition, or they say that it is ‘all in my head’” (Female, 56-60, “Italian-German”).

Table 5. Facebook Community: Community Improved Ability to Talk With Physician About IBS

<table>
<thead>
<tr>
<th>Response</th>
<th>Male (n=13)</th>
<th>Female (n=67)</th>
<th>Total (n=81)</th>
</tr>
</thead>
<tbody>
<tr>
<td>N/A</td>
<td>1 (7.7%)</td>
<td>15 (22.4%)</td>
<td>16 (19.6%)</td>
</tr>
<tr>
<td>1 (Strongly Disagree)</td>
<td>2 (16.7%)</td>
<td>8 (15.4%)</td>
<td>10 (15.4%)</td>
</tr>
<tr>
<td>2 (Disagree)</td>
<td>0 (0%)</td>
<td>10 (19.2%)</td>
<td>11 (16.9%)</td>
</tr>
<tr>
<td>3 (Neither Agree nor Disagree)</td>
<td>5 (41.7%)</td>
<td>17 (32.7%)</td>
<td>22 (33.8%)</td>
</tr>
<tr>
<td>4 (Agree)</td>
<td>1 (8.3%)</td>
<td>12 (23.1%)</td>
<td>13 (20%)</td>
</tr>
<tr>
<td>5 (Strongly Agree)</td>
<td>4 (33.3%)</td>
<td>5 (9.6%)</td>
<td>9 (13.8%)</td>
</tr>
<tr>
<td>MEDIAN</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>MEAN</td>
<td>3.4</td>
<td>2.9</td>
<td>3</td>
</tr>
</tbody>
</table>

So few individuals are reading and sharing advice on how to talk to a doctor that perhaps they feel that their communication with their physician cannot get any better. Participants might completely value the information and advice given to them by their physician as much as they value the advice of others. They may have also gotten all that they need out of the relationship with their physician. However, on a scale of 1-5 (with 5 being “strongly agree”), participants answered, “My participation in this community has improved my understanding of IBS” with a mean of 3.5 (N/A was not included in final percentages) [Table 6]. While they may value the information coming from their physician, there is still an element that they are not receiving, highlighting the physician’s partial knowledge.
Table 6. Facebook Community: Community Improved Understanding of IBS

<table>
<thead>
<tr>
<th>Response</th>
<th>Male (n=13)</th>
<th>Female (n=67)</th>
<th>Total (n=81)</th>
</tr>
</thead>
<tbody>
<tr>
<td>N/A</td>
<td>1 (7.7%)</td>
<td>7 (10.4%)</td>
<td>8 (9.9%)</td>
</tr>
<tr>
<td>1 (Strongly Disagree)</td>
<td>0 (0%)</td>
<td>1 (1.7%)</td>
<td>1 (1.4%)</td>
</tr>
<tr>
<td>2 (Disagree)</td>
<td>1 (8.3%)</td>
<td>7 (11.7%)</td>
<td>8 (11%)</td>
</tr>
<tr>
<td>3 (Neither Agree nor Disagree)</td>
<td>7 (58.3%)</td>
<td>21 (35%)</td>
<td>29 (39.7%)</td>
</tr>
<tr>
<td>4 (Agree)</td>
<td>0 (0%)</td>
<td>20 (33.3%)</td>
<td>20 (27.4%)</td>
</tr>
<tr>
<td>5 (Strongly Agree)</td>
<td>4 (33.3%)</td>
<td>11 (18.3%)</td>
<td>15 (20.5%)</td>
</tr>
<tr>
<td>MEDIAN</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>MEAN</td>
<td>3.6</td>
<td>3.6</td>
<td>3.5</td>
</tr>
</tbody>
</table>

IBS individuals come back to their physicians with more questions, ideas, and knowledge (Nettleton et al., 2005), which calls into question not the authority of the physician, but the fact that they are the only authority. This is one potential source of conflict that could reflect the low communication improvement numbers. The other is that because there is no “cure” for IBS, the community’s reification of symptoms puts even more pressure on the physician to find answers (Dixon-Woods & Critchley, 2000). While it is easy to blame the physician and the “power” of biomedicine for purporting to have all of the answers, the community is also perpetuating this power. IBS individuals are too are caught up in a system that privileges a medical diagnosis in order to be allowed to move through the sick role. Communities can empower participants and make them feel less isolated, which is especially pertinent as IBS can be a taboo subject. But they also hold the danger in reifying particular expectations that physicians simply cannot uphold due to biomedicine’s limits.
The tension with physicians is further highlighted through slightly improved communication with friends and family over communication with one’s physician. The mean on a scale of 1-5 (with 5 being “strongly agree”) was 3.4 with family and friends versus 3 with the physician (N/A and “Not Answered” were not included in final percentages) [Table 7].

Table 7. Facebook Community: Community Improved Ability to Talk to Family/Friends about IBS

<table>
<thead>
<tr>
<th>Response</th>
<th>Male (n=13)</th>
<th>Female (n=67)</th>
<th>Total (n=81)</th>
</tr>
</thead>
<tbody>
<tr>
<td>N/A</td>
<td>1 (7.7%)</td>
<td>11 (16.4%)</td>
<td>12 (14.8%)</td>
</tr>
<tr>
<td>1 (Strongly Disagree)</td>
<td>2 (20%)</td>
<td>5 (8.9%)</td>
<td>7 (10.4%)</td>
</tr>
<tr>
<td>2 (Disagree)</td>
<td>1 (10%)</td>
<td>9 (16.1%)</td>
<td>10 (14.9%)</td>
</tr>
<tr>
<td>3 (Neither Agree nor Disagree)</td>
<td>2 (20%)</td>
<td>11 (19.6%)</td>
<td>14 (20.9%)</td>
</tr>
<tr>
<td>4 (Agree)</td>
<td>3 (30%)</td>
<td>19 (33.9%)</td>
<td>22 (32.8%)</td>
</tr>
<tr>
<td>5 (Strongly Agree)</td>
<td>2 (20%)</td>
<td>12 (21.4%)</td>
<td>14 (20.9%)</td>
</tr>
<tr>
<td>Not Answered (Out of Total)</td>
<td>2 (15.4%)</td>
<td>0 (0%)</td>
<td>2 (2.5%)</td>
</tr>
<tr>
<td>MEDIAN</td>
<td>4</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>MEAN</td>
<td>3.2</td>
<td>3.4</td>
<td>3.4</td>
</tr>
</tbody>
</table>

The difference is possibly due to community participants holding less expectation from the family or friend to have any answers, and in fact, the IBS individual may come into the relationship with the authoritative knowledge (both embodied and disembodied).

Family and friends may, however, contest the existence of the illness, asserting that the IBS individual is “faking” it or becoming frustrated with their ongoing symptoms. As expressed by one participant about the page:

i liked it so it would show in my friends news feed it was my way of telling people what i have and i hoped they would read it and understand why i sometimes make excuses to get out of pre arranged parties days out etc. (Female, 31-35, “White British”)
Another participant indicated that they gained that:

This page has helped me realize I'm not alone. That my severe ibs can be coped with and it doesn't have to rule me. How to talk with my family and teach them that I'm not being a hypochondriac with the pain that comes with ibs. (Female, 18-21, “White/Scottish”)

Participation in this community provides the confidence needed for participants to come forward, as eight participants responded “confidence” when asked what they had gained from the community. But legitimizing their IBS experience through the community provides different outcomes when interacting with physicians than when interacting with family and friends. Family and friends do not purport to have all of the answers; the IBS individual may deviate from their beliefs, but friends and family may more readily accept that it is a “real” illness as IBS individuals have a network of individuals that share similar symptoms. And if their family and friends provide negative feedback, individuals can turn back to their health community for support. One person liked the page because:

I needed to connect with others who understood the challenges I am living with since having IBS. Also I am home bound more than I was before I became ill and I needed a new community, one that would not drop me for being unwell. (Female, 41-45, “Celtic New Zealander”)

Sharing or reading information about how to speak to one’s physician would also outwardly call into question the authority of the physician. Citing improvement acknowledges that a conflict with the medical system existed in the first place, thus exposing a conflict with the legitimacy of the IBS experience overall, as it is the diagnosis that partially legitimizes the IBS experience. Except for one example where the individual wanted to move away from Western medicine, no one outwardly contested the tests or treatments given to them (or not given them), and conflicts with doctors were all mentioned in light of wanting a diagnosis. Those that cited “natural” or non-prescription
treatment could be contesting Western medicine, but they could also just be *adding in* these “alternative” treatments. IBS individuals recognize the partiality in their physician’s knowledge, and by gaining more information about treatments, causes, and tests, they are attempting to participate in medicine. Verifying their discovery of new knowledge and explaining why this new knowledge does or does not fit the situation, rather than dismissing it, would help physicians better facilitate the treatment process.

These support communities demonstrate that it is okay to have different experiences requiring different intervention. Through these communities, participants may increasingly recognize the partiality of the disembodied knowledge of the physician, which can lead to frustration. They are not angry that the physician does not know everything, but rather that his or her own knowledge is not accepted in this interaction (Håkanson et al., 2010; Lorentzen, 2008). The refusal of physician to accept participant knowledge could lessen physician credibility. Communities serve the dual purpose of empowering participants by validating their knowledge and perspectives, but frustrating the IBS individual’s relationship with his or her physician in the struggle for authority. No one wins: IBS individuals feel challenged, and physicians feel challenged.

Participants’ well-being increased with the inclusion of diverse perspectives likely because it demonstrated that the physician’s challenge to their own knowledge is unfounded, and thus they began to feel “normal” again as others also do not fit the normative IBS framework. Considering all of these other perspectives disrupts the all-knowing gaze and objectivity of medicine. It re-embodies the pain, the suffering, and the knowledge of the IBS individual by situating and locating it within that individual, and it reconnects the mind with the body. Considering the perspectives of all sides does not
evolve into relativism by purporting that each side is equally valid or correct. Rather, allowing each voice and perspective into the conversation by locating their situatedness holds these perspectives more accountable for their claims, and asks why their experiences and location make these claims necessarily more valid than others.

Demographics

Race, Ethnicity, and Age

The survey also gathered some demographic data. I believe I was sensitive to pre-constructed categories of gender, race, and ethnicity when I left the responses to these questions open-ended. This allowed individuals to identify as they saw themselves rather than what categories I thought they should fit into. Analyzing the data was easy when it came to gender, as each person answered some version of either male or female, with one respondent not answering. Questions of race and ethnicity became more complicated. I fully understand the difference between the two but did not express this in the survey when I should have. I asked, “What is your race/ethnicity?” Some gave two or more answers (“Asian/Indian”) while many more only gave one (“White”). I had the naïve assumption that it would be easy for me to place people into categories after they self-defined, but this exercise demonstrated to me even the diversity within each group. Of those that responded (79 people), 60 (74.1% of all surveyed) answered that they were definitely White or Caucasian. Yet within this category, people answered that they were also Jewish, Canadian, South American, partially Indo-Pakistani, British, Italian, Russian, Irish, partially Native American, and Hispanic. I cannot make any definitive answers about their “Whiteness” when they are incredibly diverse. Twelve individuals answered a particular ethnicity that might be construed as “White” but cannot be certain: Australian,
Canadian, British, New Zealander, Welsh/British, Celtic New Zealander, and Italian
German were the unique answers (with some repeated). Nine individuals answered
Hispanic, Chinese, Spanish and Native American (Pueblo Indian), Asian/Indian,
Hispanic-Puerto Rican, Hindu, Asian, Indian, and Japanese. Open-ended questions
regarding race and ethnicity may be especially important in the study of global
communities as the definitions of these categories may vary between countries. This also
makes it more difficult for researchers from a single country to distill diverse answers
into only a few identifiable demographic categories for comparison.

Due to the dearth of studies on race and ethnicity in IBS, this might help to shed
light on the demographics of IBS individuals. This could also shed light on the
participants in these communities. These communities are global, which should be taken
into consideration when evaluating the “quality” of medical information that is shared.
Different countries pursue different avenues of treatment, have different healthcare
systems that may aid or hinder access to physicians, tests, and treatments, and have
different research agendas. A treatment that is accepted and used in one country may not
be accepted or used in another. For example, many respondents cited that they seek or
share information about the FODMAP diet. A search of the literature reveals that the
earliest articles on this treatment originate in Great Britain and Australia (Gibson &
Shepherd, 2005), and the majority still resides there. This might cause tension between
the participant and physician, as the participant could bring information to the medical
interaction that has not yet been widely accepted by that country or culture. Examining
the “quality” of information is important, yet so is reviewing its context. As IBS is an
“international” diagnosis, the global reach of its symptoms sheds light on the necessity of
paying closer attention to diversity of experience and how it demonstrates the impossibility of a single, medical authority. Each cultural system has its own relationship to healthcare (and each individual within that system has his or her own relationship with it as well), so learning from one another can on the one hand frustrate communication with one’s physician, but on the other open a new world to increase individual well-being. For example, the tendency in Western medicine to separate the mind and the body could be one reason that patients are quick to deny psychological explanations for their illness. In this tradition and healthcare system, it is either a “mental” illness or a “physical” illness. The biopsychosocial approach to IBS healthcare is a start to integrate all of these aspects in better understanding the illness, but this still tends to be linear in its approach, explaining that patients have physical reactions to how they psychologically deal with particular life situations. Looking to other medical systems and how they might approach this more fluidly or holistically could have a positive impact in developing this theory or approach even further.

With the diversity in answers, I do not feel comfortable studying the “White” experience versus the “non-White” experience. To do this, I would have to lump all of these answers together somehow, which is particularly difficult in the diversity of both “White” and “non-White” answers. It may have also been fruitful to ask about class, income, or education, as these also bear on one’s experience and may have added another “category” into which to divide individuals. But again, the diversity in geographic locale may have made this difficult to categorize. I did ask the ages of participants, which were mostly concentrated under 50 years. The highest concentrations resided in ages 26-30 (19.8%), 31-35 (12.4%), and 41-45 (14.8%). These ages may simply reflect the type of
user on Facebook, or could reflect the ages that need the most support. The diversity in responses from each age group (and thus a low number of respondents from each) do not allow for a rich analysis of differences. A supplemental question that would have better highlighted differences in the community experience would have been to ask how long it had been since diagnosis or since joining the community. This would have allowed a look into differences of what people read and gain based on time passed.

Data collected on gender does provide notable insight into the race and ethnicity of this illness. Thirteen self-identified males responded to the survey. Of these males, one did not answer race/ethnicity, one identified only as Canadian, five identified as “White” (one added European and the other added Jewish), and six identified as a race or ethnicity other than “White”: Hispanic, Asian/Indian, Hindu, Asian, Indian, and Japanese. Thus, while “non-White” was indicated in 11% of the overall respondents, this occurs in 46% of the male responses. Thirteen responses total is hardly enough to make any kind of assertion about the rest of the community or illness in general. However, questions do need to be asked about why so few men answered the survey (16%, closely mirroring overall diagnostic rates in the United States), and in addition, why so few “White” men answered the survey. While men are diagnosed far less often in the United States, they are diagnosed at higher rates in other countries, such as Sri Lanka, India, Iran, and Korea (Heitkemper & Jarrett, 2008). This may reflect the proportion of men diagnosed with IBS in the rest of the world, but could also indicate that men are less likely to join these communities, or participate in social studies of the illness. Research not only on why women are diagnosed with IBS more often in the United States, but also gender differences in the experience of IBS, may explain the differences in diagnostic rates and
even possible inequalities in access to health care (Borum, 2002).

The demographic data indicates an incredible diversity in IBS individuals. It is impossible to find a one-size-fits-all system of knowledge that would apply to all of these individuals at once, and as long as such purported objectivity and homogeneity continues, IBS individuals are going to continually feel isolated and let down by their physicians. Particularly in the diversity of race and ethnicity, different cultural systems lend themselves to different approaches to healthcare. Global conversations on the nature of the illness continue to break down the authority of medicine, but that does not mean that participants wish to step out of the system. Community participants utilize their similarities to prove that their illness is real and to demand attention for their pain and suffering, yet they also utilize their diversity to prove the partiality of all sources of knowledge and challenge the purported objectivity of medicine.

Gender Differences

So many studies on IBS, both medical and social, enroll high rates of females and then hardly, if at all, discuss differences in results between the males (if there are any) and females. One question to ask is why men are enrolled so infrequently in these studies, and if this has an impact on why women are diagnosed more often. The lack of male respondents, particularly if it represents the entire community, points us in the direction of whom we need to be including further in these conversations. Women make up the majority of individuals diagnosed with IBS, but they are not the only ones that are affected. The lack of male respondents and study participants indicates that we might have to try even harder to gain access to this population and their subjugated knowledge. Focusing studies on single populations (or excluding particular populations) of people
homogenizes the IBS experience and produces what researchers feel will be more “objective” knowledge (Epstein, 2004). Regarding disease, Foucault (1994) explains, “the more complex the social space in which it is situated becomes, the more denatured it becomes” (p. 16). The more diverse voices that come out in these health communities, the more medicine cannot hold onto their truth-claims. Communities help participants realize more and more that medical categories, into which they often do not even fit, are not so static or objective after all.

Although the population of men is extremely small, some differences did emerge, so further social research into IBS could use these responses as a basis for inquiry. More men than women first came to this community to share their IBS story with others (Men = 53.8%, Women = 22.4%) and to give advice to others (Men = 53.8%, Women = 25.4%) [Table 1]. A much higher percentage of women came to the community to learn how other people cope (82.1%), gather information (70.1%), and connect with other individuals with IBS (64.1%), which closely matches answers given by men (69.2%, 69.2%, and 61.5%, respectively). These numbers indicate that women first came to the community to connect with others and gather rather than share information, and men, while also coming here to connect and gather information, were more likely to come here to share information and personal experiences than women. Women also gathered general information at high rates. Thus, the point of initiation into the community for women was geared more toward forming emotional bonds and also gathering information (inviting people and information in), and men, while also gathering advice, were more likely to give information and advice. Noted high rates of isolation overall in an illness that is diagnosed more often in women may indicate that this isolation is a result of
women feeling that they cannot or do not want to share information or experience. This suggests a fruitful area of study in gender differences in IBS: Do men with IBS feel more or less isolated than women, and why or why not? Feelings of less isolation may coincide with presumed gender roles, with men feeling more comfortable with their bowels than women. This may also explain lower rates of diagnosis, as perhaps men are seeing physicians less often as bowel problems are more readily accepted or discussed by men (Toner & Akman, 2000), or perhaps men are taken better care of at home by women. As explained in DeVault’s (1994) work, women are often responsible for ensuring that the rest of the family is fed and nourished, while her work remains invisible and her own needs left unmet.

The men’s preference to share personal experiences and advice coincides with Mo, Malik, and Coulson’s (2009) literature review finding that men are more directive than women in separate-sex online communities and also initially in mixed-sex communities, but eventually adopt a more emotional tone in mixed-sex communities. Adopting a more emotional tone may be apparent in what participants share most often. While men said they came to the community to share personal stories (53.8%) and give advice to others (53.8%), a similar 53.8% still share personal stories or narratives, while now only 30.8% share information and advice on how to cope [Table 3]. They still share personal stories or narratives as a way to connect, but feel less inclined to be directive with information and advice in their approach as time goes on.

Women increase both their sharing of personal stories or narratives (44.8%) and information and advice on how to cope (47.8%) as they continue to be participants of the community [Table 3]. The less isolated she feels, the more likely she might be to value
her own knowledge, to speak up, and to have the confidence to offer suggestions. The more she participates in the community, the more embodied her illness becomes, and the more she begins to trust her own experience. Another possibility is that women realize that in order to gain access to all of the resources of the site, they need to open up and participate more often (Marel, 2012). One-third of respondents for both genders (34.3% of females and 30.8% of males) indicated they do not share information at all.

Men originally came to this community at a high rate because they wanted not only to share information, but also to read information about IBS. Yet, as they have been participants of this community, these rates drop in what they read. Men came to this community to gather general information on IBS (69.2%), learn about new treatments (69.2%), and read the latest medical research (46.2%) [Table 1]. I did not ask at what rate they now read general information on IBS, but their rate of now reading about new available treatments and the latest medical research dropped significantly, to 0% and 30.8% respectively [Table 2]. While not asked in their original reasons for coming to the community, only 15.4% of men read information on the cause of IBS. Thus, reading medical information, treatment information, and on the causes of IBS occurs at a very low rate in the male population that responded, and especially compared to women.

At the same time, a slightly higher percentage of men than women indicated that participation in this community improved their communication with their physician (mean of 3.4 for men versus 2.9 for women on a scale of 1-5, with 5 being “strongly agree”) [Table 5]. Thus, it may no longer be necessary, as communication with one’s physician has improved, for men to read this information in the community setting. Approximately one-third of the women respondents indicated that they read about the
cause of IBS (31.3%), new available treatments (35.8%), and recently published medical studies (31.3%), indicating that they are still looking to supplement the information they are receiving from medical professionals [Table 2]. This is, however, a slight drop in why women first came to the community, so perhaps some are in fact better able to communicate with their physician to more readily receive this information. Future research should look into this connection between the IBS individual’s gender, physician gender, and the community further. Men showed only slightly less improvement in communication with family and friends as a result of this community than women (mean of 3.2 for men versus 3.4 for women on a scale of 1-5, with 5 being “strongly agree”) [Table 7]. A closer look into gender differences of communication about IBS could reveal where needs are left unmet in particular spheres.

Taken together, these data indicate that men and women want essentially the same things, which are both informational and emotional support, but how and when they gain both of these things through the community differs. Men first gain entrance into the community from an informational standpoint, while women do so from an emotional standpoint. Each increasingly gains the other as participation continues. Men’s slight improvement in communication with physicians over women could point to the possibility that men do not expect the “friendship framework” (Davis, 1988) from their physicians as much as women, so their interactions are more satisfying; or maybe they are receiving this friendship framework and thus do not need to obtain it in the community. Women’s increased sharing of personal stories and continued high rates of reading these stories indicates that they are turning elsewhere for this personal connection, or maybe they want it from both spheres. While it appears everyone wants
both informational and emotional support, finding out how they go about these based on gender differences could help to provide better overall access to resources.

Particularly as men are diagnosed more often in some countries, issues related to healthcare access can shed even further light on women’s status in particular societies. The lack of “proven” biological etiology and yet imbalanced diagnostic rates especially highlights the need to examine the social aspects of the illness as related to gender to discover how this comments on these individuals’ situations. The medical gaze has reduced them to objects of study that have IBS, but the fact of the matter is, each individual has a real identity that is formed from a particular, situated background. It is not enough to use women more often in studies on IBS just because they are accessible or diagnosed more often, rather, their experiences as women with IBS need to be brought into the conversation. Related to the question of race and ethnicity above, there is a dearth of literature situated in the United States that addresses diversity in experience based on these demographic characteristics. Paying attention to diversity once again dismantles medicine’s ability to make overarching authoritative statements about the illness and complicates medicine’s ability to ignore unique needs and perspectives.

Local Meet-Up Community Questionnaire

In addition to the survey of the IBS Facebook community, three women ages 30-45 answered a questionnaire, two by email, and one by phone in a structured interview style. These women are part of a local meet-up group for IBS that meets in person and has telephone conference calls, an email newsletter, and an online password-protected discussion board. I added this to my methodology to provide another layer to the data. While three participants do not represent the whole community, the answers provide a
point of comparison with the online community and can direct future research into all types of communities for IBS, whether local or global.

Similarities and differences were expressed between the three women. One of the similarities between the women was that they all indicated that this group helps them to feel less alone and isolated in their condition. Pamela (Female, 40) indicated that it validates her experience with IBS, and coming together with others in the same situation proves that it is a very real illness. Beyond meeting others in the group that have the same symptoms, she also expressed that the more communities there are in existence in general, the more this proves that the illness is in fact real. Anna (Female, 33) indicated:

I feel that I have gained a sense of reassurance knowing that other have the same issues and concerns that I do and that I am not alone in managing my IBS. Staying connected in some way with other people diminishes the isolation for me in regard to my IBS.

The use of the word “reassurance” possibly indicates that she was feeling uncertain about her symptoms through isolation. Cathy (Female, 45) indicated that she joined the community because she was “feeling isolated & not getting any help” and that she has gained through the community a sense that she is “not alone.” When IBS individuals only have information and knowledge produced through medicine’s disembodied gaze, and if their embodied knowledge conflicts with this, they may feel that they are the only ones that fall out of the “normalcy” of the IBS experience. Meeting others embodies the experience by providing a diversity of perspectives, allowing them to reconnect with themselves and their own knowledge and thus make new connections with others.

As Pamela indicated, more people and communities coming forward indicates that it is in fact a real illness. Cathy answered that she felt she had contributed to the
community that “I too have IBS & will conquer this.” The community reifies the illness existence and provides something tangible to fight, treat, control, and “conquer.” Pamela, however, indicated that this community connection becomes a “double-edged sword.” Finding individuals that experience the same symptoms makes you feel less isolated, but in her experiences with IBS communities, she had also encountered much negativity and hopelessness, thus hindering her ability to become well (Peterson, 2009).

But while a community of sameness provides reassurance, IBS is incredibly diverse in its symptoms and severity. While this can contribute to feelings of uncertainty, this diversity can also act as another level of reassurance. It is okay if one treatment does not work, because everyone is different. Anna wrote: “I feel that, collectively, we are all smarter than any one of us is individually. I believe everyone has different and valuable information from which we can all learn and benefit.” This response is similar to one of the Facebook survey responses, which read: “I found that it really varies from person to person. There is no one standard relief to help the group as a whole” (Female, 36-40, “Spanish and Native American (Pueblo Indian”)]. Pamela spoke of her experience with a global online community, indicating that while it was beneficial in that you can read about so many peoples’ experiences, some in the community would actually resort to fighting over information and advice on what people should do rather than realizing that everyone is different. This observation demonstrates the varying relationships individuals can have with their illness. Some are comfortable in the diversity of the illness, while others are fighting for a community of sameness, perhaps to further legitimize the illness or their own decisions. These communities can serve as both comfort and confusion, depending on where one resides in the illness process.
The three women all joined for different reasons. Pamela indicated that she had problems with IBS for years and had joined other support groups in the past, and was looking for a new group that was local. Anna indicated that she found the community while “searching online for general IBS information.” Cathy indicated that she was “feeling isolated” and not getting any help, and a “major flare up” made her join. Like the larger online group, the women joined for both informational and emotional support, with each at a unique point in her illness. Cathy further indicated that “I did not understand what was wrong with me and it is extreme. I felt so alone even though I had support from family no one knew what I was truly going thru.” These responses further indicate that even within a smaller group setting, each comes to the community for different purposes and with different needs. This last response also highlights the idea that truly “knowing” the experience comes through embodiment. Even though Cathy’s family was “supportive,” even if physicians are supportive, they can never fully “know” the illness. Communities of individuals experiencing similar symptoms can help fill this gap.

This is further exemplified in the information individuals seek in the community. Both Anna and Cathy indicated that they sought information on doctors. While Cathy just noted “Doctors,” Anna further indicated “doctor recommendations,” and also when asked if it was important to join a local community group, she stated, “Local community group members often have good IBS-friendly doctor and dietician recommendations.” Anna also noted “FODMAPS diet, and the gluten/IBS connection,” while Cathy answered, “triggers.” Pamela noted that she was seeking a social outlet comprised of people who understand her unique life situation, and can provide insight on how to handle social
situations such as dating. Again, this respondent seeks embodied information that others cannot provide unless they have also experienced the illness.

The responses regarding doctors highlight a particular difference between local and global communities. Local communities can provide advice on specific local resources, while global communities, unless partitioned off into regional sections, can only offer general advice on IBS. Local communities, even if only online or over the phone, can better facilitate individuals trying out such advice in real life. Pamela found it life-changing when after being a part of a global online community, she spoke on the phone to individuals in a smaller group on the phone. She said that she could only read so much online and found it an incredibly positive experience to listen to other people “speak my experience.” She wanted to find a local community specifically to boost the human-to-human interaction. As expressed by a respondent in McCormick et al.’s (2012) study: “Yes you’ve got people online, but actually to physically see somebody in a room, it makes me feel like, ‘God, I’m okay’” (p. 33). Thus, as a point of comparison, global and local communities can offer their participants different resources. As also pointed out by Pamela, it is difficult to get people together in person due to severe symptoms that prevent one from leaving the house, so each community has its benefits depending on the needs of its participants. Particularly in the case of Pamela, speaking on the phone to fellow IBS individuals after being a part of a global online community was life-changing, likely because it contributed to an even more embodied experience. Future research questions could look at an individual’s participation in a global community over a long period to note changes in interactive needs. Fears that participation could become addictive are founded, however, some online community participants may eventually feel
that they have exhausted their time there and move on. Looking at the impact of these communities on the embodied experience would be useful as these communities continue to grow and impact the medical interaction.

Two of the participants indicated that their physicians do not know about their participation in the community, while Cathy said that her physician knew but did not really have any comment on her participation. In retrospect, a follow-up question to ask the other two respondents would have been why they have not told their physician, particularly as Anna specifically wrote, “It is not something I would tell her.” Pamela and Anna indicated that they had not used information from the community to speak to their doctors, while Cathy stated, “Yes, telling him I needed support because what I was being treated with was not working.” Here is an outward comment on the conflict that may arise between physician and IBS individual as a result of the community.

Regarding verifying information that they read online, the women again had three very different answers. Pamela said that she “takes everything with a grain of salt,” and will do her own research before utilizing such information. If necessary, she will ask her physician. Anna indicated that she does not verify the information she gains from either the community or her doctor, responding, “I incorporate particular information that I read into my life/treatment because it has the potential to benefit me health-wise and to reduce my IBS symptoms.” Cathy indicated that the information was already verified, “Because it is individuals living w/IBS just like I.” She trusts this information because it comes from a place of embodiment.

Other than the above comment, an outward conflict with one’s physician only arose one other time, during the interview with Pamela. She indicated that after her
diagnosis, she was made to feel crazy and could not get help from physicians. After finding a global online community, she began learning information about IBS that her physicians had never told her. For example, she expressed that she had always eaten very healthy foods including a lot of fruits and vegetables, but was still experiencing constipation. Fiber associated with these foods is not widely believed to cause constipation and is widely accepted to treat it, but she read on these boards that it caused constipation for some people. Her physician had never said anything like this to her during the diagnostic and treatment process, but it started working for her when she incorporated it into her life. Popular belief, overarching “objective” medical studies find that fiber relieves constipation, but it was making Pamela feel even worse, so she felt abnormal as her body was going against medical knowledge. When a body deviates from what is widely considered the best course of treatment or way of life, they not only become physically ill by following a different course, but this different course also renders them non-compliant, neurotic, and deviant in the eyes of medicine and society. The conflict in knowledge between overarching medical advice and the needs of each individual body can cause frustration, abandonment, and despair. Pamela’s experience especially highlights that aligning the body with medicine does not necessarily increase physical or psychological well-being.

Each of the respondents were very new participants in the community and had not participated much in it at the point of the interview, which impacted the results to such questions as what they contributed to the community and how it has affected their well-being and understanding of having IBS. Regarding her participation in other communities and even in this one, Pamela said that while communities have helped her to slowly
become more comfortable discussing her IBS with family and friends, communities are only one piece of the puzzle. Indeed, this is a particularly salient point in light of the entire thesis.

Future studies should provide comparisons between online and largely off-line communities, and how they can either benefit or negatively impact particular groups of individuals. Local communities or those involving more human interaction produce a more embodied experience. The information in these communities may be more specialized, such as what businesses or physicians cater to people with IBS, making the experience even more embodied, localized, and perhaps “real.” As framed by Pamela, she is continually looking for new communities and experienced different interactive needs after her time in an online community. Online communities have the benefit of reaching a larger amount of people and information, and their anonymous nature may allow individuals to talk about embarrassing or taboo subjects with greater ease (Hardey, 1999). My Facebook survey found that 80.3% of respondents feel more comfortable talking to people about their IBS online than in person. As expressed by Malik & Coulson (2010), online communities can become addictive, which may have a negative impact on well-being, so physicians could recognize or be accepting of community participation and help them to discover more beneficial resources if participation gets to this point. In this sense, longitudinal studies would also be beneficial, to discover how these communities impact the illness experience as it continues. Especially as clinics are seeking to create communities, and as some physicians do point their patients in this direction, understanding what type of group might best fit these individuals would be beneficial.
CHAPTER FIVE

CONCLUSION

In the case of a medically unexplained illness such as IBS, no one person or system has all of the answers. Yet, in order to maintain authority, medicine claims objectivity through the creation of normative frameworks that arise out of clinical studies. These studies reduce IBS individuals to a homogenous set of objects rather than a diverse set of individuals. Through the “objective” diagnostic criteria and guidelines that arise from these studies, medicine purports to know best how our bodies function, and what we can do to make them even better. Through these studies, IBS individuals’ knowledge becomes subjugated, as diverse voices would disrupt this gaze and claimed objectivity and authority. Medicine’s authority depends on the normative body. Because IBS individuals’ knowledge is subjugated, the only way these individuals can know themselves is through a separation of the mind and the body and by assuming the disembodied medical gaze. When their own experiences deviate from the categories and normative frameworks into which they are supposed to fit, the IBS individual feels isolated and alone, as though they are the only one experiencing these symptoms or treatment reactions. The disembodied gaze coupled with feelings of being the only one that deviates prevents individuals from having the confidence to come forward and make connections. Such isolation has a dramatic negative impact on well-being.

These feelings of isolation and the uneasiness IBS individuals feel with the
information physicians give them causes them to turn elsewhere, which has been made easier with the opening of global communication outlets such as the Internet. Communities related to health have increased dramatically in the last few years and show no signs of slowing. In these communities, participants can provide support to one another, share their own experiences, raise awareness or funding, or notify others of the latest medical information related to their illness. IBS individuals do not always actively seek out these communities, but rather may stumble upon them in their search for more general information. If an IBS individual uses the Internet at all, he or she is likely to find these communities.

Through these communities, participants realize that they are not the only ones suffering. A diagnosis should indicate that others are experiencing the same symptoms, yet participants report high levels of feeling less isolated or alone after being a part of the community. Something they heard, read, or were told about their illness makes them feel isolated in the first place. Medicine and physicians are only one part of this, as this feeling of isolation can also come from family members, friends, co-workers, or the media that does not take medically unexplained illness seriously. Despite the medical diagnosis, the lack of etiology and the lack of cure do not allow the individual to move through the sick role, reducing their illness to a psychological condition that they supposedly brought on to themselves. In all areas, individuals are trying to prove their legitimacy. They try to prove to family and friends that the illness is real, and they try to prove to physicians that their unique experience matters. Isolation occurs both when the IBS individual feels deviant from the categories and frameworks into which their body and mind are supposed to fit, and also when no one wants to believe or listen to them.
Community participants take comfort in finding other individuals that suffer as they do, that have the same or similar symptoms, and that have the same or similar reactions to particular treatments, as it re-embodies their own experience. Participants can use these communities to prove that there are others out there like them, they are not making this up, and they are sick by no fault of their own. Especially for those that deviate from what medicine considers “normal” for IBS (“I was relieved to discover my symptoms are normal for my condition”), these individuals can prove that they are not so deviant after all and that medicine’s knowledge is partial. In the same vein, community participants can draw on diversity in participant experience to further prove this partiality. Differences in experiences, in symptoms, and in reactions to treatment further dismantle medicine’s claimed objectivity. This is especially true in such a global environment as Internet communities. IBS is a global diagnosis that differs in symptoms and demographics based on country or culture, while these communities embrace a global audience. As a result, these communities situate the illness in each participant’s individual life. Participants begin to realize that there are no one-size-fits-all answers, that everyone’s experience is different and partial, and that there is no “normal,” especially in an as-yet “unexplained” illness. IBS individuals are okay with uncertainty, but they are not okay with direct challenges to their own knowledge. Especially after participation in these communities, participants realize that all knowledge is partial and incomplete, including that of their physician. If the physician’s knowledge is incomplete, there is no reason that the IBS individual’s own embodied and experiential knowledge should be dismissed. Here is where the frustration in this relationship lies.

In order to maintain authority, physicians passively incorporate the illusion of the
god-trick into their practice, but once IBS individuals see more clearly that there are multiple knowledges to consider in the illness experience, claiming objectivity can actually undermine the physician’s authority. IBS individuals’ subjugated knowledge can provide a more “objective” standpoint, as it is situated, located, and embodied. The results above indicate that IBS individuals do not want to completely step out of medicine, rather, they want to continue to be participants in it, as medicine gives them access to particular resources and also the legitimacy that comes from a diagnosis. This is evident in the exchange of information in the Facebook community involving treatment, but not necessarily tests, as more tests might provide further uncertainty or contest medicine. They want the physician’s help in navigating this illness, but they also want to feel comfortable fully integrating their knowledge into this experience and interaction.

Supportive encounters with one’s physician are not defined by the physician knowing everything, rather, they are defined by the willingness of each side to act as part of a team to find solutions that best fit the unique needs of the individual. Rather than discouraging IBS individuals from seeking out additional medical information, or automatically deeming this information potentially dangerous, physicians could acknowledge that this information exists and allow these individuals to come to them with questions without fear of judgment. Of course, the state of healthcare does not allow for lengthy medical interactions, so perhaps other lines of communication could be opened, such as physician participation in these communities, although privacy and confidentiality boundaries need to be maintained (Malik & Coulson, 2010). In this open, global environment, physicians must acknowledge that IBS individuals are going to receive medical information elsewhere, and they must offer a safe place to verify this
information. Information posted online is nearly impossible to continually evaluate, and if individuals feel let down and dismissed by their physician, they may try out this information without guidance, or branch out on their own (Meadows et al., 1997).

While this study began as a question about the gender of those diagnosed, the findings reveal that this is less about gender than it is about the dominant/subordinate relationship present in the medical interaction. Men and women both want an integration of disembodied expert medical information and embodied information that comes through the experiences of others. When and how they obtain this information differs between the genders based on the findings of this survey, but the respondent population is too small to make any definitive assertions. Further study should examine IBS individuals’ informational needs by gender within the illness of IBS. While the dominant/subordinate relationship is less about gender than anticipated, further study into the IBS experience based on gender is crucial, particularly as diagnostic rates between men and women differ from country to country. Such facts demonstrate that diagnosis may depend on socioeconomic factors such as access to healthcare or caretaking practices at home. That women are diagnosed more often in the United States does in fact comment on the status of women in this country, but assumed gender role traits (for example, that women are more embarrassed by their bowels, or that they are stressed about participating in or stepping out of the caretaking role) cannot be carelessly applied to explanations without talking to the women about their experiences. Rather, speaking directly to women and men, as their identified gender, would help to discover where the point of illness etiology lies and if this can in fact comment on if resources are being distributed equitably. Asking simply why women are diagnosed more often re-uses the
diagnostic categories that physicians have created to increase the appearance of authority (Horton-Salway, 2002). Asking questions about why categories of gender are used in diagnosis, in addition to IBS individuals’ experiences with IBS based on gender, are necessary to fully understanding the impact of this illness.

This study has a number of limitations, and is meant only to serve as a starting point. First, over 80% of the respondents were women, and all of the meet-up group respondents were women. This was noted as a major limitation of all studies of IBS, both clinical and those that studied IBS individuals’ perspectives. Men are also diagnosed with or at least experience symptoms of IBS, but continuing studies on only women perpetuates the idea that only women experience this illness. The fact that so few men responded to my survey indicates that future studies need to try harder to include this population. Studying only women homogenizes their experiences as “the” IBS experience, so providing diverse gender perspectives may begin to unravel this notion. Likewise, other demographics that interact with each individual’s experience are needed to further understand the diversity in the illness experience. My thesis did not capture this information as I had hoped. Further, while differences between genders emerged, the response rate overall was much too small to create any sound theories from the data. A related limitation was that I only asked the moderator once to post my study in the Facebook group; posting it more times would have allowed it to cycle through participants’ newsfeed multiple times, thus garnering more responses. Selection bias occurred when I selected these particular groups for study; larger-scale comparative studies are necessary. A further selection bias occurred when participants were invited to opt in. I also did not interview the creators of these groups, which would have provided
insight into the origins of these communities. A future study could include several online health community creators to determine how and why these communities are built, or what inspires individuals to take such a step. Another similar limitation is that I did not ask follow-up questions of my questionnaire participants, which would have provided clarification and richer data. Lastly, while the survey and questionnaire methods were my way of respecting the individual’s decision of whether or not to participate in the research, respondents may be following different lines of activity in their actual community participation. Studying these “natural” settings would provide an additional layer to more fully understanding the purpose and impact of these communities, but how to go about gathering these types of data presents ethical concerns that must be addressed if we are to fully respect the agency of each individual.

IBS individuals are not trying to actively challenge the authority of medicine, rather they are challenging the idea that medicine is the *only* authority. Through discovering new information about the illness and treatment, community participants are trying to better participate and be a better partner in the medical system. They are seeking to incorporate many perspectives and knowledge systems, including their own, into the search for increased well-being. In acting as a partner and better explaining treatments or tests, physician authority actually may increase rather than diminish. Allowing more room for IBS individuals’ knowledge and trusting their agency in the treatment process is a crucial step in increasing well-being in medically unexplained illness. The findings of this study indicate that individuals go to these communities to re-embody their own experiences, as they find relief and increased well-being through reading about the experiences of others. Physicians could on the one hand recognize and encourage
individuals’ need to seek out and gather this information in the quest for increased well-being, but on the other hand, individuals may not need to seek out this information or these experiences as much if their own experiences were honored and valued in the medical interaction.

It is imperative that this study be only one contribution to ongoing conversations on the role of community in the Irritable Bowel Syndrome illness experience. These communities will only continue to grow and develop and as such, their benefits and drawbacks must continue to be understood by all with an interest in healthcare. Future research steps should be to include more perspectives in these studies. This study focused on bringing to light the experiences of those that associate themselves with IBS, but the knowledge, opinions, and feelings of physicians must also be brought into the conversation to understand how these communities impact the medical interaction and thus access to care. Asking physicians about their viewpoints on patient communities for IBS, and how often these communities make their way into the medical interaction might begin to build steps to better integrate all aspects of the IBS individual’s life. In addition, a limitation to most studies on IBS (including my own) is that they include largely white, female populations and do not discuss gender differences. Further, there are few studies that note differences between other demographics, or look more closely at these demographics (age, income, education) of the women that are studied. Internet health communities in particular demonstrate the incredible diversity and global reach of this illness, so it is crucial that diversity in IBS experience be included in both medical and social studies of the illness. These studies would situate the illness and allow for a closer look into whether or not individuals are being treated equally within their healthcare
systems. While these perspectives might create a growing uncertainty about the illness, and demonstrate that there is no real “normal,” this could open up avenues for both IBS individuals and physicians to explore the uniqueness of each person’s experience and work on ways to better address needs. Another way to look at this is that it could be beneficial to start with differences and then explore whether or not there are any patterns or similarities between participants that can be addressed, rather than starting with a “norm” and then finding those who deviate.

As physicians may be concerned with the information being exchanged in these communities, and as it is clear that IBS individuals are seeking technical medical information in these settings, physicians could consider being available in these communities to answer questions or provide verified information. A balance needs to be struck, however, between replicating the medical framework that was so unsatisfying in the first place and honoring the diverse and embodied experiences of the participants. These communities are not going anywhere, and the fact that hundreds more individuals joined the IBS Facebook community over the year that this study was conducted demonstrates that these communities show no signs of slowing down. These need to be embraced, and at the very least better understood on the terms of the IBS individual, if physicians want to play a role in increasing these individuals’ well-being.
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VITA

Erin Hvizdak grew up in northwestern Wisconsin and attended the University of Minnesota-Twin Cities, where she received a Bachelor of Arts in Anthropology in 2005. From 2006 to 2010, she attended the University of Wisconsin-Milwaukee, where she earned a Master of Library and Information Science and a Graduate Certificate in Women’s Studies, and acted as a Graduate Research Assistant in the Center for Information Policy Research. While there, she won student travel and research awards and co-authored peer-reviewed articles on Internet and computer research ethics.

While at Loyola, Erin was a leading member of the Women’s Studies and Gender Studies Graduate Student Association, Archives Intern at Planned Parenthood of Illinois, and Archives Intern at the Evanston History Center. Her research at Loyola was informed by a course she took at the University of Wisconsin-Milwaukee titled Feminism, Librarianship, and Information, during which she became interested in women’s access to health information. Her primary career interest is in archival administration, particularly with women’s historical materials, and anticipates that her research at Loyola will inform future study into histories of women’s health communities and activism.

Currently, Erin is a Librarian at Morton College in Cicero, Illinois, and a Volunteer at the Frances Willard House Museum Archives in Evanston, Illinois. She is also producing a manuscript for the Woman’s Club of Evanston in Evanston, Illinois about their 125-year history. She lives in Chicago, Illinois.