The Invisible Malady: Inflammatory Bowel Disease

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> "Ill health, which is another way of describing what it can cost to maintain momentum, overtakes us when we can imagine no reason to expect it."
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> -Joan Didion, *Blue Nights*

Introduction

Life with a chronic illness is work. In physics, the second law of thermodynamics: states that all in all, we are headed to disorder. The second law tells us water can only flow downhill. Work is required to pump water uphill; it cannot do so by itself. When faced with a challenge, people need momentum to continue forward, make progress, and fight back. When the opponent is your own body, panic ensues. How does the system regain energy to find that momentum?

Crohn's disease and ulcerative colitis, collectively known as inflammatory bowel disease, are chronic inflammatory diseases of the gastrointestinal tract. Ulcerative colitis is limited to the colon, but Crohn's disease can infect the entire tract. IBD results from a complex interplay between genetic susceptibility, environmental factors, and altered gut microbiota (Torres 1741). These factors lead to a misfire in the immune system. Crohn's disease and ulcerative colitis are considered types of autoimmune diseases. This means the immune system is attacking itself in the form of bowel inflammation.

Typical patients present with diarrhea, abdominal pain, fatigue, and weight loss (Hart). Common complications include fistulas, strictures of the bowel, abscesses, and bowel obstruction (Hart). Blood tests and stool tests can give some preliminary data points. Colonoscopy and endoscopy are the only ways to confirm disease presence with certainty. Many patients present with extra-intestinal manifestations in nearly any organ system. These include joint pain, arthritis, erythema nodosum, pyoderma gangerosum, primary sclerosing cholangitis and vision problems (Levine 235). Psychological symptoms are often difficult to treat.

In this paper, you will find a brief discussion of inflammatory bowel disease (IBD) and its various treatment modalities. The disease affects nearly 28 million people worldwide (Maochen Zhang, et. al. 2388). There are drug therapies, surgical interventions, alternative options, and psychological counseling to aid a person's journey through winding path that is a chronic and incurable illness. Drug options have evolved exponentially, and surgical techniques are continually updated for optimum response. Alternative therapies are investigated and quantified relative to successful maintenance of remission. There is a continuous cycle between the body's response to medicine and the psyche of said body. An understanding of all the available options and side effects is essential. Medicine's various barometers give doctors a quantitative understanding of the patient's health.

After reviewing the medical treatments, both conventional and unconventional, I will discuss the psychological implications of life with IBD. This is the qualitative portion of a patient's well-being. With IBD comes great psychological distress, as expected. This discussion will include how activities of daily living are changed with an IBD diagnosis. Exploration of these issues is key to answer understanding how the disease impacts the day to day life of a patient. IBD is a disease that does not always diminish quantity of life but always changes the quality. Part of psychological well-being is support from others. Family, friends, and mental health professionals can appreciate the difficulties of these patients; fellow patients supporting each other is also important. Support groups are sometimes utilized to ameliorate the psychological distress of IBD. Patients surveyed for this study describe how they cope with the implications of their diagnoses. Many patients described feeling invisible, as they appear healthy from first glance. Yet, the immune system is ravaging the digestive tract.

Methods

There is an excerpt of the novel *Imagine Me Gone* by Adam Haslett where Michael, a psychologically ill character, narrates his responses to a patient intake survey (Haslett 113-156). He lists the demographics—name, doctor— then gives lengthy answers to basic questions like "family medical history, work history, prior medications" across the forty pages of prose. In response each medication he has tried, he provides extensive details and vivid memories of his time on various anti-depressants. Very little of this narrative actually describes the results of treatment. Michael says:

> "But you will come up with nothing that I haven't thought of or worried about to death already. Which is one of the reasons I fill these forms out in such detail. The only relief comes in describing it" (134).

Patients fee misrepresented in the both the private and public sphere. The disease is not commonly mentioned in film, television, art, novels, or commercials. In the few instances that IBD is mentioned, the disease is described only by its embarrassing symptoms —diarrhea and incontinence. Many physical and psychological symptoms are ignored. Publicity is the way to raise the necessary funds to promote useful studies. IBD is not at the forefront of the public support. Other charities for other diseases have entered the mainstream marketplace. Celebrities are spokespersons for cancer and other diseases. IBD has yet to achieve that status. Without widespread understanding of the disease, it is hard to raise the amount of money needed. Psychologically, people feel isolated when they are living with an invisible illness.

I explore how this isolation factors into both quantitative and qualitative measurements of disease activity. Isolation comes from many sources. People are unable to complete normal activities due to symptoms. People must miss school, work, and other important events for treatments. Legally, only some of these factors are covered by the Americans with Disabilities Act. Currently, we are debating how this disease, one of many "pre-existing conditions" of the healthcare bill, will affect health insurance options for patients. All of this takes a toll on the body.

Personal experience cannot always be quantified into statistics. Case study by online interview is utilized to better understand the factors, interpretations, and feelings about IBD representation. Access to media and support systems changes geographically. Participants are limited to 18-45 year olds in New York, New Jersey, Pennsylvania, and Connecticut. Patients in the immediate area have access to more comprehensive care. I have received multiple replies of those within the specified demographics and others outside of the region. Those outside of range have been excluded. I have masked the names of participants for their privacy. Name nor contact information were supplied with the results. Patients reply with as broad a range of answers. Demographic characteristics include age, gender, current treatment modality (both traditional and alternative), prior surgical history, symptom awareness, self-assessment of social function (employment, family, etc.), self-assessed psychological complications, and feelings about IBD representation in multiple aspects. These components are derived from 2009 study by Haapamaki, et. al. The study used two questionnaire packets of the Inflammatory Bowel Disease Questionnaire (IBDQ) and the Health Related Quality of Life questionnaire (HRQoL) (Haapamaki 961). As someone who has been a part of the IBD community for almost twelve years, I am connected to support groups (both online and in person) and patient communities across the area. The Crohn’s and Colitis Foundation offers a fundraiser/half-marathon training program. Teams exist across New York, New Jersey, Long Island, Philadelphia/Southern NJ, and New England. I have met many patients, caregivers, and supporters through this program. I approach this survey as a native ethnographer.

I have asked my subjects to describe their experiences with the disease in detail, focusing on their personal interpretations of IBD representation. Patients were obtained via Facebook posts through various IBD online support groups. As patients obtained the survey via digital IBD communities, this proves the patient is somehow utilizing an online social media platform for support. I used Google Forms. With the limitations of this disease, I felt it would be best to allow patients to reply on their own time. Patients often have issues leaving the house when symptoms flare. In-person interviews are not practical in this situation. Other studies mentioned how disclosure can be triggering to patients, so I wanted to allow people to approach the survey as they see fit. Questions were purposely left open ended. Yes/No replies are evaluated as patients choosing not to detail their disease. I also evaluated blogs available online and accessible to general patients populations and the public.

In the surveys below, it is evident there are two ways to approach the invisible illness perspective. First, many patients do not appear sick and feel as if others are not validating their pain. Clothing and makeup are used as costumes to portray healthy people. Patients do not feel well-represented to the world either in mass media or to our representatives in Washington. Very few people felt IBD is adequately portrayed in society. Doctors, patients, caregivers, and mass media representatives need to have an open dialogue. Open communication is essential to achieving this goal. I hope fellow patients reading this paper will feel as if they are represented and empowered to be active in their communities as IBD patients. Collectively, we can bring more awareness.

History of Inflammatory Bowel Disease

This World is not conclusion.
A species stands beyond—
Invisible, as Music—
But positive, as Sound—
It beckons, and it baffles—
Philosophy, don’t know—
And through a Riddle, at the last—

Sagacity, must go—
To guys it, puzzles scholars—
To gain it, Men have borne
Contempt of Generations
And Crucifixion, shown—
Faith slips—and laughs—and rallies—
Blushes, if any see—
Pluck at a twig of Evidence—
And asks a Vane, the way—
Much Gesture, from the Pulpit—
Strong Hallelujahs roll—
Narcotics cannot still the Tooth
That nibbles at the soul-

This World is not conclusion, Emily Dickinson, 1862

For physicians and patients, inflammatory bowel disease has no conclusion. There is no cure, and there is no treatment model that works for all patients. For doctors, the search for answers leads to more questions. The term "invisible" illness does not just apply to the naked eye. Doctors often are baffled by the unique quantitative and qualitative presentations of the disease. Treatments that should work, for some reason, do not provide any relief… "to guess it, puzzles scholars" even with decades of experience. In the face of uncertainty, sometimes doctors have to rely on faith in new research, that to "ask a Vane, the way" or any "twig of Evidence" will become a new treatment option.

Many suffer with a disease that has no name for years before diagnosis. Ann, a twenty-seven year old female from New Jersey, describes her experience. Ann uses multiple medications to treat her disease and participates in patient advocate programs across the country:

> *I was diagnosed nine and a half years ago on December 1, 2007, after four months of being very sick and getting no answers…though I wasn't diagnosed until this time, and didn't have severe symptoms until a few months prior, I think this was something I've had for most of my life. I've always been underweight, to the point that my pediatrician would scold me for not even making my age chart, and pull my mom aside concerned that I had an eating disorder. I believe I wasn't absorbing nutrients properly. I had stunted growth.*

My experience with Crohn's disease is somewhat similar. I was diagnosed formally within six months of experiencing severe symptoms. Once diagnosed, it had taken twelve years and eight surgeries, many medications, so many diet trials, vitamins, and alternative therapies. I am still trying to figure out what works for me. Many of my fellow patients experience this too. Betty, a thirty-eight year old female from New York, was diagnosed with ulcerative colitis seven years ago but reports she had symptoms for three years prior to her diagnosis. When asked if she feels her disease is adequately controlled, she replies:

> *Yes, finally. Though I now worry about getting sick again - didn't realize the mental health effects of this disease had on me until I got better.*

Emma, a forty-four year old female from New Jersey, was diagnosed with Crohn's disease fourteen years ago. She is frustrated by the inconclusive cause of IBD.

Continue to represent IBD as a disease we cannot control, it's not because of something we did, ate, or drank.

Patients have complicated medical histories because the root cause of the disease is not fully understood.

The earliest descriptions of inflammatory bowel disease (prior to its discovery in the twentieth century) was primarily of colitis symptoms. Hippocrates (400 BC) discussed some causes of diarrhea in some of his writings. Many nineteenth century medical schools discussed bowel inflammation even though there was no way to view the intestine objectively. In 1859, Sir Samuel Wilks first used the term "ulcerative colitis" to describe a non-infectious diarrheal syndrome. There were so many fatal diarrheal diseases at this time and no available treatments. Many died of cholera and dysentery or what may have been colitis (Mulder).

In 1909, the Royal Society of Medicine in London held the first medical conference to discuss three hundred collected cases of alleged ulcerative colitis. Patients were young adults, commonly had diarrhea with bleeding, and had little success with available treatment options. Doctors continued to discover more and more about ulcerative colitis. Only a few of those discussed treatments remain today: ileostomy, total colectomy, and blood transfusion. By the 1960s, steroids and immunosuppressive agents like 6-MP and azathioprine were utilized to treat the underlying autoimmune nature (Mulder).

Crohn's disease was founded as a separate entity in the 1930s. A few noted cases of inflammation in the small intestine or elsewhere ("regional ileitis") where documented. In 1913, Thomas Kennedy Dalziel described nine cases of a bowel with "rigor mortis" and "hyperplastic enteritis" of the intestine by biopsy. Two were fatal, the remaining seven were treated surgically (Mulder). In 1932, Burhill B. Crohn, Leon Ginzburg, and Gordon Oppenheimer first described "regional ileitis" in fourteen patients with "necrotizing" inflammation, strictures, and fistulas. All patient data was collected at Mount Sinai Hospital in Manhattan. These were patients of A.A. Berg, a surgeon at the hospital, but he did not want to be named in the project (Mulder). Crohn's name appeared first in the article; hence, Crohn's disease. It is still up for debate whether being associated with a debilitating illness for the rest of time speaks to a positive or negative legacy.

Since, doctors have created better diagnostic tools and treatments. There is even a wireless camera that moves through the bowel. Without the medical advancements of the last hundred years, doctors could not diagnosis or treat conditions properly. There was a non-infectious diarrheal illness that had no name.

Clinical Disease Indicators and Treatments

"I remember a huge tiredness coming over me, a kind of lethargy in the face of the tangled mess before me. It was like being given a maths problem when your brain's exhausted, and you know there's some far-off solution, but you can't work up the energy even to give it a go."

— Kazuo Ishiguro, *Never Let Me Go*

Treatment for IBD is a complicated puzzle. There are many options available for including medications, diets, alternative therapies, and surgery. These include bowel specific aspirins (5ASA), steroids, antibiotics, immunomodulators and biologics. At the first rung of the ladder are oral 5ASA drugs. Drugs provide relief to many patients, but need to be considered against various side effects. For example, side effects of steroids include weight gain, insomnia, puffy face, and increased risk of infection. Long term use can result in osteopenia and osteoporosis (Mayo Clinic). Antibiotics like ciprofloxacin and metronidazole are only used short-term management but can result in bacterial flora imbalances after treatment.

Patients whose disease does not respond to first and second line treatment can include biologic therapy into the drug cocktail. These can be used alone or in combination with first-line therapies. Primarily, drugs used for IBD are anti-tumor necrosis factor (anti-TNF) medications, such as infliximab, adalizumab, and certolizumab. These drugs work by binding to and essentially neutralizing TNF. This is a protein involved in inflammatory processes of the body. Vedolizumab was FDA approved for both Crohn's disease and ulcerative colitis in 2014. All of these drugs involve either intravenous or subcutaneous injection by a doctor or nurse (Mayo Clinic). Side effects, including a small risk of T-cell lymphoma, deter some patients from these therapies. However, these treatments work quickly and often help patients avoid surgery.

Gretchen, a thirty-three year old ulcerative colitis patient from Pennsylvania, describes her current state of health with adalizumab, azathioprine, and prednisone therapy.

> *Physically I am drained and sick all the time. Emotionally I'm a mess. I feel no one cares I am just a number not a person.*

There also needs to be consideration of oral supplementation of nutrients. With an inflamed digestive tract, vitamin absorption is compromised. Iron, B12, calcium, and Vitamin D are often recommended for these patients. If the disease is advanced, physicians can recommend enteral nutrition via feeding tube, or parenteral nutrition via intravenous access (Mayo Clinic).

Patients sometimes opt for a more holistic approach to inflammatory bowel disease treatment either independent of or concurrent with medical therapy. Gluten-free, dairy-free, vegetarian, vegan, and soy-free diets are considered. Patients are advised to avoid trigger foods specific to their case. Some opt to follow the Specific Carbohydrate Diet developed by Elaine Gottschall. Emma uses this as an adjunct therapy to budesonide post-operatively. Patients avoid complex carbohydrates to restore balance to bacterial flora in the digestive tract. Registered dietitians can help patients determine the best course of dietary management.

Alternative therapy is an ever-expanding avenue for IBD therapy. There is limited data that these medications clinically reduce symptoms, but many patients in online forums report improved quality of life while using alternative therapy. Some patients explain that exploring these treatments makes them feel as if they are working towards remission and attempting to utilize all available therapy. Nearly 50% of IBD patients have tried some form of alternative therapy. Most healthcare providers recommend that these are not to be used in lieu of traditional therapy, but in conjunction with traditional therapy. Options include yoga, acupuncture, hypnosis, supplements, medical cannabis, and reiki (Singh et al., 74).While curcumin is palatable, wheat grass juice can induce more nausea and diarrhea. My only attempt at consuming wheat grass was not successful. Some of the above therapies do not have extensive use to prove remission rates (Singh et. al 77). Ginger extract is known for its antiemetic properties. Despite the taboo, medical marijuana has been approved for inflammatory bowel disease treatment in many states across the United States. While still federally illegal, many states allow doctors to prescribe certain strains for many conditions. Researchers are trying to understand how the body's cannabinoid receptors work and how the plant treats symptoms (Morson). Medical marijuana has two downsides: cost and federal research funding. Often alternative therapy is prohibitively expensive and not covered by health insurance.

When all else fails, surgery is needed for advanced IBD cases. Indications for surgery include abscesses and fistulae that do not respond to antibiotic therapy, obstructive bowel patterns, and disease that does not respond to medical therapy (Hart). Sometimes an ileostomy or colostomy bag for diverted stool collection is necessary. Patients navigate the best course of treatment specific to their disease presentation.

Tabulating all the various treatment options to inflammatory bowel disease can be exhausting. To quote Kathy in Ishiguro's book, this "maths problem" seems like a problem with no answers. So many people utilize different types of complementary and alternative therapies for both psychological and physical well being.

Atul Gawande, a physician writing about flaws of medical practice, sums up the patient experience beautifully:

> "Medicine contains the entire range of problems—the simple, the complicated, and the complex—there are often times when a clinical has to do just what needs to be done. Forget the paperwork. Take care of the patient (Gawande 50)."

This type of thinking applies to my surveyed patients. Each reported different symptoms, medications, and feelings about their disease. Some patients respond to basic medications; others require intravenous infusions; yet others require extensive surgery. Some are able to manage their disease with more holistic methods. Doctors and other healthcare professionals need to follow the same guidelines as Gawande. Patients experiencing intense pain and intestinal bleeding can have normal blood work and no radiological findings. Treat the patient, not the tests. In this paper, I want to treat the patient experience, apart from the medicine. The disease impacts patients in may ways out side of the physiological system.

Brain-Gut Connection and Psychological Symptoms

"Etymologically, patient means sufferer. It is not suffering as such that is most deeply feared but suffering that degrades."

-Susan Sontag, Illness as Metaphor

With inflammatory bowel disease comes both physical and psychological pain. Research has been dedicated to the study of risk factors for psychological distress in IBD patients. Per Maochen, Zhang, et.al: "Illness perceptions are composed of five dimensions, including cause, consequences, identity, timeline, and cure/controllability" (Maochen Zhang, et. al 2388). The brain-gut connection theory links the medicine and physiology of the disease to the psychological and emotional symptoms. The psychological health of Crohn's disease and ulcerative colitis patients is studied in its own context. Studies quantify this data. The symptoms are intertwined but many doctors do not address the the physiological link between the brain and the gut. Neurobiological studies are searching for the biology behind the "conversation" between the gastrointestinal tract and the brain.

Researchers Bruno Bonaz and Charles Bernstein ask the problem at hand: Are psychological conditions a "sequel to having a chronic disease, a prelude to the chronic disease, or a combination?" (Bonaz and Bernstein). Studies focus on "psychoneuroimmunnology." This is the relationship between the central nervous, endocrine, and immune systems.

Bonaz and Bernstein list five components to this interaction:

(1) the autonomic nervous system
(2) the central nervous system

(3) the stress system (hypothalamic-pituitary-adrenal)
(4) gastrointestinal system
(5) the intestinal response/immune response

Stress induced perturbations include motility dysfunction and inflammatory responses (Bonaz). These symptoms drive psychosocial function. Depression is twice as prevalent in the IBD community than general populations. Although psychological health may come secondary to active disease, the patient's mental well-being many also contribute to a patient's perception of his/her health. This creates a complicated cycle of symptoms. In studies, patients in remission reported greater psychological well-being than those with active disease. Bonaz and Bernstein write, "it is not having the disease per se that relates to the psychological difficulties, but rather that the disease activity is pivotal" (Bonaz and Bernstein). For some patients, either having a mood disorder or risk factors for a mood disorder impacts disease progression.

However, doctors, psychologists, and alternative heath care practitioners are exploring therapeutic options to reduce this stressor. There are pharmacologic options, changing the inflammatory cascade through brain receptor protein modification. Nutritional guidelines, include a high fat diet, are linked to decreased intestinal permutability. Meditation and Tai Chi can decrease sympathetic nervous system activity. Yoga can increase parasympathetic drive (Bonaz and Bernstein). In one small study, patients were given a twelve week course of hypnosis. Outcomes demonstrated that 80% of patients completing the therapy thought their quality of life had improved while none reported worsening symptoms. 60% stopped taking corticosteroid treatment while utilizing hypnosis therapy (Todorivic 468).

Stress reduction techniques are often utilized In a study performed in India, various yoga postures and breathing and techniques were studied. Outcome measures were included heart rate monitoring, blood tests for immune markers, anxiety surveys, and a diary of clinical symptoms. This particularly study revealed that anxiety levels were more significantly reduced in ulcerative colitis patients. Crohn's disease patients did not benefit, per the indicator methods (Sharma 103-110).

These connections between the brain, the intestinal mucosa, the nerves in the intestine, and the immune system are mind-boggling (both literary and figuratively). This is the never-ending puzzle of inflammatory bowel disease treatment. Where do these factors intersect? Where do the symptoms overlap? Contradict? What are the upcoming treatments? Most importantly, how do patients cope with the time it takes to find these answers? Patients find support among family, friends, and each other. Other patients become your friends and family.

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Factors to Psychological Distress in the IBD Community

There's a certain slant of light,
On winter afternoons,
That oppresses, like the weight
Of cathedral tunes.

Heavenly hurt it gives us;
We can find no scar,
But internal difference
Where the meanings are.

None may teach it anything,
'Tis the seal, despair,-
An imperial affliction
Sent us of the air.

When it comes, the landscape listens,
Shadows hold their breath;
When it goes, 't is like the distance
On the look of death.

-Emily Dickinson, *There's a certain slant of light*

Dickinson is not known for her levity. Neither is chronic disease. She describes the cold winter of isolation, where patients feel the weight of loneliness. The condition can feel oppressive and overwhelming, weighing on patients in multiple ways. Inflammatory bowel disease does not provide a scar as an invisible illness, yet we still discern an "internal difference/ Where the meanings are" as patients grapple with the psychological effects of a lifelong incurable condition. This understand may not be taught but must be understood through despair and heartache. Although a painful "imperial affliction" of mind and body, patients can find uplifting support from various sources. The patient community —the landscape—listens and provides support to patients. All treatments, whether they be traditional, alternative, adjunctive, or supportive, attempt to create as much distance from death as possible. Dickinson typically uses grim themes in her poetry. In this paper, I would like to find ways to empower patients.

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As described, IBD comes with many unpleasant physical symptoms, even though the disease is invisible to the naked eye. No one can see the ileostomy bag, scars, and pain underneath a strong exterior. Some patients lose weight; others gain weight on prednisone. For some, it is a blessing to hide the illness behind clothing and a positive attitude. It can take time to reach a diagnosis (Krause 605) or find the proper treatment combination. I was once told "[IBD] patients are like snowflakes: no two are the same." Medication is a game of trial and error, finding what specific cocktail works for each patient. Physical pain comes and goes between periods of flare-up and remission.

Psychological symptoms can ebb and flow with the disease symptoms. Several patients reported that on days where they feel well, they feel less depressed and anxious. Maochen, Zhang, et. al. discuss that "perceived stress, regardless of its types and forms, including harassment, overload, irritability, lack of joy, fatigue, worries and tension, could lead to mood disorders and undesirable living situations" (Maochen, Zhang, et. al 2393). IBD comes with many embarrassing side effects that can affect patients' quality of life.

The psychological pain is not always addressed but just as devastating. When the disease limits a person's lifestyle, the result is depression. Many have anxiety over incontinence and food restrictions. Some patients blame themselves, "in a 'self blaming conception of illness in which the individual feels himself responsible for his illness because of the mental conflicts which have been induced'" (Farr 500). People are dissatisfied with their lifestyle. Many stressors exist to exacerbate psychosocial symptoms.

Ann faces many of the same struggles as other patients, even though she has access to extensive support networks. When asked if her symptoms are controlled adequately she described that her bowel symptoms are somewhat in check, but she still suffers from fatigue and nausea. She still needs help managing her emotional symptoms. Her anxiety and worry gets the best of her.

> *Even though I've been dealing with this for a decade now, it never gets easier to cancel plans. There's a fear of missing out, the internal struggle of "should I stay or should I go," the guilt for leaving your friends and family hanging last minute, and the worry of ruining an experience for others. There's the concern where you wonder where the bathrooms will be, what your access to them will be like, and how you can be prepared for accidents and emergencies.*

IBD patients are both at risk and often present with particular psychological factors: perfectionism, dependency, neuroticism, insomnia, anxiety, and depression. Psychological stressors can exacerbate symptoms and symptoms can exacerbate psychological stress. Studies show major life stressors, anxiety, and depression are linked to a risk of developing IBD (Ananthakrishnan 293). Most important, the diagnosis of a life-altering disease is a major life stressor.

Social Needs

Social ramifications of chronic illness are studied in the psychological academic community. Abraham Maslow's model, Hierarchy of Needs, can be applied to those with illnesses. Claudine Herzlich describes the "paradox of society": "it is society, which, through way of life, brings illness; at the same time, it is society which demands that the individual should be healthy…therein lies the paradox of society; it demands from the individual what it refuses him…" (Farr 496). Illness can exist as destruction, liberation, or occupation. Patients can behave in one of three ways (Krause 600):

(1)Destruction: Patients can be passive towards their illness and let the disease take over their life.
(2) Liberation: Patients can redefine themselves in light of their disease, finding ways to represent themselves in society.
(3) Occupation: Patients can become engaged in their own care, finding coping mechanisms and working with their healthcare professionals to find medical maintenance.

IBD patients need more rest and different food, but the need is often satisfied. By the federal requirements of the Affordable Care Act, all patients must have insurance of some type. No patients reported that they cannot meet basic needs. This leads to an analysis of the psychological and self-fulfillment needs in the pyramid. Lack of belongingness, self-esteem, and self-actualization are all reported in the patient interviews.

Belongingness is an unmet need for IBD patients. The disease limits what they can and cannot eat, where they can and cannot go, and how those outside the IBD community will respond to their diagnosis. Mariane Krause's 2003 study of IBD patients in support groups revealed:

> "Due to the fact that these are not well-known diseases, even in medical circles, during this process different diagnoses (even cancer) had been considered. This fact is related to the intense feelings of fear most participants had when they first joined the group (as we could observe in meetings and hear in the interviews). Even after the diagnosis had been made,

> they still showed fear about further complications of illness, such as developing cancer or transmitting the disease to their own children. For this reason, the seeking of information about their illness was one of their main coping strategies" (605).

Self-help groups have been shown to help patients deal and accept their diagnosis. Patients can either support each other or in a group format. In the age of social media, patients can connect to each other better than ever before. Krause states that "social support also has a beneficial effect on health through five mechanisms: social participation; being part of a social group; self worth; pleasant events, and social identities" (Krause 601). Patients learn about the disease and coping strategies from each other. Patients can also see others succeeding despite their diagnosis. Krause refers to these as normalized representation components: "a better knowledge about the illness, the perception of fewer limitations in daily life and the perception of mutual support in the self-help group" (Krause 608). This helps achieves Maslow's imperatives of belongingness and esteem needs. In her study, patients benefited from support groups. Support groups are offered in person by the Crohn's and Colitis Foundation throughout New York, Connecticut, Pennsylvania, and New Jersey.

Social media has created a new world of opportunity to connect patients around the globe. In 2013, 26% of internet users watched a video or read an article or posting about an illness (Frolhlich 1431). Frolhlich's study features many IBD patients within my chosen demographic and their interactions with peers on social media platforms. He found that patients surveyed reported increased self-esteem, better understanding of the disease, found more humor in their condition, and most importantly, felt more visible than before these interactions.

Betty explains she participates in Facebook groups - she recently "came out" on Facebook. She describes this as "liberating" and "two people reached out…to talk about it." She finds better social support online than in person. Her social life is now:

> *Relatively active…though not so when I was sick. It was hard to make plans not knowing how I would feel. I would like to be more social again, but it's hard because [sic] people got used to me bailing/not inviting me to things. I'm single and dating was not a priority when sick (how do you explain going to the bathroom 10 times on a first date?)*

Rachel, a 22 year old from Connecticut has similar concerns about romantic social interactions:

> *I get tired easily and can't drink. At 22 that sucks. Crohn's comes when it wants to and that stops me from being spontaneous and hurts my sex life.*

Brian, a 33 year old male from New Jersey with ulcerative colitis, describes his social life as "cautious. I do the best I can when I have to make important functions." While suffering from symptoms, patients find it difficult to the house and spend time away from a bathroom. In Frolhlich's study, IBD patients chose to communicate via social media platforms. Several respondents described their social lives as okay, adequate, not too active, none, very slim, meh. It can be argued that patients retreat after diagnosis due to symptoms and embarrassment. However, that does not alter the patient's perception of their psychological health.

Self actualization is a recurrent problem in IBD patients. Disease symptoms and treatments often require patients to miss school and work. Ann explained that she left her job in New York City because of extreme fatigue after her three hour commute. Charlotte, a thirty four year old female from New Jersey, was diagnosed with ulcerative colitis in 2001, and her disease evolved into colon cancer within four years. She still suffers from pouchitis (inflammation of the ileal reservoir created after resection) and subsequent symptoms. She describes her emotional state:

> *The guilt of having my young kids in school because I can't physically take care of them is unbearable and completely affects my self esteem. I feel damaged and useless. My entire day is spent focusing on taking care of myself so I can be the best mom possible for when my kids come home from school. I am so tired of being tired. I don't have the energy or strength to work and raise a family anymore. My body is fading each year.*

She feels as if her body is failing her and in turn, she is failing her children. Krause's study explains that other patients she interviewed expressed similar concerns. Parents often worry about if their child will inherit the disease. It is not unusual for IBD to run in families. Charlotte acknowledges that she suffers from depression and that she has developed a routine as a chronically ill patient. For patients with formal employment, it is difficult to obtain enough time off for sick days and treatment time. Employer disability benefits are limited. Patients feel as if they are not competitive candidates for positions because of these complications. Many patients rely on their employers for health insurance. Without jobs, they are left to find insurance on the open market. Our current representatives are creating plans to reduce insurance coverage and affordability. This is a deadly issue for IBD patients.

Representation

Patients with chronic illnesses feel invisible to their elected officials in Washington. Published studies have yet to quantify how current events in our healthcare model add to patient stress. Stressors continue to compound for patients located in the United States. Patients rely on health insurance to stay alive. Medications, surgery, hospitalizations, and ostomy supplies can run upward of $500,000 per year. Patients will reach a lifetime coverage limit, should these policies be reinstated. Deductibles, copays, and rising premiums may price patients out of adequate insurance policies. Insurance companies may be allowed to deny coverage to patients under the proposed healthcare bill, passed through the House of Representatives in May 2017. In an interview with Jake Tapper, Representative Mo Brooks (R-Ala.) said that:

> "It will allow insurance companies to require people with higher healthcare costs to contribute more to the insurance pool that helps offset all these costs, thereby reducing the costs to those people who lead good lives, they're healthy, they've done the things to keep their bodies healthy" (Gonzales).

This stressor affects the entire chronic illness community afflicted with "pre-existing conditions." Without insurance, some basic physiological needs cannot be met, and Maslow's model breaks down. The Crohn's and Colitis Foundation sponsored IBD Day on the Hill in May 2017, sponsoring patient travel expenses to Washington. Patients met with representatives about issues concerning IBD care and research.

Monica, a thirty year old female from New York City with ulcerative colitis, currently maintains her disease with biologic therapy, oral medication, and dietary restrictions. When asked about her feelings on the current health insurance battle, she says:

> I *do not feel represented in terms of my preexisting conditions and am terrified about the direction things seem to be heading. The United States does not provide sufficient support or safety net to those with a chronic illness or disability, and people with preexisting conditions are treated as a nuisance and a burden to the system.*

Multiple patients said they would die without insurance. Insurance is necessary to pay for the exorbitant cost of necessary therapies. For example, the retail price of a vedolizumab infusion at NYU Langone in Manhattan is $61,000 per dose. Access to these services is impossible without insurance.

Access to Disability Services

The invisibility of this disease prevents access to disability services. When asked about the nature of her invisible disability, Ann says:

> I think at first I felt like oh I don't qualify to be considered as having a disability but never looked at is as a negative thing. I wish I'd just done things like getting the handicap placard for emergencies. Would've saved me a lot of accidents…I think there's a layer of like, do we qualify for disability and the perception of "are we disabled enough" which is kind of ridiculous to think about. But I think at first, especially knowing no one else with it, that's how I felt because I was conditioned to think disability meant wheelchair, cane, etc.

Steve, a thirty-five year old male from New Jersey, was diagnosed with Crohn's disease fifteen years ago. He uses adalizumab and methotrexate now but has had three surgeries. He reports that he participates in a monthly support group with the Crohn's and Colitis Foundation and fundraises with Team Challenge, a half marathon program run by the Foundation. He agrees that this is an invisible illness:

> *It is definitely something you can hide, unless you are very sick and then there are physical symptoms such as weight loss or gain. But I still think that makes it invisible because a lot of people assume it's an eating disorder and not IBD.*

The Americans with Disabilities Act (ADA) covers Crohn's disease and ulcerative colitis. The civil rights law covers "impairment of a major life activity" including "operation of a major body function" (Crohn's and Colitis Foundation). This protects students and employees from discrimination or harassment due to their condition. Patients do not have to disclose the nature of their disability, just the details that pertain to the position. For example, students are allowed breaks in class for restroom access or food/medication, even if the traditional classroom setup does not support this accommodation. Reasonable accommodations must be made per the ADA guidelines. Employees do not have to disclose medical information until after an job offer is presented. Many states provide paid disability for hospitalizations or surgeries. There are some protections for IBD patients, even when both outsiders and patients do not truly see the illness. For patients too sick to work, there are additional challenges.

The Invisibility Cloak

"Harry looked down at his feet, but they were gone. He dashed to the mirror. Sure enough, his reflection looked back at him, just his head suspended midair, his body completely invisible. He pulled the cloak over his head and his reflection vanished completely"

-J.K. Rowling, *Harry Potter and the Sorcerer's Stone* (p. 201)

Current Media Representations of IBD

Patients often feel as if the disease is invisible. Despite symptoms, many do not look sick. Crohn's disease and ulcerative colitis patients are not often featured in media, such as television or movies. The limited depictions point to the embarrassing symptoms of the diseases. Many patients feel as if the gravity of the condition is not properly acknowledged. Caroline, a twenty year old female from New York, says her illness is not so invisible. She requires a feeding tube, ileostomy, port, and a wheelchair. She says she does not see representations of IBD. Her case is particularly severe, and she never sees people like her.

> *Occasionally I see IBS mentioned but it's in a mocking fashion to make fun of people who have bowel problems. Other than that the only mention is on commercials for Remicade, Humira, or Entyvio. I would like to see more positive representation in regards to people with bowel problems in general. No teasing or using them as jokes. And not playing into the stigma or ostomies as well.*

There was an CDC advertisement campaign run in 2015 featuring a woman discussing her life with a colostomy bag. "Ostomy" is used as an umbrella term for both ileostomy and colostomy. Smoking caused colorectal cancer, which led to her ostomy. For most IBD patients, the ostomy diversion is a last resort, but it is not punishment. People go onto live healthy lives with ostomies (Bernstein).

Multiple patients reported that the representation they see is in commercials for medication. A few people mentioned television shows with IBD characters. Betty said "Crazy Eye's imaginary father had UC in a scene in the latest *Orange is the New Black*…I think people know about Crohn's more b/c of the prescription drug ads." Jenny, a 35 year old female from New Jersey, said "I do see IBD mentioned on shows like *Grey's Anatomy* but there is definitely still a stigma that they are too gross to be talked about." Other related conditions have some television representation. Leonard on *The Big Bang Theory* is lactose intolerant but Charlotte says, "his disability is used for laughs, which can be both good and bad."

Donna, a thirty-one year old female with from Connecticut, feels that the duration of the illness is adequately discussed.

> *I would like to see a more nuanced view of people with IBD and all chronic conditions. I would also like to see the disease being portrayed as more chronic and less acute. When you see someone with something like IBD once they get a diagnosis, they are given one treatment (or even no treatments) and they are cured. As a result the general population thinks that it is how it works (too bad that is not true).*

Media only provides limited and sometimes inaccurate representations of inflammatory bowel disease.

Movies

Often, other chronic conditions are portrayed in movies, television, and books. Cancer is often depicted in film. The book by John Green and subsequent movie *The Fault in Our Stars* follows the love story of two teenage cancer patients finding support and humor in each other. The 2002 film *A Walk to Remember* features Mandy Moore as a high school student secretly living with leukemia. *Me and Earl and Dying Girl*, a 2015 film, tells the story of Greg and Earl as they befriend Rachel, a girl dying of cancer. These films target younger audiences, like those in my sample set.

Ann, the patient advocate, discusses finding comfort in the "cancer genre," a phrase used by the protagonist of John Green's book. Quotes from the book resonate with IBD patients.

> *I remember when the show Red Band Society started out, our community was upset with the glorified portrayal of young people living with chronic conditions. While there are many positive takeaways and I wouldn't erase my past experiences, I also wouldn't wish IBD or a chronic illness on anyone, especially kids coming of age. It's not a cool club, it's living your life every day having to factor in a serious health condition. I did like the portrayal in The*

> *Fault in Our Stars, though. I stuck more post-it tabs in that book/movie than anything I've ever read, just because so many lines and phrases and references resonated with me. I don't have cancer, but a lot of what was in the book was relevant to all young people with chronic conditions. I think we have to laugh about it to get through it sometimes, but others on the outside laughing and not fully grasping the seriousness of it is a much different story.*

I agree with Ann. I find the film beautiful and poignant, and Green writes a funny story despite the somewhat dark topic. If you have the means of picking up a copy, I highly recommend it. This quote from the book is poignant and meaningful.

"Without pain, how could we know joy?' This is an old argument in the field of thinking about suffering and its stupidity and lack of sophistication could be plumbed for centuries but suffice it to say that the existence of broccoli does not, in any way, affect the taste of chocolate." Even with pain and suffering, patients can still be optimistic.

When I was struggling with my own treatment plan, I watched a documentary called *Crazy Sexy Cancer* by Kris Carr. She is a patient living with liver cancer. Diagnosed in her late twenties, many of her concerns mirrored mine. She refused chemotherapy and discovered an all-natural treatment plan that maintains remission of her disease. Carr has expanded this into books, a blog, and speaking engagements. A friend of mine had sent me a copy of the book by the same name and I watched the film shortly thereafter. Although her treatment model was not applicable to me, she is an inspiration for patients to self-advocate for disease treatment. I feel these types of documentaries and films, appropriated for Crohn's disease and ulcerative colitis, would better represent the patient community. Documentaries can highlight the issues not usually discussed. such as hair loss and morning sickness due to medication, cleanliness and availability of bathrooms, and finding suitable dining options in a social setting. In order for this to work, multiple patients would have to participate and create personal and moving films. Ann would be an ideal candidate to create this type of film. She has already shared her story with the Finely Tuned campaign and could expand upon this format. Donna wants a more nuanced depiction of IBD patients and could proactively help change the conversation about the disease. Monica could create a documentary explaining the ACA crisis and send this to representatives. If a picture is worth a thousand words, a movie is worth even more. Betty has recently "come out" as a patient and may feel empowered to do more. Perhaps there can be power in numbers.

Television

The Mighty also polled the patient community about media representations of chronic illness in television, highlighting the comments the staff found most pointed to the problem. This is inclusive of many chronic diseases, not just inflammatory bowel disease. Anonymous patients reported these trends (Migdol). Multiple patients discussed how the television show *House* misrepresented illnesses or brushed off symptoms as ordinary. *House* aired on FOX for eight seasons. The fictional doctor Gregory House was a diagnostician, trying to find unusual conditions, adding his own sarcastic flair to each case (Migdol).

> *Lyme disease* on *'House.' It was eventually diagnosed with a 'classic bullseye rash.' Crap. Not all 'bullseye' rashes actually look like a bullseye. Many people infected with Lyme don't get a rash at all (I never had one any of the times I was infected). Also the symptoms portrayed were more consistent with Lyme that had gone untreated for a long period of time. That would mean if the patient did get a rash it would've been gone by the time the symptoms emerged.*

Another said:

> *On 'House,' a patient came into the clinic complaining of fatigue and tiredness, and said it might be fibromyalgia, and House, annoyed, prescribes him eight hours of sleep and dismisses him. That's the only time I think I've seen a portrayal of fibro in the wild.*

Grey's Anatomy depicts very unusual medical cases. The show continues to air every Thursday night on ABC and is entering its 14th season. Patients mentioned how their disease were treated on the show. One patient with Cyclic Vomiting Syndrome said:

> *They did an OK job portraying what's going on through an episode would be like. The only thing is that when we start vomiting, there is limited talking and more vomit.*

In shows like Grey's, patients often are admitted to private rooms and diagnosed, treated, and discharged within an episode. Many patients explain that diagnosis is not often so fast. In an episode this past season, one of the interns enters the emergency room with abdominal pain and asks, "could this be Crohn's?" His resident writes it off as "intern-itis" but tests reveal he actually suffers from intra-abdominal tuberculosis contracted abroad. Crohn's disease is brushed off as an unlikely possibility, even though over one million people live with a diagnosis. Another episode featured a patient that required rectal sphincter surgery following cancer and the staff mocked her frequent gas. Patients in The Mighty's survey also mentioned Crohn's disease in other shows (Migdol).

> *There was a quick and subtle reference to Crohn's disease on an episode of 'Glee'—a cheerleader was throwing up into a trash can and someone told her there wasn't even time for Crohn's disease at that moment. I thought it was kind of cool that they mentioned it because I rarely see it portrayed in the media. Sure, nausea is a really minor side effect compared to everything else we deal with, but I'll take it!*

IBD symptoms do not always occur at convenient times—often, stress of important situations can flare symptoms. I disagree with that point of view. Not all press is good press. This further supports my claim.

> *'Superstore' talked about Crohn's disease. She was faking being sick and they asked a nurse what she thought could be wrong with her…and that was her response. I understand that one day I might look O.K. and then the next day I can't come into work because I'm sick even though I don't look like it, but this character played hooky and this was how they explain her actions. It was such a slap in the face.*

The storyline of a person feigning illness does not have to include mention of any chronic disease at all.

Television shows provide immediate access to the general public. *Grey's Anatomy* pulls 7.7 million viewers in the 18-49 age bracket (Variety). *Superstore* was renewed for a third season and reaches 4.3 million viewers (Variety). *Glee* aired for six seasons and *House* for eight—these shows remain available on Netflix. If patients of all chronic illnesses, not just IBD, were to appeal to television networks, perhaps the conversation would change. Not too long ago, LGBTQ individuals were depicted stereotypically on television. It is far from perfect, but network television shows more and more positive LGBTQ relationships. I hope that accurate portrayals of chronically ill patients are next. Ann sees symptoms not typically associated with IBD on television. However, more portrayals are aired than before.

> *There was an amazingly honest portrayal of anxiety/panic attacks by Sterling K. Brown on This Is Us, one of my favorite shows from last season. I was so happy, yet shocked, to see it, because I have never watched something so raw and accurate on television or in film, etc. before. I feel like that's what I want to see with IBD: feeding tubes, infusions, ports and picc*

> *lines, vomiting, excessive fatigue, depression, intense pain…all the real horrifying intense stuff that goes beyond the bathroom and all the puns about stalls and urgency.*

Even from inside advocacy walls, Ann feels there are still issues in portrayal of IBD patients in media. As discussed regarding films, Monica, Donna, and Betty could also advocate to television production companies.

Steve mentioned that he also sees celebrity patients on TV: “Olympic Swimming Gold Medalist Kathleen Baker and NBA player Larry Nance Jr.” Celebrities “coming out” with IBD only helps publicize the media. In July, Mike McCready of Pearl Jam ran the Napa to Sonoma Half Marathon with the Crohn’s and Colitis Foundation’s Team Challenge program. Other diseases have celebrity endorsements. IBD is slowly gaining that status.

Patients are not really sure how to achieve the type of awareness needed for disease empowerment. IBD just does not have the same type of publicity as others. Steve writes, “I’d like to see IBD reach a level of awareness of cancer where they have big events.” Breast cancer awareness was mentioned as comparison. Melissa, a nineteen year old Crohn’s disease patient from New Jersey writes. “I feel like media uses severe illnesses, like cancer, to cue emotions in a sappy way.” No one is debating the horrors of cancer, but patients feel that their disease is not getting credit as a life-altering condition. Melissa concluded her interview by saying “I want people to understand some of the things I go through.”

Drug Commercials

The general public often recognizes IBD by the advertisements aired on television for drugs like Humira and Entyvio. The Entyvio advertisements show a patient’s view of the bathroom door. This illness causes symptoms above and beyond frequent bowel movements. Another ad for Xifaxan, a drug often used in IBD treatment, features a dancing colon. This was first aired during the 2016 Super Bowl. One patient explained:

Every once in awhile I’ll see a commercial on TV about a new drug for IBD or see an Activa commercial/probiotics. The drug companies are certainly talking about it…people don't often share because, well, pooping is embarrassing.

For this study, I interviewed a marketing representative employed by a drug manufacture. She explained how market research is used to determine what a patient’s life was like prior to diagnosis. This is used when describing the lifestyle patients hope to achieve by using their medication. They strive to to promote both brand and disease awareness, marketing to both healthcare professionals and consumers. Several of the IBD drug manufactures offer over the phone nursing services and copay assistance programs. For at home injections, companies offer injection training or will send out a nurse to assist. She explained how drug companies limit social media advertisements. If a patient were to report an adverse side effect on this type of platform, the company is bound to report it. She explained how the company seeks to use online banner ads and outdoor advertising, like bus shelters, subway cars, and railway stations to promote the medications. Drug companies like this consider the patient experience when illustrating the condition in their advertisements.

Ann is actively involved with many advocacy groups, including Girls with Guts, the Great Bowel Movement, and the Intense Intestines Foundation. Last summer, she connected with a IBD drug manufacture shoot a video and photos that would tell her story—this was called the “Finely Tuned” Campaign. She describes the experience:

> *Three of us attended a town hall meeting at headquarters for the campaign launch and the video premiere in February. We filmed an interview segment and also sat on a panel to*

> *answer questions for employees. This was a great experience because it was nice to see the company was not even close to what you think of when you picture "big pharma." Everyone shook our hands, thanked us repeatedly, and told us that in sharing our experiences, we help them do our jobs better. The staff was so genuine and kind—even some of the top people at* {X drug company}

Many patients feel empowered to have an active role in choosing their therapies. Ann finds relief in advocacy with the help of drug manufactures. Patients secure enough to openly discuss their condition with strangers in the form of focus groups would help create better advertisements. Caroline does not see patients like her represented in media. However, it may be psychologically empowering for patients like her to self-advocate for a change. All of these patient feel invisible, but that can change.

Support Groups

Many patients report utilizing support groups online. These are instantly available for patients in need. In the area of disability theory, experts argue that studies should focus on society's failure to properly accommodate people with long-term conditions (Saunders 1022). For comparison, I studied Benjamin Saunder's survey data of four young adult IBD patients and perceived stigma. His participants answered similarly in that they felt it hard to "come out" as an IBD patient: "all the four accounts analysed demonstrate the participants discursively constructing their IBD as having a degree of stigma associated with it, primarily because of the taboo nature of the symptoms" (Saunders 1032). Another study referred to the phenomenon as "posttraumatic growth" after diagnosis (Purc-Stephenson, et. al 1197). Improvements include personal growth, improved interpersonal relations with family, sometimes the loss of friends, recognizing resiliency, and finding a new life plan. Negative changes included psychological side effects and social isolation. Other studies are consistent with my research. Purc-Stephenson's study is entitled: 'a gift wrapped in barbed wire.'

Perhaps discussing the issues will provide catharsis…the only relief comes in describing it. Interpreting the experience is part of accepting the reality. Patients also utilize online support groups, either via chat room or Facebook. These allow for instant access when needed. I feel that patients like Steve, Rachel, Charlotte, and Gretchen could utilize support groups. Feelings of isolation are common. Charlotte would benefit from a support group geared towards parent-patients. This is a unique circumstance. She may find comfort in discussing this with fellow sufferers. All patients report feeling invisible, but other patients can provide community. Ann participates in a monthly support group and finds this technique useful. The internet has opened doors to different types of support groups. Patients can connect around the world instantly.

Blogs, etc.

Many blogs are written by IBD patients. Stephanie Hughes, a patient advocate, writes a blog called The Stolen Colon. She writes about her experiences after her colectomy and through childbirth with her ileostomy. She describers herself as a writer, health activist, and a person *living* with Crohn's disease. Hughes also runs a YouTube channel. Her most recent post commemorates her five year surgical anniversary with a ileostomy. Ostomies are a very personal matter, and Hughes writes about her experiences with humor and honesty. She questions if this is the "resentment" anniversary as she has had a complicated pregnancy with her second child, including an intestinal blockage. In contemplating the occasion, she writes:

> *So instead of being resentful today, I am trying to focus on the many positives that I have going on in my life: I have a beautiful new baby on the way that I am so excited about and my ostomy played a huge part in me being able to do that, other than dealing with the blockage issues I am healthy, I am not confined to a hospital bed, I have amazing support to help me get through the coming weeks.*

She provides inspiration to many ostomy and colectomy patients in the community.

The Mighty, a website collecting blogs written by patients with many diagnoses—physical, mental, terminal, or otherwise—allows advocates to express both positive and negative feelings about their diseases. There are 7,000 contributors across the website and over 150 million readers. Sahara-Fleetwood-Beresford writes a post entitled "I Am Grateful I Have Inflammatory Bowel Disease" and how she has managed to find her own strength and happiness with this diagnosis:

> *I get up every day and I am grateful I can do that. I go to work and I am grateful that I have a job. On the way I wear my headphones and I sing like no one can hear me and I'm grateful that I'm happy enough to do that. I go to the shops on the way home and I am grateful that I can afford food. I get home and I am grateful that I have one. I log into Facebook, respond to a few notifications, send a few texts and I am grateful for every person that is on the other end. I get in the bath and I am grateful for my body. I change my bag and I am grateful that for two months I have had no pain. I dry my hair and I'm grateful it's getting healthier. I dance around my bedroom and I'm grateful that today, I have the energy. I am grateful because I have IBD.*

Sahara now has the strength to go to work, eat, and satisfy minimum living requirements, per Maslow's hierarchy of needs. She also finds belongingness in the IBD community via social media, like many other patients reported in the surveys. Then, she can feel accomplished and self-actualized. Another patient on the site, Jenna Farmer, writes "7 Reasons I'm Grateful for IBD" in a post this past May. She writes how she changed her career and wrote a book entitled "Managing IBD: A Balanced Approach to Inflammatory Bowel Disease." Jenna explains how she feels valued in the community:

> *The IBD community has been amazingly welcoming and supportive of my blog. Nothing feels better than an email of gratitude or a Tweet saying that my article prompted a reader to contact their doctor or take action. I have always felt strongly that we each have a purpose and I feel that in some strange way, this may be mine.*

Jenna also pursued a Nutritional Therapy certification to find out what foods are most supportive to her disease treatment. Shawntel Bethea expresses the same sentiment in "10 Ways My IBD Has Made Me a Better Person" and why she is "grateful" for what IBD has taught her about herself. She has learned how to be patient with her body and acknowledging the basic needs. She has learned to self-advocate and research her own treatment plan. She also acknowledges the importance of opening up and trusting others with her story. Shawntel writes, "Now, I love sharing my story and hearing others' story of strength!"

These bloggers, among others, put their guts out there and explain their distress with inflammatory bowel disease. These woman provide positive role models to others. I also feel that men are grossly unrepresented in these circles. It is rare that men write and participate in online discussions or blogs. If male-centric websites existed, this may feel more secure. Note that more than 75% of my surveyed patients are female. Gender may be a factor in self-reported issues with inflammatory bowel disease. In a Swiss study, women responded more frequently to their survey than men and had higher levels of concern than men (Pittet, Valerie, et. al 10). This may suggest a trend in mens' willingness to participate or my ability to reach a male audience in this setting.

Many patients are afraid to describe their disease in detail on public forums. Several people reached out to confirm confidentiality guidelines while collecting this data. A mixture of open blogging and secure online chat rooms would better meet the population's needs.

Discussion of Possible Solutions and Policies

"The principal difficulty lies, and the greatest care should be employed in constituting this representative assembly. It should be in miniature an exact portrait of the people at large. It should think, feel, reason and act like them. That it may be the interest of the assembly to do strict justice at all times, it should be an equal representation, or, in other words, equal interests among the people should have equal interests in it."

John Adams, *Thoughts on Government*, 1776

Patient representation can only adequately be interpreted by those experiencing the problem—patients themselves. I have collected survey data that I feel is representative of the assembly at large and provides adequate portrayals of issues surrounding inflammatory bowel disease. There is a labyrinth of medication choices, insurance options, expenses, all the while in excruciating pain. Each opinion is only the "miniature" of the population. My survey data can only include so many patient results.

Most participants in this study were females. These subjects presented unique concerns to young female lifestyles—problems dating, having sex, raising children, and living with an embarrassing disease in a society that established a particular female body form. Many patients gain or lose weight from treatment. Steroids can cause abnormal swelling in face and excessive hair growth. Although these issues are not exclusive to women, women approach these issues in a different way. A possible solution would be specific women's support groups offered locally or even in online chat rooms. Some surveys were dispersed via Girls with Guts, an online community of young females with IBD that operates on the web and via Facebook. They offer one meet up annually at a chosen location. With the physical and financial limitations of this disease, it is often difficult for patients to convene at one city across the country. The organization offers financial assistance, but it is limited to the most needy candidates. Expanding this type of program on the local level could provide additional support. Although this does not provide a unique solution, I do feel increased advocacy through online media is a necessary communication tool. Patients can use these methods to organize meet-ups in person. Patients like Betty and Rachel who report feelings of romantic and sexual dysfunction could benefit from a female only support group or blog. I feel a male equivalent is also necessary. When discussing bodily functions and ostomies, this is often difficult to discuss in a co-ed setting. Saunder's subjects described similar issues with stigma and post-traumatic stress after diagnosis. More specific support groups are necessary.

Patients also reported feeling misrepresented by drug companies. Commercials are sometimes the only reference point the general public has to the condition. Many patients have incredible success with medications; others do not. Drug companies are developing medications they feel with help patients, yet the success rates are mixed. A possible solution to this issue is to urge drug companies to run focus groups of both patients and a control in the general public. How does your audience feel about these ads? How do outsiders perceive the disease? It would be helpful to understand how the creators of these advertisements develop the content. Then, there could be a discussion on how to improve patient representation. These drugs hold a valuable place in patient treatment and that can be advertised in better way. The Finely Tuned campaign is available only online. Broader advertisements of these efforts would help. Ann would provide wonderful insight to drug companies with her experience.

I have often thought encouraging advertisements for ostomy supplies would both expand the market and offer a new vantage point to outsiders about treatment options. Ostomies are used for many conditions outside IBD—even urinary problems. There are competing brands. Patients have to try and fail multiple bag styles, wafers, and adhesives, just like medications. However, there are no alternatives to try here. The products are incredibly expensive. One month's supply costs upward of $1,000. Products are not offered in traditional drug stores; they must be mail ordered from medical supply companies. These companies do not advertise either. I feel there is a place to utilize advertisements in a positive way. Market research can provide valuable insight to manufactures. Patients with ostomies often feel self-conscious about their bag, so an anonymous interview style would be ideal.

Patients may not be getting the care that they need in our current healthcare system. Utilizing either Obamacare or private insurance, patients choose a provider from the in-network list of doctors and hospitals. Out of network rates are prohibitively expensive. Billable rates for gastroenterologists in New York City range from $400-$800 a visit. Medications are often denied by insurance due to cost or available generic equivalent. Recently, two biosimilars to Remicade were approved by the FDA. These are called Inflectra and Renflexsis (Brennan). The drugs cannot be deemed generic—infliximab is a patented protein that cannot be duplicated—but they shown to have similar benefits. Available data does not suggest that the biosimilars are similar enough as an equal substitute, yet insurance companies can deny Remicade treatment on these grounds. Many patients reach their out of pocket maximum on insurance policies in addition to premiums. Some plans offer a pre-tax flexible spending account to help. Money is removed from the paycheck before income tax is deducted, and this is set aside in its own account for healthcare expenses. In addition, some of the drug companies (Abbvie, Janssen, UCB) offer copay assistance programs and phone nursing consults to offset some expenses for patients.

Complementary and alternative medicine providers (acupuncturists, herbalists, nutritionists, fitness providers, etc.) are often not covered by insurance and deemed out of network. Patients must pay out of pocket for these treatments. In the tristate area, these treatments are expensive. Medical marijuana is not covered by insurance. Herbal therapies available over the counter at health food stores are still costly and not eligible for reimbursement. I propose a separate pre-tax flexible spending account to allow funding for these treatments. Patients would have money set aside to experiment with these options without feeling as if they have wasted money on a failed treatment. Without insurance benefits, these options can be prohibitively expensive.

The pending healthcare bill in Congress is causing much distress for IBD patients. Patients do not feel represented by their elected officials. Those with preexisting conditions are considered to be burdens to the system. Under the "Better Care Reconciliation Act," states would be allowed to ask permission to reduce required coverage. Patients forced to utilize Medicaid benefits would see significant cuts to funding under the proposed bill. Medicaid would not be required to cover mental health benefits for patients starting in 2019 (Grayson, Hurt, Kodjak). Should these changes go into effect, many IBD patients would see significant changes and reductions to their treatment coverage and options. Patients in my study expressed concerns about this proposed bill. Patients need to point out these issues to their representative and hope their voices are heard on the Senate floor. The Crohn's and Colitis Foundation sponsors IBD Day on the Hill every May to allow patients to speak to representatives about these issues. Ann participated in this year's event with 100 other patient advocates. Even though the healthcare debate is at the forefront of the political conversation now, this has been a long time coming. Patient expenses only increase.

In the conversation about our healthcare system, many point to our neighbors in Canada as comparison. All Canadians, regardless of employment status or health, have healthcare benefits from the government. For those with chronic illness, this is an important factor. Many cannot work due to limitations of their disease. They then require Medicaid benefits. Canadian insurance does not allow coinsurance or direct payment to any provider (Bernard 1). Those who oppose "socialized medicine" do not realize that Canadian doctors are still paid per patient, just not by an insurance company. There are fewer fees associated with administrative tasks. The costs of medications varies greatly. For an Entyvio infusion in New York City, the billable rate is $61,000 each. The drug is traditionally prescribed for infusion every eight weeks, so this totals $366,000 before any other treatment costs. In British Columbia, the yearly cost is $22,451 (Ministry of Health 2). However, the Canadian system does not come without its problems for IBD patients. Only about half of the physicians are specialists and the rest are primary care provider (Bernard 4). For an advanced disease, it may be necessary to have even sub-specialists specifically trained in the condition. There are still shortages and waiting lists as the system expands, as there are in the United States. Canadians take a more progressive approach to healthcare. The United States would have to federally limit the capitalist insurance system for this to work, which is an entirely different problem in and of itself. The Canadian system does provide an example for a more comprehensive healthcare plan. Donna and Monica acknowledge the issues in the United States. They would be in the best position to advocate for change.

In the meantime, patients need better access to mental healthcare services. Often these providers do not accept insurance. There is a growing market of online therapy and psychiatry, where patients login to a video platform and attend their appointment remotely. NYU offers a fantastic walk in mental health clinic. Students can walk in for therapy without an appointment, and there is no associated fee. With proper state and federal funding, this type of model could be replicated in communities. Some patients require medication and therapy to cope with the realities of their disease, and services need to be offered accordingly. New drugs are approved to provide better control of psychological symptoms as deemed necessary by a licensed physician.

Upcoming Research

Various treatments are in development. William Sandborn at University of California-San Diego describes some new treatment options. Many drugs that are approved for other autoimmune conditions are gaining approval for IBD. Ustekinumab (Stelara), a drug originally approved for psoriasis and psoriatic arthritis was approved for IBD last year. A drug called etrolizumab, similar to vedolizumab (Entyvio) is currently in phase three clinical trials. Other studies are being conducted using the drug tofacitinib (Xeljanz), traditionally used for rheumatoid arthritis. All of these medications work along the autoimmune inflammatory pathways in the body, as they are not specific to the intestine. Many patients experience symptoms outside the intestine, so these drugs offer promise to treat multiple facets of the disease (Sandborn). Sandborn also comments on the new research in gut microbiome therapy and how may help inflammatory bowel disease cases.

Fecal transplant has been used in patients with bowel infections, but not extensively with IBD. So far, the results are not promising. In order for the transplant to be successful, patients must use the same stool donor. For many, that is not practical. Sandborn says single transplants were not effective. Other studies show different results. One conducted at Weill-Cornell in Manhattan reported 15% of patients showed improvement in four weeks following transplant (Weill-Cornell). More and more of the disease research is focused on healing the intestine, so doctors monitor progress with endoscopy. Many patients are enrolled in clinical trials in Manhattan at the various medical centers.

New styles of studies look to predict how patients will respond to certain medications and use those first. Ananthakrishan analyzed stool specimens from patients about to start Entyvio to analyze the microbial populations. Those with better symptom control had a greater abundance of potentially anti-inflammatory bacteria in their stool. Anathakrishnan is hopeful that this type of microbiome screening would doctors better determine drug effectiveness or ways to utilize probiotics in IBD patients (Massachusetts General Hospital). Many research studies utilize genetic testing outside my understanding to adequately explain in this paper. There are a plethora of studies searching for new treatments and a better understanding to the disease process. Every patient benefits from research. This helps doctors and patients find new treatment plans to better control the disease.

Fundraising dollars towards these types of research initiatives is both important and empowering. Patients reported participation in the Team Challenge program offered by the Crohn’s and Colitis Foundation. Patients raise thousands of dollars towards both research and patient programs. Cure for IBD, founded in 2016, directs funds to research institutions directly. Funds have been dispersed to Children’s Hospital of Philadelphia and Seattle Children’s Hospital since its inception. These organizations also offer local advocacy walks and support groups. As discussed, belongingness and inclusion in a specific community is beneficial and empowering to the patient and caregiver population.

Conclusion

Atul Gawande interviewed a construction crew for his book *The Checklist Manifesto.* Project site director Finn O’Sullivan told him “the biggest cause of serious error in this business is communication” (Gawande 70). Even with careful planning, there were errors in the construction of the building. Communication is key for success. I advocate for open communication between the private and public sectors of the inflammatory bowel disease community. Gawande understands that individual efforts are not always successful. People need to work for change. He writes:

> Yet they cannot succeed as isolated individuals, either—that is anarchy. Instead, they require a seemingly contradictory mix of freedom and expectation—expectation to

> coordinate, for example, and also to measure progress toward common goals…that routine requires balancing a number of virtues: freedom and discipline, craft and protocol, specialized ability and group collaboration (Gawande 79).

Patients need to come together to advocate for changes in IBD representation. Group collaboration is key. Values such as discipline, craft, and compromise are necessary for change. In order to succeed as patient advocates, people need to address basic health and wellness. Here is where a checklist can be helpful. Patients must be following with a healthcare professional, be compliant with given recommendations, maintain a stress reduction routine, and be on the lookout for possible triggers. These are what Gawande calls "pause points" to check before proceeding. He advises that checklists remain short: one cannot account for all contingencies. Stress induced perturbations include motility dysfunction and inflammatory responses (Bonaz). These symptoms drive psychosocial function. Depression is twice as prevalent in the IBD community as opposed to general populations. Although psychological health may come secondary to active disease, the patient's mental well-being many also contribute to a patient's perception of his/her health. This creates a complicated cycle of symptoms.

Once these basic needs are met, then patients can develop support systems and connect with others. Multiple studies explain how patient support groups are beneficial in many ways. Yet without physical and psychological health, people cannot be productive members of the advocacy community. The disease is never entirely in remission—I refer to it as "medically maintained"—but during healthy stretches, I try to find meaning in helping other patients. Ann is like me—even with a complicated medical history and treatment regime, she advocates for others in multiple ways. In this way, many patients find belongingness, self-esteem, and self-actualization. This can be liberating. I hope that patients and caregivers reading this study are empowered to get involved in the inflammatory bowel disease community and help fellow patients find a voice.

There is no perfect solution to this problem. But, we can do better. Another Atul Gawande memoir, *Better*, describes the steps to improve a situation, such as patient representations of inflammatory bowel disease. "Better is possible. It does not take genius. It takes diligence. It takes moral clarity. It takes ingenuity. And above all, it takes a willingness to try." In this paper, I try to find creative solutions and will try to put these into practice, advocating for the issues near and dear to my heart.

Patients want to feel included and represented living with inflammatory bowel disease. More public representations would achieve this goal. Online blogs, support groups, and on-demand counseling allows patients to cope in the meantime. This does not solve the symptoms of the disease, but these solutions would ameliorate patient dissatisfaction with current media representations. When it comes to our healthcare insurance model in the United States, advocacy is the only solution. Patients should reach out to their elected officials and explain their concerns. Inflammatory bowel disease is a "pre-existing condition" and patients would suffer without adequate insurance. Finding catharsis while treating an incurable illness like IBD is not impossible. Doctors, patients, caregivers, and mass media representatives need to have an open dialogue on and communicate the realities of the diseases. Open communication is essential to achieving this goal. I hope fellow patients reading this paper will feel as if they are represented and empowered to be active in their communities as IBD patients.

Patients want to feel included and represented as patient living with inflammatory bowel disease. Due to the symptoms of inflammatory bowel disease, patients have difficulties self-advocating. More public representations would achieve this goal. Online blogs, support groups, and on-demand counseling allows patients to cope in the meantime. This does not solve the symptoms of the disease, but these solutions would ameliorate patient dissatisfaction with current media representations. Advocacy for better solutions is the theme of this paper. When it comes to our insurance model in the United States, advocacy is the only solution. Patients should reach out their elected officials and explain their concerns. Finding catharsis while treating an incurable illness like IBD is not impossible. Doctors, patients, caregivers, and mass media representatives need to have an open dialogue about the realities of the diseases. Open communication is essential to achieving this goal. Collectively, we can bring more awareness.

When I started this course in May, I read Paul Kalanithi's book *When Breath Becomes Air.* In the diagnostic paper, I cited this meaningful quote: "Years ago, it had occurred to me that Darwin and Nietzche agreed on one thing: the defining characteristic of the organism is striving. Describing life otherwise was like painting a tiger without his stripes" (Kalanithi 143). Now, I realize how many stripes I need to consider. Describing a disease without examining all of its facets — medical, psychological, social, political, ethical — is like a tiger without its stripes. Medication, diet, therapy, spiritual healing, social interaction, **teamwork,** and **communication,** are all parts of the inflammatory bowel disease tiger.

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