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Abstract approved:

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Gluten intolerance is a condition that affects a significant portion of the world's population. While awareness about the condition has recently increased, the condition remains poorly understood and therefore commonly mis- and underdiagnosed. In this paper, I examine the challenges in obtaining a gluten intolerant diagnosis and attempt to capture the experience of living gluten-free in a wheat-dependent society. Through interviews with gluten intolerant individuals in the Pacific Northwest, I expose a perceived lack of awareness and understanding about the condition in the western biomedical community that presented challenges for the participants pre-diagnosis, as well as a perceived lack of awareness and understanding about the condition in the general community that presented challenges for the participants post-diagnosis. Based on common themes extrapolated from these interviews, I argue that the western biomedical community as a whole lacks a complete understanding of the entire spectrum of gluten intolerance and that the information about gluten intolerance in published scientific literature does not match the lived experience.

Key Words: gluten intolerance; celiac; non-celiac; anthropology, medical

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Living Gluten-Free:
An Analysis of Illness and Coping Narratives

by
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I understand that my project will become part of the permanent collection of Oregon State University, University Honors College. My signature below authorizes release of my project to any reader upon request.

Carly E. Dougher, Author

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To Beach, my inspiration
To Robert, Mom, and Dad, my support
And to all the gluten intolerant among us.

Chapter 1

Introduction

Lori was a senior in high school when she woke up one morning to find that she was unable to move her big toe. Over the next two weeks, paralysis spread throughout her feet until she was no longer able to walk. Soon she also began to experience a similar paralysis in her hands and fingers. In addition to her paralysis, Lori experienced chronic fatigue and weakness. She was only seventeen. Extremely concerned, her parents took her to Oregon Health Science University (OHSU) for a complete examination. After two weeks of testing, physicians at OHSU still could not determine the cause of her sudden paralysis. Frustrated and worried, her family then flew her out to Minnesota to have more testing done at the Mayo Clinic. After ten days of testing at Mayo, the paralysis persisted and she again returned home without answers. In the mean time, her mother frantically searched the Internet for possible clues. Out of desperation, Lori's mom took her to a local naturopath in their hometown. After running a biofeedback examination, the naturopath told her that she could not tolerate gluten and dairy and needed to remove both substances from her diet at once. She immediately eliminated both gluten and dairy from her diet. After one week, Lori started noticing that she had more energy. Four months later, Lori could move her feet again and was able to walk.

Unfortunately, stories like Lori's are not as uncommon as they may seem. In this paper, I examine the challenges that families in the Pacific Northwest commonly face during the process of obtaining a gluten intolerant diagnosis. In it, I attempt to capture the experience of living gluten-free in a wheat-dependent society. Based on common themes collected from interviews with gluten intolerant individuals, I argue that the western

biomedical community as a whole lacks a complete understanding of the entire spectrum of gluten intolerance and that the information about gluten intolerance in published literature does not match the lived experience.

Gluten intolerance is a condition in which individuals are intolerant of proteins found in wheat, rye, and barley, collectively known as gluten (McManus, 2003). Ingestion of gluten triggers an immune response that causes highly variable symptoms in susceptible individuals. A strict dietary avoidance of gluten is necessary to eliminate such symptoms and to prevent further damage to the individual's body (Sollid, 2000). The most well known form of gluten intolerance is celiac disease, a condition characterized by damage to the intestinal villi (Fasano, 2001). While not as commonly recognized, non-celiac gluten intolerance can be every bit as serious as celiac gluten intolerance (Hadjivassiliou, 2010). The western biomedical community has developed and accepted multiple diagnostic techniques to identify celiac individuals, but methods for identifying non-celiac gluten intolerance lag significantly behind (Silva, 2010).¹

My first exposure to gluten intolerance was in college when I moved into a house with a roommate who had celiac disease. I was intrigued as I intimately witnessed how ingestion of wheat, such a seemingly innocent grain, had such a profound effect on her health. Coincidentally, and unbeknownst to me, my roommate was not the only one in the house who was gluten intolerant. For seven years I battled a series of seemingly unrelated symptoms that greatly decreased my ability to participate fully in life. During this period of time, I lived with constant and severe nausea, headaches, bloating, reflux, constipation, diarrhea, and heavy menstrual cycles. I have also had a tremor in my hands

¹ A thorough literature review on the topic of gluten intolerance can be found in chapter two.

since early childhood. I struggled to maintain a constant weight regardless of how active I was. I was chronically tired and fatigued, and thus, had difficulty participating in high school social events. As a result of my chronic health struggles, my social life suffered significantly.

Eventually, my symptoms became so severe that it was too painful to eat and so my doctors put me on a clear liquid diet to allow my stomach a chance to rest. In January of my senior year in high school, I was hospitalized. All of my lab work came back normal. An upper endoscopy revealed gastritis² but the biopsy to screen for celiac disease, came back negative indicating no villi atrophy or degeneration. When I was discharged from the hospital, my physicians recommended that I drink milkshakes to increase my calorie intake and eat crackers and other soft foods to keep from stressing my digestive system. They also prescribed a high dose of Prilosec. After I got out of the hospital, my symptoms persisted.

I left for college in Seattle that Fall. I gained weight quickly, and by the second term, I had put on almost thirty pounds. My health continued to decline, and so I decided to seek treatment from multiple physicians in the Seattle area. Thinking that the cause of my condition was hormonally linked because of my heavy periods, mood swings, and hair loss, I saw numerous gynecologists, as well as primary care physicians and gastroenterologists. I was on and off birth control in a desperate attempt to alleviate any hormonally related symptoms. My health continued to affect my social life in college. I felt very trapped by my condition as I did not want to commit to anything and then have to withdraw or cancel at the last minute because of how poorly I felt.

² Gastritis: an inflammation of the stomach lining.

My first summer in college was the beginning of my lowest point. I became extremely, *extremely* constipated. I went weeks without bowel movements. My abdomen was so extended that I appeared pregnant. I could barely keep my eyes open for more than seven hours a day. My body was chronically fatigued, and I felt as if I had run a marathon each day. Thinking that my constipation could be related to a dairy intolerance, I eliminated all dairy from my diet. The dairy-free diet helped in that it reduced a significant portion of my bloating and the severity of my constipation, but other than that, my main symptoms of nausea, headaches, tremor, and irregular bowel movements persisted. I stayed in Seattle for another term and then returned home to Corvallis and transferred to Oregon State University to be closer to my doctors and to receive more support from my family.

My immune system was weak and nearly every virus that my friends got...I got. Later that year, I developed a terrible case of *mononucleosis* that knocked me off my feet and took months to recover from. Over the next year and a half, my symptoms vacillated between incapacitating and barely tolerable. Some days were better than others, but I clearly did not have any days that I would now describe as healthy days. Last summer, out of desperation, my parents sent me up to OHSU to meet with a primary care practitioner in the women's center. After hearing my story, my physician ran some blood work to probe for signs of gluten intolerance. When all my blood work came back normal, she suggested that I try a gluten-free diet anyway. After only a week on the gluten-free diet, I started to notice significant changes in gastrointestinal symptoms. Over the following month, my headaches disappeared, and I realized that I had had tunnel vision for years. I also discovered that in addition to the headaches, I had what I would

now describe as “thick brain fog”; I had difficulty with memory, concentration, and focus. The longer that I was off gluten, the easier and easier it became for me to think, and my mind began to feel altogether much clearer. Within a few months, my tremor completely disappeared. Since going gluten-free, I have not had a single migraine. My bowel movements became regular, as did my menstrual cycles. My weight stopped fluctuating, and my bloating disappeared. I had energy, my joints stopped aching, and my nausea was gone. For the first time in my life, I felt healthy.

Having had two endoscopies with biopsies and a celiac serological panel to rule out celiac disease, my physicians and I were surprised by my drastic response to a gluten-free diet. Both frustrated and inspired by my journey to health, I began researching gluten intolerance. I quickly discovered that my long diagnostic voyage was not as rare and unique as I had initially believed. I now realize that I was by no means alone, as many people have experienced a plethora of symptoms with an unidentified cause.

Given the cluster of symptoms that I experienced over an extended period time and subsequent relief on a gluten-free diet, I am in a unique position as a researcher. As an insider to the condition, I bring both the compassion and that first hand experience that has allowed me to so effectively elicit illness narratives with gluten intolerant individuals our community. My own illness experience has allowed me to both better identify discrepancies between the scientific literature and the reality of the condition, as well as to ask more probing questions of the participants in this study. Together, study participants and I are uniquely positioned to help expose, and ultimately rectify, what I argue are the lived realities of the condition.

There were thirteen primary participants in this study. Participants qualified for this study by identifying as gluten intolerant or as the caregiver of a gluten intolerant individual. In an effort to protect the identities of the participants, all names have been changed and locations omitted. All participants live in the Pacific Northwest. Each participant faced unique challenges in their journey to a gluten-free lifestyle, yet all experienced a definite benefit from removing gluten from their diet. In the pages that follow I will present the results of my study based on the interviews collected outlining the discrepancies between the published literature about gluten intolerance and the lived experience. In doing so, I will highlight a need for increased awareness about the condition and identify areas in need of future action that may ease the maintenance of a gluten-free lifestyle.

Chapter 2

Literature Review

Gluten intolerance is a genetically inherited condition that manifests as an immune-mediated response to the consumption of gluten. Untreated, gluten intolerance has the potential to be a debilitating condition that greatly reduces quality of life and results in systemic damage that can, in some, be fatal. Once diagnosed, gluten must be completely eliminated from the diet in order to alleviate symptoms and prevent further systemic damage. Gluten intolerance is a life-long condition, and thus, gluten must be permanently eliminated even after symptoms subside. In this chapter, I present a review of the peer-reviewed, scientific literature available on gluten intolerance, and in so doing, demonstrate significant gaps in research and understanding within the Western scientific community.

Definitions

In order to better understand how the scientific community perceives gluten intolerance, it is imperative that we begin our literature review by defining the condition.

Gluten Intolerance

The definition of gluten intolerance, also known as gluten sensitivity, is inconsistent within the current, scientific literature. For the purpose of this paper, I define gluten intolerance as an immune-mediated condition triggered by the consumption of gluten (Hadjivassiliou, 2010). Gluten intolerant individuals experience a wide spectrum of symptoms upon ingesting gluten and the degree of severity of symptoms is

highly variable. Gluten intolerance is *not an allergy* in that ingestion of gluten by gluten intolerant individuals does not trigger an immunoglobulin E, IgE, response, the response characteristic of an allergic reaction. The response to gluten is also not immediate like an allergic reaction, but delayed with symptoms presenting anywhere from 15 minutes, to hours, to days after exposure depending on the individual. Individuals who are intolerant of gluten experience physiological distress and systemic damage upon the consumption of gluten. Gluten intolerance is a general term that can be broken down into two sub-categories: celiac and non-celiac gluten intolerance.

Celiac Gluten Intolerance

Celiac gluten intolerance, more commonly known as celiac disease, is often the only form of gluten intolerance that is recognized by the western medical and scientific communities. Everyone who has celiac disease is gluten intolerant, but not everyone who is gluten intolerant has celiac disease. This is an extremely important distinction to keep in mind in order to understand the full spectrum of gluten intolerance. Celiac disease is classified as an autoimmune disease. Individuals with celiac disease exhibit a specific response to the consumption of gluten that manifests in the proximal region of the small intestine and is characterized by atrophy of the intestinal villi (Fasano, 2001). Other signs of damage to this portion of the small intestine include crypt cell hyperplasia, lymphocytic infiltration of the epithelium (immune cells in the lining of the intestine), and increased density of leukocytes in the lamina propria (Farrell, 2002). Collectively these indications of disease are termed the celiac lesion (Sollid, 2000). For this reason, celiac disease is often considered an intestinal disorder, although individuals with celiac

disease may not present with any intestinal symptoms (Cranney, 2003). Celiac disease is considered to be an inherited condition and is also referred to as gluten sensitive enteropathy, celiac sprue, and nontropical sprue.

Non-Celiac Gluten Intolerance

Those who are gluten intolerant, but do not exhibit specific damage to the intestinal villi, indicating celiac disease, are non-celiac gluten intolerant. The term non-celiac gluten intolerance covers a greater spectrum of sensitivities. Anyone who experiences alleviation of symptoms on a gluten-free diet can, for all intensive purposes, be termed non-celiac gluten intolerant. As stated earlier, everyone who has celiac disease is gluten intolerant, but not everyone who is gluten intolerant has celiac disease. Those that fall into the later category are non-celiac gluten intolerant. Non-celiac gluten intolerance can be every bit as severe as celiac gluten intolerance (Wangen, 2008). It has been predicted that non-celiac gluten intolerance is significantly more prevalent in the general population (Wangen, 2008), yet at this point in time, there is little to no information available on non-celiac gluten intolerance in the scientific literature. Recognition of this form of gluten intolerance is, however, becoming increasingly common in the popular literature and in clinical findings.

Much of the scientific and popular literature available fails to differentiate between celiac and non-celiac gluten intolerance (Fasano, 2003)(Sudbrack, 2010). Until recently, the scientific and medical communities defined gluten intolerance as celiac disease. In doing so, researchers and medical practitioners dismiss those who do not have

damage to the intestinal villi as not gluten intolerant. As the stories included here so clearly indicate, such inconsistencies in defining the condition may have significant impacts on patient care.

Dermatitis Herpetiformis

Dermatitis herpetiformis is a specific bumpy skin condition associated with gluten intolerance that is characterized by immunoglobulin A (IgA) deposits in the skin (Fasano, 2001). Most literature links *dermatitis herpetiformis* to celiac disease specifically rather than to gluten intolerance in general.

Gluten

Gluten is a term that refers to a collection of similar proteins found in wheat, rye, and barley. In these grains, gluten proteins are storage proteins that provide essential nutrients to the seedling during germination (Sollid, 2000). In baking, gluten is the component in flour that creates the elastic texture that is particularly desirable in breads and other baked goods. Unfortunately, when consumed even by healthy individuals, the body is unable to efficiently and completely break down the proteins into their basic amino acid components (Shan, 2002). Due to the protein's high proline concentration, the digestive enzymes in the stomach and the small intestine, known as proteases, are unable to break down the gluten proteins into anything smaller than large protein fragments (Sollid, 2000)(McManus, 2003). These fragments have been identified as the "toxic" culprits that elicit an immunological response in gluten intolerant individuals. The peptides derived from wheat gluten, are divided into two main categories: gliadin

and glutenins. In barley and rye, these protein fragments are known as hordeins and secalins, respectively (McManus, 2003). The most well-known and commonly studied of these fragments is gliadin. Gliadin is thirty-three amino acids in length and has been identified as a major player in gluten intolerance (Green, 2006). Originally, it was believed that only the gliadin fragments were responsible for celiac disease, and thereby gluten intolerance. However, research done in 2006 in the United Kingdom (UK) revealed high structural similarities between the two fragment types, predicting a role for the glutenins in the disease mechanism as well (Howdle, 2006).

Symptoms and Associated Conditions

As stated previously, the symptoms and conditions associated with gluten intolerance are highly variable. Over 300 symptoms and conditions have been identified as associated with gluten intolerance. From the gastrointestinal tract to the brain, gluten intolerance has a wide range of effects on the human body. Before non-celiac gluten intolerance was recognized, it was believed that you were not gluten intolerant unless you had celiac disease. It was also believed that celiac disease presents in a very specific pattern characterized by chronic diarrhea, excessive weight loss, failure to thrive, malabsorption, and abdominal distention (Fasano, 2001). The medical community recognized the condition strictly as a pediatric condition as those with celiac disease would not make it to adulthood without a proper diagnosis and treatment with a gluten-free diet. Now it is known that celiac disease can present at any stage of life. Furthermore, it is also known that not everyone who is gluten intolerant presents with the same symptoms or pattern of symptoms. What is even more surprising is that not

everyone who is gluten intolerant experiences gastrointestinal symptoms at all and some may be entirely asymptomatic. Recently, there has been a substantial increase in awareness about how exposure to gluten in gluten intolerant individuals affects the nervous system (Ford, 2009). An article published in the *Journal of the American Medical Association* in 2009 announced that the classically defined presentation of celiac disease is in fact less common than non-classical presentations (Green, 2009).

A diagnosis of gluten intolerance and subsequent gluten elimination is imperative as continued exposure to gluten in gluten intolerant individuals is linked to significantly increased risks of malignancy, chronic disease, and other autoimmune conditions (Boelaert, 2010)(Zwolinska-Wcislo, 2009). It is still unknown whether the chicken came before the egg but given that the trigger of gluten intolerance is a known environmental trigger that is linked to over 300 different symptoms it is highly likely that gluten plays a significant role in the development of these and other conditions as well.

To emphasize the prevalence of myths and common misconceptions associated with the condition, an article published as recently as 2000 in the *Annual Review of Immunology* stated that celiac disease “commonly presents in early childhood with classic symptoms including chronic diarrhea, abdominal distention, and failure to thrive” (Sollid, 2000). The article went on to acknowledge that the condition may also present in adults citing symptoms of “anemia, fatigue, weight loss, diarrhea, constipation, and neurological symptoms” (Sollid, 2000). We now know that this classical presentation of symptoms is only a very small piece of the entire spectrum of symptoms associated with celiac disease and non-celiac gluten intolerance. Unfortunately, such descriptions continue to appear in the scientific literature.

Upon diagnosis, adherence to a strict gluten-free diet is paramount to achieving health as repeated exposure to gluten results in further systemic damage to the body. An article published in the *Journal of Pediatric Gastroenterology and Nutrition* in 1997 emphasized the direness of the situation by stating that the premalignancy of celiac disease “is no longer open to doubt” (Marsh, 1997). Marsh and colleagues extend this conclusion beyond celiac disease applying the premalignant label to untreated, non-celiac gluten intolerance as well.

Prevalence

Not more than thirty years ago, gluten intolerance was considered to be an extremely rare condition that was strictly a childhood disease. Now it is estimated that one in 100 to one in 150 Americans have celiac disease meaning nearly three million individuals are living with celiac disease in North America alone (Fasano, 2001). It is important to note, however, that these numbers are for celiac disease only—not gluten intolerance in general. When looking more generally at the prevalence of gluten intolerance, experts are now estimating that at least one in ten people are affected by the consumption of gluten...if not more (Ford, 2009). Even more, as pointed out by the director of the Celiac Disease Center at Columbia University, Peter Green, the identified genetics suggest prevalence rates of as high as 30-40% (Columbia Chronicle, 2010).

Another common misconception concerning the prevalence of gluten intolerance is that celiac disease only affects people of European descent. It is now widely accepted that gluten intolerance is prevalent wherever wheat, rye, and barely are a component of a population’s diet. A 2010 study in the *World Journal of Gastroenterology* directly

addressed this misconception by highlighting significant prevalence rates of celiac disease in Middle Eastern and North African countries (Barada, 2010).

Mechanism

In order to understand the mechanism behind gluten intolerance, it is essential that one must first understand a concept known as gut permeability. For a long time, it was unknown how gluten peptides could “break through” the intestinal lining in order to interact with the body’s immunological machinery. While many questions still remain, we now have a solid foundation in understanding behind the mechanism by which gluten peptides get through the protective barrier of the small intestine and enter the *lamina propria* and the blood stream. The key to understanding this mechanism is a protein produced by the human body known as zonulin.

In 2000, the Center for Celiac Research at the University of Maryland School of Medicine, published a study in *Lancet* identifying zonulin as a protein that modulates intestinal permeability (Fasano, 2000). Then in 2008, the same Center for Celiac Research, published a study in *Gastroenterology* outlining a strong connection between zonulin, gliadin, and intestinal permeability (Lammers, 2008). The mechanism presented by these leaders in celiac research is as follows. Upon ingestion, gluten is modified by the proteases in the stomach into gliadin and glutenin fragments. The gliadin fragments then bind to a receptor known as the chemokine receptor CXCR3 which is located on small intestine epithelial cells and immune cells. Once gliadin binds to the CXCR3 receptor, a mechanism takes place by which zonulin is released (Lammers, 2008). The zonulin then stimulates the disassembly of the tight junctions of the small intestine.

Intact, these tight junctions are responsible for creating an impermeable seal between epithelial cells of the small intestine. In breaking down the tight junctions, the release of zonulin (as triggered by gliadin binding to the CXCR3 receptor), ultimately results in an increased permeability of the small intestine when exposed to ingested gluten. It is interesting to note that the authors also reported an increased expression of the CXCR3 mRNA in intestinal tissue collected from individuals known to be afflicted with celiac disease (Lammers, 2008).

So, how is the permeability of the small intestine related to the immune response associated with gluten intolerance? Once exposure to gluten causes the intestine to become more permeable via the release of zonulin, small proteins, like gliadin, and potentially other foreign bodies as well, can then pass through the protective barrier of the small intestine and enter the *lamina propria* and the blood stream (Lammers, 2008). After entering the blood stream, these proteins can then travel throughout the body resulting in a systemic immune-mediated response to the foreign antigens.

In celiac disease specifically, the immunological response presents directly at the small intestine based on the following mechanism. There are two primary gene loci that are associated with celiac disease, HLA-DQ2 and HLA-DQ8. The HLA-DQ2 variant is more prevalent in diagnosed cases of celiac disease than is the HLA-DQ8 variant (McManus, 2003). Recent research, however, suggests that there are as many as 27 associated gene loci (Dubois, 2010). If and how variants (or mutants) of these genes affect the development of celiac disease is still to be determined (Plenge, 2010). The roles of the HLA-DQ2 and HLA-DQ8 variants are better studied and defined. These genes encode proteins known as class-II human leukocyte antigens (HLA).

In general, class II HLA proteins are responsible for presenting foreign proteins to T-cells stimulating an immunological response. In individuals with celiac disease, it is believed that an enzyme known as tissue transglutaminase in the subepithelial layer of the small intestine (the lamina propria) modifies gliadin peptides via deamination of glutamine residues (which have a neutral charge) to glutamic acid residues (which have a negative charge) (McManus, 2003). This deamination of the gliadin peptide allows it to better fit into the binding-site groove of the HLA-DQ2 presenting protein. Thus, the modified gliadin peptides have a higher affinity for the HLA-DQ2 molecule allowing for the elicitation of an immunological response (McManus, 2003).

Upon binding, the HLA molecule presents the ‘foreign’ gliadin peptide to a helper T-cell, specifically known as a CD4+ T-cell, which then activates a T-cell mediated immunological response. To elicit the immunological response that damages the small intestine, as in the case of celiac disease, the CD4+ T-cells activate the production of cytokines that then destroy the intestinal mucosa in a manner that is characteristic of celiac disease—crypt hyperplasia, lymphocytic infiltration of the epithelium, and atrophy of the intestinal villi. In individuals who do not have the celiac lesion, this immunological response is understood to occur in other areas of the body rather than at the intestinal mucosa causing the damage and inflammation that results in the vast list of symptoms and conditions associated with gluten intolerance. Unfortunately, non-celiac gluten intolerance is not well studied.

Diagnosis

In 1950, the *New York Times* published an article on celiac disease with a headline that read “‘Celiac Disease’: Most Children Are Now Cured But Cause Is Still Unknown” (*New York Times*, 1950). At the end of this article appeared the following:

“Sixty years ago celiac disease was incurable and often even fatal. Today cures are certain in over 90 per cent of the cases, and deaths are rare. There is no doubt now that by experimenting with the diet, it is no longer difficult to diagnose a case of celiac disease.” (*New York Times*, 1950). Sixty years after this article went to print, this statement is still not accurate. While we have figured out that gluten is at the root cause of the ailments of celiac disease, and we have identified a means of treatment via a gluten-free diet, obtaining a diagnosis remains a constant challenge in the clinical setting.

There are three primary avenues of testing for gluten intolerance: serological testing, biopsy, and genotyping. Unfortunately, most of these methods of testing to attain a diagnosis are specific to celiac disease rather than gluten intolerance in general. Below is a brief overview of the current diagnostic techniques available.

Serological Testing

Anti-tissue transglutaminase (anti-tTG IgA)

This test identifies anti-bodies in the bloodstream that recognize tissue transglutaminase - the enzyme that was mentioned in the mechanism section above and is responsible for the deamination of gliadin specific to celiac disease (Sudbrack, 2010). To test for the presence of this antibody in the laboratory, the technician performs an enzyme-linked

immunosorbent assay, more commonly known as an ELISA. A positive anti-tTG IgA is indicative of an autoimmune mechanism associated with celiac disease.

Antiendomysial IgA (EMA)

This test screens for the presence of anti-endomysial antibodies and is also specific to celiac disease. Like a positive anti-tTG IgA, a positive EMA also indicates the presence of an autoimmune mechanism associated with celiac disease (Sudbrack, 2010).

Anti-Gliadin Antibodies (AGA)

This test screens for the presence of antibodies specific to the gliadin fragments in the bloodstream. A positive AGA tests indicates that your body recognizes gliadin as a foreign substance and targets it for an immune-mediated elimination (Sudbrack, 2010). What is particularly fascinating about this test is that much of the medical community believes that this test can result in false positives as elevated levels are associated with many other diseases and not celiac disease alone. In these cases, gluten intolerance is then not recognized by the scientific literature if other signs of celiac disease are not present. It is important to remember that you can be gluten intolerant, meaning that you have an immunological response to the consumption of gluten, and not have celiac disease. A study examining the diagnosis of celiac disease in adults in 2010 stated that, “some diseases may interfere in the results, leading to false-positives, such as chronic hepatic disease, heart failure, arthritis, diabetes mellitus, and intestinal inflammation disease” (Sudbrack, 2010). Such a “false-positive” is questionable as all of these conditions are associated with gluten intolerance.

Duodenal Biopsy

The “gold standard” for a celiac diagnosis is a positive duodenal biopsy indicating the presence of the celiac lesion. A positive biopsy is definitive for celiac disease, while a negative biopsy remains inconclusive. There are multiple reasons why a biopsy can be negative in a celiac individual. First of all, the region of the celiac lesion can be missed when taking the biopsy, as the lesion is not visible with the scope alone. Secondly, the biopsy is read by a lab technician leaving room for error based on lack of experience and human error. Finally, minimal mucosal changes in microvillous structure may not be detectable by conventional light microscopy (Sbarbati, 2003). Furthermore, a negative biopsy does not mean that the individual does not have non-celiac gluten intolerance. Therefore, a negative biopsy does not mean that the individual is not gluten intolerant, it merely means that the celiac lesion was either not present or not observed.

Genetic Testing

Two primary haplotypes have been identified as associated with celiac disease, HLA-DQ2 and HLA-DQ8. Presently, it is believed that the presence of these genetic markers does not confirm celiac disease, but their absence is believed to indicate a near definite negative (Sudbrack, 2010). It has been reported that 30%-40% of the population carries these gene variants, but only 2%-3% present with the disease (Green, 2009). The role of these gene product variants in the disease mechanism is still not fully understood. Again, this testing is specific to celiac disease. Further research is needed to identify additional genetic markers.

Summary of Key Points

The definitions of gluten intolerance and its celiac/non-celiac subcategories are used inconsistently in scientific, medical, and popular literature. Because non-celiac gluten intolerance lacks the technology for a specific diagnosis, research on this form of gluten intolerance is non-existent in the scientific literature. In addition, research on gluten intolerance in general is limited to research on celiac disease further restricting the scientific literature available. Gluten intolerance is a spectrum condition, and thus, does not have an identifiable set of symptoms that clearly establishes affected individuals as gluten intolerant making recognition of the condition presentation challenging. Celiac patients are the exception as they are identified by the celiac lesion. It is important to note, however, that the presenting symptoms are just as highly variable in celiac individuals as those presenting in non-celiac gluten intolerant individuals, and identification of the celiac lesion requires an invasive procedure that frequently is not ordered and is not reliable. The actual prevalence rates of gluten intolerance are difficult to ascertain as the symptom presentation is so varied and the diagnostic tools, which will be presented in following sections, are largely inadequate, making identification of gluten intolerant individuals challenging.

Chapter 3

Methods

In this study, I interviewed individuals who self-identified as gluten intolerant or as caregivers of gluten intolerant individuals. Participation in this study was entirely voluntary, and participants were primarily gathered using a snowball sampling method. Flyers detailing the study were also placed in local facilities that serve gluten intolerant individuals (Appendix A). All interviews were audio recorded and then transcribed at a later date, and all names and locations used in this study were changed to protect the identity of the participants. Each interview typically lasted between thirty minutes to one hour and thirty minutes, depending on the amount of time it took for the participant to fully reveal his or her story. The interviews were conducted at a location of the participant's choosing often in a home setting or at a local restaurant. One interview was conducted over the telephone, as the participant was not able to meet in person.

I chose to elicit illness narratives (Kleinman, 1980) with gluten intolerant individuals in an attempt to capture the voices of the lived experience. The voices of the participants helped to reveal what it is like to live gluten free in a wheat-dependent society, as well as the differences between the lived experience and what the scientific community recognizes as the gluten intolerant experience. During the interviews, I talked with the participants about their diagnostic journeys, as well as their experiences living gluten free sharing my own experience in order to set the tone for the level of detail I hoped to elicit. This also helped to establish me as an insider. Each interview began with a brief overview of the participant's story describing their experience in developing a gluten free lifestyle. The unique experience of each individual interviewed

required that the interviews be open-ended and minimally scripted. A list of questions used to guide the interview was formulated at the beginning of the study and referenced throughout the interviews to ensure a rich, thorough, semi-directed interview (Appendix B). The ultimate goal of each interview was to gather enough information to develop a complete and detailed picture of each participant's lived experience of gluten intolerance. Questions were asked pertaining to the participants' experiences both pre- and post-diagnosis to ensure an exhaustive analysis of the effects of gluten intolerance on each individual's life. I presented an extensive list of common symptoms and conditions associated with gluten intolerance to each individual and then requested that each participant take the time to indicate which symptoms and conditions they experienced. This list was used to document the spectrum of associated conditions and to ensure that the effects of each condition were discussed during the interview.

Thirteen people from the Pacific Northwest were interviewed for this study. As gluten intolerance is a highly variable condition in both symptom presentation and severity, it was essential that enough people were interviewed to exemplify the full spectrum of the condition. As two of these individuals were caretakers of gluten intolerant individuals, the experiences of twenty gluten intolerant individuals were documented. Future studies with increased samples sizes are urgently needed. Unfortunately, time constraints limited the number of participants that were able to participate in this study. In future studies, a larger sample size will create a more complete presentation of gluten intolerance and the gluten free lifestyle. This study creates a solid foundation for future studies laying the groundwork for further investigation into the lived experience of gluten intolerance.

Once all interviews were collected, the interviews were analyzed using modified grounded theory based on the methodology developed by Charmaz (2006). This constant, comparative, incident-by-incident analysis allowed for identification of commonalities between the lived experiences of those interviewed, as well as differences between the lived experience and the scientific literature. Upon receipt of approval from Oregon State University's Institutional Review Board (IRB), I began conducting interviews with participants. Following the guidelines established by the IRB to ensure ethical research, I asked the participants to share their stories that led them to a gluten-free lifestyle. Throughout each interview, I aimed to gather rich, intensive data seeking quality and depth.

After all interviews were collected and transcribed, I began an initial coding process following Charmaz's methodology highlighting general terms that identified common themes. The next coding phase was an incident to incident phase which allowed for a thorough comparison of the participants' experiences (Charmaz, 2006). Finally, a focused coding phase was performed in order to further synthesize the incident to incident coding and develop a more complete picture of the lived experience of gluten intolerance. Results were presented and conclusions drawn based on this coding scheme. In order to ensure that my perception and understanding of the participant's experiences truly match their lived experiences, I plan to return a summary of my findings and conclusions to the participants for review and then conduct follow-up group interview. This process, called member checking (Charmaz 2006), will allow the opportunity for critique, feedback, and expansion of my conclusions.

Being gluten intolerant myself allowed for the development of a unique platform for such an investigation as having such a personal understanding of the condition allowed me to better understand the participants' condition. One of the first questions that all my participants almost always asked me was, "Are you gluten intolerant?" I quickly realized that once they discovered that I am gluten intolerant as well, they appeared relieved and more at ease to discuss what was at times a very difficult topic. Furthermore, my perspective also reduced defensive communication, as the participants knew that I had confidence in their experience and, as a result, they were more likely to open up and more fully disclose their experiences. Knowing that we had a shared condition, allowed many of the participants to feel more comfortable discussing the challenges associated with the condition both pre- and post- diagnosis. More importantly, understanding the condition through my own lived experience allowed me to ask better questions about the participants' experiences—questions that a non-gluten-intolerant interviewer may not have known to ask. Because the lived experience is so different than what is presented in the scientific and medical communities, my insight into the condition enhanced my ability to collect, describe, and identify the data.

Chapter 4

Meeting the Participants

Sandy was a freshman in high school when she developed a painful bunion on her left foot. Eventually the pain worsened to the point where she needed to have surgery. On the day of the surgery, the hospital ran routine blood work to clear her for surgery. When the results came back, her physicians were astonished to find that her ferritin and hematocrit levels were dangerously low. Her ferritin was zero and two, and her hematocrit was 19-20. They canceled the surgery and immediately started running tests. When they could not figure out what was going on, they sent Sandy to the hematologists at Seattle Children's Hospital for further evaluation.

At Children's they put her on iron supplements and were eventually able to get her above a critical point. Once the specialists got her levels up sufficiently, they assumed everything was fine, and they stopped looking for a cause. Soon after, Sandy was hit with a severe case of *mononucleosis*, and her iron levels dropped again. At this point, Sandy was experiencing other symptoms including severe joint pain, respiratory problems, and rashes in addition to the painful bunion and abnormal blood levels. Dissatisfied with her daughter's care, Sandy's mother, Colleen, made an appointment with an acupuncturist to discuss Sandy's condition with. Within two minutes of hearing Sandy's story, the acupuncturist told Colleen that he thought Sandy had celiac disease, and suggested that Colleen take Sandy to a naturopath.

Looking back, Sandy's mother has identified many health conditions that Sandy had experienced throughout her childhood that she has now linked to Sandy's gluten intolerance, like rotting molars. Presently, when Sandy gets contaminated with gluten,

she experiences intense joint pain, involuntary muscle jerks, diarrhea, and breaks out in horribly itchy rashes. Soon after going gluten-free, Sandy's bunion disappeared and she no longer needed a surgery that was very risky at her age. As she continued to eat gluten-free, the rest of Sandy's symptoms began to disappear.

Colleen, Sandy's mom, discovered she was gluten intolerant after researching about gluten intolerance for her daughter and learning that there is a genetic link. She decided to try the gluten-free diet and was amazed at the difference it made in her seemingly asymptomatic life. After going gluten-free, Colleen realized that she had been having joint pain and congestion, all of which disappeared on the gluten-free diet. She also realized that when she would eat gluten-containing foods, she would get bloated, which prior to going gluten-free, she attributed to being full.

Martina was a senior in college when she figured out that she was gluten intolerant. For years, she had experienced a series of symptoms that eventually led to the surgical removal of her large intestine when she was a freshman in college. Her symptoms, however, persisted after the surgery. She was hospitalized multiple times, and her doctors remained unable to find the root cause of her problems. Eventually, she developed a kidney infection and an autoimmune disease known as *psarcadosis*. Then one day, a guest speaker came into her nutrition class and talked about celiac disease. As Martina listened to the speaker, she began to suspect that she might be gluten intolerant and have celiac disease. Martina ordered the testing herself through Enterolab and her results came back positive. Since going gluten-free, Martina's gastrointestinal symptoms

have improved, she has significantly more energy, her emotional well-being has improved, her brain fog has lifted, and her joint pain has disappeared.

Veronica was a Registered Nurse (RN) in the emergency room when she developed an atypical, perihilar pneumonia. She then developed a systemic yeast infection, and then, as she describes: *“From that point on, my health spiraled down over the next three years.”* She continued to have fluid in her lungs, swollen lymph nodes, four plus pitting edema, anemia, night sweats, insomnia, peripheral neuropathy, constipation, gas, and severe joint pain. She had rashes all over her body, and she began to lose her sense of taste and smell. She saw allergists, internists, family practitioners, dermatologists, ophthalmologists, ER doctors, and EMTs hoping for answers, but unfortunately none of them had any. Eventually she gave herself six months to live: *“I gave myself six months to live at that point, but I actually prayed that it wouldn’t take six months because I felt so bad.”* Out of desperation and determination to continue to live for her 10-year-old daughter, Veronica went to a dermatologist who she had never seen before.

“So I went to see a doctor in town who is a dermatologist, and I gave her nurse the list of things that were wrong with me from head to toe. I said I don’t know if it is all related, but here is the list. She went back in and talked to the doctor, and the doctor came back in and said ‘I know what is wrong with you.’” Veronica was lucky to have eventually found a dermatologist who was aware of and able to recognize *dermatitis herpetiformis*, the skin condition associated with gluten intolerance. This dermatologist then took a blood sample and a skin biopsy and informed Veronica that she must go on a gluten free diet. Two weeks later, Veronica received her test results. They were

negative. Veronica, however, had noticed that she was feeling better on the diet so she decided to remain gluten-free regardless of the test results. Four months later, her health had improved dramatically. Veronica did not die and she is now healthier than ever.

Taylor was also a senior in college when she discovered that she was gluten intolerant. For years she had suffered from extreme fatigue, an inability to focus, psoriasis, and bloating. She never saw a doctor for her complaints, but she had heard from a friend about the diet and decided to give it a try. Within the first month of removing gluten from her diet, Taylor noticed that her bloating had decreased, that she had significantly more energy, and that her concentration had improved. She also experienced a considerable improvement in her mood.

Eve figured out that she was gluten intolerant when she was in her mid-fifties. For as long as she could remember, Eve experienced frequent gassy stomachs following meals. In her early-forties, she was diagnosed with Grave's disease. As a result of her hyperthyroidism, Eve underwent radioactive iodine treatment to destroy her thyroid. A family member was diagnosed with gluten intolerance a year ago and suggested that Eve try a gluten-free diet given her history with thyroid disease and stomach distress. After eliminating gluten from her diet, Eve was surprised by an alleviation of symptoms that prior to the gluten-free diet she had not recognized as being abnormal. In addition to gastrointestinal relief, she also experienced increased energy, as well as improved memory and concentration.

Anastasia discovered that her daughters were gluten intolerant after her eldest daughter, Maya, stopped growing and was unable to gain weight. She had constant diarrhea and had dark circles under her eyes. When Maya was two, Anastasia started her on an elimination diet based on reading that she had done online. From the elimination diet, they discovered that Maya is gluten intolerant. Now all three of Anastasia's children live entirely gluten-free and have severe reactions to gluten when contaminated.

Annie discovered that her children and husband are gluten intolerant after years of health problems dealing with a wide spectrum of symptoms. Her oldest child, Bidy, was chronically constipated and had coordination, gross motor, and fine motor developmental delays. Her second oldest, Ferolinand, was an inactive baby who was quiet and would do nothing but lay on the couch. As he got older, he was unable to potty-train and had chronic diarrhea. He also needed speech therapy and two years of occupational therapy. Annie's third child, Blue, was a colicky baby and screamed for her first few months of life. Blue also needed speech therapy. *"They fell off the charts on the bottom, but it wasn't just height and weight and stomach stuff, it was the way their coordination developed, it was the way they were using the sides of their bodies together...it was their ability to write their ability to jump, their ability to swing. I mean it was just shocking how many layers there were to the effects and the consequences of the 'oh it's nothing' which is what we got [from the physicians]."*

Annie heard about gluten intolerance from her mother-in-law and then decided to take Ferolinand to the doctor and demanded testing. His tests came back "off the charts." Annie's husband then went in and had his blood work done, and his tests came back

positive as well. So the whole family went gluten-free. By the time that they thought to test Bidy, they had already been gluten-free for six months, so her blood work came back negative. Blue was a baby at the time and did not get tested. The whole family noticed differences within days of going gluten-free. Annie described the difference in her family as “miraculous.”

Rachel had lived for years with chronic abdominal pain, bloating, gas, diarrhea, and constipation before discovering that she was gluten intolerant. After being diagnosed with IBS, Rachel heard about gluten intolerance through a friend. Within two or three weeks, Rachel started noticing a difference, and then after six weeks, Rachel noticed such significant improvements that she became sure that she is gluten intolerant. Rachel has never been tested for gluten intolerance because she went on the diet before testing and does not want to eat gluten again for testing purposes. Rachel was also vitamin B12 deficient and experienced peripheral neuropath in the form of tremors and numbness in the feet.

Jeffrey discovered that he was gluten intolerant after three years of chronic intestinal problems, fatigue, and brain fog. After a series of testing and clinical examinations, Jeffrey’s physician recommended that he try a gluten-free diet for a week. Jeffrey followed his physician’s recommendation, but did not notice an improvement in symptoms after a week without gluten, so he reintroduced gluten back into his diet. As his symptoms persisted, Jeffrey continued to do his own research and talked with other people who experienced similar symptoms. In doing so, Jeffrey was informed that

sometimes it takes longer than a week to notice an improvement in symptoms, so he tried the gluten-free diet again except this time he stayed on the diet for a month. According to Jeffrey, a month was just about the right amount of time. At the end of the month, Jeffrey noticed that not only did his stomach problems begin to disappear, but he also noticed that he had more energy and his mind was clearer.

Bess was diagnosed two years ago after her sister was hospitalized due to an undiagnosed case of celiac disease. Bess had experienced thirty years of joint pain, frequent stools, and brain fog. Her symptoms were not the classical gastrointestinal symptoms so she did not consider being tested for celiac disease after her sister was diagnosed. Two or three years after her sister was diagnosed, Bess was in for her annual gynecological appointment and indicated on her family history form that her sister has celiac disease. When her gynecologist saw this, she immediately recommended that Bess be tested for celiac disease as well. Her gynecologist's father-in-law has celiac disease and she was thus, well informed about the disease. Bess's blood results came back positive. A follow-up biopsy a few months later confirmed the results, as indications of intestinal repair were present in the biopsy. Since going gluten-free, Bess continues to notice improvements in her health throughout her body—even in her dental health.

Lori was graduating from high school when she discovered that she is gluten intolerant. For her entire life, Lori had complained of stomachaches and irregular bowel movements. Her physicians diagnosed her with IBS. Then one morning, Lori woke up to find that one of her toes “didn't work.” Over the next two weeks, paralysis spread throughout her feet

and in her hand to the point where her feet became completely paralyzed, and she could no longer walk. Lori was chronically fatigued, and she felt extremely weak. Lori's parents took her to OHSU for testing, and when OHSU failed to provide her with answers, Lori's parents sent her to the Mayo Clinic for further testing and examination. The specialists at the Mayo Clinic could not identify the cause of her sudden paralysis so Lori and her family returned home. Desperate for an answer, Lori's mom did some research online and sent Lori to see a naturopath. The naturopath performed a bio-feedback test and determined that Lori is gluten and dairy intolerant. Lori went off both gluten and dairy, and within one week her energy began to improve. Four months later, Lori could move her feet again.

Nicki describes herself as a child as the “sickest kid out of four kids.” Now in her thirties, Nicki finally understands why. A year and a half ago, Nicki discovered that she is gluten intolerant. Throughout her life, Nicki battled what she described as a weak immune system and chronic digestive issues. By the time that she was in college on sports scholarships, Nicki's health became so disruptive that she had to make a difficult decision and quit her college athletics. She saw every specialist that she “could think of under the sun” and was unable to obtain any relief. In addition to her digestive symptoms, Nicki's weight fluctuated dramatically and she was chronically fatigued.

Over the next fifteen years, Nicki was treated with various prescriptions and was unable to receive any answers pertaining to the cause of her health problems. Nicki felt as if her physicians were not hearing her and had one doctor even tell her that everything that she was experiencing was “all in [her] head” and that she “should go see a

psychiatrist.” As her health continued to spiral downward, Nicki was told that she was “just this side of going into full-blown Hashimoto thyroiditis.” When she was “not responding well” to the medications prescribed to her for the thyroiditis, Nicki decided to see a nurse practitioner for her annual. For the first time, Nicki felt like her complaints were being heard. After a \$1,600 blood panel ordered by her nurse practitioner, Nicki’s celiac panel came back positive.

Chapter 5

Results

Each individual participating in this study experienced a very unique journey in discovering his or her gluten intolerance. In this chapter, I present themes extrapolated from the interviews that expose commonalities in the lived experiences of gluten intolerant individuals living in a wheat dependent society. The following analysis is divided into two subsets: pre-diagnosis and post-diagnosis themes.

Pre-Diagnosis

In this section, I highlight common themes that emerged from the interviews with the participants in study about their experience of gluten intolerance prior to receiving a diagnosis. In so doing, I expose the lived experience pre-diagnosis and emphasize the participant's perceptions of the medical community's awareness and its subsequent effect on their diagnostic experiences.

At the beginning of each interview, I requested that the participant begin by sharing their experience with me about how they came to discover that they are gluten intolerant. In describing their experiences of the diagnostic process, participants unfailingly used two words in their descriptions—long and frustrating. Throughout their journeys, the majority of the participants sought care from multiple practitioners, received various misdiagnoses, and experienced many years of symptoms and subsequent systemic damage before identifying gluten as the root cause of their ailments. One participant even described the length of her journey in terms of the thickness of her

medical file. “I don’t remember a lot of it...I was just very out of it, but I have like an inch and a half thick medical file though...”

As evidenced by the high degree of variability in the symptoms reported (Appendix C), the complexity in clinical presentation appears to have complicated the diagnostic process in individuals who sought professional care. As Colleen pointed out, “it’s not your typical cramping, food poisoning, diarrhea stuff...it’s more your whole body—yet it’s an intestinal thing.” The symptoms reported affected every system in the body from the skin, to the gut, to the brain. As such, participants’ reactions to gluten serve as evidence of the extremely broad spectrum of symptoms associated with gluten intolerance. As Anastasia explained: “People ask me ‘well what are the symptoms—how do you know?’ And you know it’s different for every single person. There is no concrete set of symptoms—there’s just not—there will never be. It effects every person differently...everybody reacts to it differently.” Eve said: “I was resistant at first because I didn’t experience any of the GI symptoms associated with gluten intolerance, but then I figured I had nothing to lose because I was tired of feeling this way...if there was anything that would help I was willing to do it.”

Such differences in symptoms even appear within families. As Annie pointed out, the symptoms that present in her four children vary. One child gets severely constipated, while the other three have diarrhea. As Annie explains:

“It is very, very obvious...all of them have very different symptoms including Valentine because a couple times, the whole family has gotten ‘glutened’ and he will scream like [Blue] did. So Bidy gets stomach pains and constipation. Ferolinand gets lethargic and spacey and everything goes straight through him for weeks. Blue just screams. She gets really angry and ornery and everything goes through her.”

Annie's family was not the only example of such differences, as many participants revealed that they experience different symptoms than their other gluten intolerant family members, and some are without any major gastrointestinal signs at all. After finding out that her sister had celiac disease, Bess did not think that she too was gluten intolerant because she did not exhibit the same symptoms that her sister had experienced. "My sister, she kept saying, 'you should get tested,' 'you should get tested,' and I was like 'I don't have any of those problems.'" In not recognizing the spectrum of symptoms, Bess's diagnosis was delayed.

Many of those who sought professional medical care presented with laundry lists of seemingly unrelated symptoms and were misdiagnosed. Such misdiagnoses ranged from IBS, to eczema, to eating disorders, to devastating neurological conditions. As Sandy explained: "The doctors kept asking me if I ate enough. They weren't convinced that I wasn't anorexic or bulimic...They kept telling me that I had an eating disorder" Lori said: "For something so simple really, I mean it wasn't cancer or Lou Gehrig's disease...you know all these things that they thought it was...and really it took a lot to figure out what was wrong...so very frustrating."

Three individuals participating in this study reported that they had originally been diagnosed with IBS before they discovered that they were gluten intolerant. Jeffery explained his frustration with the diagnostic process by describing his experience receiving a diagnosis of irritable bowel syndrome (IBS). He said:

"I was very frustrated—frustrated with terms like okay you have irritable bowel syndrome. Whenever somebody calls something a syndrome, whenever I hear a doctor say that, I think 'So you don't know what is wrong with me?' I went in years ago when I was a teenager and my heel hurt really badly whenever I ran or walked so I went to the doctor, and he said, 'Well you have what we call painful heel syndrome,' and I

laughed, and he said, ‘No, that is really what we call it.’ And I said, ‘So, what causes it?’ and he said, ‘Well, we are not sure.’ That is when I first realized what syndrome means...it’s a euphemism. It means we don’t know what is wrong with you. So irritable bowel syndrome I realized has become a blanket term. So my process was a frustrating journey.”

In addition to the misdiagnoses, participants reported a lack of trust in their physicians, and many expressed concerns over whether their providers believed them as they explained what they were experiencing. Many also reported that they felt that their physician dismissed their symptoms as ‘normal.’ One participant extended this analysis beyond the physician perspective saying that it reflects an attitude adopted by society as a whole. Anastasia made this connection using diaper rash as an example. She said:

“I know for a lot of people, diaper rash is a common thing where every baby gets diaper rash...I think that is bunk. They do not naturally get diaper rash. There is something going on...there is another piece of the puzzle. It makes me nuts when people are like ‘oh just buy some you know whatever,’ [they are] like ‘this balm is the best balm for it’...NO. You need to see what its root cause is.”

Many participants also said that their physicians failed to do more than treat symptoms. Often the participants acknowledged that they had felt like their physicians were not looking for the cause of their symptoms. As Martina explained:

“My senior year of college I got a kidney infection so I went on antibiotics and the third day on my antibiotics I started to get bruises all over my legs and arthritis in my joints and that is when I found out that I had psarcadosis...and they didn’t know why I had that. So that was another thing that they just kind of waited for it to go away and then it went away and they were like ‘oh well it went away so it’s not a big deal. We don’t know what caused it.’”

Colleen said:

“Sandy had to go to a dentist that specialized in pediatric dentistry, and they wouldn’t believe me that she hadn’t been given a juice bottle and

here I am, you know, it's obvious that we are of a certain intelligence, intellect, education, and socio-economic background that we wouldn't do that and that I am a caring mother that I wouldn't do that and it never dawned on these dentists that there was something that was the cause of all this."

Annie reported: "We just struggled with her and her pain and her bleeding and being frustrated all the time and [her doctors] kept saying 'it's just who she is.'" Colleen summarized her experience with the physicians as she fought to obtain a diagnosis for her daughter's failing health. She said:

"When we went to the hematologist at Children's...they ran all these tests on her and they said, 'well you know sometimes this happens when you are really athletic.' And I am telling you as a mother, the one thing that really, really pisses me off...when anybody ever says 'well this is just what happens.' My response to that is BS. What is the root cause?"

In some cases, this lack of trust resulted in the participants questioning their own experiences. These individuals expressed that their physicians' disbelief in their experiences discounted their suffering and ultimately resulted in self-doubt. Martina described her experience by saying:

"I started to feel like I was crazy when I was going to the hospital all the time and they were asking me: 'Well, do you think you know how to go to the bathroom?'...or they would be like 'Oh, you are just dehydrated.'...so I definitely started to doubt myself and think well maybe I'm just a hypochondriac. You start to think maybe this is normal."

Nicki explained: "I had a doctor at one point tell me that it was in my head and that I should go see a psychiatrist. That didn't fly well... I kept thinking I'm going nuts I am going crazy obviously it has got to be me...it's not anything else. My husband was really awesome for me because he kept being like 'No, no, no...You are still you. Something physically is not right.' At that point I had to trust him because I had doctors tell me everything under the sun that it could be, it wasn't, they dinged around it but never hit it."

From the time of onset of symptoms to diagnosis, all participants reported that they experienced a significantly lower quality of life. The degree to which their lives were affected however, varied significantly among participants. Annie said:

“I mean literally we had a child who cried every day because he knew he wanted to use the potty and he would run and run and would literally just leave trails...weeping because he was like ‘What is wrong with me?’ He was like ‘I know how to go potty’ and he could pee in the potty but he could not hold his bowels. Within a week [of starting the gluten-free diet] we had a kid that wouldn’t cry every time that she went to the bathroom because it hurt. [Before going gluten-free] we had a kid that couldn’t walk to the park and he was almost four...he would literally just lay on the couch all day and do nothing. He was too tired to play.”

Veronica’s health had declined so much that she did not feel as if she could continue on living. She reported: “I gave myself six months to live...but I actually prayed that it wouldn’t take six months because I felt so bad...so I prayed to die but I had a ten year old daughter at the time and I thought well that is kind of not a good thing if I die and she is ten.” Taylor said that her energy-level before removing gluten from her diet prevented her from participating fully in her days activities. She said: “I wasn’t able to wake up and feel pretty good and then go you know?, throughout my day and go to work and do this and do that without feeling sick...without feeling super tired...and just all those factors combined to make me feel out of balance.” Rachel explained: “I would definitely say that my health was holding me back because I just felt bad all the time.”

Depression was common among the participants prior to diagnosis. Martina explained: “I think it’s really hard for people not to get depressed in these situations. First of all you have no energy. I mean I was so sick...I had no energy...I couldn’t eat anything because every time I would I would be sick...I would just sit on the floor in my dorm room by myself just staring at the TV. And I mean anyone who knows me, knows

that that is not me.” Bess described her experience with depression associated with her gluten intolerance by saying: “I just always had the feeling like there is some reason that I feel like this. I would even have signs of depression and I would think you know I’m not really depressed I’m very happy in my life but I would have some feelings of depression.”

Participants reported that their health prevented them from participating in social gatherings, limited their relationships, and reduced their ability to actively function as a member of society. Sandy who was a star high school athlete at the time and who would later become a college athlete acknowledged that her undiagnosed gluten intolerance had prevented her from participating in her athletics. “I felt like I couldn’t do what I loved to do at that time...that was really hard for me.” Like Sandy, as a college athlete, Nicki reported that her health prevented her for participating in her athletics. She said: “As I got older, it got worse to the point where I was in sports and I had college scholarships and everything, and I found myself just getting sicker and sicker and sicker. So I made my decision my junior year of college to quit basketball and all other things involved.”

Rachel, Martina, and Bess reported that their undiagnosed gluten intolerance affected their ability to interact socially with others. Rachel said: “Mostly I would just go and do things anyway but I would say at least several times a week I would be uncomfortable enough that I wouldn’t want to go out or I wouldn’t want to do anything and I would stay at home.” Martina said: “It was crappy. I was tired all the time...exhausted...I didn’t really interact with people because I was so tired.” Bess said: “I feel like the gluten makes me feel like I am ADD or something; your brain is just kind of in this fog, and I kind of feel like I am better socially [off gluten] than I was.”

Jeffrey said that his undiagnosed gluten intolerance affected his ability to do his job. He said: “The thing that really cinched it wasn’t so much the intestinal problems, although that should have been a problem, it was the brain fog—it was the inability to do my job.” Taylor reported that her condition affected her confidence level. She stated: “This [condition] has affected my school, my jobs, and my confidence. My confidence is probably the number one biggest thing that the gluten free diet has noticeably helped me to feel better about.” As a mother, Annie watched as her child struggled to participate in extracurricular activities with other children her age. Annie explained: “The first time [Biddy] tried [gymnastics but] she couldn’t [do it]...it was like the sides of her body could not work together. And she wanted to learn the violin and the teacher kept saying she can use this side and she can use this side but she can’t use them together. Since going gluten free, all of the sudden, they are working together.”

For many, it was not until they were entirely gluten-free until they recognized how fully their lives were affected by their health. Participants reported that they normalized their condition to some degree and did not realize the full extent of their misery until they removed gluten from their diet. Jeffrey said: “I didn’t know that life didn’t have to be like this.” Martina reported: “Half the time that my stomach hurt I wouldn’t even say anything you know, you just get used to it and you kind of deal with it—but it would always hurt.” Rachel said: “I didn’t even know how much pain I was in until I stopped eating gluten and then felt normal for the first time. Like ‘oh my stomach doesn’t hurt’...I didn’t even realize that my stomach did hurt every day. I just normalized it so I just noticed the absence of it.”

In addition to the symptoms that they experienced themselves, many participants watched family members suffer from undiagnosed gluten intolerance and others suspect that undiagnosed gluten intolerance can be linked to the pre-mature death of their relatives. Bess explained:

“It’s really sad for me too because I lost my dad and we are pretty sure he had it and now his only brother just passed away and all of those relatives on my dad’s side, they were all diagnosed with Alzheimer’s and dementia and you just wonder...you just totally wonder...I mean I am convinced that if they would have been eating right they probably wouldn’t have been diagnosed the way they were, but nobody will ever know because they are gone.”

Veronica reported: “I lose at least one relative every year—at least. They die. Because they don’t listen...so I just have to live with it.”

Beyond the reduced quality of life, participants reported that their undiagnosed gluten intolerance resulted in unnecessary surgeries and invasive procedures. Many also stated that they were prescribed serious pharmaceuticals for symptom management. As a freshman in college, Martina had her colon removed. She explained: “I came to college and was just really sick in college...my large intestine was bigger than it was when I was 16...they said well we have to remove it because it is never going to get better unless we do. So they removed my large intestine but never found out what the problem was.” Lori was subject to many invasive and expensive tests and examinations. She reported: “I had a lot of MRIs and an EEG and a spinal tap, CAT scans, and lots and lots of blood tests.” Veronica received many prescriptions and underwent multiple surgeries that she now recognizes as unnecessary and related to her undiagnosed gluten intolerance. She explained: “I had been given multiple prescriptions...I was given prednisone...a whole litany that would have filled a grocery sack. In the mean time, my health continued to

spiral down to the point in October of 2006 where I had sinus surgery...which didn't help at all...I almost did have a bilateral mastectomy because my lymph nodes were swollen under my arm pits. I had lumpy bumpy breasts. Glad I didn't have that done." As a sophomore in high school, Sandy was given heavy pharmaceuticals and almost underwent a risky surgery in an attempt to manage symptoms related to her undiagnosed gluten intolerance. Her mother, Colleen, reported:

"The thing that is so frustrating to me about being a celiac or a gluten intolerant is that [Sandy] would have had unnecessary surgery...and she was on prednazone... and hydroxine...these are not insignificant drugs. She was on prednazone for four months in eighth grade. And then she was on all these allergy medications on a regular basis so it was just stuffing her full of all this stuff to keep symptoms down, which at the time, I appreciated because it kept her out of the ER."

Annie reported that she believes that her children's untreated gluten intolerance resulted in developmental delays that required occupational therapy. She noted that in her children the length of time of exposure to gluten is directly proportional to the length of time in occupational therapy required. She explained: "Biddy was in occupational therapy for about a year, Ferolinand for about two years, and Blue only like six months."

Although the majority of participants saw multiple physicians for their gluten related ailments, none of the participants received a diagnosis as gluten intolerant from a primary care MD. Out of the 13 individuals interviewed, eight of them figured out that they were gluten intolerant by themselves. Of the remaining five, one was diagnosed by a dermatologist, one by an acupuncturist, one by a nurse practitioner, another by a naturopath, and the last by a gynecologist. None of the participants were told that they were gluten intolerant by their gastroenterologists or their pediatrician. Colleen highlighted her frustration with the diagnostic process by highlighting a perceived lack of

responsibility for the condition within the medical community. Based on her experience with the challenge in obtaining a diagnosis for her daughter's gluten intolerance, Colleen said: "One of the issues that needs to be addressed is: 'where does the responsibility for this lie?'"

Martina explained her perception of her physicians' knowledge about the condition by saying: "None of my physicians ever mentioned it to me—nobody ever did. And you would think, you know now looking at it, I think I had typical symptoms of CD. I didn't have the classical symptoms but the constipation and the *psarcadosis*, which is an autoimmune disease, I had issues of CD and nobody ever looked for it. Nobody even mention it. They tested me for everything under the sun except for that." Similarly Veronica said:

"I asked every doctor that I saw, was there any chance that I am allergic to wheat or dairy and was this what was causing all of this. And they unequivocally said 'no.' No, 'hey there is this weird disease you might have'...none of that...it was just 'no'... I saw allergists, internists, family practice doctors, dermatologists, eye doctors, EMTs...and not one of them picked up on it...plus all the ER docs I worked with. I would say that I saw thirty doctors overall."

Lori reported: "[My doctors] didn't talk about a gluten free diet. My parents, actually my mom, was researching this whole time trying to figure something out and she came across celiac disease...even just my parents suggesting that I take a test, it was just like 'uh yeah no it's not going to be celiac disease, they were just very skeptical about the whole thing.'" Annie explained: "We kept saying, 'Well could it be food? Could it be this?' and they kept saying oh no, she is just constipated and it can't be celiac and these other things because its not the same sort of category as far as her symptoms go...we went through several doctors and kept saying could you just check for this, that, and the other

thing, and a couple doctors said well we will try these invasive tests, but they wouldn't consider any dietary factors because they said it's just not as common as you think, and it's just not a problem."

Rachel also emphasized how a perceived lack of knowledge about the condition on the part of her physicians directly resulted in challenges in obtaining a diagnosis. Rachel reported: "My experience of the diagnostic process was that it was just incredibly frustrating. It's just no one, no one, no one...naturopaths, acupuncturists, doctors...no one said anything to me like 'oh have you ever heard of gluten intolerance or even any other food allergies or anything other than IBS.'" Bess felt as if her doctors had failed her. She said: "I really felt let down. I felt like those doctors...that doctor in one...should have said 'hey you know she has complained of these things, maybe there is something going on,' but I felt like they didn't really listen to me when I went in."

Colleen acknowledged that she perceived a greater awareness about gluten intolerance within the alternative medicine community compared to the western MD community. To emphasize her point, Colleen shared her story of talking with an acupuncturist about her daughter's condition. She said:

"So I made an appointment with the acupuncturist to just take a half an hour of his time and go through the last three years of history because I said to him 'look this kid is one of the most driven, healthy, strong kids and takes good care of herself.' I mean her eating habits, even when she was eating a lot of wheat were whole wheat and peanut butter good fruit veggies not junk and I knew she didn't have an eating disorder so I went through the whole history and in two minutes he said to me 'she is allergic to wheat...you need to get a good naturopath. Look up celiac disease on the Internet.'"

Some participants were tested for gluten intolerance using the testing methods mentioned in chapter two. For many of the participants in this study, these tests came

back negative and were thus informed that they were not gluten intolerant. Lori stated: “They did [some testing] to figure out if I had celiac disease and they immediately dismissed it...they didn’t suggest ‘well you could try it I guess.’” Veronica had already started the diet by the time her tests results came in and so she decided to stay on the diet regardless. She explained: “[When I] got home [from my trip I] called for the lab results and she said ‘well you don’t have celiac disease, they are both negative.’ And so I was sitting at my kitchen counter kind of sobbing, and my husband comes in and goes ‘what’s wrong,’ and I said ‘well I don’t really have it’ and he goes ‘but you are better...in two weeks you’re stuff is getting better so why don’t you just stay on the diet.’ And so I did.” Annie mentioned: “So we were tired and here we were trying to switch to a whole new diet and it didn’t even occur to us with Biddy...by the time we got her tested we had already been gluten-free for probably six months so her test came back normal.”

Many participants who figured out that they are gluten intolerant without a diagnosis from a physician refuse to get tested. For these participants, further validation of their condition is no longer necessary. Taylor explained: “For me this has been primarily a lifestyle change and I don’t care if some stupid test says that I don’t have it. I feel better and you know my like works better. I am not feeling sick.” Anastasia stated: “I never felt like I needed a formal diagnosis for her because it was clear to me that [gluten] was her issue...I mean the results from taking her off gluten were not immediate, but the result of her having gluten *is* immediate and severe.”

Multiple participants mentioned that they believe that the majority of physicians do not recognize the unreliability of the current testing methods. Veronica stated: “A lot of doctors are stuck with, if you have a positive blood test you have to have a positive

biopsy to confirm it. And what we know is that those biopsies are not conformational. Even the doctors that know anything say that and plus they do it so wrong so often it's not even considered the gold standard anymore—it's considered the tarnished silver, if that." Bess reported that she is concerned that her kids are gluten intolerant, but the limited availability of diagnostic techniques is making obtaining an official diagnosis a challenge. She explained:

"I am still not convinced that my kids...I have three kids...and all of them have different health issues that I see as being possibly related to gluten. They have all three had the blood work, and it was all negative for all of them. My youngest had the biopsy and that was negative also. My oldest son has the skin that looks like DH and he is actually waiting on a biopsy that they are running. It's frustrating because the testing is not very easy. I mean if it shows positive than that is great but if it doesn't you know I wont be convinced until they either have it and they find out that they have it. I wont be convinced really because I see things in all of them...things that I had...things that I complained of."

Anastasia also expressed her concerns with the current available diagnostic technology. She said: "So many people fly under the radar with blood tests and they are like 'oh I am totally fine,' you know? I think it gives people a false sense of security that you know because it doesn't show up in your blood that you are just okay you can do whatever you want. I mean [negative tests] give you a license to harm yourself...it just makes me nuts." Both Bess and Nicki who received positive test results mentioned that they feel very lucky. Bess said: "So I really felt fortunate that my gynecologist knew about celiac disease, ran the tests, and that my blood work came back positive because if it wouldn't have, I probably would never had more testing done." Nicki said: "So she asked if she could take a \$1600 blood panel and it tested everything from like thyroid to celiac disease. I actually showed positive on that. So it was pretty much pure luck."

After figuring out that they were gluten intolerant, many participants went back and talked to their physicians that had failed to identify gluten as the cause of their ailments. Most of these participants felt that their physicians expressed doubt and skepticism, however a few felt that their physicians were intrigued and open to the concept. Lori reported: “Some of [my doctors] checked up on it and I told them what happened but some of them didn’t believe me...but a couple of them were really surprised and excited and were like ‘oh, I have other patients that you know that this could help’... They were definitely very skeptical about what we were telling them...” Veronica said: “They thought [celiac disease] was a childhood disease and that there was no way I could have it. [They would also say] it is just a diet change and there is no way I could have it. I think it scared [my dermatologist] because...I would have died if I would have not stayed on a gluten-free diet despite the fact that she said I didn’t need to be on it.” Colleen explained: “When I went back to the pediatric associates who were her pediatricians and told them that she has been diagnosed with celiac disease they were pretty ambivalent about it. Martina documented: “I just emailed my surgeon the other day. I love him so I don’t want to like...like he basically said ‘oh that is interesting but you know diagnosis isn’t really my job as a surgeon’...but I went back the other day and told [my primary care physician] and she was so interested...she was really curious about it which I thought was really good.”

One participant’s physician had recommended that he try the gluten-free diet for a week and monitor for improvement. When the participant did not notice improvements in a week’s time, the physician told him gluten intolerance was not the cause of his ailments. Such a short recommended trial period further exemplifies the lack of

knowledge about the condition in the medical community. Jeffrey explained: “At some point he suggested gluten intolerance and so he said go for a week off gluten and so I did and I didn’t really notice anything...and then at some point I decided to try to just stay off of wheat for a longer period of time because I had talked to a number of people that said well you need longer than a week. So I went off for a month and it was dramatic.”

Various participants identified the perceived lack of awareness and knowledge of gluten intolerance among the medical community as a reflection of the western medical attitude and healthcare system. Martina explained her position by stating: “We are a for-profit healthcare system and people want to push meds and pharmaceutical companies.”

Lori said:

“There is maybe just a very large gap between natural medicine and western medicine that I wish would get closed because I think the two would work really, really well together but there is just a huge disconnect between them...I think most of their hearts are in the right place but I just feel like there is a huge chunk missing in the typical medical perspective. They typically want to do surgery and testing and that kind of thing but if you just support they body it can heal itself. I just don’t think its in that line of thinking really, you know if you are that sick, it can’t just be from gluten. It has got to be like something wrong with your intestines or something which I mean there is but it can’t be solved that easily.”

Rachel said:

“Maybe people have an inkling that well I don’t really think I have IBS or whatever it is that they have been diagnosed with but the doctor doesn’t really want to listen to them because the patient is not supposed to know what they are talking about and the doctor always knows best. And there is that attitude that I think that a lot of doctors have. You just live in a body—what do you know? Not all doctors obviously, but I think that attitude still persists. So that was a really big frustration of mine.”

Veronica mentioned: “They are really good at writing prescriptions but they are not good at diagnosing anything. They don’t look for anything to diagnose anymore. They treat

everything with prescription. So we are a pill-based healthcare. So ethically I have an with that.”

As a nurse who experienced a long and devastating journey to discovering that she is gluten intolerant, Veronica has a particularly unique perspective on the topic of the medical community’s awareness. Veronica explained:

“So I had a huge paradigm shift as a nurse learning this information going from the emergency department where you know...‘greet ‘em, meet ‘em, treat ‘em, and street ‘em.’ That was our thing, you know, ‘shoot’n about.’ Going hey, you know, we missed a whole disease here...all these people are coming in repeatedly, our frequent fliers are people that umm, come in with undiagnosable abdominal pain, they have addiction issues, they have schizophrenia, migraine headaches, etc.”

Other participants saw the lack of awareness about gluten intolerance as a reflection of society. Eve explained:

“When you watch TV everything is ‘eat grains, eat grains, eat grains—it is the healthy thing to do,’ ‘whole wheat,’ ‘the food pyramid—have whole wheat!’ I never would have thought that eating whole wheat bread was working against me because I thought that was the right thing to do. When you are bombarded with that kind of media and you grow up with it, you never really question whether or not it’s healthy. The government is telling you to do it too!”

Speaking as a mom, Anastasia said:

“...nobody says to you IT’S WHEAT! You know? Nobody says to you that it’s the noodles, and the cookies, and the cake, and you know the whole wheat bread that you think is really healthy...and then as a mom you are like ‘oh my gosh, if only I had known,’ you know? Every single time you put something in your kid’s mouth you think you know—it’s just the guilt. THE GUILT IS SEVERE. I mean of course you want to do what is best for your child and when you are giving your kid whole wheat bread you think you are doing the right thing.”

Annie acknowledged: “...we really ate pretty healthy—whole grains, you know?! FOR CRYING OUT LOUD!...I had no idea how completely it would screw up my family!”

The majority of the participants in this study indicated that they were highly proactive throughout their journey to health. Jeffrey explained the importance of being proactive in the current health climate by saying:

“We have a tendency to go into medical professionals and say ‘well tell me what is wrong with me’ and then trust that and I think we have, with the advent of the internet and also we are getting in touch with other people who have a problem...through the process I learned I was frustrated. I was feeling that I that I wasn’t getting better and then I realized I needed to quit trusting an outside source—I needed to start taking initiative. The process taught me a lot. It taught me to be a little bit more careful, maybe a little more skeptical, and a little more practical. That frustration then was translated into learning. It is research and application.”

Post-Diagnosis

After discovering their gluten intolerance, some participants returned to their doctors and asked them why they had not suggested a gluten-free diet. Participants reported a range of explanations delivered by their physicians that suggest that many misconceptions about the gluten-free diet exist within the medical community. Veronica reported:

“Most of the doctors will say that the diet is much too hard and they couldn’t do it so they don’t want their patients to do it...they argue with me. They tell me that it’s so hard and I’m like ‘no it’s not, I do it.’ And they go ‘yes it is.’ And I go no it’s not. And they say ‘yes it is,’ and I go ‘okay fine.’ I had one physician tell me that she thought it was a disservice to patients to diagnose celiac disease because the diet was so hard so she didn’t even look for it.”

Martina said: “[My primary care physician] kept being like ‘so is it really hard?’ ‘What is the hardest part?’ And I was like no its not really that hard as long as I don’t go out to eat or don’t eat at friends’ houses and am careful. She was like it just seems so difficult.”

Colleen explained: “She said, ‘you know, we [as doctors] are better about it now, but the

tough thing about things like celiac disease is that it is hard for patients to maintain the diet' ...so there is an element out there that that is very true for but I find that having lived the diet for over a year and a half –and I will continue to live it—it is easy.”

When questioned about the manageability of the diet, participants said that the diet was relatively easy and often explained that the gluten-free diet is more of a lifestyle change than a diet. Colleen explained: “You don’t even look at things that have a lot of gluten in them the same way. It’s weird. You finally get to that point where it’s not even food.” Anastasia stated: “Really, honestly, it’s not hard. And really, honestly, I don’t feel like we are making any sort of sacrifice and truly, honestly, I don’t even think about it...it becomes second nature and you just do what you have to do, you know?”

Rachel commented: “I think it is a really easy diet to follow once you get really into it.”

Martina said: “I don’t really struggle with the diet. I guess at first I did because my fiancée and I are really big foodies but we are just foodies in a different way now. I mean we cook a lot so we might be different because of that, but I don’t know, we just don’t go out to eat as much as we used to.” Lori explained: “The gluten-free diet has changed my life pretty dramatically. The way I feel...how I pick out food now...it is not a bad thing at all, but it is very different.” Anastasia reported:

“Its not that hard! And that’s what people are always saying...’well what do you feed [your kids]?’ There are a bagillion different foods that are naturally gluten-free. Do your kids eat apples? There you go. Your kid eats meat? Okay there you go...go eat some rice with some vegetables on it! What is wrong with you?...I mean you would think that common sense would lead people to just like buy a steak and some vegetables, but it doesn’t.”

Overall participants concluded that symptom relief overrides the loss of dietary freedom. Rachel explained: “The main thing is that your symptoms go away so you

have this enormous incentive to do it. I feel great when I don't eat gluten and I feel like crap when I do, so it's not difficult to follow. I don't feel limited." Jeffrey said: "Part of it was 'oh no I have to give up pasta and bread and all this other stuff' but frankly that was outweighed by the fact that I was feeling better and so that was a small sacrifice."

Taylor mentioned: "I mean it was kind of hard but after about a week I started to feel a difference from eating the different food and I just felt better and had more energy."

Bess stated: "I think I really responded differently than most people because the first thing I thought was that I just tried to think of all the foods that I normally eat that are gluten free already and so I think that really helped me a lot. I did try to focus on meat, vegetables, you know things that I already cook a lot of...soups and homemade things that I knew I could eat right off." Anastasia acknowledged: "I think a lot of people really stress-out about like 'oh but my kid is not going to get to have x, x, and x. But if you give them the self-awareness to know how it affects them and you know you are fulfilling their nutritional needs at home, then they don't have those constant cravings for it." Eve explained: "The relief of symptoms definitely overrides any adjustments that you have to make. Initially feels overwhelming because it is a dramatic change in lifestyle but it gets easier."

Self-awareness became a common theme throughout the interviews. Participants expressed that the gluten-free diet has allowed them the opportunity to learn how to better listen to their bodies and know what they need. Rachel explained:

"I am just completely aware of my body in a way that I wasn't before. Like I know how to please my body and what it needs and what it doesn't need and what is making it feel good and what is making it feel bad in a way that I couldn't before...and not just related to gluten but related to everything in my life. I now know what it feels like to feel good so I can tell what things are making it feel good and what things are

making it not feel good. I am way more in tune than I think most people are.”

Lori stated:

“I definitely pay attention to my body now—like signals—and how I feel which I never even paid attention to before. I always thought people were weird when they were like ‘listen to your body.’ I can tell if I’m going to get sick now and so even just like a cold and typically I can head it off before I get it because I can notice changes and stuff which I think is pretty cool because a lot of people aren’t able to do that.”

Annie highlighted the essence of this awareness by explaining in terms of the importance of having an active role in one’s own health. She stated: “In a way, it’s good because my older two know that they have an active role in being healthy and they are old enough to understand that.” Anastasia reported that she was relieved that her daughter understands how gluten impacts her health at such a young age. “[Mary] gets the connection between gluten and not feeling good.”

Bess mentioned that the gluten-free lifestyle has changed her relationship with food. She explained: “I just look at food now as a fuel for my body instead of something that makes me feel good to eat. I try to get the right fuel that I need. I think that is really important for everybody. Veronica had a similar experience in that she reports that she now listens more to what she believes her body is telling her it needs. She explained: “I have actually gone through periods of time where I will eat like avocado and I cannot get enough avocado...and that is my little theory, that [your body] will tell you what you need to eat and you better damn well eat a lot of it.”

Some participants mentioned that understanding what was going on with their bodies—what was causing all their symptoms—was a big relief. Colleen stated: “It is way better understanding what it is and what causes the symptoms so you don’t feel like

all these random things are happening to you and also understanding the long-term negative impacts if you don't follow that kind of diet." Annie mentioned: "It has been relieving...to see the changes...I mean to from such huge problems to feeling like there is some hope for our kids because for a while there I was feeling like there was something wrong with our kids and there was it wasn't something that wasn't fixable." Jeffrey highlighted: "So I felt tremendous joy at finding what the problem is because that to me is a big part of it." Lori explained: "I'm not crazy!" Sandy stated: "I started to get really freaked out that what was happening to me was out my control and I couldn't do anything about it."

Participant's also often identified many ways in which the gluten-free diet has improved their lives. For Martina, the gluten-free lifestyle has provided her with the health to allow her to challenge her body and mind in new exciting ways. She explained: "I ran a half-marathon two weeks ago, I always have energy, I am working two jobs, I go out..." For Eve and Lori, the adoption of the gluten-free lifestyle provided them with an opportunity and excuse to learn how to cook and to become more creative in the kitchen. Eve said: "I have learned to cook—and I have never cooked. I have always left that up to my husband. It is kind of fun! Gluten-free food can taste just as good as other food."

Lori said:

"Being gluten-free I think is probably the best thing that has ever happened to me just because it has opened my life up to so many different things that I never would have done or been to. It is definitely not something to be afraid of. Relating to more people, understanding myself better, it has given me just more of an incentive to you know learn the different things that are out there and cultural things like different countries that eat different foods that you know aren't gluten and its just very interesting. I am interested in more things than I think I would have been before I think."

While participants acknowledged that there were many positive aspects of the gluten-free lifestyle, they also reported many challenges. These challenges stemmed primarily from three categories—cross-contamination issues, lack of community awareness, and social stigma. Eve stated that for her, managing cross-contamination in even minimally processed foods is constant challenge. She said: “The hardest part of the gluten-free diet is trusting the labeling. What the FDA allows to be considered gluten-free and what actually *is* gluten-free are two different things. The gluten-free diet would be simple if you could trust labeling. Cross-contamination is a huge factor that is often neglected by manufacturers and food service providers.” Similarly Annie said, “It is so hard because you think you are safe with something and then we were hearing this big thing about Snyders and how they are going to start labeling things gluten-free but they aren’t really going to be...it makes me so angry because people don’t get it. You cant just take croutons out of a salad...and that has happened more than a few times...” Like Eve and Annie, Jeffrey mentioned his frustrations with the food allergen labeling system. He said: “This says GF therefore it is gluten-free or if it didn’t say GF but didn’t say wheat I thought I am in good shape and then somebody pointed out well if it is processed on shared machinery with wheat...this continues to be the hardest part.”

Veronica who has been gluten-free for multiple years acknowledged that she continues to learn about new concerns with product safety to this day. She stated: “At this point I am now 3 years plus 4 months into a gluten-free diet and I continue to learn a lot and continue to teach a lot and to find products that are labeled gluten free but aren’t. I am just amazed at how much there is to do everyday.”

In addition to being aware of what they choose to consume, participants mentioned that they also have to ward off accidental contamination from non-food products that they use and come in contact with on a daily basis such as beauty and hygienic care products. Anastasia explained: “It’s the worst in shampoo. Vital wheat protein is in like every shampoo! How does that happen?! Toothpaste even sometimes...you know and they are able to totally change those anytime. I mean you can’t just keep buying the same thing just because you used it before. They can just do whatever.” Eve emphasized: “It seems like wheat is in everything—moisturizers, lipsticks, make-up, soaps, sun blocks, hair spray...its on tables in coffee shops...it’s everywhere.”

Even when the cook at home, participants mentioned that they are constantly on the look-out for potential sources of contamination. Martina explained: “I really just cook everything myself and try to stick with fresh stuff...but I get nervous with that too. Like apples...the little stickers on apples...I always think like ‘hmmmm...I wonder’...” Most participants rarely, if ever, eat out and when they do, they know it is a risk even when ordering off a gluten-free menu because they know that the chance of contamination is extremely high. Eve explained: “Eating out will always be a risk because people don’t always realize how extremely carefully they have to handle your food to prevent cross-contamination.” Veronica stated: “I eat out. I play Russian roulette.” Rachel said: “We generally don’t eat out—ever—even at places with gluten free menus because both of us tend to get sick from contamination almost every time we do. It is always a gamble and I feel like it is usually not worth it.” Annie explained: “We

don't eat out very much. It is sort of a roulette and we hope for the best." Sandy stated: "What I trust is what I make."

As a mom, Anastasia struggles to keep her children free of contamination when they participate in social activities or group gatherings. She explained: "And that's the thing too, if she gets accidentally 'glutened' at the church potluck or whatever it will take that next whole week for her to recover and that's just not worth it...its just not."

Anastasia also mentioned that because she has always cooked from scratch and feeds her family primarily at home, transitioning to a gluten-free diet has been less of a challenge for her and her family than she suspects it is for others. She explains:

"For people who rely a lot on convenience foods...those are the people that are going to have the hardest time eating gluten-free. I have always cooked everything from scratch so for us to transition to cooking gluten-free was not that hard I mean I just switched out a few flours. It wasn't really that big of a deal. But for people who rely on packaged foods. It's a really big transition. Cause then it's like you can't buy a cake at the store anymore then you don't have cake. And that is hard for people. We have cake, we have cookies, we have muffins, and....but you know for people who have take out pizza every Friday night then their whole rhythm of life is disrupted."

All participants mentioned that the lack of community awareness about the level of sensitivity and cross-contamination was a constant struggle. Martina explained:

"Like at first it was hard because people, especially my parents, wouldn't understand and they would go out and buy all these gluten free products for me, which is really nice but it's like not really gluten free. They just didn't understand it and you feel bad and there is a guilt thing. But now like everyone knows and I guess I'm kind of getting over the guilt thing and I just kind of say this is how it is."

Annie stated: "I mean people don't think about that but kids should be able to go to a party and just have a good time and not have to worry about can I even touch the table?"

Anastasia explained: "[My kids are] really vigilant which is really great but you know

you just wonder how long it is going to last because of other people saying things like ‘oh well, one bite won’t hurt you’ or you know stuff like that. I mean even my own dad for a long time was saying that to the girls and just being like ‘oh just one bite, you’re at Papa’s house.’ No! Ahhhhh! That’s the really hard thing.”

The participants who were mothers of young children pointed out that the community’s lack of awareness presents even more challenges with cross-contamination for children. Anastasia highlighted the challenges in keeping her children contamination free when she brings them out into the community and Annie emphasized the challenges of contamination in the school and church settings. Anastasia explained:

“I wish there was like a snack ban on kids’ areas. You know you thin about all those people and goldfish crumbs everywhere! Like even at the park you can’t get away from it because somebody always has a bunch of gluten in their hands like graham crackers and goldfish or whatever! They are offering it around and their kids are dragging it all over the park...when you have a crawler putting stuff in her mouth...you have to constantly watch or you know if some kids have been playing up on the playground equipment eating snacks, then Mary can’t go up there because she can’t get her hands in all the crumbs and I can’t just like carry bleach everywhere to wipe every surface down before she touches it.”

Annie stated:

“I am glad that we home school them because trying to keep the classroom uncontaminated...I mean the play dough issue alone would have been insane in preschool...and then they will get in trouble because like we will be at church and kids aren’t supposed to get into the snacks or touch food before the meal starts but they will go in and start prepping their plate because they know if they don’t get what is gluten-free first...it is going to get contaminated. But there is always going to be a grown-up who forgets and they will yell at the kids.”

Participants also reported that they believe that the community as a whole does not recognize the seriousness of their condition. Various participants acknowledged that they were concerned that gluten-free was being treated as a fad diet. Taylor stated: “I

think that sometimes people think that I am on an Atkins Diet or something where it's like 'oh just this one carb won't hurt.'" Colleen explained: "What I appreciate about the whole gluten-free awareness stuff is that there are more products available, what I hate about it is that it is like 'oh the latest trend' and 'oh it's not serious.'" Colleen also expressed frustration with the lack of community awareness as she feels that the severity of the condition is often misunderstood. She explains: "The thing that cracks me up about the whole thing is because it is food it is not serious. Food is probably the most intimate relationship you consistently have. How does that not make sense?" Jeffrey also mentioned that he believed that society's resistance to acceptance of the condition is related to the fact that the condition's trigger is dietary. He explained:

"I think we have a tendency when things are dietary or allergy thing we tend to think of the asthmatic kid at camp and think oh its psychosomatic and just get over it you are a wuss and you know toughen up. And I think that gets very frustrating for those of us who realize how much it impacts our lives, and so I think that's why its good to hear other people say no this is real because you do you start to feel like 'oh, am I just being a wus?' And I'm not [a wuss]...well I was because I was miserable. 'I need to take a nap.' 'I don't feel good.' 'My tummy hurts.' You just start to sound like the asthmatic kid at camp that everybody hates. I become the guy that everybody hates. And then I go to restaurants, 'excuse me does this have wheat in it?' You know...oh god...and then your friends just stop inviting you out. Which is good because then you stay home and cook."

Furthermore, both Jeffrey and Colleen emphasized that they believe that the community's lack of acceptance stems from a lack of understanding within the general community about the severity of the condition. Jeffrey highlighted his perception of the general community's awareness stating: "I mean talk about intolerance, when you talk about wheat/gluten intolerance, it's like 'oh get over it.' It is so frustrating because you

want to say ‘you wouldn’t say that to somebody in a wheelchair.’ You know what I mean? It’s like if it is food related there is this sort of intolerance that occurs there.”

Colleen made a plea for increased awareness by emphasizing the severity of the consequences of contamination: “...please be respectful of food allergies because the stuff they have to go through if they are exposed to stuff...it isn’t like they are just going to have diarrhea...they wish that was all that could happen to them.”

Beyond the lack of community awareness, many participants mentioned that they perceive a similar lack of knowledge about what it means to be gluten-free within the medical community as well. Martina acknowledged this perceived deficit in awareness by again punctuating the fact that going gluten-free is more than a diet change—it is a lifestyle change. She explained:

“We hear a lot about doctors saying ‘oh just go gluten-free’ and then people walk out of their office not really knowing what that means not really realizing how huge the lifestyle change is and just thinking ‘oh I’m just not going to eat wheat and I’m going to be fine.’ That is not it at all. And I wish somebody had like sat down with me and talked to me about it. And that is like not to plug the gluten free RN but that is what she does now she offers that education that the doctors don’t because she never got that education either. And you know most people don’t. Their doctor doesn’t sit down and explain it to them.”

Rachel came to a similar conclusion: “The doctor says ‘oh you have celiac disease’ or ‘oh you have gluten intolerance’ now go out into the world and figure it out....most people don’t get any information from their doctors.”

Bess was so concerned that her physician did not understand the condition that when she changed doctors, she brought a book on her condition with her for her physician to read. Bess explained:

“I went to my new doctor that I chose and I actually took the celiac disease book in there and I asked him if he would mind reading it because

I wanted him to know about celiac disease because I wanted him to you know be my doctor and I chose him because I felt like he listens better....I don't really feel confident in my current doctor's knowledge of celiac disease. I wouldn't say he would be my first person I would go to. Mostly I am doing my own research. I mean I will continue to point out things to him."

Multiple participants pointed out that they felt like their doctors were not knowledgeable about what the next steps should be after a diagnosis was made. After receiving her diagnosis, Bess was sent to a dietician for information about the condition but Bess expressed that after her visit she felt as if she already knew more about the condition than the dietician. Bess explained: "The first doctor, the one I don't go to anymore, he said 'well, would you like to go to a dietician? You can have a visit with a dietician.' So I did that and all she really said is you have to read labels and this is how you read a label." Martina stated: "I understand that a lot of older medical professionals didn't get any training in it what-so-ever but I wish that they would be a lot more open to learning about it."

Rachel, Sandy, and Veronica's concern with post-diagnostic care focused more on a perceived lack of awareness about how to provide the body with what it needs to heal on its own. Rachel explained: "Like most people who get of gluten, they don't know that they should also have their vitamin levels checked. And that is a really big issue because you cant just correct that by stopping eating gluten. Most of the time you are so deficient that you have to have some kind of therapeutic vitamin shock treatment to get you healthy again." Sandy stated: "When you're body is that depleted and you are that sensitive to things, until you repair that intestinal lining...part of that isn't just taking you off of wheat. There should be a better way of informing you of what you need to do—what supplements you need to repair it because the faster that you repair it the less

damage will occur.” Veronica emphasized: “It has been a long process and I have seen at times three chiropractors because they all do different things...so I did some of what I call critical care healing with one chiropractor and she was fabulous. She got me through a certain stage and then I started to see other people that would help me in different areas.”

Participants noted that the lack of community awareness can, at times, be draining. Some expressed that such a lack of awareness made the validation of their suffering a constant struggle. Bess explained: “You know it’s kind of frustrating because some people go, ‘oh you’re not that sensitive...you can’t be that sensitive that you can’t use my mayonnaise that I have in my refrigerator, can you?’ Yeah. And so some people go, ‘oh you are taking it to the extreme’ but we know what we have to do.” Annie mentioned: “Explaining it more than once to the same people gets exhausting. You get angry and you get to the point where you stop wanting to do social stuff...it would be really nice if people would just remember without me having to put like a big sticker on my kid, like tape on the forehead that says ‘PLEASE DON’T FEED THE BEAR!’”

Others also expressed that a lack of community awareness presented additional challenges in daily activities. Rachel stated:

“The main thing is I wish I could safely eat at other people’s houses. I wish we could go to friends’ houses for dinner and not have to worry about what they made and how it was prepared and did they put it on the same cutting board with the bread...I wish that occasionally we could just eat out without worrying about it. That after a long day of working and we don’t want to cook dinner we could just order Chinese food or something.”

Jeffrey described his experience explaining how culture and societal values dictate the management of this condition as he lives in a wheat-dependent society. He stated: “To one of my students who is left-handed, I said ‘you know left-handed people,’ my father always tells me because he is left-handed, ‘left-handed people tend to be smarter but they also have a shorter life expectancy.’ And my student said, ‘that’s because we live in a right-handed world.’ In some ways I guess I feel like we live in a wheat/gluten world.”

Others see the lack community’s knowledge about gluten intolerance as a reflection of societal values that makes living gluten-free more challenging. Martina explained how maintaining a gluten-free diet can present challenges in social interactions, traditions, and rituals. She said:

“I think food is a really integral part of our society and our community and it brings people together and I think people feel very threatened if you don’t take part in that. So like when I first started working at a restaurant all my co-workers would be like ‘why aren’t you eating with us? Why aren’t you eating with us?’ and I would be like ‘I can’t, I can’t eat anything here.’ And they would be like ‘just have one french fry, just have one.’ And they would be like trying to force me to eat this french fry and I would be like ‘I cant eat the french fry like you don’t understand.’ It bothers people when you aren’t eating and they are. And I mean I want to eat too but you can’t. And I think that is like really threatening to a lot of people. So I think that is hard.”

Similarly Jeffrey said:

“I think eating is such a social thing in our society. If you don’t drink and you are with friends who drink or if you do drink and are with friends who don’t drink, there is sort of this....you become part of the out group and that sort of bother them because it is such a social activity...you know you find yourself getting defensive because you make certain choices in your life and your friends know you in a certain context.”

Annie emphasized the prevalence of food in social gatherings by discussing her experience with food being incorporated into nearly every social activity: “Everything is centered and surrounded by food and you can’t do anything without food. I mean it is all

about food, and everything has to be about an activity around food and why can't it be an activity where we walk together or we go do this and that together?"

After watching her daughter navigate a gluten-free lifestyle in college, Colleen state: "College has got to be the worst time socially for people with these things. You are in this environment where all this stuff is expected if you wan to be a normal person." Sandy added to her mom's statement by addressing a few of the social challenges that she faced as a gluten-free college student. She explained: "It's a nice thing to go out with people and it's a great way to get to know people too and if you don't drink really and you cant really go out to eat with people then what? Ask them to go for a walk? Yeah right!"

Annie found it frustrating to watch her young kids have to always worry about food in social interactions. She stated: "I think for the most part [my kids] are good about it but it is hard being different. It makes them kind of self-conscious. I think it embarrasses them when friends come over who aren't gluten-free to lunch or whatever because we have such different meals...they aren't bad meals they are just different meals."

Some participants emphasized the importance of their support groups, the people that they surround themselves with for support, in their ability to live gluten-free. Colleen explained: "You need a support system that is going to allow you to function and do the things you want to do...a place for you to be healthy that allows you to do the things that you want to do." Martina relies heavily on her fiancée. "My fiancée is pretty much completely gluten-free now which is really helpful and supportive." Lori's friends are conscientious about finding safe alternatives that they can all share. "My friends are very

curious about it and very supportive like if we go out the go wherever I can eat and stuff so they have been really great about it.”

Jeffrey identified the benefits of sharing his experience with other gluten intolerant individuals. He explained: “Its good to have validation particularly in a society that tends to say well you are being wimpy.”

Many participants, however, also noted that the gluten-free lifestyle has strained some of their relationships. Martina stated: “I think my friends are tired of hearing about it. Especially the ones that I am close to because like friends that aren’t as close they will ask me questions about it and so I will tell them but I can tell like my friends who are with me all the time are like ‘oh god here goes Martina again on her soap box.’ Most of my friends know about it and understand the issues...some still think I’m crazy but that’s okay.” Rachel said: “My husband at the time, my ex-husband now, was a lot less happy about it. He was not happy about me trying a gluten-free diet because if it meant that I was not going to eat gluten ever again he was not happy about not being able to go out for pizza together or you know that sort of stuff but I mean when it turned out that [I really am gluten intolerant] he was very supportive...but he was more resistant.” Eve mentioned: “It changes your social life because it is something that people do regularly like going to your friends house for dinner—so that is hard—but people adjust.”

While their health presented challenges in their social life, many participants also noted how their gluten intolerance has actually helped them to form new relationships.

Anastasia explained:

“We meet friends at church who are also gluten-free—their whole family—and it is so exciting for us to get together. When she brought her kids over here the first time...the baby was crawling around and eating some gluten-free cheerios off the floor and she had that moment you could

just see she had that moment of panic and the she was like oh everything is safe here. Wouldn't it be amazing if everywhere you went you didn't have to have those constant moments of panic where you worry about what has gotten into their mouths?"

Annie stated: "What is such a great thing about going to our other gluten-free friends'...[the kids are] able to just play with their friends and run to the table and grab something without having to stop and ask." Jeffrey shared:

"People who aren't wheat/gluten intolerant tend to get annoyed or they are like 'oh how interesting' or 'sucks to be you' and then they will say like 'oh, you should meet so and so.' I was at a party and then this woman came up, I didn't know her, and she grabbed my arm practically like I was a relative and was like 'you too?!'" And then you get into this really interesting thing where you share your story...you find a commonality that is important because it affected your life so dramatically. Its not just like oh yeah I cant eat this or I cant eat that. It is this realization that it is real and it reaffirms importance of it when you meet somebody else who has gone through it."

When asked what they would like the next step to be in the gluten-free community, participants most commonly mentioned tighter food labeling regulations.

Sandy stated: "What worries me too about too many gluten-free products is that people improperly label." Jeffrey requested increased regulation from the FDA. He explained:

"I have a friend who is so deathly allergic to peanuts that he doesn't eat in restaurants. Can you imagine a product that said completely peanut-free and then it kills them...then there would be litigation...but when you feel terrible and your life is messed up for two months, they don't see it as a that big of a deal...I would like to see the FDA get a little more, particularly because I think it is an ethical issue, being a little bit more policing so that these terms can't just be thrown on and misrepresented."

Bess mentioned: "I would also like to see the labeling law make them use gluten as an allergen instead of wheat. Just take it the extra step all the way to the gluten, right there, 'contains: gluten,' so we don't have to read every little fine print thing that is on the package. How hard is it for them to set up their bag printing to say gluten-free or not."

Annie stated: “Food labeling is still a joke. I usually rely on other people because I can’t call everything. Our policy is we just pass if we don’t know.”

Both Bess and Rachel emphasized the level of sensitivity that needs to be considered in the regulation of food labeling by acknowledging the problems that dry gluten in the facility can present. Rachel stated: “Flour in the air is really, really, really bad. I mean I own a gluten-free bakery and flour gets everywhere on everything I mean you can’t really have flours in your bakery and not have contamination or in your restaurant.” Bess explained: “If it is in a facility that is doing some dry commercial cereals or something, I don’t see how they can get that out of the air. It is almost like okay we’ll just say that it is gluten-free then more people will buy it and we will make money.”

Some participants also hope for a social change that is less centered around food and thus more accepting and accommodating for everyone with food allergies and intolerances. Annie stated: “It would be really nice if there was enough awareness not just for celiac but for kids with food issues if everything didn’t have to be about food.”

Many also think that the next step should be focused on an increased awareness in the medical community. Rachel requested increased testing by saying: “I think it should be a screening that happens with kids...I mean you aren’t going to catch it all...first of all we need better tests...but you know they [would] catch way more than is being caught right now here in the US. And then I think that doctors should immediately recommend people for a nutrient deficiency analysis.” Martina requested increased awareness in the MD educational curriculum: “I would like to see all medical professionals get at least one nutrition class because right now MD schools don’t teach any nutrition at all.” Lori

requested an increased awareness within the medical community because she believes the demand and necessity should be enough of a driving force. She stated: “I think this is something that people need to know more about because I think that a lot of people are you know suffering and you know this could be the solution to it.” Veronica requests that gluten intolerance be considered more often within the medical community as a differential diagnosis. She stated:

“The doctors don’t want to diagnose celiac disease because there is no pill for it...we are a profit driven healthcare system in this country so the only way they make money is if people are sick. The only way they can make money for the hospital is if they do a lot of testing. I feel that celiac disease should be in the differential diagnosis no matter what you go see your doctor for not just chronic diarrhea which is one of the only things they look for.”

Whether participants hope for a future social or medical paradigm shift, the universal theme extrapolated from this portion of the interviews is that an increased awareness will reduce challenges associated with gluten intolerance and will work to make the community more accepting of and safe for the gluten intolerant among us.

Chapter 6

Discussion

Those who are gluten intolerant and living in a wheat-dependent society experience potentially preventable hardship both pre- and post-diagnosis. Currently, the presentation of the condition in the scientific literature does not match the lived experience exposed by the illness narratives collected for this study. In this section, I address this discontinuity and evaluate its effects on society's awareness of gluten intolerance from the perspective of study participants.

The current scientific literature on gluten intolerance is limited and presents an incomplete picture of the entire spectrum of the condition. The majority of the published literature focuses on classical celiac disease and, for the most part, fails to even recognize non-celiac gluten intolerance. When non-celiac gluten intolerance is mentioned, it is not the focus of the study and is often referred to as gluten sensitivity, a term with a weak and less serious connotation than celiac disease. In addition, only recently has non-classical gluten intolerance begun to appear in the scientific literature. As mentioned previously, the current scientific literature defines gluten intolerance haphazardly often interchanging the terms gluten intolerance and celiac disease. Therefore, without acknowledging celiac disease as a specific subset under the gluten intolerance umbrella, the scientific literature makes it easy to assume that an individual is not gluten intolerant if that individual does not have celiac disease. This error in understanding is a common misconception in both the western biomedical community and the general population. Furthermore, non-classical celiac disease, the presentation of celiac disease that is now clinically more prevalent than classical celiac disease, is less prevalent in the scientific literature than

classical celiac disease. Such disproportionate coverage creates an incomplete picture and contributes to widespread misunderstanding and missed diagnoses.

Why is there an absence of information on non-celiac and non-classical celiac gluten intolerance in the western biomedical literature? There are three primary factors that contribute to such an imbalanced presentation. First of all, celiac disease is defined specifically as an autoimmune disorder, and is thus, used as a model for studying other autoimmune disorders. Celiac disease is a useful model for the study of other autoimmune conditions because: 1) it has a known environmental trigger (gluten), 2) genetic markers associated with the condition have been identified, and 3) the celiac lesion and various serological abnormalities are known and are observable consequences of the condition allowing for a clear separation of celiac/non-celiac participants. This last point brings us to a second contributing factor leading to the imbalanced presentation within the scientific literature. Non-celiac gluten intolerance lacks the ability to identify controls for the experiment. Because there are currently no consistently identifiable markers for non-celiac gluten intolerance, experimental design is challenging. Finally, financial opportunity dictates research in the present pill-based, for-profit health care system. Currently there is little financial incentive to finance research on gluten intolerance, and as a result, the funding is not available.

The lack of sufficient methods of testing presents an additional hurdle that interferes with the establishment of non-celiac gluten intolerance awareness. As mentioned above, there are currently no reliable testing methods for non-celiac gluten intolerance. It is therefore difficult to gather quantitative “evidence” of non-celiac gluten intolerance beyond reported alleviation of symptoms upon removal of gluten from the

diet. Society currently struggles to recognize patient reported improvements in wellness as sufficient evidence of a serious condition. This is especially true if the condition lacks a definite title or label.

It has been well documented that western biomedical schools spend very little time on celiac disease and even less, if any, on non-celiac gluten intolerance (citation). Assuming that physicians then get their knowledgebase about gluten intolerance from the clinical and scientific literature, it is likely that physicians are not receiving sufficient information about the condition.

In this study, the majority of the participants focused their pre-diagnostic discussion on their perceptions of physician awareness and knowledge about gluten intolerance. Participants identified multiple factors that they believed to have contributed to their frustrating diagnostic process including, but not limited to, inability of physicians to recognize non-classical symptom presentation, lack of physician trust/belief in what the patient was experiencing, failure on the behalf of the physician to search for a root-cause of ailments, and lack of recognition of insufficient methods of testing, all of which can be contributed to a general lack of physician awareness and knowledge about gluten intolerance. The absence of non-celiac gluten intolerance and non-classical celiac gluten intolerance in the scientific literature supports these participant drawn conclusions.

If the above assumption is correct and physicians are unable to get sufficient information about gluten intolerance from the scientific literature and are not receiving adequate training about the condition in western biomedical school, how can physicians be well informed about the condition? This study serves as a preliminary study that highlights the lack of physician knowledge as seen from the perspective of the patient.

Future studies are needed that include western biomedical practitioners in order to determine if the participants' perceptions of the physicians' gluten intolerance knowledgebase matches the physicians' knowledge about the condition.

Unfortunately, the lack of awareness about gluten intolerance does not end with the physician. The lack of awareness within the western biomedical community translates into a lack of awareness in the general population. If the health professionals who are the perceived experts do not recognize the condition, society as a whole will struggle to accept the condition. Societal perceptions are often a direct reflection of western biomedical perceptions. This translation was evident in this study during the post-diagnosis discussions.

Participants identified society's dependence on food-centered social activities as one of the greatest challenges in living in a wheat-dependent society. When the majority of social interactions involve food, a lack of awareness of non-gluten intolerant individuals is isolating for those who are gluten intolerant and often results in social pressures and emotional distress. Such a lack of understanding has the potential to alter social dynamics, contributing to relational tensions, interpersonal stress and reduced social support for those who are affected. There is little information in the popular literature that addresses this concern. Furthermore, the information that is available in the popular literature is often misleading and incorrect, fostering many of the misconceptions associated with the condition. Popular literature that provides non-gluten intolerant individuals with *accurate* information that helps them to better understand what it is like to be gluten intolerant in today's wheat-dependent society is needed.

The lack of awareness within communities creates additional problems for those who discover that they are gluten intolerant without medical testing or after receiving negative test results. Participants expressed that when their tests came back negative, they faced questioning, disbelief, and skepticism from both the western biomedical and general communities. Such doubt created additional challenges in finding support from peers and caused emotional distress as participants were forced to constantly defend their position. These additional challenges again exemplify society's reliance on quantitative data, as well as society's dependence on the western biomedical community for analysis.

In addition to the social implications of gluten intolerance post-diagnosis, participants expressed a constant struggle with finding foods that are safe for them to consume. Participants uniformly stated that the gluten-free diet would not be very challenging if cross-contamination was not a concern. Many participants stated that other people often doubted their level of sensitivity to contamination, making it difficult to determine the safety of foods that they did not prepare themselves. They also often mentioned that they felt non-gluten intolerant individuals did not understand all the steps that need to be taken in order to ensure that their food is prepared for them in a manner that is safe for them to consume. This lack of safety then resulted in changes in the participants' social behavior. Many participants no longer eat out or eat at friends' houses. Some participants mentioned that social opportunities could improve with greater awareness and understanding.

Confounding the challenges presented by a lack of general community awareness is a lack of awareness and regulation within the food services industry. Presently the FDA defines "gluten-free" as any product containing less than 20 parts per million (ppm)

of gluten. This limit was not set based on a determined level of gluten consumption for sensitive gluten intolerant individuals. Instead this limit was put in place based on food testing technologies available in year; 20 ppm was a limit that the FDA thought was consistently attainable and reliably detectable. Multiple participants expressed their frustration with “gluten-free” foods not being truly gluten-free and put increased awareness and regulation in the food service industry at the top of their wish list.

As reported by participants, a lack of community awareness presented continued challenges post-diagnosis as they continue to live in a wheat-dependent society. The absence of community awareness presents significant challenges in managing social interactions, as well as in identifying contamination-free foods. Again, this study serves as preliminary research that identifies a lack of community awareness as perceived by the participants. Further studies are needed that incorporate non-gluten intolerant participants in order to more accurately evaluate community understanding and awareness.

Chapter 7

Conclusion

In this thesis, I have argued that the western biomedical community as a whole lacks a complete understanding of the entire spectrum of gluten intolerance, and that the information about gluten intolerance in published literature does not match the lived experience. Based on interviews with gluten intolerant individuals, I have gathered data that exposes the experiences of these participants on their journey to a gluten-free lifestyle and have identified common challenges that the participants faced both pre- and post-diagnosis.

During the discussions about their pre-diagnostic experiences, participants identified a perceived deficit in physician knowledge about all forms of gluten intolerance. These participants attributed their long and frustrating diagnostic processes to their physicians' lack of knowledge about gluten intolerance. Many had undergone unnecessary surgeries, invasive procedures, prescriptions, and chronic systemic damage before receiving a diagnosis. In addition to pre-diagnosis challenges related to lack of physician knowledge, participants simultaneously faced poor physical and mental health and a decreased quality of life. Participants recognized that this decreased quality of life affected their ability to do their jobs, go to school, exercise, form and maintain relationships, communicate effectively, and actively participate as a member of society. Participants noted that they believe an increased awareness in the western biomedical community will improve the diagnostic process, preventing unnecessary procedures and associated patient suffering.

Challenges that participants' identified in the post-diagnosis portion of the interviews were often related to a general lack of community awareness. Participants connected this lack of community awareness to increased social stigma, emotional fatigue, relational tension, and chronic frustration. Most participants noted that the change in diet resulted in further lifestyle changes that ultimately resulted in various alterations of their social rituals and interactions. These participants acknowledged that the gluten-free diet was more than a change in eating habits; it entailed a complete change in lifestyle. Furthermore, all participants mentioned that one of their greatest challenges in living a gluten-free lifestyle continues to be identifying safe gluten-free foods that are free of possible cross-contamination. Many gluten intolerant individuals are so sensitive to contamination that trace amounts not detectable by the human eye can cause weeks, if not months, of health consequences. Participants connected the lack of community awareness to their challenges in finding safe, contamination-free food.

Until the western biomedical community acknowledges the dire consequences of untreated gluten intolerance in all forms, society will continue to view the gluten-free diet as nothing more than a choice or a fad rather than a necessary lifestyle change. For this reason, I propose that future studies focus efforts on increasing awareness within the western biomedical community. By increasing physician awareness, many of the challenges identified by the participants both pre- and post-diagnosis have the potential to be reduced. Increased physician awareness will directly reduce the pre-diagnostic challenges by aiding in future diagnoses and may eventually, indirectly lessen the identified post-diagnostic challenges. Because physicians hold positions of authority in our culture, their improved awareness and sanctioning of gluten intolerance as "real" are

crucial steps toward increasing community awareness and acceptance. Increased community awareness has the potential to increase society's acceptance of gluten intolerance and reduce social stigma. Greater consumer awareness also has the potential to demand and enforce greater regulations and restrictions on gluten-free food processing. By increasing physician awareness, community awareness will follow and ultimately, a safer environment will be created for those who must live gluten-free.

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Appendices

Appendix A

Appendix B

Sample Interview Questions

Before we begin, I would just like to remind you that if at any point during this interview we come to a question that you are uncomfortable answering, we can skip the question.

Also, if you should begin to feel emotionally overwhelmed or distraught during this process, we can end the interview immediately.

Do you have any questions about the informed consent document before we begin?

Let's start off by going back to the beginning. When did you notice that you were not feeling well?

What were you doing at the time in your life?

Had you experienced any significant stress during that time?

What did your daily routine and diet look like?

How did your health affect your life prior to diagnosis?

Did you feel like your health was holding you back in any way?

What were you experiencing, both emotionally and physically, when you were not feeling well?

At what point did you seek medical attention?

What symptoms were you experiencing at this time?

Were you diagnosed as gluten intolerant by this same physician that you originally saw?

Did they refer you to any specialists?

What tests were performed? What were the results?

How many medical professionals did you see before you were diagnosed?

How long were you unwell before you were diagnosed?

How would you describe this process of diagnosis?

Emotionally, how did this process affect you?

What was your doctor's initial response to the symptoms that you presented with?

Did your doctor suggest a gluten free diet to you?

What was your initial response to the idea of going gluten free?

How did you feel after going gluten free?

Did you feel confident in your doctors' knowledge about gluten intolerance?

What were your doctors' reactions to your physical response to a gluten free diet?

What was your doctor's official diagnosis (if any)?

Did you do any research on your own?

Had you heard of gluten prior to your diagnosis?

Did any of your symptoms persist?

What did you find most frustrating about the new diet?

How strictly did you stick to the diet at first?

Do you feel in any way limited by this diet?

How long did it take to notice a change in your health after you started your diet?

What resources did you use to learn how to live gluten free?

How often are you contaminated?

What symptoms come back upon contamination?

What have you learned about your body from this experience?

Did this experience strengthen or weaken your trust in the medical community?

How has the gluten free diet affected/changed your life?

How long have you been gluten free?

Have you discovered that you have any other intolerances or allergies other than gluten?

What is your life like now?

Do you have any family members that you know are gluten intolerant as well?

What was your family's reaction to your diagnosis?

What are a few of your favorite gluten free resources?

Are you a member of a gluten intolerant support group?

Do you know other people who are gluten intolerant as well?

Appendix C

Participant Reported Symptoms

Anastasia

Digestive

Abdominal pain

cramping

diarrhea

enamel defects in teeth

lactose intolerance

other food intolerances/allergies (dairy)

reflux

vomiting

Skin

eczema

hives

rashes

itchiness

redness

dark circles under eyes

Physical Well-Being

fatigue

weight loss

inability to gain weight

Mind/Neurological

insomnia/difficulty sleeping

Musculoskeletal

short stature

Respiratory

Asthma

congestion

shortness of breath

wheezing

Ivan (1), Annie (2),

Biddy (3), Ferolinand (4), Blue (5), Valentine (6)
As Reported by Annie

Digestive

Abdominal pain 1,2,3,4,5,6
 aphthous ulcers 1
 autoimmune hepatitis (grandmother)
 bloating 1,2,3,4,5,6
 canker sores 1,2,3,4
 colon cancer (great-grandfather)
 constipation 2,3,5
 cramping 1,2,3,4,5
 diarrhea 1,3,5,6
 dyspepsia 1,2,3
 enamel defects in teeth 1,3,4
 encopresis 3,4,5
 excessive burping 1,3
 gas 1,2,3,4,5,6
 heartburn 1,2,3
 intestinal bleeding 2
 nausea 1,2,3,4,5
 occult blood in stool 2,3
 pancreatitis (paternal family history)
 primary biliary cirrhosis (maternal family history)
 reflux 1
 sore throat, chronic 2
 steatorrhea – fatty stools 2,3
 vomiting 1

Skin

Acne 1,2
 Eczema 2 (maternal family history)
 dry skin 2,3
 hives 2
 rashes 2
 itchiness 2,3
 dark circles under eyes 1,2,3,4,5,6

Pernio 2

alopecia areata – hair loss 2

Emotional

Anxiety 1,2,3

Irritability 1,2,3,4

Depression 1,2,3

ups & downs 1,2,3,4,5

Physical Well-Being

Fatigue 1,2,3,4,5

weight loss 1,3,4

weight gain 2

poor endurance 1,2,3,4

inability to gain weight 4

chronic fatigue 2

Mind/Neurological

Autism (family history)

ADHD 1,2,3

difficulty concentrating 1,2,3

mental fog 1,2,3

insomnia/difficulty sleeping 1,2,3

ataxia/difficulty with balance 3,4

Musculoskeletal

Fibromyalgia 2 (family history)

muscle aches 1,2,3

joint pain 1,2,3

osteoporosis (family history)

short stature 3,4 (family history)

Respiratory

Asthma 1,2,3

chronic sinusitis 1,2

congestion 1,2,3,4

wheezing 2,6

Reproductive health

irregular cycle 2

infertility 2

heavy period 2

miscarriage 2 (3 miscarriages)

Head

Headaches 2

Migraines 2

alopecia areata (hair loss) 2

Miscellaneous

Anemia 2,4

iron deficiency 2,4

vitamin B12 deficiency 2,4

Raynaud's syndrome 2

Malignancies/Cancer

colon cancer (paternal family history)

Serological Tests

Anti-Gliadin Antibody (AGA) 1 (Borderline), 3 (inconclusive), 4 (off the chart)

Bess

Digestive

Abdominal pain (occasional)

aphthous ulcers

 bloating

 cramping

 dyspepsia

enamel defects in teeth

 esophagitis

 gas

 GERD

 heartburn

 lactose intolerance

 reflux

 steatorrhea – fatty stools

 villous atrophy

Skin

 dry skin

itchiness

dark circles under eyes

cutaneous vasculitis (family history?)

erythema nodosum (family history)

behcet's disease

Emotional

anxiety

irritability

depression

ups & downs

Physical Well-Being

fatigue

weight loss

weight gain

Mind/Neurological

difficulty concentrating

mental fog

insomnia/difficulty sleeping

peripheral neuropathy (numbness/tingling of hands or feet)

Musculoskeletal

arthritis

fibromyalgia (suggested at age 24)

muscle aches

joint pain

polymyositis

Respiratory

chronic sinusitis

shortness of breath

Reproductive Health

infertility (trouble getting pregnant first time)

heavy period

light period

delayed start of menstruation

premature menopause

miscarriage (tubal ligation)

Head

headaches

migraines (some)

Autoimmune Disorders

Addison's disease (symptoms of)

hypothyroidism, autoimmune

villous atrophy

Miscellaneous

Anemia (sometimes)

iron deficiency (sometimes)

vitamin B12 deficiency (maybe)

pulmonary hemosiderosis

Serological Tests

Anti-Gliadin Antibody (AGA) IgA and IgG - Positive (both IgA and IgG)

Endomysium Antibody (EMA) Testing - Positive

Tissue Transglutaminase (tTG) Antibody Testing - Positive

Tissue Biopsy

Small Intestine Biopsy – Positive (with signs of recovery – three months later)

Colleen

Symptoms list not returned in time for publication.

Eve

Digestive

colon cancer (family history)

lactose intolerance (family history)

Emotional

anxiety

Physical Well-Being

fatigue

weight loss

Mind/Neurological

insomnia/difficulty sleeping

Musculoskeletal

arthritis
 joint pain
 muscle stiffness
 osteopenia
Autoimmune disorders
 Graves' Disease
Malignancies/Cancer
 colon cancer (family history)

Jeffrey

Symptoms list not returned in time for publication.

Lori

Digestive
 Abdominal pain
 bloating
 gas
 diarrhea
 IBS
 lactose intolerance
 nausea
 other food intolerances/allergies (dairy)
 mouth sores
Skin
 acne
 depigmentation
Emotional
 depression
Physical Well-Being
 weight gain
 chronic fatigue

Mind/Neurological

difficulty concentrating

mental fog

ataxia/difficulty with balance

peripheral neuropathy (numbness/tingling of hands or feet)

tremor

Musculoskeletal

rheumatoid arthritis (family history)

muscle aches

joint pain

loss of strength

Reproductive Health

delayed start of menstruation

Autoimmune Disorders

hypothyroidism, autoimmune (family history)

Miscellaneous

vitamin B12 deficiency

vitamin D deficiency

Martina*Digestive*

Abdominal pain

Ulcers (paternal grandmother and grandfather)

bloating

canker sores

constipation

cramping

enamel defects in teeth (sister)

esophagitis (father)

gas

GERD (father)

gastroparesis

heartburn (father)

intestinal bleeding (doctor said it was from the meds)

IBS - brother

nausea

reflux - father

sore throat, chronic (white spots!)

vomiting

Skin

acne

dark circles under eyes

erythema nodosum

alopecia areata – hair loss

Emotional

anxiety

irritability

depression

ups & downs

Physical Well-Being

fatigue

weight loss

poor endurance

chronic fatigue

failure to thrive

short stature (compared to the rest of my family)

Mind/Neurological

difficulty concentrating

mental fog

peripheral neuropathy (numbness/tingling of hands or feet) (two left toes)

Musculoskeletal

arthritis

muscle aches

joint pain

loss of strength

short stature

Respiratory

shortness of breath

Reproductive Health

irregular cycle

light period

miscarriage (mother)

Head

migraines (sister, maternal grandmother, two uncles)

Autoimmune Disorders

sarcoidosis

Miscellaneous

anemia

Serological Tests

Anti-Gliadin Antibody (AGA) IgA or IgG – Positive (stool)

Endomysium Antibody (EMA) Testing – Positive (stool)

Tissue Transglutaminase (tTG) Antibody Testing – Positive (stool)

Genetic Testing - Positive

Nicki

Digestive

Abdominal pain

bloating

canker sores

constipation

cramping

diarrhea

elevated liver enzymes

enamel defects in teeth

gas

heartburn

intestinal bleeding

IBS

lactose intolerance

nausea

occult blood in stool

other food intolerances/allergies (melons, pineapple, tomatoes, mangos, cashews, milk)

reflux

sore throat, chronic

vomiting

Skin

dry skin

hives

rashes

itchiness

psoriasis welts

redness

dark circles under eyes

alopecia areata – hair loss

Emotional

anxiety

ups & downs

Physical Well-Being

fatigue

weight loss

weight gain

poor endurance

chronic fatigue

failure to thrive

Mind/Neurological

difficulty concentrating

mental fog

insomnia/difficulty sleeping

ataxia/difficulty with balance

peripheral neuropathy (numbness/tingling of hands or feet)

Musculoskeletal

muscle aches

joint pain

loss of strength

Respiratory

asthma

congestion

shortness of breath

wheezing

Reproductive Health

irregular cycle

heavy period

premature menopause

Head

headaches

migraines

alopecia areata (hair loss)

Autoimmune disorders

hypothyroidism, autoimmune

Miscellaneous

iron deficiency

vitamin B12 deficiency

vitamin K deficiency

folate deficiency

cystic fibrosis

Serological Tests

Anti-Gliadin Antibody (AGA) IgA or IgG - Positive

Endomysium Antibody (EMA) Testing - Positive

Tissue Transglutaminase (tTG) Antibody Testing – Positive

Rachel

Digestive

Abdominal pain

bloating

constipation

cramping

diarrhea

excessive burping

gas

GERD

IBS

lactose intolerance

nausea

occult blood in stool

sore throat, chronic

Skin

dark circles under eyes

Emotional

anxiety

depression

Physical Well-Being

fatigue

Reproductive Health

heavy period

Miscellaneous

vitamin B12 deficiency

Raynaud's syndrome

Sandy

Digestive

Abdominal pain

bloating

constipation

cramping

diarrhea

elevated liver enzymes

enamel defects in teeth

gas

other food intolerances/allergies (please specify: dairy, peanuts, eggs, almonds, latex)

Skin

dermatitis herpetiformis

hives

rashes

itchiness

Emotional

anxiety

Physical Well-Being

fatigue

chronic fatigue

Mind/Neurological

mental fog

insomnia/difficulty sleeping

peripheral neuropathy (numbness/tingling of hands or feet)

Musculoskeletal

joint pain

loss of strength

Respiratory

asthma

congestion

shortness of breath

Reproductive health

irregular cycle

delayed start of menstruation

Head

headaches

Autoimmune Disorders

villous atrophy

Miscellaneous

anemia

iron deficiency

vitamin B12 deficiency

vitamin K deficiency

folate deficiency

Veronica

Digestive

Abdominal pain

aphthous ulcers
bloating
canker sores
colon cancer
constipation
cramping
diarrhea
dyspepsia
enamel defects in teeth
encopresis
excessive burping
fructose intolerance
gas
GERD
heartburn
IBS
lactose intolerance
nausea
other food intolerances/allergies (garlic)
reflux
sore throat, chronic
steatorrhea – fatty stools
villous atrophy (don't know for sure, but assume)
vomiting
Skin
acne
eczema
dermatitis
dermatitis herpetiformis
dry skin
rashes
itchiness
psoriasis welts
redness
dark circles under eyes
urticaria

hereditary angioneurotic edema

cutaneous vasculitis

alopecia areata – hair loss

ichthyosiform dermatoses

Emotional

anxiety

irritability

depression

ups & downs

Physical Well-Being

fatigue

weight gain

poor endurance

inability to gain weight

chronic fatigue

Mind/Neurological

autism

ADHD

difficulty concentrating

cerebellar atrophy

mental fog

insomnia/difficulty sleeping

ataxia/difficulty with balance

peripheral neuropathy (numbness/tingling of hands or feet)

Musculoskeletal

arthritis

fibromyalgia

rheumatoid arthritis

muscle aches

joint pain

osteoporosis

osteopenia

osteomalacia

loss of strength

multiple sclerosis

Respiratory

asthma

chronic sinusitis

congestion

shortness of breath

wheezing

Reproductive Health

irregular cycle

heavy period

premature menopause

Head

alopecia areata (hair loss)

Autoimmune Disorders

Graves' disease

secondary hyperparathyroidism

sarcoidosis

Sjogrens syndrome

thyroiditis

villous atrophy

Miscellaneous

anemia

iron deficiency

vitamin B12 deficiency

vitamin K deficiency

folate deficiency

Raynaud's syndrome

Serological Tests

Anti-Gliadin Antibody (AGA) IgA or IgG - Negative

Endomysium Antibody (EMA) Testing - Negative

Tissue Transglutaminase (tTG) Antibody Testing - Negative

Tissue Biopsy

Skin Biopsy - Negative

Genetic Testing

HLA-DQ2 - homozygous