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# Searching for Validation: An Analysis of the Experience of Non-Celiac Gluten Sensitivity (NCGS)

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Searching for Validation:

An Analysis of the Experience of Non-Celiac Gluten Sensitivity (NCGS)

By

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\* \* \* \* \*

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of the requirements for

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## ABSTRACT

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The prevalence of gluten free diets has skyrocketed in recent years. The food industry has taken notice with a market projected to grow to \$7.59 billion by the year 2020. Adhering to a gluten free diet has become easier to follow than ever before. There are a variety of reasons for going gluten free. The majority of individuals choosing a gluten free diet are those trying to lose weight or, more broadly, attempting a healthier lifestyle. Yet others have no choice in the matter and must exclude gluten due to medical diagnoses, such as those suffering from celiac disease and wheat allergies. In addition, a growing number of patients claim to suffer from “Non-Celiac Gluten Sensitivity” (NCGS).

Despite the significant increase in those claiming gluten sensitivities, there is minimal discussion regarding this phenomenon in the social science literature. In general, little is known about NCGS, yet patients have persuasive claims of severe discomfort that is relieved following the elimination of gluten from their diet. Scientists acknowledge a biological component to NCGS, but currently lack the ability to identify a conclusive etiology. Therefore NCGS remains an illness without a disease. Those who suffer from illnesses without a known cause find it to be more socially problematic than individuals whose conditions have a clear pathology. People with NCGS frequently must seek diagnosis and treatment beyond the physician’s office and feel the need to define themselves as “real gluten free”. My participants are not only quick to separate themselves from the gluten free diet fad, but rather actively critique it, claiming it delegitimizes those who have genuine gluten related disorders. Thus, this paper examines the experiences of individuals suffering from NCGS and their desire to medicalize their condition.

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## **Chapter 1: Introduction/Literature Review**

### **Introduction**

The prevalence of gluten free diets has skyrocketed in recent years. As of January 2013, about 30 percent of adults claim to cut down or avoid eating gluten entirely (NPD Group, 2013). This number of people is greater than ever before. Paralleling this trend has been the increase in celiac disease diagnoses. In 2003, a large epidemiological study found that 1 out of every 133 Americans has the disease, a number that shocked medical professionals (Moore, 2014). Since this finding, there has been an increase in attention to gluten elimination diets. The food industry has followed this progression, creating a near \$2.5 billion market (Sapone et al., 2012). By 2020, the market is projected to grow to \$7.59 billion (Bender, 2017). The percentage of food sales in the United States attributed to gluten free items rose from 2.8 percent to 6.5 percent from just 2013 to 2015 (Bender, 2017). More specifically in the restaurant industry, the incidence of Americans ordering a gluten free item off of the menu has more than doubled between 2009 and 2013 (NPD Group, 2013). The food industry has capitalized on the ever-increasing desire to avoid gluten by offering more and more food options. Going gluten free has become easier than ever.

There are a variety of reasons for becoming gluten free. Some people suffer from celiac disease, which is an autoimmune disease that attacks the lining of the digestive system, breaking down its ability to properly absorb nutrients and minerals (Copelton & Valle, 2009). Although much rarer, some people suffer from a wheat allergy similar to any other allergy such as peanuts. Wheat allergies affect 0.4 percent of the population and involve skin, respiratory and gastrointestinal symptoms, which categorize it as a “true allergic response” (Klein, 2014). A

third group of gluten free dieters include those who are trying to lose weight or, more broadly, attempting to be healthier. This idea has been fueled by the promotion of gluten free diets in publications such as *Wheat Belly; Lose the Wheat, Lose the Weight* (Koning, 2015). The final reason for becoming gluten free that I will focus on is referred to as non-celiac gluten sensitivity (NCGS). There is not much known about NCGS in the literature but researchers have begun to investigate this increasingly reported phenomenon. These patients have persuasive claims of severe discomfort and relief once eliminating gluten from their diet (Catassi, 2015). However, it is difficult to diagnose and is largely identified through process of elimination. Scientists acknowledge the lack of certainty related to the biology behind NCGS, but progress is still being made. The *Annals of Nutrition and Metabolism* published an article showing a clear cause and effect relationship between the ingestion of gluten and the appearance of symptoms. The experiment was double blind and placebo-controlled, proving the legitimacy of the concerns of NCGS sufferers (Catassi, 2015).

Despite the growing number of people who are claiming gluten sensitivities and adopting a gluten free diet, there is minimal discussion regarding this phenomenon in the social science literature (Moore, 2014). Those who suffer from food intolerances find it to be more socially problematic than individuals who are pathologically legitimized (Nettleton et al, 2010). Therefore, it is important to attempt to further understand the sociocultural phenomenon at place. Due to the increasing popularity of gluten free diets, I initially wanted to examine this choice and understand how it became a fashionable health trend. However, I realized that my participants were not only quick to separate themselves from the fad, but rather actively critique it.

Those who do not suffer gastrointestinal issues as a result of ingesting gluten, and choose to adopt gluten free diets as a popular lifestyle choice, contribute to the perception that going

gluten free is an optional health alternative as opposed to a necessary dietary regimen needed for symptom relief. For NCGS sufferers, the dietary restriction is considered necessary for improving their gastrointestinal issues and in many cases, relieving feelings of haziness and joint pain. Those with NCGS tend to view a gluten free diet not as a choice, but as a necessity. Yet they perceive fad dieters as discrediting or undermining their claims to a gluten intolerance. Thus, those suffering from NCGS desire to dissociate themselves from fad dieters, and wish to have their suffering acknowledged as a medical condition, yearning for the legitimacy that accompanies biomedical recognition. Therefore, this thesis examines the experiences of individuals suffering from NCGS who find it to be more socially problematic than conditions that have a clear pathology. They have a desire to medicalize the condition to alleviate stresses of validation in order to focus on the healing process. I also explore how they came to become diagnosed, and their attempts receive guidance and/or help others in the community by suggesting NCGS as a potential reality.

## **Literature Review**

A vital component to any society is the food that its members consume. Some food items remain staples in a diet while others go in and out. There are often events or scientific findings that influence the direction and duration of these trends. The fear of fat in the 1990's was the result of inadequate scientific evidence and understanding leading to the creation of the first dietary guidelines in America (Aubrey, 2014). This went so far as the Surgeon General's Office declaring fat "the single most unwholesome component of the American diet" (Taubes, 2001, p. 1). Fat was pinpointed as the villain; any way that fat could be eliminated was seen as a positive choice (Aubrey, 2014; Taubes, 2001). The food industry got on board with this notion quickly,

but they still had to make their products taste good so that consumers would continue to buy them. The solution was simple: remove fat and add sugar (Aubrey, 2014). Although the original intention of the dietary guidelines was to reduce heart disease, it consequently provoked other health conditions of worry. Researchers now suggest opting for “good” fats with less of a focus on “bad” saturated and trans fats (Fats and Cholesterol, 2016). Whereas there used to be no distinction in type of fat, today consumers are far more aware of the differences between an avocado or almond and a greasy bag of potato chips.

In line with the recommendation to avoid fat is the egg scare that occurred around the same time period. The problem, as with other high fat foods, had to do with a very black and white approach as opposed to looking at the food in its entirety. Eggs were scrutinized for their high cholesterol content, however moderate egg consumption has more recently been found to have no association with heart disease in healthy individuals (Eggs, 2017). The cholesterol found in an egg has less of an effect on a person’s harmful cholesterol than previously thought. Impacting poor health of our bodies far more are saturated and trans fats (Eggs, 2017). As with the fear of fat in America, eggs maintained a bad reputation for many years. These fads were propagated due to incomplete scientific evidence after an attempt to eradicate heart disease (Aubrey, 2014). Similarly, the increase in gluten free diets that emerged after the increase in celiac disease diagnoses in 2003 has contributed to yet another dietary fad (Copelton & Valle, 2009; Moore, 2014). A current gap in the scientific knowledge exists regarding the impact of gluten on the body. While there is definitely a fad component to gluten free diets for perceived health purposes, gluten differs from fat and eggs in the sense that the scientific community acknowledges their limited comprehension rather than succumbing to oversimplification. The areas that are highly researched, though, can be confidently reported without misleading

consumers. As opposed to gluten free dieters, gluten sensitivities are not just a trend. Sufferers see real results, as opposed to the fat free trend that resulted in increased rates of obesity and diabetes (Aubrey, 2014).

### **Gluten Related Disorders in Context**

In order to analyze the social implications of gluten free diets, we first need to understand what exactly gluten is and the types of restrictions that it puts on people. Gluten is a mixture of storage proteins present in the seeds of wheat, barley, and rye. The gluten provides nutrition for the seed to germinate. Gluten is responsible for the elastic and viscous consistency typical of many types of dough. On a biochemical level, this is “due to the formation of interchain disulfide bonds between gluten proteins and hydrogen bonds between glutamine residues that are abundantly present in all classes of gluten proteins” (Koning, 2015). This network forms a desirable texture across a wide range of food applications. Under normal circumstances, digestive enzymes break down long chains of proteins into smaller segments called peptides. The majority of these peptides can be broken down further, absorbed by the small intestine, and then transported around the body. However, in patients with celiac disease, this does not occur; digestive enzymes cannot break down the long chains of gluten for these individuals. These undigested peptides trigger an immune response in the digestive tract (Healthcare Professional Resource for Gluten Related Disorders, 2017). The villi in the small intestine become damaged, preventing the proper absorption of vitamins and minerals (Moore, 2014). As of now, patients with celiac disease have been told to eliminate gluten from their diet. Scientists are currently working on a pill to aid in the digestion of the gluten proteins while still being able to withstand the highly acidic environment of the stomach, but there is still more testing that needs to be done (Koning, 2015).

Accounting for about 0.75 percent of the population, celiac disease is just one reason people remove gluten from their diets (Klein, 2014). Celiac disease, along with wheat allergy, are the two gluten related disorders that can be fully explained biologically. Wheat allergy is less common, affecting only about 0.4 percent of the population (Klein, 2014). Just like any other food allergy, it involves an overreaction of the immune system. Once wheat is ingested, it triggers a reaction that can range from mild symptoms, such as rash, itching, or swelling, to more severe symptoms such as trouble breathing, wheezing, or even loss of consciousness (Wheat Allergy, 2016). The wheat allergy response is not triggered by gluten specifically, meaning these individuals are able to eat sources of gluten that do not contain wheat such as barley. An important group of people to look at is those with gluten sensitivity, referred to as non-celiac gluten sensitivity (NCGS). The terminology of the syndrome is being debated with the option of non-celiac wheat sensitivity, implying that gluten itself may not actually be the cause of discomfort. Although the first cases were reported in the 1970s, it has been “rediscovered” following the 2012 work by Sapone and colleagues. Since that time, the amount of papers and people being treated have grown exponentially. It is important to note, however, that many of these cases are self-diagnosed without the verification of a physician (Catassi, 2015).

NCGS is defined as a syndrome characterized by intestinal and extra intestinal symptoms related to the ingestion of gluten containing foods in subjects who are not affected by either celiac disease or wheat allergy (Catassi, 2015). Although not entirely clear yet, evidence suggests that NCGS is slightly more common than celiac disease. NCGS includes symptoms similar to irritable bowel syndrome (IBS) such as abdominal pain, bloating, and bowel habit abnormalities. It also includes symptoms of “systemic manifestations” such as foggy mind, headache, fatigue, joint and muscle pain, leg or arm numbness, dermatitis (for example skin rash), depression, and

anemia (Catassi, 2015). There is a complicated relationship between NCGS and IBS symptoms. Through a randomized, double blind placebo controlled trial of non-celiac individuals, 68% of patients in the gluten group reported symptoms that were not adequately controlled compared to 40% in the placebo group (Biesiekierski et al, 2011). More specifically, the group that ingested gluten had significantly worse pain, bloating, dissatisfaction with stool consistency, and tiredness. This suggests that NCGS may exist, despite not knowing the mechanism to explain why (Biesiekierski et al, 2011). Whereas Biesiekierski's study compared a gluten group to a placebo group, Sabatino and colleagues additionally switched participants after one week, allowing for comparisons to be made not only between groups (gluten vs. placebo) but also between individuals' own reactions in alternating conditions. The gluten or placebo was delivered through a pill to provide the study with further control, as opposed to Biesiekierski's study where subjects were given slices of bread and muffins. The results of the studies were consistent. The intake of gluten significantly exacerbated symptoms, including abdominal bloating, pain, foggy mind, depression, and aphthous stomatitis (canker sores) (Sabatino et al, 2015).

Despite much testing being done in the scientific community, there are still no biomarkers or mechanisms known for the diagnosis of NCGS. However, scientists such as Biesiekierski, Sabatino, and colleagues were able to find a relationship between gluten ingestion and the appearance of symptoms in double blind placebo controlled studies. In essence, they have evidence that gluten is hurting a group of individuals who do not have celiac disease or wheat allergy, but they do not know the exact cause. This distinguishes NCGS from other constructed illnesses, since there is some scientific backing, but not enough. It is important to note that some scientists have recently become interested in the effects of gluten on the normal

immune system, that is, individuals who do not exhibit any problems with gluten. This is relevant because questions will be raised as to whether we should all reduce gluten intake or not, regardless of the presence of celiac disease, wheat allergy, or NCGS. Dieting for weight loss aside, are there other benefits to a gluten free diet? There are studies going on to understand the different biological effects, but many are still unanswered. One study suggests a possibility for disease initiation upon exposure to gluten. Despite suspecting impacts of gluten on the average person's body, scientists are currently far from saying anything with certainty (Koning, 2015).

This brings us to the last group of individuals who remove gluten from their diets, which includes people who believe it is healthier, or are trying to lose weight. It is likely that this mindset behind gluten is somewhat of a fad. I plan to argue that the perception of gluten in this fad-like state is driving the desire for the medicalization for individuals with NCGS. The unjustified talk and practice relating to gluten seems to invalidate those with NCGS, since the science has not yet been able to fully justify them.

#### *Anthropology of Gluten Related Disorders*

There is not much literature in the social sciences about gluten related disorders and NCGS specifically. Legitimization of celiac disease symptoms and different paths to diagnosis are largely studied by Copelton and Valle (2009) in their article "*You Don't Need a Prescription to go Gluten-Free*": *The Scientific Self-Diagnosis of Celiac Disease*. Although celiac disease is one of the most common autoimmune disorders in the United States, a large majority is undiagnosed since the symptoms are similar to those of IBS. Even when celiac disease is diagnosed, it is often delayed or misdiagnosed initially (Copelton & Valle, 2009). Despite the scientific support for celiac disease, there are still concerns regarding the social experience of the

disease. Although celiac disease is recognized fully in the medical community for its known physiological cause, it differs from classic diseases in part for its broad range of symptoms from gastrointestinal distress to more distant consequences from poor nutrient absorption. Even more so than that, though, is the idea that the treatment is non-medical. Therefore, as the title of the article implies, anybody can follow the treatment for celiac disease, “you don’t need a prescription” (Copelton & Valle, 2009).

Due to the non-medical component of celiac disease, there is not one typical path to diagnosis as set forth by clinical practice guidelines. Copelton and Valle identify two other routes to celiac disease identification: self-diagnosis and scientific self-diagnosis. The first involves reports of individuals who show an improvement on a gluten free diet while the latter involves patients ordering laboratory tests without the need for a physician’s approval. Although this isn’t viewed as a legitimate diagnostic tool to the medical community, many individuals find great comfort in using scientific tests to make their claim seem more legitimate than self-diagnosis alone. The basis for self-diagnosis includes unexplained symptoms, unsatisfactory medical diagnoses, access to medical information, and a supportive self-help community (Copelton & Valle, 2009; Barker, 2008). The search for help for these patients is often a long process involving multiple doctors in an attempt to find more information, each encounter involving continued discouragement. Patients note complaints of physician incompetence, invasive testing, and inaccuracy of test results to name a few. When a patient has already self-diagnosed by linking symptoms with removal of gluten from the diet, it is quite unsatisfying to receive a negative test result. This gets further complicated because in order to be properly tested for celiac disease, the individual needs to incorporate gluten into his or her diet for the biopsy and antibody test to respond to. These patients face a dilemma: should they eat the gluten that

they believe is making them sick and potentially receive the same negative results? For some individuals, just the act of feeling better is enough.

I did a bit of reading on the Internet and the symptoms kept ringing true to my situation. So I went on an informal [gluten free diet], and after a few days I started feeling better...But I thought, well maybe it's just my imagination. You know, your mind can do a lot of things. So I went back to eating gluten again and after a couple days I was really sick...so then I said, well maybe there is something to this (Moore, 2014, p. )!

For Mick, a subject in Copelton and Valle's study, the act of getting better upon treatment was convincing enough to maintain a gluten free diet. Some people, though, are not as satisfied with these results as Mick. Upon telling a local celiac disease support group leader of his self-diagnosis, the leader would not give him the packet of information and food samples that had been given out to the rest of the group. This incident made Mick more reserved to reveal the source of his diagnosis in the future. This is a typical reason for a self-diagnosed individual to seek out medical legitimization: to gain social support. Some individuals use pseudo scientific tests despite the lack of scientific validation because they see the value that a medical definition offers, despite conventional methods failing them (Copelton & Valle, 2009).

Despite its differences, understanding the social experience and desire for diagnosis in celiac disease is important for the context that it gives to NCGS. *"But we're not hypochondriacs": The Changing Shape of Gluten Free Dieting and the Contested Illness Experience* by Moore does an excellent job of shedding light to the expansion of gluten free dieting beyond the traditional setting. It shares some similarities with Copelton and Valle's article, but the main differences stem from the lack of a scientific etiology for NCGS. Whereas the celiac disease patients were frustrated with the unreliability of the diagnostic testing, NCGS

patients lack that option all together. Since doctors cannot provide a diagnosis, these patients question medical authority. This relationship is diminished even further when the patient starts to feel better from some mechanism other than advice from a physician. A participant of the study, Mike, makes this message clear: “It was frustrating because you were feeling better and you follow a doctor’s advice and you get worse and you start wondering, ‘What the hell is going on?’” (Moore, 2014) It wasn’t until Mike tried his own idea of removing gluten that he started to feel some relief. Some participants go beyond questioning the physician to challenging “underlying assumptions about the life course and the medical approach to the body,” going so far as to question the way we as a society deal with chronic diseases. JoAnn believes that most problems in general that Americans face can be attributed to diet and lifestyle, comparing NCGS to a disease like obesity.

And so, for all of that, I think modern medicine is not so good. I’m skeptical of it. And I’m especially skeptical because I see them steer people wrong so much, and try and push them towards pills and interventions that have side effects and risks, when often less invasive approaches [will work] (Moore, 2014, p. ).

Others, like Nina, take this view even further to question not only the knowledge of physicians, but their integrity as well:

I knew lots of people who went to the doctor and the doctor didn’t know what was wrong, or said or treated the wrong thing. It just flipped me out. The amount of money, time, frustration, ill repair. Why would anyone choose this path... They are so clouded by their signs and symptoms because they don’t know if it’s the medication causing the problem, or food, or disease, or environment (Moore, 2014, p.).

Another key point of Moore’s study is the trend of diagnosing others that goes on in the NCGS community. This can be in the form of blogs, books, podcasts, or even just intervening in

strangers' conversations. They have had poor experiences with the medical community and feel such relief from their current practices. They have a desire to inform others of the miraculous transformation that they have experienced. This often goes beyond the gastrointestinal symptoms that are typically thought of. Symptoms such as arthritis or skin problems are less often associated with gluten, and some people such as Christy put all of their devotion into creating more success stories like her own.

I'm starting to not be able to go out in public. I see little kids with bright red patches on their cheeks, or dark circles, or... see a friend whose kids missed 40 days of school last year, and he doesn't believe it's wheat. The mainstream articles still all say the same thing, [one in 133 have celiac]. Call it what you want: gluten sensitivity, gluten intolerance, celiac. I think out of 133 people, maybe 120 of them should not eat wheat (Moore, 2014, p.).

There is a difference between these NCGS individuals compared to Copelton and Valle's participant, Mick, who believes that he has celiac disease despite inaccurate test results that frequently occur. Mick can simply omit the piece of information that he is self-diagnosed and still receive validation from others. That is not the case with those suffering from NCGS. NCGS is not recognized as a true medical condition like celiac disease is. This is why individuals such as Christy and the many others like her promote the effectiveness of a gluten free diet for a variety of health purposes. The more people there are who know and come to accept this practice as normal, the more legitimacy people with NCGS will receive over time.

### **Medicalization and Contested Illness**

An analysis of the illness experience would not be complete without the idea of social constructs. A social construct appears to refer to some obvious or naturally given phenomenon, when in fact

the phenomenon has been created by a particular society at a particular time (Barker, 2010). Social constructionism helps shed light to seemingly simple questions that are actually more complex. Even something as broad as ideas can be a social construct, as they are not true or false since they are affected by different social contexts. Illness is also a phenomenon shaped by social experience and shifting knowledge. Something can be considered an illness in one time period or part of the world while not acknowledged as one in another. The idea of who is correct and which illnesses are real is not as important as understanding why ideas regarding the illnesses appear, change, or persist (Barker, 2010). This is not to disregard the scientific aspect of the disease, but rather to change focus to what characterized it as a disease in the first place. For example, HIV/AIDS was first discovered due to the social aspects surrounding it, however it is clearly linked to biological pathology. Some illnesses are not as clear biologically, however, and must be defined as a medical problem (Barker, 2010).

Related to social construction of medical knowledge is the concept of medicalization: when human experiences come to be defined, experienced, and treated as medical conditions (Conrad, 2007). Medicalization can be applied to a wide range of events that we largely take for granted. Some examples include mental disorders, sexual dysfunction, ADHD, and everyday processes such as infertility, childbirth, and death. While medicalization appears to be increasing over time, there are also instances of demedicalization like homosexuality and masturbation (Conrad, 2007). These were once considered to be abnormal, deviant behaviors, but have since been reimagined. Often medicalization is viewed in a negative sense, as with over-medicalization, but that is not the case with NCGS. However, one must be aware that there can be consequences of medicalization. By defining a problem as medical, it calls for a medical treatment when that may not always be necessary. Sometimes certain types of suffering require

political, economic, or social change instead. The blame of over-medicalization is not just on the physician. Patients are increasingly active participants in the medicalization of their experiences as they often search to solve and legitimize their suffering (Conrad, 2007; Barker, 2010).

Many people who yearn to legitimize themselves suffer from a contested illness. The Copelton & Valle and Moore articles set the stage for this idea. NCGS is contested because there is a clash between medical knowledge and patient experience. This is still true for celiac disease, although to a lesser extent, due to the difficulty in diagnosis and type of treatment that anyone can attempt. People with contested illnesses have medically unexplainable symptoms causing much uncertainty amongst physicians. These illnesses are not associated with any specific organic abnormality and are diagnosed based on observations and patients' subjective reports of symptoms. Often times they are diagnosed by exclusion after other possibilities are ruled out. These sufferers, though, provide persuasive accounts of their distress while having to deal with medical uncertainty and skepticism. They search for a medical explanation and remedy but to no avail after countless tests. Being told that nothing is wrong, along with real or perceived accusations that they are faking, leads many individuals to prove to themselves and everyone around them wrong. A diagnosis not only helps the patient, but also helps the physician. It represents knowledge about the patient's experience and indicates a protocol for treatment (Barker, 2010).

The way in which a patient with a contested illness receives a diagnosis can be quite interesting. Since they have trouble getting it from one physician, they often search around to many physicians to find one willing to diagnose. With or without this official diagnosis from a medical professional, they will often self diagnose from the stories of friends, a magazine, or largely the Internet (Barker, 2010; Moore, 2014). Virtual illness support communities often

provide shelter for someone with a contested illness and create an illness identity. They are eager to hear support from those similar to themselves. Those with contested illnesses are not a huge minority. Most of us live now or will in the future with a medically uncertain affliction that negatively affects our quality of life. A diagnosis for contested illnesses provides relief to an overarching cultural dilemma. The increasing creation of contested illnesses speaks to the way we acknowledge and address the normalization of suffering in society (Barker, 2010).

Chronic Fatigue Syndrome (CFS) is a classic case of a contested illness that can help us to understand NCGS. CFS is characterized by extreme fatigue that cannot be explained by any other medical condition, with a cause that scientists are not entirely sure of (Chronic Fatigue Syndrome, 2016). People with CFS risk being denied social recognition since symptoms are vague, making it easy to accuse them of faking it. It is common for these sufferers to have awful symptoms, seek help, and be turned down by doctors. Many people are told that they are making up the pain, so much so, that they actually start to believe that they are imagining it (Dummit, 2006). Someone with CFS or NCGS may feel extremely ill, but without a diagnosis, society will constantly challenge him or her. They put so much effort into trying to prove the way they feel, that it gets in the way of the healing process (Hadler, 1996). When your experience is confirmed through medicalization, relief can finally begin.

## **Methodology**

I was initially interested in examining how the gluten free fad became so popular, and the reasons that people were so compelled to adhere to the diet. I imagined it would be easy to find these fad dieters since they are increasingly prevalent in society, but quickly realized something different. The subjects that I spoke to initially all had a gluten related disorder. These individuals

constantly spoke about the fad and critiqued the idea, yet I could not find fad dieters to speak to. I realized that fad dieters were not as open to identifying themselves as gluten free since it may be something they are just trying for now, or have tried temporarily in the past. This realization reshaped the thesis and methodology. My interest was shifted towards gluten related disorder individuals' desire to separate themselves from the fad in search for greater legitimacy.

With a greater focus on people with gluten related disorders, this thesis draws from a combination of semi-structured interviews, informal interviews and conversations mainly with college students and professors. Participants were identified through purposive and snowball sampling. Purposive, also referred to as judgment, sampling involves searching for information based on a specific motive. The purpose was to find gluten related disorder individuals, so I sought out these specific types of people. These individuals were largely found through snowball sampling, which involves locating key individuals who led me to the names of other individuals who are gluten free. Many people know somebody who is gluten free, so snowball sampling was very effective. I spoke to 6 individuals with celiac disease, 2 with wheat allergy, 8 with NCGS, and 4 with other reasons for eliminating gluten from the diet. In addition to these in-depth interviews, I also had several informal conversations with individuals about their experiences related to gluten related disorders, including various medical practitioners such as a gastroenterologist who has a focus in celiac disease, a pediatrician, and a registered dietitian. These discussions were important to informing my analysis and understanding of NCGS and gluten related disorders. Specific individuals mentioned have been assigned pseudonyms to ensure their anonymity.

I used participant observation at The Capital Region Allergen and Gluten Free Expo, which took place in Crossgates Mall in Albany, New York. I heard about the expo from a

Facebook advertisement and did some further online research to learn more about it. The expo took place on the first floor of the mall where over fifty exhibitors were set up in rows of tables with information to share. Some stands focused more on education through pamphlets and conversations while others gave out food samples and items for purchase. Many local businesses were present, but a few individuals in particular were showcased including chefs and a physician. The Internet connected me with the gluten free expo, and also led me to research virtual communities. I used a search engine to find gluten free blogs and forums, which led me to an abundance of information. People on blogs and forums would often reference other websites, including podcasts and online documentaries. Similar to snowball sampling, one online source led me to many others.

## **Conclusion**

This thesis aims to analyze the social consequences of NCGS as an illness without a disease. These individuals have convincing stories of severe distress from ingesting gluten and relief once it is removed from the diet. I will first analyze the symptoms and experiences of individuals with different gluten related disorders in Chapter 2 by examining their narratives to understand how they feel, perceive, and live with their illness. I will look at how people make sense of their suffering as individuals who are misunderstood, misdiagnosed, and/or socially judged as “fussy” eaters. Next, Chapter 3 will look at how NCGS sufferers navigate in our society of medical hegemony. This affects the push towards the medicalization of NCGS and the desirability of a diagnosis despite an unknown pathophysiology. Only through the medicalization of NCGS can the stigma of being on a gluten free diet be diminished. Chapter 4 will analyze the process that occurs after the physician’s office fails the NCGS sufferer. Individuals must seek out their own

diagnoses, answers, and assistance from different types of support levels. This stage is crucial for transmitting and receiving information to help the sufferer and others in a similar situation navigate through the illness. I will briefly touch upon questionable communities that exist, its perpetuation of the fad, and potential consequences for true sufferers. Chapter 5 will consider where the gluten free community is headed, and implications it may have for the future of NCGS.

## **Chapter 2: The Gluten Experience**

### **Introduction**

Individuals with adverse reactions from gluten endure a wide range of symptoms. The most common symptoms are those related to digestive system discomfort, but others range from brain fog and haziness to joint pain to side effects from malnutrition. While there is some overlap between all gluten related disorders, celiac disease and wheat allergies are distinguished from non-celiac gluten sensitivity (NCGS) based on the known clinical manifestation in the medical community. Despite the strides towards a clinical understanding of NCGS, a medical diagnosis remains elusive. This gap in knowledge of understanding how NCGS works on a biochemical level is significant when considering the sufferers' experiences.

Those afflicted with celiac disease or wheat allergy have a confirmed medical diagnosis that lends legitimacy and support to their suffering. Despite their frequent frustration with the need to detach themselves from the gluten free fad, they find a sense of comfort once they are able to explain themselves as being "real gluten free." On the other hand, those suffering from NCGS feel as if they must constantly defend their condition given that there is not an official medical malady they can claim. Not only do they face both silent and verbal interrogation over the validity of their illness by family and friends, but also within the medical profession. They do not have the same support from medical professionals, who they themselves are uncertain of the NCGS patient and his or her symptoms.

These experiences contribute to the unique suffering of those with gluten related disorders. Through analyzing their illness experiences, we can better make sense of patient suffering and how they deal with their illness and negotiate everyday social relationships (Brown

et al., 2010). Anthropological investigations of illness experiences focus on 1) narratives-the stories that people tell about their illnesses 2) experiences- how people feel, perceive, and live with their illness and 3) meaning- the ways in which people make sense of their suffering (Brown et al., 2010). Thus, this chapter more closely examines illness narratives of celiac disease, wheat allergy, and NCGS in order to better understand how sufferers a) experience and live with their illnesses and b) navigate the perception of gluten free as a fad. In particular, this chapter analyzes the experiences of two individuals, Taylor and Joe, highlighting various aspects of their narratives that connect to a more general experience of suffering amongst those with gluten related disorders. Through the narratives of these informants, we can better understand how sufferers of gluten related disorders deal with their invisible, chronic illness; how they have to communicate to everyone from friends to waiters about their condition; how they make meaning and community out of an illness that is misunderstood, misdiagnosed, and/or socially judged as “annoying,” “picky,” or “fussy” eaters. Compared to the everyday individual, those on gluten free diets learn to navigate restaurants, grocery stores, and dining halls in order to fulfill a basic life sustaining need. They must learn to come to terms with their illness and cope with its impact on those around them. It is important to not get caught up in the truthfulness of participants’ statements since there is so much unclear related to gluten free diets. What is more important, though, are people’s perceptions and how that shapes their experiences.

## “Real Gluten Free”: Taylor’s Case Study

### *Symptoms*

My mom, five siblings, and I all have had celiac disease. I went through the process of eating gluten when I was younger before being diagnosed when I was five years old. At that point, I had already experienced my teeth growing in really badly, some not having enamel and I was also underweight. I was having symptoms that were just kind of in line with malnutrition, and I don’t know if it’s directly from celiac but I just wasn’t healthy and my sisters were having the same sort of things going on... I’m not *that* sensitive. I know my roommate has celiac disease and if she has the tiniest bit of gluten she will throw up and she says ‘oh if I ate gluten I would have to get my stomach pumped.’ I have never had such a bad reaction like that, but I will definitely feel sick. I can tell if I’ve had something with gluten in it but its nothing crazy. I’m used to it by now so I can tell what I can and cannot have for the most part unless it has to do with contamination and I have to ask someone in a restaurant... My mom was sick until about her twenties because nobody really knew about celiac disease. She was really underweight; she couldn’t even go out because she would feel sick out. I wonder if she is more sensitive now because she was so sick and maybe I am less sensitive because I never got to the point where I was so unhealthy.... I wonder if that is why and if so, maybe I should be more careful with cross contamination and stuff so it doesn’t get worse if that’s possible.

Most individuals suffering from a gluten related disorder often live with difficult symptoms years before being diagnosed. Taylor<sup>1</sup>, a sophomore at Union College, was diagnosed early on as a child after experiencing symptoms related to poor nutrient absorption. Taylor’s mother, who herself has celiac disease as do her other children, quickly noticed red flags related to celiac disease within Taylor at a young age and intervened immediately. While other individuals that Taylor knows with celiac disease experience more severe discomfort, hers is not so bad. Taylor

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<sup>1</sup> Taylor was interviewed on October 5<sup>th</sup>, 2016

accounts this to the fact that she avoided ingesting gluten so early in her life, starting at age five. She may have done less damage to her gastrointestinal tract, and therefore has less intense symptoms. However, Taylor believes that this is a reason to be careful when it comes to cross contamination, so that she does not feel worse in the future. Taylor benefitted from her family's medical history and knowledge of celiac disease, and therefore did not suffer for years before being diagnosed, as in case of most patients.

Another student from Union College who I interviewed, Dana<sup>2</sup>, was not as lucky. Dana was not diagnosed with celiac disease until two years ago when she was a freshman in college, giving her plenty of time to eat gluten prior to then. Her symptoms were more focused on gastrointestinal pain, and had less to do with malnutrition. Dana did say that she weighed very little in high school for her tall height, but did not think about it being related to her celiac disease. Similarly, a Union College senior, Lisa<sup>3</sup>, also experiences abdominal discomfort from eating gluten, but in addition gets rashes due to her wheat allergy. Lisa is currently in the early stages of diagnosis where she is still trying to figure out what works for her. It is not a severe allergy that could cause an anaphylactic shock, but nevertheless has real consequences. She has had these symptoms for several years but was never willing to give up gluten until now, which she credits to increased maturity.

In addition to the more known symptoms, eating gluten can also cause a range of lesser-known symptoms that require individuals to seek relief. An older woman, Mary, was interviewed at The Capital Region Allergen & Gluten Free Expo<sup>4</sup> in Albany, where she was giving out samples of homemade bread created by her son to help with her arthritis. Mary had been taking

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<sup>2</sup> Dana was interviewed on October 20th, 2016

<sup>3</sup> Lisa was interviewed on October 4th, 2016

<sup>4</sup> The Capital Region Allergen & Gluten Free Expo took place on October 22, 2016 in Crossgates Mall in Albany, NY

many medications for her arthritis and was getting tired of it. She heard from word of mouth that being gluten free might help, so she decided to give it a try. Ever since, she feels like she does not need any medication and swears by the effectiveness of a gluten free diet. Similarly, a recent college graduate, Marissa<sup>5</sup>, and her mother have very severe arthritis. Ever since going gluten free, her need for medications has reduced. She used to take three pills a day and now only takes one. Although not as severe as arthritis that needs medication, Brad<sup>6</sup> experienced much joint pain and lethargy prior to going on a gluten free diet. Symptoms such as “brain fog” and “haziness” are referred to often, especially with Joe who will be analyzed in further detail. Some individuals start off removing gluten from their diet for reasons such as abdominal pain, but notice feeling much clearer incidentally. They did not realize that they were experiencing such lethargy until the symptom was relieved. With the exception of Lisa’s rashes, others cannot see these symptoms, which makes celiac disease and NCGS invisible illnesses. Because of this, it is so important for these individuals to articulate their condition to others in order to receive justification and understanding. Because their chronic disease is invisible, they have to go through the additional step of educating others, as opposed to a visible illness where the suffering can be assumed. Many sufferers of gluten related disorders regard this explanation as a necessary nuisance of their illness experience.

### *Eating Out*

It is easy to eat in my house because we have gluten free everything. My dad also eats gluten free even though he doesn’t have celiac disease. It is difficult eating out depending on the restaurant... Like if a restaurant cooks the French fries in the same fryer as onion rings with breadcrumbs then I can’t have the French

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<sup>5</sup> Marissa was interviewed on November 4th, 2016

<sup>6</sup> Brad was interviewed on October 11th, 2016

fries. Sometimes I don't check about cross contamination as much as I should... last night I went out to eat with my dad at Johnny's in Schenectady and they have gluten free pasta so I got mussels for an appetizer, and gluten free penne a la vodka. Sometimes its really easy like that especially now since more places have gluten free pasta or gluten free pizza. Some places will have a gluten free menu or flag the gluten free foods on their menu like steak or fish or salad. But some places I go I just can't really eat anything so I will just get a salad or I will ask them if I can get a random piece of meat or fish or whatever. For the most part it is pretty easy. I am not a picky eater so if I do end up just getting a salad somewhere, I don't really mind... I think that NCGS could definitely be legitimate but what makes me a little skeptical is when it comes to ordering at a restaurant. Lets say you are at a restaurant and someone says that they are gluten sensitive or allergic to it but they aren't really. If you don't seem so concerned about it then the restaurant wont think it is a big deal and won't be as careful with cross contamination. If it wasn't a big deal for that person then they wont take it as seriously for the person with celiac disease or who is really sensitive. If the restaurant isn't careful then that person could get sick. It makes me a little less trusting of places because these people make others think that it's not that big of a deal, maybe not deliberately but because they just brush it off.

It is easy for Taylor to eat a gluten free diet at home because it affects her entire family. Her household has been eating this way for her entire life, so her diet is never a worry in that setting. The major concern is going out to eat at restaurants. Compared to when her mother had to navigate the gluten free world when she was younger, there are many more options today. Still, though, there are struggles to finding something to eat. Not only does she have to think about what is in her meal, but also what her meal might be touching in the kitchen. Something as simple as going out to eat at a restaurant often comes with challenges for those suffering from gluten related disorders. Despite the fact that there are so many more options today, nevertheless there are concerns for cross contamination. Because of this, those with gluten related disorders

bear the burden of having to educate others and must either be more assertive about their dietary needs or settle for safer options.

Being on a gluten free diet requires a thought process that is not necessary otherwise. Lisa tends to look ahead of time at menus online before going to a restaurant to see what options they have. Most people on a gluten free diet will ask if there is a gluten free menu, but the flagging system that Taylor mentions is more common. Dana says that she always asks, "First if there is a gluten free menu and if they don't have a menu I usually stick to salad and things that wouldn't have any contamination. Even things that you wouldn't think have gluten in them may, such as soy sauce." When deciding what food to order at restaurants, Dana always chooses to be on the safer side. For people who experience more immediate gastrointestinal pain such as Dana, cross contamination is a more crucial and immediate concern. Dana often gets frustrated when waiters ask her "how allergic" she is and the answer is "very." It is a struggle for her because she feels like a bother and that they do not fully understand how serious this is for her. In order to avoid these interactions, she usually just orders something that she is sure is free from gluten. Like Taylor and Dana, these individuals are often not picky eaters. This is more out of a necessity than anything else. If they were picky, there would be many times where they would simply have nothing to eat.

Brad, a biochemist, has had a similar experience with restaurants. After being on a gluten free diet for about a year since hearing from a colleague that it could help his lethargy and joint pain, he has noticed, "there are some restaurants that are much better than others. People are much more accepting of it and restaurants are more accepting of it than ever before and I think that has helped a lot. It's still not easy but it's easier." Brad is not very careful when it comes to cross contamination because he acknowledges that it is not so important for him compared to

someone with celiac disease. It is not as harmful for him if he ingests gluten because he will just feel temporary fatigue. Despite the increasing ease of finding gluten free options outside of the home, there is still that extra effort that needs to be made, whether it is to look at menus ahead of time or ask for something to be made specifically for you. These individuals constantly need to be making judgment calls as to what is safe to order. On top of cross contamination, they need to be mindful of the degree to which the waiters and chefs take it seriously. Although likely not on purpose, the relaxed attitude of fad dieters may have severe consequences for others, making them desire the separation between the two to be even greater.

### *Do Not Count on Losing Weight*

I feel like a lot of people eat gluten free because they think it makes you skinny... This has become a fad diet but it sounds silly to me to say you are doing it to lose weight... I know that I wouldn't chose to do it if I didn't have to but it's their choice. It's kind of weird to me because it's one thing to go gluten free and not eat carbs and bread at all, but if you are replacing it with gluten free bread then it's not any healthier at least calories wise. I do a fine job of finding all the unhealthy food. It's just a little weird to me. I think the only reason I would be a little bit healthier is because of the inconvenience. Like I could find a gluten free donut somewhere if I really wanted it but it takes a little bit more effort. If it is not available in front of me I won't get it. Or if I get a burger and they don't have any gluten free buns, then there is a bunch of calories I won't eat. I also think it makes me healthier because I have to be conscious to some extent of what I put into my body, I can't just pick it up and eat it...

Like Taylor, most people I interviewed were in agreement that removing gluten from the diet is not inherently healthier. When people think of a gluten free diet, they often imagine removing things like bread, pasta, and many baked goods. It seems logical that removing these items would

help you to lose weight. What does not seem logical is when people replace regular bread with gluten free bread, or regular pasta with gluten free pasta. These alternatives are just as caloric, if not more, than their gluten filled counterparts. When gluten is removed from products, companies often add more of the ingredients that are not as healthy to make up for the lost texture and flavor.

In response to those who chose to eat gluten free for weight-loss, Lisa stated that she “thinks it’s kind of silly but whatever works...it’s not how I would go about it but who am I to judge...If you are like me and you’re really into anything bread related and you cut out gluten and don’t buy supplemental snacks and bread then yea, you can definitely lose weight because you are taking out a food group.” If you don’t “fall into the trap” of eating gluten free cookies, for example, then it does make sense to lose weight. Lisa contributes weight loss to a low carb diet, as opposed to a low gluten diet. Dana says that choosing to eliminate gluten is, “really not healthy if you think about it. I have to substitute a lot of the things that normal people eat with other things, like rice is gluten free but that is not healthy. I eat a lot of rice. The gluten free bread is not better than normal bread.” The substitutes are not healthier alternatives. “If anything you have to find carbs to fill you up since you can’t have the other carbs that have gluten in them.” Dana emphasizes that the weight loss idea with gluten makes no sense to her. Dana sees carbohydrates as a food group that leaves her feeling full and satisfied. Since she cannot eat many types of carbohydrates with gluten, she searches for the carbohydrates that she can eat instead of eliminating the food group all together. Rice is a common example of a food that many gluten free individuals chose to eat that is not lacking in calories. Many individuals with gluten related disorders get frustrated at the common belief that eating gluten free is a healthier diet alternative, when in fact those people really mean carbohydrate-free.

*This is Not a Choice*

One of my friends at home was just not well so she tried being gluten free and my other friends were making fun of her because they didn't think she needed to be. Because of experiences like this, I feel like I need to tell people that I am 'real gluten free.' When people hear that I am gluten free they usually ask if I have celiac disease or if I am just doing it as a diet. I would be eating every piece of pizza in sight if it were a choice.

The majority of people I interviewed do not want to be gluten free, but they have no other choice given that the ingestion of gluten will make them ill. Nevertheless, they are frequently asked to qualify their condition. Are they "really" gluten free? Or is this just a health choice? Like Taylor, many sufferers of gluten related disorders similarly comment that the gluten free trend has created the need to distinguish themselves from the fad. For example, Taylor's friend from home was ridiculed for going gluten free because she did not "need" to. But what constitutes needing to? Is it a celiac disease or wheat allergy diagnosis? Would NCGS suffice? For some people, it may be sufficient as long as it is not for weight loss. For others, however, it may be a clear-cut medical diagnosis. In order to cover her bases, Taylor prefaces conversations with people with the fact that she is "real gluten free." This is her way to ensure immediately that people know that her diet "choice" is rather a consequence of her body's pathophysiology.

There was a woman, Harley<sup>7</sup>, in front of me in the line at the Gluten Free Expo to speak to the gastroenterologist at the "Ask the Doctor" booth. I asked her if she was gluten free and she responded with her concern that she may have celiac disease, and that she would like to discuss her symptoms with the doctor. When asking if she would avoid gluten just to be safe, she said that she would never eliminate gluten unless the doctor told her to and she had no other choice.

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<sup>7</sup> Harley was interviewed on October 22, 2016

Harley does not think it is worth doing unless it is absolutely necessary since it seems like such a burden. Dana says that “there are some people that do it just for fun, which I don’t understand but the fact that there are those people, I think that makes other people think ‘oh it’s not that serious, its fine if there’s some sort of contamination.’” She has a friend who is just going gluten free “for fun,” which is hard for Dana to understand. There are also people she knows who say they are going to try it but then still eat some gluten. Similarly, Lisa says “When I talk to people about my gluten free diet they think I am doing it because of a fad, but I actually have stomach issues and rashes.” These individuals who are doing it for medical purposes describe the diet as something you would not do unless you had to. People who are doing it to lose weight may not see it as so much of a burden because they can stop at any point that they would like, whereas others cannot. The trend seems almost incomprehensible for many gluten related disorder sufferers. To Brad, “there’s no point in going gluten free just because it’s hip or cool or trendy. Nobody gives up Guinness because it’s trendy.” But if you are doing it as a fad, you can pick and choose when to do it and when to not. Like Dana mentioned, people might try to be gluten free but then still eat a little bit of gluten when it is convenient for them. This is problematic as it reduces the legitimacy of those suffering with gluten related disorder. It makes it more challenging for them when they insist on the need to have absolutely no gluten. The laid back mindset positioned onto people from fad dieters can have serious consequences for those who are “real gluten free.”

## Be Prepared to Wait: Joe's Case Study

### *Symptoms*

I was first gluten free when I was fourteen or fifteen, about four years ago. And before that I was dairy free, so I was sort of used to allergies. When I was twelve or thirteen I found out that I wasn't supposed to be eating gluten, but it wasn't such a severe thing, it was more of a minor allergy. Since I was already off of dairy, I was just so annoyed that I couldn't have that, that I just was like screw it, I'm going to eat gluten anyways, so I sort of ignored it... When I was older I went to a nutritionist who told me I really shouldn't be eating gluten. I wasn't celiac but she told me that I had an intolerance. She was saying that it was shutting down my digestive enzymes because of this intolerance and making it so that I can't digest glucose for scientific reasons I don't quite fully understand. It was messing up my digestive system and creating inflammation in my stomach. A lot of the way I looked came from the puffiness and the reason I was gaining weight so rapidly was because I couldn't digest any of the sugars so my body was fighting itself. At that point seeing my body after losing weight I was a lot more receptive and even though it was hard, I was willing to stop. Now I have noticed that without eating gluten for about four years, when I do eat gluten, I'm much more sensitive than I ever was before, to the point where several months ago I actually ate a piece of licorice that had wheat in it, which I didn't know about because I didn't think licorice would be something like that and my tongue swelled up like an allergen reaction, not just an intolerance reaction where I think I have sort of developed an allergy since my body doesn't have the same defenses. I have heard this a lot with allergies where people have become more sensitive to things. People say it is okay to eat these things once in a while but my mantra is that it's never worth it. The only times I would ever eat gluten or dairy now would be from the best place of that item, like if it is from the world's greatest cake factory, and even then I usually don't eat it, I just try it. It is never worth how sick I feel and how hard it is on my body. More than anything, when I eat gluten I feel really sluggish and my stomach just hurts, like constantly hurts. Specifically, diarrhea, gassiness, and just intestinal discomfort. Grogginess is usually the first thing that hits me, and that happens pretty quickly. What I've noticed compared to dairy is that gluten hits slower and not as hard, but can last,

if I eat enough of it continuously, up to like three days whereas if I drank a glass of milk right now I would feel awful for the night but feel fine the next day.

Joe is a freshman at Union College, originally from Los Angeles, California. I chose to highlight him as a case study because he was the most adamant about his views and the most aware about his illness compared to the other participants. He has gone on to do extensive research far beyond just the illness, but to potential causes by looking at trends in the wheat industry throughout history. Joe remains an outlier in terms of how he came to try the gluten free diet. He was initially advised against eating gluten from someone in the alternative medicine field, but Joe was resistant because he had already removed dairy from his diet. Joe was an overweight child and had attempted numerous times to get healthier. He went to a summer weight loss program a few years later, lost the weight, and felt great. He went to see a nutritionist to maintain his healthy weight who again suggested he try the gluten free diet, this time saying that he was sensitive to gluten, which gave him his puffy appearance. It was not until that point where he had associated eating fewer carbohydrates at the summer camp, and therefore less gluten, with weight loss that he was more willing to try it.

Removing gluten from the diet is not just a medical necessity, as there must also be a willingness on the part of the sufferer to change his or her diet. When symptoms are more severe, it is easier to make the switch, as seen with Dana. She saw the medical necessity of the diet change in a very straightforward manner and adhered immediately. When symptoms do not seem as severe initially, there must be a point where the individual comes to terms with the illness and realizes that it is in his or her best interest. This is similar to Lisa's recent decision to try removing gluten from her diet due to a suspected wheat allergy. While she has been recommended to try the diet in the past, she credits this attempt to an increased maturity and

being “ready.” Similarly, Taylor went through a phase where she did not adhere to the gluten free diet because she did not really understand what it was doing for her. She had not come to terms with her illness prior to that point. Finally sticking to the diet may seem like a necessity that forces you to comply, but it takes an acceptance and coming to terms with the situation to actual make it happen.

Joe now notices that his symptoms are much worse if he is exposed to gluten and thinks that it is never worth eating, that is unless it is the best food of that type ever made. Only then is the chance of grogginess and stomach pain worth it. Despite his current emphasis on keeping to a gluten free diet, Joe was not quick to get on board in the first place. Joe’s initial apprehension towards eliminating gluten was similar to Brad’s in that Joe already had to restrict dairy from his diet. Brad originally heard that giving up dairy would help with his lethargy and joint pain, but that diet would be much harder for him due to the fact that he keeps kosher. He already does not eat meat outside of the home, so eliminating dairy as well seemed to be too difficult for him. For individuals with celiac disease or wheat allergy, it is clearer what the proper treatment is, which is to simply eliminate gluten. For NCGS sufferers, however, they often have to experiment with different food groups in order to see what it really is that is causing the suffering. This makes it hard for NCGS individuals to navigate their illness since there is often a lack of a definitive answer.

### *Grocery Shopping and Dining Halls*

The problem with gluten free items is because of the market and the ingredients. The upcharge is insane. What most people would pay for an item is like triple. I’ve noticed its basically standardized triple the price of what it usually would be. And I would understand a little bit more because they have to go out of their way to make it because it’s a smaller market that they are providing for and the

ingredients tend to be a little bit more expensive but honestly, I do feel that there is sort of an abuse with the allergen hype, especially with gluten allergies because its so recently popularized. If I want to get dairy free, gluten free cake, I am spending like four dollars to six if it is a nice cake and that is insane. I always have my parents buy me stuff and being at this school I have the option to go to the allergen section of the dining hall. The standard substitute item would be gluten free bread at home but if I go to a restaurant I will see if they have a dessert that I can eat. I would say bread and dessert are the two items that I feel like I need. Desserts are really hard to find so whenever I find one I totally freak out. It's rare to find, especially one that is good. I spend more money on this stuff and its absurd, but you have to. I think Union's options for schools are pretty impressive, but I think for the world, they are probably just meeting enough. Because I don't have celiac disease, I can go to the regular section and get foods that probably have cross contamination. I pretty much ignore it and it probably isn't good for me but if I were stressed about cross contamination, my options would go from ten to two. I wouldn't be able to eat almost anything. There isn't enough food in the allergen section of the dining hall for me to feel like I can live off of it. Even if there is food in there, it is hard to find a balanced meal. Compared to my boarding school in Utah, this is phenomenally better. All they offered was gluten free bread, so whatever they were serving, they threw it on a gluten free bun. There were days where I would talk to the chef and be like 'hey man, I feel like I'm not being provided for and I'm paying college prices to go to this school' and he's like 'you know we try to accommodate but some days its just the salad bar for you.' I understand that, but it's still shitty to hear. You pay money to go to a school where you're not provided for.

A huge barrier that Joe faces is the high cost of buying gluten free items. It is understandable since food companies are catering to a smaller group of people and the ingredients cost more, but he still thinks that the industry takes advantage of the situation. Joe also attributes high prices to the fact that these items have a shorter shelf life, so fewer items can be made at a time to ensure that nothing is wasted. Unfortunately, the higher prices are just something that sufferers have to

deal with. Lisa and Brad also mention the expense burden, but acknowledge that there is little that can be done about it. Many of the bakery owners at the Gluten Free Expo actually started baking gluten free items to make cheaper alternatives for themselves and/or loved ones, but that takes some effort and skill that not everybody has the time or patience for.

At the college dining hall, Joe claims that it is hard to find a balanced meal. While there may be a full meal choice available, you are restricted by only having one option. If a normal person does not like one meal item served, they simply look to the next option. But for Joe, if he does not like the one gluten free option, then he is on his own to find dinner for that day. This goes back to the pickiness mentioned previously. Gluten free individuals do not have the luxury of being picky, and have to deal with their options as best as they can. Whereas Taylor and Dana are content with a salad, Joe is more concerned with finding items from different food groups to get the nutrients for a balanced meal. This makes it a little bit harder for him, but he makes up for this in his more relaxed view on cross contamination. Dana, for example, is very strict with cross contamination and would rather have a less sufficient meal than get sick whereas Joe has less of a fear of cross contamination. Therefore, he is able to get a piece of meat or vegetables from the regular section of the dining hall that may or may not have come into contact with gluten. All individuals need to decide what is more important for them in order to learn to live with his or her restriction. Joe speaks up and tries to advocate for himself to get the food that he needs, but is often told that he needs to just work with what he has. This is frustrating for Joe, but it is something he has gotten used to.

### *Being a Burden*

I constantly feel like I am being a burden. That is the hardest part I would say about being gluten free. Like for example, when I go to Rathskellar, it takes me

about five minutes to order my food and I know people are hating me and I feel embarrassed because these people don't deal with gluten free orders enough to know how to process it. I have a reputation with my friends like 'oh you don't want to go get a meal with Joe. Be prepared to spend twenty minutes ordering.' But that's what happens. I have to talk to them about different substitutes and options. Like one day I went to a restaurant with my friends and wanted to order a steak, but the steak came with a sauce that I couldn't have, and all I wanted was a regular sauce. I even would have accepted ketchup, but you know they wanted to provide because it was an expensive steakhouse and they felt bad. The waitress was giving me some options that I couldn't have so she got the hostess who then got the chef to come out to the table and before I knew it, there were three people helping me and the chef ended up making me my own fancy sauce but it was a twenty minute ordeal. Honestly, I wish I just said I didn't want sauce. Everyone was laughing and I know they were annoyed. I always feel like a burden. I am always hassled by friends who say 'our meals would have been here if it weren't for Joe.' Also, I have gone on trips with schools where they have a budget and it's awkward because they have to spend an extra meal's worth for me that they didn't account for. I have had times where I have ended up paying for my own meal when it was supposed to be provided for because its just too much of a hassle to express my dietary needs.

Students all the time question me asking if I am really gluten free or if it is just an option for me. They ask if I am doing a diet. People will see me eat fries and say 'oh doesn't that have gluten in it.' And that's the other thing. Sometimes I want to cheat a little bit just to try something but after making people go through the burden of waiting or having to order something extra, I can't, because then its like 'oh you're not even gluten free.' It makes it seem un-legit but if I ate four of that I would be really sick. It is hard to get away with without making people question you.

Joes says that the hardest part for him about being gluten free is the constant burden he feels from the individuals he impacts, whether it is making them wait a longer period of time to order, or spending extra money on a separate meal just for him. He thinks that he should not have to

feel this way because it is not his fault, but it is hard to relay that message to people. He gets a bad reputation amongst friends that makes them not want to get a meal with him. Friends of Joe often ask if he is “really gluten free,” which ties back to Taylor’s desire to preface her interactions with people. All Taylor needs to say to people, though, is that she has celiac disease and they immediately understand. Since Joe has NCGS, it is not as straightforward. He needs to give more of an explanation of himself in order to receive validation.

Similarly to Taylor as well, people constantly question Joe, asking if certain things he eats are gluten free such as French fries. If you stick to being gluten free all the time, then outsiders can get on board. However, if you ever steer off the gluten free path just to try something, it can invalidate everything that you have worked to prove. Dana mentions this frustration with people who claim to need to be gluten free, but then “cheat” at times when it is convenient for them. Dana does not live by this same mentality because the side effects are not worth it for her, even if she is going to the greatest cupcake store in the world. It is understandable for people like Dana to get frustrated with people who want to cheat because it causes people to invalidate the collective gluten free community. But Joe claims to be “really gluten free,” it just works differently for different people. There are not only differences between celiac disease and NCGS individuals, but also variation within the two groups. The NCGS differences are clearer since people often show different symptoms at different severities, but there are also differences amongst celiac disease individuals. Just looking at Taylor and Dana, it is clear that Dana is more sensitive to the effects of gluten and therefore has to be more careful about cross contamination. This common mentality of cheaters bothers Joe because he has to sensor what he eats, not only for himself now, but also for the approval and validation of others. Most gluten free individuals, regardless of their diagnosis, want other people to understand and

justify what they are doing. NCGS individuals, though, feel more of that burden since they are more narrowly understood.

### **Conclusion**

Through an analysis of the illness narratives of Taylor and Joe, we are able to better understand how individuals deal with the burden of their invisible, chronic illness. They must deal with the frustration of being deemed as eating gluten free for healthy eating purposes as opposed to recognizing that gluten makes them physically ill. They must communicate their justification to get acceptance, as well as ensure the safety of the food they are receiving. It is about more than just symptoms, and just as much about navigating social situations. Individuals with a gluten related disorder must deal with inconveniencing those around them, not only for chefs having to accommodate them but also friends having to wait. They must deal with the constant questioning of peers as to what food is being put into their bodies as their legitimacy is questioned. NCGS individuals more specifically have to always filter what they do to avoid scrutiny from outsiders. Despite the type of gluten related disorder, whether medically recognized or not, being gluten free is not a choice.

## Chapter 3: Medicalization and the Quest For Recognition

### Introduction

Illnesses exist far beyond the scope of medicine to encompass the cultural realities of the time period in which they exist. What constitutes as a medical disorder has shifted throughout history as medical knowledge and society both evolve. Homosexuality, for example, was considered a disease until 1973 when the classification was removed from the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) (Silverstein, 2008). Activists helped to change misinformed views of the sexual orientation, attempting to decrease stigma and helping to establish civil rights protections (Silverstien, 2008). In addition to removing medical classifications, cultural circumstances have also led to the increase in many diagnoses since society's views of what constitutes normalcy are constantly transforming. Many previously nonmedical problems are becoming defined and treated as medical problems, a process that scholars call "medicalization" (Conrad, 2007). A problem that people experience shifts so that it is described in medical terminology, understood through a medical framework, or "treated" with a medical intervention (Conrad, 2007). Similar to the demedicalization of homosexuality, medicalization can have benefits as well. Having a problem classified as medical can provide social acceptance and focus resources on ways to help sufferers. Non-celiac gluten sensitivity (NCGS) individuals yearn for medical recognition of their illness to provide greater legitimacy of those around them. The medicalization of NCGS would not only reduce stigma, but it would also allow for advancement in the field through increases in scientific studies, accommodations, and overall acceptance.

There can be degrees of medicalization. Factors affecting the degree of medicalization are likely "the support of the medical profession, discovery of new etiologies, availability and

profitability of treatments, covered by medical insurance, and the presence of individuals or groups who promote or challenge medical definitions...” (Conrad, 2007 p. 6). In the case with NCGS, we see multiple factors contributing to the medicalization process. To begin with, there is increasing support from the medical profession. Many physicians recognize that their patients are suffering, but acknowledge that they do not have the medical knowledge to help. They often tell patients that they cannot say for sure that a gluten free diet will alleviate their symptoms, but suggest trying it regardless since they have seen scenarios where it has helped. Some physicians have seen so many instances of patient suffering that they have decided to do their own research to help sufferers get answers. The discovery of new etiologies is crucial for the state of the medicalization of NCGS. NCGS differs from celiac disease and wheat allergy, which are both medicalized, in that the cause is still unknown. New scientific evidence, however, supports the idea of underlying pathophysiology despite details still being unclear (Biesiekierski et al, 2011; Sabatino et al, 2015). This undetermined etiology places NCGS into a limbo state where it still does not receive all of the support that its sufferers need. NCGS can still become medicalized without more biological discoveries, but it would significantly help the process to unfold.

The availability and profitability of treatment for NCGS exists in the shifting increase of gluten free availability of food options. By 2020, the market for gluten free foods is projected to grow to \$7.59 billion (Bender, 2017). Its presence goes far beyond grocery stores to accommodate individuals throughout restaurants and dining halls. NCGS coverage by medical insurance is somewhat irrelevant for the illness right now since the treatment is not in the medical realm, but it is possible that this could change in the future if medical interventions are discovered. Arguably the biggest factors affecting the medicalization of NCGS are the sufferers and their family and friends who promote it by challenging its current state in the medical

community. Without this group of individuals, there would be no urgency to define the set of symptoms.

Understanding the benefits of a medical diagnosis can be understood by comparing NCGS to celiac disease or wheat allergy. What does the medicalization of these illnesses offer those groups of people that are beneficial? In other words, why is medicalization appealing? While I am examining positive aspects of medicalization, it is important to note that there are also negative aspects to this process. A label can confine a person to behaving in a way that is often limiting. Viewing a set of symptoms in a medical way can sometimes stigmatize a group of individuals to be viewed as sick. For example, when homosexuality was viewed as a disease in the past, it constrained individuals with the belief that there was something wrong with their pathophysiology (Evans et al., 2010; Silverstein, 2008). The medicalization of an illness can also have negative consequences since it can lead to over-diagnosis. Over-diagnosis is more of a problem when a disease has a medical treatment since a person can be ingesting chemicals and therefore bearing risks that they may not need to. Over-medicalization can also decrease the legitimacy of those who really do have the disease, as in the case with ADHD. Since so many people are prescribed medication, it makes those who really do need them feel less validated (Conrad, 2007).

With the case of NCGS, however, medicalization would provide a variety of benefits. A diagnosis would decrease stigma for sufferers. Currently, they experience an initial shame when telling people that they cannot eat gluten because they fear that outsiders will assume they are doing it for reasons within their control. A diagnosis tells people that avoiding gluten is not a choice so that they do not have to tell others themselves. The constant need to justify oneself becomes tiring. “If you have to prove you are ill, you can’t get well” (Hadler, 1996). Someone

with NCGS may experience feeling extremely ill, but without a diagnosis, society will constantly challenge them. They spend so much effort trying to prove the way they feel, which gets in the way of the healing process (Hadler, 1996). When your experience is confirmed, the results can be therapeutic; bringing a name to symptoms brings relief. It brings reassurance to the sufferer that symptoms are real and not the cause of something they made up in their head (Hadler, 1996). Furthermore, a label would help to distinguish them from the fad and from being a “fussy eater” to being a person who gets ill if they do not follow their restriction guidelines. It provides legitimacy to the symptoms they experience and their need to have alternative food choices. This chapter examines the setting for which the medicalization of NCGS is taking place, the persistence of suffering currently without a diagnosis, and what sufferers have to gain from an NCGS label.

### **A Consumer Driven Illness**

We live in a society where the biomedical perspective dominates. The physician-patient relationship is unequal in that the physician holds the information and status while the patient is expected to comply without questioning medical authority (Weber, 2016). The physician is trained to examine the illness experience to uncover the cause rooted in pathophysiology. Although not always useful, the patient is taught to think this way as well. “The patient learns to focus on symptoms-record them, quantify them, live them to the fullest, and describe them in hopes of teasing out any iota of meaningfulness” (Hadler, 1996). Brad, too, thinks “as a society, we’ve moved to a point where when people don’t feel well, they want a reason. I certainly have that, I need to know why. It’s not enough to just treat symptoms I want to know why.” A patient just like Brad is looking for a diagnosis to help him or her understand what is going on. He has a

scientific background, but most people feel this way regardless of whom they are. They often go crazy searching for meaning from a diagnosis, despite there not always being one that a test can lead you to. When this medical hegemony fails patients, they decide to put matters into their own hands, which was definitely the case for Brad. He hunted for meaning to explain his symptoms. Medicalization is changing, in that physicians are no longer the main players. Joining them are equal or possibly even more powerful players in the medicalization process, the patients advocating for their own care (Conrad, 2007).

### *Physicians First*

While not as central to the medicalization process as they were in the past, physicians are still important players. Most individuals suffering from NCGS symptoms first seek help from the physician. They go to the doctor in hopes of finding answers. For many illnesses, a physician is necessary to perform a diagnostic test and administer a medical treatment (Conrad, 2007). For an NCGS individual, all tests will come back negative. They do not have celiac disease, wheat allergy, or any other diseases or allergies. Some physicians may suggest trying a gluten free diet while others will decide to do so outside of the influence of the medical office. Where NCGS is different than many other illness is that the treatment does not require a prescription. Anybody can get access to gluten free foods. Individuals with NCGS often want their physician for legitimacy purposes, but they do not physically need anything from them; they can manage their illness alone if need be.

In Lisa's case, tests for her likely wheat allergy came back unclear. While she has had stomach pains in the past where gluten elimination was suggested, she more recently has focused on her rash symptoms, which lead her to a dermatology office.

It was almost looking like a bad break out on my face, it wouldn't go away but it was like a rash and it's not commonly on your face. It's more on your arms type of thing but it's really possible when we talked about how diet would play into that. It's not something that [the physician] is necessarily going to recommend but would understand that it could make sense. Her medical opinion would be that diets not going to do anything but as a side bar it was kind of like patients have had success with it in the past.

Tests performed on Lisa in the medical setting did not come back with any conclusive evidence. She may have a wheat allergy or some form of NCGS, but there was no concrete data telling Lisa that she cannot ingest gluten. The physician made it clear that from the perspective of her medical expertise, she cannot provide any definitive treatment plans that are known to be effective in the medical community. What the physician can give, though, is advice from experiences treating other patients. While she cannot understand why, other patients in a similar situation to Lisa have had success so it is worth suggesting. This is not an isolated incident. Many physicians are increasingly suggesting treatment plans for patients with suspected NCGS based on first hand experience with patients who were once suffering, and no longer are. This goes against medical hegemony in an extremely productive way. The physicians are going against what has been engrained in their mind, data and proof, to be more open-minded about best treating patients. Other individuals will go to the physician initially, just like Lisa, but they do not get the same type of positive feedback as a stepping-stone towards relief from suffering.

### *Anyone Else Second*

NCGS individuals often go to physicians who are gatekeepers, yet when this does not result in satisfactory care, they search beyond the medical profession and seek further answers. When Brad and his daughter were experiencing “joint pain, lethargy, brain fog, and fatigue,” they first

went to their physician to figure out what was going on, yet nothing seemed wrong with them based on the medical tests. As a scientist and research-oriented individual, Brad decided to take matters into his own hands and search through the literature in hopes of finding answers, and he did.

There is an association between Chronic Fatigue Syndrome and autoimmune diseases. So I started reading and I called my friend at Hopkins who is an expert in Chronic Fatigue. I met him at a conference a couple of years ago. We got to talking and he said ‘you know, we found in a study that 30 percent of patients with Chronic Fatigue Syndrome have an undiagnosed, delayed type of sensitivity response to dairy.’ And he said ‘that’s only 30 percent of the patients. What about everybody else?’ So I said ‘could it be gluten?’ and he said ‘that’s our next study.’ So I thought, okay, joint pain, fatigue, lethargy, brain fog. It adds up to be Chronic Fatigue Syndrome and have some autoimmune component. So I told this to my wife and told her that I think we should put our daughter on a gluten free diet and she said to me ‘you know, what’s good for the goose is good for the gander.’

Despite much hesitancy to take the leap and give up gluten, Brad told his wife that he would try it for a few weeks, and to much mixed emotions, it alleviated both his and his daughter’s symptoms. Brad did not find any solid evidence that eliminating gluten would help him, but it made sense to him that it could potentially work based on his on literature review and conversation with a colleague in the field. Brad saw this connection between gluten and his symptoms as where medicine is headed next. At the point where nothing has relieved suffering in the past, eliminating a food item is worth trying. The worst-case scenario is that nothing would change, in which case he would simply return to his normal diet. While it does help, a PhD is not required to search for answers. If symptoms are debilitating and physicians provide no help, searching the Internet is a natural next step for many individuals.

In addition to Brad, there were two other women I spoke to who reported gluten affecting their joints. I met Mary at the Gluten Free Expo in Albany where she was giving out samples of gluten free bread that she sells, the recipe of which was created by her son to help with her arthritis. Mary had originally been under the care of a physician to aid in the treatment of her arthritis, which resulted in the need to take many different medications. While already frustrated with the amount of medication she was taking, Mary heard that gluten might aggravate the joints, so she decided to try eliminating gluten from her diet. Ever since, she feels like she does not need any arthritis medication. She swears by the effectiveness of a gluten free diet, despite the judgments of others. Most prominently, she calls out physicians for being in denial of the real impact that gluten has. Mary found a better alternative for her suffering than that which the physicians offered. Mary questions the knowledge of the medical community and their inability to recognize that there may be a better solution to medication than they are aware of.

Similarly, Marissa, a recent college graduate, and her mother have been suffering with arthritis for many years. Since going gluten free, her need for medications has greatly reduced. She used to take three pills a day and now only takes one. Similar to Lisa, Marissa initially got the idea from a physician who said it is possible it could work, but he does not have any medical proof. Marissa has looked further into the treatment of her arthritis with a gluten free diet by exploring books about the negative impacts of gluten, such as *Grain Brain: The Surprising Truth about Wheat, Carbs, and Sugar--Your Brain's Silent Killers* by David Perlmutter MD. Like many people with NCGS, Marissa took the education into her own hands since she did not get much information from her physician. Because there is no formal evidence, the consensus on the effectiveness of a gluten free diet is inconclusive amongst physicians. Some question it entirely while others are more open-minded after seeing successes amongst patients. Yet even the open-

minded physicians are still hesitant when giving advice to patients by prefacing the suggestion with the fact that this is not within the scope of their knowledge, shifting the responsibility from the physician to the patient.

### **Alternative Diagnoses**

Even when a physician is able to help guide a patient to try a gluten free diet, there is still no diagnosis that is made. Sufferers are lead to often self-diagnose, or get a diagnosis via word of mouth or by a friend. While diagnoses from a physician seem more legitimate, it is often not possible, so sufferers settle for the next best thing.

Brad's diagnosis essentially came from the recommendation of a colleague while Mary's was through word of mouth. Brad mentions this trend himself, "there is also a word of mouth type of spread where one person hears of another trying a gluten free diet so people do it even though they haven't been tested." People become intrigued by what they hear, and consider it for themselves since nothing else has helped up until this point. Although initially suggested by a physician, Marissa's diagnosis was propagated by information that she read in books. In addition to her readings, Marissa hears a lot of theories about gluten in her workplace, a special education classroom. Of nine autistic young children in the class, four are gluten free. Information has spread about the relationship between gluten and poor brain health, so many autistic parents believe it is worth trying for their children. The negative beliefs surrounding gluten in some aspects spread the negative thoughts of gluten in others. Since Marissa hears how gluten is bad for the brain, it further confirms her negative conception of gluten during her self-diagnosis and discussions about possible diagnoses for others.

Diagnosis-seeking behavior is a crucial aspect for the medicalization of NCGS. “This kind of self-labeling, information exchange, and pursuit of diagnosis fuels the social engine medicalizing” NCGS (Conrad, 2007 p. 59). This type of behavior strengthens the cultural aspects of medicalization, only further propagating it. When a person labels himself or herself, it brings more attention to the need for such a label.

### *Taylor's Diagnosis*

Taylor's diagnosis seeking behavior is quite distinctive, and only further shows how crucial it is towards the medicalization of NCGS. She identifies as having celiac disease, so much so that she considers herself “real gluten free” during conversations with people. The reality is, she was never actually given the celiac disease diagnosis from a physician, despite there being a test to identify the disease.

I have celiac, my mom has it, and all of my sisters have it, I have four sisters. I also have a younger brother and we haven't tested him but we are kind of assuming he has it. He is on a gluten free diet. As of now, to be tested, you have to be sick already. All of us went through that, we ate gluten. I was five when I was diagnosed and at that point my teeth were not great, some of them didn't have enamel...I was having symptoms just in line with malnutrition... my sisters had the same sort of things going on and we didn't want that to be my brother...Actually when I was diagnosed, I tested negative for it both times. But my mom knew, I had all of the symptoms and stuff. So she just put me on the diet and ever since I've stayed because we kind of just know I have it.

Taylor directly says it herself: “I have celiac.” But she really does not know for sure since the test came back negative, not only once but twice. Still, though, Taylor has a family who is extremely knowledgeable, so it makes sense that she really does have celiac disease. She has many of the symptoms of celiac disease along with an extensive family history. The negative

results actually helped to fuel Taylor's "rebellious stage." "I knew I tested negative so I would argue that I don't really have [celiac disease]. It doesn't matter, so I would go eat gluten at my friends' houses." Even Taylor was hesitant of her diagnosis at one point that her mom had to reassure her that just because the test was negative, does not mean she does not have it. Her mom told her that when she is done growing, she can eat gluten for a month and get tested, but it never seemed worth it for Taylor because in order to be tested, you have to get sick. Without eating gluten, the physician would not be able to see the negative impact that gluten has on the body of individuals with celiac disease. At this point in her life, Taylor trusts that she has celiac disease because she feels ill when she accidentally eats gluten. She blames the test results on something faulty occurring in the lab at the time since false results happen from time to time. Taylor also does not have her celiac disease managed by a gastroenterologist since her family is so knowledgeable about the subject. This is just another example of how sufferers are taking matters into their own hands and relying less on the physician. The fact that she identifies as having celiac disease despite not being absolutely positive speaks great lengths to the importance of a diagnosis and the shift towards a diagnosis that can be made by someone other than the physician.

### **What is there to Gain?**

The flow of knowledge about NCGS, along with the increases in self-diagnosis leads to a community of sufferers who are collectively seeking medicalization. This leads to the push for more information to be discovered through further studies, great awareness amongst physicians, and the growing gluten free market in grocery stores and restaurants. Through this

medicalization process, sufferers are yearning for something invaluable: a label. With this label comes a variety of benefits that they cannot get from anything else.

The most common similarity amongst all of the individuals interviewed with a gluten related disorder is the fact that they do not want to be confused with “the fad,” meaning individuals who avoid eating gluten for reasons beyond celiac disease, wheat allergy, or NCGS. Most commonly, they are doing so because they believe it will make them healthier, or lose weight. Giving up gluten for these “wrong reasons” has become somewhat stigmatized in our society, leading gluten related disorders to sometimes be stigmatized when the intentions of these individuals is not initially known. Lisa says “when I talk to people about my gluten free diet they think I am doing it because of a fad, but I actually have stomach issues and rashes.” For Dana, “there are some people that do it just for fun, which I don’t understand but the fact that there are those people, I think that makes other people think ‘oh its not that serious...’” But it is serious for these sufferers. To mitigate this problem, Taylor prefaces her conversations with the fact that she is “real gluten free.” People would often ask if she has celiac disease or is just doing it to lose weight, so it is easier to let her disease be known right away. Taylor wants people to be clear that this is not a decision that is under her discretion. “I would be eating every piece of pizza in sight if it were a choice.” Having a medical diagnosis proves to people that the choice is not their own. That is what celiac disease and wheat allergy individuals currently have that NCGS sufferers want. Individuals like Lisa, Dana, or Taylor may be initially annoyed at the stigma they receive, but as soon as they make their condition known, they get immediate approval from others. They no longer need to constantly explain themselves. They are legitimized in two words: celiac disease or wheat allergy.

NCGS sufferers do not have this luxury. Even when they explain themselves, it never truly ends. Just like the medicalized individuals, Joe experiences “students all the time question me asking if I am really gluten free or if it is just an option for me. They ask if I am doing a diet.” But it doesn’t stop there. Even close friends who are well aware of his situation question him constantly.

Sometimes I want to cheat a little bit just to try something but after making people go through the burden of waiting or having to order something extra, I can’t, because then its like ‘oh you’re not even gluten free.’ It makes it seem un-legit but if I ate four of that I would be really sick. It is hard to get away with without making people question you.

Joe has to be very careful of his actions so that he does not make people question him even more than they already do. If he decides to “cheat” even in the smallest way, it automatically delegitimizes his need for alternative food choices despite the burden Joe puts on other people while making them wait twenty minutes for him to place his complicated order. For a medical condition, people are willing to go through that because it is not the sick person’s choice. But for a non-medical condition, someone like Joe will be confused with just a “fussy eater.”

Furthermore, having a diagnosis confirms your experience, which can have a therapeutic effect. Giving a name to symptoms and disability brings relief, which can allow the individual to start the process of relieving their suffering. If the individual has to constantly prove they are ill, the process is delayed. When people constantly question what Joe is eating, saying “doesn’t that have gluten in it?” then Joe is constantly on edge trying to prove himself. Instead of eating in a certain way for his own sake, it turns into eating to appease outsiders’ assumptions of how the sick person must act. This type of behavior only makes the NCGS individual continue to suffer, when they should instead be striving towards relief.

## **Conclusion**

In a society where the biomedical community has the ultimate authority, NCGS sufferers try to seek validation from inside of the physician's office. When all tests come back negative or inconclusive, they have no choice but to search for answers beyond what is understood in terms of pathophysiology. Increasingly now as greater awareness of NCGS spreads, some doctors suggest that gluten may be the symptom-inducing culprit. Regardless, the sufferer can only receive an NCGS diagnosis outside of the medical community from word of mouth, friends, or yourself. NCGS individuals are on a quest towards medical recognition to lead towards awareness of the illness, as well as to further progress in the form of scientific studies, accommodations, and recognition. Only through the medicalization of NCGS can the stigma of being on a gluten free diet be diminished. Sufferers will no longer need to prove that they are not a part of the fad. The fact that this is not a choice can be better understood, all bringing legitimacy to these sufferers. The burden they put on others will be justified because it is beyond the person's control, not because they are "picky." Once NCGS individuals stop having to prove themselves, their experiences will be confirmed and they will finally be able to get relief.

## **Chapter 4: The Role of Community in NCGS**

### **Introduction**

The medicalization of non-celiac gluten sensitivity (NCGS) is largely patient and consumer driven. NCGS individuals desire recognition of their condition, which can lead to greater emotional and physical support as well as advancement in scientific knowledge and medical treatment. When patients have unexplainable symptoms, they often first seek validation from the medical community. When that process fails them, individuals have no choice but to take matters into their own hands. Given the lack of well-known information, acknowledgement, and acceptance from the physician's office, individuals with NCGS have to search for their own diagnoses, answers, and assistance. They seek out and sometimes even create their own communities for addressing their concerns and educating others who are at a different stage in the journey. Sufferers may not be able to get a concrete empirical answer, but they can get tips from people who have gone through a similar situation.

The current model of our healthcare system is geared more towards acute illnesses or injuries and less towards chronic diseases, especially invisible ones like NCGS (Wagner et al, 2001). An immediate problem is often seen and treated right away. This comes with a sense of instant gratification for both the patient and the physician. This system creates a very passive patient since there is no need to acquire any sort of self-management skills, as the doctor takes care of everything (Wagner et al, 2001). This is not the case for chronic illnesses that cannot be treated quickly and completely, requiring continuous support and care. The responsibility shifts from the physician to the patient, requiring him or her to become an active participant in the management of care. In addition to dealing with symptoms, NCGS sufferers have to cope with

emotional impacts and lifestyle adjustments. They need to find support for their physical, psychological, and social demands beyond the world of medicine (Wagner et al, 2001). Thus, this chapter looks at the community for gluten related disorders and NCGS in particular and addresses what role this community has served in the lives of these individuals. Communities large or small and face-to-face or through the Internet are all important for support, legitimizing suffering, and educating people whose questions up until this point have yet to be answered.

### **Family and Community**

The smallest scale of community that individuals with a gluten related disorder receive is from their family members. Even if they do not have the same types of physical distress, they do bear the burden of much of the psychological anguish. Family has a major influence on the way a person adjusts to and manages his or her illness. A large benefit of family members for chronically ill patients and NCGS in particular is ease of following treatment, or removing gluten from the diet (Martire et al, 2004). Those who are fortunate enough to have a solid family support system find it easier to adhere to and cope with their necessary lifestyle changes.

When the medical community is unable to provide a diagnosis and treatment, individuals seek treatment elsewhere. Their first line of support often comes from family members who want to help. This is certainly the case with Brad, who initially became concerned with gluten not just because of his own symptoms, but mainly because of his daughter's symptoms. Brad's daughter has a support system that was able to search for answers for her, coming to this NCGS realization through word of mouth and a recommendation from colleagues. We also see on the other end how Taylor's mother is a key advocate for those with gluten related disorders by helping to educate and support others. Whenever family members tell Taylor's mom about

symptoms they are having that could be related to celiac disease, she tells them that they should try the diet. Some cousins have given it a try, but then stopped when they did not think it was doing anything to help their symptoms. She does not suggest that everybody would benefit from a gluten free diet like some other healthy lifestyle advocates, but thinks it is worth trying especially since celiac disease is hereditary and so many members of their immediate and extended family members have the disease.

In addition to just gathering information about gluten related disorders and self-diagnosing, the next challenge is then the choice and practice of eating gluten free. As mentioned previously, it is not easy to follow this lifestyle and those who have to follow this diet for health reasons insist that they would not choose to do this given how difficult it is. Therefore, having a community, in particular a family, that offers support is key in terms of managing to actually eat gluten free. We see this very much so with Taylor whose entire family eats gluten free. Since removing gluten is the norm in Taylor's household, it is very easy and stress free to find food in her home. Even her father, who is the only family member without celiac disease, follows the gluten free diet since everybody else needs to do so and it is readily available to him, but also to be supportive. Taylor never has to worry about what she eats when she is at home, or even out to eat with the family since her mother takes charge of directing the process. Taylor has it easier than most due to her extensive family support system. This goes beyond just her immediate family since other extended family members are gluten free, while the rest simply understand its importance. Being surrounded by individuals who do not doubt eating habits makes it much easier to live with the gluten related disorder.

Although at a much smaller scale, Brad and his daughter have a similar family support system pertaining to their gluten free diet. Brad's initial motivation for finding out what may be

causing particular symptoms was to relieve the discomfort that his daughter was feeling. The desire for information was more to help her, but secondarily helped Brad as well since he tried the diet alongside her as a form of motivation. Since they both felt better after removing gluten from their diets, Brad and his daughter decided it was best if they continued. The two support each other along this new journey, advising each other in regards to new things to try and others to avoid. Most importantly, they have a person who they are close to who understands what it is like to be going through this process. It is nice to know there is someone to go to who understands what you are going through, whether you take advantage of it or not.

This form of parent-child assistance was common amongst others whom I interviewed at The Allergen and Gluten Free Expo. Mary, for example, was suffering from severe joint pain, which lead her to live gluten free. She had constantly complained about the poor bread options, so her son decided to try to form his own tasty recipe. This was in fact the norm of the gluten free companies. One business originated because the owner's children had a gluten related disorder, while two sisters, one of which had a gluten related disorder, formed another. In fact, one business sold gluten free pet food since a dog owner could no longer serve her pet gluten. Often times, business stem from the needs of family members and successful recipes that arose from years of trial and error. So many other people outside of the family experience the same desire for food that they are allowed to eat, without sacrificing the taste component. Recognizing this niche environment, these once family centered businesses branch out to help a larger community with similar difficulties.

### *The Capital Region Allergen and Gluten Free Expo*

Some individuals have the assistance of family members or friends to help cope with their gluten related disorder while others are lacking in that area. There are other forms of community to help fill that void, or supplement existing support systems, on the local level. One example is The Capital Region Allergen and Gluten Free Expo, “a comprehensive educational experience for those who suffer from allergies, asthma, gluten sensitivities and celiac disease.” It took place in Crossgates Mall in Albany, New York, whose main sponsors were MVP Health Care, Price Chopper, and Saratoga Schenectady Gastroenterology Associates. These sponsors, along with the connection to food allergies, show an association between gluten free living and the medical community and therefore increased validity. This is shown even further with the message from a main planner of the expo, Christine Sisto Mertes.

I'm more than just the co-owner of Capital Affairs, the event planning firm of the Capital Region Allergen & Gluten Free Expo. I am also the mother of a 8 year old daughter and 6 year old son who, like me, suffer from a myriad of auto immune disorders which impact our daily lives...I have lived their discomfort, remedied their ailments, and sought a better way of life for them. But none of it could have prepared me for my daughter's diagnosis of Celiac Disease, less than a year after my own personal diagnosis of this very difficult disease. It has been quite a journey. There is so much that a family faces when learning that one of its members has been diagnosed with an allergy or immune disorder. Emotions range from fear to one of empowerment. You finally have your answer, but what comes next? From finding the right team of practitioners, to determining pharmaceutical or natural treatments, to formulating the most beneficial diet ... there is much to consider. At the Capital Region Allergen & Gluten Free Expo, we hope to offer guests a comprehensive educational experience. We will feature a diverse slate of sponsors and vendors with a passion to share their expertise with the newly diagnosed, as well as anyone looking to expand their knowledge. But nothing we offer will be more valuable than the direct face-to-face conversations between consumer and vendor. Each of our guests have a hunger

and sincere desire to learn about products, treatments and activities that will enhance their potential for wellness. I should know...I am one of them!

Christine experiences coping with chronic illnesses including celiac disease on the familial level, and aims to use that experience to support the community. With so much to consider when dealing with these problems, it helps to listen to other people who have gone through it before. Christine emphasizes the benefit of the direct face-to-face conversations on the consumer's journey towards wellness. There are benefits to online resources, but there is a gained element when speaking about these issues in person.

Spanning a large section of the first floor of the mall were over fifty exhibitors set up in rows of tables with information to share with anyone in the community who was interested. Some stands focused more on education while others gave out food samples and items to purchase. While many local businesses were present, a few individuals in particular were showcased. These highlights included two cooking demonstrations along with the "Ask the Doctor" booth presented by a gastroenterologist. The expo had a variety of different outlets for individuals seeking community for support and knowledge. Although businesses wanted to sell their product, it was done in a tasteful way to make their intentions seem sincere. Yes, it is a business, but it was obvious that these local gluten free product companies wanted to help individuals so that they do not have to go through all of the time and effort experimenting like they had done. They are genuinely happy to make a positive impact on the lives of those suffering from gluten related disorder, and family members who struggle to provide support.

## **Virtual Communities**

With Internet access allowing consumers to get information about almost anything, it is no surprise that chronically ill individuals would use it as a resource to guide them through their illnesses. A study by Coulson and Knibb (2007) aims to explore the participation in online support groups for individuals affected by food allergies, which has parallels to understanding gluten related disorder behaviors. The participants of this study state a variety of benefits for participating in an online support group. Firstly, these outlets are extremely accessible. There is no time limit to the support; participants are not limited by their schedule since there is 24-hour access to these communities. Most emphasized is the social support that many sufferers yearn for, reducing their feelings of social isolation. While some times family and friends are there for support, this is not the reality for many others. Participation in these online communities alleviates the feelings of loneliness for many. These feelings are linked, for some, to the feelings of stigma and shame regarding their allergies, which is often also present with NCGS. Having a community on the Internet spreads feelings of empathy and encouragement to others who need it without the spread of judgment. Furthermore, support group members are seen as reputable sources for providing information about the topic. This information could range from clarifying uncertain facts to sharing recipes and book recommendations. Lastly, an online support group can be a useful vehicle for coping with a person's own situation. Online support systems have shown to increase the quality of life for many individuals coping with food allergies, which can also be seen with NCGS and other gluten related disorder.

### *Personal Narratives*

Many online resources involve individuals who are suffering from a gluten related disorder who want to share their stories and narratives to help others who may be experiencing similar difficulties. This social support can make individual who follow a gluten free diet feel less alone. An example of one blog is *Adventures of a Gluten Free Mom*. This blogger is a mom with celiac disease who has children with symptoms of celiac disease but has had ambiguous test results, similar to Taylor's situation with her family. She has a lot to share about her experiences to help others along their gluten free journey.

Gluten is a puzzle, one of the most confusing you will ever encounter. When my family was required to embrace the gluten-free lifestyle I was completely overwhelmed. From learning how to read food labels, talking with my doctor(s), sending my kids out into a world that wasn't safe for them, and all the while trying to maintain any semblance of a social life, I was flummoxed. Learning to adjust to unfamiliar foods, as well as give up on many old favorites, is hard enough. But trying to navigate a social, cultural, medical, and financial climate that is simply not built for your overly restrictive lifestyle is a daunting task. It seems that at almost every step of the way over the last two and half years, I have had to learn to adjust and overcome. This blog and its content are the parts of my personal journey that I have chosen to share with the world (and you will find that I choose to share a lot!).

This gluten free mom acknowledges how difficult it is to navigate this unique world socially, culturally, medically, and even financially. With constant struggles along the way, it helps others in a similar situation to go through it as well with some advice and stories to look back on for reference. This blog aims to help other mothers in particular to give them someone to relate to so they do not feel like they are going through this battle by themselves. The transparency of this website gives the reader a sense of comfort as formalized by the disclaimer. First off, she says "I

am not a doctor or any other trained medical professional for that matter, so please keep that in mind.” Also, the gluten free mom acknowledges that she often gets free samples of products to try, but writes about them honestly. She values the trust that she has gained between the consumers and herself. Even the advertisements on the website are regulated, so as to not promote anything that has questionable goals.

The duo Shauna James Ahern and Daniel Ahern are authors of another personal narrative blog. Shauna is a writer, photographer, and baker, while Daniel is a chef. Their approach to the blog is a little bit different. With the help of her husband, Shauna shares gluten free recipes while sharing bits of her life with the reader, most of the time having nothing to do with her gluten related disorder at all. When explaining what their site is about, they focus on family, friends, and food.

Here, we share stories of family, friends, and the food that gathered us around the table. We love to tell the stories of the creative people who move us: bakers, sculptors, cider makers, chefs, and photographers. And we share the insights we’ve gleaned about gluten-free baking after playing with flours for more than a decade. We’re a couple of goofballs who love food. We love thinking and talking about food, cooking food, photographing food, and sharing food. We love feeding our people... I am alive. That life involves being gluten-free, but there are so many more parts to it: funny stories, exhilarating travel, tender moments with my husband, discoveries in mouthfuls, falling down and laughing at myself, and learning how to live in the moment, every moment I am alive.

The two are all about the daily pleasure that food brings. Instead of focusing on gluten as a major roadblock, it is rather a minor background note. “Oh, and Shauna has celiac, an autoimmune disorder that means her body reads gluten as a toxin. That’s why this site is gluten-free. But I’m much more interested in living joyfully with this than in deprivation. I’m all about the yes.” Shauna and Daniel are food lovers who just happen to cook gluten free. This is a different

approach since it does not stress the difficulties of a gluten free lifestyle. This may be refreshing to some people who are tired of viewing their disease as a burden, rather than just a part of their life. Shauna discusses her difficult journey from being so ill from eating gluten to now removing it, but it is not the focus of her blog. She provides a refreshing and encouraging perspective to those living a gluten free lifestyle, which may offer individuals an alternative coping strategy. While not everyone is a chef (or married to one in Shauna's case), there are so many simple ways to not let gluten stop you from living your life, and Shauna wants to teach you about it.

### *A Broader Community Approach*

There is a shift in online communities involving not only personal experience accounts, but also those that then aim to provide additional community support beyond the online experience.

Websites such as *Gluten Free Living* and *Glutino* provide some narratives and recipe suggestions, but go beyond that to attempt to put people into contact with more resources such as local support groups and associations. *Glutino* provides a list of support groups nationwide to encourage the continuation of support.

Following a gluten-free lifestyle is considerably easier with the help of a local support group. Participation in a gluten-free support group helps to remind you that you are not alone in this process. You can share stories, taste new gluten-free products and swap gluten-free recipes!... Living a gluten-free lifestyle can be challenging, but there are many resources available online where you can visit for the most up-to-date information. Here are some of our favorites...

Glutino is a brand that sells gluten free products, but they offer far more help than simply telling consumers to buy their products. They navigate this fine line by offering their food in a tasteful way without forcing anything upon you. *Gluten Free Living* offers such a wide range of information to help sufferers navigate the community from sharing recipes, ways to save money,

and even tips while traveling as a few examples. This website also provides resources and support to try to connect people with regional or local support groups to connect with other gluten free individuals in your area. They even provide a list of camps that are safe for kids who need to be gluten free.

These broader based online communities also contribute to nationwide support and attempts to expand from local branches to organizing needs on a national level through policy, education, and research. A major example of this is the *Gluten Intolerance Group (GIG)*. Their mission is to empower the gluten free community through consumer support, advocacy, and education. The website provides a lot of similar types of recourses as other gluten free support communities, but their goal goes beyond each individual to look at the gluten free community as a whole. Instead of connecting consumers to other resources or local support systems, GIG takes a slightly different approach.

GIG Branches and Generation GF Groups are found in multiple locations and allow you to connect with others in your local gluten-free community. Through events, fundraisers, and group meetings, our GIG Branches and Generation GF Groups will allow you to become more involved in the promotion and advocacy of the gluten-free lifestyle.

GIG wants to support individuals, but they do so by looking at the bigger picture. They want to create a safe environment for those who need stricter regulations on gluten free products. A problem that many people were having was the contamination of oats during processing and storage, making a once gluten free product no longer so. GIG led the effort to standardize the production of gluten free oats to ensure that they are in fact pure. GIG is making effective change to make it safer for individuals with gluten related disorder.

The Gluten Intolerance Group (GIG), the leader in the certification of gluten-free products and food services, announced that, in collaboration with leading oat

processors, it has published an industry agreed-upon definition and requirements for operating under a “Purity Protocol”—a claim made by processors for the provision of gluten-free oats. The “Definition of the ‘Purity Protocol’ for Producing Gluten-Free Oats”, written by GIG and published by AACC International (formerly the American Association of Cereal Chemists), provides transparency to the industry and gluten-free consumers, and it allows for auditing of the Purity Protocol claim.

GIG provides further transparency through their dedication to research and verification. A program of GIG, the Gluten Free Certification Organization (GFCO) is one of the top performers in the “verification of quality, integrity, and purity of gluten-free products. GFCO inspects products and manufacturing facilities for gluten, in an effort to maintain strict industry standards.” There is also a training program, Gluten-Free Food Services (GFFS) that works with “food service establishments who would like to serve gluten-free consumers. GFFS works with experts in food preparation to develop, educate, and train service establishments to meet and adhere to the highest gluten-free standards.” These two programs are examples of ways in which GIG aims to help the gluten free community on a national level through the promotion of quality standards and policies to make life safer for gluten free individuals.

### **Communities with Questionable Intentions**

More often than not, communities aim to benefit the group of people who are in need of a support system and advice about navigating through their illness. There are some communities, however, that confuse the issue, questioning the reality of gluten sensitivities. It seems that some groups notice the increasing market of gluten free products and aim to capitalize at the expense of perpetuating the issue as a health fad. Some online blogs do so by talking about the diet as a way for everyone to be healthy. Gluten free is frequently lumped together with other diets, such

as vegan or paleo, yet these are very different. Sometimes the distinction between “real gluten free,” as Taylor calls it, and the fad is quite clear, but other times it is less so. Some people may not feel well and are unable to get answers, so they try a variety of different diets. Gluten may not be the cause of their problems, but it is a viable option since gluten is not necessary to sustain life. If the person feels better afterwards, even if it is not necessarily from gluten then he or she will continue adhering to the diet. This elimination process benefits the individual, but often gives gluten a bad reputation without being positive that gluten is the symptom-inducing culprit.

Andrea is the creator of a food cart that sells “healthy, quick food that tastes amazing” and a blog called *I Love My GFF*. GFF is an acronym for gluten free food, but her website is about much more than just gluten free. In fact, the focus is on nutrition and health instead.

Like most American kids, I grew up on a steady diet of processed food incorporated into home cooked meals and relied heavily on fast and frozen foods throughout college and early in my career to get through the busy days. In 2008, fed up with bothersome symptoms (sinusitis, joint pain, and skin rashes), I began an extensive search working with a naturopath to get to the root of these issues. The search showed me that gluten and excessive dairy consumption make me feel terrible and I would be foolish to eat them (although sometimes I still cheat). The journey led me down the rabbit hole of whole food living. I’ve learned to cook and prepare healthy foods to maximize flavor while maintaining nutrition, and to substitute what I was accustomed to with something different and better for my body.

Andrea reports symptoms similar to individuals with NCGS, but her focus is slightly different from other people I have spoken to and read about. She refers to gluten free and healthy as interchangeable terms. Her blog has a variety of different topics, some pertaining to gluten but many not. One example entitled *Running on Empty* discusses the harmful effects of skipping meals. Lunch is the focus of the article since it is your “refuel stop when you’re in the middle of

the day. Skipping lunch will result in cravings, mood swings, and hunger.” Breakfast is the meal that we typically think of when hearing about skipping meals, so reading about lunch seemed a bit unusual. The last paragraph of the blog post addresses this confusion.

There’s a reason why we serve our delicious and nourishing quinoa bowls at lunchtime. They’re exactly the food you need to replenish your energy reserves for a productive and fulfilling day. Not only is the timing just right, but our delicious recipes give you something to savor and take your mind off work, and their optimal balance of nutrients help to restore energy, keep your blood sugar stable, keep you full longer, and quench your hunger for REAL, good food!

It is no surprise that lunch is the meal emphasized on Andrea’s website, because she sells quinoa bowls for lunch on a food cart. When bloggers appear to sell products, it makes the information that they relay seem less reputable and trustworthy.

It is not my intention to judge people’s incentives for going gluten free, but it is important to be critical of some communities who potentially perpetuate gluten free as a fad. Even if a blogger such as Andrea really does have a gluten sensitivity, her message becomes hazy when seemingly interchanging the terms gluten free and healthy. The website and food cart business is less about gluten free, and more about providing a sustainable meal to get you through the day. The business also targets people who are on a paleo, vegetarian, and vegan diet to name a few. Just the name of the business itself is misleading: I love my gluten free food. A more accurate message would be: I love my healthy, sustainable food that also happens to be gluten free since I am gluten sensitive. This may seem harmless to some people, but using gluten free to mean healthy has the potential to invalidate so many individuals who suffer from gluten related disorders.

Another blogger with questionable intentions and potential to perpetuate the fad is Chris Kresser, who is knowledgeable in the in the fields of ancestral health, paleo nutrition, and

functional and integrative medicine. His understanding of these areas started after his personal experience recovering from a chronic illness that began while he was traveling in Southeast Asia. After seeking help from many physicians only to get no concrete answers, Kresser “decided to take matters into his own hands.” After years of research and studying, he got his health in line and shares his experiences to help inform others who may be going through something similar. Besides being on a much larger scale, a major difference between the two blogs is Kresser’s formal training in addition to personal experience. He received a degree in Chinese and integrative medicine at the Acupuncture & Integrative Medicine College, but he is not a physician. Kresser’s education has legitimacy, but the way he portrays himself on the main page of his website with a white coat may fool readers into believing that he is something that he is not.

Chris Kresser’s blogs and podcasts are not all focused on gluten, but there is a large amount of information on the subject that he relays. He has written many articles about the realness of gluten sensitivities despite mainstream backlash. Titles range from *Is Gluten Sensitivity Real?* to *When Gluten-Free Is Not a Fad*. Much of the content in these articles matches up with other research that has been done on gluten as well as personal narratives that I have encountered. One article, for example, *3 Reasons Gluten Intolerance May Be More Serious Than Celiac Disease* immediately seems skeptical based on the title, but the content has much value to it. He argues that celiac disease is much easier to diagnose than NCGS and that current cultural attitudes mean that more people will remain undiagnosed. Furthermore, many doctors and patients are not serious enough about treatment. This article does not say that the biological aspect of NCGS is more detrimental than celiac disease, but the cultural implications make it so that less people take it seriously and follow the diet that they are supposed to.

Concern regarding Kresser is not the content of articles, but rather the environment in which this information is placed. Similar to Andrea's blog, the website is about health, stating on the home page, "Let's Take Back Your Health— Starting Now." There is an implication that being gluten free must be healthy because it is discussed on a healthy living website. Kresser also has a store with a wide selection of products to purchase for many different health problems that he discusses in his book, from anxiety and depression to weight loss, digestion, and heart disease. Unlike other bloggers such as the gluten free mom, Kresser does not supply any disclaimers on his website, which raises questions about the legitimacy of his content and potential conflicts of interest. Ultimately, websites like Andrea's and Kresser's delegitimizes individuals with gluten related disorders by relaying the notion of health with a gluten free diet. When this confusion arises, it has the potential to invalidate sufferers who are not going on the diet to be healthy or lose weight, but because they would have severe symptoms otherwise.

#### *A Deeper Look into Gluten Theories*

Chris Kresser was featured on an episode of the podcast, *The Benefits of Gluten Free Living*. Here, he discusses his personal story and about living with the paleo diet. When discussing gluten, Kresser brought up similar points that Joe had also mentioned going back into history to compare our diets to what our ancestors ate, which largely excluded wheat. I would like to delve into these claims because they highlight a recurring perspective in the NCGS community. These viewpoints are important because many individuals with a gluten related disorder rely on information they receive from others since clear, objective data is not readily available. Kresser is an example of an Internet community relaying this information while Joe is a receiver of this

information. Virtual communities have a large impact on the knowledge circulating the rest of the gluten free community.

Joe first mentions the creation of the food pyramid and its impact on our food choices today. He claims that we do not need wheat in our diets, but the influence of the wheat farmers forced this mindset. The creation of a tool to advise people about what to eat came into place initially as a way to prevent nutrient deficiencies that affected many Americans in the 1950s (Nestle, 1993). The focus later shifted to the prevention of chronic diseases, or in other words, from “eat more” to “eat less” (Nestle, 1993; Smallwood, 2013). Issues arising from poor diet, such as diabetes and heart disease became more critical. To combat these problems, the USDA advised people to eat less fats and cholesterol, but with that suggestion came political backlash. Much of the initial response was from dairy and meat farmers since the foods they sold were advised against, such as whole milk, eggs, and beef. These farmers lobbied tremendously and had an influence of the changing dietary recommendations from “decrease consumption of meats” in 1977 to “suggest 2-3 servings... of cooked lean meat” in 1992 (Nestle, 1993). This change shows how big of an influence economics plays in the issue of food recommendations, giving root to Joe’s skepticism.

The USDA wanted to create a visual representation to help relay their dietary recommendations. The food pyramid’s shape was created to help individuals chose food properly in response to a crisis of high food prices. With a limited budget, the aim was to help people decide what was an essential food and what was supplementary (Smallwood, 2013). The triangular shape was used to clearly visualize proper portions. The USDA adopted this idea to aid in their chronic disease prevention goal. Luise Light, the leader of a group of nutritionists who developed the original food pyramid in the United States, shed light as to what was going on

at the time. The version of the pyramid came back revised in shocking ways. “As I later discovered, the wholesale changes made to the guide by the Office of the Secretary of Agriculture were calculated to win the acceptance of the food industry.” Light goes on to mention the wheat industry specifically:

It also hugely increased the servings of wheat and other grains to make the wheat growers happy... Our recommendation of 3-4 daily servings of whole-grain breads and cereals was changed to a whopping 6-11 servings forming the base of the Food Pyramid as a concession to the processed wheat and corn industries. Moreover, my nutritionist group had placed baked goods made with white flour — including crackers, sweets and other low-nutrient foods laden with sugars and fats — at the peak of the pyramid, recommending that they be eaten sparingly. To our alarm, in the “revised” Food Guide, they were now made part of the Pyramid’s base.” And, in yet one more assault on dietary logic, changes were made to the wording of the dietary guidelines from “eat less” to “avoid too much,” giving a nod to the processed-food industry interests by not limiting highly profitable “fun foods” (junk foods by any other name) that might affect the bottom line of food companies (Smallwood, 2013).

Despite input from professionals, changes were made to the Food Pyramid in response to economic incentives and political backlash. This piece of history circulates in communities, making people question ingesting wheat, and consequently, gluten all together. This often gives people with gluten related disorder comfort, since it is “normal” not to eat wheat since our ancestors did not. People believe that we only eat so much of it today as a result of political endeavors. Stories circulate in online communities and in person to provide justification for the way that they feel.

Another large claim that Joe made had to do with the addition of gluten in bread in the United States in order to increase the protein content to make the low cost item more sustainable. This claim was more difficult to find information about. One reason might be because adding

protein to a food is often considered positive, and recent literature focuses on the negatives in regard to gluten. Most articles aim to expose gluten as either harmful or neutral at best. A 2006 article discusses the uses of gluten and notes the fortification of flours to increase its protein content, however with more emphasis on improving the structure quality and less on nutritional value (Day, 2006). Bakers desire different gluten levels to obtain different consistencies of baked goods. Despite current backlash against gluten, it is still used in higher quantities for certain recipes. Bread flour is sold in grocery stores, which is simply all-purpose flour with the addition of gluten. This will provide a more desirable texture when making a recipe for bread or pizza dough for instance. In addition to the texture enhancement, gluten also contributes to structural rigidity and water absorption capacity that can also improve the shelf life, something that Joe also noted. He attributed the poorer shelf life span of gluten free foods to one of a few reasons why the price of these goods is so high. With a shorter shelf life, stores have to worry about throwing away gluten free items more than their counterparts. Information about the addition of gluten that Joe talks about gives meaning to claims of NCGS since it is not something that is natural found in nature at such a high quantity. The spread of this idea throughout gluten free communities resonates with participants' understanding as to why they may feel sick and further validates the suffering of those with NCGS, like Joe, who sees his condition as a negative result of humans interfering with food.

## **Conclusion**

Since the medicalization of NCGS is consumer driven, individuals have to search beyond the medical community for their own diagnoses, answers, and support. They are in need of a community, no matter how big or small. For some, the family provides a solid support system for

finding information, along with making it easier to actually eat gluten free. Sometimes it is effective to search into the local community for face-to-face support and advice from individuals who know what the situation is like, such as at The Capital Region Allergen and Gluten Free Expo. A meeting place like this allows a person to know what resources they have near by, from buying food items or to simply talking to an understanding individual. It is increasingly popular to search for support on the Internet through online support communities and blogs. While these may not have the same in-person benefits, they are easily accessible at all times of the day from any location, provide social support and encouragement during a time that may cause feelings of isolation, and provide coping strategies to help people feel better about themselves and how to deal with issues that may arise. There are all different types of online support. Some provide personal narratives and advice from the perspective of a caring friend. Others are on a larger, less personal scale, but offer far more resources. Some types of communities contribute to the expansion from local branches to needs on a more sizable scale through the promotion of policy changes, education, and research. Communities for NCGS and gluten related disorders have the potential to not only help on the individual level, but the entire gluten free community as well. While it is unproductive to question people who claim to be “real gluten free,” it is important to be critical of certain communities that seem to perpetuate the gluten free fad. Doing so extends the suffering of individuals with gluten related disorders and NCGS in particular whose intentions are often questioned.

## **Chapter 5: Conclusion**

The prevalence of gluten free diets is greater than ever before, with about 30 percent of adults claiming to cut down or avoid eating gluten entirely (NPD Group, 2013). The food industry has followed this progression with a market that is projected to grow to \$7.59 billion by the year 2020. (Bender, 2017). The food industry has capitalized on the ever-increasing desire to avoid gluten by offering more and more food options both in grocery stores and restaurants. Going gluten free is easier now than it has ever been.

Some individuals avoid eating gluten to try to lose weight, or more broadly be healthier. In addition to this fad, there are three types of gluten related disorders, including celiac disease, an autoimmune disease that attacks the lining of the digestive system, wheat allergy, that is similar to any other “true allergic response,” and non-celiac gluten sensitivity (NCGS) (Copelton & Valle, 2009; Klein, 2014). NCGS is a syndrome characterized by intestinal and extra intestinal symptoms related to the ingestion of gluten containing foods in subjects who are not affected by either celiac disease or wheat allergy (Catassi, 2015). NCGS includes symptoms similar to IBS, such as abdominal pain, bloating, and bowel habit abnormalities. It also includes symptoms of “systemic manifestations” such as foggy mind, headache, fatigue, joint and muscle pain, depression, and anemia (Catassi, 2015). There is not much known about NCGS in the literature but researchers have begun to investigate this increasingly reported phenomenon. These patients have persuasive claims of severe discomfort and relief once eliminating gluten from their diet (Catassi, 2015). However, it is difficult to diagnose and is largely identified through process of elimination. Scientists acknowledge the lack of certainty related to the biology behind NCGS, but advancement towards finding an etiology and treatments is still being made.

Despite the growing number of people who are claiming gluten sensitivities and adopting a gluten free diet, there is minimal discussion regarding this phenomenon in the social science literature (Moore, 2014). Those who suffer from food intolerances find it to be more socially problematic than individuals who are pathologically legitimized (Nettleton et al, 2010). Therefore, it is important to attempt to further understand the sociocultural phenomenon at place. Those who do not suffer gastrointestinal issues as a result of ingesting gluten, and choose to adopt gluten free diets as a popular lifestyle choice, contribute to the perception that going gluten free is an optional health alternative as opposed to a necessary dietary regimen needed for symptom relief. For NCGS sufferers, the dietary restriction is considered necessary for improving their gastrointestinal issues and in many cases relieving feelings of haziness and joint pain. Those with NCGS tend to view a gluten free diet not as a choice, but as a necessity. Yet they perceive fad dieters as discrediting or undermining their claims to a gluten intolerance.

Those suffering from NCGS desire to dissociate themselves from fad dieters, and wish to have their suffering acknowledged as a medical condition, yearning for the legitimacy from the biomedical community that is widely accepted in this society. NCGS sufferers try to seek validation from the physician's office first, but when all tests come back negative or inconclusive, they have no choice but to search for answers elsewhere. Some physicians are starting to recognize the effects that gluten can have on some people, but physicians struggle to help given their limited capabilities.

The medicalization of NCGS is a consumer driven process, requiring individuals to search beyond the medical community for their own diagnoses, answers, and support. They are in need of a community, big or small. For some, the family provides support for finding information, and making it easier to abide by the diets strict guidelines. Some people do not have

the same type of support from family members or want to supplement their family community. Some individuals search for help within the local community for face-to-face support and advice from individuals who are in a similar situation, such as at The Capital Region Allergen and Gluten Free Expo. It is increasingly popular to search for support on the Internet through online support communities and blogs or forums. These types of communities are desirable because they are easily accessible at all times of the day from any location. They provide social support and encouragement during a time that may cause feelings of isolation, and provide coping strategies to help people feel better about themselves and how to deal with issues that may arise. Some types of virtual communities provide personal narratives and advice from a more personable perspective, whereas others are on a larger scale that offer more resources. Communities for NCGS and gluten related disorders have the potential to not only help on the individual level, but the entire gluten free community as well by educating establishments and promoting safer industry standards. While it is unproductive to question people who claim to be “real gluten free,” it is important to be critical of certain communities that seem to perpetuate the gluten free fad. Doing so extends the suffering of individuals with gluten related disorders and NCGS in particular whose intentions are often questioned.

### **Future Implications**

As briefly mentioned in Chapter 1, there is recent research regarding enzyme supplementations in the form of a pill for individuals with celiac disease and NCGS. Gluten is highly resistant to degradation in the gastrointestinal tract, an issue scientists are trying to combat (Koning, 2015). Oral supplements have been proposed to help cut these enzymes to aid in digestion. Some proposed enzymes were not effective since it does not work in a very low pH environment like

the stomach. More enzymes have been analyzed that have been found to work in the stomach while being safe for the human subjects involved, but more testing needs to be done (Koning, 2015). There are currently gluten enzymes, known as glutenase, on the market such as GlutenEase, Digest Gluten Plus, and Gluten Cutter (Glutenase Supplements for Gluten Intolerance, 2015). These pills are supposed to work like a supplement for individuals with lactose intolerance that helps to break down the lactose sugar found in milk. The gluten supplements contain a variety of enzymes, one of which was mentioned in Koning's article, a peptidase. Some of these supplements also contain "digestion-friendly" ingredients such as ginger, peppermint oil, and probiotics (Glutenase Supplements for Gluten Intolerance, 2015).

Staff at the University of California, Berkley could not find clinical trials showing that the glutenase supplements on the market are effective and safe for people with celiac disease and NCGS. Dr. Stefano Guandalini, medical director of the University of Chicago Celiac Disease Center, says that none of the currently available supplements can be trusted to adequately digest gluten like they claim, saying "they are totally ineffective in reducing the fractions of gluten that are toxic for celiac patients" (Glutenase Supplements for Gluten Intolerance, 2015). There are some anecdotes of success with glutenase supplements, but the overwhelming majority of evidence does not support its success. The current state of a gluten digestion supplement is poor, but improvements could have huge implications for people with NCGS. With a successful formula, NCGS individuals could better acclimate to society. They would no longer have to be viewed as a "picky" eater and be a burden to those around them by requiring special food. They would just have to take a pill before eating gluten, just like individuals with lactose intolerance often do. Furthermore, a pill would provide an option to alleviate symptoms beyond an elimination diet. This type of scientific treatment using enzyme supplementation would provide

legitimacy within the medical community since it would identify a solution to a pathophysiological problem. This biomedical advancement would aid in the medicalization process, providing NCGS individuals with greater validation, as their intentions would be legitimized as separate from the diet fad.

There is currently a void of research relating to NCGS in the social sciences, and anthropology in particular. While there are great hopes for scientific advancement, these have yet to be realized. In the meantime, more work is needed to further legitimize individuals suffering with NCGS. Thus, NCGS individuals are on a quest towards medical recognition, in an effort to raise awareness of the illness, as well as to further progress in the form of scientific studies, accommodations, and recognition. Through the medicalization of NCGS, the stigma of being on a gluten free diet may be diminished, relieving their association with the fad and the image that they are “picky” or “fussy” eaters. Moreover, they hope it will help to justify the burden they feel they place on others as they strive to manage their symptoms. Most importantly, the recognition of NCGS as a medical condition would help to explain, legitimize, and normalize their experiences, which is a critical to alleviating suffering.

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