Celiac Disease and Gluten Intolerance at Southern New Hampshire University

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April 2014

Abstract

This research explores Southern New Hampshire University students' awareness of celiac disease and gluten intolerance, and aims to determine the percentage of the Southern New Hampshire University student body affected by these conditions. The full version will be submitted to the Honors Program and Southern New Hampshire University to complete HON 401, as part of the requirements for graduation from the University Honors Program. I first provide context for my research by defining gluten and describing the foods in which it is found. I then define the condition of gluten intolerance (or sensitivity) and compare it to the characteristics and symptoms of celiac disease. I document my own experiences with gluten intolerance and provide statistical information about the prevalence of celiac disease and gluten intolerance worldwide, within the United States, and among Southern New Hampshire University students. I also report statistics regarding the demographic of most commonly afflicted persons and explore the hypothesized reasons for the affliction of this demographic in particular. Additionally, I consider different arguments for the recent increase in reported celiac diagnoses. My faculty mentor for this research is Professor David Cox.

The methods used include the collection of primary and secondary data from empirical studies in medical journals, news articles, student surveys and individual student interviews. The survey sample data collected is used to make conclusive statements about the prevalence and level of awareness that Southern New Hampshire University students exhibit of these conditions through quantitative techniques such as summary statistics and confidence intervals. The interviews are used for qualitative comparison to my experience of a gluten intolerant life. These results drive my conclusions about potential steps to be taken by decision makers regarding dining options to accommodate the increasing number of individuals on campus with celiac disease or gluten intolerance.

Celiac Disease and Gluten Intolerance at Southern New Hampshire University

When I was young, I experienced common seasonal allergies, including tree pollen and dust. I usually had nasal congestion which occasionally developed into sinus infections. As I grew older, my symptoms became more frequent and intense, until sinus congestion was constant. My mother finally conducted an experiment of sorts, firstly upon herself. She found that when she consumed breads, pastas, and fried foods, she experienced negative physical reactions. Very discreetly, my mother began to exclude breads and pastas from my diet by excluding these kinds of foods from her grocery list. After months of this dietary limitation, she noticed my sinus congestion was no longer present. Years later, I finally realized that this affliction was real. I learned that many others in my family experienced the same symptoms I did. We learned that the common ingredient in every food that harmed us was gluten, and as the foods containing this ingredient disappeared from our diets, so too did our symptoms disappear.

Gluten is a protein naturally found in wheat and grains closely related to wheat, such as barley, rye and sometimes oats (Cambridge University Press, 2000). Additionally, gluten can be found as an additive in medicines, vitamins, and other unexpected products (Celiac Disease, 2012). According to the "Cambridge World History of Food," published by the Cambridge University Press, the wheat kernel "is made up largely of the endosperm, the interior part of the grain," and endosperm cells in turn are made of starch particles that are surrounded by storage proteins (Cambridge University Press, 2000). These storage proteins are called gluten, and they contain the amino acids glutamine and proline (Cambridge University Press, 2000). These amino acids are found in the gluten proteins that act in the manifestation of celiac disease (Cambridge University Press, 2000). Specifically, the segment of the gluten protein called gliadin is is

harmful to those with celiac disease or a gluten sensitivity, according to the United States National Library of Medicine (2013).

Many people, including myself, have a sensitivity or intolerance to gluten. According to Dr. Arthur Agatston, medical director of wellness and prevention for Baptist Health South Florida, gluten sensitivity is a spectrum, on one end of which are those who have found that reducing the amount of gluten in their diet gave them more energy for high endurance activities (2013). On the other far end of the spectrum, however, are those who experienced many physical ailments until they decreased the amount of gluten they consumed or eliminated it entirely (2013). Agatston states that gluten sensitivity was only recognized recently, and millions of people now consider themselves gluten-sensitive or intolerant (2013). This idea is supported by a proposal co-authored by Alessio Fasano, director of the University of Maryland's Center for Celiac Research, as well as a study done in Australia which determined that "subjects with suspected gluten sensitivity had substantially fewer symptoms on a gluten-free diet than control subjects who unknowingly ingested gluten" (Beck, 2012). Each of these cases provides evidence of the existence of gluten sensitivity as a condition separate from celiac disease.

Celiac disease is a condition in which the immune system of the afflicted person attacks the lining of the small intestine when gluten is ingested (Celiac Disease, 2012). During this internal assault, the "tiny, fingerlike protrusions" called villi are damaged (Celiac Disease, 2012). As the villi are attacked, they become shorter until they flatten (U.S. National Library of Medicine, 2013). Because villi allow the small intestine to absorb nutrients from food, people with celiac disease may easily become malnourished. This autoimmune response is the primary differentiating factor between gluten sensitivity or intolerance and celiac disease. Antibodies are present in the blood of those diagnosed with celiac disease that are absent in the blood of people

who are sensitive or intolerant to gluten (Beck, 2012). Also unlike gluten sensitivity, celiac disease is a condition that has been acknowledged for many years.

Some commonly recognized symptoms of celiac disease are diarrhea, abdominal pain, and weight loss; people diagnosed with celiac disease who display these symptoms are said to have a "classical" presentation of the condition, according to Winson Lo, M.D. and associates (Changing Presentation, 2003). People suffering from celiac disease more commonly, however, have various health problems without gastrointestinal symptoms, or a "nonclassic" form of celiac disease (U.S. National Library of Medicine, 2013). For some, celiac disease will present no symptoms, which is called "silent celiac disease" (U.S. National Library of Medicine, 2013). Although these people are asymptomatic, celiac antibodies are still present in their blood and damage to the small intestine still results from its existence. The symptoms of celiac disease have historically caused difficulty in prompt diagnosis, because of their nonspecific nature.

Dr. Joseph Murray refers to celiac disease in his article as "a heritable condition" (The widening spectrum, 1999). He explains that "family co-occurrence" is common; siblings that share a specific type of the human leukocyte antigen[1] "have a 40% likelihood of concordance for celiac disease" and identical, or monozygotic, twins "have a 70% concordance" for the condition (1999). If the conditions for the development of celiac disease were strictly hereditary, one might expect this incidence to be closer to 100%, which suggests that there are other factors involved in the development of the condition.

Asymptomatic individuals with celiac disease will likely not seek diagnosis for the condition as there seems to be no indication of a problem. As previously discussed, however, despite an absence of symptoms, those with silent celiac disease will still experience damage to their intestinal villi. According to the U.S. National Library of Medicine, intestinal inflammation

[1] Specifically the HLA type DQW2 or genotype DR5/DR7

and insufficient absorption of nutrients as a result of damaged villi can lead to problems like "anemia, vitamin deficiencies, … defects in the enamel of the teeth, chronic fatigue, joint pain, poor growth, or infertility" as well as neurological issues such as "headaches, depression, attention deficit hyperactivity disorder, and recurrent seizures" (U.S. National Library of Medicine, 2013). In extreme cases, Dr. Murray notes, celiac disease may lead to T cell lymphoma of the small intestine (The widening spectrum, 1999). This can cause fatal results to the affected individual, and emphasizes the importance of prompt celiac diagnosis and treatment.

According to S. Lohi, of the Paediatric Research Center in Finland, "[u]ntil the late 1970s, the suspicion of [celiac] disease was based mainly on clinical symptoms such as [diarrhea], malabsorption and weight loss. The disease was considered to be rare; the prevalence was estimated to be as low as 0.03% worldwide" (Lohi, et al., 2007). Many studies have been conducted since to provide a more accurate representation of the prevalence of celiac disease. Dr. Murray notes that multiple studies conducted worldwide using serological methods based on population found there was a "prevalence of celiac disease of 1 in 250-500 in most countries studied" as of 1990, many of which were European countries (Murray). According to the U.S. National Library of Medicine, celiac disease has been estimated to affect 1 in every 100 people worldwide as of 2013 (Celiac Disease, 2013). Comparing this to Murray's 1990 estimate, it is clear that the prevalence of celiac has increased.

A larger and more recent study was conducted by Dr. A. Rubio-Tapia with contributions from others, including Dr. Murray, in 2012. This study consisted of 7,798 individuals in the United States who participated in the 2009-2010 National Health and Nutrition Examination Survey. Serological tests were conducted, and of the sample group 35 participants were found to have celiac disease. At a confidence level of 95%, the researchers were able to determine that

the prevalence of celiac disease in the United States, as of 2010, was 1 in 141 people (Rubio-Tapia, et. al., 2012).

Melinda Beck's article in *The Wall Street Journal* mentions some gastroenterologists' claims that "for every patient with celiac disease, they see six to eight who have the same symptoms, but without the tell-tale antibodies or intestinal damage needed to confirm celiac" (New Guide, 2012). If this is accurate, gluten sensitivity may be more common for people in the United States than celiac disease. As gluten sensitivity was only recognized as a legitimate condition in recent years, however, more time is needed to obtain statistical information about its frequentness in the United States and worldwide.

Why are celiac disease and gluten sensitivity becoming more common? Researchers have considered many possibilities for such dramatic growth in celiac diagnoses over the past 20 years. Some place blame upon the increased processing our food now receives, particularly those foods containing wheat. Researchers at the Mayo Clinic such as Dr. Murray believe the increased prevalence of celiac disease and gluten sensitivity most likely "involves the wheat itself, which has undergone extensive hybridization as a crop and undergoes dramatic changes during processing that involves oxidizers, new methods of yeasting, and other chemical processes" (Celiac Disease: On the Rise, 2010). As the wheat is modified, both evolutionarily and through these artificial processes, its properties may change, and may subsequently have new effects on the body.

According to Agatston, the increase in celiac diagnoses can be attributed in part to "the significant increase in our gluten intake over the past 50 years due to the ubiquity and overconsumption of products made with highly refined wheat flour" (Gluten: 5 things, 2013). There is, indeed, an omnipresence of gluten in commonly consumed foods. Besides its inclusion

in breads and pastas, gluten and ingredients derived from gluten, such as monosodium glutamate, are being used as additives in foods that otherwise do not naturally contain either. This is likely contributing to the increase in individuals' adverse reactions to gluten.

Another theory for the increase in celiac diagnoses of the past 20 years is the hygiene hypothesis, which states that "the developing immune system has to be stimulated by exposure to infectious agents, bacteria, or parasites in order to develop properly" (Celiac Disease: On the Rise, 2010). Because we have become increasingly better at removing such undesirable microbes from our environment, our immune systems as infants and children have not been sufficiently challenged, and therefore have been weakened. As a result, autoimmune disorders such as celiac disease have become more common for children and adults alike.

Various sources acknowledge that the increase in celiac diagnoses may be due to an increased awareness of the condition over the past few decades. Because many of the symptoms of celiac disease can be attributed to other ailments and conditions, as previously discussed, those with the condition often live for years with undiagnosed celiac disease. As aforementioned, "silent" celiac may be more common than the classic presentation of the disease, and according to Peter Green, director of the Celiac Disease Center at Columbia University, "[this is] partly why celiac disease is underdiagnosed" (Beck, 2012).

For all of those who recognize that celiac disease and gluten sensitivity are legitimate conditions with actually increasing rates of affliction, some firmly believe that the increased awareness of a gluten free lifestyle is not due to an increase in allergies and is, in fact, a result of newfound popularity in the media. Dr. David Stukus, allergist at Nationwide Children's Hospital, claims that people attribute their ailments to gluten, despite his statement that a "gluten allergy" does not exist (The Huffington Post UK, 2013). According to Stukus, the increase in

cases of gluten sensitivity or intolerance is simply a misinterpretation of individuals' actual allergies (The Huffington Post UK, 2013). Nutritionist Alice Mackintosh blames the "gluten-intolerant bandwagon" for the increase in cases of gluten intolerance, as a result of its coverage in the media (The Huffington Post UK, 2013). This argument claims that individuals are misguidedly seeking gluten as a scapegoat for their health issues. To state, however, that the increase in gluten intolerance and celiac disease is imagined is, as Dr. Murray calls it, "a self-fulfilling prophesy" (Murray, 1999). According to Murray, a "heightened suspicion or awareness of celiac disease results in a substantially increased rate of diagnosis" (The widening spectrum, 1999). While there may be truth behind reports that some are going "gluten-free" in an attempt at weight loss or an overall "healthier" lifestyle despite their lack of dietary need for such a change, one cannot, because of it, discount the legitimacy of gluten sensitivity, which has been recognized as a genuine condition. There may be some validity to the idea of simple underestimation, meaning some of the reported cases of celiac disease may simply have been previously undetected. But according to the work of Ludvigsson, Rubio-Tapia, Murray and others, celiac disease is actually becoming more common in people within the United States and worldwide and cannot be fully explained by previous underestimation.

The prevalence of celiac disease throughout the world and the United States has been researched. How widespread gluten sensitivity is remains uncertain. How common are these conditions, though, at Southern New Hampshire University? How aware are students at Southern New Hampshire University of celiac disease and gluten sensitivity or intolerance? How many adhere to a gluten free diet? How many should?

I crafted and distributed a survey to a sample of 220 undergraduate day students at Southern New Hampshire University. Of the 220 students surveyed, five indicated that they

were either diagnosed with celiac or deemed gluten intolerant, or 2.27% of the sample. Four of these respondents are female, and one is male. Because this number considers both celiac disease and gluten sensitivity, it cannot be compared to the national celiac disease rate of 1 in 141, or 0.71% (Rubio-Tapia, et. al., 2012). However, using the binomial distribution, as well as the knowledge of a minumum of two celiac positive respondants and a maximum of four celiac positive respondents, we determined that at a 95% level of confidence, the number of student respondants with celiac disease was statistically equivalent to the national percentage. We found with 95% confidence that the percentage of students sampled who have at least some working knowledge of gluten and its effect on some people was between 75% and 85% [2] (Figure A).

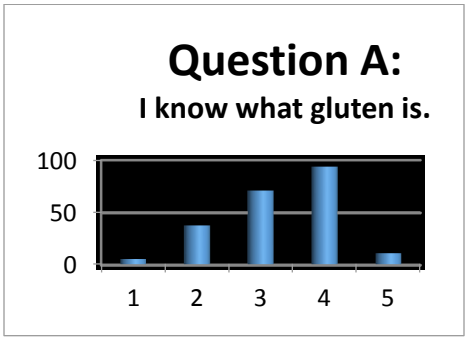

Figure A: Breakdown of responses for Question A of the student survey, where

1-no knowledge,

2-minimal knowledge,

3-some working knowledge,

4-moderate knowledge,

5-very high level of knowledge

This percentage is close to the percentage of students who personally know at least one individual who has either celiac disease or an intolerance or sensitivity to gluten, which was 71% of the students sampled. Because these percentages are close, one might like to infer causation; student awareness is so substantial because many undergraduate day students know at least one person with celiac disease or gluten intolerance. To draw causation from this correlation would be misleading, however. The overall probability of students being at least somewhat aware of gluten is 80% (176 out of 220); expectedly, a 90% probability exists of being at least somewhat aware in those sampled, given that they knew someone who has celiac disease or gluten

[2] Survey participants who selected either option 3, 4 or 5 for question A

intolerance. Even those who indicated that they did not personally know someone, though, showed a 58% probability, and those unsure of whether they know someone showed a 52% probability of having at least a working knowledge of gluten. As evidenced by the sample, and in conjunction with what is known of the proposed reasons for the increase in celiac and gluten intolerance diagnoses, there could be many other factors contributing to this awareness of gluten and its potential effects, including the increased popularity of gluten-free diets for athletes and weight loss seekers.

Based on the sample, 25 out of 220 (11.36%) said that they sometimes, usually, or always follow a gluten free diet (Figure C).

Figure C: Breakdown of responses for Question C of the student survey, where

1-never,

2-have tried it,

3-sometimes,

4-usually,

5-always

This means that 20 participants said that they were not gluten intolerant or celiac-positive, but that they sometimes or usually follow a gluten free diet anyway[3]. Responses of this kind show that arguments reflecting the "gluten free bandwagon" aren't baseless, if we assume that these survey responses are reflective of the campus population and the percentage of individuals following a gluten free diet is in line with the general population's percentage. Interestingly, sixteen of the twenty (80%) who responded in this way were female. We therefore conducted a

[3] None of the respondents who said that they did not have celiac disease or gluten intolerance stated that they always follow a gluten free diet anyway.

hypothesis test to determine if the proportion of females who are at least somewhat aware[4] of gluten was greater than the proportion of males, and found that to be true (from a p-value of .00187). Plainly stated, we were able to say with 95% confidence that females on campus are generally more aware than males are of gluten and its effects on those with a sensitivity, intolerance or allergy.

Considering the awareness exhibited by students, one might expect more extensive accommodations from dining services. I performed personal interviews of two current undergraduate day students to compare their experiences of living with celiac disease or gluten sensitivity to my own, and learned that they both feel dining accommodations on campus are inadequate given their dietary needs. To remedy this, I recommend that that those in dining services with the ability to make changes consider a few actions. Firstly, I recommend the promotion of a deeper understanding for dining service staff of celiac disease and gluten intolerance through further education about each, including differences, preparation precautions, and the conditions' increasing prevalence. Secondly, promotion of the use of gluten free grains, such as rice, corn, and millet, especially when used as thickeners for sauces or soup, or as breading on fried foods. Thirdly, expansion of the selection of prepackaged gluten free options available. Celiac disease and gluten intolerance are becoming more prevalent in the United States, and we have found that the campus population is fairly representative of the country's in this regard. Taking these recommendations into consideration will help Southern New Hampshire University to better accommodate its students' dietary needs.

[4] Survey response was either 4 or 5 for question A

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