A DESCRIPTIVE STUDY OF ALTERNATIVE GRAIN CONSUMPTION AMONG INDIVIDUALS WITH CELIAC DISEASE

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ABSTRACT

The gluten-free diet is becoming increasingly popular as more people are diagnosed with and become aware of celiac disease. However, little is known about the nutritional quality of the diet, especially in terms of grain consumption and the nutrients provided by these foods. For the general population, grain consumption provides a large amount of daily vitamins, minerals, and fiber. Therefore, being able to describe the grain consumption of individuals with celiac disease may shed a crucial light on nutritional quality of the gluten-free diet. Data was obtained by means of a survey conducted at a Midwest hospital’s annual celiac conference. The sample of convenience consisted of 220 people, 174 of which provided usable data. The survey focused on daily consumption of grain servings, types of grains consumed (cooked grains versus pre-prepared grain products), variety of grains consumed, and reasons for avoiding specific grains. Data from 174 usable surveys were used for statistical analysis. Over 80% of the sampled population consumes less than half of the daily recommended amount of grain servings. Only 1.1% consumes the recommended daily amount. Three-fourths of participants prefer pre-prepared grain products over grains. No matter the product type, rice (both brown and white) and corn make up the majority of grains or grain ingredients eaten regularly. Respondents identified many reasons for avoiding different grains, which can support both clinicians and the food industry, in efforts to improve the grain consumption of people with celiac disease.
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Chapter 1: Introduction

Background and Significance

Celiac disease is an auto-immune disease affecting 1 in 133 people in the United States. Following a gluten-free diet is the only treatment for the disease, as gluten is the environmental trigger that causes the autoimmune inflammatory attack of the small intestine. Gluten is a storage protein commonly found in wheat, rye, and barley. Oats often contain found to contain gluten, but it is thought that they are not inherently gluten-containing; rather, it is thought that oats are often cross contaminated with wheat or other gluten sources during harvesting, milling, and processing.

Gluten is therefore commonly found in grains and grain products made from wheat, rye, barley, or oats; so eating any of these grains or hybrids of these grains can cause damage to the intestine. Similarly, any pre-prepared grain products such as bread, cereal, pasta, or bakery items that are made from any of these gluten-containing grains can initiate an autoimmune reaction. Gluten in as small amounts as 10 parts per million consumed is all that is needed to initiate a reaction. As much as one-fiftieth to one-one hundredth of a slice of bread has been found to contain enough gluten to cause damage. With the ability of such small amounts to cause enormous reactions, the protection against cross-contamination of gluten-free grains and grain products is crucial.
Several gluten-free alternative grains exist, but it is unclear which, if any, the individual with celiac disease consumes or how much they consume. Especially of concern is whether or not these individuals typically meet current recommendations for adequate daily grain servings.

Most gluten-containing grains and grain products are enriched with important vitamins and minerals lost during the milling, harvesting, or processing of the grain; making grains an important source of necessary vitamin and minerals in the diets of the general population. For this reason, current nutrition recommendations suggest that one should consume at least 6 servings of grain per day, with the higher end of the range suggesting 11 servings.

Since gluten is found in so many commonly eaten grains and grain products, it is thought that individuals with celiac disease may avoid grains altogether, or consume less than recommended amounts of grain servings per day. This poses a problem, since individuals with celiac disease are already at risk for nutrient deficiencies due to the malabsorptive nature of the disease.

Prolonged regular gluten-consumption can cause secondary health problems due to nutrient deficiencies. The autoimmune nature of the disease puts the individual with celiac disease at risk for acquiring additional autoimmune diseases is gluten is not permanently avoided. Lastly, the inflammatory nature of the disease greatly increases the risk of malignancy, not limited to the gastrointestinal tract, at a much younger age than is typical.

Aside from long-term consequences of regular gluten consumption, the immediate effects of gluten consumption are often extremely uncomfortable, painful, and can last
from days to weeks. Therefore, once an individual is aware that they have celiac disease, fear may play a major role in consumption (or lack thereof) of grain products; simply due to the potential immediate and long-term consequences of gluten-consumption. However, it is important that the celiac population consumes alternative grains and grain products so that they are consuming adequate vitamins and minerals a day and not further contributing to often already-existing nutrient deficiencies. Being able to describe the grain consumption of individuals with celiac disease may give clues to Registered Dietitians and other health professionals on what needs to be addressed at or shortly following diagnosis.

**Purpose of Research Study**

This study was developed to describe the consumption of alternative grains and grain products within a population of individuals with celiac disease. As mentioned, recent research points to the need for more evaluation of dietary intake for the celiac population in regards to their consumption of gluten-free grains and grain products as well as their reasons for consuming or avoiding certain grains. This study ultimately aims to describe ways in which to improve the gluten-free diet, in terms of both improving actual products and grain options, as well as ways to improve the celiac population’s knowledge and implementation of the diet.

The researcher tested the following hypotheses:

1. Individuals with celiac disease do not consume adequate servings of gluten-free grains.

2. Individuals with celiac disease consume the majority of their grain servings from pre-prepared products rather than from cooked grains.
3. Individuals with celiac disease are misinformed or unaware of many gluten-free alternative grains.

The researcher sought to achieve the following objectives:

1. Describe the grain consumption patterns of individuals with celiac disease.  
   (Survey questions 7-10 provide the address this objective.)

2. Describe other factors associated with consumption of grains. 
   (Survey questions 1-6 address this objective.)

List of Definitions

Alternative grain: Any type of grain which does not contain gluten; also referred to as “gluten-free grain.” Examples include: amaranth, millet, quinoa, rice, tef, and montina.

Celiac disease: A multi-systemic autoimmune condition, in which the small intestine is damaged upon ingestion of gluten.

Cross-contamination: The indirect transfer of any amount of gluten from one place (particularly food item) to another.

Gluten: A storage protein found in wheat, rye, and barley

Gluten-free diet: The only treatment for celiac disease; A diet in which the grains wheat, rye, and barley, as well as any of their derivatives, are completely removed.
| **Grain:** | A collective term for any variety of small, hard seeds which are the edible fruit of certain grasses. In their whole forms, grains are rich in carbohydrates (including fiber), vitamins, minerals, fats, oils, and protein. |
| **Cooked grain:** | A single type of grain that is eaten in as close to its whole form as possible (very little additional processing). Examples include boiled rice, quinoa, and oats. |
| **Grain product:** | Any pre-prepared food item that contains one or more grains as the main ingredient(s) and undergoes various steps of processing. Examples include bread, breakfast cereal, pasta, and bakery items. |
Chapter 2: Review of Literature

Background

Celiac disease is a chronic multi-systemic disease affecting nearly 1 in every 133 people in the United States\textsuperscript{1}, with some studies suggesting an even higher prevalence.\textsuperscript{8,19} This is more than double the prevalence of Crohn’s disease, ulcerative colitis, and cystic fibrosis combined.\textsuperscript{20} The disease is more prevalent in women, individuals under sixty years of age, people of European descent, and those living further away from the equator.\textsuperscript{1,21}

Although the disease is a malabsorptive disorder of the digestive tract, the roots are auto-immune.\textsuperscript{8} In fact, celiac disease is rather unique in the autoimmune world, as it is the only such disease with a known environmental trigger. Gluten, a storage protein commonly found in wheat, rye, and barley, is responsible for the immense inflammatory reaction experienced in celiac disease.\textsuperscript{8} Therefore, elimination of these grains (and derivatives of these grains) is considered effective treatment for the disease.\textsuperscript{8,15,17,22} This can be difficult, however, as gluten is found in a multitude of convenient pre-packaged products, either as an unsuspected gluten-containing ingredient, or as a result of cross-contamination.\textsuperscript{2}

Upon gluten ingestion, several short-term consequences often result. Gluten reactions vary greatly between individuals regarding time of onset, symptoms
experienced, severity of symptoms, and duration of reaction. Onset of symptoms can be anywhere from minutes after gluten is ingested to hours or even days. Symptoms experienced over the course of a reaction can include gastrointestinal discomfort, pain, bloating, gas, nausea, diarrhea, migraine headaches, mouth ulcers, development of a skin rash (“dermatitis herpetiformis”) and extreme fatigue. Severity can range from symptoms that are barely noticeable to extreme discomfort and debilitating pain. Duration can be a matter of hours, several days, or upwards of one to two weeks.\textsuperscript{8,16}

Aside from the undesirable short-term effects that come with gluten ingestion, several significant long-term consequences can result from regular ingestion of gluten. Some of these long-term consequences include an increased risk (nearly ten-fold) for development of intestinal cancer or lymphoma,\textsuperscript{16} the acquisition of additional autoimmune diseases,\textsuperscript{18,23} and the development of multiple secondary diseases related to nutrient deficiencies.\textsuperscript{2,6,8,24} Without adherence to a gluten-free diet, celiac disease can in this sense be life-threatening if left untreated.\textsuperscript{3} Thus, dietary compliance is imperative.

Only during recent years has the nutritional quality of the gluten-free diet been scrutinized in greater depth.\textsuperscript{12} Studies focusing on body composition, biochemical assessment, and/or presence or absence of secondary nutrient deficiency-related diseases in long-term gluten-free diet followers have shown that the diet may not be optimally provide a healthy and adequate diet.\textsuperscript{10,11,22,25}

Grains in general are known to provide essential nutrients that are difficult to find in other foods.\textsuperscript{26} Despite the fact that the common grains of wheat, rye, and barley contain the toxic element of gluten, a wide array of alternative grains exists, which are naturally gluten-free.\textsuperscript{2,26} These alternative grains can provide the necessary nutrition that
may be lacking in a typical gluten-free diet. Therefore, the purpose of this study is to describe what types of alternative grains are actually being consumed as part of the “typical” gluten-free diet; as well as what factors may play into the grain-related diet choices of these individuals, so that steps can be taken to improve the overall diet quality.

Since grains make up the primary food group in which gluten is found, they are oftentimes minimally consumed or even avoided altogether by individuals with celiac disease. Various reasons exist that could possibly explain this pattern. For instance, recent research discovered that grains typically thought to naturally be gluten free (e.g. quinoa, amaranth) have in some cases been contaminated with gluten during harvesting, milling, or processing; therefore, those with celiac disease may be afraid to consume grains altogether due to the fear of cross-contamination. Furthermore, research supports the notion that the gluten-free diet is expensive to maintain, so cost may be an issue, especially for gluten-free grains that are not widely available.

**Prevalence and Incidence**

Celiac disease is estimated to affect about 1 of 133 people in the United States, nearly 1% of the U.S. population. This includes both diagnosed and (frequently) undiagnosed individuals. Controversy exists over whether the disease is becoming more prevalent or is simply being diagnosed more, with increasing awareness of the condition. Despite the increasing incidence, celiac disease is still thought to be largely underdiagnosed. Certain populations have been identified as having an increased risk for development of the disease, including first-degree relatives of affected persons, individuals with Downs Syndrome, and people already affected by another autoimmune
disease, particularly Type 1 Diabetes Mellitus and Hashimoto’s thyroiditis.\(^2\) Diagnosis statistics also point out that celiac disease diagnosis, is more common in adults, females, and those younger than age 60.\(^2,8\)

**Pathophysiology**

The specific cause of celiac disease is unknown, though research suggests involvement of both genetic and environmental factors in its development and manifestation.\(^8,19\) Once a person is in the active disease state, it is known that gluten is the environmental trigger responsible for damage. However, the environmental factor which triggers the manifestation of celiac disease is unknown. As the genetic halotype can be found in many people who never go on to develop celiac disease, an external environmental factor is assumed to be responsible for triggering the actual manifestation of the disease.\(^8\)

**Symptoms and Clinical Presentation**

Clinical presentation of celiac disease appears in a variety of ways. Some symptoms are immediate upon ingestion of gluten, while some are more long-term. Short-term symptoms are often largely gastrointestinal in nature, such as bloating, constipation, unusually frequent and foul-smelling gas, pain, discomfort, bulky stools, diarrhea, steatorrhea, and sometimes nausea and vomiting.\(^8\) Upon gluten ingestion, these more immediate symptoms vary greatly between individuals, especially regarding time of onset (post-gluten consumption), combination of symptoms, severity of symptoms, and duration of reaction.\(^3,8\) Onset of symptoms can be anywhere from minutes after gluten is
ingested to hours or even days.\textsuperscript{3,8} Severity can range from barely noticeable to extreme discomfort and debilitating pain, and duration can be a matter of hours, several days, or upwards of one to two weeks.\textsuperscript{3,8,28}

Other non-gastrointestinal yet fairly immediate symptoms that can often occur include migraine headaches, mouth ulcers, development of a skin rash (called “dermatitis herpetiformis”) and extreme fatigue.\textsuperscript{3,8}

Some individuals may have celiac disease without experiencing any gastrointestinal discomfort or recognizable symptoms. Rather, they may present with problems such as iron deficiency, stunted growth, unexplained weight loss, infertility, osteoporosis, other autoimmune diseases, or even cancer.\textsuperscript{8,17} These conditions may actually in this sense be comorbidities, and therefore be indicative of an underlying celiac disease.

\textbf{Comorbidities}

The types of comorbidities whose discovery often leads to the diagnosis of underlying celiac disease are conditions that will continue to occur (or may begin to occur, if they had not been present yet) if celiac disease is left untreated. As mentioned earlier, these can include the development of cancer or additional autoimmune diseases, as well as diseases related to nutritional deficiencies.\textsuperscript{6} Other conditions have been known to occur in celiac disease, including neurological problems, infertility, dermatitis herpetiformis, and dental enamel hyperplasia.\textsuperscript{2}

Cancer is another comorbidity possible with untreated celiac disease. In fact, if left untreated, celiac disease increases the risk for development of intestinal cancer or lymphoma by almost ten-fold.\textsuperscript{16}
Similarly, untreated and non-compliant celiac disease sufferers are 3 to 10 times more likely than the general population to develop an additional autoimmune disease. Conditions particularly encountered include, but are not limited to rheumatoid arthritis, thyroid disease, systemic lupus erythematosus, autoimmune liver disease, Turner syndrome, William’s syndrome, Addison’s disease, alopecia areata, Sjogren’s syndrome, and psoriasis.\(^8\)

**Morbidity and Mortality**

Duration of time spent with undiagnosed and untreated celiac disease has been correlated in several studies with an individual’s heightened risk of developing such severe comorbidities.\(^2,33\) However, other research has demonstrated that length of exposure does not play a significant role in the likelihood of developing additional autoimmune diseases, but rather that the introduction of gliadin to the immune system too early in life may play a role in modifying the immune response and therefore “predispose susceptible individuals, not only to overt coeliac disease, but also to autoimmune diseases in general.”\(^18,23\) Therefore, celiac disease can be fatal if gluten is not permanently avoided.\(^3\)

**Nutrient deficiencies and Related Comorbidities**

In celiac disease, the most commonly malabsorbed nutrients include iron, folate, and calcium, due to the damaged state of the proximal part of the small intestine, where these nutrients are mainly absorbed.\(^2\) Depending on how long a person has been suffering from untreated celiac disease, the amount of damage to the small intestine (in terms of intensity and amount of affected surface area) may be more significant. This can result in additional malabsorption of fat and carbohydrates, especially lactose. When fat is
malabsorbed, fat-soluble vitamins A, D, E, and K, also cannot be absorbed, thus continuing the chain reaction. \(^2\) People with untreated celiac disease are also likely to be deficient in fiber, magnesium, zinc, and other B vitamins such as thiamin, niacin, B12, and riboflavin.\(^6\)

Complications resulting from these deficiencies are often present at diagnosis, and are sometimes the primary problem presented, leading to discovery of the underlying celiac disease.\(^8\) Such complications include iron deficiency anemia, osteopoenia and/or osteoporosis, and pernicious anemia in some cases.\(^2\)

Research conducted by Mora, et. al, showed that about 40\% of patients newly diagnosed with celiac disease were found to also have osteopoenia, and 26\% to have osteoporosis, making osteoporosis the leading cause of morbidity in untreated CD patients.\(^24\) Consistent with these findings, Meyer et al., in a study looking at “Osteoporosis in a North American Adult Population with Celiac Disease,” found that only 28\% of participants had normal bone densities as defined by the World Health Organization. These findings reflected the BMD of all participants, regardless of whether their celiac disease was treated or untreated. The authors also noted that their results were consistent with similar studies in Europe and South America, saying that “virtually every study of adults with celiac disease has found BMD to be significantly reduced.”\(^34\)

Many of these complications are reversible simply through the implementation of a gluten-free diet, which allows the villi to heal and absorb nutrients properly, but some may require vitamin and mineral supplementation and/or further medical intervention.\(^2\) Sometimes it may simply be a matter of the GFD on its own not being enough of a force to correct problems as quickly as desired. However, due to the autoimmune nature of the
disease, immunologic alterations in the body may also be contributing to the comorbidity. For instance, in the Mora et al. study on children with celiac disease-induced osteoporosis, results suggested that immunologic reactions may play a role in bone metabolism, impairing the function of bone cells, and thus affecting bone mineralization.\textsuperscript{24}

**Testing and Diagnosis**

The diagnosis of celiac disease requires the combination of multiple tests. Serological tests are typically performed when CD is first suspected. This process is less invasive than alternative methods, and seeks to detect the presence of certain characteristic antibodies in the blood.\textsuperscript{3,8}

Following a positive blood test, confirmation, made by performing histological testing in the form of biopsy of the intestinal mucosa of the proximal small intestine. The intestinal biopsy is currently the most accurate method for detecting the presence of celiac disease, and is therefore known as the gold standard of testing.\textsuperscript{3,8} This histological method, performed via upper endoscopy, allows for both the discovery of any physical damage to the intestinal villi, and subsequently, the determination of damage severity. If the villi in the tissue sample appear flattened under the microscope (as measured by villous height), and/or changes are identified in crypt hyperplasia and intraepithelial lymphocytosis, diagnosis of celiac disease is likely.\textsuperscript{8}

Improvement of symptoms, as well as serological and histological results, therefore indicate recovery and control of celiac disease. Repeat test procedures can be conducted on a regular basis to evaluate the success of an individual’s incorporation of the gluten free diet.\textsuperscript{16,28}
The Gluten-Free Diet (Treatment)

Since gluten has been identified as the environmental trigger in celiac disease, the solution for treatment is simple: a diet free of gluten. As researchers See and Murray summarize, there are four main goals in the treatment plan for CD. The first is to relieve symptoms. Secondly, allow the intestine to heal. Thirdly, reverse the consequences of malabsorption. And lastly, accomplish all of the previous three goals “while enabling the patient to maintain a healthy, interesting, practical GFD.” Without exposure to gluten, the intestines are allowed to heal, which allows for alleviation and eventual elimination of symptoms, and ultimately leads to the reversal of disorders related to malabsorption.

With strict adherence to the GFD, patients with celiac disease can typically expect to return to full health and live a normal-lifespan. Symptoms can improve in as little as two weeks of following the diet, and serological improvements have been found to improve, even return to normal, within the first 6 to 12 weeks. The villi of the small intestine, however, may take up to two years to completely heal, once the GFD has been initiated, therefore long-term compliance is critical.

Although every effort should be made to remove gluten from the diet entirely, complete avoidance may not be realistic. Since gluten is such a common food component, and as little as 10 parts per million (ppm) is thought to be capable of triggering damage, it is likely to be accidentally ingested from time to time. Beyond the “10 parts per million,” controversy still exists over what is an acceptable safe amount of gluten to be ingested by individuals with celiac disease, and studies have shown that this
level varies between individuals. Current food labeling laws reflect this inconsistency in research for tolerable amounts of gluten, as there is currently no standard (ppm) that a product must meet to be labeled “gluten-free.”

Gluten is the collective term for the storage proteins (prolamins) in wheat (gliadin), rye (secalin), and barley (hordein). Aside from these three grains, many other hybrids and derivatives of these grains exist, which then inherently contain gluten.

The gluten-containing grains, flours, and starches include: barley, bulgar, cereal binding, chapatti flour (atta), couscous, dinkel, durum, einkorn, emmer, farina, farro, fu, gluten, gluten flour, graham flour, kamut, malt (and malt in the forms of extract, flavoring, syrup, and vinegar), matzoh meal, oats (including oat bran and oat syrup), orzo, rye, seitan (wheat meal), semolina, spelt, triticale, and wheat (including forms of bran, germ, and starch).

Although many grains contain gluten, several grains exist that are gluten-free and therefore safe for a person with celiac disease to consume. These grains have proteins other than gliadin, secalin, and hordein. Gluten-free grains, flours, and starches include: amaranth, arrowroot, bean flours (garbanzo, fava, romano), buckwheat, corn, fava, flax seed, garbanzo beans, garfava flour (garbanzo+fava bean), hominy, mesquite flour, millet, montina flour, nut flour and nut meals, uncontaminated oats, peas flour, potato flour, potato starch, quinoa, rice (brown, white, sweet, wild, jasmine, basmati, glutinous rice, rice polish, rice bran), sago, sorghum flour, soy flour, tapioca (manioc, cassava, yucca), teff (tef) flour.
Nutrient Recommendations

In the United States, the Recommended Daily Allowance (RDA) and the Dietary Reference Intake (DRI) serve as current nutrient guidelines for the population. The guidelines vary depending on age, sex, and other factors such as pregnant or lactating statuses. Appendices A and B display the specific recommendations for each category.\(^{36,37}\)

In order to enhance the likelihood of people meeting these nutrient guidelines, current recommendations suggest that the general population consume six or more servings of grain on a daily basis.\(^{12}\)

Since nutrient deficiencies are prevalent among individuals with celiac disease, research suggests that recommendations for certain nutrients should be higher than those of the general population. Cynthia Kupper, in a study on “Dietary Guidelines and Celiac Disease,” identified and compared common nutrient deficiencies, as combined from several studies, at different chronological points in the life of an individual with celiac disease as well as different aspects of the diet: time of diagnosis, time when the GFD is being followed, GF products as a whole, and long-term adherence to the GFD. Fiber, folate, niacin, and B-12 were identified as common nutrient deficiencies for all four aspects investigated, leading the author to recommend increasing the recommendations for these nutrients for individuals with celiac disease.\(^{6}\)

Nutrient Content of Grains

In general, grains vary in terms of their natural nutrient content, regarding amounts of macronutrients (protein, carbohydrate, and fat), micronutrients (vitamins and minerals), and fiber.\(^{26,38,39}\)
Since the harvesting, milling, and processing of grains consequently takes away nutritional value, the FDA requires that grain products be enriched with vitamins and minerals that are stripped during processing. In 1998, the FDA added on to this standard, requiring that all enriched grain products also add folic acid. ¹¹

**Quality of the Gluten-Free Diet**

Although the gluten-free diet has proven to be effective for treatment of celiac disease and relief of associated symptoms, it may not provide an adequate source of all nutrients. ¹⁰,¹¹,¹²,¹³ For this reason, nutrient deficiencies may continue to occur, or other new deficiencies may develop, upon implementation of the gluten-free diet in individuals with celiac disease. ⁶ As mentioned, removing gluten from the diet allows the intestinal villi to heal and absorb nutrients properly, thus treating the disease, but little research has been done to determine the actual dietary intake and quality of that intake in individuals who follow the diet. Only in the last five to ten years has research begun to look at this concern. ¹²

In 2005, Tricia Thompson *et al.* analyzed the three-day food records of 47 individuals with celiac disease, looking specifically at dietary intake of carbohydrates, dietary fiber, iron, calcium, and grain food servings. Of the 8 men and 39 women studied, the majority of the men met minimum requirements for most nutrients analyzed. Carbohydrates were the only nutrients, of all nutrients analyzed, in which the majority of both males (88%) and females (87%) consumed amounts which fell within the guidelines used (the Acceptable Macronutrient Distribution Range). Less than half of all females, however, were meeting minimum requirements for each of the nutrients analyzed except carbohydrates. Only 21% of female participants were found to consume the
recommended minimum amount of daily grain servings; and when looking at iron, fiber, and calcium, only 44%, 46%, and 31% of females were consuming minimum recommended amounts of these nutrients, respectively. Considering the poor nutritional quality of most of the participants’ gluten-free diets in this study, the authors recommend that more research needs to be done in this area. Secondly, the authors state that individuals with celiac disease should take special care to consume recommended amounts of gluten-free grain foods (they recommended 6-11 servings) on a daily basis, and should also increase their intake of thiamine, riboflavin, iron, and calcium in their non-grain foods. Finally, the authors highly encouraged the use of a multivitamin for all individuals with celiac disease, and other additional supplements as needed by each individual.12

Recent studies have expanded on these findings, looking specifically at the consequences of nutritionally poor gluten-free diets, such as the ones described by Thompson et al. These studies have shown that certain nutrient deficiencies discovered at the time of diagnosis often continue to exist, even after a strict gluten-free diet has been consistently followed, and of even greater concern, these studies have found that other new deficiencies may develop.6,12,26 A variety of factors including accidental gluten ingestion, secondary food sensitivities, limited variety of food intake, and lack of enrichment and fortification in gluten-free grains and products contribute to the risk of nutrient deficiency.6,12 As Cynthia Kupper points out, gluten-free products without enrichment tend to be lower in fiber, iron, folate, thiamin, riboflavin, and niacin.6.
Research has verified that gluten-free flours are not consistently fortified, whereas flours from wheat, rye, and barley are fortified with several vitamins and minerals, including B-vitamins and iron.\(^2,6,26\)

In a study analyzing actual food products rather than reported dietary intake for nutrient quality, Thompson found that ready-to-eat gluten-free cereals, breads, and pasta products were rarely fortified with folic acid, iron, and dietary fiber, as opposed to their gluten-containing counterparts. In this study, Thompson also points out that the general population gets over one-fourth of their daily intake of folate and nearly 40% of their daily intake of iron from ready-to-eat cereals and yeast breads.\(^11\)

**Summary**

In summary, celiac disease and the gluten-free diet are becoming more prevalent in society. Although a gluten-free diet is effective treatment for celiac disease, many nutrients may be lacking in the diet. Of particular concern are nutrients that the general population typically obtains from consumption of grains and grain products. Alternative grains exist, which are naturally gluten-free, which contain a wide array of nutrients, but they are not as common in the American diet as the gluten-containing grains. Research has shown that individuals with celiac disease often avoid grains altogether since they are a common source of gluten. In addition, pre-prepared products such as bread, cereal, pasta, and bakery items made from gluten-free grains are often not enriched or fortified like their gluten-containing counterparts. Since individuals with celiac disease are already at risk for nutrient deficiencies due to the nature of the disease, a lack of grain consumption poses a potential problem, as it would both hinder the ability to recover from pre-existing deficiencies and enhance the likelihood of developing new deficiencies.
Therefore, research is needed to better determine the grain consumption patterns of individuals with celiac disease, as well as determine reasons for avoiding certain grains, so that efforts can be made to improve the overall quality of the gluten-free diet, thereby reducing the amount and severity of nutrient deficiencies experienced.
Chapter 3: Methodology

Introduction

The gluten-free diet is becoming increasingly popular as more people are diagnosed with and become aware of celiac disease. However, limited research has examined the nutritional quality of the diet, especially in terms of grain consumption. For the general population, grain consumption provides a large amount of daily vitamins, minerals, and fiber. Therefore, being able to describe the grain consumption of individuals with celiac disease may shed a crucial light on nutritional quality of the gluten-free diet.

Purpose

This study was developed to describe the consumption of alternative grains and grain products within a population of individuals with celiac disease. Recent research points to the need for more evaluation of dietary intake for the celiac population in regards to their consumption of gluten-free grains and grain products as well as their reasons for consuming or avoiding certain grains. This study ultimately aims to describe ways in which to improve the gluten-free diet, in terms of both improving actual products and grain options, as well as ways to improve the celiac population’s knowledge and implementation of the diet.
Hypotheses

The researcher tested the following hypotheses:

1. Individuals with celiac disease do not consume adequate servings of gluten-free grains.
2. Individuals with celiac disease consume the majority of their grain servings from pre-prepared products rather than from cooked grains.
3. Individuals with celiac disease are misinformed or unaware of many gluten-free alternative grains.

Research Objectives

The researcher sought to achieve the following objectives:

1. Describe the grain consumption patterns of individuals with celiac disease.
   (Survey questions 7-10 provide the address this objective.)
2. Describe other factors associated with consumption of grains.
   (Survey questions 1-6 address this objective.)

Subjects

An IRB application was submitted to Nationwide Children’s Hospital on October 19, 2010. The application was assigned to the committee “IRB Expedited Committee” on October 22, 2010. The committee met on October 26, 2010, and the application was approved on October 29, 2010.

No consent forms were included for this study, as each survey contained a brief explanation of the research being conducted, as well as an explanation that surveys were
completely anonymous, asking that participants not include any identifying information. Brief directions on how to complete the survey were also included in this section, encouraging participants to be as truthful as possible in answering all of the questions.

The population studied was a convenience sample of individuals voluntarily attending Nationwide Children’s Hospital’s 23rd Annual Celiac Conference in Columbus, Ohio on October 30, 2010, who agreed to complete and return a survey provided at the conference. This conference is known to be one of the largest conferences on celiac disease in the Midwest, and generally attracts over 500 people from multiple states.

**Design**

The present study was descriptive in nature and used survey methodology to obtain information.

**Instrumentation**

A sixteen-question survey (see Appendix C) was created based from the current literature supporting the nutrition therapy for celiac disease. Using the literature, questions were designed to assess the alternative grain consumption of people with celiac disease.

In order to gather information needed to achieve the first research objective (“Describe the grain consumption patterns of individuals with celiac disease”), four survey questions were developed. One multiple choice question sought to obtain the amount of grain servings (given examples of a “serving size”) consumed on a typical day by the person with celiac disease. Another question asked if the individual with celiac disease consumed more of their daily grain servings from cooked grains (i.e. rice, quinoa, oats) or pre-prepared grain products (i.e. bread, cereal, pasta, cookies). Two more
questions were set up in table-form, which addressed consumption of specific grains. The first of these asked the participant to describe (via check mark) how often the person with celiac disease consumes a grain or grain product containing each of the grains listed in the table (17 grains in total), on a scale of “eat regularly” (defined as once per week or more), “eat sometimes” (defined as once per month or more), and “eat never.” The question immediately following this question was set up similarly, with the same grains listed in the left-hand column, only this question asked the participant to describe (via check mark) reasons for avoiding any of the grains mentioned. The options, by column, included “I don’t avoid,” “contains gluten,” “possibly contaminated with gluten,” “too expensive,” and “I’ve never heard of it,” with a final column for “other” reasons. Grains listed in these two questions were chosen according to those grains currently identified in the literature and those available on the market in the United States. Grains that contain gluten (wheat, rye, and barley) were intentionally included on this list to validate the participant’s knowledge of gluten free grains.

In order to gather information needed to achieve the second research objective (“Describe other factors associated with consumption of grains”), additional questions were developed. Basic demographic questions were included, such as age and gender, to help describe the celiac population surveyed in this study, as well as draw possible correlations to grain consumption habits. Two more questions were included for correlational purposes, seeking to determine if being the responsible party for shopping and/or food preparation has an effect on grain consumption habits.

An additional survey question asking whether or not the participant had been clinically diagnosed with celiac disease was included to serve as a source of exclusion
criteria. Any survey participant who was not clinically diagnosed with celiac disease was excluded from the study. A question asking for age at diagnosis was included to possibly draw correlations between age since diagnosis and grain consumption habits.

A few questions were included solely for the purpose of being used for future research. One question addressed whether or not the survey participant had been referred to, met with, and/or obtained nutrition counseling from a Registered Dietitian. Two more questions were asked to obtain information on participants’ use (if any) of dietary supplements, with the intent being to, in future studies, possibly compare supplement usage to grain consumption patterns and make inferences about the resulting total nutrient intake.

Content validity was determined by evaluation from three Registered Dietitians, including a nationally-recognized expert in celiac disease. Adaptations to the survey were completed following this evaluation. Changes included removal of a “Yes/No” question that asked if the participant has trouble digesting grain products. This question was removed due to the confusion it might have added to interpretation of survey results. For instance, participants who have trouble digesting grain products may or may not have been clinically diagnosed with celiac disease. Likewise, participants clinically diagnosed with celiac disease may or may not have had symptoms that indicated trouble digesting grain products. The demographic question regarding gender was established in its place.

**Data Collection**

On the day of the conference, the survey was distributed by volunteers working at the conference. As conference attendees entered the Education Building at Nationwide Children’s Hospital, they were asked to participate in the research. A brief verbal
description was given, and the participants were instructed to fill out the survey at any point throughout the day, and then return surveys to one of three labeled boxes found within the conference area.

Since official number of attendees was unknown prior to the event, 400 surveys were printed. Of the 400 copies originally available for distribution, 77 remained undistributed at the end of the day, indicating a total of 323 surveys were distributed. Of those surveys distributed, only 220 were returned to collection boxes. Therefore the response rate was calculated to be 68.1%.

Assumptions

1. The survey that was developed is an effective method to measure the grain consumption for celiac patients via the patient or the caregiver.
2. The survey was completed accurately and truthfully by the celiac patient and/or their caregiver.
3. The survey was completed by the individual with celiac disease.

Data Analysis

Data was analyzed in several steps. First, survey answers were coded and organized into an Excel spreadsheet. Closed-ended questions were coded by numbers, and open-ended questions were separated into categories. Data was analyzed via the SPSS statistics software program, allowing for correlations and trends to be assessed.  

Once all survey answers were recorded and coded, certain surveys were eliminated from the study according to exclusion criteria. Surveys completed by someone other than the celiac disease patient (i.e. a caregiver) were excluded due to the possibility of the person without celiac disease answering the survey questions according to their
own practices rather than the celiac individual. Surveys were also excluded if the person filling out the survey had not been officially diagnosed with celiac disease (i.e. gluten intolerant, self-diagnosed, etc.), as the study was designed to specifically describe the celiac disease population. Therefore, of the original 220 surveys returned, 174 surveys were usable for analysis.
Chapter 4: Results and Conclusions

Results

The results of this study suggest that individuals with celiac disease may not be consuming enough grain products while maintaining a gluten-free diet. Further conclusions can be drawn from this, suggesting that if one is not consuming enough grain products, he or she is also not consuming adequate vitamins, minerals, and fiber that the general population typically acquires from grain consumption. Another conclusion from the research is that several barriers exist which seem to keep celiac disease patients from consuming many of the gluten free alternative grains or grain products.

Eighty percent of study participants reported consuming less than three servings per day (see Table 1). This is less than half of the recommended daily number of servings, which is 6-11 servings per day. In fact, about one-third of participants (31.6%) reported consuming only one serving or less of grains per day. Less than one-fifth (only 19%) of the sample population reports a daily grain serving intake of 4 or more servings per day; and only 1.1% of the sample population was found to regularly consume adequate servings of grains (6 or more servings) on a daily basis. This expands on the Thompson, et al. findings from 2005, in which 21% of female respondents did not meet recommended grain servings per day.
<table>
<thead>
<tr>
<th>Grain Servings</th>
<th>Frequency (n=174)</th>
<th>Percent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;1 per day</td>
<td>16</td>
<td>9.2</td>
</tr>
<tr>
<td>1 per day</td>
<td>39</td>
<td>22.4</td>
</tr>
<tr>
<td>2-3 per day</td>
<td>84</td>
<td>48.3</td>
</tr>
<tr>
<td>4-5 per day</td>
<td>31</td>
<td>17.8</td>
</tr>
<tr>
<td>6 or more per day</td>
<td>2</td>
<td>1.1</td>
</tr>
<tr>
<td>Total</td>
<td>172</td>
<td>98.9</td>
</tr>
<tr>
<td>Missing Answer for Question</td>
<td>2</td>
<td>1.1</td>
</tr>
<tr>
<td>Total Sample Size</td>
<td>174</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Table 1. Reported Daily Grain Consumption

Regarding the type of grain consumed – grains (such as rice, quinoa, or oats) – or grain products (such as bread, cereal, pasta, or cookies) – results showed that the overwhelming majority of study participants were three times as likely to choose grain products over grains themselves (see Table 2). In other words, nearly 75% of the 162 participants who answered this survey question showed a preference for grain products over cooked grains. This means that only 25%, one-fourth, of survey responders reported a preference for cooked grains. Since only 162 of the 174 usable surveys contained an answer for this question, 7% of the sample was unaccounted for. However, even if all twelve survey participants who chose not to answer this question indeed prefer the minority, cooked grains, still less than one-third of the sample population (30.5%) will have shown a preference for cooked grains.
<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>Percent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grains (i.e. rice, quinoa, oats)</td>
<td>41</td>
<td>25.3</td>
</tr>
<tr>
<td>Grain Products (i.e. cereal,</td>
<td>121</td>
<td>74.7</td>
</tr>
<tr>
<td>bread, pasta, cookies)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total answered</td>
<td>162</td>
<td>93.1</td>
</tr>
<tr>
<td>Missing Answer</td>
<td>12</td>
<td>69.0</td>
</tr>
<tr>
<td>Total sample</td>
<td>174</td>
<td>100</td>
</tr>
</tbody>
</table>

*Table 2. Reported Consumption of Grains vs. Grain Products*

Seventeen different grains were explored in this study, in terms of grain consumption and reasons for possible avoidance (see Table 3). Three of these grains were wheat, rye, and barley, to describe how much, if any, gluten-containing grains were still being consumed by the individual with celiac disease. One of the grains included was oats, but did not specify between gluten-free oats and regular oats. The majority of grains included (thirteen in total) were alternative grains that are naturally gluten-free. These thirteen grains were: amaranth, buckwheat, corn (grits, polenta), flax, millet, quinoa, rice flour or white rice, brown rice, sorghum, soy flour, tapioca, tef, and montina.
<table>
<thead>
<tr>
<th></th>
<th>Eat Regularly</th>
<th>Eat sometimes</th>
<th>Never eat</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Percent</td>
<td>n</td>
</tr>
<tr>
<td>Amaranth*</td>
<td>8</td>
<td>5.1</td>
<td>30</td>
</tr>
<tr>
<td>Barley</td>
<td>0</td>
<td>.0</td>
<td>5</td>
</tr>
<tr>
<td>Buckwheat*</td>
<td>11</td>
<td>6.8</td>
<td>58</td>
</tr>
<tr>
<td>Corn*</td>
<td>108</td>
<td>63.5</td>
<td>51</td>
</tr>
<tr>
<td>Flax*</td>
<td>47</td>
<td>28.5</td>
<td>76</td>
</tr>
<tr>
<td>Millet*</td>
<td>10</td>
<td>6.3</td>
<td>41</td>
</tr>
<tr>
<td>Oats</td>
<td>44</td>
<td>26.3</td>
<td>76</td>
</tr>
<tr>
<td>Quinoa*</td>
<td>31</td>
<td>19.1</td>
<td>83</td>
</tr>
<tr>
<td>White rice/ rice flour*</td>
<td>128</td>
<td>75.3</td>
<td>38</td>
</tr>
<tr>
<td>Brown Rice*</td>
<td>123</td>
<td>72.8</td>
<td>42</td>
</tr>
<tr>
<td>Rye</td>
<td>1</td>
<td>.6</td>
<td>4</td>
</tr>
<tr>
<td>Sorghum*</td>
<td>20</td>
<td>12.7</td>
<td>67</td>
</tr>
<tr>
<td>Soy flour*</td>
<td>20</td>
<td>12.3</td>
<td>83</td>
</tr>
<tr>
<td>Tapioca*</td>
<td>70</td>
<td>42.2</td>
<td>69</td>
</tr>
<tr>
<td>Tef*</td>
<td>6</td>
<td>3.9</td>
<td>33</td>
</tr>
<tr>
<td>Montina*</td>
<td>3</td>
<td>1.9</td>
<td>26</td>
</tr>
<tr>
<td>Wheat</td>
<td>5</td>
<td>3.0</td>
<td>3</td>
</tr>
</tbody>
</table>

*Gluten-Free (Alternative) Grain

Table 3. Specific Grain Consumption

Of the thirteen gluten-free grains, six of the grains were each reported to be ‘never eaten’ by almost half or more than half of survey responders. Specifically, 57% report that they never eat buckwheat, 68% report that they never eat millet, 75% report that they never eat tef, 76% report that they never eat amaranth, and 81% report that they never eat montina. Almost half (44%) of responders report that they never eat sorghum.
For the remaining seven gluten free grains, white rice/rice flour, brown rice, and corn were the three grains most commonly consumed, with only 2.4% of survey responders reporting “never eat” for both white rice/rice flour and brown rice, and only 6.5% reporting that they never eat corn. Two more of the grains, flax and quinoa, were reported by over one-fourth of the responders to be completely avoided (26% and 30%, respectively).

Of all the grains eaten regularly, results show that both kinds of rice, white and brown, together account for 43% of the grains eaten regularly. Corn, which makes up almost 20% of the grains eaten regularly, together with rice then make up 61% of the grains noted to be consumed regularly in this sample population.

Amaranth, tef, and montina were the three least commonly-eaten and most commonly-avoided gluten-free grains. In fact, all three of these grains were found to be avoided by more than 75% of survey participants. Only 5.1% reported eating amaranth regularly, 19% reported sometimes, and over 75% reported that they never eat it. For tef, 3.9% reported eating it regularly, 21.4% reported eating it sometimes, and 74.7% (nearly three-fourths) report that they never eat it. For montina, 1.9% reported eating regularly, 16.8% report eating sometimes, and 81.3% reported that they never eat it.

Regarding wheat, barley, and rye, the gluten-containing grains, only 8 people (4.8% of survey responders) answered that they consume wheat either sometimes or regularly. Only 5 people (3% of survey responders) report consuming barley sometimes or regularly. Rye was reported to be consumed either sometimes or regularly by 5 people (3% of survey responders).
About half of the sample population reported that they eat oats ‘sometimes’. The other half of the population was split fairly evenly between ‘regularly’ and ‘never’ (26.3% and 28.1%, respectively).

One of the possible correlations explored during statistical analysis was whether or not being the primary grocery shopper or cook in the household could possibly impact amount of grains consumed daily, type of grain servings preferred, or variety of grains consumed, as well as reasons for avoiding certain grains. Results showed that whether or not a person does the grocery shopping or cooking in the household does not appear to have a correlation with improved daily grain consumption (see Table 4).

The number of years since diagnosis was able to be calculated by obtaining current age and age at diagnosis on the survey. Answers from all the participants who reported both ages were grouped into three sub-categories for the purpose of statistical analysis: 5 or less years, 6-10 years, and more than 10 years. Study results showed that number of years since diagnosis does not seem to impact improved grain consumption in terms of servings per day (see Table 5). As it relates to type of grains consumed, all

<table>
<thead>
<tr>
<th>Servings</th>
<th>No</th>
<th>Percent</th>
<th>Yes</th>
<th>Percent</th>
<th>No</th>
<th>Percent</th>
<th>Yes</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;1 per day</td>
<td>2</td>
<td>9%</td>
<td>14</td>
<td>9%</td>
<td>2</td>
<td>6%</td>
<td>14</td>
<td>10%</td>
</tr>
<tr>
<td>1 per day</td>
<td>6</td>
<td>26%</td>
<td>33</td>
<td>22%</td>
<td>10</td>
<td>32%</td>
<td>29</td>
<td>21%</td>
</tr>
<tr>
<td>2-3 per day</td>
<td>9</td>
<td>39%</td>
<td>75</td>
<td>50%</td>
<td>12</td>
<td>39%</td>
<td>72</td>
<td>51%</td>
</tr>
<tr>
<td>4-5 per day</td>
<td>5</td>
<td>22%</td>
<td>26</td>
<td>17%</td>
<td>6</td>
<td>19%</td>
<td>25</td>
<td>18%</td>
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<tr>
<td>6 or more per day</td>
<td>1</td>
<td>4%</td>
<td>1</td>
<td>1%</td>
<td>1</td>
<td>3%</td>
<td>1</td>
<td>1%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Category</th>
<th>No</th>
<th>Percent</th>
<th>Yes</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grains</td>
<td>3</td>
<td>14%</td>
<td>38</td>
<td>27%</td>
</tr>
<tr>
<td>Grain products</td>
<td>19</td>
<td>86%</td>
<td>102</td>
<td>73%</td>
</tr>
</tbody>
</table>

Table 4. Correlations Between Grain Consumption and Grocery Shopper/Cook Status


Table 5. Correlations Between Grain Consumption and Years Since Diagnosis

<table>
<thead>
<tr>
<th>Years since diagnosis</th>
<th>Servings</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>&lt;1 per day</td>
<td>1 per day</td>
<td>2-3 per day</td>
<td>4-5 per day</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>&lt;1 per day</td>
<td>9</td>
<td>11%</td>
<td>3</td>
<td>11%</td>
</tr>
<tr>
<td>1 per day</td>
<td>19</td>
<td>23%</td>
<td>7</td>
<td>25%</td>
</tr>
<tr>
<td>2-3 per day</td>
<td>38</td>
<td>46%</td>
<td>12</td>
<td>43%</td>
</tr>
<tr>
<td>4-5 per day</td>
<td>16</td>
<td>20%</td>
<td>6</td>
<td>21%</td>
</tr>
<tr>
<td>6 or more per day</td>
<td>0</td>
<td>0%</td>
<td>0</td>
<td>0%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Grains</th>
<th>Grain products</th>
</tr>
</thead>
<tbody>
<tr>
<td>25</td>
<td>49</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>6-10 years</th>
<th>&gt;10 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grains</td>
<td>1</td>
<td>4%</td>
</tr>
<tr>
<td>Grain products</td>
<td>26</td>
<td>96%</td>
</tr>
</tbody>
</table>

Subgroups were found to consume more grain products than grains, as mentioned earlier. However, results were able to show that the subgroup of people diagnosed in the last 5 years consume more cooked grains (34% of this subgroup) than the subgroups of people diagnosed 6-10 years ago or more than 10 years ago (4% and 21% respectively).

Reasons for avoiding certain grains were also explored (see Table 6). Particularly of interest are the six most commonly-avoided alternative grains: amaranth, buckwheat, millet, tef, montina, and sorghum.

The majority of survey respondents who avoid amaranth (57%, over half) say they do so because they’ve never heard of it. Seven percent believe amaranth to contain gluten, and 9% avoid it because they consider it to be too expensive.

Those who avoid buckwheat do so mostly because they believe it either contains or is contaminated with gluten (44%). However, over one-third (38%) avoid buckwheat due to “other” reasons not listed on the survey. Eleven percent have never heard of it, and 8% avoid it because of expense.
For those who avoid millet, never having heard of the grain was the most common reason for avoidance (37%, over one-third, of responders who avoid). Thirteen of the people who avoid millet (17%) believe that it is contains gluten, and 8 people (11%) believe it may be contaminated.

Tef, one of the most commonly avoided grains altogether, is mainly avoided by this survey population because participants (63%) have never heard of it. About 12 percent of those who avoid tef do so because they think it contains gluten, and 5% do so because they think it may be contaminated with gluten.

Montina was another commonly avoided grain. Results show that almost 80% of the people who avoid montina do so because they have never heard of it. Since 90 people account for over about 52% of the entire survey population, it could be said that over 50% of the survey population has not heard of the alternative gluten free grain, montina.

About 38% (16) of those who avoid sorghum do so because they’ve never heard of it. A total of 11 responders (26%) report their reason for avoidance as being that sorghum either contains gluten or is possibly contaminated with gluten.
Contains gluten | Possibly contaminated | Too expensive | Never heard of it | Other | TOTAL Reasons for Avoidance
---|---|---|---|---|---
Amaranth | 6 | 7.1 | 2 | 2.4 | 8 | 9.4 | 48 | 56.5 | 21 | 24.7 | 85
Buckwheat | 12 | 22.6 | 11 | 20.8 | 4 | 7.6 | 6 | 11.3 | 20 | 37.7 | 53
Corn | 1 | 10.0 | 1 | 10.0 | 2 | 20.0 | 1 | 10.0 | 5 | 50.0 | 10
Flax | 2 | 6.7 | 3 | 10.0 | 7 | 23.3 | 3 | 10.0 | 15 | 50.0 | 30
Millet | 13 | 17.3 | 8 | 10.7 | 4 | 5.3 | 28 | 37.3 | 22 | 29.3 | 75
Quinoa | 3 | 11.5 | 3 | 11.5 | 3 | 11.5 | 8 | 30.8 | 9 | 34.6 | 26
White rice/ rice flour | 1 | 20.0 | 1 | 20.0 | 2 | 40.0 | 0 | 0.0 | 2 | 40.0 | 5
Brown Rice | 0 | 0.0 | 0 | 0.0 | 1 | 50.0 | 0 | 0.0 | 0 | 0.0 | 2
Sorghum | 6 | 14.3 | 5 | 11.9 | 2 | 4.8 | 16 | 38.1 | 13 | 31.0 | 42
Soy flour | 2 | 6.3 | 6 | 18.8 | 2 | 6.3 | 6 | 18.8 | 16 | 50.0 | 32
Tapioca | 1 | 8.3 | 0 | 0.0 | 1 | 8.3 | 3 | 25.0 | 7 | 58.0 | 12
Tef | 12 | 12.2 | 5 | 5.1 | 5 | 5.1 | 62 | 63.3 | 14 | 14.3 | 98
Montina | 4 | 3.5 | 4 | 3.5 | 3 | 2.6 | 91 | 79.1 | 13 | 11.3 | 115
TOTAL* | 63 | 10.7 | 53 | 9.0 | 44 | 7.5 | 272 | 46.2 | 157 | 26.7 | 589
(Oats) | (7) | (7.3) | (86) | (89.6) | (1) | (1.0) | (0) | (0.0) | (2) | (2.1) | (96)

Table 6. Reasons for Avoiding Alternative Grains

The reasons for avoiding any of the specific alternative grains overall, in order from most popular reason to least popular reason are as follows: “never heard of the grain;” “other;” “contains gluten;” “possibly contaminated with gluten;” and “too expensive.” Answers in the “other” category included reasons such as: “don’t like the taste,” “hard to find,” “don’t know how to use,” “sensitive to/ does not agree with
stomach/ seem to get celiac reaction,” and “allergic also” (usually referring to soy).

Therefore, many reasons exist that may explain why people avoid certain grains in particular, why they consume more grains overall.

Specific grain consumption (including gluten-containing grains), in order from least consumed to most consumed, are as follows: barley (97.0%); rye (97.0%); wheat (95.1%), montina (81.1%); amaranth (75.9%); tef (74.7%); millet (67.9%); buckwheat (57.1%); sorghum (44.9%); soy flour (36.8%); quinoa (29.6%); oats (28.1%); flax (25.5%); tapioca (16.3%); corn (6.5%); and rice (2.4% each for brown rice, and white rice/rice flour) (see Figure 1).
Discussion

It has already been suggested that the celiac community needs to take extra care in consuming adequate amounts of grain servings daily, since grains are known to contribute a large portion of vital nutrients to the diets of the general population. Much research points to the fact that grains are an important source of vitamins and minerals, as well as fiber, in the American diet.\textsuperscript{11,12} Consuming adequate amounts of nutrients is extremely important for individuals with celiac disease, as they are likely to have existing nutrient deficiencies because of the malabsorptive nature of the disease prior to dietary avoidance of gluten.\textsuperscript{2,6,8,24,34} The results of the present study help to define what the celiac population is actually consuming in terms of daily grain servings in general, as well as describing the consumption of specific grains. The amount of grain servings consumed daily, as hypothesized in other studies, has been shown to be far less than the recommended daily amount (6-11 servings per day)\textsuperscript{12} for an overwhelming majority of survey participants. Therefore, a great need for education still exists regarding the wide array of gluten free alternative grains to individuals with celiac disease, as well as education regarding the importance of consuming adequate amounts of grain servings.

In order to meet the requirements for daily grain servings, various research studies have suggested that the celiac disease population consume at least 6 servings of alternative grains daily.\textsuperscript{10,11,12,26} However, individuals with celiac disease in this study were found to avoid many of the alternative grains. Though the higher cost of gluten-free foods compared to their gluten-containing counterparts has been brought to attention in other studies as a very real burden to consuming gluten-free grains and grain products,\textsuperscript{31,32} the findings of this study show that never having heard of some grains
seemed to be the most common reason for avoidance. This finding expands on and may add further detail to existing research that has found grain servings in general to be under-consumed by the celiac disease population.\textsuperscript{11,12}

Misconceptions about various grains, however, could also be a large contributor to the celiac community’s apparent lack of grain consumption. For instance, many of the participants in this study believed many of the gluten-free alternative grains to contain gluten. This could, in part, be due to lack of knowledge and awareness about the existence of certain grains, but it could also be partly due to recent findings that grains thought to be inherently gluten-free have (in one study) been found to contain trace amounts of gluten as a result of cross-contamination.\textsuperscript{30}

Results also suggest that individuals with celiac disease prefer convenience foods over grains that must be cooked or prepared; however, the general population may also share this preference.\textsuperscript{11,12} Nevertheless, since many gluten free pre-prepared products are often not fortified like their gluten-containing counterparts,\textsuperscript{10,11,12} and considering what seems to be a less-than-adequate intake of grains by individuals with celiac disease, perhaps companies should be encouraged to enrich and/or fortify their gluten-free products.

Registered Dietitians could thus play a pivotal role in improving overall grain consumption in individuals with celiac disease by educating the celiac community and clearing up any misconceptions that may exist. Furthermore, in order to prevent consumption of alternative grains that may be gluten-contaminated, Registered Dietitians
should take special care to educate the celiac disease population about purchasing and consuming alternative grains and flours that are “Certified Gluten-Free,” rather than trusting that certain grains are inherently gluten-free.

**Limitations**

This study had several limitations and possible confounding factors that must be acknowledged. First of all, the sample population of individuals with celiac disease was a sample of convenience attending a large celiac conference. For this reason, those taking the survey may already have a heightened awareness of the gluten-free diet (and thus grain alternatives) as compared to a typical person, and thus may not be an accurate representation of the larger celiac community. However, as grain consumption was found to be poor even among these individuals, grain consumption would likely be even worse among the less pro-active celiac disease population. Still, future studies may want to consider a random sample, rather than a sample of convenience.

Secondly, data was collected by means of a survey. As with most surveys, questions may be interpreted differently from person to person and therefore may give rise to different types of answers for each question. As far as specific questions go, there was no specification on this survey between “regular oats” and “gluten-free oats.” Several participants wrote in “only if gluten-free” in the “oats” portions of the survey, so results that show rather high consumption of oats may be skewed. Future studies may therefore want to discern between (or have separate categories for) “regular” and “gluten-free” oats.
Future Research

Future research may also want to examine where individuals with celiac disease are obtaining their information regarding the gluten-free diet, specifically as it applies to alternative grains and the importance of consuming adequate amounts of grain servings; so that correct information can be provided at diagnosis rather than retroactively by clearing up misconceptions. Of particular interest may be to find out how many individuals with celiac disease receive nutrition counseling from a Registered Dietitian upon diagnosis (or shortly after), and whether or not this counseling was effective. Even more specifically, such studies may want to compare the effectiveness of gluten-free diet counseling from a celiac-specific Registered Dietitian versus a Registered Dietitian without specific training.

To follow up on the recent Thompson et. al study regarding contamination of grains thought to be inherently gluten-free, future studies may want to look at whether individuals with celiac disease choose only foods that specifically say “gluten-free,” even if the grain is not thought to contain gluten, or if they typically buy foods that are thought to be naturally gluten-free, regardless of whether the term “gluten-free” is present.

Lastly, future research may want to look into availability and accessibility of grains, versus states/regions/cities of residence of study participants. Similarly, such research may want to explore where study participants are doing their primary grocery shopping (specific stores, types of stores, etc.).

Conclusion

The present study sought to describe the grain consumption of individuals with celiac disease. Results suggest that grain consumption is inadequate in this population, in
terms of amount and variety. Lack of awareness of various alternative grains and fear of gluten contamination were found to be major contributors to this poor intake. As the celiac disease population is already at risk for nutrient deficiencies, and grains are known to provide a large amount of nutrients to the general population, both Registered Dietitians as well as the food industry could play major roles in improving nutrient intake via grain consumption, by respectively educating and marketing to the celiac disease population. Additional studies, however, would be useful in determining the generalizability of these results to the larger celiac disease population.
Chapter 5: A Descriptive Study of Alternative Grain Consumption among Individuals with Celiac Disease

Abstract

The gluten-free diet is becoming increasingly popular as more people are diagnosed with and become aware of celiac disease. However, little is known about the nutritional quality of the diet, especially in terms of grain consumption and the nutrients provided by these foods. For the general population, grain consumption provides a large amount of daily vitamins, minerals, and fiber. Therefore, being able to describe the grain consumption of individuals with celiac disease may shed a crucial light on nutritional quality of the gluten-free diet. Data was obtained by means of a survey conducted at a Midwest hospital’s annual celiac conference. The sample of convenience consisted of 220 people, 174 of which provided usable data. The survey focused on daily consumption of grain servings, types of grains consumed (cooked grains versus pre-prepared grain products), variety of grains consumed, and reasons for avoiding specific grains. Data from 174 usable surveys were used for statistical analysis. Over 80% of the sampled population consumes less than half of the daily recommended amount of grain servings. Only 1.1% consumes the recommended daily amount. Three-fourths of participants prefer pre-prepared grain products over grains. No matter the product type, rice (both brown and white) and corn make up the majority of grains or grain ingredients eaten regularly. Respondents
identified many reasons for avoiding different grains, which can support both clinicians and the food industry, in efforts to improve the grain consumption of people with celiac disease.

**Introduction**

Celiac disease is known to affect at least 1 in 133 people in the United States. It is well-established that the gluten-free diet is the only treatment and is effective if followed strictly. As more people are diagnosed and become aware of celiac disease, the gluten-free diet is becoming increasingly popular. However, little is known about the nutritional quality of the gluten-free diet, especially in terms of grain consumption. For the general population, grain consumption provides a large amount of daily vitamins, minerals, and fiber. Therefore, being able to describe the grain consumption of individuals with celiac disease may shed a crucial light on quality of the gluten-free diet.

**Methods**

A survey was conducted at Nationwide Children’s Hospital in Columbus, Ohio, in 2010 at an annual celiac conference, providing a sample of convenience. The survey focused on daily consumption of grain servings, types of grains consumed (cooked grains versus pre-prepared grain products), variety of grains consumed, and reasons for avoiding specific grains. Current literature supporting the nutrition therapy for celiac disease was used as a base for developing the sixteen-question survey. Content validity was determined by evaluation from three Registered Dietitians, including a nationally-recognized expert in celiac disease. Adaptations were completed following this evaluation, and a total of 323 surveys were distributed; 220 returned and 174 used for
statistical analysis. Survey answers for open-ended questions were grouped into categories, and answers for closed-ended questions were coded numerically to allow for quantitative data analysis via the SPSS statistics software program.  

**Results and Discussion**

Using the US Dietary guidelines as a reference, over 80% of the sampled population consumed less than half of the daily recommended amount of grain servings. Only 1.1% consumed the minimum of 6 servings. Three-fourths of participants prefer pre-prepared grain products over cooked grains. Rice (both brown and white) and corn were the most commonly consumed grains, making up 61% of grains and grain ingredients eaten regularly. The most common reasons for avoiding specific grains were: not having heard of the grain, “other” reasons, the belief that the grain contains gluten, belief that the grain was contaminated with gluten, and financial expense of the grain. Common reasons in the “other” category were related to undesirable taste of the grain, lack of availability or accessibility of the grain, lack of knowledge on how to use the grain, occurrence of celiac-like reaction when the grain is consumed, or presence of an additional allergy.

It has already been suggested that the gluten-free diet may not be providing adequate nutrients to the celiac disease population. Some research has even begun to look at nutrient intake from grains, and the comparison of gluten-free grains and products to gluten-containing grains and products. Results of the present study further the understanding of what the celiac disease population is actually consuming, in terms of specific grains, and types and amounts of grains servings. This study, as many prior studies have hypothesized, showed that the celiac disease population indeed may be not
consuming adequate amounts of daily grain servings. Although economic burden of gluten-free grains and grain products has been brought to attention in recent research and is definitely a barrier to consuming certain grains, results of this study suggest that another perhaps even bigger reason for specific alternative-grain avoidance may be lack of awareness of alternative grains. Therefore, the need exists for education about the wide array of gluten free alternative grains for individuals with celiac disease, as well as education regarding the importance of consuming adequate amounts of grain.

Misconceptions about various grains (for instance, believing a grain to contain gluten, when it is actually gluten-free) could be a large contributor to why the celiac community may not be consuming enough grains on a daily basis. However, fearing that a supposedly gluten-free grain might be contaminated may not be a result of a misconception, but actually a legitimate possibility, as recently established.

Results also suggest that individuals with celiac disease may prefer convenience foods over grains that must be cooked or prepared; however, the general population may also share this preference. Nevertheless, countless studies have shown that gluten-free pre-prepared products are often not fortified like their gluten-containing counterparts. Therefore, considering what seems to be a less-than-adequate intake of grains by individuals with celiac disease (a population already likely to have various nutrient deficiencies) when grains have been found to be a major source of vitamins, minerals, and fiber for the general population, the food industry should be encouraged to enrich and/or fortify their gluten-free products.
Registered Dietitians could also play a pivotal role in improving overall grain (and, therefore, ultimately nutrient)\textsuperscript{10,11} consumption in individuals with celiac disease by educating the celiac community and clearing up any misconceptions that may exist.

This study had several limitations and possible confounding factors that must be acknowledged. The study population was a sample of convenience attending a large celiac conference. Those taking the survey may already have a heightened awareness of the gluten-free diet (and thus grain alternatives) as compared to other celiac patients, and thus may not be an accurate representation of the larger celiac community. However, as grain consumption was found to be poor even among these individuals, grain consumption would likely be even worse among the less pro-active celiac disease population. Future studies should consider a random sample, rather than convenience.

Secondly, data was collected by means of a survey. As with most surveys, questions may be interpreted differently from person to person and therefore may give rise to different types of answers for each question. Specifically in this survey there was no clarification between “regular oats” and “gluten-free oats.” Several participants wrote in “only if gluten-free” in the “oats” portions, so results that show rather high consumption of oats may be skewed. Future studies may therefore want to discern between (or have separate categories for) “regular” and “gluten-free” oats.

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Lastly, future research may want to look into availability and accessibility of grains, versus states/regions/cities of residence of study participants. Similarly, such research may want to explore where study participants are doing their primary grocery shopping (specific stores, types of stores, etc.).

Conclusion

The present study sought to describe the grain consumption of individuals with celiac disease. Results suggest that grain consumption is inadequate in this population, in terms of amount and variety. Lack of awareness of various alternative grains and fear of gluten contamination were found to be major contributors to this poor intake. As the celiac disease population is already at risk for nutrient deficiencies, and grains are known to provide a large amount of nutrients to the general population, both Registered Dietitians as well as the food industry could play major roles in improving nutrient intake via grain consumption, by respectively educating and marketing to the celiac disease
population. Additional studies, however, would be useful in determining the generalizability of these results to the larger celiac disease population.
References Cited


### Dietary Reference Intakes (DRIs): Recommended Dietary Allowances and Adequate Intakes, Vitamins

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**NOTE:** This table (taken from the DRI report, see margin note) presents Recommended Dietary Allowances (RDAs) in bold type and Adequate Intakes (AIs) in ordinary type followed by an asterisk (*). An RDA is the average daily dietary intake level sufficient to meet the nutrient requirements of nearly all (97-98%) healthy individuals in the group. It is calculated from an Estimated Average Requirement (EAR). If sufficient scientific evidence is not available to establish an EAR, and thus a recommendation, an AI is then developed. For breastfed infants an AI is the mean intake. The AI for other life stages and gender groups is believed to cover the needs of all healthy individuals in the group, but lack of data or uncertainty in the data preclude being able to specify with confidence the percentage of individuals covered by this intake.

*As retinol activity equivalent (RAE). 1 RAE = 1 μg retinol, 12 μg β-carotene, 24 μg α-carotene, or 24 μg β-cryptoxanthin. The RAE for dietary provitamin A carotenoids is two-fold greater than retinol equivalents (RE), whereas the RAE for preformed vitamin A is the same as RE.

†As cholecalciferol. 1 μg cholecalciferol = 40 IU vitamin D.

‡Under the assumption of minimal sunlight.

§As α-tocopherol. α-Tocopherol includes RRR-α-tocopherol, the only form of α-tocopherol that occurs naturally in foods, and the 20 stereoisomeric forms of α-tocopherol (RRR-, RRS-, RRRS-, and RRSR-α-tocopherol) that occur in fortified foods and supplements. It does not include the 20 stereoisomeric forms of α-tocopherol (SSR-, SSRS-, SSRSS-, and SSRSSR-α-tocopherol) also found in fortified foods and supplements.

‖As maximum equivalent (ME): 1 mg of α-tocopherol = 60 mg of α-tocotrienol. (Note: α-tocopherol is a term that includes all naturally occurring forms of vitamin E, whereas α-tocotrienol is a specific form of vitamin E found in some plant oils.)

*As dietary thiamine equivalents (DTE). 1 DTE = 1 μg thiamine + 0.6 μg of thiamine and thiamine propionate or thiamine pyrophosphate + 0.5 mg of thiamine plus thiamine propionate taken as an empty stomach.

**Although AIs have been set for chlorine, there is little data to assess whether a dietary supply of chlorine is needed at all stages of the life cycle, and it may be that the chlorine requirement can be met by endogenous synthetic sources in these stages.

Because 0.5 to 2% of other people may malabsorb food-bound B12, it is advisable for these older than 50 years to meet the RDA by consuming foods fortified with B12, or a supplement containing B12.
It is assumed that women will continue consuming 400 μg from supplements or fortified food until their pregnancy is confirmed and they cease prenatal care, which ordinarily occurs after the end of the peri-conceptional period—the critical time for formation of the neural tube.

Appendix B: Nutrient Recommendations – Minerals
| Life Stage | Group | Calcium (mg/d) | Chromium (µg/d) | Copper (mg/d) | Fluoride (mg/d) | Iodine (µg/d) | Iron (mg/d) | Magnesium (mg/d) | Molybdenum (µg/d) | Phosphorus (mg/d) | Selenium (µg/d) | Selenite (µg/d) | Zinc (mg/d) | Manganese (mg/d) | Phosphorus (mg/d) | Iodine (µg/d) | Selenium (µg/d) | Selenite (µg/d) | Zinc (mg/d) |
|-----------|-------|---------------|----------------|--------------|---------------|--------------|------------|----------------|----------------|----------------|----------------|---------------|-------------|----------|----------------|----------------|----------------|----------------|---------------|---------|
| Infant    | 0 to 6 mo | 200* | 200* | 0.01* | 114* | 0.27* | 30* | 0.053* | 2* | 150* | 15* | 2* | 0.02* | 0.15* |
| 6 to 11 mo | 200* | 200* | 0.01* | 220* | 0.1* | 25* | 0.3* | 11 | 75* | 0.6* | 5* | 275* | 20* | 3 | 0.7* | 0.37* | 0.57* |
| Children  | 1-3 y | 700 | 11* | 280 | 0.7* | 90 | 1.8* | 17 | 400 | 70 | 3 | 3.0* | 1.0* | 1.5* |
| 4-6 y | 1600 | 17* | 450 | 1* | 100 | 1.5* | 20 | 500 | 100 | 5 | 3.0* | 1.6* | 1.5* |
| Males     | 2-5 y | 1200 | 15* | 700 | 2* | 120 | 1.5* | 10 | 250 | 10 | 8 | 4.5* | 1.5* | 2.3* |
| 6-10 y | 1200 | 15* | 900 | 3* | 140 | 2.3* | 14 | 350 | 15 | 9 | 5.7* | 1.5* | 2.3* |
| 11-14 y | 1400 | 15* | 1200 | 3* | 200 | 3.0* | 16 | 420 | 20 | 11 | 6.7* | 1.5* | 2.3* |
| 20-35 y | 1600 | 15* | 1500 | 3* | 250 | 3.8* | 18 | 500 | 25 | 11 | 7.5* | 1.5* | 2.3* |
| 36-74 y | 1600 | 15* | 1500 | 3* | 250 | 3.8* | 18 | 500 | 25 | 11 | 7.5* | 1.5* | 2.3* |
| Females   | 2-5 y | 1200 | 21* | 700 | 2* | 120 | 1.6* | 12 | 250 | 10 | 5 | 4.5* | 1.5* | 2.3* |
| 6-10 y | 1600 | 24* | 900 | 3* | 140 | 2.0* | 14 | 350 | 15 | 9 | 5.7* | 1.5* | 2.3* |
| 11-14 y | 1200 | 25* | 1200 | 3* | 200 | 3.0* | 16 | 420 | 15 | 11 | 6.7* | 1.5* | 2.3* |
| 20-35 y | 1600 | 25* | 1500 | 3* | 250 | 3.8* | 18 | 500 | 25 | 11 | 7.5* | 1.5* | 2.3* |
| 36-74 y | 1600 | 25* | 1500 | 3* | 250 | 3.8* | 18 | 500 | 25 | 11 | 7.5* | 1.5* | 2.3* |
| Pregnant  | 18-26 y | 2000 | 35* | 1000 | 3* | 220 | 2.0* | 20 | 350 | 15 | 11 | 5.7* | 1.5* | 2.3* |
| 27-50 y | 1600 | 36* | 1600 | 3* | 260 | 2.3* | 22 | 450 | 20 | 11 | 6.7* | 1.5* | 2.3* |

**NOTE:** This table is taken from the DRI Reports, www.nap.edu, presents Recommended Dietary Allowances (RDAs) in bold type and Adequate Intakes (AIs) in ordinary type followed by an exclamation mark (!). An RDA is the average daily dietary intake level sufficient to meet the estimated requirements of nearly all (97-98 percent) healthy individuals in a group. It is calculated from an Estimated Average Requirement (EAR). If sufficient scientific evidence is not available to establish an EAR, and thus calculate an RDA, an AI is usually developed. For healthy breastfed infants, an AI is the average intake. The AI for other life stages and gender groups is believed to cover the needs of all healthy individuals in the group, but lack of data or uncertainty in the data precludes being able to specify with confidence the percent of individuals covered by this intake.

Appendix C: Data Collection Survey
Nutrition Survey: Nationwide Children’s Hospital

In our research, we are interested in finding out about the types of grains and grain products that you eat. Please answer each question below as truthfully as you can. Do not write any identifying information on this form. This is an anonymous survey. The data will not be linked to you in any way. When you are finished, please place the survey in the box provided at the registration desk.

1. What is your age? __________ years

2. What is your gender? Male Female

3. Have you or your child been clinically diagnosed with Celiac Disease? Yes No

4. If yes, age at diagnosis: __________ if no, then finished.

5. Who does the grocery shopping in your household?
   a. Self  
   b. Parent/ Caregiver  
   c. Sibling  
   d. Someone else

6. Who does most of the cooking in your household?
   a. Self  
   b. Parent/ Caregiver  
   c. Sibling  
   d. Someone else

7. How many grain servings do you eat in a typical day?
   (1 serving = 1 oz slice of bread, 1 cup cooked grain)
   a. less than 1 serving/day
   b. 1 serving/day
   c. 2-3 servings/day
   d. 4-5 servings/day
   e. 6 or more servings/day

8. Which of the following would you say you consume MORE often:
   a. Grains (i.e. rice, quinoa, oats)
   b. Grain products (i.e. bread, cereal, pasta, cookies)

9. How would you describe how often the person with Celiac Disease consumes each of the following grains/ grain products? (For each grain, place a checkmark under whichever column best describes your habits. For example, if you never eat amaranth, place a checkmark in the ‘Eat never’ column, for ‘Amaranth’).

<table>
<thead>
<tr>
<th>Grain or Grain Product (such as cereal, bread, cookie, pasta) that contains:</th>
<th>Eat Regularly (1/week or more)</th>
<th>Eat Sometime (Once a month or more)</th>
<th>Eat Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Amaranth</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. Barley</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. Buckwheat</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>d. Corn (grits, polenta)</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>e. Flax</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f. Millet</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>g. Oats</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>h. Quinoa</td>
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<td></td>
<td></td>
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<tr>
<td>i. Rice flour or white rice</td>
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<td></td>
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<tr>
<td>j. Brown rice</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>k. Rye</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>l. Sorghum</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>m. Soy flour</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>n. Tapioca</td>
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<td>o. Tef</td>
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<tr>
<td>p. Montina</td>
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<td></td>
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</tr>
<tr>
<td>q. Wheat</td>
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</tbody>
</table>
10. For any grain that the person with Celiac Disease avoids, please indicate the reason:
(For example, if you’ve never heard of amaranth, and therefore have never eaten it, place a checkmark in the “I’ve never heard of it” column, for “Amaranth”).

<table>
<thead>
<tr>
<th>Grain or Grain Product (such as cereal, bread, cookie, pasta) that contains:</th>
<th>Don’t eat</th>
<th>Contains Gluten</th>
<th>Possibly Contaminated with Gluten</th>
<th>Too Expensive</th>
<th>I’ve never heard of it</th>
<th>Other (Explain)</th>
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<td>n. Tapioca</td>
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</table>

11. How do you decide if a food is allowed on your diet? (Circle ALL that apply)
   a. Read the label
   b. Look for words “gluten free”
   c. Read the ingredients
   d. Ask my doctor
   e. Call the manufacturer
   f. Ask my Registered Dietitian
   g. Ask another healthcare professional
   h. Look it up online
   i. Friends and family
   j. Other

12. Have you been referred to a Registered Dietitian?
   a. Yes
   b. No

13. How often did you meet with a Registered Dietitian?
   a. I never met with a Registered Dietitian
   b. 1 time
   c. 2-3 times

14. Did a Registered Dietitian provide nutrition counseling for you?
   a. Yes
   b. No

15. Do you take a multivitamin?
   a. Yes
   b. No

16. Do you take any additional supplements because of Celiac Disease? (circle ALL that apply)
   a. Iron
   b. Calcium
   c. Folate
   d. B-vitamin complex
   e. Vitamin C
   f. Herbal supplements:
   g. Other:
   h. Other: