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Dr. Kelly Webber, Director of Graduate Studies

CELIAC DISEASE: A GLUTEN FREE DIET AND DIET QUALITY

THESIS

A thesis submitted in partial fulfillment of the
requirements for the degree of Master of Science in the
College of Agriculture
at the University of Kentucky

By

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Lexington, Kentucky

Director: Dr. Kelly Webber, Professor of Dietetics and Human Nutrition

Lexington, Kentucky

2013

ABSTRACT OF THESIS

CELIAC DISEASE: DIET QUALITY AND A GLUTEN FREE DIET

The media has highlighted a proposed link between a gluten free diet (GFD) and weight loss. However, research related to weight gain and a GFD for persons with celiac disease (CD) has shown the opposite effect. A GFD is the only known treatment for persons with CD. If a patient with CD consumes a diet high in GF processed foods, weight management may be difficult to achieve.

Participants with self-reported CD completed a modified GF food frequency questionnaire (FFQ) to assess typical dietary consumption of whole grains, sweets, fruits, vegetables and regular soda. Additionally, body mass index (BMI) and exercise were assessed.

The results of this study found that whole grain, fruit and vegetable intakes were low among celiac patients. Additionally, BMI was on the high end of the normal weight range. The results of this study indicate that a greater emphasis should be placed on nutritional quality when counseling patients with CD. Registered dietitians should focus their diet counseling sessions with CD patients on a nutritious naturally GF diet in order to better manage weight.

Keywords: gluten free diet, celiac disease, dietary intake, BMI, registered dietitian

Taylor Michele Stauble

July 9, 2013

CELIAC DISEASE: A GLUTEN FREE DIET AND DIET QUALITY

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July, 9 2013
Date

This thesis is dedicated to my biggest supporter and favorite gluten free cook, my mother,
Dawn Stauble.

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Chapter One: Introduction

There has been an increase in the diagnosis of celiac disease in the United States (U.S.) (Ukkola A, Mäki M, Kaukinen K, et al 2012). Celiac disease is a genetically mediated autoimmune disease that occurs as a response to the consumption of the storage protein gluten, in the diet. Gluten is found in foods that contain wheat, rye, and barley (Cheng, Pardeep, Lee, Green 2010). Patients with celiac disease who ingest gluten, encounter histological alterations in their small bowel that may lead to disturbances in nutrient absorption. The only known treatment of celiac disease consists of a lifelong gluten free diet (GFD) (Bao & Bhagat 2012). A diagnosis of celiac disease can mean a significant change in diet for many people. Individuals with celiac disease may be overcompensating for eating a gluten free diet and have difficulty maintaining a healthy weight.

Problem

Recently attention related to weight gain and a GFD for celiac patients has risen. Research suggests that the exclusion of gluten from the diet is proportional to an increase in weight (Dickey, William, and Natalie Kearney, 2006). More specifically, a high proportion of overweight patients will gain further weight with gluten exclusion. Excluding gluten from one's diet is associated with an increase in body fat stores. While this can be a positive effect for underweight patients, dietary advisors need to be aware of this association. In relation to CD, is it important to assess whether or not persons on a GFD will have a higher body mass index (BMI) than the average person (Dickey, William, and Natalie Kearney, 2006).

In the United States, food manufacturers have begun to produce several processed and pre-packaged foods specifically for those who follow a GFD. In comparison to gluten containing processed foods, gluten free foods contain higher amounts of fat, calories, sodium and sugar and lower amounts of dietary fiber, vitamins and minerals (Wild, Robins, Bueley, Howdle 2010). In general people who eat a diet higher in fruits, vegetables and protein and lower in processed foods are better able to maintain their weight than those consuming large amounts of processed

foods. Thus, if a patient with CD consumes a diet high in gluten free processed foods, weight management may be difficult to achieve. While consumption of whole fruits, vegetables, dairy products, non-gluten containing grains and unprocessed meats (i.e. a naturally gluten free diet) would provide adequate nutrition for those on a GFD, it appears that sales of processed gluten free foods are high. This suggests a need to further investigate CD, GFD and BMI.

Purpose

There is little information regarding body weight and the effect of a GFD amongst patients with CD in the United States (Cheng et al 2010). This study was conducted to determine, among a sample of those who report a diagnosis of CD and follow a GFD, typical dietary consumption of whole grains, sweets, fruits, vegetables and regular soda. In addition, this study compared BMI and exercise frequency of persons with CD to persons that live in Kentucky.

Objectives

The goal of this paper is to characterize the sample population of persons in a celiac support group using information on gender, race, income, education, dietary intake and exercise habits. Additionally, BMI, fruit and vegetable consumption and exercise habits will be compared with the Kentucky average.

Significance

Celiac disease is becoming a hot topic amongst health professionals. It is of great importance that Registered Dietitians (RD) incorporate nutritionally dense GF foods in their counseling sessions with celiac patients. RD's must be aware of the potential for these patients to gain weight on a GFD.

Assumptions

This study assumes that the participants were accurate and honest in their responses to the self-report survey.

Limitations

The limitations for this study involve the exclusion of persons not in the Celiac Groups of Louisville or Lexington, Kentucky. In addition, weight prior to diagnosis and a GFD was not assessed. BMI measurements are based on participant's honesty regarding their current weight. This self-report could potentially skew results. Additionally, participants may have a lack of knowledge related to their dietary intake.

Chapter Two: Review of Literature

Pathophysiology of Celiac Disease

It is estimated that one in 133 Americans have celiac disease (CD). An estimated 3 million Americans across all races, ages, and genders suffer from celiac and 95% of persons with celiac are undiagnosed or misdiagnosed with other conditions (www.celiac.org). CD occurs both in adults and children and is predominately seen in the female population (female to male ratio, 2-3:1) (Bao et al 2012).

Upon diagnosis, patients with CD may present diarrhea, abdominal pain, bloating, and anemia. In addition, patients with CD may also present weight loss, weight gain, constipation, neurological symptoms, dermatitis herpetiformis, delayed puberty, osteoporosis, infertility, vitamin and protein deficiencies, gastroesophageal reflux, joint pain, fatigue, and elevated liver enzymes (Bao et al 2012) (Smith & Goodfellow 2011). CD is associated with a number of autoimmune disorders such as type 1 diabetes mellitus, autoimmune thyroid disease, Addison disease, autoimmune thyroid disease, primary biliary cirrhosis, and immunoglobulin (Ig) A deficiency. The prevalence of CD is also increased in patients with genetic disorders such as Down syndrome and Turner syndrome. It should be noted that a large number of patients with CD have had a previous diagnosis of irritable bowel syndrome (IBS). Previously CD was recognized as a malabsorption disorder, however, it is now recognized that the presence of obesity does not exclude the possibility of CD (Bao et al 2012).

When patients with CD ingest gluten, the villi (tiny hair-like projects in the small intestine that absorb nutrients from food) are damaged and unable to absorb nutrients from food, this often results in villous atrophy. This response is due to the autoimmune reaction to gluten (www.celiac.org). There is a strong genetic predisposition to CD and certain genetic markers are present in affected individuals (NIH). The autoimmune response to gluten is represented in lab values as HLA antigens -DQ2 and -DQ8, as well as autoantibodies to tissue transglutaminase [tTG2] (Fric). Gluten interacts with these HLA molecules to activate an abnormal mucosal

immune response and induce tissue damage. After excluding gluten from their diet, most celiac patients experience remission from symptoms and damage to the intestinal mucosa is repaired (NIH 2004).

Figure 2.1: Normal duodenum mucosa with normal villi

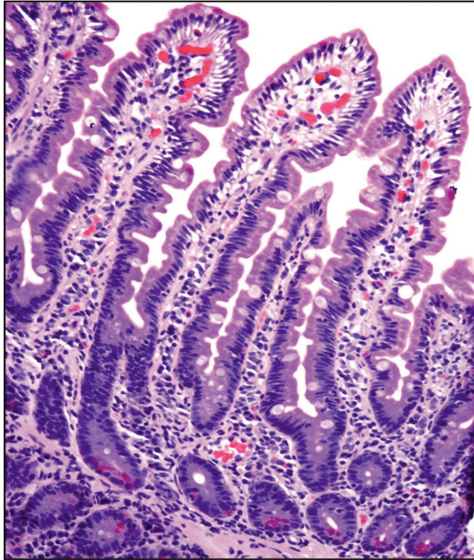
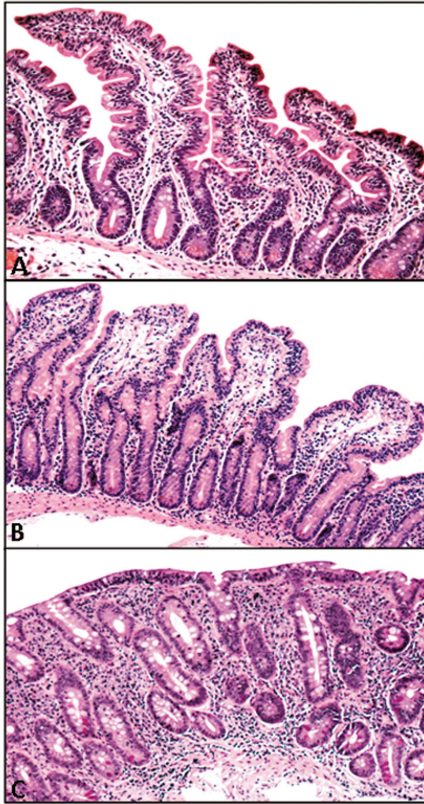


Figure 2.2: Villous atrophy present in Celiac Disease

a). Nonatrophic lesion b). Moderate villous atrophy c). Total villous atrophy



According to the US National Institute of Health consensus statement, serological testing is recommended as the first step in pursuing a diagnosis of CD. If the patient has a positive celiac antibody test result, a duodenal biopsy is recommended (NIH). Antibody tests can only suggest the presence of CD; they cannot confirm it (celiac.org). A small-bowel mucosal biopsy is the current gold standard for diagnosing CD (Bao et al 2012), except those with biopsy-proven dermatitis herpetiformis (NIH). For testing purposes, patients should seek guidance from a gastroenterologist (gastrointestinal (GI) specialist). Additionally, a registered dietitian may refer patients to a GI specialist if they suspect CD is the culprit for GI distress in patients. It is important to note that all serological tests and small-bowel biopsies need to be performed while the patient is on a gluten-containing diet (Bao et al 2012).

Since the consumption of gluten is the main contributor of CD, a GFD remains the only casual therapy (Fric, Gabrovska & Nevoral 2011). A GFD is defined as one that excludes wheat, rye, and barley. Even small quantities of gluten may be harmful. Oats appear to be safe for most individuals with celiac disease, however, there is potential for cross contamination with gluten during processing. A lifelong commitment to a GFD is essential for patients with celiac disease. While the diet may pose as a hardship, a GFD diet can offer the patient a much better quality of life (Smith et al 2011).

According to the US National Institute of Health consensus statement, the following are six key elements in the management of individuals affected by celiac disease:

Consultation with a skilled dietitian

Education about the disease

Lifelong adherence to a gluten-free diet

Identification and treatment of nutritional deficiencies

Access to an advocacy group

Continuous long-term follow up by a multidisciplinary team

In order to provide a guideline for managing the CD, these elements can be useful for persons with a recent diagnosis or untreated CD. For patients with CD, a GFD can also aid in the avoidance of most complications and offer an effective cure (Fric et al 2011). Learning about CD and how to identify gluten-containing products is associated with improved self-management (NIH 2004).

Treatment of Celiac Disease- Gluten Free Diet

The only known treatment for CD is a lifelong gluten free diet (GFD). Several factors should be considered when evaluating patients with CD. Patients should have a biopsy confirmed diagnosis of CD. This is to prevent misdiagnosis via antibody testing. A GFD is important for CD

patients. There is little evidence to suggest that individuals with CD on a GFD have good nutritional status (Wild, Robins, Burley & Howdle 2010). Studies suggest that CD patients tend to gain weight while on a GFD (Dickey et al 2006). The proposed increase in weight may be due to low dietary compliance, coping strategies, or poor nutritional values of GF foods. Processed GF foods may have a lower nutritional value than processed gluten containing foods. A study conducted by Wild, Robins, Burley, and Howdle (2010); found that both men and women with CD consumed more energy from fat and carbohydrates when compared with data from the Northern region population of the National Diet and Nutrition Survey of Adult.

Individuals with CD, who adhere to a GFD, may have altered views of nutritional quality. Whether a food item is gluten free or not, may take precedence over nutritional value. Individuals with CD may place a greater emphasis on consuming items that have been modified to be gluten free, instead of choosing naturally gluten free items, such as fresh fruits and vegetables. By studying the food choices made by individuals with CD, nutritional quality and dietary compliance can further be assessed. It is of importance to also investigate the weight of individuals with CD before diagnosis and after adherence to a GF to diet. This will allot for a better analysis of the nutritional composition of individuals with CD.

Celiac Disease and Gluten Free Dietary Adherence

It has been suggested that despite a GFD, some treated CD patients continue to show signs of malnutrition, as evidenced by low body weight and reduced BMI. Patients that continue to be underweight may have incomplete intestinal mucosal recovery, as a result of poor gluten free dietary compliance or the GFD itself (Bardella, Fredella, Prampolini, Molteni, Giunta & Bianchi 2000). “The current ‘gold standard’ for assessing compliance with a GFD is data collection by the patient, which is then discussed in a diet interview. At the end, a doctor or an expert dietitian expresses a subjective evaluation on the patients compliance with the GFD” (Biagi, Andrealli, Bianchi, Marchese, Klersy & Corazza 2009, p. 885). Questions regarding a

patient with CD's dietary compliance can be based on the strategies that a patient uses to avoid eating gluten. This way of questioning makes it easier to compare different groups of people (Biagi et al 2009).

In a study by Hopman, Koopman, Whit, & Mearin (2008), patients with a gluten containing diet (GCD) stated that their reasoning for consuming gluten was because their physician informed them that CD can be cured or because they experience no symptoms after gluten ingestion. Physicians and registered dietitians (RD) must counsel CD patients on the importance of adhering to a life-long 100% GFD. It is important for physicians to discuss the health risks a patient takes when allowing gluten into their diet.

Celiac Disease and Dietary Intake

It has been suggested that patients with CD who follow a strict GFD have a lower energy intake than patients who are only partially compliant (Smecuol, Gonzales & Mautalen 1997). In a study by Bardella et al 2000, it was reported that patients on a GFD consumed a lower percentage of energy as carbohydrates and a higher percentage of energy as fats than did the control subjects. These food choices were due to the fact that patients tended to choose the wrong natural foods. CD patients ate less GF bread, pasta, and pizza, than control subjects, and tended to prefer eggs, meat, and cheese to increase satiety. It has been suggested that fat and protein consumption increases on GFD (Bardella et al 2000). However, little information is available regarding protein intake and a GFD in persons with CD.

Dietary advice regarding nutrient balance is becoming an important part of medical nutrition therapy with regards to CD. Health related quality of life (HRQL) is also a contributing factor to the choices that a CD patient will make in regards to food consumption. A study conducted by Hopman et al (2008), confirmed previous theories that CD patients show worse general health perception when comparing HRQL with a reference population. However, these CD patients had better scores concerning physical domains. Strict adherence to a GF diet should

be implemented to all CD patients to increase health related quality of life and to prevent comorbidities and complications of CD.

There has been little evidence to suggest that nutritional deficiency is a significant problem in adults diagnosed with CD, nor is there evidence that these individuals have good nutritional status. Calcium is noted as a specific nutritional recommendation for persons with CD (Guidelines). Wild, Robins, Bueley & Howdle (2010), identified that the female CD patients in their study had significantly lower intakes of fiber, magnesium, iron, zinc, manganese, selenium, and folate. Men and women in this study both consumed significantly more energy from fat and carbohydrates than the cohort study. Women also consumed more energy in the form of protein, while men did not.

Nutrition therapy for CD has traditionally been centered around foods that are allowed and foods that are not allowed on a GFD. Thompson, Higgins, Lee & Sharrett (2005), confirmed the theory that an emphasis should be placed on the nutritional quality of the GFD, especially the consumption of iron, calcium, and fiber among women.

Body Mass Index and Celiac Disease

The diagnosis of CD can take several years to confirm and often times the diagnosis can be delayed by patients with a normal or high body mass index (BMI). Typically, doctors have regarded CD as a malabsorption disease; this is due to the limited absorption of nutrients in the gut. Patients with malabsorption issues are typically thin and fall in the underweight range on the BMI scale; this is related to diarrhea and decreased food intake. It is now suggested that when patients are diagnosed with CD, the majority are in the normal BMI range and some are overweight or even obese. (Cheng et al 2010). There is concern that patients gain weight once adhering to a GF diet. In a study conducted by Dickey et al (2006), 82% of initially overweight CD patients had gained weight while on a GFD and the proportion of overweight patients increased from 26% to 51%. The GFD is a potential cause of morbidity and the diet should be

tailored to the individual patient by a dietetic advisor (Dickey et al 2006). With this being said, there is still limited information regarding BMI and the effect of a GFD in patients with CD in the United States (Kabbani, Goldberry, Kelly, Pallav, Tariq, Peer, Hansen, Dennis & Leffler 2012).

Given the limitations of prior studies, Kabbani et al (2012), analyzed the changes in BMI in individuals after diagnosis of CD. BMI distributions at diagnosis and after treatment were compared to regional population data from the 2007 National Health Interview Survey. This study also assessed the influence of GFD adherence on weight class and weight change and significant differences between the two groups. The subjects with CD were more likely to be underweight (6.8% vs. 2.3%) or normal weight (61.3% vs. 38.9%) and less likely to be overweight (20.5% vs. 34.8%) or obese (11.5% vs. 24.0%) compared with the population data. In patients with CD who were underweight at the time of diagnosis, the majority (65.2%) maintained a normal weight at follow-up, however, 30.4% remained underweight. Few CD patients became overweight or obese (4.4%). In the normal weight category, 80% remained in the same weight class and 17% became overweight or obese. For patients who were overweight at diagnosis, 64% remained overweight, while 18.7% became normal weight and 17.3% became obese. The poorly adherent group showed an increased tendency towards weight loss compared with those with good adherence (15% vs. 8%). The study concluded that the weight of the CD group significantly increased after initiating a GFD. However, the majority of patients remained in the same BMI category. The study also suggests that there may be a link between obesity and poor GFD adherence which may reflect behavioral or food related differences between the two groups that contribute both to excess weight gain and poor diet adherence (Kabbana et al 2012). The study by West, Logan, Card (2004), also confirms the findings of Kabbani et al (2012). This study found that out of 2,649 English celiac patients with recorded BMI, 6% were underweight, 66% were normal and 28% were overweight (including 5% obese) by World Health Organization (WHO) criteria.

Research regarding weight gain and a GFD often provide conflicting results. A study conducted by Cheng et al (2010), suggested the majority of CD patients are of normal BMI upon diagnosis. This study demonstrated that the diagnosis of CD and its treatment with a GFD resulted in improvement in an already favorable BMI pattern. The largest increase in BMI was in the underweight group. However, weight loss was not pronounced in the patients who were overweight or obese at the time of diagnosis. The underweight group had a significantly longer follow-up, which may have contributed to this group having the greatest change in weight.

Due to the fact that 42.4% of the underweight group advanced to a normal BMI range and 16.7% of the overweight/ obese group lowered to a normal BMI range, it can be noted that a GFD may have a beneficial impact on BMI. This study also suggests that while many patients, especially in the normal BMI range, may have demonstrated a weight gain, they usually did not change their BMI category. It is important to note that while this study did not find a link between an increase in BMI and persons with CD following a GFD, a nutritionist closely monitored the participants in this study. The criteria for its participants involved a 3 month checkup after diagnosis of CD and then annually (Cheng et al 2010). It is likely that close monitoring by nutrition professionals was associated with a healthier BMI for its participants. Few celiac patients are classified as underweight and almost half are recognized as overweight. The classic CD symptom of diarrhea is seen less often in overweight patients, therefore other symptoms must be taken into account (Dickey, William & Kearney 2006). A large portion of overweight CD patients will gain weight on a GFD, thus it is important to assess all nutritional components of a GFD (Dickey et al 2006).

Celiac Disease and Physical Activity

Making healthy food choices can aid in weight management. Exercise has been shown to significantly improve weight loss and weight management outcomes. Energy expenditure or energy loss (i.e. exercise habits) has not been studied exclusively in CD patients (Capristo et al

2000). Celiac disease is frequently associated with fatigue, which limits the desire to exercise, and reduces social and physical activities (Passananti, Sanronicola, bucci, Andreozi, Ranaudo, Di Giacomo and Ciacci 2012). More than half of the participants in a study by Passananti et al 2012, reported low physical activity both before and after a GFD. It should be noted that physical activity did increase slightly after the implementation of a GFD (Passananti et al 2012). The increase in physical activity may be due to the cessation of fatigue that is often brought on by CD. In addition to a nutritionally balanced GFD, the inclusion of physical activity should be implemented in the treatment plan for persons with CD. Additional research regarding physical activity and CD is needed to provide a better assessment of weight in persons with CD.

Research Purpose

The purpose of this research was to investigate dietary choices and BMI of persons with CD. If persons with CD direct their daily dietary choices towards foods that are processed gluten free, then the importance of a nutritionally balanced GFD may not be fully understood. Examining the dietary responses related to the consumption of whole grains, fruits, vegetables and sweets, as well as BMI and exercise habits of persons with CD, registered dietitians can reassess the GFD and make appropriate recommendations to improve the nutritional status of these persons.

Research Questions

1. Do persons with celiac disease exercise more frequently than the average person?
2. What is the frequency of consumption for whole grains, sweets, fruits and vegetables in persons with CD?
3. Are persons with CD in Kentucky likely to have a higher BMI than in the general population of Kentucky?

This study adds to research regarding CD by characterizing a sample of CD patients in regards to diet, exercise habits, and BMI. This study seeks to disclose the types of foods persons with CD consume and to offer insight to Registered Dietitians (RD) whom will be counseling these individuals.

Chapter Three: Methodology

Methodology

This study was approved by the University of Kentucky office of Research Integrity, nonmedical Institutional Review Board. The project earned approval in February 2013.

This study used a survey to assess the dietary intake of persons with CD. This study utilized data that was obtained through one survey that was distributed at the Louisville chapter meeting on February 22, 2013. At the time of the study, the Lexington, KY CD support group was not holding meetings. An online copy of the survey was made available from February 1, 2013- March 1, 2013 to both the Louisville and Lexington chapters and was conducted on a volunteer basis. The survey collected data regarding demographics, diet, and exercise habits and height and weight.

Population and Sample Selection

The study population consisted of persons who are members of the Louisville and Lexington CD support groups. The target population consisted of adults (18 years and older).

Research Design

The study survey was administered in person and via online through Qualtrics. Participants volunteered to take the survey. There was no control or experimental group, nor was deceit involved. The presidents of both chapters were approached through email with a request for member participation. An e-mail was sent to member listservs stating the background of the researcher, the purpose of the study and a link to the survey. The survey consisted of a modified version of the Food Frequency Questionnaire (FFQ). The FFQ was adapted from NHANES 2009. The modified questions were tailored to incorporate gluten free foods. The responses were based on the frequency of foods eaten.

Data Collection

Self-administered questionnaires were made available online and via paper copies. Two paper copies of the survey were manually entered into Qualtrics, while the remainder was completed online.

Measurements/ Instruments

Data was assessed to determine the frequency of foods that the participant's typically consumed. The vast majority of the survey listed foods and asked the participant's to select how frequently they consume these foods. In addition, participants were asked to include their height and weight in order to calculate and assess their BMI. Exercise habits were measured by asking if the participants have participated in any physical activity within the past 30 days. Participants were asked to mark "yes" if they have participated in physical activity or "no" if they have not. Frequency of exercise was not assessed. Additionally, participants were asked to list dietary supplements used.

Data Analysis

Data was assessed using SPSS version 18. Food frequency data were divided into categories of monthly, weekly or daily consumption. Categories explored in relation to each other were gender, income, biopsy confirmed diagnosis, BMI, exercise, income per year and education. In order to determine relationships, a chi-squared test was used to determine if a relationship existed between these categories. Additionally, BMI was correlated with consumption of whole grains, sweets, vegetables, fruit and regular soda. To determine a significance level, an alpha level of 0.05 or less was used.

Chapter Four: Results

Characterization of sample

Demographics:

The final sample consisted of a random sample of 145 persons with self-reported CD. The participants consisted of one hundred and eleven females (77%), twenty six males (18%) and eight not reported (6%). The ethnicity of the participants consisted of 94% Caucasian (n=136), 1% African American (n=1) and 6% unknown (n=8). The average BMI was 25 kg/m² and 61% reported having a biopsy confirmed diagnosis of CD.

Participants were asked to indicate their household income. The income per year category is classified as persons making under \$70,000 per year, persons making \$70,000 to \$120,000, persons making over \$120,000 per year and persons unsure of their income. Participants earning less than \$70,000 accounted for 38.2% (n=47) and those earning \$70,000 to \$120,000 accounted for 34.1% (n=42). Participants earning over \$120,000 accounted for 16.3% (n=20) and 11.4% reported being unsure of their income (n=14).

Educational background was assessed. The educational category classifies participants into two categories: less than a four year degree and a four year college degree and above. Participants with less than a college degree made up 39.3% (n=53), those with a four year college degree and above a four year degree made up 58.5% (n=79) and 2.2% reported unsure (n=3).

BMI was calculated for each participant that reported his or her current height and weight. Underweight persons made up 3.1% (n=4), 51.5% (n=67) were normal weight, 29.2% (n=38) were overweight and 16.2% (n=21) were obese.

Results showed that 63.8% (n= 88) stated they have had a biopsy confirmed diagnosis and 36.2% (n=50) stated they have not had a biopsy confirmed diagnosis. One third of participants have not had a confirmed diagnosis of CD.

Each subject was asked to disclose whether or not they exercise and if so, how often are they exercising. Persons who reported exercising accounted for 70.3% (n=97), while 29.7%

(n=41) reported that they do not exercise. Of those who reported exercising, 22.7% reported exercising two times per week, 47.4% reported exercising 3-4 times per week, 14.4% reported exercising 5-6 times per week, and 5.5% reported exercising 6-7 times per week.

Table 4.1 Illustrates the demographic make-up of the sample

Table 4.1: Demographics

Sample Size: n = 145

Gender		
	N = subjects	Percentage
Female	111	76.6%
Male	26	17.9%
Not reported	8	5.5%

Ethnicity		
	n = subjects	Percentage
Caucasian	136	93.8%
African American	1	0.7%
Not reported	8	5.5%

Income		
	n = subjects	Percentage
>\$70,000	47	32.4%
\$70,000- \$120,000	42	28.9%
>\$120,000	20	13.8%
Unsure	14	9.7%
Not reported	22	15.2%

Table 4.1 continued

Education		
	n = subjects	Percentage
less than a college degree	53	36.5%
4 year degree and above	79	58.5%
Unsure	3	2.2%

Table 2 Illustrates BMI of the participants, whether or not the participants have a biopsy confirmed diagnosis of CD and the participants exercise frequency.

Table 4.2: BMI, Biopsy and Exercise

BMI		
	n = subjects	Percentage
Underweight	4	2.8%
Normal	67	46.2%
Overweight	38	26.2%
Obese	21	14.5%
Not reported	15	10.3%

Biopsy		
	n = subjects	Percentage
Biopsy	88	60.7%
No Biopsy	50	34.5%
Not reported	7	4.8%

Exercise		
	n = subjects	Percentage
Yes	97	66.9%
No	41	28.3%
Not reported	7	4.8%

Frequency of Consumption

When eliminating unreported responses (n=7), 5% (n=7) reported consuming whole grains two times per day, 17.3% (n=24) reported one time per day, 11.5% (n=16) reported 5-6 times per week, 15.8% (n=22) reported 3-4 times per week, 23.8% (n=33) reported 1-2 times per week, 20.1% (n=28) reported 1-3 times per month and 6.5% (n=9) reported never eating whole grains.

Participants were asked to report on their consumption of GF chocolate and candy, pastries, cookies and ice cream. To better assess a daily consumption of GF desserts, each of these categories were totaled in order to determine the frequency of sweets (desserts) consumed. When eliminating unreported responses, 24.5% (n=34) reported consuming sweets two times per day, 13.7% (n=19) reported one time per day, 20.9% (n=29) reported 5-6 times per week, 13.7% (n=19) reported 3-4 times per week, 20.1% (n=28) reported 1-2 times per week, 4.3% (n=6) reported 2-3 times per month and 2.8% (n=4) reported never eating whole grains.

Participants were asked to report on their consumption of lettuce and vegetables. In order to determine a frequency of consumption of vegetables, these categories were combined. When eliminating unreported responses, 32.4% (n=45) reported consuming whole grains two times per day, 38.1% (n=53) reported one time per day, 10.1% (n=14) reported 5-6 times per week, 10.8% (n=15) reported 3-4 times per week, 7.9% (n=11) reported 1-2 times per week and 0.7% (n=1) reported 2-3 times per month.

Participants were asked to report on their consumption of fruit. In order to determine a frequency of consumption, fruit and fruit juice categories were combined. When eliminating unreported responses, 38.7% (n=53) reported consuming fruit two times per day, 8.8% (n=12) reported one time per day, 12.4% (n=17) reported 5-6 times per week, 19.7% (n=27) reported 3-4 times per week, 12.4% (n=17) reported 1-2 times per week and 5.8% (n=8) reported 2-3 times per month and 2.2% (n=3) reported never consuming fruit.

Table 4.3 illustrates the sample's consumption of whole grains, sweets, vegetables and fruit

Table 4.3: Consumption of whole grains, sweets, vegetables and fruit & whole grain consumption

Whole Grains		
	Frequency	Percent
Never	9	6.2
1x last month	16	11.0
2-3x last month	12	8.2
1x per week	20	13.7
2x per week	13	8.9
3-4x per week	22	15.1
5-6x per week	16	11.0
1x per day	24	16.4
2 or more times per day	7	4.8
Not reported	7	4.8

Table 4.3 continued

Sweets consumption

	Frequency	Percent
Never	4	2.7
2-3x last month	6	4.1
1x per week	13	8.9
2x per week	15	10.3
3-4x per week	19	13.0
5-6x per week	29	19.9
1x per day	19	13.0
2 or more times per day	34	23.3
Not reported	7	4.8

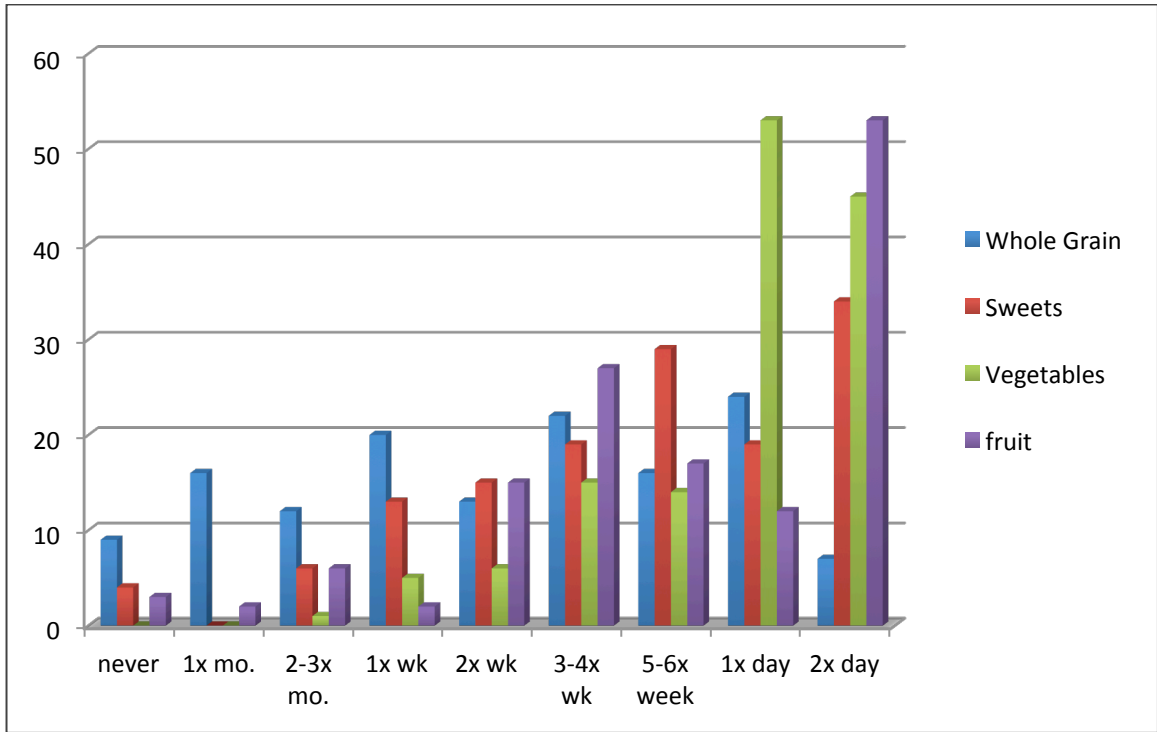
Vegetable Consumption

	Frequency	Percent
2-3x last month	1	0.7
1x per week	5	3.4
2x per week	6	4.1
3-4x per week	15	10.3
5-6x per week	14	9.6
1x per day	53	36.3
2 or more times per day	45	30.8
Not reported	7	4.8

Table 4.3 continued

Fruit consumption		
	Frequency	Percent
Never	3	2.1
1x last month	2	1.4
2-3x last month	6	4.1
1x per week	2	1.4
2x per week	15	10.3
3-4x per week	27	18.6
5-6x per week	17	11.7
1x per day	12	8.3
2 or more times per day	53	36.6
Not reported	8	5.5

Figure 4.1: Average consumption of whole grains, sweets, vegetables and fruit over a 30 day period



Comparisons Based on Gender

T-tests

A t-test was conducted to measure gender differences on exercise frequency and consumption of regular soda, total fruit, total vegetable, total whole grain and total sweets. The t-test found no differences between males and females with regards to these categories.

Additionally, a t-test showed that BMI category did not differ based on gender (p-value: 0.34)

Table 4.4: Illustrates a comparison of gender and exercise frequency and consumption of soda, fruit, vegetables and whole grain (note: all p-values are insignificant)

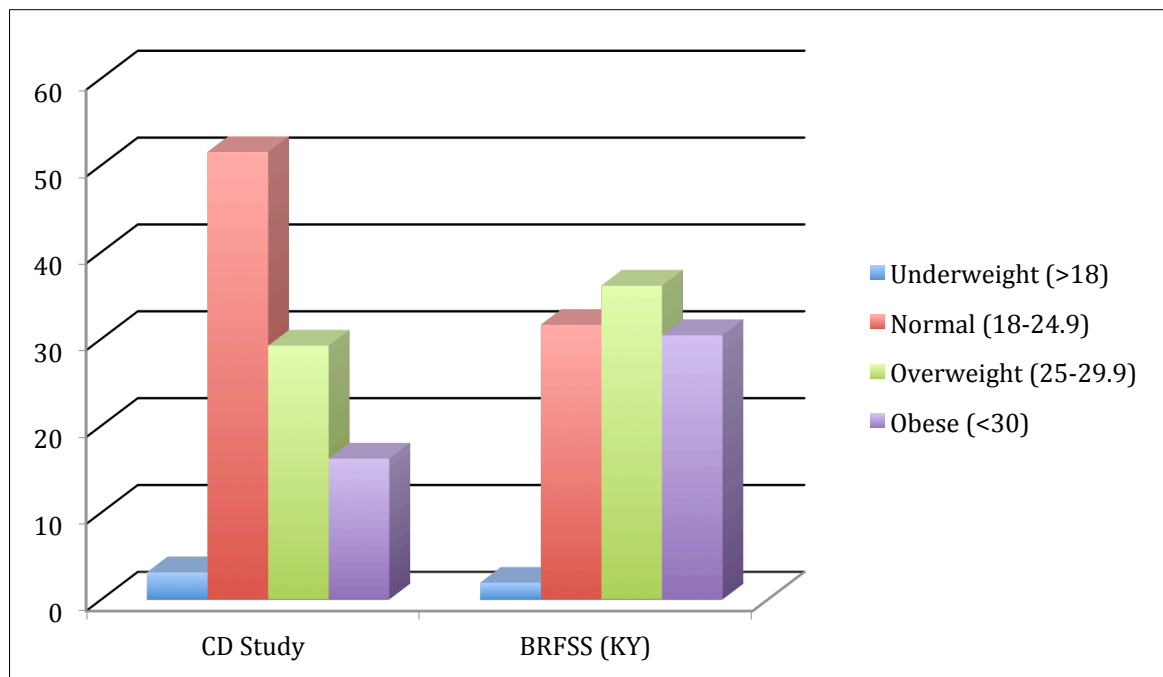
Males vs. Females	
	p-value
Exercise frequency	0.30
Regular soda	0.12
Fruit	0.61
Vegetables	0.21
Wholegrain	0.99
Sweets	0.33

Data Comparison to Kentucky Average

BRFSS and BMI

BMI for this study was compared to BRFSS data for Kentucky in 2011. Participants in this study reported 3.1% (n=4) under weight, 51.5% (n=67) were normal weight, 29.2% (n=38) were overweight and 16.2% (n=21) were obese. The 2011 BRFSS BMI data for Kentucky reported 1.9% underweight, 31.6% normal weight, 36.1% overweight and 30.4% obese.

Figure 4.2: Comparison of BMI between study participants and the Kentucky average in 2011

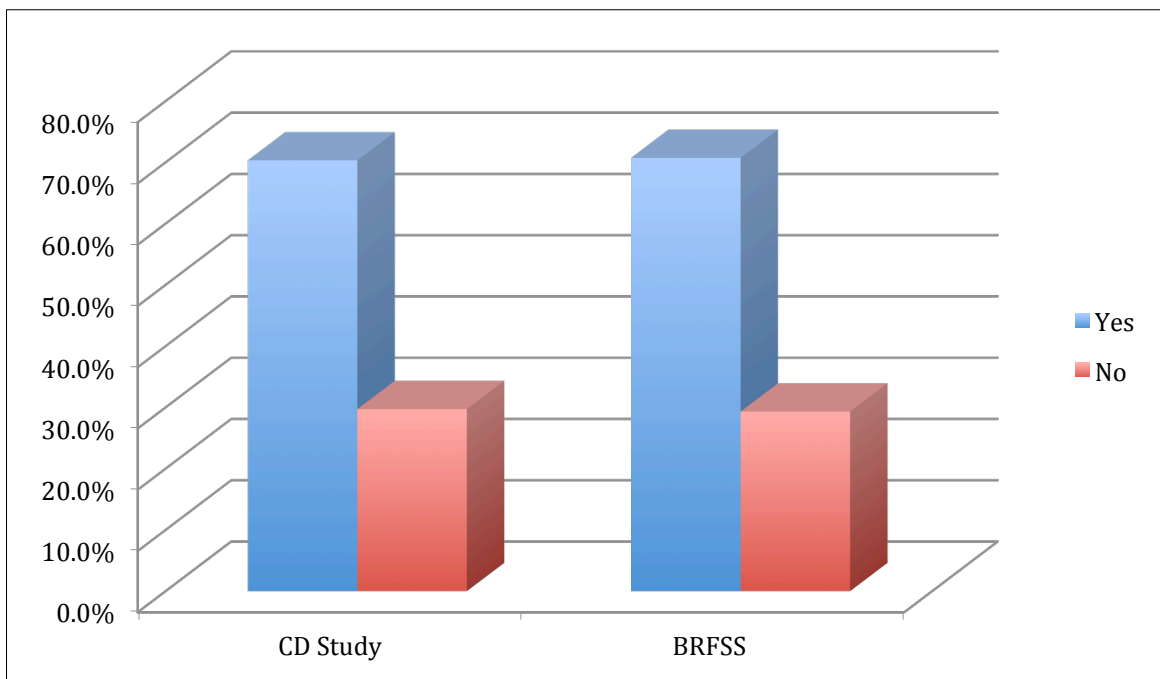


BRFSS and Exercise

Exercise frequency for this study was compared to BRFSS data for Kentucky in 2011. When eliminating participants that did not respond to exercise frequency, this study found that 70.3% (n=97) of persons reported participating in physical activity during the past month, while 29.7% (n=41) reported they did not. BRFSS data for Kentucky reported 70.7% of persons

participated in physical exercise during the past month, while 29.3% reported they did not. The reported number of persons that have participated in physical exercise in Kentucky during a 30-day span has increased from 45.7% in 2009 to 70.7% in 2011. The results of this study are consistent with BRFSS data for Kentucky for physical activity participation.

Figure 4.3: Reported physical activity of persons in this study and the Kentucky average in 2011



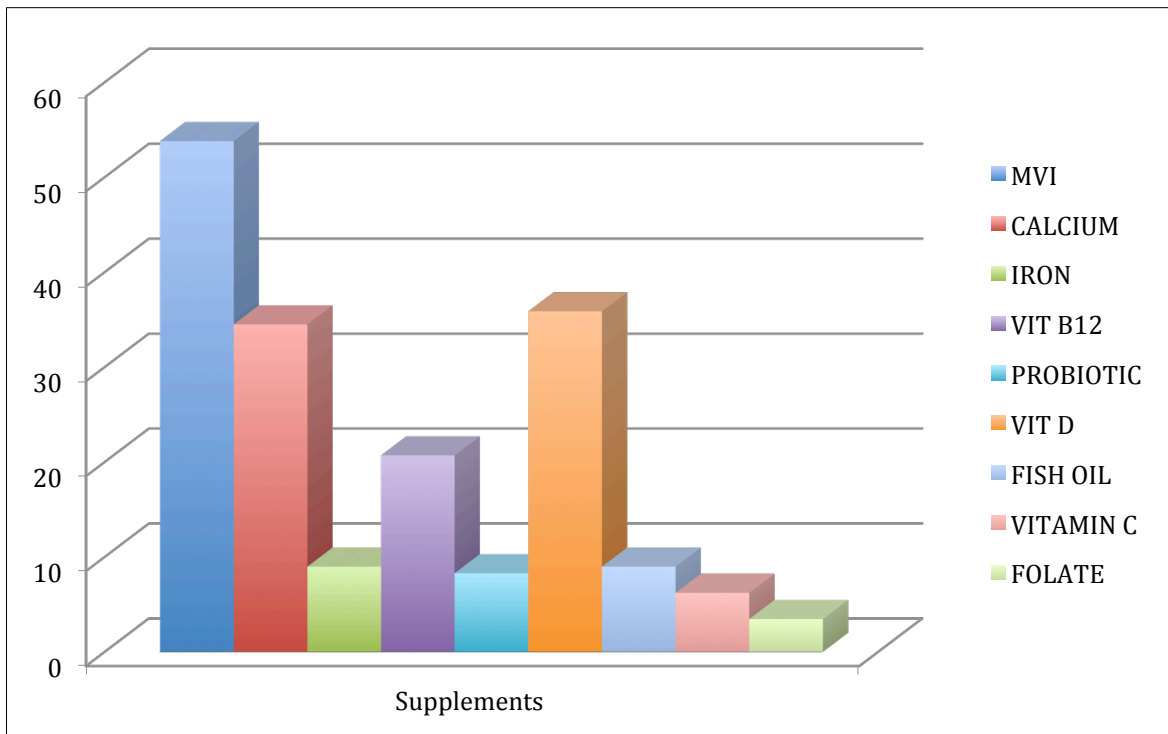
BRFSS and Fruit and Vegetable Consumption

According to Kentucky BRFSS 2009 data, a total of 21.1% of adults did consume a daily average of ≥ 5 times/day servings of fruits and vegetables. This number has increased from 2002 BRFSS data, where 23% of adults did consume a daily average of ≥ 5 times/day servings of fruits and vegetables. This study found that 16.6% of persons with CD did consume a daily average of ≥ 4 times/day servings of fruits and vegetables.

Supplemental Usage

A gluten free diet can prove to be a very restricted diet and thus eliminates certain fortified foods such as grains, breads and cereals. Persons on a GFD may often take supplements to make up for the nutritional gap in their diets. This study found that 53.7% of persons on a GFD are taking a daily multivitamin, 34.5% are taking calcium, 9% are taking an iron, 20.7% are taking a vitamin B12, 8.3% are taking a probiotic, 35.9% are taking vitamin D, 9% are taking fish oil, 6.2% are taking vitamin C and 3.4% are taking folate.

Figure 4.4: Usage of supplements



Chapter Five: Discussion and Conclusions

The purpose of this study was to characterize the sample population of persons with CD, to compare differences between males and females and to compare BMI, fruit and vegetable consumption and exercise likelihood with the average person in Kentucky. The characterization of this data will be beneficial for future interventions between dietitians and persons with CD. This study also investigated the consumption of whole grains, fruits and vegetables, as well as regular soda and sugar-laden sweets. Additionally, the study investigated supplemental use and biopsy confirmed diagnosis of persons in a celiac support group.

With regards to the characterization of the sample, more women than men have a diagnosis of CD, which coincides with previous research. Additionally, the vast majority of members in the two celiac groups are white (94%), 1% is black and 5% did not respond. These results are consistent with the results of Lebwohl, Tennyson, Holub, Lieberman, Neugut and Green 2012, which found that 88% of persons with a diagnosis of CD were white, 9% were black and 3% marked race as other (n=13,091). Interestingly, the income of persons involved in a celiac support group is rather high when compared to the average Kentucky income.

This study found a link between high income and participation in celiac support groups. Seventy four percent of the participants reported an annual income of \$70,000 or more. The median household income in Kentucky from 2007-2011 was \$42,248 (US Census). The average income of this group suggests that persons with a higher income are more inclined to join a celiac support group. The proposed reason behind this link may be due to the financial burden of the diagnosis process.

Physicians can recommend the celiac support groups to patients that are newly diagnosed. Physicians from rural communities should have access to support groups in nearby cities. Members of a celiac support group may have a higher income, which in turn allows them to have better access to healthcare and thus a referral to a celiac support group. A higher income may also provide more available time to join a celiac support group due to less financial stress.

Additionally, this study questioned whether income is associated with biopsy confirmed diagnosis of CD and it was concluded that no correlation exists.

In addition to an estimated higher income, persons in this study also have on average a higher level of education than the average person in Kentucky. More than half of this studies participants reported having a 4 year degree or higher. A higher educational level may also coincide with the overall higher income of participants. Additionally, persons with a higher education level may have a better understanding of adequate healthcare and be more responsive to a healthcare providers recommendation to join a celiac support group.

It is important to note that not all persons in these support groups have been medically diagnosed with CD. A small bowel biopsy diagnosis of CD is the gold standard and without this, a true diagnosis is unclear. A biopsy is the only true testament for diagnosing CD and without this test; damage to the small intestine cannot be assessed. It is important to note that self-diagnosis cannot truly confirm CD and thus, CD may not be the true cause of the person's symptoms.

Two thirds of the participants in this study stated they have had a small intestinal biopsy confirmed diagnosis of CD. The results of this study are consistent with the findings of Lebwohl et al 2012, which found that only 51% of the celiac patients in their study had a biopsy confirmed diagnosis of CD. One third of the participants in this study have not had a biopsy confirmed diagnosis of celiac disease. This statistic may be of importance for physicians and dietitians due to the possibility that CD may not be the culprit for the symptoms patients have presented. While others who have not had a biopsy may prove to have CD, it is not certain. Serological testing has a high sensitivity and specificity; however, the diagnosis is not always straightforward. The possibility of false positive results may occur when using only serological testing. It is possible that serological tests may have false positives as a result of other immune or inflammatory conditions (Fasano and Castassi 2012). It is important for physicians and dietitians to explain the importance of having a biopsy to confirm the diagnosis of CD.

It is important for physicians and dietitians to consider a timeline when diagnosing CD. Gluten must be present in the diet for a minimum of four weeks in order to detect damage of the small intestine. Patients may choose to eliminate gluten from their diet and report feeling better after the removal process. Typically patients do not want to add gluten back into their diet for fear of feeling worse again. This situation often leads to self-diagnosis of CD.

The patient's diet should be evaluated to determine if gluten is the culprit for discomfort or if the new diet is nutritionally balanced. If the new diet consists of less processed foods and a higher consumption of naturally GF foods such as fruit, vegetables and lean protein, the healthier diet may be to blame for feeling better instead of the removal of gluten. Persons in the group may have experienced symptoms of CD and through the elimination of gluten, find that a GFD is a cure all to their distress. However, a GFD may result in a limited diet and thus limited amounts of high fat foods (i.e. fried chicken, pizza, baked goods), which in turn could be the culprit behind the GI distress.

Females make up the vast majority of these celiac support groups. The study hypothesized that gender will not play a role in the dietary consumption of whole grains, sweets, vegetables or fruit. In addition, it was hypothesized that gender will also not influence the likelihood of an exercise regimen. Results concluded that these hypotheses are valid and thus gender did not influence dietary consumption nor did it influence exercise habits. Additionally, gender is not a valid predictor in the likelihood that a person will have a biopsy confirmed diagnosis of CD nor is gender a predictor of income. There was also no association between BMI and gender. From these findings it is suggested that gender is not a relevant factor in the likelihood that a persons with CD is exercising. The findings also suggest that gender is not a predictor in consuming a balanced diet that focuses on high consumption of whole grains, fruits and vegetables and limits regular soda and sweets in persons with CD. It is also unlikely to accurately predict whether or not a person with CD will have a higher BMI based on gender

alone. It is evident that many factors other than gender must be taken into account when predicting reasons for inadequate exercise, poor dietary habits and an inactive exercise regimen.

Body weight is used as an indicator for individual health. A BMI score provides a comparison for an ideal or desirable weight range. According to the CDC, BMI is an indicator of body fatness and can be used as an indicator for chronic diseases and weight-related issues. BMI can be an indicator of an increased risk for developing multiple chronic diseases and also provides a guideline for assessing nutrition status. Research has shown that both high BMIs and low BMIs can indicate increased morbidity and mortality rates. Being overweight or obese puts additional stress on joints and requires additional work from vital organs. According to the CDC, regular physical activity and decreased caloric intake might reduce a person's BMI.

From this study, it is found that persons with CD have a lower incidence of obesity when compared to the state average in Kentucky. Additionally, it was found that persons with CD are more inclined to have a normal BMI than the average person in Kentucky. Persons with CD may have a lower BMI due to the restriction of a GFD.

The average KY BMI has a higher incidence of measuring in the overweight or obese category than does a person with CD. While gluten free processed foods may be higher in calories and fat and contain less vitamins and minerals, it is evident that persons with CD may have a more nutritionally balanced diet than persons on a regular diet. In theory, the limited access to gluten free foods at restaurants may play a role in the lower incidence of BMI scores. Busy schedules may influence the average person in KY to dine out more frequently, whereas a person with CD may have limited access to gluten free foods at restaurants and thus may cook more meals at home which in turn can help to limit added calories, sodium and fat. In addition, it may be more difficult for persons with CD to snack between meals due to the limited access of gluten free foods in vending machines and/or limited access to gluten free foods at fast food restaurants. Therefore, a limited diet may be the source behind a higher incidence of normal BMI's for persons with CD when compared to the state average.

Along with BMI, it is important to note that more than half of persons in this study reported exercising which will aid in weight maintenance. This information will further show that during counseling with a registered dietitian, the focus should be shifted on a nutritionally balanced diet and the development of an exercise regimen in order to lose or maintain weight.

Some research has suggested that persons with CD are more inclined to gain weight due to a GFD, while others suggest that persons on a GFD tend to lose weight. This study was unable to compare current weight and pre-diagnosis weight, which does not allow for a theory regarding weight and persons with CD. However, this study was able to compare the reported BMI of its participants and the BRFSS data of Kentuckians. This comparison allowed for a better generalization of health with regards to persons with CD and the average person from Kentucky. The results of this study were conclusive with the results of the study conducted by Cheng et al 2010 and by Kabbani et al 2010 which showed celiac patients of both sexes had a more favorable BMI than the national figures of NHANES. This study by Cheng et al 2010 showed a greater rate of normal weight celiac patients and fewer celiac patients in the category of overweight and obese. It is important to note that BMI does not take body composition into account, thus cannot be a true indicator of nutritional status

Our research questioned how often persons in this study are eating gluten free sweets and if this figure correlates with BMI. This study found no correlation between BMI and consumption of sweets. However, 61% (n=82) of participants reported consuming GF sweets (not including fruit) at least 5-6 times per week and 41% of those persons reported consuming sweets 2 or more times per day. Regardless of gluten free or not, desserts such as cakes, pies, cookies and candies should be consumed within moderation in order to aid in weight management.

It is difficult to manage one's weight when foods that are high in simple sugars (i.e. cakes, pies, cookies) are consumed on a daily basis. Foods that are modified to be GF tend to be higher in calories and fat and low in fiber due to the inadequate nutritional makeup of gluten free flour. The process of removing gluten in baked goods results in a dense and less flavorful end

product. Companies add additional sugar to compensate for the less flavorful gluten free product. Registered dietitians must counsel celiac patients on the importance of moderation with regards to foods that are nutritionally inadequate.

Our research also questioned if persons with self-reported CD reported exercising more frequently than the average person in Kentucky. This study found that 70.3% of persons reported exercising, while 29.7% (n=41) reported they do not exercise. This information was compared to exercise data trends in Kentucky via BRFSS. In 2011, it was reported that 71% of persons in Kentucky reported exercising regularly, while 29% reported they do not exercise. These findings suggest that persons in this study are exercising as much as the average person in Kentucky. This data does not suggest a significant difference in exercise frequency between persons with CD and persons that do not have CD.

Physical activity can also provide assistance with losing and maintaining weight. According to the Center for Disease Control and Prevention (CDC), physical activity reduces one's risk for heart disease, colon cancer, stroke, type 2 diabetes, osteoporosis and obesity. The development of colon cancer and osteoporosis are of greater concern for persons with CD, thus exercise should be recommended by dietitians and physicians. To encourage physical activity, dietitians should discuss the link between exercise and weight loss/management to persons with CD.

Exercise is an important factor to consider with regards to weight management. It is known that regular exercise can contribute to better weight management and therefore persons may be more inclined to have a normal BMI. Weight management can contribute to a decrease in risk of diabetes and heart disease. Thus, it is important for registered dietitians to counsel patients with CD on the importance of physical activity and weight management.

Unhealthy eating contributes to obesity and a number of chronic diseases, including diabetes and cardiovascular disease. Those that eat more fruits and vegetables as part of a healthful diet are more likely to have a reduced risk of chronic diseases and weigh less. In

addition to exercise, an increase in fruit and vegetable consumption can aid in weight management. The results of this study found that persons with CD are consuming less fruits and vegetables than the average adult in Kentucky. While the number of servings per day was different when compared to BRFSS data (≥ 5 times/day vs. ≥ 4 times/day), this study still found significantly lower reports of fruit and vegetable consumption even with a decrease in the recommended daily consumption. Fruit and vegetables provide many vitamins and minerals and they also provide fiber that can aid in decreasing cholesterol and help maintain fullness, which can assist with weight management. Fruits and vegetables in their natural setting are gluten free and intake of these foods should be encouraged in persons with CD.

Poor eating habits contribute to obesity and a number of chronic diseases, including diabetes and cardiovascular disease. Those that eat more fruits and vegetables as part of a healthful diet are more likely to have a reduced risk of chronic diseases and weigh less.

Research has shown that processed gluten free foods lack many essential vitamins and minerals, thus supplementation is often recommended by physicians. More than half of the participants in this study reported taking a multivitamin. Additionally, calcium and vitamin D supplementation rank high among participants. The use of calcium and vitamin D supplements may be due to the high female population and their increased risk for osteoporosis.

The use of probiotics has gained popularity over the past few years. Collado, Donat and Ribes-Koninck 2009 studied organisms that survive and thrive in the intestines of celiac patients. They found elevated levels of gut destroying bacteria, including *Bacteroides* and *Clostridium leptum*, in patients with CD that were and were not treated with a GFD (Collado et al 2009).

A GFD does not always normalize gut microflora levels, evidence is beginning to point to supplementation with probiotics as potential tools for beneficially modifying microflora populations in order to reduce inflammatory responses in celiac patients. If persistent GI symptoms continue even while following a GFD, patients should be evaluated for small intestinal bacterial overgrowth (SIBO) (Malterre 2009).

According to Malterre 2009, a Swedish study followed celiac patients for 10 years who were on a GFD and noted they continued to have vitamin deficiencies regardless of their GFD. It should be noted that there is a link between vitamin deficiencies, elevated total plasma homocysteine levels and cardiovascular disease. Persons with CD are more susceptible to folic acid, vitamin B12 and vitamin B6 deficiencies due to the likelihood of elevated homocysteine levels. Eleven to forty one percent of celiac patients have vitamin B12 deficiencies due to the complexity and location of absorption (i.e. terminal ileum). In order to treat B12 deficiencies, intramuscular injections and/or oral dosing should be utilized. Additionally, vitamin D and Iron deficiencies have been found in persons with CD that follow a GFD. Due to changes in physiological functions in CD, vitamin and mineral absorption may be challenged and may not normalize completely in persons on a GFD. Physicians and dietitians should follow up with celiac patients on a GFD and monitor vitamin and mineral levels (Malterre 2009).

While participants in this study have reported adequate daily consumption of fruits and vegetables, the consumption of GF whole grains is rather low. GF breads are typically made of rice flour and in turn are low in fiber. The removal of wheat, rye and barley from the diet results in seeking new ways to incorporate GF whole grains. Grains such as buckwheat, quinoa and brown rice can be incorporated into a GF diet to increase whole grain consumption amongst persons with CD. Whole grains have been shown to reduce cholesterol levels and provide a great source of healthy carbohydrates. Whole grains are important in all diets, especially a GFD that has been shown to be low in fiber.

Limitations

The data collection used in this study was a self-administered survey given to recruited members of the Lexington and Louisville CD support groups. Participants may not have answered the questions accurately with regards to their food consumption. A primary area of expected bias or inaccurate response includes the report on weight and height that was used to

determine BMI. Respondents tend to overestimate their height and underestimate their weight, leading to underestimation of BMI and of prevalence of overweight and obesity

It is important to note that this sample was a very unique population due to the income and education of the members. Due to these findings, the assessment would not be applicable to all CD patients, as this was a specialized population.

This study served as a useful tool to associate diet quality and CD. Limitations of this study include recollection of foods consumed during the past month. Participants may have recorded inaccurate annual income and educational background. These study-excluded persons with CD that are not involved in the Lexington or Louisville support groups. As with self-reported sample surveys, this data might be subject to systematic error resulting from no coverage, nonresponse, or measurement.

Implications for Dietitians

Dietary management is the only therapy for CD. Patients with CD need to be aware of foods that contain gluten and also how they can implement a healthy GFD. Dietitians should consider the diet of persons with CD and focus on the nutritional quality as well as the elimination of gluten. Diets that include processed gluten free foods have more fat, calories and sugar and less vitamins, minerals and fiber than processed foods with gluten. When counseling patients with celiac disease, dietitians should focus on foods that are naturally gluten free, such as lean protein, fresh fruit and vegetables. Dietitians should also advise patients on the use of alternate gluten free grains (i.e. buckwheat and quinoa).

As with any diet, moderation is key when managing weight, thus processed gluten free foods should be limited. When counseling patients with CD, dietitians should emphasize the importance of GF grains. CD patients may be timid when it comes to the inclusion of GF whole grains due to the exclusion of common grains such as whole wheat bread or couscous. Patients may have difficulty pinpointing GF whole grains and need assistance on ways to include GF

whole grains. Dietitians should also stress the importance of having a biopsy confirmed diagnosis of celiac disease to patients. This confirmed diagnosis could allot for a better understanding of the severity to the small intestinal damage. In addition, the biopsy will provide a true diagnosis and decrease the risk of masking another relatable disease state.

Future Research

Additional research should consider pre and post diagnosis weight of participants with CD to further assess the relationship between a GFD and BMI. Researchers would benefit by expanding the study to include persons outside of a CD support group.

This study may not be a true representation of persons in Kentucky. Based on the high income and education of persons in this study, a comparison of dietary intake to the Kentucky average may be limited. The average person in Kentucky makes less money and has a lower education level, with this being said, persons in a celiac group may be more inclined to have a healthier diet and access to better healthcare. Additional research would benefit from comparing persons that have celiac disease and are in a support group with persons not in a support group.

The modified FFQ used in this study was modified to include GF foods. Future research would benefit from the use of a full FFQ that is modified to be GF. Diet quality can be better assessed with a full version of a FFQ due to the results offering a better representation of food consumption over the past 30 days.

With the increased popularity of probiotic use, research may also benefit from a study related to CD and different types of probiotics. Research related to probiotic use in persons with CD would be beneficial for GI specialists and dietitians due to their proposed success in regulating digestive systems and contributing to a healthier gut.

Conclusion

Based on the findings, the sample that was surveyed is different from the average person in Kentucky. Participants reported high income and high education. The population surveyed for this study was quite unique. There are significantly more women than men in CD support groups, which may have a direct effect on diet quality and food consumption

The results of this study found that whole grain, fruit and vegetable intakes were low among celiac patients. Additionally, BMI is borderline between normal and overweight. Through this evidence, it is evident that a greater emphasis should be placed on nutritional quality when counseling patients with CD. With such a high number of overweight and obese persons in the United States, it is important for dietitians to teach patients with CD about the low nutritional quality of processed GF foods and how they can choose healthier options that are naturally GF. Per Cheng 2010, dietitians should shift the focus of their counseling sessions with CD patients from foods they can no longer consume to foods that are healthy and GF.

There are currently two focuses when counseling patients with CD: foods that are GF and foods that are not GF. Counseling persons with CD should be refocused in order to demonstrate how the patient can eliminate gluten and maintain or restore a nutritionally balanced diet. Educating patients on a nutritionally balanced GF diet will provide persons with CD with the knowledge to make better food choices. Making a conscious effort to control weight can help to control the likelihood of being overweight or obese, which is associated with greater risks for developing diabetes and other weight related issues.

Appendices

Appendix A: Survey

Dietary Questionnaire Screener

Hello, my name is Taylor Stauble from the University of Kentucky Dietetics and Human Nutrition department. We are asking [Louisville and Lexington] Celiac Disease Groups to take part in a questionnaire about their eating habits and health. The information we gather from this survey is aimed to help us understand the health impact of a gluten free diet. This project will help us to develop a proposal aimed at improving diet quality in persons with celiac disease and it may help us to understand more about the association between weight and dietary habits. You have been pre-selected from those in your city based on your association with the celiac disease support group and your answers will be kept confidential. My instructions are for you to complete the following questionnaire.

These questions are about foods you ate or drank during the past month, that is, the past 30 days. NEED to include more about the study, who to contact with questions, etc. Look at the IRB for informed consent to see what is required. When answering, please include meals and snacks at home, at work or school, in restaurants, or any place else. Mark an [x] to indicate your answer. To change your answer, completely fill the box for the incorrectly marked answer then mark an X in the correct one. Your answers are important. If at any time you wish to stop the survey you may. If at any time you wish to skip a question you may. We appreciate your time and thoughts regarding this questionnaire.

First I would like to ask some questions about you in general...

1. Are you Hispanic or Latino?

- Yes
- No
- Unsure
- Prefer not to answer

2. Which one or more of the following would you say is your race:

- White
- Black or African American
- Asian
- Native Hawaiian or Other Pacific Islander
- American Indian or Alaska Native
- Other
- Unsure
- I do not wish to respond

3. Last year, what was your total household income from all sources before taxes?

- Under \$5000

- \$5-\$7,500
- \$7,500-\$10,000
- \$10-\$12,500
- \$12,500-\$15,000
- \$15,000-\$20,000
- \$20-\$25,000
- \$25-\$30,000
- \$30-\$40,000
- \$40-\$50,000
- \$50-\$70,000
- \$70-\$90,000
- \$90-\$120,000
- Over \$120,000
- Unsure

4. What is the last grade in school you completed?

- Grade school only
- Some high school
- Graduated high school
- GED
- 1 or 2 years college, no degree
- Graduated junior or community college
- Vocational/technical degree
- 3 or 4 years of college, no degree
- Bachelor's degree
- Some graduate school work
- Graduate degree (ex: MA, MS, Ph.D., JD...)
- Unsure

5. Are you currently:

- Employed for wages

- Self-employed
- Out of work for more than 1 year
- Out of work for less than 1 year
- A Homemaker
- A Student
- Retired
- Unable to work
- Unsure
- Refused

6. What is your gender?

- Male
- Female
- Do not wish to answer

Now I would like to ask some questions about your health status.

7. Have you had a biopsy confirmed diagnosis of celiac disease?

- Yes
- No
- Not sure

8. Do you exercise on a weekly basis? If no, skip to question #11.

- Yes
- No

10. If yes, how often per week do you exercise?

- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 6-7 times per week

11. Do you take any supplements? (If no, please skip to question 13)

- Yes

- No

12. Which supplements do you take? (Mark all that apply)

- Multivitamin
- Calcium
- Iron
- Vitamin B12
- Folate
- Vitamin D
- Other: (Please list)_____

The next set of questions asks about your eating habits in the past month.

13. During the past month, how often did you eat hot or cold cereal? Mark one.

- 1 time last month
- 2-3 times last month
- 1 time per week
- 2 times per week

14. During the past month, what kind of cereal did you usually eat? – *Print cereal.*

15. During the past month, how often did you have any **milk** (either to drink or on cereal)? Include regular milks, chocolate, or other flavored milks, lactose-free milk, buttermilk. Please do not include soy milk or small amounts of milk in coffee or tea. *Mark one.*

- Never
- 1 time last month
- 2-3 times last month

- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week

- 1 time per day
- 2-3 times per day
- 4-5 times per day
- 6 or more times per day

16. During the last month, what kind of milk did you usually drink? *Mark one.*

- Whole or regular milk

- 2% fat or reduced-fat milk
 - 1%, ½%, or low-fat milk
 - Fat-free, skim or nonfat milk
 - Soy milk
 - Other kind of milk *-Print milk-*
-

17. During the past month, how often did you drink **regular soda or pop** that contains sugar? Do **not** include diet soda. *Mark one.*

- Never
- 1 time last month
- 2-3 times last month

- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week

- 1 time per day
- 2-3 times per day
- 4-5 times per day
- 6 or more times per day

18. During the past month, how often did you drink **100% pure fruit juices** such as orange juice, grape and pineapple juices? Do **not** include fruit-flavored drinks with added sugar or fruit juice you made at home and added sugar to. *Mark one.*

- Never
- 1 time last month
- 2-3 times last month

- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week

- 1 time per day
- 2-3 times per day
- 4-5 times per day
- 6 or more times per day

19. During the past month, how often did you drink coffee or tea that had sugar or honey added to it? Include coffee and tea you sweetened yourself and presweetened tea and coffee drinks such as Arizona Iced Tea and Frappuccino. Do **not** include artificially sweetened coffee or diet tea.

- Never
- 1 time last month
- 2-3 times last month

- 1 time per week

- 2 times per week
- 3-4 times per week
- 5-6 times per week

- 1 time per day
- 2-3 times per day
- 4- 5 times per day
- 6 or more times per day

20. During the past month, how often did you drink **sweetened** fruit drinks, sports or energy drinks, such as Kool-Aid, lemonade, Hi C, cranberry drink, Gatorade, Red Bull or Vitamin Water? Include fruit juices you made at home and added sugar to. Do **not** include diet drinks or artificially sweetened drinks.

- Never
- 1 time last month
- 2-3 times last month

- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week

- 1 time per day
- 2-3 times per day
- 4-5 times per day
- 6 or more times per day

21. During the past month, how often did you eat **fruit**? Include fresh, frozen or canned fruit. Do **not** include juices.

- Never
- 1 time last month
- 2-3 times last month

- 1 time per week
- 2 times per week

- 3-4 times per week
- 5-6 times per week

- 1 time per day
- 2 or more times per day

22. During the past month, how often did you eat a green leafy or lettuce **salad**, with or without other vegetables?

- Never
- 1 time last month
- 2-3 times last month

- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week

- 1 time per day
- 2 or more times per day

23. During the past month, how often did you eat any kind of **fried potatoes**, including French fries, home fries, or hash brown potatoes?

- Never
- 1 time last month
- 2-3 times last month

- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week

- 1 time per day
- 2 or more times per day

24. During the past month, how often did you eat any **other kind of potatoes**, such as baked, boiled, mashed potatoes, sweet potatoes, or potato salad?

- Never
- 1 time last month
- 2-3 times last month

- 1 time per week

- 2 times per week
- 3-4 times per week
- 5-6 times per week

- 1 time per day
- 2 or more times per day

25. During the past month, how often did you eat refried beans, baked beans, beans in soup, pork and beans or any other type of cooked dried beans? Do **not** include green beans.

- Never

- 1 time last month
- 2-3 times last month

- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week

- 1 time per day
- 2 or more times per day

19. During the past month, how often did you eat brown rice or other cooked whole grains, such as quinoa? Do **not** include white rice.

- Never

- 1 time last month
- 2-3 times last month

- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week

- 1 time per day
- 2 or more times per day

20. During the past month, not including what you just told me about (green salads, potatoes, cooked dried beans), how often did you eat **other vegetables**?

- Never

- 1 time last month
- 2-3 times last month

- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week

- 1 time per day
- 2 or more times per day

21. During the past month, how often did you have Mexican type **salsa** made with tomato? (I would like to change this to fast food or pasta)

- Never

- 1 time last month
- 2-3 times last month

- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week

- 1 time per day
- 2 or more times per day

22. During the past month, how often did you eat **pizza**? Include frozen pizza, fast food pizza, and homemade pizza.

- Never

- 1 time last month
- 2-3 times last month

- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week

- 1 time per day
- 2 or more times per day

23. During the past month, how often did you have **tomato sauces** such as with spaghetti or noodles or mixed into foods such as lasagna? Do **not** include tomato sauce on pizza.

- Never

- 1 time last month
- 2-3 times last month

- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week

- 1 time per day
- 2 or more times per day

24. During the past month, how often did you eat any kind of **cheese**? Include cheese as a snack, cheese on burgers, sandwiches, and cheese in foods such as lasagna, quesadillas, or casseroles. Do **not** include cheese on pizza.

- Never

- 1 time last month
- 2-3 times last month

- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week

- 1 time per day
- 2 or more times per day

25. During the past month, how often did you eat **red meat**, such as beef, pork, ham, or sausage? Do **not** include chicken, turkey or seafood. Include red meat you had in sandwiches, lasagna, stew, and other mixtures. Red meats may also include veal, lamb, and any lunchmeats made with these meats.

- Never

- 1 time last month
- 2-3 times last month

- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week

- 1 time per day
- 2 or more times per day

26. During the past month, how often did you eat any **processed meat**, such as bacon, lunchmeats, or hot dogs? Include processed meats you had in sandwiches, soups, pizza, casseroles, and other mixtures. Processed meats are those preserved by smoking, curing, or salting, or by the addition of preservatives. Examples are: ham, bacon, pastrami, salami, sausages, bratwursts, frankfurters, hot dogs, and spam.

- Never

- 1 time last month
- 2-3 times last month

- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week

- 1 time per day
- 2 or more times per day

27. During the past month, how often did you eat gluten free **whole grain bread** including toast, rolls and in sandwiches? Whole grain breads include brown rice flour, almond meal/flour, and buckwheat flour. Do **not** include gluten free white bread.

- Never

- 1 time last month
- 2-3 times last month

- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week

- 1 time per day
- 2 or more times per day

28. During the past month, how often did you eat **chocolate** or any other types of candy? Do **not** include sugar free candy.

- Never

- 1 time last month
- 2-3 times last month

- 1 time per week
- 2 times per week
- 3-4 times per week

- 5-6 times per week
- 1 time per day
- 2 or more times per day

29. During the past month, how often did you eat gluten free **doughnuts, sweet rolls, Danish, muffins, or pastries**? Do **not** include sugar free items.

- Never
- 1 time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2 or more times per day

30. During the past month, how often did you eat gluten free **cookies, cake, pie or brownies**? Do **not** include sugar free kinds.

- Never
- 1 time last month
- 2-3 times last month
- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week
- 1 time per day
- 2 or more times per day

31. During the past month, how often did you eat gluten free **ice cream or other frozen desserts**? Do **not** include sugar free kinds.

- Never
- 1 time last month
- 2-3 times last month
- 1 time per week

- 2 times per week
- 3-4 times per week
- 5-6 times per week

- 1 time per day
- 2 or more times per day

32. During the past month, how often did you eat **popcorn**?

- Never

- 1 time last month
- 2-3 times last month

- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week

- 1 time per day
- 2 or more times per day

33. During the past month, how often did you eat at a fast food restaurant?

- Never

- 1 time last month
- 2-3 times last month

- 1 time per week
- 2 times per week
- 3-4 times per week
- 5-6 times per week

- 1 time per day
- 2 or more times per day

34. During the past month, how often did you eat at a causal dining or fine dining restaurant?

- Never

- 1 time last month
- 2-3 times last month

- 1 time per week
- 2 times per week

3-4 times per week

5-6 times per week

1 time per day

2 or more times per day

35. What is your current weight (in pounds)? _____

36. What is your height (in feet)? _____

Appendix B: Statistical Analysis of Survey Results

Independent Samples Test									
	Levene's Test for Equality of Variances		t-test for Equality of Means						
	F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
								Lower	Upper
Equal variances assumed	.376	.541	1.050	94	.296	.227	.216	-.202	.655
Equal variances not assumed			1.188	39.126	.242	.227	.191	-.159	.613
Equal variances assumed	16.059	.000	1.548	134	.124	.792	.512	-.220	1.805
Equal variances not assumed			1.160	29.635	.255	.792	.683	-.603	2.187
Equal variances assumed	3.990	.048	-.512	132	.610	-.237	.462	-1.151	.678
Equal variances not assumed			-.435	30.872	.666	-.237	.544	-1.346	.872
Equal variances assumed	.006	.937	-.015	134	.988	-.008	.512	-1.021	1.006
Equal variances not assumed			-.015	36.407	.988	-.008	.529	-1.080	1.065
Equal variances assumed	.016	.900	1.541	134	.126	.681	.442	-.193	1.556
Equal variances not assumed			1.585	39.017	.121	.681	.430	-.188	1.550
Equal variances assumed	1.544	.216	-1.248	134	.214	-.379	.304	-.980	.222
Equal variances not assumed			-1.104	33.381	.278	-.379	.343	-1.077	.319

Group Statistics					
	gender	N	Mean	Std. Deviation	Std. Error Mean
exercise_freq	male	21	3.33	.730	.159
	female	75	3.11	.909	.105
regular_soda	male	26	3.19	3.335	.654
	female	110	2.40	2.055	.196
fruit_freq	male	25	6.80	2.550	.510
	female	109	7.04	1.967	.188
wgrain_total	male	26	5.19	2.450	.480
	female	110	5.20	2.326	.222
sweets_total	male	26	7.15	1.953	.383
	female	110	6.47	2.044	.195
veg_total	male	26	7.38	1.627	.319
	female	110	7.76	1.334	.127

Correlations

		veg_total	sweets_total	wgrain_total	BMI	fruit_freq	exercise_freq
veg_total	Pearson Correlation	1	-.092	.033	.068	.482**	.123
	Sig. (2-tailed)		.283	.700	.429	.000	.231
	N	139	139	139	136	137	97
sweets_total	Pearson Correlation	-.092	1	.083	.042	.213*	-.180
	Sig. (2-tailed)	.283		.330	.630	.012	.078
	N	139	139	139	136	137	97
wgrain_total	Pearson Correlation	.033	.083	1	-.086	.205*	-.209*
	Sig. (2-tailed)	.700	.330		.317	.016	.040
	N	139	139	139	136	137	97
BMI	Pearson Correlation	.068	.042	-.086	1	.083	.003
	Sig. (2-tailed)	.429	.630	.317		.341	.981
	N	136	136	136	136	134	95
fruit_freq	Pearson Correlation	.482**	.213*	.205*	.083	1	-.007
	Sig. (2-tailed)	.000	.012	.016	.341		.949
	N	137	137	137	134	137	96
exercise_freq	Pearson Correlation	.123	-.180	-.209*	.003	-.007	1
	Sig. (2-tailed)	.231	.078	.040	.981	.949	
	N	97	97	97	95	96	97

** . Correlation is significant at the 0.01 level (2-tailed).

* . Correlation is significant at the 0.05 level (2-tailed).

Appendix C: IRB Approval and Documentation



EXEMPTION CERTIFICATION

Office of Research Integrity
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PI phone #: (502)310-9894

FROM: Institutional Review Board
c/o Office of Research Integrity

SUBJECT: Exemption Certification for Protocol No. 13-0014-X4B

DATE: February 1, 2013

On February 1, 2013, it was determined that your project entitled, *Diet Quality and Celiac Disease*, meets federal criteria to qualify as an exempt study.

Because the study has been certified as exempt, you will not be required to complete continuation or final review reports. However, it is your responsibility to notify the IRB prior to making any changes to the study. Please note that changes made to an exempt protocol may disqualify it from exempt status and may require an expedited or full review.

The Office of Research Integrity will hold your exemption application for six years. Before the end of the sixth year, you will be notified that your file will be closed and the application destroyed. If your project is still ongoing, you will need to contact the Office of Research Integrity upon receipt of that letter and follow the instructions for completing a new exemption application. It is, therefore, important that you keep your address current with the Office of Research Integrity.

For information describing investigator responsibilities after obtaining IRB approval, download and read the document "PI Guidance to Responsibilities, Qualifications, Records and Documentation of Human Subjects Research" from the Office of Research Integrity's Guidance and Policy Documents web page [<http://www.research.uky.edu/ori/human/guidance/htm#PIresp>]. Additional information regarding IRB review, federal regulations, and institutional policies may be found through ORI's web site [<http://www.research.uky.edu/ori/>]. If you have questions, need additional information, or would like a paper copy of the above mentioned document, contact the Office of Research Integrity at (859) 257-9428.

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Images

Figure 1: Archives of Pathology & Laboratory Medicine, Jul2012, Vol. 136 Issue 7, p738

Figure 2: Archives of Pathology & Laboratory Medicine, Jul2012, Vol. 136 Issue 7, p739

Vita

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Education:

- University of Louisville, Bachelors of Arts in Communication, Dec. 2007
- Dietetic Internship: University of Kentucky, July 2013

Professional Positions:

- Teaching Assistant, University of Kentucky, Department of Dietetics and Human Nutrition, Aug. 2011 - Dec. 2012
- Research Assistant, University of Kentucky, Department of Dietetics and Human Nutrition, Feb. 2011 - Jun. 2011
- Business Development Manager, Snelling Staffing, Oct. 2008 – Jan. 2010

Professional Publications:

- Recipe analysis, “The Gluten-Free Choice”, Montgomery County Extension Services. December 2012.