

2011

Celiac disease: increasing awareness for a better life

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CELIAC DISEASE:
INCREASING AWARENESS FOR A BETTER LIFE

A Dissertation

Submitted to the Graduate Faculty of the
Louisiana State University and
Agricultural and Mechanical College
in partial fulfillment of the
requirements for the degree of
Doctor of Philosophy

in

The School of Human Resource Education
And Workforce Development

by

Sheetal Verma-Bueche
B.S. Louisiana State University, 1995
M.S. Louisiana State University, 1997
December 2011

DEDICATION

This work is dedicated to my children Logan and Malini Bueche. They are the reason that this study became a reality. Logan, you are one of the kindest people I know. You have made me proud in ways that I couldn't imagine. Continue to grow to be a strong, caring and compassionate person. Malini, you are so special to my heart. You make me laugh and I am proud that you are turning into a strong, independent, yet caring and compassionate person. Knowing that both Logan and Malini will be advocates for Celiac Awareness lifts my spirits every day. Your lives will touch so many people.

I also dedicate this work to my father, Dr. Satish Verma. He is a testament on how to love children through any situation. I am honored when people say "here's the next Dr. Verma" although, I know very well that I will never be able to fill your shoes. Thank you for pushing me to do the best at whatever I choose to do and Thank you for loving me no matter what. To my mother, Nirmala Verma, whose traits of stubbornness and persistence are surely ever present in me and a major reason I was able to complete my studies.

To my husband, James, you have been there for me in countless ways and you have done so with a willing spirit. Thank you for not giving up on me during this sometimes never-ending journey. I love you more than you will ever know.

ACKNOWLEDGMENTS

This journey to achieving a Doctor of Philosophy is one of many highs, its own share of lows, and one that is not finished without the support of a village to carry you to the end. I want to begin by thanking my esteemed committee for their encouragement and expertise throughout this entire process. Dr. Earl Johnson, you are truly one of the kindest, most interesting educators I have ever had the privilege of knowing. Thank you for your encouragement throughout this process and the reminders that I could achieve this amazing goal. Dr. Janet Fox, from the beginning as I sat in your class, I knew that you would be able to stoke my passion for helping others. Dr. Catherine Lemieux, you have always brought calm to the storm, and I am so grateful for your constant guidance both inside and outside of class. I am so very blessed to have someone like you whom I respect not only as a colleague, but as my friend. I consider myself blessed to have been under the direction of such an amazing committee throughout this entire process. Dr. Henrique Cheng, thank you, for looking out for me. I was a little nervous when I found out that I would have someone who knows so much and is so passionate about my subject area.

To my committee chair, Dr. Michael Burnett, there are no words that can capture my gratitude for all you have done for me during this entire process both academically, professionally, and personally. You are one of the most intelligent, passionate, kind, and respectful individuals that I have ever met. Your dedication to guiding me through this process is unwavering, and watching you get excited about research gave me a little spark. You always wanted the best for me and my future. You pushed me academically when I didn't think I could be pushed any more, and for that I am so grateful. Thank you for teaching me to be a scholar that always seeks to produce cutting edge research. You know how I feel about the subject.

Without the support of the Metabolic Center of Louisiana, this project would have never been possible. Thank you to Dr. Bhushan, Dr. Flood and Mr. Marrioneaux for recognizing the need in carrying out this research. Also, thank you to Dr. Bhushan for your creative guidance throughout the development and implementation of this study. Your subject matter expertise led to an amazing end project and well executed study. You are an advocate for your patients. Thank you for encouraging me to stay the course and your unwavering belief in this research.

Through the partnership with the Metabolic Center of Louisiana the vision in my head came to life. Thank you to the entire team (Jaci, Natasha, Natalie, Devin, L.J., Jenna, Adair, Emilia, Ms. Kay, Lauren, Ms. Edna and Letisha) for your support to building this learning environment and seeing it through from conceptualization to implementation. We still have a ways to go. Not many people in life can say they love their job and the people they work with each day. I am blessed to be one of those people that can make this assertion. To my work family and partners, thank you so much for not only your hard work every day but for your friendship. Kate, Nedra, Tuan and Natalie, Thank you for sifting through page after page of information, showing me how to make tables, entering data, figuring out how to number pages and doing this all with a smile! You all are going to do amazing things with your life, and I am honored to call you all my friend.

Thank you to the entire faculty of the School of Human Resource Education and Workforce Development. I came to this school as a graduate student from another program many, many years later and was welcomed with open arms. I am leaving as a richly blessed student on every level one could imagine. Thank you, to Ms. Ann Harrington and Chelsea Lewis, for all of the support you have provided to me both academically and personally. I will keep the Cupcakes coming. There are many times when students don't know where to turn for answers about the doctoral process, but when you have a friend like Dr. Mary Leah Coco, the

doctoral process is certainly much easier. Thank you Mary Leah for answering question after question about paperwork, rules, procedures, and anything else I couldn't figure out. This was a lot. You are such a wonderful person, and I am so grateful for all you have done for me. Thank you for always having faith in my abilities even when I didn't. I am very ready to do normal friend things.

There are so many friends to whom I owe a world of gratitude for their support, patience, guidance, and love over these last few years. To Sudha Rawal, Jenee Boudreaux (always Boudreaux to me), Deirdre Richard (Dee), Nicole Palfi and Rhonda Lepisto, thank you for loving my family through these last years. You have lifted my family up in prayer and offered many words of encouragement. Thank you for helping carry us through this process and for loving my beautiful Logan and Malini, and your friendship. This has been an amazing circle of support as I trudged through this daunting process. Each of your families has prayed for guidance and fortitude for my family as we crossed this finish line together. I am so grateful for each of you. Thank you for praying for me. Thank you especially to Dee, for your prayers, jokes, and reassurance while I traveled down this road. Your phone calls to wish me well and uplifting messages sustained my spirit on those days when I thought I would never reach this point. Thank you for blessing me with your friendship.

Of course, last but never least, my family. To my wonderful husband, James, I am eternally grateful for your words of love and motivation. Thank you for enriching my life. You have been here for me through times in which I didn't deserve, for this I will always love you. To my father, thank you for steadfastly praying for me as I went through this journey. Your endless support and unconditional love is breathtaking. Thank you, to my mother, who continues to nourish our bodies so our minds can be sustained. To my sweet son Logan and daughter Malini, I love you more than you could ever imagine. God gave me the greatest gifts when you

were born, and I will always cherish you. To Madhu, Mukul, Ji, and Lisa, no words can tell you how much I appreciate your support on this journey. To Neelabh, and My favorite mother-in-Law, Ruthie, you are patient, kind, funny, sometimes tacky, but endlessly faithful. Thank you for taking this adventure with me.

Whenever I was overcome with self-doubt or unsure of a decision I had made along the journey, I would lean upon my father, Dr. Satish Verma. Dad, you have sustained my spirit through this entire journey, and I pray to god that he continue to provide your undeserved love, mercy, and faithfulness that you have so graciously bestowed upon me. I can only hope I have made you proud.

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ABSTRACT

The purpose of this study was to determine the awareness and knowledge of Celiac Disease/Gluten Intolerance (CD/GI), among clients of a medical facility in the southern portion of the United States. A researcher-designed awareness/knowledge instrument was used to study a random sample of clients of a medical facility. Data were collected from 404 clients at the medical facility. Data collected included whether or not participants were aware of the disease, a 30-item knowledge instrument, and their demographic characteristics.

Exploratory factor analysis revealed four identifiable subscales in the knowledge instrument: Symptomology, Diagnosis, Treatment, and Interaction with Other Conditions and Overall Knowledge Score. Multiple Regression analysis was used to determine the amount of variance in the knowledge subscales explained by the demographic characteristics.

Results showed that a majority of the participants (53.2%) was unaware of CD/GI. The majority of participants did not know or inaccurately responded to 18 of the 30 statements in the knowledge of CD/GI instrument. Variables related to Awareness included Ethnicity, Marital Status, Highest Level of Education, Annual Family Income, and Physical Examination by their Primary Care Physician (PCP). Variables related to one or more knowledge subscales were Gender, Whether or Not Participants had Children, Highest Level of Education, Physical Examination by their PCP, and Distance Traveled from Home to Medical Facility. The variances explained in the knowledge subscale scores and the overall knowledge score from selected demographic variables ranged from 18.2%-22.4%.

It was concluded from the study that there is a lack of awareness and minimal knowledge of CD/GI among the clients of the medical facility. Also, knowledge of CD/GI is a multi-factor concept which offers future research and application opportunities.

Recommendations included research on designing and implementing more robust knowledge assessment instruments, education and publicity programs to increase awareness of CD/GI among the general public and enabling physicians to improve their diagnostic skills. The study was considered significant because the results could enable medical and health professionals and nonprofit organizations to direct their education and research efforts to address the many issues that arise from the disease, from heightening awareness, to amelioration, to treatment, to drug therapy.

CHAPTER 1

INTRODUCTION

Rationale

Quality of Life (QoL) is a phrase used to refer to an individual's total well-being. This includes all emotional, social, and physical aspects of an individual's life (Renwick, 2005). However, in the context of medicine or healthcare, the concept of Health Related Quality of Life (HRQoL), refers to how an individual's well-being may be affected over time by a disease, disability, or disorder (Wilson, 1995). The current concept of HRQoL acknowledges that individuals associate their actual situation with their personal expectations (Wilson, 1995). The latter can vary over time and react to external influences such as length and severity of illness, family support, etc. One may ask why is it important to recognize an individual's quality of life? Understanding QoL is becoming an increasingly important healthcare topic because the relationship between cost and value raises complex issues, often with high emotional attachment because of the potential impact on human life (Lucas, 2002). For instance, healthcare providers must refer to cost-benefit analysis to make economic decisions regarding access to expensive drugs that may prolong life for a short time and/or provide a minimal increase in quality of life (Wilson, 1995). There is a growing field of research concerned with developing, evaluating, and applying quality of life measures within health-related research (Wilson, 1995).

For good quality of life, individuals should be physically healthy (free from chronic disease, pain, or a debilitating condition), in good mental health, economically stable/comfortable, following a productive career, and leading a life with positive attitudes and feelings of physical, emotional and social well-being (R. Bhushan, M.D., Personal Communication, January 10, 2011).

There are many illnesses that can lead to a poor quality of life if not diagnosed and treated. Celiac Disease (CD) is one of them. Individuals with Celiac Disease can exhibit symptoms and experience health conditions which make them feel poorly and may generate unpleasant quality of life, perceptions and experiences. CD is a lifelong digestive disorder caused by a mediated toxic reaction to a protein called gluten found in wheat, barley, rye and oats resulting in damage to the small intestine, thus interfering with the body's capacity to properly absorb food nutrients, and creating other more serious health conditions (Fasano, 2009).

This disease has been known as a disorder of the abdomen and mentioned in the medical lexicon for almost 10,000 years. It was first described in the second century AD by Aretaeus Cappadocia, a contemporary of the Roman physician Galen, who used the Greek word "koeliakos," which means "suffering of the bowels" (Losowsky, 2008). However, only in 1888 AD did Samuel Gee of St Bartholomew's Hospital give the classical clinical description of CD (Mugema, 2009). The definitive discovery of the cause of the disease, and specifically distinguishing it from other common digestive disorders and their symptoms, has been more recent, within the last four decades (Fasano, 2009). Since then, much progress has been made by the medical profession in further investigating the etiology of the disease and treatment measures. However, medical practitioners have been slower in their response to diagnosing and treating the disease in their patients. Due to the lack of, or minimal awareness of, the disease among the general public (Fasano, 2009) and Primary Care Physicians (PCP), in particular (Zipser, Farid, Baisch, Patel & Patel, 2005) with regard to the incidence, prevalence, proximal cause and characteristic symptoms of the disease, there is a need for confirmatory serological testing and diagnosis. These issues complicate the situation and delay treatment of affected individuals, sometimes up to 10 years (Fasano, 2009).

CD is a permanent inflammatory disease of the small intestine triggered by the ingestion of gluten-containing cereals in genetically predisposed individuals (Fasano, 2009). Damage to the small intestine is caused by an immunologically toxic reaction to the ingestion of gluten which interferes with the absorption of nutrients (Fasano, 2009). Even small amounts of gluten in foods can affect those with CD and cause health problems. Damage can occur to the small bowel even when there are no symptoms present (Fasano, 2009; Mugema, 2009).

Fasano (2009) reported that a gluten-free diet is the only way currently known to avoid the adverse effects of the disease and while drug therapy research, including incorporation of enzymes into drugs to break down gluten and other alternative therapeutic leads continues there is no significant breakthrough in sight. There has been some encouraging development in natural foods-based drugs such as thymus extract, quercitin, and enzymes (Rourke & Tirone, 2007). There are expectations of an \$8 billion CD drug therapy market by 2019, but in the near term, the only way for gluten-sensitive individuals to lead a relatively healthy life is to observe strict compliance with a gluten-free diet for as long as they live and make the necessary lifestyle changes that a strict food regimen requires (Fasano, 2009).

Besides disrupting the breakdown and absorption of food in the small intestine and causing digestive disorders, CD impacts the body's auto-immune system and causes other significant disorders, such as general fatigue, foggy thinking, infertility, reduced bone density, neurological disorders, some cancers, psychosocial manifestations (National Foundation for Celiac Awareness (NFCA, 2003). Due to the growing importance and prevalence of CD in the United States, private and public initiatives at the national level have been undertaken. Two non-profit organizations have been established to promote public awareness of the disease which should lead to an increase in the rate and accuracy of diagnosis and reduce the time for diagnosis.

The agenda of the Celiac Disease Foundation (CDF) which was established in 1990, and the NFCA, which was established in 2003, includes education, advocacy, and facilitating research to better understand the causes, mechanisms, and treatment of CD (CDF, 1990; NFCA, 2003). The NFCA maintains that awareness brings treatment, which brings improvement in the QoL for those with CD. NFCA's goal is to reduce the time to diagnosis and reduce the devastating impact of undiagnosed CD, including the contraction of other diseases such as cancer, diabetes, osteoporosis, and an "autoimmune cascade" (NFCA, 2003). The National Institutes of Health (NIH) Consensus Development Conference on CD held in 2004 brought together scientists, physicians, and public interests' representatives to discuss various aspects of CD, including diagnosis, prevalence, manifestations and long-term consequences, testing protocols, disease management, and future research (NIH, 2005). Among its recommendations was the need for heightened public awareness of CD and the education of physicians, registered dietitians, and other healthcare providers. This recommendation laid the foundation for the development of the CD awareness campaign. Implementing the recommendation led to research initiatives with medical practitioners and other health personnel to determine how these professionals could be involved in raising public awareness, the creation of the awareness campaign website, and production of publicity and communication material for medical professionals and the general public (Rewers, 2005; James, 2006).

Statistics on the incidence and prevalence of CD show its world-wide reach. The numbers have been growing as reported by medical diagnoses and statistics. Furthermore, studies in other countries with different age groups, ethnic groups, and demographic variables have further verified this trend (Rewers, 2005; James, 2006).

In the United States, the upward trend in the incidence and/or diagnosis of CD has been observed. A recent study published in the journal *U.S. Pharmacist* reported that increased diagnostic testing led to uncovering more cases than earlier thought in the United States. Before the year 2000, in two studies only 1 in 4,800 and 1 in 10,000 people in the United States had been diagnoses with CD. More recent studies found a much higher incidence of 1 in 133 in the general population, with 1 in 22 and 1 in 56 among first-degree and second-degree relatives (Fasano et al, 2003). It is estimated that patients diagnosed with CD now make up 0.5-1.0 % of the general population in the United States, which equates to three million Americans with the disease. On top of this alarming statistic, under-diagnosis and misdiagnosis can result in individuals having the disease for as many as 10 years without knowing they have it.

Statement of the Problem

The general public lacks awareness and knowledge of CD, its incidence, causes, symptoms, dietary and other treatment options (R. Bhushan, M.D., Personal Communication, January 10, 2011). In addition, the lack of sensitivity to the disease in primary care medical practices, combined with confounding symptoms commonly encountered by medical practitioners, complicates early and/or correct diagnoses and detection, which challenges the abilities of, and increases the burden of proof for attending physicians (R. Bhushan, M.D., Personal Communication, January 10, 2011). An issue that arises in determining awareness and knowledge of CD in the general public is the lack of measurable instruments. The researcher was unable to locate any appropriate instrumentation, hence the need for development and implementation of such tools.

A web-based Celiac Disease and Gluten-Free Forum (2005) received support from over 25 individuals who commented on their personal or vicarious experiences with the disease –

symptoms and complications, diagnostic difficulties, diet, bodily and lifestyle effects on health and living – and joined the forum sponsors in a plea for generating greater public awareness.

The NFCA, established in 2003, has been emphasizing the need for greater awareness through awareness campaigns, general publicity, and special activities. In addition, the NIH Consensus Panel (2004) of medical, policy, and political interests developed a six-point program to further advocate the need for research and emphasis and general public/medical profession awareness and activities.

Lack of public awareness of CD, combined with misdiagnosed and/or delayed diagnosis among patients under treatment, exacerbates the problems associated with the disease, which undermines the health and well-being of the individual, community, and society. Enhancing awareness among the general public regarding the prevalence of CD would create a climate of better screening, earlier diagnosis and treatment of the disease, as well as increasing patient responsibility for personal health, including consuming a gluten-free diet, seeking proper treatment, and complying with treatment recommendations. These measures would complement ongoing strategies for raising awareness of and combating the disease. Due to the fact that CD and the body's reaction to the consumption of gluten are inextricably linked the two terms, "Celiac Disease" and "Gluten Intolerance (GI)," are used together to reinforce the connection in the public's mind.

Purpose of the Study

The primary purpose of this study was to determine the level of awareness and knowledge of CD/GI among patients of a medical facility in the southern portion of the United States. Additional questions addressed in this study were (a) "Are the awareness and knowledge

of the sample about CD/GI related to their demographic characteristics?”, and (b) “What portion of the sample’s awareness and knowledge is explained by their demographic characteristics?”

Objectives of the Study

Objective 1. Describe the clients of a medical facility in the southern portion of the United States on the following selected demographic characteristics:

- a) Age
- b) Gender
- c) Ethnicity
- d) Marital Status
- e) Number of Children
- f) Highest Education Level
- g) Occupation/Profession
- h) Annual Family Income
- i) Distance Traveled from Home to the Medical Facility
- j) Years since Last Physical Exam by participant’s PCP
- k) Years since Last Seen by Any Physician

Objective 2. Determine the awareness and knowledge of CD/GI, among the clients of a medical facility in the southern portion of the United States.

Objective 3. Determine if identifiable sub-scales exist in the instrument designed to measure the awareness and knowledge of CD/GI among clients of a medical facility in the southern portion of the United States.

Objective 4. Determine if a relationship exists between the awareness and knowledge of CD/GI and the following selected demographic characteristics of clients of a medical facility in the southern portion of the United States:

- a) Age
- b) Gender
- c) Ethnicity
- d) Marital Status
- e) Number of Children
- f) Highest Education Level
- g) Occupation/Profession
- h) Annual Family Income
- i) Distance Traveled from Home to the Medical Facility
- j) Years since Last Physical Exam by participant's PCP
- k) Years since Last Seen by Any Physician

Objective 5. To determine if a model exists explaining a significant portion of the variance in the knowledge of CD/GI among clients of a medical facility in the southern portion of the United States from the following selected demographic characteristics:

- a) Age
- b) Gender
- c) Ethnicity
- d) Marital Status
- e) Status and Number of Children
- f) Highest Education Level

- g) Occupation/Profession
- h) Annual Family Income
- i) Distance Traveled from Home to the Medical Facility
- j) Years since Last Physical Exam by participant's PCP
- k) Years since Last Seen by Any Physician

Definition of Terms

For the purpose of this study, the following definitions are offered to assist in the understanding of terminology as it relates to this study:

Awareness of CD/GI. Denotes whether the study participants are aware that there is a disease called CD/GI.

Knowledge of Celiac Disease/Gluten Intolerance. Denotes whether the study participants know about CD/GI, either as unique concepts or all concepts used in the survey instrument of this study to describe the disease/condition.

Auto-immune Disease. A disease that is linked to the auto-immune system of the body which causes it to react adversely and harm the specific organ involved (R. Bhushan, M.D., Personal Communication, January 10, 2011).

Celiac Disease/Gluten Intolerance. A health condition in which an individual cannot tolerate the protein, gluten, found in all strains of wheat, rye, barley, and oats, and has an auto-immune reaction affecting the digestive system and other organs. Celiac Disease, Gluten Intolerance and Gluten Sensitivity are all used synonymously in the literature. Since "Gluten" is becoming more prominent in the food industry the two terms were used together for ease of understanding of study participants (R. Bhushan, M.D., Personal Communication, January 10, 2011).

Gluten-free Diet. A diet based on foods that do not contain gluten (K. Blumberg, RD, Personal Communication, January 17, 2011).

Health-Related Quality of Life. This refers to how an individual's well-being may be affected over time by a disease, disability, or disorder (Wilson, 1995).

Quality of Life. A phrase used to refer to an individual's total well-being. This includes all emotional, social, and physical aspects of an individual's life (Renwick, 2005).

Persons with CD/GI. Individuals diagnosed with Celiac Disease.

Limitations of the Study

There are two specific limitations within this study. They include:

1. The clients of one private clinic specializing in autoimmune disorders are not representative of the general public who seek medical attention in health facilities, and hence the findings of the study can be extrapolated to the general public.
2. The instrument used in the study was researcher developed and there were no other instruments available in the literature for reference and support.

CHAPTER 2

LITERATURE REVIEW

Information for this literature review on Celiac Disease (CD) was gathered from conference proceedings, research journals, consumer magazines, empirical research, internet sites, and personal interviews with medical professionals.

Quality of Life Issues

For many people, being diagnosed with CD brings a feeling of relief and the end to a long, frustrating road of unknowns. However, the diagnosis can also raise more questions, including "What kind of life am I going to have now?" The answer to that question is "It depends." The official recommendation of the American Gastroenterological Association Institute (2006) regarding the treatment of CD is strict compliance to a gluten-free diet. While being diagnosed with CD may be out of an individual's control, the quality of life one may experience after diagnosis may be within their control largely based on adherence to a gluten-free diet.

There are many things that are important for people to know about CD and quality of life. People diagnosed with celiac disease will feel better after implementing a gluten-free diet (R. Bhushan, M.D., Personal Communication, January 10, 2011). Two studies (Mustalahti et al., 2002; Nachman et al., 2010) examined quality of life, gastrointestinal symptoms, and dietary adherence in participants diagnosed with CD. Their quality of life and gastrointestinal symptoms were compared to those of healthy non-celiac participants.

At the time of diagnosis, Mustalahti et al. (2002) reported that the healthy non-celiac group and the group with screen-detected CD had similar quality of life assessments, which were significantly higher than those of the symptom-detected group. For gastrointestinal symptoms, the researchers reported the same trend. Gastrointestinal symptoms at diagnosis were

significantly worse in the symptom-detected CD group than in the screen-detected celiac disease group or the healthy, non-celiac group (Mustalahti et al., 2002). However, these symptoms were similar in the screen-detected CD and healthy non-celiac groups. Nachman et al. (2010) reported similar findings. At diagnosis, participants with CD reported significantly lower quality of life and significantly more gastrointestinal symptoms and depression than the healthy, non-celiac group (Nachman et al., 2010)

One-year later, Mustalahti et al. (2002) found that after a year on a gluten-free diet, quality of life increased for participants in both the screen-detected and symptom-detected groups. In fact, quality of life for the symptom-detected group matched the quality of life of the healthy non-celiac participants, and the quality of life in the screen-detected group was higher than the healthy, non-celiac participants. For both groups diagnosed with CD, gastrointestinal symptoms decreased at the one-year follow-up. Gastrointestinal symptoms for the screen-detected CD group were lower than the symptoms of the healthy, non-celiac group (Mustalahti et al., 2002). Nachman et al. (2010) again reported similar findings. At the one-year follow-up, participants with CD reported a significantly higher quality of life and a significant decrease in gastrointestinal symptoms and depression compared to diagnosis. Their quality of life, gastrointestinal symptoms, and depression were not significantly different from the healthy, non-celiac group. In order to maintain a better quality of life where symptoms are not prevalent, individuals with CD must stay on a gluten-free diet for the long term and be strictly compliant (Nachman et al., 2010).

Four years later, Nachman et al. (2010) reported that many of the gains identified at the one-year follow-up for participants diagnosed with CD were not sustained at the four year time point. Some participants did not adhere to a strict diet. Compared to their assessments at the one-

year time point in five dimensions of their quality of life--social function, general health perception, role limitations due to physical problems, role limitations due to emotional problems, and vitality--participants reported a significant decrease. Depression was significantly worse and significantly more participants had depression scores that categorized them as experiencing moderate to severe depression (Nachman et al., 2010). When compared to the healthy group, participants with CD reported a significantly lower quality of life, more gastrointestinal symptoms (with the exception of constipation), and increased depression at the four-year time point. Also, when compared to the healthy group, participants with classic CD reported significantly lower quality of life for the five domains and significantly more symptoms for the diarrhea and constipation syndromes (Saqui, 2011).

Participants with CD who were strictly compliant with a gluten-free diet reported significantly higher quality of life than partially compliant participants. Also, across all dimensions, strictly compliant participants had similar outcomes compared to the healthy group with the exception of general health perception in the quality of life assessment, which was still higher than that of partially compliant participants (Saqui, 2011). With strict compliance to a gluten-free diet over the long term, one can experience a level of quality of life that is similar to the quality of life experienced by people without CD (Saqui, 2011).

An individual's perception of how compliant they are may be skewed. In a study conducted by Leffler et al. (2008), compliance with a gluten-free diet was self-reported by participants with CD, evaluated by a dietitian with expertise in the disease and the diet, and analyzed by a tissue transglutaminase IgA antibody or tTG test. The dietitian rated 44.2% of the participants as having "excellent" adherence and 34.4% as having "good" adherence (Saqui, 2011). However, when self-reported, adherence to a gluten-free diet was overestimated. Seventy

percent (70.1%) of participants rated themselves as strictly adherent when in fact their tTG was elevated (Saqui, 2011). These findings point to an important question: Is one aware when they are being less than diligent with the gluten-free diet? While someone with CD may think they are being strictly compliant with their diet, outside confirmation of adherence by a tTG test or nutritional evaluation from a physician and dietitian with expertise in CD may be helpful to keep them on track (American Gastroenterological Association Institute, 2006). Some people may have an easier time adhering to a gluten-free diet; others may be at risk for non-adherence (Saqui, 2011). On the questions of whether they were married and had other food intolerances, people with CD who answered "yes" to either question followed the strict regimen of their gluten-free diet better than those who answered "no" to either question, according to research conducted by Leffler et al. (2008). Other factors associated with better gluten-free diet adherence included:

- Believing that accidental and purposeful gluten exposure has important health ramifications
- Reporting good understanding of a gluten-free diet
- Scoring higher on a gluten-free diet knowledge quiz
- Ability to follow a gluten-free diet when traveling, dining out, or during social events
- Ability to follow a gluten-free diet despite changes in mood and stress level

Edwards George et al. (2009) also identified several factors associated with adherence to a gluten-free diet. The authors reported that higher levels of non-adherence as evaluated by a dietitian were associated with:

- Higher depression
- Higher levels of anxiety

- Lower levels of conscientiousness, order, self-discipline, deliberation, and readiness to re-examine values

Additionally, Ciacci, Lavarone, Siniscalchi, Romano & De Rosa (2002) identified anger as the main emotion associated with non-adherence. None of these studies established a cause and effect relationship. However, the findings can help educate people diagnosed with CD and those who treat them who may be at risk for poor quality of life and increased symptoms due to non-adherence. To keep feeling better and increase the likelihood of compliance over the long term, it is important to seek support, education, and follow-up (Saqui, 2011). In response to the difficulties in altering long-standing dietary habits and maintaining compliance with a gluten-free diet, the American Gastroenterological Association Institute (2006) recommended that people with CD join a CD support group and have regular follow-up evaluations. Over half of the participants in a study conducted by Leffler et al. (2008) belonged to a CD support group, and a high percentage of these participants (86.5%) reported the membership was helpful. Two professionals identified by most participants as being helpful in providing information and support for the gluten-free diet included their dietitian (63.0%) and gastroenterologist (57.1%). Their PCP (35.7%) and pharmacist (22.7%) were identified by fewer participants as being helpful. The Internet was cited by most of the participants (85.1%) as being most helpful in learning about a gluten-free diet followed by their dietitian (64.9%), gastroenterologist (50.6%), friends with CD (48.7%), friends without CD (44.8%), other media (43.5%), and their PCP (24.7%). Isolation, lack of knowledge, and inconsistent follow-up can negatively impact an individual's ability to feel better (Leffler et al., 2008).

Finally, although alternative treatments for CD are being investigated for the future, keeping these points in mind will help someone have a better quality of life today.

Even while on a diet, health-related quality of life may be lower in people with CD (Häuser, Stallmach, Caspary & Stein, 2007). Studies in the United States have found that quality of life becomes comparable to the general population after staying on the diet, while studies in Europe have found that quality of life remains lower, although the surveys were not quite the same (Häuser et al., 2007). Men tended to report more improvement than women (Goddard & Gillett, 2006).

The above-referenced studies on quality of life and CD, conducted with persons diagnosed with CD, were intended to determine self-perceived quality of life, gastrointestinal symptoms, and adherence to a gluten-free diet. Various methodologies and measurement tools were used in the studies, including quality of life personal assessments, self-reported gluten-free dietary adherence, dietitian and diagnostic evaluations of gluten-free regimens, and serological testing, as considered appropriate by several researchers.

The studies by Mustalahti et al. (2002) and Nachman et al. (2010) with persons diagnosed with CD/GI confirmed the value of following a gluten-free diet in achieving a level of quality of life and decreasing gastrointestinal symptoms which were comparable to the levels reported by healthy, non-celiacs at the time of diagnosis. One year later, Mustalahti et al. (2002) reported that the level of QOL and decrease in GI symptoms were sustained. However, four years later, Nachman (2010) reported that the gains initially achieved in quality of life, decreased GI symptoms, and less depression/anxiety did not hold up because of uneven adherence to the dietary regimen. Saqui (2011) added evidence to the recommendation for compliance with a gluten-free diet by determining that quality of life assessments by strict compliers were higher than the assessments by partial compliers, and as good as those by healthy non-celiacs.

Since strict dietary compliance with a gluten-free regimen is such a critical part of the CD/GI lifestyle, factors that can influence the level of compliance become important.

Leffler (2008) suggested that self-perception of compliance may be skewed with a tendency for

overestimation on the part of the individual; hence the need for outside confirmation. Attitudes and emotions can also play a part: Ciacci et al. (2002) identified anger's role in non-adherence, and Edwards George et al, (2009) determined that higher levels of non-adherence were associated with higher depression and anxiety, and lower levels of conscientiousness, order, and self-discipline. In consideration of the challenges faced by persons with CD/GI with regard to their diet, the American Gastroenterological Association Institute (2006) recommends that persons with CD/GI would be helped in adhering to a gluten-free diet by joining support groups and undergoing follow-up evaluations by dietitians and gastroenterologists.

History and Background of Celiac Disease

In the context of QoL and HRQoL, the impact of CD on individuals, communities, and societies is significant because of its growing incidence worldwide (Fasano, 2009). Ironically, the emergence in the last 20 years of an illness identified and labeled “celiac disease” is linked to the revolutionary discovery of seeds which led to the domestication of crops, the development of scientific agriculture, and the large-scale production of food grains in Man's quest to feed the world (Fasano, 2009).

Celiac disease acquired a name in the first century AD, when Aretaeus of Cappadocia, a Greek physician, reported the first scientific description, calling it *koiliakos*, after the Greek word for “abdomen,” *koelia*. British physician Samuel Gee is regarded as the modern father of Celiac Disease. In a 1987 lecture he described CD “as a kind of chronic indigestion which is met with in persons of all ages, yet it is especially apt to affect children between one and five years old, correctly surmised that errors in diet may perhaps be a cause, but could not pinpoint the true nature of the disease” (Dowd & Walker-Smith, 1974). It is now known that CD is triggered by ingesting a protein in wheat called gluten or eating similar proteins in rye and barley (R. Bhushan, M.D., Personal Communication, January 10, 2011).

Identification of gluten as the trigger in CD occurred after World War II when Dutch pediatrician Willem-Karel Dicke observed that a war-related shortage of bread in the Netherlands led to a significant drop in the death rate among children – from greater than 35% to essentially zero (Fasano, 2009). When wheat once again became available, the mortality rate rose to previous levels. Other scientists corroborated Dicke’s observation and concluded that the major protein in wheat, gluten, was the culprit (Fasano, 2009).

Fasano (2009) provided the foregoing account of the origin of CD in an article in *Scientific American* entitled “Surprises from Celiac Disease.” In the same article, Fasano (2009) reported that gluten and its relatives, once absent in the early human diet of fruits, nuts, tubers, and meats, began to kill people, often children, whose bodies would have reacted abnormally to them. Repeated exposure to such proteins would eventually have depleted sensitive individuals’ ability to absorb nutrients from food, caused abdominal pain and diarrhea, and emaciated, starved bodies (Fasano, 2009). Fasano (2009) found the following:

If these deaths had been noticed at the time, the cause would have been a mystery. Over the past twenty years, however, scientists have pieced together a detailed understanding of CD. They now know that it is an autoimmune disorder, in which the immune system attacks the body’s own tissues that the disease arises not only from exposure to gluten and its ilk but from a combination of factors, including predisposing genes and abnormalities in the structure of the small intestine. (p32)

CD is an excellent example of the way in which the trio of an environmental trigger (gluten and its likeness), susceptibility genes, and a small intestine abnormality (leaky or weak gut) may play a role in autoimmune disorders, wherein the immune system attacks the body’s own tissues (Fasano, 2009). The environmental trigger is manifested as a reaction to gliadin, a

prolamin (gluten protein) found in wheat, and similar proteins present in the crops of the tribe Triticeae, which includes other cultivars such as barley and rye (Fasano, 2009). Upon exposure to gliadin, and certain other prolamins, the enzyme transglutaminase modifies the protein and the immune system cross-reacts with the small-bowel tissue, causing an inflammatory reaction (Binning, 2010). This leads to a truncating of the villi or hair-like structures lining the small intestine, interfering with the absorption of nutrients, because the intestinal villi are responsible for absorption (Binning, 2010). The only known effective treatment is a lifelong gluten-free diet. While the disease is caused by a reaction to wheat proteins, it is not the same as wheat allergy (Di Sabatino & Corazza, 2009).

Incidence and Prevalence of Celiac Disease

According to the NFCA, One out of every 133 Americans has CD, equivalent to nearly 1% of the U.S. populations (NFCA, 2003). However, 95% of people with CD remain undiagnosed or misdiagnosed. This means that up to three million Americans across all races, ages, and gender suffer from CD and only about 200,000 are aware they have the condition (NFCA, 2003). The NFCA indicated that 17% of Celiac patients in the U.S. have an immediate family member who also has CD, that it may be as many as 10 years on average that a person has to wait to be correctly diagnosed, and that \$5,000-\$12,000 is the average cost of misdiagnosis per person per year, not including lost work time (NFCA, 2003).

The prevalence of clinically diagnosed CD (symptoms prompting diagnostic testing) was 0.05%–0.27% in various studies (Catassi et al., 1999). However, population studies from parts of Europe, India, South America, Australia and the USA (using serology and biopsy) indicated that the prevalence may be between 0.33%-1.06% in children and 0.18%–1.2% in adults (van Heel & West, 2006). People of African, Japanese and Chinese descent are rarely diagnosed; this reflects

a much lower prevalence of the genetic risk factors (Catassi et al., 1999). Population studies also indicated that a large proportion of persons with CD remain undiagnosed; this may be a result of many clinicians being unfamiliar with the condition (Zipser et al., 2005).

A large multi-center study in the U.S. found a prevalence of 0.75% in not-at-risk groups, rising to 1.8% in symptomatic patients, 2.6% in second-degree relatives of a patient with CD, and 4.5% in first-degree relatives (Fasano et al., 2003). This profile is similar to the prevalence in Europe (Fasano et al., 2003). Other populations at increased risk for CD, with prevalence rates ranging from 5% to 10%, include individuals with Down and Turner syndromes, Type 1 diabetes, and autoimmune thyroid disease, including both overactive and underactive thyroid (Barker & Liu, 2008).

Historically, CD was thought to be rare, with a prevalence of about 0.02% (Barker & Liu, 2008). Recent increases in the number of reported cases may be due to changes in diagnostic practice. Increasingly, there is evidence that CD may be becoming more common in the United States which would influence the propensity of physicians' ordering tests. However, tests may lose their usefulness if the patient is already following a gluten-free diet because intestinal damage begins to heal within weeks of gluten being removed from the diet and antibody levels decline over months (R. Bhushan, M.D., Personal Communication, January 10, 2011). For those who have already started on a gluten-free diet, it may be necessary to perform a re-challenge with 10 g of gluten (four slices of bread) per day over 2–6 weeks before repeating the investigations (R. Bhushan, M.D., Personal Communication, January 10, 2011). Those who experience severe symptoms (e.g. diarrhea) earlier can be regarded as sufficiently challenged and can be tested earlier (R. Bhushan, M.D., Personal Communication, January 10, 2011).

Symptoms of Celiac Disease

The condition has several other names, including CD (with *œ* ligature), c(o)eliac sprue, non-tropical sprue, endemic sprue, gluten enteropathy or gluten-sensitive enteropathy, and gluten intolerance (Losowsky, 2008). Classic symptoms of CD include abdominal distension, chronic diarrhea, vomiting, weight loss (or stunted growth in children), and fatigue (Fasano, 2009). However, these may be absent and symptoms in other organ systems may arise. A growing portion of diagnoses is being made in asymptomatic persons as a result of increased screening (van Heel & West, 2006). Some patients are diagnosed with symptoms related to the decreased absorption of nutrients or with various symptoms which, although statistically linked, have no clear relationship with the malfunctioning bowel (Di Sabatino & Corazza, 2009). Given this wide range of possible symptoms, the classic triad of causes, symptoms, and effects is no longer a requirement for diagnosis (Di Sabatino & Corazza, 2009).

Some individuals have persisting digestive symptoms or mouth ulcers, osteoporosis, and fractures (Faulkner-Hogg, Selby, & Loblay, 1999). Symptoms suggestive of irritable bowel syndrome may be present, and there is an increased rate of anxiety, fatigue, dyspepsia, and musculoskeletal pain (Faulkner-Hogg et al., 1999). Many people with CD also have one or more additional food allergies or food intolerances, which may include milk protein (casein), corn, and soy (Faulkner-Hogg et al., 1999). Genetically predisposed people of all ages from middle infancy onward are susceptible to the disease (van Heel & West, 2006). Children between nine and 24 months tend to show bowel symptoms and growth problems shortly after first exposure to gluten-containing products (van Heel & West, 2006). Older children may have more mal-absorption-related problems and psychosocial problems, while adults generally have problems

with absorption (van Heel & West, 2006). Many adults with subtle disease only have fatigue or anemia (van Heel & West, 2006).

Links with Other Medical/Health Conditions

CD has been linked with a number of medical/health conditions described below. In many cases, it is unclear whether the gluten-induced bowel disease is a causative factor or whether these conditions share a common predisposition (R. Bhushan, M.D. Personal Communication, January 10, 2011). Dr. Bhushan reported that IgA (an “anti-gluten” antibody) deficiency is present in 2% of patients with CD; in turn, the condition carries a tenfold increased risk of CD. Other features of this condition are an increased risk of infections and autoimmune disease.

Dermatitis herpetiformis: This itchy skin condition has been linked to an enzyme in the skin with small-bowel changes identical to those in CD and may respond to gluten withdrawal even if there are no gastrointestinal symptoms. It occurs more often (in 2%) in patients with CD (Marks, Shuster & Watson, 1966).

Neurological associations: Epilepsy, ataxia (coordination problems), myelopathy, peripheral neuropathy, and schizophrenia have all been linked with CD, but the strength of these associations and the causality are still subject to debate (R. Bhushan M.D., Personal Communication, January 10, 2011)

Growth failure and/or pubertal delay: In later childhood, issues can occur even without obvious bowel symptoms or severe malnutrition. Evaluation of growth failure often includes Celiac screening (Di Sabatino & Corazza, 2009).

Miscarriage and infertility: Recurrent miscarriage can occur as well as unexplained infertility (Di Sabatino & Corazza, 2009).

Hyposplenism (a small and underactive spleen): It is unclear whether this actually increases infection risk in the same way as in other people without a functioning spleen (Di Sabatino & Corazza, 2009).

Other autoimmune disorders: Diabetes Mellitus Type 1, Autoimmune Thyroiditis, Primary Biliary Cirrhosis, and Microscopic Colitis (R. Bhushan, M.D., Personal Communication, January 10, 2011).

Death: Individuals with CD are at a 40% increased risk of death. This risk increase has been seen in both adults and children. Risk increases have been shown for death from cancer and cardiovascular disease (R. Bhushan, M.D., Personal Communication, January 10, 2011).

Screening, Testing and Diagnosis of Celiac Disease

CD is insidious as it is an immune-mediated small bowel condition that exhibits only subtle extra-intestinal manifestations in a variety of organ systems. Therefore, diagnosis can be easy to miss (Devlin, Andrews & Beck, 2004). However, good laboratory screening tests and effective treatment are available. Family practitioners should consider CD in patients who present with confounding symptoms as candidates for further screening, testing, and diagnosis (Devlin, Andrews & Beck, 2004).

There is significant debate on the benefits of screening. Some studies suggested that early detection would decrease the risk of osteoporosis and anemia (van Heel & West, 2006). In contrast, a cohort study in Cambridge suggested that people with undetected CD had a beneficial risk profile (less overweight and lower cholesterol) for cardiovascular disease (van Heel & West, 2006). Due to its high sensitivity, serology (blood testing) has been proposed as a screening measure because the presence of antibodies would detect previously undiagnosed cases of CD and prevent its complications in those patients (American Gastroenterological Association,

2001). Serology may also be used to monitor adherence to diet as antibody levels remain elevated in those who still ingest gluten (Rewers, 2005).

In the United Kingdom, the National Institute for Health and Clinical Excellence (NICE) recommends screening for CD in patients with newly diagnosed chronic fatigue syndrome and irritable bowel syndrome. Other clinical scenarios in which screening may be justified include Type 1 Diabetes, unexplained iron-deficiency anemia, Down's syndrome, Turner's syndrome, Lupus, and Autoimmune Thyroid Disease (National Institute for Health and Clinical Excellence, 2009). It has been argued that higher rates of diagnosis and early diagnosis would benefit patients, the gluten-free foods industry, and the medical profession (NFCA, 2003).

A 2010 initiative by the Celiac Disease Research Center at Columbia University, headed by Dr. Peter Green, has reportedly diagnosed 2,400 people each year and is dedicated to increasing the rate of CD diagnosis in the United States, expecting that a higher rate of and more rapid diagnosis would lead to a higher rate of support for research on the disease and entrepreneurial efforts to increase public and industry awareness of the gluten-free/gluten sensitivity lifestyle. Support would translate into more grocery stores and restaurants offering gluten-free foods and gluten-free cooking to gluten-intolerant consumers, and increased government support through research grants for the study of CD as an autoimmune disease to research centers such as the Celiac Disease Research Center at Columbia University (Green, 2008).

A study conducted by members of the Celiac Disease Center at Columbia University Medical Center examined a large managed-care database to show reduced healthcare costs after the diagnosis of CD. The reductions were attributable to decreased trends in office visits, laboratory tests, diagnostic imaging, and endoscopy procedures in those diagnosed with the

disease (Green, 2008). The recommendation was for greater physician education in the various modes of presentation and manifestations of CD and more use of widely available screening blood tests that detect the disease (Green, 2008).

Serological blood tests are the first line of investigation required to make a diagnosis of CD. Professional guidelines recommend that a positive blood test be followed by an endoscopy/gastroscopy and biopsy (Hill, Dirks & Liptak, 2005). A negative blood test may still be followed by a recommendation for endoscopy and duodenal biopsy if clinical suspicion remains high due to the 1 in 100 "false-negative" result (Hill et al., 2005). As such, tissue biopsy is still considered the gold standard in the diagnosis of CD. An upper endoscopy with biopsy of the duodenum or jejunum is performed. It is important for the physician to obtain multiple samples (four to eight) from the duodenum (American Gastroenterological Association, 2001). Not all areas may be equally affected; if biopsies are taken from healthy bowel tissue, the result would be a false negative (American Gastroenterological Association, 2001). Most patients with CD have a small bowel that appears normal on endoscopy; however, five concurrent endoscopic findings have been associated with a high specificity for CD: scalloping of the small bowel folds, paucity in the folds, a mosaic pattern to the mucosa (described as a "cracked-mud" appearance), prominence of the sub mucosa blood vessels, and a nodular pattern to the mucosa (Niveloni et al., 1998).

Until the 1970s, biopsies were obtained using metal capsules attached to a suction device (Mee, Burke, Vallon, Newman, & Cotton, 1985). The capsule was swallowed and allowed to pass into the small intestine. After X-ray verification of its position, suction was applied to collect part of the intestinal wall inside the capsule (Mee et al., 1985). Often-utilized capsule systems were the Watson capsule and the Crosby-Kugler capsule. This method has now been

largely replaced by fiber-optic endoscopy, which has higher sensitivity and lower frequency of error (Mee et al., 1985).

The majority of the proteins in food responsible for the immune reaction in CD are the prolamins. Prolamins are found in cereal grains with different grains having different but related prolamins (van Heel & West, 2006). Gliadin in wheat is the best-understood member of this family, but other prolamins in barley and rye may contribute to CD. However, not all prolamins will cause this immune reaction, and there is controversy that the prolamins found in oats could induce this response in CD (van Heel & West, 2006).

Treatment of Celiac Disease

At present, the only effective treatment of CD is a life-long, gluten-free diet. Fortunately, if the disease is diagnosed early enough and patients stay on a gluten-free diet, it is highly likely that the architecture of the small intestine returns to normal, or close to it, and gastrointestinal symptoms disappear (Fasano, 2009). No medication exists that will prevent damage or prevent the body from attacking the small intestine when gluten is present (R. Bhushan, M.D., Personal Communication, January 10, 2011). Strict adherence to the diet allows the intestines to heal, leading to resolution of all symptoms in most cases, and depending on how soon the diet is begun, can also eliminate the heightened risk of osteoporosis and intestinal cancer (R. Bhushan, M.D., Personal Communication, January 10, 2011). In many countries, gluten-free products are available on prescription and may be reimbursed by health insurance plans. The diet can be cumbersome, but failure to comply may cause relapse.

A gluten-free diet can have a considerable impact on daily living. Understanding the factors associated with non-adherence is important in terms of supporting patients with their condition (R. Bhushan, M.D., Personal Communication, January 10, 2011). To investigate

factors associated with adherence to a gluten-free diet in adults with CD, a literature search of multiple electronic databases using a pre-determined search string for literature between 1980 and November 2007 identified 38 relevant studies which were included in the review. Rates for strict adherence ranged from 42% to 91% depending on definition and method of assessment and were the lowest among ethnic minorities and those diagnosed in childhood. Adherence was most strongly associated with cognitive, emotional, and socio-cultural influences, membership of an advocacy group, and regular dietetic follow-up (Charnock, Hall & Rubin, 2009). Screen and symptom-detected celiac patients did not differ in their adherence to a gluten-free diet (Charnock et al., 2009). It was concluded that the existing evidence for factors associated with non-adherence to a gluten-free diet is of variable quality. Further and more rigorous research was recommended to characterize those individuals most likely to be non-adherent to assist them better with their treatment (Charnock et al., 2009).

Studies of dietary compliance to a gluten-free diet have been conducted with patients and their families in different dimensions and for various purposes (Lee, Ng, Zivin & Green, 2007). While the number of such studies may be limited, they shed light on several issues that impact those individuals and/or families who live with CD.

One such gluten-free diet compliance study of 73 biopsy-confirmed CD children was conducted in an outpatient gastroenterology clinic of a children's hospital in Athens, Greece to evaluate their compliance or noncompliance, their knowledge about CD, as well their personal and parental well-being (Roma et al., 2010). The children ranged from 5 to 14.5 years (median age 9.4) with 58% reporting compliance. Reasons for non-compliance were poor palatability (32%), eating out (17%), poor availability of gluten-free products, and asymptomatic disease diagnosed by screening (11%) (Roma et al., 2010). Sixty five percent of patients reported good

acceptance of the gluten-free diet while 17% of the families reported hindrance in travel and 46% reported problems with eating at restaurants (Roma et al., 2010). Most families experienced difficulties detecting gluten from the food label. Suggestions to improve quality of life included better labeling of gluten-containing ingredients (76%), and more gluten-free foods in supermarkets (58%) and restaurants (42%) (Roma et al., 2010).

A second study of gluten-free dietary compliance of CD diagnosed children attending a pediatric ward in a hospital in India had the goal of identifying compliance barriers and evaluating psychosocial behavior of the children with a 35-item standard Pediatric Symptom Checklist (Chauhan, Kumar, Dutta, Basu & Kumar, 2010). Of the 64 children with complete assessments, dietary compliance was higher among younger children, children whose mothers were better educated and whose parents had knowledge and understanding of the disease, children from nuclear families, and children from families with higher incomes (Chauhan et al., 2010). School adjustment problems for persons with CD/GI included observing dietary restrictions at school and on field trips and a general lack of understanding of the disease among teachers. Psychosocial adjustment problems were more common among persons with CD/GI, including such things as pain, anger, irritability, non-observance of rules, blaming others, teasing, and refusing to share (Chauhan et al., 2010).

In a third study, conducted by Umea University, Sweden, researchers used adolescents and focus groups to collect data. The data were used to report the everyday life of persons with CD/GI and the underlying issues faced by them in complying with a gluten-free diet (Olsson, Hornell, Ivarsson & Sydner, 2008). Adolescents are notoriously non-compliant, but why this may be so and what their perceptions and experiences are in managing the disease and observing a gluten-free regimen are relatively unknown (Olsson et al., 2008). The results showed that

significant others of adolescent persons with CD/GI had insufficient knowledge of the disease, that gluten-free foods were not easily available, that gluten-free foods were not considered palatable, and that the needed social support was lacking (Olsson et al., 2008). The recommendations in this study included empowerment strategies for persons with CD/GI to optimize desired outcomes.

In yet another study conducted in Brazil, the goal was to determine if knowledge of CD and dietary compliance were related. The findings of the study with a sample of patients registered with the Brazilian Celiac Association showed that patients' knowledge of typical characteristics of the disease (i.e., a genetic predisposition, a permanent condition, and that gluten is a protein, found in wheat, rye, barley, and oats) was positively related to their dietary compliance (de Moraes, Fagundes-Neto & Sdepanian, 2001)

In the above-mentioned studies the samples included individuals diagnosed with CD in Greece, India, Sweden and Brazil. Methods used to gather data included focus groups, compliance surveys and pediatric checklists. All of the studies focused on dietary compliance. Barriers to noncompliance in the various countries included palatability, poor availability of gluten-free products, travel, eating out, the lack of knowledge of caregivers, school adjustment, and psychosocial factors.

The term gluten-free is generally used to indicate a supposed harmless level of gluten rather than a complete absence (Akobeng & Thomas, 2008). The exact level at which gluten is harmless is uncertain and controversial. A recent systematic review tentatively concluded that consumption of less than 10 mg of gluten per day is unlikely to cause histological abnormalities, although it noted that few reliable studies had been done (Akobeng & Thomas, 2008). Regulation of the label gluten-free varies widely by country. In the United States, the Federal

Drug Administration (FDA) issued regulations in 2007 limiting the use of "gluten-free" in food products to those with less than 20 parts per million (ppm) of gluten. The current international Codex Alimentarius standard allows for 20 ppm of gluten in so-called "gluten-free" foods. Gluten-free products are usually more expensive and harder to find than common gluten-containing foods (Lee et al., 2007). Since ready-made products often contain traces of gluten, some persons with CD may find it necessary to cook from scratch. Wheat varieties or subspecies containing gluten and related species, such as barley and rye, induce symptoms of CD. A small minority of Celiac patients also react to oats. It is most probable that oats produce symptoms due to cross contamination with other grains in the fields or in the distribution channel (Kupper, 2005). Generally, oats are not recommended, though gluten-free oats are available in some locales and may be tried with caution. Other cereals, such as maize (corn), quinoa, millet, sorghum, teff, amaranth, buckwheat, rice, and wild rice are safe for patients to consume.

Non-cereal carbohydrate-rich foods, such as potatoes and bananas, do not contain gluten and do not trigger symptoms (Di Sabatino & Corazza, 2009).

Various approaches are being studied that would reduce the need for dieting. All are still under development, and are not expected to be available to the general public for a while: for example, genetically engineered wheat species or wheat species that have been selectively bred to be minimally immunogenic; a combination of enzymes that would enable CD patients to consume gluten-containing products (Siegel et al., 2006).

The lack of classical medical research on CD focused on development of drugs and drug therapy regimens appears to rest on the notion that the prescription of a gluten-free diet is the best remedy currently available. Since medical research in the United States is largely driven by the pharmaceutical industry, there is no financial incentive to find a cure for CD. There is also

no International Statistical Classification of Disease (ICD) code for gluten sensitivity, which means that the World Health Organization (WHO) has not assigned a code number to gluten sensitivity which would then require that WHO would have to classify and monitor the disease and its symptoms for large scale tracking and study (Green, 2010).

Social and Religious Issues

There are many social and religious issues that arise in the life of the celiac. Most mainstream Christian churches offer their communicants gluten-free alternatives to the sacramental bread, usually in the form of a rice-based cracker or gluten-free bread. These include United Methodist, Christian Reformed, Episcopal, Lutheran, The Church of Jesus Christ of Latter-day Saints, and many others. Roman Catholic doctrine states that for a valid Eucharist, the bread must be made from wheat. In 2002, the Congregation for the Doctrine of the Faith approved German-made low-gluten hosts, which meet all of the Catholic Church's requirements, for use in Italy; although not entirely gluten-free, they were also approved by the Italian Celiac Association (Adams, 2002). Some Catholic celiac sufferers have requested permission to use rice wafers; such petitions have always been denied (Associated Press, 2004).

The issue is more complex for priests. Though a Catholic (lay or ordained) receiving communion under either form is receiving Christ "whole and entire"—his body, blood, soul, and divinity—the priest, who is acting *in persona Christi*, is required to receive under both species when offering Mass—not for the validity of his Communion, but for the fullness of the sacrifice of the Mass (Ratzinger, 2003). On August 22, 1994, the Congregation for the Doctrine of the Faith barred persons with CD/GI from ordination, stating, "Given the centrality of the celebration of the Eucharist in the life of the priest, candidates for the priesthood who are affected by CD or suffer from alcoholism or similar conditions may not be admitted to holy

orders”. However, the Church also recognized that one should proceed with due diligence in administering this ruling (Ratzinger, 2003). As of January 2004, an extremely low-gluten host became available in the United States. The Benedictine Sisters of Perpetual Adoration in Clyde, Missouri, produce low-gluten hosts safe for persons with CD/GI approved by the Catholic Church for use at Mass. The hosts are made and packaged in a dedicated wheat-free, gluten-free environment. Gluten-content analysis found no detectable amount of gluten, though the reported gluten content is 0.01% as that was the lowest limit of detection possible with the utilized analysis technique. In an article from the *Liturgy: Gluten-free hosts*, Dr. Alessio Fasano was quoted as declaring these hosts perfectly safe for celiac sufferers (McNamara, 2004).

The Jewish festival of Pesach (Passover) may present problems with its obligation to eat matzo, which is unleavened bread made in a strictly controlled manner from wheat, barley, spelt, oats, or rye (Adams, 2002). This preparation method does not allow for many other grains that are normally used as substitutes for people with gluten sensitivity, especially for Ashkenazi Jews, who also avoid rice. Many kosher-for-Passover products avoid grains altogether and are therefore gluten-free. Potato starch is the primary starch used to replace the grains. Consuming matzo is mandatory on the first night of Pesach only (Adams, 2002). Jewish law holds that a person should not seriously endanger one's health in order to fulfill a commandment. Thus, a person with severe CD is not required, or even allowed, to eat any matzo other than gluten-free matzo. The most commonly used gluten-free matzo is made from oats (Juravel, 2006).

Awareness of Celiac Disease

The premise of this study, as substantiated in the literature, is that the general public may not be aware that there is a disease such as CD and/or may have only minimal knowledge of the characteristics of the disease, such as the level of incidence and prevalence of the disease in the

general population, disease symptoms, preventive measures, and alleviation and treatment options. There are several reasons for this lack of awareness, including the fact that identification, confirmation, and treatment measures for the disease have only been discovered in the last three decades and there is severe under-diagnosis and/or misdiagnosis of the disease (R. Bhushan, M.D., Personal Communication, January 10, 2011). The relatively high incidence of CD in the U.S. (1 in 133 individuals), and its steady increase worldwide calls for publicity and dietary education initiatives directed at the public, increased medical profession sensitivity, multipronged research, and expansion of gluten-free food options to make the lives of persons with CD/GI less difficult (R. Bhushan, M.D., Personal Communication, January 10, 2011).

Due to the lack of awareness and knowledge of CD, instruments and tools to assess levels of knowledge should be developed and implemented. A sense of competence or self-efficacy is associated with many positive outcomes (Smith, Wallston, & Smith, 1995). A measure of a sense of competence in the domain of health behavior has not been developed (Smith et al., 1995). Strategies and activities to raise public awareness and assist people who have CD have been implemented. A few representative examples of awareness-raising and ameliorative strategies are cited below.

The mission of the two non-profit national organizations, CDF and NFCA, is to raise public awareness. A variety of activities and programs are undertaken by these organizations each year. These have been ongoing for over 15 years.

A long-time celiac patient, Margaret Walsh of San Francisco, started a campaign in 2006 with the five-year goal of raising \$1 million for increasing public awareness and providing support to persons with CD/GI (Meron, 2006).

Gluten-free food manufacturers and outlets offer a variety of innovative gluten-free products. L&J Popcorn, based in Chicago, offers three flavors of popcorn in Chicago-area food stores, is raising awareness and funds, and donates a portion of its profits to the University of Chicago Celiac Disease Center. Founder and Chief Popcorn Officer, Debbie Gordon, oversees ongoing tests for a gluten-free certified product to inspire customer confidence. Why test corn? “Because,” says Debbie “Gluten is hidden in a lot of things. Soy is okay, but soy sauce has wheat in it” (Egolf, 2010).

In 2006, a gluten-free cooking spree was organized by Drexel University School of Public Health and the NFCA. The event featured tasting of doctor and student-chef-made cuisine. Celebrity chefs, authors, and television personalities joined to promote the event. Highlighting the event, Drexel University School of Public Health’s home page remarked, “Celiac was once viewed by the medical community as a rare disease; only recently did the National Institutes of Health announce that it affects millions of people and the only real treatment is to follow a gluten-free diet. With new labeling laws in 2006 that require all food allergens to be disclosed...chefs need to present at least 4-5 meals that are celiac-friendly daily” (Drexel University, 2006).

The personal story of Alice Bast, Executive Director of the NFCA (Main Line Media News, 2010), is illustrative of the diagnostic conundrum of the celiac syndrome. She suffered multiple miscarriages and a full-term stillbirth as a result of undiagnosed celiac. On the occasion of the NFCA fundraiser “Appetite for Awareness” in December 2010, she reminisced, “For years I lived with unexplained symptoms...my symptoms got so bad my hair began falling out and teeth began chipping regularly...I thought I was dying of cancer! Many physicians overlooked my celiac disease...When our veterinarian suggested that maybe I had some sort of food

intolerance, she literally saved my life... A new gastroenterologist, my 23rd physician, suggested that I might have a rare autoimmune disease called Celiac Sprue...an endoscopy confirmed the diagnosis. I was elated. Finally – I did not have cancer, I wasn't dying and I wasn't crazy.” Bast went on a mission and founded the NFCA to help people obtain a prompt and accurate celiac diagnosis. Bast stated, “I wanted to help those diagnosed with celiac disease live happy, healthy, gluten-free lives.”

Only three studies were found in the literature on public awareness (one study) and physician awareness (two studies) of specific aspects of CD.

A Celiac Health Pilot Survey was conducted by the Ottawa Chapter of the Canadian Celiac Association (CCA) in 2003 to determine the feasibility of a national survey and to determine chapter members' knowledge of health-related information about CD. The success of the pilot survey encouraged the CCA to plan for a national survey. Survey information about the disease obtained from chapter members provided useful insights into public knowledge of the disease. With a 76% response rate from 414 Chapter members using the Modified Dillman's Total Design Method for Mail Surveys (Dillman, 1978), it was found that the mean age of survey participants was 55.5 years and the mean age at diagnosis was 45 years (Cranney, Zarkados, Graham & Switzer, 2003). The majority of patients had abdominal pain, diarrhea, fatigue, or weight loss. Prior to diagnosis, 30% of the participants consulted four or more family doctors. Thirty-seven percent of individuals were told they had either osteoporosis or osteopenia, and 45% reported that they found following a gluten-free diet very or moderately difficult. The quality of life of individuals with CD was comparable to the mean quality of life of Canadians. Other findings of interest were: 10% of first-degree relatives had been diagnosed with CD; 97% of individuals said they were instructed to follow a gluten-free diet with 78% stating that their

health improved a lot after starting a gluten-free diet; 64% noted a reaction if they accidentally consumed gluten – 79% reported diarrhea, 76% bloating, 66% abdominal pain, 37% extreme weakness or fatigue, and 27% nausea and vomiting (Cranney et al., 2003). The study concluded that important issues remained to be addressed: delays in diagnosis; awareness and follow-up of associated medical conditions; screening of first degree relatives for CD; improved training of health professionals including family physicians and nutritionists (Cranney et al., 2003).

Two studies were conducted with physicians to determine their awareness of CD. In the first study, a survey of 200 pediatricians, family practitioners, and endocrinologists conducted collaboratively by the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) and the Children's Digestive Health and Nutrition Foundation (CDHNF) revealed a lack of physician understanding about CD among children. The survey results supported the clear and urgent need to promote awareness of the individuals at risk, the associated conditions, the proper method of screening, and the necessary step of confirming the diagnosis with an intestinal mucosal biopsy. Regarding diagnosis, only 16% of the participants chose the most appropriate first line of serological screening, while a majority did not recognize the need for biopsy confirmation before starting patients on a gluten-free diet (PR Newswire, 2005). The results also suggested that up to 50% of individuals tested with an antibody test may not have had the disease at all, and may unnecessarily be recommended to consume a gluten-free diet, while others at risk were not being properly screened, identified, and placed on a gluten-free diet. Also of concern was the fact that less than 65% of the participants recognized that a life-long gluten-free diet had to be maintained (Celiac Disease and Gluten-Free Forum, 2005). Of further concern was the lack of awareness of associated conditions, such as Type 1 diabetes, and the necessity of screening first-degree relatives. Overall, the survey indicated the need to provide

medical professionals with as much information as possible about the disease (PR Newswire, 2005).

In a second study of physician awareness of CD, surveys completed by 2,440 patients in a support group were analyzed for frequency of diagnosis by physician specialties, and 132 questionnaires completed by PCPs were analyzed to assess their knowledge of CD. In the patient study, only 11% were diagnosed by PCPs (internists and family doctors) versus 65% by gastroenterologists. Physician surveys indicated that only 35% of PCPs had ever diagnosed CD. Almost all physicians knew of wheat intolerance, but few (32%) knew that the onset of symptoms in adulthood is common. Physicians were aware (90%) of diarrhea as a symptom, but fewer knew of other common symptoms or of associations with diabetes, anemia or osteoporosis or of antibody test diagnosis techniques (Zipser et al., 2005). The study concluded that lack of physician awareness of adult onset symptoms, associated disorders, and use of serology testing may contribute to under-diagnosis of CD (Zipser et al., 2005).

It can be concluded from the physician studies reported above that there is a general lack of awareness and diagnostic skill of GD/GI. The samples included were physicians and persons with CD. Methods used to gather data were survey instruments and questionnaires. Results indicated that there is a need for increased physician awareness and knowledge.

Summary of Literature Review

CD/GI is a medical condition that has a significant impact on an individual's HRQoL and QOL for several reasons. CD is a permanent inflammatory disease of the small intestine triggered by the ingestion of gluten-containing cereals in genetically predisposed individuals (Fasano, 2009). It is difficult to diagnose because its symptoms mimic those of common digestive ailments; therefore, it can be misdiagnosed or under diagnosed for a long period of

time, sometimes up to 10 years, during which time damage continues to affect the digestive and autoimmune systems.

Classic symptoms of CD include abdominal distension, chronic diarrhea, vomiting, weight loss (or stunted growth in children), and fatigue (Fasano, 2009). However, these may be absent and symptoms in other organ systems may arise. A growing portion of diagnoses is being made in asymptomatic persons as a result of increased screening (van Heel & West, 2006). The high incidence of CD/GI in the US; 1 in 133 individuals, (Fasano, 2009), in Europe; 1 in 130 to 300 people, (NFCA, 2003) and its steady increase worldwide calls for publicity and dietary education initiatives directed at the public, increased medical profession sensitivity, multipronged research, and expansion of gluten-free food options to make the lives of persons with CD/GI less difficult.

Needed confirmatory serological tests are, therefore, delayed or not done. This valuable information could help the general public and/or those affected by the disease to become more aware of and seek knowledge about it. The literature revealed that physician recommendations for screening and testing of suspected cases would lead to early diagnosis of CD/GI with a number of positive effects for patients and the medical community alike

As mentioned earlier, the only treatment for CD/GI is a gluten-free diet. It is encouraging to note that there is a large variety of gluten-free foods that are manufactured and marketed around the world. Therefore, persons with CD/GI have many food alternatives to enrich their diet and improve their QOL perceptions. Furthermore, the gluten-free foods industry chain from raw materials and ingredients to processing, cooking, packaging, marketing, and sales has been growing significantly and is reported to be of the order of \$12 billion by 2012.

The premise of this study, partially substantiated in the literature, is that the general public may not be aware that there is a disease such as CD/GI, and/or may have only minimal knowledge of the characteristics of the disease, such as the level of incidence and prevalence of the disease, disease symptoms, preventive measures, and alleviation and treatment options. There are several reasons for this lack of awareness, including the fact that identification, confirmation, and treatment measures for the disease have only been discovered in the last three decades, there is serious under-diagnosis and/or misdiagnosis of the disease, and there are other mitigating factors. The implications of this review of literature are that there is a lack of awareness and knowledge of CD/GI among patient populations and that there is a lack physician awareness, sensitivity and diagnostic skill.

CHAPTER 3

METHODOLOGY

Population and Sample

The target population for the study was defined as all clients who seek medical services in organized medical facilities in the southern United States. The accessible population was defined as all clientele who were established, regular clients of one medical clinic specializing in autoimmune disorders in a medium-sized city in a southern state of the United States. Under the circumstances prescribed for drawing the sample to collect data for the study, the accessible population also included adult(18 yrs or older) individuals who accompanied the patients when they visited the clinic for their regularly scheduled visit, if the date of their visit fell within the period designated by the researcher for data collection. According to the data collection plan, both regular patients and a person accompanying them, if the latter chose to participate, were provided with the survey instrument at the clinic's reception area, and requested to respond to the questions in the instrument. Furthermore, according to the data collection plan, a minimum of 400 surveys were to be distributed to clients/accompanying individuals. The minimum sample size for the study according to Cochran's formula for calculating sample size was 392.

Calculations are as follows:

$$n_o = \frac{t^2 (p)(q)}{d^2}$$
$$n_o = \frac{(1.98)^2 (.5)(.5)}{(.05)^2}$$
$$n_o = \frac{3.92 (.5)(.5)}{.0025}$$
$$n_o = \frac{(.98)}{.0025} = 392$$

where

t = risk that the researcher is willing to take that actual error exceeded acceptable error

p = proportion of the population in the category of interest (aware of CD/GI) (estimated to be 50%)

q = proportion of the population NOT in the category of interest ($1-p$) or 50%)

d = acceptable margin of error (5% or .05)

Details of the procedure followed are provided in the section on data collection.

Instrumentation

A researcher-designed survey instrument was developed to collect data from the designated study participants. Information and ideas useful in framing the questions which were included in the instrument were attained from the literature review, including the theory and practice behind medical and health aspects of the disease, sociological and psychological understandings and implications, and awareness and knowledge of Celiac Disease/Gluten Intolerance (CD/GI) in the general public and among medical professionals. The survey enabled the participants to provide desired demographic information and respond to questions eliciting their awareness of CD/GI and knowledge of CD/GI.

The survey instrument had four parts. Part I dealt with attention to personal health in seeing the participant's PCP and any physician; Part II included a question on whether clients had heard of CD/GI which would indicate awareness or lack of awareness; Part III consisted of a series of 30 statements about different aspects of CD/GI (nature of the disease, causes and symptoms, incidence and prevalence in adults and children, links with other medical conditions, and treatment options including consumption of gluten-free foods, and other aspects) which asked for the individual's level of agreement on a five-point Likert-type scale from strongly disagree to strongly agree as an indicator of their knowledge; and Part IV had questions to elicit

information regarding demographic characteristics of the sample – Age, Gender, Ethnicity, Marital Status, Whether or Not They had Children and Number of Children, Highest Level of Education, Occupation or Profession, Total Annual Family Income, and Distance Traveled from Home to Medical Facility.

In Part III the instrument which measured the level of Agreement-Disagreement with Knowledge statements about CD/GI, contained 12 negatively-worded statements out of the total of 30 statements in this section. This meant that disagreement (Strongly Disagree and Disagree) with the statements indicated that the participants knew that the statements were incorrect; therefore, by inference, had more knowledge about them. For sake of measurement consistency in the analysis, the response codes were Strongly Agree (1), Disagree (2), Agree (4), Strongly Agree (5) were coded as 5, 4, 2 and 1 respectively. The negatively-worded statements (including the item numbers) are listed below as they appear in the instrument:

Statement #3 CD/GI affects the bladder

Statement #6 CD/GI is a food allergy

Statement #8 Diagnosis of CD/GI requires that the individual has all symptoms

Statement #9 CD/GI affects only children

Statement #11 Adults with CD/GI experience only the symptom of fatigue

Statement #14 There is an effective medication that can be taken to treat CD/GI

Statement #19 CD/GI affects 1 in 5 Americans

Statement #22 Exercising daily will eliminate all the symptoms of CD/GI

Statement #23 People with CD/GI can eat foods with barley to avoid symptoms

Statement #25 If you test negative for CD/GI once, you will never get it

Statement #26 People who believe they have CD/GI should go on a Gluten-free diet before being tested

Statement #28 All people with CD/GI are underweight

The instrument was pilot-tested for face and content validity to ensure that the questions and statements were measuring the intended information. This was done by seeking confirmation from the (a) The Clinic's Medical Director, and (b) the researcher's Graduate Committee including three faculty members of the School of Human Resource Education and Workforce Development and one faculty member from the School of Social Work. Suggestions were made by the pilot-test group to modify the wording of certain questions, to make changes for removing ambiguity and improving clarity and precision of the knowledge statements, and incorporating additional questions on personal health into the instrument.

A copy of the survey instrument is at Appendix A. The researcher obtained the Institutional Review Boards' required approval for conduction of the study. A copy of the Approval Form is included in Appendix C.

Data Collection

The plan for collecting data was drawn up by the researcher in consultation with the facility's medical director and concerned staff including the Patient Services Representative and Clinical Staff members. It was decided that the most expeditious and feasible way to gather the information from clients was to get them to complete the survey when they registered with the Patient Services Representatives at the facility's front desk. This was done as they waited for their appointment time in the reception area. A clip board and pencil was given to each client with appropriate explanation of the purpose of the study, the request to participate in the study, and, if they agreed to comply, they were given the survey instrument and the instructions for its completion. Once they filled out the information, the Patient Services Representative or other designated staff member of the facility collected the completed survey and place it in a

predetermined area. Individuals (one or more adults) who accompanied clients on their visit day were offered the opportunity to participate in the survey. If they chose to do so, the clinic staff followed the same process as for clients. Both types represent the convenience sample for the purpose of this study and would be analyzed as a single group. The researcher, who works as the administrator of the facility, collected the completed surveys at the end of each day.

Data collection began on May 2, 2011 and was completed on May 13th, 2011. During this period of 14 days, 404 surveys were completed by clients and accompanying individuals. Data collection proceeded smoothly and according to plan.

CHAPTER 4

FINDINGS

CD/GI is a worldwide health problem, which, in the United States, has been reported to afflict 1% of the U.S. population, or three million Americans (NFCA, Handout, 2003).

Misdiagnosis and under diagnosis contribute to the long time, sometimes up to 10 years, it takes to confirm that an individual has the disease (NFCA, Handout, 2003). The disease is triggered when a protein, gluten, found in wheat and similar grains ingested in food, interacts with the body's genetically predisposed autoimmune system and a small intestine abnormality occurs which causes the body to exhibit the condition (NFCA, Handout, 2003).

Lack of public awareness and the difficulty experienced by physicians to correctly diagnose the disease by isolating it from other confounding conditions, exacerbates the situation for the general public and the medical community. While considerable research on the medical aspects of CD/GI has been done, this researcher could not find any definitive studies on the awareness and knowledge of the disease/condition among the general public. Therefore, this study was conducted to primarily address the research question "Is the convenience sample aware of and have knowledge of CD/GI?" A secondary research question was "Are awareness and knowledge among the convenience sample related to their demographic characteristics, and how much of the variance in knowledge can be explained by demographic characteristics?" Five objectives were stipulated, and appropriate methodology, was followed to achieve the stated objectives. This chapter presents the findings obtained from the study according to the objectives.

Objective 1

Describe the population of clients of a medical facility in the southern portion of the United States on selected demographic characteristics:

- a) Age
- b) Gender
- c) Ethnicity
- d) Marital Status
- e) Status and Number of Children
- f) Highest Education Level
- g) Occupation/Profession
- h) Annual Family Income
- i) Miles Traveled from Home to the Medical Facility
- j) Years since Last Physical Exam by participant's PCP
- k) Years since Last Seen by Any Physician

Age

Participants were described on the demographic characteristic age. Age was measured by asking the study participants to answer the question "What is your current age?" The ages of participants ranged from a low of 18 years to a high of 83. The mean age was 46.1 years (SD = 14.32). To further describe participants on their age, categories were created and the number and percentage of participants in each category were provided. The age categories established were 10 years in length each beginning at 18 years of age and continuing to "More than 65 years". The age category with the largest number of participants was the 46-55 year category (n = 92, 22.9%). The category of 18-25 years had the smallest number of participants (n = 31, 7.7%). Frequencies and percentages of participants in each age category are presented in Table 1.

Table 1**Age of Clients of a Medical Facility in the Southern Portion of the United States**

Age	n ^a	%
18-25 years	31	7.7
26-35 years	78	19.4
36-45 years	87	21.6
46-55 years	92	22.9
56-65 years	81	20.2
More than 66 years	33	8.2
Total	402 ^a	100.0

Note. Mean age = 46.1 years, SD = 14.32 years; minimum=18; maximum=83

^an = 402, Two participants did not respond to the item requesting age

Gender

Participants were described on their demographic characteristic gender. There were 305 females (75.5%) and 99 males (24.5%). Frequencies and percentages of participants in each gender category are presented in Table 2.

Table 2**Gender of Clients of a Medical Facility in the Southern Portion of the United States**

Gender	n	%
Female	305	75.5
Male	99	24.5
Total	404	100.0

Ethnicity

Participants were described on their demographic characteristic ethnicity. Ethnicity was measured by asking participants to choose a group in response to the question, “Which ethnic group do you identify with?” The options given included Caucasian, African-American,

Hispanic, Biracial, Native American, and Other. If participants chose “Other” they were asked to report the specific ethnic group with which they associated. The highest percentage of clients (71.5%, n=288) was in the Caucasian ethnic category and the second highest percentage (21.3%, n=86) was in the African-American ethnic category. The lowest percentage of participants were in the ethnic category Biracial (0.7%, n=3). Frequencies and percentages of participants in each ethnic category are presented in Table 3.

Table 3

Ethnicity of Clients of a Medical Facility in the Southern Portion of the United States

Ethnicity	n ^b	%
Caucasian	288	71.5
African-American	86	21.3
Asian	8	2.0
Hispanic	6	1.5
Native American	6	1.5
Other ^a	6	1.5
Biracial	3	.7
Total	403	100.0

^aEthnicities specified included French Cajuns (n=4), French heritage (Mulatto) (n=1), and Indian (n=1). ^b One participant did not respond to the item requesting ethnicity

Marital Status

Participants were described on their demographic characteristic marital status. The options given included Single (Never Married), Married, Divorced, Widowed and Separated. The highest percentage of participants (n=265, 65.6%) was in the Married category, and the second highest percentage (n=70, 17.3%) was in the Single category. The lowest percentage of

clients in the marital status category was Separated (n=8, 2.0%). Frequencies and percentages of participants in each marital status category are presented in Table 4.

Table 4

Marital Status of Clients of a Medical Facility in the Southern Portion of the United States

Marital Status	n	%
Married	265	65.6
Single (Never Married)	70	17.3
Divorced	50	12.4
Widowed	11	2.7
Separated	8	2.0
Total	404	100.0

Number of Children

Participants were described on their characteristic the number of children they have. The participants were asked “Do you have children” and “if yes, how many?” When asked if they had children, 301 (75.1%) said yes, and 100 (24.9%) said no. Three individuals did not respond to the question.

To the follow-up question to those who said they had children, 49 did not specify how many children they had. The number of children reported by participants who answered this question (n=252) were divided into the following categories; One Child, Two Children, 3-4 Children and 5-8 Children. The highest percentage of participants had Two Children (n=120, 47.6%). The next highest percentages of participants had 3-4 Children (n=69, 27.3%), and One Child (n=53, 21.0%). The lowest percentage of participants (n=10, 2.1%) reported having 5-8 Children. The mean number of Children reported was 2.2 Children and the standard deviation was 1.08. Frequencies and percentages of participants in each category are presented in Table 5.

Table 5**Number of Children Reported by Clients of a Medical Facility who Indicated they had Children in the Southern Portion of the United States**

Number of children	n	%
1	53	21.0
2	120	47.6
3-4	69	27.3
5	10	4
Total	252 ^a	100.0

Note. Mean number of Children = 2.2, SD =1.076

^a301 participants indicated that they had children, 49 of these did not specify the number of children

Highest Level of Education

Participants were described on their demographic characteristic highest level of education. The response categories for highest level of education were: Some High School, High school/GED, Some College, Associate Degree, Bachelors Degree, Masters Degree, Doctoral Degree and Other. The education level that was reported by the largest number of participants (n=119, 29.6%) was “Some College,” and the level that was reported by the second largest number (n=113, 28.1%) was “Bachelors Degree.” The education level that was reported by the smallest number of participants (n=9, 2.2%) was “Doctoral Degree.” Frequencies and percentages of participants in each education category are presented in Table 6.

Table 6**Highest Level of Education of Clients of a Medical Facility in the Southern Portion of the United States**

Highest Level of Education	n	%
Some High School	24	5.7
High School/GED	64	15.9

table cont.

Some College	119	29.6
Associate Degree	36	9.0
Bachelors Degree	113	28.1
Masters Degree	34	8.5
Doctoral Degree	9	2.2
Other ^a	3	1.0
Total	402 ^b	100.0

^aOther levels of education specified included; Masters + 30 (n=1); Graduate of three trade schools (n=1); Registered Nurse (n=1),

^bTwo participants did not respond to the item identifying Highest Level of Education

Total Annual Family Income

Participants were described on their characteristic total annual family income.

Participants were asked to indicate one of four categories which included: Less than \$25,000, \$25,000-\$49,999, \$50,000-\$74,999 and \$75,000 or more.

Table 7

Total Annual Family Income of Clients of a Medical Facility in the Southern Portion of the United States

Annual Family Income	n	%
Less than \$25,000	34	10.6
\$25,000-49,999	71	22.0
\$45,000-74,999	76	23.6
\$75,000 or more	141	43.8
Total	322	100.0

Note. Eighty-two participants did not respond to the item identifying total annual family income

The largest percentage of participants (n=141, 43.8%) reported a total annual income of \$75,000 or more. The smallest percentage of participants (n=34, 10.6%) reported a total annual income of

Less than \$25,000. Frequencies and percentages of participants in each income category are presented in Table 7.

Distance Traveled

Participants were described on their characteristic distance traveled in miles from their home to the medical facility. Four travel distance categories were provided for participants. They included: Less than 10 miles, 10-50 miles, 51-100 miles, and More than 100 miles. The majority of participants (n=242, 60.7%) traveled 51-100 miles to the Clinic from their home. The lowest percentage of participants (n=2, .5%) traveled more than 100 miles to the Clinic from their home. Frequencies and percentages of participants in each category are presented in Table 8.

Table 8

Distance Traveled from Home to a Medical Facility by Clients in the Southern Portion of the United States

Distance traveled (miles)	n	%
Less than 10	119	29.8
10-50	242	60.7
51-100	36	9.0
More than 100	2	0.5
Total	399 ^a	100.0

^a Five participants did not respond to the item identifying distance traveled.

Number of Years since Last Physical Exam by Participant's PCP

Participants were described on their demographic characteristic the number of years since their last physical exam by their PCP. This was measured by asking the participant "How long has it been since your last physical exam by your PCP?" The categories provided were: Less than a year, 1-3 years, 3-5 years and More than 5 years. The majority of participants (n=228, 56.4%) reported that the number of years since their last physical exam by their PCP was less than 1

year. The lowest percentage of clients (n=20, 5.0%) had a physical exam by their PCP from 3-5 years ago. Frequencies and percentages of participants in each category are presented in Table 9.

Table 9

Number of Years since Last Physical Exam by their PCP of Clients of a Medical Facility in the Southern Portion of the United States

Number of years since last physical exam by participant's PCP	n	%
Less than 1 year	228	56.4
1-3 years	134	33.2
3-5 years	20	5.0
More than 5 years	22	5.4
Total	404	100.0

Number of Years since Last Seen by Any Physician

Another characteristic on which the participants were described was the number of years since their Last Seen by Any Physician. This was measured by asking the participant "How long has it been since you have seen any physician?"

Table 10

Number of Years since Last Seen by Any Physician by Clients of a Medical Facility in the Southern Portion of the United States

Number of years since last visit any physician	n	%
Less than 1 year	358	88.6
1-3 years	37	9.2
3-5 years	7	1.7
More than 5 years	2	0.5
Total	404	100.0

The categories provided were: Less than a year, 1-3 years, 3-5 years and More than 5 years. The majority of participants (n=358, 88.6%) reported that it had been “Less than 1 year” since they had seen any physician. The response category that was reported by the smallest group of participants (n=2, 0.5%) was “More than 5 years.” Frequencies and percentages of participants in each category are presented in Table 10.

Participants Occupation/Profession

To identify the occupation/profession of participants, they were asked to respond to an open-ended question; “What is your current occupation or profession?” A total of 288 participants responded to this item. To summarize the data received in response to this question, the researcher examined each response and combined those that were clearly the same profession, ie. Lawyer/Attorney; Homemaker/Housewife and Manager/Administrator. After this procedure was completed 106 different occupations/professions were identified. The retired category had the largest number of participants.

Table 11

Ten Most frequently reported Occupations/Professions of Clients of a Medical Facility in the Southern Portion of the United States

Occupation/Profession	n	%
Retired	38	13
Sales	28	10
Housewife	24	8
Teacher	20	7
Manager	18	6
Student	14	5
Secretary	8	3
Self Employed	8	3
Private	7	2
RN	7	2
Total	172	59

Note. The distribution of 172 participants in the top 10 occupations/professions represents 59% of the sample. The listing of the occupations/professions of the remaining participants is shown in Appendix B.

The 10 occupations/professions that were most frequently reported are presented in Table 11. A complete list of occupations/professions of participants is shown in Appendix B.

Objective 2

Determine the awareness and knowledge of CD/GI among the population of clients of a medical facility in the southern portion of the United States.

This objective was analyzed for (a) Awareness of CD/GI, and (b) Knowledge of CD/GI among study participants.

To determine Awareness of CD/GI, at the beginning of the survey instrument, study participants were asked the question, “Have you ever heard of CD/GI?” If they answered “Yes,” they were classified as being aware of the disease, and if they answered “No,” they were classified as not being aware. One hundred eighty-nine participants (46.8%) responded that they had heard about the disease/condition, while 215 participants (53.3%) said they had not heard about the disease/condition.

Of those participants who said they had heard about the disease/condition, 104 of them (55.6%) indicated how they had heard about it, while 85 (44.4%) did not provide this information. The different ways in which participants heard about CD/GI are given below along with the respective number of participants.

How participants heard about CD/GI	Number of participants
Know people/friends who have CD/GI	39
Doctor/Nurse	16
Television	15
Relatives have CD/GI	9
Medical Clinic	7
Internet	6
School	6
Read in book/article/library	4
Health Food Store	1
Work	1
Total	104

Knowledge of CD/GI was obtained from study participants by asking those that answered that they had heard of CD/GI to indicate on a five-point Likert-type scale if they strongly agreed, agreed, did not know, disagreed, or strongly disagreed with 30 statements about CD/GI. The responses to each of the 30 items were analyzed for frequencies, means, and standard deviations to provide information on the extent of knowledge of CD/GI. An interpretive scale for the means was developed to assist the researcher in determining the extent to which the participants agreed or disagreed with individual statements. The scale was as follows:

Range of means	Interpretation
4.5 - 5.0	Strongly Agree (SA)
3.5 – 4.49	Agree (A)
2.51 – 3.49	Don't Know (DK)
1.51 - 2.50	Disagree (D)
1.0 – 1.50	Strongly Disagree (SD)

The level of agreement-disagreement of clients with the statements is shown in Table 12. These statements are ordered according to the highest to lowest mean. The two statements with the highest level of agreement had a mean greater than 4.0. These two statements were “CD/GI symptoms show up as a reaction to eating foods which contain gluten” (mean=4.26, SD=.865), and “Gluten-free products are becoming more available in supermarkets” (mean=4.10, SD=.723). Both of these items were classified in the “Agree” interpretive category. One statement had a mean less than 2.0, which was “CD/GI affects only children” (mean=1.95, .955). This item was classified in the “disagree” interpretive category. Overall, responses from participants were interpreted such that they “Agreed” with 12 items, were classified as “Don’t Know” for 14 of the items, and “Disagreed” with 4 items.

Table 12

Level of Agreement with CD/GI Statements among Clients Who Indicated that they were Aware of CD/GI Attending a Medical Facility in the Southern Portion of the United States

Statements	Level of Agreement ^a							Mean	SD	Int ^b
	Freq	SD	D	DK	A	SA	Tot			
#4 CD/GI symptoms show up as a reaction to eating foods which contain gluten	n	2	6	22	69	90	189	4.26	.87	A
	%	1.1	3.2	11.6	36.5	47.6	100.0			
#29 Gluten-free products are becoming more available in supermarkets	n	1	3	26	106	53	189	4.10	.72	A
	%	.5	1.6	13.8	56.1	28.0	100.0			
#21 Gluten is found in wheat flour	n	2	13	37	77	60	189	3.95	.94	A
	%	1.1	6.9	19.6	40.7	31.7	100.0			
#7 CD/GI symptoms may include chronic diarrhea, vomiting, fatigue and/or weight loss	n	0	4	50	91	44	189	3.93	.76	A
	%	0.0	2.1	26.5	48.1	23.3	100.0			
#1 Some people are genetically predisposed to CD/GI	n	0	7	71	71	40	189	3.76	.83	A
	%	0.0	3.7	37.6	37.6	21.2	100.0			
#5 Hair-like structures called villi in the small intestine lose their ability to digest food in persons with CD/GI	n	1	5	84	58	41	189	3.70	.86	A
	%	.5	2.6	44.4	30.7	21.7	100.0			
#17 Accurate diagnosis of CD/GI is often disguised by other medical conditions which mimic the disease	n	1	2	76	84	26	189	3.70	.74	A
	%	.5	1.1	40.2	44.4	13.8	100.0			
#27 People with CD/GI must eat a Gluten-free diet for the rest of their lives	n	2	8	82	69	28	189	3.60	.83	A
	%	1.1	4.2	43.4	36.5	14.8	100.0			
#18 A majority of physicians under-diagnose CD/GI	n	1	7	88	70	23	189	3.57	.77	A
	%	.5	3.7	46.6	37.0	12.2	100.0			
#2 CD/GI is a disorder of the autoimmune system	n	2	10	93	52	32	189	3.54	.87	A
	%	1.1	5.3	49.2	27.5	16.9	100.0			
#16 A gluten-free diet is the only effective treatment for CD/GI	n	2	21	73	63	30	189	3.52	.93	A
	%	1.1	11.1	38.6	33.3	15.9	100.0			
#30 Parents, siblings and/or children of confirmed CD/GI	n	1	2	102	66	18	189	3.52	.70	A
	%	.5	1.1	54.0	34.9	9.5	100.0			

table cont.

#20 Stressful events can trigger the onset of CD/GI	n	5	7	103	54	20	189	3.41	.83	DK
	%	2.6	3.7	54.5	28.6	10.6	100.0			
#12 There is an increased risk of other autoimmune diseases if one has been diagnosed with CD/GI	n	2	10	108	47	22	189	3.41	.80	DK
	%	1.1	5.3	57.1	24.9	11.6	100.0			
#6° CD/GI is a food allergy	n	8	35	46	77	23	189	3.38	1.1	DK
	%	4.2	18.5	24.3	40.7	12.2	100.0			
#13 CD/GI may be linked to an itchy skin condition	n	2	8	125	40	14	189	3.30	.71	DK
	%	1.1	4.2	66.1	21.2	7.4	100.0			
#10 Older children with CD/GI may have psychosocial problems (ex. Family problems, irritability, difficulties with peers)	n	7	12	114	36	20	189	3.26	.87	DK
	%	3.7	6.3	60.3	19.0	10.6	100.0			
#19° CD/GI affects 1 in 5 Americans	n	2	12	145	21	9	189	3.12	.63	DK
	%	1.1	6.3	76.7	11.1	4.8	100.0			
#15 CD/GI may be linked to various neurological diseases, such as Seizure Disorder	n	6	23	144	11	5	189	2.93	.64	DK
	%	3.2	12.2	76.2	5.8	2.6	100.0			
#3° CD/GI affects the bladder	n	14	23	122	25	5	189	2.92	.81	DK
	%	7.4	12.2	64.6	13.2	2.6	100.0			
#14° There is an effective medication that can be taken to treat CD/GI	n	12	36	104	31	6	189	2.91	.86	DK
	%	6.3	19.0	55.0	16.4	3.2	100.0			
#24 People with Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder should avoid a gluten-free diet	n	14	22	140	10	3	189	2.82	.72	DK
	%	7.4	11.6	74.1	5.3	1.6	100.0			
#23° People with CD/GI can eat foods with barley to avoid symptoms	n	12	42	111	17	7	189	2.81	.83	DK
	%	6.3	22.2	58.7	9.0	3.7	100.0			
#26° People who believe they have CD/GI should go on a Gluten-free diet before being tested	n	23	33	108	21	4	189	2.74	.89	DK
	%	12.2	17.5	57.1	11.1	2.1	100.0			
#8° Diagnosis of CD/GI requires that the individual has all symptoms	n	31	60	73	17	7	188	2.52	1.0	DK
	%	16.5	31.9	38.8	9.0	3.7	100.0			

table cont.

#25 ^c If you test negative for CD/GI once, you will never get it	n	29	54	94	6	6	189	2.50	.90	DK
	%	15.3	28.6	49.7	3.2	3.2	100.0			
#28 ^c All people with CD/GI are underweight	n	36	58	78	12	5	189	2.43	.96	D
	%	19.0	30.7	41.3	6.3	2.6	100.0			
#11 ^c Adults with CD/GI experience only the symptom of fatigue	n	41	61	67	14	6	189	2.38	1.0	D
	%	21.7	32.3	35.4	7.4	3.2	100.0			
#22 ^c Exercising daily will eliminate all the symptoms of CD/GI	n	38	74	67	7	3	189	2.28	.88	D
	%	20.1	39.2	35.4	3.7	1.6	100.0			
#9 ^c CD/GI affects only children	n	72	70	36	7	4	189	1.95	.96	D
	%	38.1	37.0	19.0	3.7	2.1	100.0			

^aResponse scale: 5=Strongly Agree (SA), 4=Agree (A), 3=Don't Know (DK), 2=Disagree (D), 1=Strongly Disagree (SD)

^bInterpretive Scale. This column is an interpretation of the mean on the agreement-disagreement response scale for each item using the following interpretive scale: 4.51-5.0=Strongly Agree (SA); 3.51 – 4.50=Agree (A); 2.51 – 3.50=Don't Know (DK); 1.51 – 2.50=Disagree (D); 1 – 1.50=Strongly Disagree (SD).

^cNegatively worded statements in the instrument

Objective 3

Determine if identifiable sub-scales exist in the instrument designed to measure the knowledge of CD/GI among clients of a medical facility in the southern portion of the United States.

Information used to accomplish this objective was drawn from the section of the survey in which participants who reported that they had heard of CD/GI were asked to identify the level of knowledge of 30 items describing various aspects of CD/GI. Responses were reported on a five-point Likert-type scale ranging from “Strongly Disagree” to “Strongly Agree.” To accomplish this objective, the researcher used factor analysis to determine if underlying constructs could be identified in the scale.

The first step in conducting the factor analysis was to determine the optimum number of factors to be extracted from the scale. An initial factor analysis was conducted to assist in accomplishing this task. This analysis utilized principal component analysis with varimax

rotation of the factors. A combination of latent root criterion, scree test criterion, and the percentage of variance criterion was used to determine the most appropriate number of factors to be extracted from the data. These criteria led the researcher to identify the number of factors as four, five or six. Each of these models was subsequently examined. The six factor model was eliminated because some of the factors included only a small number of items (two and three) and the amount of variance explained by the last two factors was less than 5.0%.

When the five factor solution was examined, several of the items were found to have substantial cross-loadings, and the percentage of variance explained by the fifth factor was below the 5.0% threshold. Additionally, for two of the factors, the researcher was unable to identify clear content theme for the items that were grouped together. The four factor model was selected due to the clarity of the connection among the items in the factors formed, the fact that each of the four factors met the criterion of explaining at least 5% of the scale variance, and the strength of the loadings of the items in each factor including the low number of substantial cross-loadings (see Table 13).

Cronbach's alpha was used as a measure of internal consistency or reliability of the researcher's instrument. Alpha coefficients range in value from 0 to 1 and may be used to describe the reliability factors extracted from multi-point formatted questionnaires or scales. The higher the score, the more reliable the generated scale is. Nunnally (1978) has indicated 0.7 to be an acceptable reliability coefficient. A commonly accepted rule of thumb for describing internal consistency using Cronbach's alpha is as follows: (Cronbach et al., 2004)

$\alpha \geq .9$	Excellent
$.9 > \alpha \geq .8$	Good
$.8 > \alpha \geq .7$	Acceptable
$.7 > \alpha \geq .6$	Questionable
$.6 > \alpha \geq .5$	Poor
$.5 > \alpha$	Unacceptable

Table 13**Rotated Component Matrix Showing Factor Loadings for the Factor Analysis of the Knowledge of CD/GI:**

Item	Factor 1	Factor 2	Factor 3	Factor 4
#30	.782			
#1	.689			
#12	.598			
#10	.528			
#29	.503			
#17	.470			
#2	.461		.410	
#13	.401			
#5	.360			
#9		.692		
#25		.687		
#8		.616		
#26		.595		
#28		.563		
#22 ^a		.532	.424	
#11		.462		
#23 ^b		.272		
#16			.759	
#7			.550	
#14			-.539	
#27			.503	
#4			.462	
#18			.452	
#21			.384	
#15				.634
#19				.558
#20				.545
#6				.541
#24				.501
#3				.388

Note. Only Cross-Loadings greater than .35 are included in Table 13

Note. Eigenvalues and % of Variance for the factors are Factor 1: ev=5.579, %v=18.598; Factor 2: ev=2.875, %v=9.582; Factor 3: ev=2.116, %v=7.052; Factor 4: ev=1.689, %v=5.629

^aStatement #22 loaded on two factors, Factor 2 (Factor Loading = .532) and Factor 3 (Factor Loading = .424). Although Factor Loading of this statement was higher for Factor 2 identified as Subscale Symptomology, the statement was included in Factor 3 identified as Subscale Treatment, because its content made it a better fit in Factor 3.

^bStatement #23 had a Factor Loading of .272, below the predetermined criterion of .35; hence it was excluded from Factor 2.

The first factor labeled by the researcher as Diagnosis contained nine items. The Diagnosis subscale score suggests an overall assessment of an individual's physical, mental and emotional well-being. The Diagnosis subscale mean was 3.59 with a standard deviation of .47. The Diagnosis subscale reliability as measured by Cronbach's alpha was .78. This indicates that this subscale is reliable. The item means and standard deviations for the Diagnosis subscale are shown in Table 14. The item "Gluten-free products are becoming more available in supermarkets" had the highest mean of 4.10, (SD= .72).

Table 14

Statements Loading on Factor 1 Diagnosis Subscale for the Factor Analysis of the Knowledge of CD/GI

Factor 1: Diagnosis	Mean ^a	SD
#29 Gluten-free products are becoming more available in supermarkets	4.10	.72
#1 Some people are genetically predisposed to CD/GI	3.76	.83
#17 Accurate diagnosis of CD/GI is often disguised by other medical conditions which mimic the disease	3.70	.74
#5 Hair-like structures called villi in the small intestine lose their ability to digest food in persons with CD/GI	3.70	.86
#2 CD/GI is a disorder of the autoimmune system	3.54	.87
#30 Parents, siblings and/or children of confirmed CD/GI patients are at higher risk of the disease	3.52	.70
#12 There is an increased risk of other autoimmune diseases if one has been diagnosed with CD/GI	3.41	.80
#13 CD/GI may be linked to an itchy skin condition	3.30	.71
#10 Older children with CD/GI may have psychosocial problems (ex. Family problems, irritability, difficulties with peers)	3.26	.87

Note. Cronbach's Alpha: .78

^aOverall Mean=3.59

The item “Older children with CD/GI may have psychosocial problems (ex. Family problems, irritability, and difficulties with peers)” had the lowest mean of 3.26, (SD=.87).

The second factor identified as Symptomology subscale contained six items.

Symptomology suggests symptoms and related conditions associated with CD/GI which can be exhibited in physical, mental and emotional ways. The Symptomology subscale mean was 3.52 with a standard deviation of .55.

Table 15

Statements Loading on Factor 2 Symptomology Subscale for the Factor Analysis of the Knowledge of CD/GI

Factor 2: Symptomology	Mean ^a	SD
#9 ^b CD/GI affects only children	4.05	.96
#11 ^b Adults with CD/GI experience only the symptom of fatigue	3.63	.99
#28 ^b All people with CD/GI are underweight	3.56	.98
#25 ^b If you test negative for CD/GI once, you will never get it	3.49	.90
#8 ^b Diagnosis of CD/GI requires that the individual has all symptoms	3.48	1.0
#26 ^b People who believe they have CD/GI should go on a Gluten-free diet before being tested	3.27	.89

Note. Cronbach’s Alpha: .70

^aOverall Mean=3.52

^b Negatively worded statements on the instrument, coding was reversed for computation of factor subscale scores

The Symptomology subscale reliability as shown by Cronbach’s alpha was .70. This indicates minimum value for gauging reliability. The item means and standard deviations for

Symptomology subscale are shown in Table 15. The item “CD/GI affects only children” had the highest mean of 4.05 with a standard deviation of .96. The item “People who believe they have

CD/GI should go on a Gluten-free diet before being tested” had the lowest mean of 3.27 with a standard deviation of .89.

The third factor identified as Treatment subscale contained eight items. Treatment for CD/GI is currently identified as a strict gluten-free diet. The Treatment subscale mean was 3.71 with a standard deviation of .49.

Table 16

Statements Loading on Factor 3 Treatment Subscale for the Factor Analysis of the Knowledge of CD/GI

Factor 3. Treatment	Mean ^a	SD
#4 CD/GI symptoms show up as a reaction to eating foods which contain gluten	4.26	.87
#21 Gluten is found in wheat flour	3.95	.94
#7 CD/GI symptoms may include chronic diarrhea, vomiting, fatigue and/or weight loss	3.93	.76
#22 ^b Exercising daily will eliminate all the symptoms of CD/GI	3.72	.88
#27 People with CD/GI must eat a Gluten-free diet for the rest of their lives	3.60	.83
#18 A majority of physicians under-diagnose CD/GI	3.57	.78
#16 A gluten-free diet is the only effective treatment for CD/GI	3.52	.93
#14 ^b There is an effective medication that can be taken to treat CD/GI	3.09	.86

Note. Cronbach’s Alpha: .70

^aOverall Mean=3.71

^bNegatively worded statements on the instrument, coding was reversed for computation of factor subscale scores

The Treatment subscale reliability as shown by Cronbach’s alpha was .70. This indicates minimum value for gauging reliability. The item means and standard deviations for the Treatment subscale are shown in Table 16. The item “CD/GI symptoms show up as a reaction to eating foods which contain gluten” had the highest mean of 4.26 with a standard deviation of .87.

The item “There is an effective medication that can be taken to treat CD/GI” had the lowest mean of 3.09 with a standard deviation of .86.

The fourth factor identified as Interactions with Other Conditions subscale contained six items. Interactions with other conditions suggest that CD/GI can be linked to other disorders and can affect an individuals’ overall well-being. The Interactions with Other Conditions subscale mean was 3.10 with a standard deviation of .44. The Interaction with Other Conditions subscale reliability as shown by Cronbach’s alpha was .56. This indicates that the subscale is not reliable.

Table 17

Statements Loading on Factor 4 Interactions with Other Conditions for the Factor Analysis of the Knowledge of CD/GI

Factor 4: Interaction w/ Other Conditions	Mean ^a	SD
#20 Stressful events can trigger the onset of CD/GI	3.41	.83
#3 ^b CD/GI affects the bladder	3.08	.81
#15 CD/GI may be linked to various neurological diseases, such as Seizure Disorder	2.93	.64
#19 ^b CD/GI affects 1 in 5 Americans	2.88	.63
#24 People with Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder should avoid a gluten-free diet	2.82	.71
#6 ^b CD/GI is a food allergy	2.62	1.05

Note. Cronbach’s Alpha: .56

^aOverall Mean=3.10

^bNegatively worded statements on the instrument, coding was reversed for computation of factor subscale scores

The item means and standard deviations for Interactions with Other Conditions subscale are shown in Table 17. The item “Stressful events can trigger the onset of CD/GI” had the highest mean of 3.41 with a standard deviation of .83. The item “CD/GI is a food allergy” had the lowest mean of 2.62 with a standard deviation of 1.05.

Objective 4

Determine the relationship between the awareness and knowledge of CD/GI and the following selected demographic characteristics among clients of a medical facility in the southern portion of the United States:

- a) Age
- b) Gender
- c) Ethnicity
- d) Marital Status
- e) Number of Children
- f) Highest Education Level
- g) Occupation/Profession
- h) Annual Family Income
- i) Distance Traveled from Home to Medical Facility
- j) Years since Last Physical Exam by participant's PCP
- k) Years since Last Seen by Any Physician.

Awareness and Demographic Characteristics

Participants were asked if they had ever heard of CD/GI. If participants had not heard of the disease then they were coded as 0, and if they had heard of the disease then they were coded as 1. Thus awareness was measured in this study as a dichotomous variable with 0 indicating lack of awareness and 1 indicating awareness. The statistical procedure selected to determine if a relationship existed with selected demographic characteristics was based on the most appropriate and most interpretable procedure for each of the independent variables. Davis (1971) has provided a scale to enable researchers to interpret simple linear correlation coefficients. The scale considers the magnitude of the correlation coefficients ranging from -1.0

to +1.0 and assigns interpretive labels to them. The interpretive scale developed by Davis (1971) for the correlation coefficients obtained in the analysis is as follows.

<u>Correlation Coefficient</u>	<u>Interpretation</u>
.01-.09	Negligible
.10-.29	Low
.30-.49	Moderate
.50-.69	Substantial
.70 or greater	Very Strong

The researcher will use Davis' (1971) interpretation scale in assessing the strength of the association reflected in the correlation coefficients reported in the study.

Age

The first demographic characteristic examined for its relationship with Awareness of CD/GI was the age of the participant. The relationship between these variables was measured using the Point Biserial Correlation Coefficient. The calculated correlation was $r = .01$ ($p = .79$); therefore, no statistically significant relationship was found between Awareness of CD/GI and Age.

Gender

Another demographic characteristic that was examined for its relationship to Awareness of CD/GI was gender. Since both of these variables were dichotomous (Awareness - not aware = 0; aware = 1; Gender - female = 1, male = 2), the Chi-Square Test of Independence was used to measure this relationship. The resulting statistic (Chi-Square = 2.603, with 1 degree of freedom, $p = .107$) indicated that Awareness of CD/GI and Gender were independent.

Ethnicity

Another characteristic which was examined for a relationship with Awareness of CD/GI was ethnicity of the study participants. Ethnicity was measured as a categorical variable with seven categories including: Caucasian, African-American, Hispanic, Biracial, Native American,

Asian/Pacific Islander and Other. The Chi-Square Test of Independence was judged to be the most appropriate procedure for examining the relationship between these variables. However, when the Chi-Square was computed 10 of the 14 cells in the 2x7 cross-tabulation table were found to have expected frequencies of less than five. Since the maximum number of cells with expected frequencies of less than five in a Chi-Square Test of Independence is 25% (in this case 3.5), this analysis was judged to be unacceptable.

The researcher's alternatives for addressing this analysis problem were to either eliminate the categories of the ethnicity variable with low frequencies or to collapse cells of the ethnicity variable into a smaller number of categories. In this situation, the researcher chose to eliminate all cells with total frequencies of less than 10. Therefore, the only categories of ethnicity that were included in the analysis were Caucasian and African-American. When the Chi-Square Test of Independence was conducted with the revised ethnicity variable, the resulting statistic ($X^2 = 20.425$, $p < .001$) indicated that the variables ethnicity (defined as Caucasian or African-American) and Awareness of CD/GI (defined as aware or not aware) were not independent.

Table 18

Cross-tabulation of Awareness of CD/GI and Ethnicity among Clients of a Medical Facility in the Southern Portion of the United States

Aware	Caucasian	African-American	Total
Yes n	167	26	193
%	58.0	30.2	51.6
No n	121	60	181
%	42.0	69.8	48.4
Total n	288	86	374
%	100.0	100.0	100.0

Note. Chi-Square = 20.425, $p < .001$

The nature of the association between the variables can be seen by examining the contingency table presented in Table 18. The majority of the Caucasian participants in the study (58%) indicated that they were aware of CD/GI while a majority of the African-American participants in the study (69.8%) indicated that they were not aware of CD/GI (see Table 18).

Marital Status

Another characteristic that was examined for a relationship with awareness of CD/GI was Marital Status of the study participants. Marital status was measured as a categorical variable with five categories which included: Single (Never Married), Married, Divorced, Widowed and Separated. The Chi-Square Test of Independence was judged to be the most appropriate procedure for examining the relationship between these variables. When the Chi-Square was computed the resulting statistic (Chi-Square = 12.287, with 4 degrees of freedom, $p = .015$) indicated that the variables Marital Status and Awareness of CD/GI were found to be not independent.

Table 19

Cross-tabulation of Awareness of CD/GI and Marital Status among Clients of a Medical Facility in the Southern Portion of the United States

Aware		Single (Never Married)	Married	Divorced	Widowed	Separated	Total
Yes	n	30	151	22	4	1	208
	%	42.9	57.0	44.0	36.4	12.5	51.5
No	n	40	114	28	7	7	196
	%	57.1	43.0	56.0	63.6	87.5	48.5
Total	n	70	265	50	11	8	404
	%	100.0	100.0	100.0	100.0	100.0	100.0

Note. Chi-Square = 12.287, $p = .015$

The nature of the association between the variables can be seen by examining the contingency table presented in Table 19. The majority of the married participants indicated that they were aware of CD/GI whereas, a majority of the participants in the Single (Never Married) (57.1%), Divorced, (56.0%), Widowed, (63.6%), and Separated (87.5%) categories were not aware of CD/GI. (See Table 19).

Children

Another characteristic that was examined for a relationship with Awareness of CD/GI was whether or not the study participants had children. Whether or not participants had children was measured as a categorical variable which included: Yes – have children or No – do not have children. The Chi-Square Test of Independence analysis was judged to be the most appropriate procedure for examining the relationship between these variables. The resulting Chi-Square statistic of $\chi^2 = .906$, ($p = .341$) indicated that there was no relationship between Awareness of CD/GI and whether or not participants had children.

Number of Children

Those participants reporting that they had children were asked to specify how many children they had. The relationship between awareness of CD/GI and number of children was analyzed using the Point Biserial Correlation Coefficient. The resulting statistic was determined to be $r = .02$ which was not statistically significant ($p = .775$).

Highest Level of Education

Another characteristic which was examined for a relationship with awareness of CD/GI was Highest Level of Education of the study participants. Highest Level of Education was measured as an ordinal variable with seven levels including: Some High School, High School/GED, Some College, Associates Degree, Bachelors Degree, Masters Degree, Doctoral

Degree. The participants who indicated “Other” for Highest Level of Education ($n = 4$) were eliminated from the analysis, since a clear indication of the nature of their education level was not available. The Spearman’s Rank Correlation Coefficient was judged to be the most appropriate procedure for examining the relationship between the awareness of CD/GI and Highest Level of Education. The resulting statistic, $r_{\text{rho}} = .26$ ($p < .001$), was statistically significant. This result indicated that there is a positive relationship between awareness of CD/GI and Highest Level of Education. The nature of this relationship was such that participants with higher levels of education tended to be aware of CD/GI more so than those with lower levels of Education. According to Davis (1971), there was a “Low” association between Highest Level of Education and Awareness.

Total Annual Family Income

Another characteristic which was examined for a relationship with awareness of CD/GI was total annual family income of the study participants. Total Annual Family Income was measured as an ordinal variable with four categories which included: Less than \$25,000, \$25,000-\$49,999, \$50,000-\$74,999, \$75,000 or more. The Spearman’s Rank Correlation Coefficient was judged to be the most appropriate procedure for examining the relationship between the awareness of CD/GI and total annual family income. The resulting statistic, $r_{\text{rho}} = .20$ ($p < .001$), was statistically significant. This result indicated that there is a positive relationship between awareness of CD/GI and total annual family income. Participants who report higher income tended to report being aware of CD/GI more so than those with lower levels of income. According to Davis (1971), there was a “Low” association between Total Family Income and Awareness.

Distance Traveled

Another characteristic which was examined for a relationship with Awareness of CD/GI was the number of miles traveled by the study participants from their home to the clinic. Distance traveled was measured as an ordinal variable with four categories which included: Less than 10 miles, 11-50 miles, 51-100 miles, More than 100 miles. The Spearman's Rank Correlation Coefficient was judged to be the most appropriate procedure for examining the relationship between the Awareness of CD/GI and Distance Traveled from the participants' home to the medical facility. The resulting statistic, was $r_{\text{rho}} = .06$ ($p = .211$), was not statistically significant. This result indicated that there is a no relationship between awareness of CD/GI and the distance that the participants traveled from their homes' to the medical facility.

Years since Last Physical Examination by the Participant's PCP

Another characteristic which was examined for a relationship with Awareness of CD/GI was "Years since Last Physical Exam by the participant's PCP". This demographic was measured as an ordinal variable with four categories, which included: Less than 1 Year, 1-3 Years, 3-5 Years, and More Than 5 Years. The Spearman's Rank Correlation Coefficient was judged to be the most appropriate procedure for examining the relationship between the Awareness of CD/GI and Years since Last Physical Exam by their PCP. The resulting statistic, $r_{\text{rho}} = .10$ ($p = .043$), was statistically significant. The nature of this relationship was such that, participants that reported more years since their Last Physical Exam by their PCP tended to be aware of CD/GI more so than those who reported less years since their Last Physical Exam by their PCP. According to Davis (1971), there was a "Low" association between Years since Last Physical Examination by the Participant's PCP and Awareness.

Years since Last Seen by Any Physician

Another variable measured, “Years since Last Seen by Any Physician” was measured as an ordinal variable with four categories, which included: Less than 1 Year, 1-3 Years, 3-5 Years, and More Than 5 Years. Due to low numbers in the categories 3-5 years and More than 5 years, these two categories were combined with the Category 1-3 years and renamed “One-year or More.” The Chi-Square test of independence was judged to be the most appropriate procedure for examining the relationship between the Awareness of CD/GI and Years since Last Seen by Any Physician. The resulting Chi-Square, ($\chi^2 = .707$, 1 df, and $p = .40$) indicated that the variables, Awareness of CD/GI and Years since Last Seen by Any Physician were independent.

Knowledge and Demographic Characteristics

Knowledge of CD/GI was identified in Objective 3 through factor analysis to have four knowledge subscales, and one Overall Knowledge Score (Knowledge Subscale/score). These were identified as Symptomology subscale, Diagnosis subscale, Treatment subscale, Interactions with Other Conditions subscale.

Age

To examine the relationships between Age and Knowledge of CD/GI, the researcher used the Pearson Product Moment Correlation Coefficient to determine relationships between the variable, Age, and each of the Knowledge scores. As shown in Table 20, there were no statistically significant correlations between Age and the Knowledge scores.

Table 20

Relationship between Age and Knowledge of CD/GI among Clients of a Medical Facility in the Southern Portion of the United States

Knowledge Scores	r^a	n	p	DD ^b
Treatment	-.12	187	.10	Low
Interaction w/ Other Conditions	.09	187	.22	Negligible

table cont.

Overall Knowledge Score	-.05	187	.47	Negligible
Symptomology	-.04	187	.60	Negligible
Diagnosis	-.001	187	.96	Negligible

^a Pearson Product Moment Correlation Coefficient

^b Interpretation Scale (Davis, 1971): .01-.09= negligible, .10-.29=low, .30-.49=moderate, .50-.69=substantial, .70 or greater=very strong.

Gender

The next demographic characteristic which was used to examine relationships with the Knowledge subscales/score was Gender. Since gender is a nominal, dichotomous variable, the analysis that was determined to be most appropriate was the Independent t-test. This was selected to maximize the ease of interpretation of test results for comparison of knowledge of CD/GI by Gender. The Levene's Test for Equality of Variances was used to test the assumption of homogeneity of variance. None of the F values for these tests were significant; therefore, the t-tests calculated assuming equal variances were used. The t-values and probability levels obtained from this analysis are shown in Table 21.

Table 21

Comparison of Knowledge of CD/GI by Gender among Clients of a Medical Facility in the Southern Portion of the United States

Knowledge Scores	Gender	n	Mean	SD	t	df	Sig(2-tailed)
Overall Knowledge	Female	150	3.50	.37	2.863	187	.01
	Male	39	3.31	.35			
Symptomology	Female	150	3.64	.61	2.521	187	.01
	Male	39	3.37	.53			
Treatment	Female	150	3.75	.49	2.361	187	.02
	Male	39	3.54	.47			
Diagnosis	Female	150	3.60	.49	.510	187	.61
	Male	39	3.55	.42			
Interaction w/ Other Conditions	Female	150	2.96	.29	.179	187	.86
	Male	39	2.95	.26			

The means for the Overall Knowledge Score, Symptomology subscale score, and Treatment subscale score were statistically significantly different by categories of gender. In all cases, where comparisons were significant, the mean knowledge score for females was higher than the mean knowledge score for males (See Table 21).

Ethnicity

The next demographic characteristic which was examined for relationships with Knowledge of CD/GI subscales/score was Ethnicity. Due to low numbers of participants in the ethnic categories, Hispanic, Biracial, Native American, Asian/Pacific Islander, and Other, these categories were excluded from the analysis. Therefore, only Caucasian and African-American categories were used. The analysis that was determined to be most appropriate was the Independent t-test. This was selected to maximize the ease of interpretation of test results for comparison of knowledge of CD/GI by Ethnicity. The Levene's Test for Equality of Variances was used to test the assumption of homogeneity of variance. None of the F values for these tests was significant; therefore, the t-test calculated assuming equal variance was used.

Table 22

Comparison of Knowledge of CD/GI by Ethnicity among Clients of a Medical Facility in the Southern Portion of the United States

Knowledge Scores	Ethnicity	n	Mean	SD	t	df	Sig(2-tailed)
Symptomology	Caucasian	154	3.62	.58	1.772	174	.08
	African-American	22	3.39	.64			
Overall Knowledge	Caucasian	154	3.48	.37	1.484	174	.14
	African-American	22	3.36	.37			
Interaction w/ Other Conditions	Caucasian	154	2.96	.28	.697	174	.49
	African-American	22	2.92	.28			
Diagnosis	Caucasian	154	3.58	.46	.513	174	.61
	African-American	22	3.53	.47			
Treatment	Caucasian	154	3.71	.49	-.225	174	.82
	African-American	22	3.73	.50			

The t-values and probability levels obtained from this analysis are shown in Table 22.

There were no statistically significant differences in the mean scores for any of the scale/subscale between the Caucasian and African-American ethnic groups.

Marital Status

Another characteristic that was examined for relationships with Knowledge subscales/score was Marital Status of the study participants. Only three categories of Marital Status were used to study the relationships between Marital Status and Knowledge of CD/GI. These included; Single, Married and Divorced. The categories Widowed and Separated were excluded from the analysis due to the fact that they had low numbers of participants.

Table 23

Comparison of the Knowledge of CD/GI by Marital Status among Clients of a Medical Facility in the Southern Portion of the United States

Knowledge Scores	df	F ^a	Sig(2-tailed)
Treatment	2,181	.671	.51
Overall Knowledge	2,181	.535	.59
Interaction w/ Other Conditions	2,181	.420	.66
Diagnosis	2,181	.319	.73
Symptomology	2,181	.225	.80

^aOneway Analysis of Variance

One-way Analysis of Variance was used as the statistical procedure to determine difference among means of the various scales by Marital Status. Results of the analysis in Table 23 show that there were no statistically significant differences in the mean Knowledge subscale scores among the three categories of Marital Status examined.

Whether or not Participants had Children

The next demographic characteristic that was examined for relationships with Knowledge of CD/GI subscales/score was whether or not participants had children. The analysis that was

determined to be most appropriate was the Independent t-test. This was selected to maximize the ease of interpretation of test results for comparison of Knowledge of CD/GI by whether or not Participants had Children. The Levene's Test for Equality of Variances was used to test the assumption of homogeneity of variance. The F values obtained when Levene's Test for Equality of Variances was computed showed a significant-value for the Treatment subscale. In this instance, the t-value with equal variances not assumed was used. With regard to the other scores, the t-value with equal variances assumed was used.

Table 24

Comparison of Knowledge of CD/GI by Whether Clients of a Medical Facility in the Southern Portion of the United States Have Children

Knowledge Scores	Children	n	Mean	SD	t	df	Sig(2-tailed)
Treatment ^a	Yes	145	3.66	.459	-2.011	185	.05
	No	42	3.85	.565			
Interaction w/ Other Conditions	Yes	145	2.97	.266	1.092	185	.28
	No	42	2.91	.332			
Overall Knowledge	Yes	145	3.44	.348	-1.005	185	.32
	No	42	3.50	.456			
Diagnosis	Yes	145	3.57	.462	-.798	185	.43
	No	42	3.64	.528			
Symptomology	Yes	145	3.57	.579	-.598	185	.55
	No	42	3.63	.683			

^aUsed separate variance estimate due to violation of homogeneity of variance assumption

The t-values and probability levels obtained from this analysis are shown in Table 24. The results show that participants who did not have children had a higher Treatment subscale score (mean=3.85, SD=.565) as compared to those participants who had children (mean=3.66, SD=.459).

Number of Children

The relationship between knowledge of participants and the number children they had was examined using the Pearson Product Moment Correlation procedure. For the knowledge

scores there were no statistically significant relationships with number of children. The results of the analysis are shown in Table 25.

Table 25

Relationship between Knowledge of CD/GI and Number of Children of Clients of a Medical Facility in the Southern Portion of the United States

Knowledge Scores	r ^a	n	p	DD ^b
Interaction w/ Other Conditions	.15	117	.12	Low
Diagnosis	.14	117	.12	Low
Treatment	-.11	117	.24	Low
Symptomology	.02	117	.88	Negligible
Overall Knowledge	.001	117	.10	Negligible

^a Pearson Product Moment Correlation Coefficient

^b Interpretation Scale (Davis, 1971): .01-.09= negligible, .10-.29=low, .30-.49=moderate, .50-.69=substantial, .70 or greater=very strong.

Highest Level of Education

To examine the relationships between Highest Level of Education and Knowledge of CD/GI, the researcher used the Spearman's Rank Correlation Coefficient between the variable, Highest Level of Education and each of the Knowledge scores. As with the awareness measure, the participants who indicated "Other" for Highest Level of Education (n = 4) were eliminated from the analysis, since a clear indication of the nature of their education level was not available.

When these correlation coefficients were examined the Knowledge score that was found to have the highest degree of association with Highest Level of Education was the Diagnosis subscale (r = .24, p = .001). This relationship was described as a "Low" association using Davis' (1971) descriptors. The nature of the association was such that participants with a higher level of education completed tended to have higher Diagnosis subscale score. Two other knowledge scores were found to have significant correlations with the highest level of education completed (the Overall Knowledge and the Treatment Subscale). All of the statistically significant

associations were described as “Low” (Davis, 1971). The nature of each of the statistically significant correlations was such that higher education levels tended to be associated with higher knowledge scores (see Table 26).

Table 26

Relationship between Highest Level of Education and Knowledge of CD/GI among Clients of a Medical Facility in the Southern Portion of the United States

Knowledge Scores	r_{ρ}^a	n	p	DD ^b
Diagnosis	.24	187	.001	Low
Treatment	.19	187	.01	Low
Overall Knowledge	.17	187	.02	Low
Symptomology	.13	187	.07	Low
Interaction w/ other conditions	-.02	187	.82	Negligible

^a Spearman Rank Correlation Coefficient

^b Interpretation Scale (Davis, 1971): .01-.09= negligible, .10-.29=low, .30-.49=moderate, .50-.69=substantial, .70 or greater=very strong.

Total Annual Family Income

To examine the relationships between Total Annual Family Income and Knowledge of CD/GI, the researcher used the Spearman’s Rank Correlation Coefficient between the variable, Total Annual Family Income and each of the Knowledge subscales/score. Total Annual Family Income was measured as an ordinal variable with four categories which included: Less than \$25,000; \$25,000-\$49,999; \$50,000-\$74,999; More than \$75,000. As shown in Table 27 there were no statistically significant correlations between Total Annual Family Income and the Knowledge scores.

Table 27

Relationship between Total Family Income and Knowledge of CD/GI among Clients of a Medical Facility in the Southern Portion of the United States

Knowledge Scores	r_{ρ}^a	n	p	DD ^b
Diagnosis	.13	163	.09	Low
Overall Knowledge	.05	163	.55	Negligible

table cont.

Symptomology	.04	163	.59	Negligible
Interaction w/ other conditions	.02	163	.76	Negligible
Treatment	-.02	163	.77	Negligible

^a Spearman Rank Correlation Coefficient

^b Interpretation Scale (Davis, 1971): .01-.09= negligible, .10-.29=low, .30-.49=moderate, .50-.69=substantial, .70 or greater=very strong

Distance Traveled from Participants Home to Medical Facility

Another characteristic which was examined for a relationship with Knowledge of CD/GI was the Number of Miles Traveled by the study participants from their home to the medical facility. Number of Miles Traveled was measured as an ordinal variable with four categories which included: Less than 10 miles, 11-50 miles, 51-100 miles, and More than 100 miles.

To examine this relationship the researcher used Spearman's Rank Correlation Coefficient between the variable, Distance Traveled and each of the Knowledge scores.

Table 28

Relationship between Distance Traveled and Knowledge of CD/GI among Clients of a Medical Facility in the Southern Portion of the United States

Knowledge Scores	r_{rho}^a	n	p	DD ^b
Symptomology	-.18	188	.01	Low
Overall Knowledge Score	-.14	188	.01	Low
Treatment	.08	188	.25	Negligible
Interaction w/ Other Conditions	-.05	188	.51	Negligible
Diagnosis	-.05	188	.53	Negligible

^a Spearman Rank Correlation Coefficient

^b Interpretation Scale (Davis, 1971): .01-.09= negligible, .10-.29=low, .30-.49=moderate, .50-.69=substantial, .70 or greater=very strong.

When these correlation coefficients were examined the Knowledge scores that had statistically significant relationships with Distance Traveled were the Symptomology subscale score ($r=-.18$, $p=.01$) and Overall Knowledge score ($r=-.14$, $p=.01$). These relationships were described as a “Low” association using Davis’ (1971) descriptors. The nature of the statistically significant relationships was such that participants who traveled a shorter distance from their home to the medical facility tended to have higher knowledge scores on the Symptomology subscale and Overall Knowledge than those who traveled a longer distance (Table 28).

Participants Last Physical Exam by their PCP

The relationship between Knowledge of CD/GI subscales and the Overall Knowledge Score, and Years since the participants’ last physical exam by their PCP were examined. Years since Last Physical Exam by their PCP was measured as an ordinal variable and included, Less than 1 year, 1-3 years, 3-5 years and More than 5 years. The researcher used the Spearman’s Rank Correlation Coefficient to determine these relationships.

Table 29

Relationship between Participants Last Physical Exam by their PCP and Knowledge of CD/GI among Clients of a Medical Facility in the Southern Portion of the United States

Knowledge Scores	r_{rho}^a	n	p	DD ^b
Diagnosis	.08	189	.25	Negligible
Symptomology	-.07	189	.33	Negligible
Overall Knowledge Score	-.05	189	.46	Negligible
Interaction w/ other conditions	-.03	189	.71	Negligible
Treatment	-.01	189	.89	Negligible

^aSpearman’s Rank Correlation Coefficient

^bInterpretation Scale (Davis, 1971): .01-.09= negligible, .10-.29=low, .30-.49=moderate, .50-.69=substantial, .70 or greater=very strong

There were no statistically significant correlations between Participants years since their last Physical Exam by their PCP and the Knowledge scores (see Table 29).

Participants Last Seen by Any Physician

The relationship between knowledge of CD/GI scores and Years since the Participants' had last seen Any Physician were examined. This demographic characteristic was measured as an ordinal variable and included the options Less than 1 year, 1-3 years, 3-5 years and More than 5 years. The researcher used the Spearman's Rank Correlation Coefficient to determine these relationships. When these correlation coefficients were examined the Symptomology subscale was found to be statistically significant with a "Low" association with Years since Last Seen by Any Physician (See Table 30). The nature of the relationships of the Symptomology subscale with Years since Last Seen by Any Physician showed that participants who visited any type of physician in the last year were less knowledgeable than those who had visited any physician in 1-3 years.

Table 30

Relationship between Participants Last Visit to Any Type of Physician and Knowledge of CD/GI among Clients of a Medical Facility in the Southern Portion of the United States

Knowledge Subscale/Score	r_{rho}^a	n	p	DD ^b
Symptomology	-.17	189	.02	Low
Overall Knowledge Score	-.14	189	.06	Low
Interaction w/ other conditions	-.04	189	.58	Negligible
Diagnosis	.04	189	.60	Negligible
Treatment	-.01	189	.86	Negligible

^a Spearman's Rank Correlation Coefficient

^b Interpretation Scale (Davis, 1971): .01-.09= negligible, .10-.29=low, .30-.49=moderate, .50-.69=substantial, .70 or greater=very strong.

Objective 5

Determine if a model exists explaining a significant portion of the variance in the Awareness of Celiac Disease and Knowledge of CD/GI among clients of a medical facility in the southern portion of the United States from the following selected demographic characteristics:

- a) Age
- b) Gender
- c) Ethnicity
- d) Marital Status
- e) Whether or Not Participants had Children
- f) Number of Children
- g) Highest Education Level
- h) Occupation/Profession
- i) Total Annual Family Income
- j) Distance Traveled from Home to the Medical Facility
- k) Years since Last Physical Exam by their PCP
- l) Years since Last Seen by Any Physician

To accomplish this objective multiple regression analyses were performed. This was achieved using the Overall Knowledge Score, the Symptomology subscale score, the Diagnosis subscale score, the Treatment subscale score, and the Interaction with Other Conditions subscale score as the dependent variables. The other variables were treated as independent variables, and stepwise entry of the variables was used due to the exploratory nature of the study. In the regression equation, variables were added that increased the explained variance by one percent or more as long as the overall regression equation remained significant.

In conducting the multiple regression analysis, four of the variables to be treated as independent variables which were categorical in nature had to be recoded as dichotomous variables in preparation for entry into the analysis. These variables included Ethnicity, Marital Status, Highest Level of Education, and Whether or Not Participants Had Children. Gender was a categorical variable, but since it is a natural dichotomy, it did not need to be restructured.

The first of these variables was Ethnicity of the study participants. Six of the eight categories of Ethnicity had less than 10 participants and this was not considered to be adequate to use them as separate variables of investigation. The largest of these minority groups was African-American which was represented by 86 (21.37 %) of the participants. Therefore, the restructured dichotomous variable was established as the participant was either Caucasian or not Caucasian and African-American or not African-American. It was in this format that the Variable Ethnicity was entered into the analysis.

The variable, Marital Status, was measured in five categories of response – Married, Single, Divorced, Widowed, and Separated. The frequencies in all of the response categories, except Separated, were judged by the researcher to be adequate to use as separate independent variables. Separated was excluded due to the fact that it had low numbers. The response categories that were included were Married or not Married, Single or not Single, Divorced or not Divorced, and Widowed or not Widowed.

The variable, Whether or Not Study Participants had Children, was measured as a natural dichotomous variable of Having Children or Not Having Children. Therefore, it was not restructured.

Overall Knowledge

For descriptive purposes, bivariate or two-way correlations between the independent variables (demographic characteristics) and the Overall Knowledge Score of CD/GI among clients of the medical facility are presented in Table 31. Out of the 14 variables examined, five were found to be significantly related to Overall Knowledge of CD/GI. The variable that had the highest correlation with the Overall Knowledge scores was Education ($r=.22$, $p=.01$). The nature of the significant relationships was such that there was a positive correlation between the variables Highest Level of Education, Whether or not they were Caucasian, and Whether or not they were Divorced and Overall Knowledge of CD/GI. On the other hand, Gender and Distance traveled which were also significantly correlated were negatively related. Coding for the variable Gender indicates that female participants tended to have higher overall knowledge scores.

Table 31

Relationship between Selected Predictor Measures and Overall Knowledge of CD/GI among Clients of a Medical Facility in the Southern Portion of the United States

Predictor Measures	r^a	p
Education	.22	.01
Distance traveled	-.21	.02
Caucasian	.20	.02
Divorced	.17	.04
Gender ^b	-.17	.05
African-American	-.12	.12
Single	-.11	.15
Married	-.09	.20
Age	-.08	.22
Widowed	-.05	.31

table cont.

Whether or not participants had children	.04	.34
Primary Care Visit	-.04	.34
Any Physician	-.04	.36
Income	.01	.46

Note. n=99

^a Pearson Product Moment Correlation Coefficient

^b Gender coded: Female=1, Male=2

A further step of preparation for conducting the regression analysis was to test for excess multicollinearity among the independent variables in the analysis. The procedure that was used for testing multicollinearity was to examine the tolerance values. Tolerance, as defined by Hair, Black, Babin, Anderson & Tatham (2006), is “the amount of variability of the selected independent variable not explained by other independent variables” (p.227). Hair et al. (2005) suggested that a tolerance value of less than .10 indicates excessive multicollinearity. The tolerance values in this analysis ranged from .44-.99, therefore, no instances of excess multicollinearity were judged to be present in this data.

The results of the multiple regression analysis utilizing Overall Knowledge of CD/GI as the dependent variable is shown in Table 32. The variable which entered the regression model first was Highest Level of Education. Considered alone, this variable explained 5% of the variance in Overall Knowledge of CD/GI among participants of a medical facility in the southern portion of the United States. Four additional variables explained an additional 13.2% of the variance in Overall Knowledge of CD/GI. Those variables were the following: Gender, Caucasian, Divorced, and Distance Traveled. These five variables explained a total of 18.2% of the variance in Overall Knowledge of CD/GI (see Table 34). The nature of the influence of these variables that entered the model was such that individuals with a Higher Level of Education,

individuals who identified with the Caucasian ethnicity, and individuals who were divorced tended to have higher Overall Knowledge of CD/GI. The other two variables that entered the model, Gender and Distance Traveled from Home to the Medical Facility, had the following influence on Knowledge of CD/GI: female participants tended to have higher knowledge than male participants, and participants who traveled shorter distances from their home to the medical facility tended to have higher knowledge.

Table 32

Regression of Overall Knowledge of CD/GI on Selected Demographic Characteristics among Clients of a Medical Facility in the Southern Portion of the United States

ANOVA

Source of Variance	df	MS	F-ratio	p
Regression	5	.42	4.138	.002
Residual	93	.10		
Total	98			

Model Summary

Model	R ² Cumulative	R ² Change	F Change	Sig. F Change	Coefficients Beta
Education	.050	.050	5.141	.026	.194
Gender ^a	.086	.035	3.716	.057	-.198
Caucasian	.121	.035	3.764	.055	.194
Divorced	.153	.033	3.608	.061	.174
Distance Traveled	.182	.029	3.287	.073	-.174

Variables not in the Equation

Variables	t	Sig. t
Married	1.248	.215
Whether or not participants had children	.495	.622
Any Physician Visit	.429	.669
Single	-.312	.755
African-American	-.345	.731
Income Level	-.493	.623
Years since Last Primary Care visit	-.591	.556
Age	-.640	.524
Widowed	-.1080	.283

^aGender coded: Female=1, Male=2

Symptomology Subscale

For descriptive purposes, bivariate or two-way correlations between the independent variables (demographic characteristics) and the Symptomology Subscale of CD/GI among clients of the medical facility are presented in Table 33. Out of the 14 variables examined, four were found to be significantly related to the Symptomology subscale. The variable that had the highest correlation with the Symptomology subscale was Distance traveled ($r = -.26, p = .001$).

Table 33

Relationship between Selected Predictor Measures and the Symptomology Subscale of CD/GI among Clients of a Medical Facility in the Southern Portion of the United States

Predictor Measures	r^a	p
Distance traveled	-.26	.001
Caucasian	.18	.04
Education	.17	.04

table cont.

Gender ^b	-.17	.05
Divorced	.15	.07
Whether or Not Participants Have Children	.07	.26
Income Level	.05	.31
Age	-.02	.41
Married	-.05	.31
Years since Last Primary Care visit	-.07	.24
Any Physician Visit	-.08	.22
Single	-.08	.21
African-American	-.09	.18
Widowed	-.11	.15

Note. n=99

^aPearson Product Moment Correlation Coefficient

^bGender coded: Female=1, Male=2

The nature of the significant relationships was such that there was a positive correlation between the variables Highest Level of Education, and whether or not they were Caucasian and the Symptomology subscale. On the other hand, Gender and Distance traveled which were also statistically significant were negatively correlated.

The procedure that was used for testing multicollinearity was to examine the tolerance values. Hair et al. (2005) suggested that a tolerance value of less than .10 indicates excessive multicollinearity. The tolerance values in this analysis ranged from .13-.98, therefore, no instances of excess multicollinearity were judged to be present in this data.

The results of the multiple regression analysis utilizing the Symptomology subscale of CD/GI as the dependent variable are shown in Table 34. The variable which entered the

regression model first was Distance Traveled from Home to the Medical Facility. Considered alone, this variable explained 6.6% of the variance in the Symptomology subscale among participants of a medical facility in a southern state of the United States. Six additional variables explained an additional 14.2% of the variance in the Symptomology subscale. Those variables were the following: Caucasian, Gender, Divorced, Married, Highest Level of Education, and Single. These seven variables explained a total of 20.8% of the variance in the Symptomology subscale. The nature of the influence of these variables that entered the model was such that individuals with a Higher Level of Education, individuals who identified with the Caucasian ethnicity and individuals who were divorced, married or single had higher knowledge of the Symptomology subscale. The other two variables that entered the model, Gender and Distance Traveled from Home to the Medical Facility, had the following association with the Symptomology subscale: female participants tended to have higher knowledge than male participants, and participants who traveled shorter distances from their home to the medical facility tended to have higher knowledge.

Table 34

Regression of Symptomology Subscale of CD/GI Knowledge on Selected Demographic Characteristics among Clients of a Medical Facility in the Southern Portion of the United States

ANOVA

Source of Variance	df	MS	F-ratio	p
Regression	7	.872	3.407	.003
Residual	91	.256		
Total	98			

Model Summary

Model	R² Cumulative	R² Change	F Change	Sig. F Change	Coefficients Beta
Distance Traveled	.066	.066	6.880	.010	-.226
Caucasian	.102	.036	3.845	.053	.181
Gender ^a	.134	.032	3.537	.063	-.213
Divorced	.156	.021	2.387	.126	.600
Married	.178	.022	2.516	.116	.515
Education	.195	.017	1.976	.163	.167
Single	.208	.012	1.409	.238	.168

Variables not in the Equation

Variables	t	Sig. t
Whether or Not Participants Have Children	.397	.692
Any Physician Visit	-.015	.988
Age	-.024	.981
Income Level	-.157	.876
Widowed	-.191	.849
African-American	-.245	.807
Years since Last Primary Care visit	-.932	.354

^aGender coded: Female=1, Male=2

Diagnosis Subscale

For descriptive purposes, two-way correlations between the independent variables (demographic characteristics) and the Diagnosis Subscale of CD/GI among clients of the medical

facility are presented in Table 35. Out of the 14 variables examined, five were found to be significantly related to the Diagnosis Subscale. The variable that had the highest correlation with the Diagnosis subscale was Education ($r = .30, p = .001$). The nature of the significant relationships was such that there was a positive correlation between the variables Highest Level of Education, Income, and Caucasian and the Diagnosis Subscale.

Table 35

Relationship between Selected Predictor Measures and Diagnosis Subscale of CD/GI among Clients of a Medical Facility in the Southern Portion of the United States

Predictor Measures	r^a	P
Education	.30	.001
Income Level	.23	.01
Caucasian	.21	.02
Age	-.20	.03
African-American	-.18	.04
Single	-.15	.07
Distance Traveled	-.13	.11
Years since Last Primary Care visit	.11	.14
Divorced	.11	.15
Any Physician Visit	-.09	.19
Widowed	-.06	.28
Gender ^b	-.05	.31
Whether or Not Participants Have Children	.05	.31
Married	-.01	.48

Note. $n = 99$

^aPearson Product Moment Correlation Coefficient

^bGender coded: Female=1, Male=2

On the other hand, Age and African-American which were also statistically significant were negatively correlated.

The procedure that was used for testing multicollinearity was to examine the tolerance values. Hair et al. (2005) suggested that a tolerance value of less than .10 indicates excessive multicollinearity. The tolerance values in this analysis ranged from .26-.97, therefore, no instances of excess multicollinearity were judged to be present in this data. The results of the multiple regression analysis utilizing the Diagnosis subscale as the dependent variable are shown in Table 36. The variable which entered the regression model first was Education. Considered alone, this variable explained 9.1% of the variance in the Diagnosis subscale among participants of a medical facility in a southern state of the United States. Six additional variables explained an additional 12.4% of the variance. Those variables were the following: African-American, Age, Income, Divorced, Married, and Gender. These seven variables explained a total of 20.8% of the variance in the Diagnosis subscale among participants of a medical facility in a southern state of the United States. The nature of the influence of these variables that entered the model was such that individuals with a higher level of education and higher annual family income, and individuals who were married or divorced had a higher Diagnosis subscale. The other three variables that entered the model, African-American, Age, and Gender had the following association with the Diagnosis subscale: female participants tended to have higher knowledge than male participants, African-American participants tended to have higher knowledge than Caucasian participants, and younger participants tended to have higher knowledge than older participants.

Table 36

Regression of Diagnosis Subscale of CD/GI Knowledge on Selected Demographic Characteristics among Clients of a Medical Facility in the Southern Portion of the United States

ANOVA

Source of Variance	df	MS	F-ratio	p
Regression	7	.645	3.571	.002
Residual	91	.181		
Total	98			

Model Summary

Model	R ² Cumulative	R ² Change	F Change	Sig. F Change	Coefficients Beta
Education	.091	.091	9.700	.002	.276
African-American	.128	.037	4.124	.045	-.166
Age	.157	.028	3.182	.078	-.157
Income Level	.173	.016	1.831	.179	.129
Divorced	.185	.013	1.434	.234	.362
Married	.205	.020	2.293	.133	.290
Gender ^a	.215	.010	1.207	.275	-.105

Variables not in the Equation

Variables	t	Sig. t
Whether or Not Participants Have Children	.919	.361
Years since Last Primary Care visit	.709	.480
Caucasian	.675	.501

table cont.

Single	.460	.647
Any Physician Visit	-.170	.865
Widowed	-.376	.708
Distance Traveled	-.904	.368

^aGender coded: Female=1, Male=2

Treatment Subscale

For descriptive purposes, two-way correlations between the independent variables (demographic characteristics) and the Treatment Subscale among clients of the medical facility are presented in Table 37. Out of the 14 variables examined, three were found to be significantly related to the Treatment Subscale. The variable that had the highest correlation with the Treatment subscale was Education ($r = .28, p = .003$). The nature of the significant relationships was such that there was a positive correlation between the variable Highest Level of Education and the Treatment Subscale. On the other hand, Age which was also statistically significant was negatively correlated.

Table 37

Relationship between Selected Predictor Measures and Treatment Subscale of CD/GI in Clients of a Medical Facility in the Southern Portion of the United States

Predictor Measures	r^a	p
Education	.28	.003
Age	-.20	.02
Divorced	.17	.05
Gender ^b	-.15	.07
Single	-.14	.09
Widowed	.13	.10

table cont.

Married	-.12	.11
Caucasian	.09	.18
Income Level	-.08	.20
Whether or Not Participants Have Children	-.08	.22
Any Physician Visit	.08	.23
Years since Last Primary Care visit	.02	.41
Distance Traveled	.02	.43
African-American	.01	.46

Note. n=99

^aPearson Product Moment Correlation Coefficient

^bGender coded: Female=1, Male=2

The procedure that was used for testing multicollinearity was to examine the tolerance values. Hair et al. (2005) suggested that a tolerance value of less than .10 indicates excessive multicollinearity. The tolerance values in this analysis ranged from .13-.98, therefore, no instances of excess multicollinearity were judged to be present in this data.

The results of the multiple regression analysis utilizing the Treatment subscale as the dependent variable are presented in Table 38. The variable which entered the regression model first was Education. Considered alone, this variable explained 7.6% of the variance in the Treatment subscale among participants of a medical facility in the southern portion of the United States. Six additional variables explained an additional 14.8% of the variance. Those variables were the following: Age, Income, Gender, Divorced, Single, and Years since Last Seen by Any Physician. These seven variables explained a total of 22.4% of the variance in the Treatment subscale. The nature of the influence of these variables that entered the model was such that individuals with a higher level of education had higher knowledge than those who had a lower

level of education, individuals who were divorced had a higher level of knowledge than those who were not divorced, and individuals who had seen any physician in more recent years had a higher level of knowledge than those who had not seen a physician in recent years. The other four variables that entered the model, Age, Income, Gender, and Single had the following association with the Treatment subscale: younger participants tended to have higher knowledge than older participants, individuals with lower annual family incomes tended to have higher knowledge than those with higher annual family incomes, female participants tended to have higher knowledge than male participants, and single participants tended to have higher knowledge than those who were not single.

Table 38

Regression of Treatment Subscale of CD/GI Knowledge on Selected Demographic Characteristics among Clients of a Medical Facility in the Southern Portion of the United States

ANOVA

Source of Variance	df	MS	F-ratio	p
Regression	7	.642	3.756	.001
Residual	91	.171		
Total	98			

Model Summary

Model	R ² Cumulative	R ² Change	F Change	Sig. F Change	Coefficients Beta
Education	.076	.076	7.940	.006	.310
Age	.112	.036	3.904	.051	-.188
Income Level	.143	.031	3.484	.065	-.180

table cont.

Gender ^a	.167	.024	2.707	.103	-.167
Divorced	.191	.024	2.714	.103	.149
Single	.202	.012	1.348	.249	-.167
Any Physician Visit	.224	.022	2.540	.114	.157

Variables not in the Equation

Variables	t	Sig. t
Caucasian	.844	.401
Widowed	.814	.418
Distance Traveled	.346	.730
Married	.046	.963
African-American	-.347	.729
Whether or Not Participants Have Children	-.555	.580
Years since Last Primary Care visit	-.584	.560

^aGender coded: Female=1, Male=2

Interaction with Other Conditions Subscale

For descriptive purposes, two-way correlations between the independent variables (demographic characteristics) and the Interaction with Other Conditions subscale among clients of the medical facility are presented in Table 39. Out of the 14 variables examined, one was found to be significantly related to the Interaction with Other Conditions subscale. The variable that had the highest correlation with the Interaction with Other Conditions subscale was African-American ($r = -.24, p = .009$). The nature of the significant relationship was such that there was a

negative correlation between the variable African-American and the Interaction with Other Conditions subscale.

Table 39

Relationship between Selected Predictor Measures and Interaction with Other Conditions Subscale of CD/GI among Clients of a Medical Facility in the Southern Portion of the United States

Predictor Measures	r^a	p
African-American	-.24	.009
Caucasian	.16	.06
Gender ^b	.10	.16
Whether or Not Participants Have Children	.09	.32
Widowed	-.05	.32
Years since Last Primary Care visit	.04	.35
Single	.03	.39
Age	.03	.39
Distance Traveled	-.03	.40
Education	-.02	.41
Divorced	-.02	.42
Married	-.02	.42
Any Physician Visit	.01	.48
Income Level	-.01	.47

Note. n=99

^aPearson Product Moment Correlation Coefficient

^bGender coded: Female=1, Male=2

The procedure that was used for testing multicollinearity was to examine the tolerance values. Hair et al. (2005) suggested that a tolerance value of less than .10 indicates excessive multicollinearity. The tolerance value in this analysis was .99, therefore, there was no instance of excess multicollinearity judged to be present in this data.

The results of the multiple regression analysis utilizing the Interaction with Other Conditions subscale as the dependent variable. The variable which entered the regression model first was African-American. Considered alone, this variable explained 5.7% of the variance in Interaction with Other Conditions subscale among participants of a medical facility in a southern state of the United States. One additional variable explained an additional 1.2% of the variance in the Interaction with Other Conditions subscale. This variable was whether or not participants had children. These two variables explained a total of 6.9% of the variance in the Interaction with Other Conditions subscale. The nature of the influence of these variables that entered the model was such that African-Americans had lower levels of knowledge of interaction with other conditions than those individuals who were not of African-American ethnicity, and individuals with children had a higher level of knowledge of interaction with other conditions than those individuals who did not have children.

Table 40

Regression of Interactions with Other Conditions Subscale of CD/GI Knowledge on Selected Demographic Characteristics among Clients of a Medical Facility in the Southern Portion of the United States

ANOVA

Source of Variance	df	MS	F-ratio	P
Regression	2	.217	3.552	.032
Residual	96	.061		
Total	98			

Model Summary

Model	R² Cumulative	R² Change	F Change	Sig. F Change	Coefficients Beta
African-American	.057	.057	5.846	.017	-.249
Whether or Not Participants Have Children	.069	.012	1.243	.268	.110

Variables not in the Equation

Variables	t	Sig. t
Single	.972	.334
Any Physician Visit	.576	.566
Gender ^a	.456	.650
Years since Last Primary Care visit	.315	.754
Age	.248	.804
Distance Traveled	-.122	.903
Education	-.164	.870
Caucasian	-.166	.869
Divorced	-.209	.835
Income Level	-.300	.765
Widowed	-.401	.689
Married	.461	.646

^aGender coded: Female=1, Male=2

CHAPTER 5

SUMMARY, CONCLUSIONS, IMPLICATIONS and RECOMMENDATIONS

Summary

- **Purpose of the Study**

The primary purpose of this study was to determine the awareness and knowledge of CD/GI among patients of a medical facility in the southern portion of the United States. It is assumed that patient awareness and knowledge in the setting of a private medical facility that is open to the general public who have health issues arising from metabolic disorders would be representative of public awareness and knowledge of CD/GI.

- **Objectives of the Study**

Objective 1. Describe the population of clients of a medical facility in the southern portion of the United States on the following selected demographic characteristics:

- a) Age
- b) Gender
- c) Ethnicity
- d) Marital Status
- e) Status and Number of Children
- f) Highest Education Level
- g) Occupation/Profession
- h) Annual Family Income
- i) Distance Traveled from Home to the Medical Facility
- j) Years since Last Physical Exam by their PCP
- k) Years since Last Seen by Any Physician

Objective 2. Determine the awareness and knowledge of CD/GI, among the population of clients of a medical facility in the southern portion of the United States.

Objective 3. Determine if identifiable sub-scales exist in the instrument designed to measure the awareness and knowledge of CD/GI among clients of a medical facility in the southern portion of the United States.

Objective 4. Determine the relationship between the awareness and knowledge of CD/GI and the following selected demographic characteristics of clients of a medical facility in the southern portion of the United States:

- a) Age
- b) Gender
- c) Ethnicity
- d) Marital Status
- e) Status and Number of Children
- f) Highest Education Level
- g) Occupation/Profession
- h) Annual Family Income
- i) Distance Traveled from Home to the Medical Facility
- j) Years since Last Physical Exam by their PCP
- k) Years since Last Seen by Any Physician

Objective 5. To determine if a model exists explaining a significant portion of the variance in the awareness and knowledge of CD/GI among clients of a medical facility in the southern portion of the United States from the following selected demographic characteristics:

- a) Age
- b) Gender

- c) Ethnicity
- d) Marital Status
- e) Status and Number of Children
- f) Highest Education Level
- g) Occupation/Profession
- h) Annual Family Income
- i) Distance Traveled from Home to the Medical Facility
- j) Years since Last Physical Exam by their PCP
- k) Years since Last Seen by Any Physician

- **Methodology**

The target population for the study was defined as all clients who seek medical services in organized medical facilities in the southern United States. The accessible population was defined as all clientele who were established, regular patients of one medical clinic specializing in autoimmune disorders in a medium-sized city in a southern state of the United States. The accessible population also included individuals who accompanied the patients when they visited the clinic for their regularly scheduled visit. The minimum sample size for the study according to Cochran's formula for calculating sample size was 392.

A researcher-designed survey instrument was developed to collect data from the designated study participants. Information useful in framing the questions in the instrument were gleaned from the literature review, including the theory and practice underlying medical and health aspects of the disease, sociological and psychological underpinnings, and awareness and knowledge of CD/GI in the general public and among medical professionals.

The survey instrument had four parts. Part I dealt with attention to personal health in seeing a PCP and any physician; Part II included a question on whether clientele had heard or not

heard of CD/GI which would indicate awareness or lack of awareness; Part III consisted of a series of 30 statements about different aspects of CD/GI to determine the individual's level of agreement-disagreement on a five-point Likert-type scale from strongly agree to strongly disagree as an indicator of their knowledge; Part IV had questions on demographic characteristics of the sample – Age, Gender, Ethnicity, Marital Status, Whether or Not Participants had Children and Number of Children, Highest Level of Education, Occupation/Profession, Annual Family Income, Years since Last Physical Examination by a PCP, Years Since Last Seen by Any Physician, and Distance Traveled from Home to the Medical Facility. The instrument was pilot-tested for content validity to ensure that the questions and statements were measuring the intended behavior. Suggestions made by the pilot-test group were incorporated into the instrument.

A copy of the survey instrument is at Appendix A.

Data Collection

The plan for collecting data was developed by the researcher in consultation with the clinic Medical Director, the Patient Services Representative, and Clinical Staff. It was decided that the best way to gather the information from clients was to get them to complete the survey when they registered with the receptionist at the clinic's front desk. This was done as they waited for their appointment time in the reception area. A clip board and pencil was given to each client with appropriate explanation of the purpose of the study, the request to participate in the study, and, if they agreed to comply, they were given the survey instrument and the instructions for completing the information. Once they filled out the information, the receptionist or other designated staff member of the clinic collected the completed survey and placed it in a predetermined area. Individuals (one or more adults) who accompanied clients on their visit day

were offered the opportunity to participate in the survey. If they chose to do so, the clinic staff followed the same process as for clients. The researcher collected the completed surveys at the end of the day.

Data collection was started on May 2, 2011 and completed on May 13, 2011. During this period of 14 days, 404 surveys were completed by clients and accompanying individuals. .

- **Findings**

Objective 1. Describe the population of clients of a medical facility in the southern portion of the United States on selected demographic characteristics:

The Age of participants ranged from 18-83 years, with a mean of 46.1 years, the majority of the participants (75.5%) were female. Three-fourths of the participants were Caucasian (71%), and slightly over one-fifth was African-American. Two-thirds of the participants were married (65.6%) and Three-fourths of the participants had children (75.1%), the majority of them (68.6%) had one child or two children. The mean number of children was 2.2. Nearly one-half of the participants reported having a college degree (48.8%), and nearly one-third had some college (29.6%). Nearly two thirds of the participants reported total annual family income over \$50,000, with 43.8% reporting income over \$75,000. A total of 288 participants responded to this item. To summarize the data received in response to this question, the researcher examined each response and combined those that were clearly the same profession. After this procedure was completed 106 different occupations/professions were identified.

On the question of years since last physical examination by a PCP, 56.4% reported less than 1 year, and 33.2% reported 1-3 years. Nearly all participants had seen a physician of some type for some health issue in the last 1 year. Nearly a third of the participants traveled less than 10 miles (29.8%), but a significant number traveled between 10 and 50 miles (60.7%).

Objective 2. Determine the awareness and knowledge of CD/GI among the population of clients of a medical facility in the southern portion of the United States

Thirty statements on various aspects of CD/GI were presented to study participants to determine their level of agreement-disagreement with each statement. Twelve statements were negatively worded, so that disagreement of the participants with these statements would indicate more knowledge regarding CD/GI. Participants' answers were provided on a 5-point Likert-type scale of Strongly Disagree (1), Disagree (2), Don't Know (3), Agree (4), Strongly Agree (5).

The data, as presented in the findings chapter (Table 12), showed that the means of the 30 statements ranged from 1.95 to 4.26. Participants "agreed" with 12 statements, were "uncertain" about 14 statements, and "disagreed" with 4 statements. Participants did not "strongly agree" or "strongly disagree" with any statement.

Objective 3. Determine if identifiable sub-scales exist in the instrument designed to measure the knowledge of CD/GI among clients of a medical facility in the southern portion of the United States.

Information for this objective came from the responses to the 30 items in the Knowledge of CD/GI instrument. To further summarize this information, which was obtained on a 5-point Likert-type scale from strongly disagree to strongly agree, factor analysis was used to determine if underlying constructs could be identified in the scale. Before the factor analysis could be run, the 12 negative statements in the knowledge instrument had to be recoded as follows: Strongly Agreed (recoded 5 as 1), Agreed (recoded 4 as 2), Disagreed (recoded 2 as 4), and Strongly Disagreed (recoded 1 as 5). Four factors were identified using an exploratory factor analysis. The four factors identified were: (1) Factor 1, Sub-scale Diagnosis with nine items (statements); Factor 2, Sub-scale Symptomology with six items; Factor 3, Sub-scale Treatment with eight

items; and Factor 4, Sub-scale Interaction with Other Conditions with six items. Reliability of the four subscales, as revealed by the values obtained for Cronbach's Alpha, were: Factor 1: .77; Factor 2: .70; Factor 3: .71; Factor 4: .56.

Objective 4. Determine the relationship between Awareness and Knowledge of CD/GI and selected demographic characteristics.

- **Awareness of Celiac Disease/Gluten Interaction and Demographic Characteristics**

The relationships between 12 selected demographic characteristics of the study participants and Awareness of CD/GI were analyzed by appropriate statistical procedures to determine which characteristics were significantly related. The characteristics studied were Age, Gender, Ethnicity, Marital Status, Status of Children, Number of Children, Highest Level of Education, Total Annual Family Income, Years since Last Physical Examination by a PCP, Years since Last Seen by Any Physician, Distance Traveled from Home to Medical Facility.

No statistically significant relationships were found between Awareness of CD/GI among study participants and their Age, Gender, Whether or Not they had Children, Number of Children for those who reported Having Children, Years since Last Seen by Any Physician, and Miles Traveled from Home to the Medical Facility. Statistically significant relationships existed between Awareness of CD/GI and each of the following demographic characteristics.

Ethnicity. A majority of Caucasians (n=167, 58.0%) was aware of CD/GI, while a majority of African-Americans (n=60, 69.8%) was unaware.

Marital Status. A majority of participants in the Married category (n=151, 57.0%) was aware of CD/GI, as compared to majorities of participants in the categories of Single (Never Married) (n=40, 57.1%), Divorced (n=28, 56.0%), Widowed (n=7, 63.6%) and Separated (n=7, 87.5%) who were unaware of the disease/condition.

Highest Level of Education. Highest Level of Education was measured as an ordinal variable with eight levels - Some High School, High School/GED, Some College, Associate Degree, Bachelors Degree, Masters Degree, Doctoral Degree, and Other. The Spearman's Rank Correlation Coefficient was used to measure the relationship between highest level of education and Awareness of CD/GI. The result indicated that there is a positive relationship between Awareness of CD/GI and Highest Education Level.

Total Annual Family Income. Total Annual Family Income was measured as an ordinal variable in four incremental categories of \$25,000. The Spearman's Rank Correlation Coefficient Correlation Coefficient was used to determine its relationship with Awareness of CD/GI. Participants who reported higher income tended to report being aware of CD/GI more than those who reported lower levels of income.

Years since Last Physical Examination by their PCP. Years since Last Physical Examination by their PCP, which was measured as an ordinal variable in four incremental time categories, was analyzed by the Spearman's Rank Correlation Coefficient Correlation Coefficient procedure to determine relationship with Awareness of CD/GI. Participants who reported fewer numbers of years since their last physical examination by a PCP tended to report being more aware of CD/GI than those who reported more number of years.

Knowledge of CD/GI and Demographic Characteristics

The relationships between 12 selected demographic characteristics of the study participants and Knowledge of CD/GI were analyzed by appropriate statistical procedures to determine which characteristics were significantly related. Four knowledge subscales were derived through factor analysis of the knowledge survey instrument: Diagnosis, Symptomology,

Treatment, and Interaction with Other Conditions. The fifth scale was the Overall Knowledge Score which included all of the items in the scale.

The characteristics studied were Age, Gender, Ethnicity, Marital Status, Whether or not Participants had children, Number of Children for those reporting children, Highest Level of Education, Total Annual Family Income, Years since Last Physical Examination by a PCP, Years since Last Seen by Any Physician, Distance Traveled from Home to Medical Facility.

No statistically significant relationships were found between Knowledge of CD/GI, as identified in the four knowledge sub-scales and the Overall Knowledge Score, among study participants and their Age, Ethnicity, Marital Status, Number of Children Reported, Total Annual Family Income, and Years since Last Physical Examination by a PCP. However, statistically significant relationships existed between Knowledge of CD/GI (one or more of the Knowledge Sub-scales and/or the Overall Knowledge Score) and the following demographic characteristics:

Gender. The independent t-test, showed differences between the mean scores of males and females for the Overall Knowledge Score ($t=2.863$, 187 df, $p<.01$), the Symptomology subscale score ($t=2.521$, 187 df, $p<.01$), the Diagnosis subscale score ($t=2.521$, 187 df, $p<.01$), and the Treatment subscale score ($t=2.361$, 187 df, $p=.02$). In all cases, the mean knowledge score for females was higher than the mean knowledge score for males.

Whether or Not Participants Had Children. The independent t-test, showed differences between the mean scores for participants who had children and participants who did not have children in the Treatment subscale score ($t=-2.011$, 185 df, $p<.05$). The results showed participants who did not have children had a higher Treatment subscale score (mean=3.85) as compared to those participants who had children (mean=3.66).

Highest Level of Education. The Spearman's Rank Correlation Coefficient procedure was used to examine the relationship between Highest Level of Education and each of the Knowledge scores.

There were three Knowledge subscale scores that had positive associations with Highest Level of Education, they included Diagnosis, Overall and Treatment. The nature of the association was such that participants with a higher level of education completed tended to have higher Diagnosis subscale scores. All of these associations were described as "Low" (Davis, 1971), except for Knowledge of Interaction with Other Conditions Subscale which was "Negligible" (Davis, 1971).

Years since Last Seen by Any Physician. The relationships between Knowledge scores, and Years since Last Seen by Any Physician as reported by participants were examined, using the Spearman's Rank Correlation Coefficient procedure. The Symptomology subscale score and the Overall Knowledge Score were found to have a "Low" (Davis, 1971) association with Years since Last Seen by Any Physician. The nature of the relationship of the Symptomology subscale score with Years since Last Seen by Any Physician showed that participants who visited a physician in more recent years were less knowledgeable about CD/GI than those who had not visited a physician recently.

Distance Traveled from Home to Medical Facility. The Pearson Product Moment Correlation Coefficient procedure was used to examine the relationship between the variable, Number of Miles Traveled from Home to the Medical Facility, and each of the Knowledge scores.

There were two scores that showed positive relationships with Number of Miles Traveled. They included the Symptomology subscale and Overall Knowledge. These

relationships were described as a “Low” association, using Davis’ (1971) descriptors. The nature of the relationships was such that participants who traveled a shorter distance from their home to the medical facility had higher knowledge scores in the Symptomology subscale and Overall Knowledge than those who traveled a longer distance.

Objective 5. Determine if a model exists explaining a significant portion of the variance in the Awareness of CD and Knowledge of CD/GI among clients of a medical facility in the southern portion of the United States from the following selected demographic characteristics:

- a) Age
- b) Gender
- c) Ethnicity
- d) Marital Status
- e) Status and Number of Children
- f) Highest Education Level
- g) Occupation/Profession
- h) Annual Family Income
- i) Distance Traveled from Home to the Medical Facility
- j) Years since Last Physical Exam by their PCP
- k) Years since Last Seen by Any Physician

To accomplish this objective, multiple regression analyses were performed, using “Overall Knowledge Score,” “Symptomology” subscale, “Diagnosis” subscale, “Treatment” subscale and “Interaction with other conditions” subscale as the dependent variables.

Demographic characteristics were treated as independent variables, and stepwise entry of these variables was used due to the exploratory nature of the study. In the regression equation,

variables were added that increased the explained variance by one percent or more as long as the overall regression equation remained significant.

Overall Knowledge Score. Results of the multiple regression analysis utilizing the Overall Knowledge Score as the dependent variable showed that the variable which entered the regression model first was Education. Considered alone, this variable explained 5% of the variance in the Overall Knowledge Score. Four additional variables explained an additional 13.2% of the variance in the Overall Knowledge Score. Those variables were: Gender, Caucasian, Divorced, and Distance Traveled. These five variables explained a total of 18.2% of the variance. The nature of the influence of these variables that entered the model was such that individuals with a Higher Level of Education, individuals who identified with the Caucasian ethnicity, and individuals who were divorced had higher overall knowledge of CD/GI. The other two variables that entered the model, Gender and Distance Traveled from Home to the Medical Facility, had the following association with Overall Knowledge of CD/GI: female participants tended to have higher knowledge than male participants, and participants who traveled shorter distances from their home to the medical facility tended to have higher knowledge.

Symptomology subscale. Results of the multiple regression analysis utilizing the Symptomology subscale as the dependent variable showed that the independent variable which entered the regression model first was Distance Traveled from Home to the Medical Clinic. Considered alone, this variable explained 6.6% of the variance. Six additional variables explained an additional 14.2% of the variance in the Symptomology subscale. Those variables were Caucasian, Gender, Divorced, Married, Highest Level of Education, and Single. These seven variables explained a total of 20.8% of the variance in the Symptomology subscale. The nature of the influence of these variables that entered the model was such that individuals with a

Higher Level of Education, individuals who identified with the Caucasian ethnicity, and individuals who were divorced, married or single had higher Knowledge of Symptomology of CD/GI. The other two variables that entered the model, Gender and Distance Traveled from Home to the Medical Facility, had the following association with Knowledge of Symptomology: female participants tended to have higher knowledge than male participants, and participants who traveled shorter distances from their home to the medical facility tended to have higher knowledge.

Diagnosis subscale. Results of the multiple regression analysis utilizing the Diagnosis subscale as the dependent variable showed that the independent variable which entered the regression model first was Education. Considered alone, this variable explained 9.1% of the variance. Six additional variables explained an additional 12.4% of the variance. Those variables were the following: African-American, Age, Income, Divorced, Married, and Gender. These seven variables explained a total of 20.8% of the variance in the Diagnosis subscale. The nature of the influence of these variables that entered the model was such that individuals with a higher level of education and higher annual family income, and individuals who were married or divorced had higher knowledge. The other three variables that entered the model, African-American, Age, and Gender had the following association with Knowledge of Diagnosis of CD/GI: female participants tended to have higher knowledge than male participants, African-American participants tended to have higher knowledge than Caucasian participants, and younger participants tended to have higher knowledge than older participants.

Treatment subscale. Results of the multiple regression analysis utilizing the Treatment subscale as the dependent variable showed that the independent variable which entered the regression model first was Education. Considered alone, this variable explained 7.6% of the

variance. Six additional variables explained an additional 14.8% of the variance. Those variables were Age, Income, Gender, Divorced, Single, and Years since Last Seen by Any Physician. These seven variables explained a total of 22.4% of the variance in the Treatment subscale. The nature of the influence of these variables that entered the model was such that individuals with a higher level of education had higher knowledge than those who had a lower level of education, individuals who were divorced had a higher level of education than those who were not divorced, and individuals who had seen any physician in more recent years had a higher level of knowledge than those who had not seen a physician in recent years. The other four variables that entered the model, Age, Income, Gender, and Single had the following association with Knowledge of Treatment of CD/GI: younger participants tended to have higher knowledge than older participants, individuals with lower annual family incomes tended to have higher knowledge than those with higher annual family incomes, female participants tended to have higher knowledge than male participants, and single participants tended to have higher knowledge than those who were not single.

Interaction with Other Conditions subscale. Results of the multiple regression analysis utilizing the Interaction with Other Conditions subscale as the dependent variable showed that the variable which entered the regression model first was African-American. Considered alone, this variable explained 5.7% of the variance. One other variable explained an additional 1.2% of the variance. This variable was whether or not participants had children. These two variables explained a total of 6.9% of the variance in the Interaction with Other Conditions subscale. The nature of the influence of these variables that entered the model was such that African-Americans had lower levels of knowledge of interaction with other conditions, than those who

were not of African-American ethnicity, and individuals with children had a higher level of knowledge of interaction with other conditions than those individuals who did not have children.

Conclusions, Implications, and Recommendations

Conclusion One

The sample of the study differed, from the general public in the state in which the study was conducted.

This conclusion is supported by the finding that a majority of the clients of the medical facility included in the study sample were female (75.5%), Caucasian (71.5%), had some college or had completed a college degree (67.8%), and had a total family annual income of over \$50,000 (67.0%). U.S. Census data for the state in which the study was conducted showed that females made up 51.4% of the population (2009). With regard to ethnicity, the Caucasian population in the state was reported to be 62.6% (U.S. Census, 2010), With regard to highest level of education, 20.6% of the states' population had completed a Bachelors degree or higher (U.S. Census, 2009). U.S. Census income data showed the Median annual household income in 2009 as \$42,460.

The implication of this finding, which corroborates one of the limitations of the study, is that the sample of this study is not representative of the general population of the state. Therefore, this researcher believes when the study is revised and replicated to a broader random sample, the likelihood of the results of the data will show that this sample will have less awareness and knowledge of CD/GI.

The researcher recommends organizations, such as, the National Foundation for Celiac Awareness (NFCA) and the Celiac Disease Foundation (CDF) conduct studies on a broader random sample of the general public's awareness and knowledge of CD/GI. Collaborative

studies among teaching institutions, the health and food sectors of industry, and foundations with the responsibility to educate the public about the disease could be considered by these organizations.

This researcher recommends that the NFCA which created GREAT (Gluten-free Resource Education and Awareness Training) which has developed and started to implement a variety of services to raise awareness about celiac disease and the gluten-free diet, work in conjunction with community volunteers. Community volunteers can be developed with the help of the Celiac Sprue Association (CSA) which organizes support groups throughout the country, with both local and regional support from the organization. The services provided by the NFCA include, the GREAT Association which leads manufacturers through the steps that they need to follow to safely provide a branded gluten-free product to the foodservice and grocery industries. It offers a network of individuals and companies who are experts in specialty areas of the gluten-free industry.

Also included is, GREAT Dietitians. This service prepares dietitians in foodservice to lead direct food programs which address the needs of those on a gluten-free diet. In addition to its focus upon the foodservice industry, GREAT Dietitians also touches upon the skills a dietitian might use in a clinical setting. This program can be implemented in school systems across the nation.

The GREAT Kitchens program takes chefs, bakers and managers through a systematic curriculum that provides specific protocols for preparing gluten-free foods. This online program includes a toolkit containing a narrated training PowerPoint for managers and a bi-lingual training DVD for all new hires including wait-staff.

The NFCA has designed activities to meet the educational needs of PCPs and other healthcare professionals responsible for routine care and follow up of celiac patients. There is an opportunity to further educate PCPs and nurses on how to effectively recognize the signs and symptoms associated with the debilitating disease. Through a web-based multimedia initiative, the activity will aim to increase the rate of diagnosis and improve subsequent outcomes for patients with celiac disease.

Conclusion Two

The majority of clients of the targeted medical facility is conscious of and takes active steps to meet their health and medical needs.

This conclusion is based on the findings that 56.8% of the study participants had a physical examination by their PCP in the last year and 88.6% of them had seen some type of physician in the last year.

The implications of these findings would suggest that clients of other medical facilities throughout the country are open to learning about CD/GI. This researcher would interpret from this information that when individuals make it a point to visit physicians as they should they are striving for a better quality of life. Therefore, they will be open to educating themselves for a healthier lifestyle.

If clients are representative of those in other medical facilities in the same city or even the same state then a substantial portion of the population is open to learning about health related issues.

This finding is consistent with Wilson's (1995) reporting of individual health becoming an overriding consideration where health related quality of life (HRQoL) issues are the primary

concern. Wilson (1995) also reported that the concept of HRQoL acknowledges that individuals relate their actual situation to their personal expectations.

Based on this conclusion and these findings, the researcher recommends that educational materials, previously developed by the Celiac Sprue Association regional offices, which include symptom checklist, testing and treatment options be distributed to healthcare facilities including but not limited to physicians' offices.

The researcher further recommends that the NFCA collaborate with the American Medical Association, American Association for Clinical Endocrinologists and the American Gastroenterological Association and promote celiac knowledge certification for healthcare professionals. The NFCA has several certifications for various disciplines that work directly with persons with CD/GI. This will allow for continuing education opportunities for these healthcare professionals. The NFCA has developed learning objectives that can be found by primary care providers. They can choose from two different formats to learn about celiac disease. The first is a multimedia, web-based program that includes presentations by distinguished faculty as well as access to comprehensive online resources. The second is a newsletter containing recommendations from the distinguished faculty. The newsletter, can be widely distributed by healthcare organizations and interested parties. This evidence-based interactive activity includes defining celiac and the spectrum of gluten sensitivity, the gluten-free diet, patient case studies, comprehensive resources, and an "Ask the Expert" feature.

This researcher recommends that the NFCA utilize GREAT (Gluten-free Resource Education and Awareness Training) and work in conjunction with various health professionals. The GREAT Allied Health program is an easy-to-follow, web-based learning program that

includes case studies. It provides the occupational therapist an in-depth understanding of celiac disease so it can be recognized in the client population.

The GREAT Mental Health program includes professionals working in the behavioral health field as part of the healthcare team empowered to diagnose those with celiac disease and support them with the gluten-free diet. Typically those serving people with mental health disorders are overlooked, or they only receive generic information about the disorder.

Strategies for partnering with the medical team to facilitate a diagnosis, as well as being a resource for other hospital personnel are integral components. This is particularly important for nurses in in-patient settings as they are the primary caregivers and are responsible for communicating the ongoing presentation of patients' symptoms to the attending healthcare provider.

Conclusion Three

The majority of clients of the sample using the medical facility are not aware of CD/GI. This conclusion is based on the finding of the study that 53.2% of the study participants responded "No" to the question "Have you ever heard of CD/GI?"

A logical extension of this conclusion would be to ask why a majority of the sample is unaware of the disease, and to suggest some possible reasons. For one, the classic symptoms of celiac disease, including abdominal distension, chronic diarrhea, vomiting, weight loss (or stunted growth in children), and fatigue may be absent and symptoms in other organ systems may arise. These could be missed if increased screening for the disease is not done, as is now recommended (van Heel & West, 2006). Also, the awareness and treatment skill among medical professionals is low, as shown by only 11% of PCPs being able to diagnose the disease in one study (Zipser et al., 2005). There is an inadequate sensitivity to and skills by physicians, for

recognizing and treating the disease in terms of diagnosis, recommending serological screening and a gluten-free diet, and discerning connections with other medical conditions (Cranney et al., 2003). Furthermore, this lack of awareness and inadequate diagnostic skills on the part of physicians means that medical clinics and hospitals and the medical professionals that service them may not pay much attention to the need for publicity and informational materials to educate the general public and their patients/clients.

This researcher recommends that organizations such as Health and Nutrition Departments within universities, especially land grant universities which have a public service mandate, work collaboratively with the NFCA and the CDF to replicate an awareness and knowledge study of CD/GI with a broader sample. This researcher further recommends that the Celiac Sprue Association work in conjunction with their regional offices to develop support groups. These groups should then raise awareness and knowledge through targeted and general education programs, awareness campaigns, development and dissemination of learning resources. Groups can share the “Are You the ONE?” brochure developed by the CDF with friends and family who are unaware of celiac disease and its symptoms. Groups can recommend that employees at their companies conduct programs such as “Pay \$5 to wear jeans to work on Friday” to raise awareness and funds for CDF at the office. These groups can also request CDF brochures and Quick Start Diet Guides and give to teachers and healthcare providers at their child’s school or day care center.

Additionally, the researcher recommends, Athletes 4 Awareness, an organization committed to raising awareness for various diseases including Celiac Disease through sports related activities. Community Celiac Disease Support groups should create awareness utilizing programs such as Team Gluten-Free which is a fundraising program that provides a simple way

for runners, walkers, cyclists and tri-athletes to raise awareness and funds for Celiac Disease. The money raised by Team Gluten-Free participants goes directly towards summer camp scholarships for children on the gluten-free diet as well as Celiac Disease research, support and awareness programs. In order to participate in a Team Gluten-free event, individuals can select any race in any city that they wish to participate. The race can be any distance (5K, 10K, half marathon, full marathon, etc.) and any activity (walk, run, cycle, swim, etc.). The individuals join Team Gluten-Free via Mail, fax or email by getting additional information at their website Teamglutenfree.org.

Conclusion Four

Knowledge of different aspects of CD/GI among clients of the medical facility who are aware of the disease is minimal.

This conclusion is supported by the finding that the knowledge of participants as interpreted by their mean response scores ranged from 1.95 to 4.26. The majority of the individual statements of the researcher-designed CD/GI knowledge instrument indicated participants being unsure, or lacking knowledge. This conclusion is further supported by the finding that the majority of participants did not know or inaccurately responded to 18 of the 30 statements in the knowledge of CD/GI instrument. This finding is also consistent with the expert opinion of an Endocrinologist certified by the National Foundation for Celiac Awareness, who stated that the general public may have only minimal knowledge of the characteristics of the disease, such as the level of incidence and prevalence of the disease in the general population, disease symptoms, preventive measures, and alleviation and treatment options (R. Bhushan, M.D., Personal Communication, January 10, 2011).

Research on knowledge of CD/GI is extremely limited. This is consistent with the fact that there have been only three studies conducted on public awareness and knowledge (one study) and physician awareness (two studies). A Celiac Health Pilot Survey was conducted by the Ottawa Chapter of the Canadian Celiac Association (CCA) in 2003 to determine the feasibility of a national survey and to determine chapter members' knowledge of health-related information about CD (Cranney et al, 2003). This study was conducted with individuals who were already diagnosed with the disease. Two studies were conducted with physicians to determine their awareness of CD. In the first study, a survey of 200 pediatricians, family practitioners, and endocrinologists conducted by the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) revealed a lack of physician understanding about CD among children.

In a second study of physician awareness of CD, surveys completed by 2,440 patients in a support group were analyzed for frequency of diagnosis by physicians from various medical specialties, and 132 questionnaires completed by PCPs were analyzed to assess their knowledge of CD. The study concluded that lack of physician awareness of adult onset symptoms, associated disorders, and use of serology testing may contribute to under-diagnosis of CD (Zipser et al., 2005).

Based on this conclusion and the findings the researcher recommends that additional studies utilizing currently available or newly developed instruments be conducted by University Departments, and organizations such as the Pennington Biomedical Research Organization and the Robert Wood Johnson Foundation. Beginning with the original survey, the results of the factor analysis can be looked at to revise the instrument based on identifiable factors. The researcher recommends that the survey be disseminated by various service organizations

including Medical Facilities, Schools, and Restaurants to a broader random sample in order to gather data which would be more representative of the general population. Once the survey instruments are collected a Research based organizations such as the Robert Woods Johnson Foundation should analyze the data and report the findings to organizations that are set up to increase knowledge, such as the Celiac Disease Foundation.

Conclusion Five

Knowledge of CD/GI is a multi-factor concept which offers methodological research, and practical study and application opportunities.

This conclusion is supported by the finding that knowledge of CD/GI as determined by the instrument used in the study had four identifiable factors or subscales which were named as Symptomology subscale and included nine knowledge statements, Diagnosis subscale and included six knowledge statements, Treatment subscale and included eight knowledge statements, and Interaction with Other Conditions subscale and included six knowledge statements. In addition, an Overall Knowledge Score was determined to exist.

The implications of these findings reveal opportunities for reviewing the subscale statements for ambiguity and introduce new items that may improve its reliability. These efforts would also include opportunities for strengthening the instrument for use with different populations to make results more generalizable.

This researcher recommends that the researcher-designed instrument be revised and then used in a variety of clinical, health, and general-purpose settings with different populations to refine the instrument, increase its robustness, strengthen its reliability estimate, and develop norm-referenced data to expand its utility. The University of Chicago conducts a free, celiac blood screening day to test people who are at risk for celiac disease. Each year they test nearly

500 participants, who come to the University of Chicago from all over the country. Many of the participants would not otherwise have had access to celiac disease testing, either because their doctors refused to carry out the tests, their insurance would not cover the cost or they were uninsured altogether. The revised instrument could be disseminated during the screening to gather additional data on awareness and knowledge.

This researcher further recommends that results from the expanded studies serve as the basis for development of appropriate need based programs. These programs might include educational programs for use by Registered Dietitians, Social Workers and Medical Doctors. Topics might include: Gluten-Free meal planning, grocery store visits, label reading, social eating and coping strategies for living with CD/GI.

Conclusion Six

Models from selected demographic characteristics existed that explained portions of the variance in knowledge of CD/GI.

This conclusion is supported by the finding that selected demographic characteristics of the participants explained the following levels of variance in four Knowledge Subscales, identified through exploratory factor analysis of the CD/GI Knowledge instrument, and the Overall Knowledge Score: Symptomology subscale (20.8%); Diagnosis subscale (20.8%); Treatment subscale (22.4%); Interaction with Other Conditions Subscale (6.9%); Overall Knowledge Score (18.2%).

The implication of this conclusion and finding is that large portions of the variances in the Overall Knowledge Score and the four identified Knowledge Subscales are not explained by the demographic characteristics studied. For one, it is possible that other demographic characteristics, such as place of residence, health and wellness competences and behaviors and

other individual and socio-psychological variables could have a role in knowledge acquisition. It is also possible that other situational and contextual factors, including available sources of and access to health-related information, individual predispositions, perceptions, and behaviors which were not studied could have an influence. Furthermore, the issue of adequacy of the knowledge instrument used in the study could be raised. This was a new, researcher-designed instrument, using information about CD/GI from the literature and suggestions from knowledgeable individuals with whom the researcher works and consulted for ideas and suggestions. Cronbach's Alpha values for three of the four subscales and the overall scale were determined to be over .70, which is considered to be an adequate measure of reliability (Cronbach, 2004). All of these possibilities point to the need to ensure that the measuring instrument is maximally effective in measuring these and possibly other dimensions of knowledge of CD/GI.

Table 41 shows the variables (demographic characteristics) that entered the five significant multiple regression equations for the knowledge subscales and the Overall Knowledge Score. The variables, Divorced Marital Status and Female Gender, entered four models: the variable, Highest Level of Education, entered three models; and the variables, Age, Ethnicity (Caucasian), Ethnicity (African-American), and Distance Traveled, entered two models. This would suggest these demographic characteristics are important predictors of the Knowledge of CD/GI which should be considered in designing association and/or causation studies in this area of inquiry.

To elaborate this point, the researcher feels this finding-conclusion is an important principle for guiding future research. The finding-conclusion suggests that the number of times a demographic variable entered the different subscale models could be interpreted as a measure of its strength in predicting knowledge of the various aspects of CD/GI as defined in

the study instrument. Following this line of reasoning, as determined in this study, Divorced Marital Status and Female Gender, which entered four models, likely are the strongest predictors of knowledge of CD/GI , and should be assigned the highest priority for inclusion in research designs, particularly experimental and/or quasi-experimental research, involving hypotheses testing.

Table 41

Demographic Characteristic Variables entering the Multiple Regression Analysis Subscale Models of Knowledge among Clients of a Medical Facility in the Southern Portion of the United States

Demographic	Overall Knowledge	Symptomology	Diagnosis	Treatment	Interaction
Age			X	X	
Gender	X (F)	X (F)	X (F)	X (F)	
Ethnicity	X (C)	X (C)	X (AA)		X (AA)
Marital Status	X (D)	X (D,M,S)	X (D,M)	X (S,D)	
Children?					X
No of Children					
Education	X		X	X	
Income			X	X	
Distance Traveled	X	X			
PCP Exam					
Any Physician Visit				X	
Number of Variables	5	6	7	7	2

Note. X= Demographic Characteristic that entered the model.

A similar logic in designing research could be used to assign differential priority for selecting demographic characteristics which entered three models (Highest Level of Education),

and demographic characteristics which entered two models (Age, Ethnicity- Caucasian, Ethnicity-African-American, and Distance Traveled). Since research design and implementation constraints are invariably important, this type of guidance could be useful in decision-making.

This researcher recommends further research in knowledge studies focused on CD/GI among a broader sample which could be conducted by Universities, Land Grant Colleges, as well as the University of Chicago's Celiac Center. Survey instruments should be disseminated to the University Health Centers through the Health and Nutrition Departments of the universities. Student Orientation would be a significant opportunity for dissemination of the survey instrument. This researcher believes this would allow for a higher response rate. Once the surveys are acquired and the organizations determine the needs of the demographic responses, needs based awareness programs can be developed and implemented. These programs can be conducted by dietitians and social workers, as well as faculty in the Health and Nutrition departments through seminars on campuses throughout the country.

This researcher recommends, Children's Hospital in Boston introduce its Celiac Disease Education and Support Program to the Celiac Sprue Association regional offices to encourage increased education to local support groups throughout the country. Their education and support program strives to make life easier and fun for families dealing with Celiac Disease. Their program includes online resources and take-home DVDs. In 2009, Children's Division of Gastroenterology and Nutrition released the instructive comic book, "Amy Goes Gluten-Free: A Young Person's Guide to Celiac Disease." This book is designed to help children navigate the diagnosis of celiac disease. It includes pages of colorful pictures, nutrition information and activities. This educational material should be distributed at various health fairs throughout the country.

This researcher recommends the University of Chicago collaborate with healthcare facilities throughout the country to offer the Gluten-Free Care Package. This is a basket of gluten-free resources, including a gluten-free food guide, support group information and food samples to instruct dietitians and patients on the gluten-free diet. This program was started in 2001, since its inception they have distributed thousands of Gluten-Free Care Packages to newly diagnosed patients with celiac disease, all over the country.

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APPENDIX A

SURVEY INSTRUMENT

Dear Study Participant,

When people are aware of medical conditions, treatment for this condition begins which often brings improved quality of life. This is certainly the case for individuals diagnosed with Celiac Disease and gluten intolerance. The lack of awareness and knowledge of Celiac Disease and gluten intolerance, combined with misdiagnosed and/or delayed diagnosis by physicians, worsens the problems associated with the disease. This situation in turn, undermines individuals' societal health and well-being. Our goal, for this study, is to determine the level of awareness so as to reduce the time of diagnosis and the impact of undiagnosed Celiac Disease. In raising awareness for Celiac Disease and gluten intolerance we will advance research, education, and screening among medical professionals and the community. These programs of awareness, education, advocacy, and research among the general public and the medical community need to be emphasized.

As a client of this medical facility, we are asking you to help us in determining the awareness of Celiac Disease and gluten intolerance among individuals who receive healthcare. As a first step in this effort, we need to determine if you are aware of Celiac Disease and gluten intolerance and the extent to which you are aware of specific aspects of the disease. Your assistance will be a tremendous help in developing and implementing programs in such a way that we can aid the community.

The answers you provide are strictly confidential and will not be shared with anyone outside of the staff. You will never be personally identified in any way regarding your participation in this study. By filling out this anonymous survey you signify your consent to take part in the study and permit me (the researcher) to use this data in the proposed research.

This study has been approved by the LSU IRB. For questions concerning participant rights, please contact the IRB chair, Dr. Robert C. Mathews, 578-8692, or irb@lsu.edu.

Thank you for your cooperation and assistance.

I. Personal Health

1. How long has it been since your last physical exam by your PCP?

- ☐ Less than a year
- ☐ 1-3 years
- ☐ 3-5 years
- ☐ More than 5 years

1.1 How long has it been since you have seen any physician?

- ☐ Less than a year
- ☐ 1-3 years
- ☐ 3-5 years
- ☐ More than 5 years

II. Awareness of CD/GI

2.1 Have you ever heard of CD/GI? Check **yes** or **no**.

- ☐ YES (Proceed to section III) How did you hear about it? _____
- ☐ NO (Proceed to item 4.1)

2.2 If you answered **NO** to question 2.1, please proceed to **Section IV**.

III. Statements (Celiac Disease(CD) and Gluten Intolerance(GI) are the same)

If you answered **YES** to Question 2.1, you will find listed below a series of statements addressing various traits, symptoms and effects of Celiac Disease and gluten intolerance. For each statement please circle the number that indicates your level of agreement/disagreement that the statement is accurate in its description of CD/GI using the following scale: (1) Strongly Disagree (SD), (2) Disagree (D), (3) Don't Know (DK), (4) Agree (A), or (5) Strongly Agree (SA).

Statements connected with CD/GI	SD	D	DK	A	SA
3.1 Some people are genetically predisposed to CD/GI	1	2	3	4	5
3.2 CD/GI is a disorder of the autoimmune system	1	2	3	4	5
3.3 CD/GI affects the bladder	1	2	3	4	5
3.4 CD/GI symptoms show up as a reaction to eating foods which contain gluten	1	2	3	4	5
3.5 Hair-like structures called villi in the small intestine lose their ability to digest food in persons with CD/GI	1	2	3	4	5
3.6 CD/GI is a food allergy	1	2	3	4	5
3.7 CD/GI symptoms may include chronic diarrhea, vomiting, fatigue and/or weight loss	1	2	3	4	5
3.8 Diagnosis of CD/GI requires that the individual has all symptoms	1	2	3	4	5

3.9 CD/GI affects only children	1	2	3	4	5
3.10 Older children with CD/GI may have psychosocial problems (ex. Family problems, irritability, difficulties with peers)	1	2	3	4	5
3.11 Adults with CD/GI experience only the symptom of fatigue	1	2	3	4	5
3.12 There is an increased risk of other autoimmune diseases if one has been diagnosed with CD/GI	1	2	3	4	5
3.13 CD/GI may be linked to an itchy skin condition	1	2	3	4	5
3.14 There is an effective medication that can be taken to treat CD/GI	1	2	3	4	5
3.15 CD/GI may be linked to various neurological diseases, such as Seizure Disorder	1	2	3	4	5
3.16 A gluten-free diet is the only effective treatment for CD/GI	1	2	3	4	5
3.17 Accurate diagnosis of CD/GI is often disguised by other medical	1	2	3	4	5
3.18 A majority of physicians under-diagnose CD/GI	1	2	3	4	5
3.19 CD/GI affects 1 in 5 Americans	1	2	3	4	5
3.20 Stressful events can trigger the onset of CD/GI	1	2	3	4	5
3.21 Gluten is found in wheat flour	1	2	3	4	5
3.22 Exercising daily will eliminate all the symptoms of CD/GI	1	2	3	4	5
3.23 People with CD/GI can eat foods with barley to avoid symptoms	1	2	3	4	5
3.24 People with Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder should avoid a gluten-free diet	1	2	3	4	5
3.25 If you test negative for CD/GI once, you will never get it	1	2	3	4	5
3.26 People who believe they have CD/GI should go on a Gluten-free diet before being tested	1	2	3	4	5
3.27 People with CD/GI must eat a Gluten-free diet for the rest of their lives	1	2	3	4	5
3.28 All people with CD/GI are underweight	1	2	3	4	5
3.29 Gluten-free products are becoming more available in supermarkets	1	2	3	4	5
3.30 Parents, siblings and/or children of confirmed CD/GI patients are at higher risk of the disease	1	2	3	4	5

IV. Personal Characteristics (For each question listed below, please check the box that represents the most appropriate response regarding your characteristics.)

4.1 What is your current age? _____

4.2 What is your gender?

Female ☐ Male ☐

4.3 Which ethnic group do you identify with?

Caucasian ☐

African-American ☐

Hispanic ☐

Biracial ☐

Native American ☐

Asian/Pacific Islander ☐

Other (Please specify) _____

4.4 What is your marital status?

Single (never married) ☐

Married ☐

Divorced ☐

Widowed ☐

Separated ☐

4.5 Do you have children? ☐ Yes ☐ No

If yes, how many? (both minor and adult)

Number of children _____

4.6 What is the highest level of education you completed?

Some High School ☐

High School/GED ☐

Some College ☐

Associates degree ☐

Bachelors degree ☐

Masters degree ☐

Doctoral degree ☐

Other (Please specify) _____

4.7 How many miles did you travel from home to the Metabolic Center?

Less than 10 ☐

11-50 ☐

51-100 ☐

More than 100 ☐

4.8 What is your current occupation or profession?

4.9 Which of the following categories best represents your total annual family income?

<\$25,000 ☐

\$25,000-\$49,999 ☐

\$50,000-\$74,999 ☐

\$75,000 or more ☐

Please review your responses to ensure that all questions have been answered.

Thank You for taking your time to help our community.

If you would like to learn more about Celiac Disease and gluten intolerance, please complete this section and return to a staff member.

Preference	Yes	No
Printed Material	<input type="checkbox"/>	<input type="checkbox"/>
E-mail (a)	<input type="checkbox"/>	<input type="checkbox"/>
Address (b)	<input type="checkbox"/>	<input type="checkbox"/>
Training classes at clinic	<input type="checkbox"/>	<input type="checkbox"/>

(a) My e-mail is _____

(b) My address is _____

APPENDIX B

PARTICIPANTS REPORTED OCCUPATION/PROFESSION

Occupation/Profession	Count	Occupation/Profession	Count	Occupation/Profession	Count
Retired	38	Chemical Plant	1	Pipe Fitter	1
Sales	28	Childcare	1	Plant Operator	1
Housewife	24	Civil Judicial	1	Plumber	1
Teacher	20	Clerical	1	Principal	1
Manager	18	CMA	1	Production	1
Student	14	Consultant	1	Project Estimator	1
Secretary	8	Counselor	1	Psychologist	1
Self Employed	8	CRC	1	Receptionist	1
Private	7	Dance Instructor	1	Recovery Work	1
RN	7	Dietician	1	Reporter	1
Assistant	6	Electrician	1	Retail	1
Business Owner	5	EMS	1	School Bus Driver	1
Librarian	5	EMT	1	Seamstress	1
Medical	5	Engineer	1	Security Officer	1
IT	4	Farmer	1	Service Tech	1
LPN	4	Fire Marshall	1	Sitter	1
Tech	4	Fireman	1	Sonographer	1
Bus Driver	3	Fitness Coach	1	Stock Clerk	1
Customer Service	3	Graphic Designer	1	Telecommunication	1
Lawyer	3	Health Food	1	Teller	1
Police officer	3	Healthcare	1	Therapist	1
Accounting Clerk	2	Instructor	1	Unemployed	1
Billing	2	Laid Off	1	Welder	1
Claims Rep	2	Law	1		
Coach	2	Lawn care	1		
Coordinator	2	Loan originator	1		
CPA	2	Marine Surveyor	1		
Doctor	2	Massage Therapist	1		
Finance	2	Medical Records	1		
Government	2	Metal Worker	1		
Lab Tech	2	MLT	1		
Real Estate	2	Mortgage Underwriter	1		
Sheriff	2	Notary	1		
Supervisor	2	NP	1		
University	2	Nurse	1		
Volunteer	2	Office Clerk	1		
Activities Director	1	OLOL	1		
Auditor	1	Personal Trainer	1		
Banker	1	Petroleum Dist	1		
Barber	1	Phlebotomist	1		
Business Office	1	Photographer	1		
Caregiver	1	PI	1		

VITA

Sheetal Malini Verma-Bueche was born in Baton Rouge, Louisiana, on April 29, 1972, to Satish Verma and Nirmala Verma. She is a 1990 graduate of Baton Rouge Magnet High school. In 1995, she earned a Bachelor of Science degree in psychology from Louisiana State University, and in 1997 she earned a Master of Social Work from Louisiana State University. Sheetal is the truly blessed mother of Logan Jalik and Malini Laila and wife of James Bueche, Jr. She is the proud younger sister of Madhu Bhushan and Mukul Verma. She was awarded the degree of Doctor of Philosophy in the Louisiana State University Fall 2011 Commencement Ceremony.