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What is the Relationship Between Quality of Life and Coping Strategies of Adults with Celiac Disease Adhering to a Gluten Free Diet?

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WHAT IS THE RELATIONSHIP BETWEEN QUALITY OF LIFE AND COPING STRATEGIES OF ADULTS WITH CELIAC DISEASE ADHERING TO A GLUTEN FREE DIET?

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By

Melissa Marie Smith

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WHAT IS THE RELATIONSHIP BETWEEN QUALITY OF LIFE AND COPING STRATEGIES OF ADULTS WITH CELIAC DISEASE ADHERING TO A GLUTEN FREE DIET?

By

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Approved March 25, 2009

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ABSTRACT

WHAT IS THE RELATIONSHIP BETWEEN QUALITY OF LIFE AND COPING STRATEGIES OF ADULTS WITH CELIAC DISEASE ADHERING TO A GLUTEN FREE DIET?

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March 25, 2009

Dissertation Supervised by Linda Goodfellow, PhD, RN

Until recently, celiac disease was thought to be rare in the United States. However over the past ten years, the reported prevalence has increased from 1 in 4600 persons to 1 in 133 persons. The latest estimate makes the prevalence comparable to the prevalence in Europe, where the disease is considered to be common.

Celiac disease is a chronic illness occurring in genetically susceptible persons resulting in inflammatory changes in the upper small bowel as a consequence of intolerance to the gliadin in ingested wheat, rye, and barley. Fortunately, celiac disease can be effectively managed by strict adherence to a gluten free diet. However, dietary management can be quite challenging.

The present descriptive, correlational research study included 156 adults self-reporting a diagnosis of celiac disease. The purpose of this study was to examine factors and perceived causes that interfere with adherence to a gluten free diet, to identify coping strategies, and to examine the relationship between coping strategies and quality of life.

The theoretical framework was a combination of two theoretical models: 1) Lazarus model of stress and 2) the model of behavioral self-regulation by Carver and Sheier. Instruments used were the Demographic Information and Health and Diet History Questionnaire, the Psychological General Well-Being Index, and the Brief COPE.

Results from the study indicated that problems outside the home, especially in restaurants and the expense of gluten free foods are factors that interfere with dietary adherence. A moderate negative relationship was found between quality of life and stress with 54 percent of participants reporting a minimal amount of stress. Emotion focused coping was found to have a negative effect on quality of life.

Recommendations based on research findings suggest further investigation of the negative relationship between quality of life and stress with a more controlled sample. Nurses can also investigate the use of cognitive-behavioral interventions to decrease the negative effects of emotion focused coping.

DEDICATION

This dissertation is dedicated to my sons, Jeremy and Joshua.

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LIST OF ABBREVIATIONS

AEA Antiendomysium antibody

AGA Antigliadin antibody

AIDS Acquired Immune Deficiency Syndrome

EMA Antiendomysial antibody

GF Gluten free

GFD Gluten Free Diet

GIG Gluten Intolerance Group

HIV Human immunodeficiency virus

HLA Human leukocyte antigen

IBD Inflammatory Bowel Disease

IgA Immunoglobulin A antibody

IgG Immunoglobulin G antibody

NIH National Institute of Health

PGWBI Psychological General Well-Being Index

QOL Quality of Life

SSL Secure sockets layer

tTG anti-tissue transglutaminase antibody

Chapter 1

Introduction

1.1 Background of the Study

Although it can occur at any age, celiac disease is most often recognized as a disorder affecting the pediatric population. The demonstrated prevalence in children under age 5 is reported to be 0.9 percent (Hoffenberg, MacKenzie, Barriga, Eisenbarth, Bao, Haas et al., 2003). Celiac disease can occur in either gender, but women predominate over men with a 3:1 ratio. In the United States (US), celiac disease has been regarded as an uncommon disorder in adults; however, it is quite common in Europe. In 1991, the prevalence was 1 in 4, 600 of the US population (Green, Stropoulos, Panagi, Goldstein, McMahon, Absan et al., 2001). In the United Kingdom, prevalence is believed to be at least 1 in 100 of the population (Mendoza, 2005). Dickey, Hughes, and McMillan (2001) reported that based on serologic screening studies the worldwide prevalence is estimated to be at 1 in 166. Fasano et al. (2003) reported the prevalence of celiac disease in the US to be 1 in 133, which is comparable to the prevalence demonstrated in Europe. Interestingly, due to the wide range of clinical manifestations diagnosis is often delayed with a reported mean of 11 years before diagnosis (Green & Jabri, 2003; Green et al., 2001). For persons living in the US, diagnosis normally occurs in the 4th and 6th decades of life (Green et al., 2001). Public awareness of celiac disease was brought to the forefront June 28-30, 2004 with the National Institutes of Health (NIH) Consensus Development Conference Statement of Celiac Disease. Issues of protean manifestations, epidemiology, diagnostic testing, and treatment of celiac disease were initially addressed by the NIH (NIH, 2004). Therefore, the increased prevalence (0.5 to 1.0 percent of the United States population) in celiac disease diagnosis is related to an increased awareness in the disease and serology testing, which has resulted in earlier detection.

It is unclear whether celiac disease is encountered in specific ethnic minorities. Brar, Lee, Lewis, Bhagat, and Green (2006) identified nine (1.3 % of all patients) African-American patients with celiac disease from an anonymous database of 700 celiac disease patients. Other studies have indicated that the prevalence among individuals immigrating to the United Kingdom from Northern India, Pakistan, and Bangladesh may be as high as in white Caucasians (Butterworth, Banfield, Iqbal, & Cooper, 2004). Prevalence of celiac disease among ethnic minorities in the United States needs to be determined.

In addition, factors that influence dietary compliance need to be assessed in order to evaluate affects on quality of life (Brar et al.). Although collecting information related to race or ethnicity was considered, it was not obtained because of the stated discrepancies related to prevalence and the need to identify factors that influence dietary compliance in order to evaluate affects on quality of life. Finally, race or ethnicity was not the focus of this study.

Celiac Disease

Celiac disease is a chronic illness that often occurs in genetically susceptible persons which results from inflammatory changes in the proximal small bowel (Bazzigaluppi, Roggero, Parma, Brambillasca, Meroni, Mora et al., 2006; McGough & Cummings, 2005). Celiac disease has also been shown to involve the entire small bowel

(Green & Jabri, 2003). It is a systemic disease related to a permanent intolerance to the alcohol-soluble protein fractions (prolamin) of wheat (gliadin), rye (secalin), and/or barley (hordein) that are ingested, thus initiating damage to small bowel mucosa (Howdle, 2002; Meize-Grochowski, 2005; Mendoza, 2005). Celiac disease can be effectively managed by diet. Management requires strict adherence to a gluten free diet, which eliminates exposure to the prolamin fraction of proteins found in wheat, rye, and barley with some individuals also demonstrating sensitivity to oats (avenins) (Howdle, 2002; McGough & Cummings, 2005; Mendoza, 2005).

Classifications of Clinical Manifestations

Because celiac disease is a multisystem disorder, it may present with varied clinical manifestations. Categories, which are described later, have been developed to better manage the disease (Libonati, 2007; Meize-Grochowski, 2005).

In addition to diarrhea and anemia, other classic signs and symptoms of celiac disease manifested in adults include weight loss, bloating, abdominal pain, and steatorrhea. Atypical signs and symptoms include urinary tract infections, joint pain, weight gain, constipation, headache, irritable bowel syndrome, gastroesophageal reflux disease, and depression (Libonati, 2007). Associated disorders include type 1 diabetes, Down's syndrome, and chronic liver disease specifically biliary cirrhosis (Dickey & McMillan, 1998; Gale, Wimalaratna, Brotodiharjo, & Duggan, 1997; Talal, Murray, Goeken, & Sivitz, 1997). Complications related to celiac disease include small bowel adenocarcinoma, esophageal and oropharyngeal squamous carcinoma, non-Hodgkin lymphoma, osteoporosis, and neurologic disorders such as peripheral neuropathy, cerebral ataxia, epilepsy and migraines (Alaedini & Green, 2005; Green & Jabri, 2003; Mendoza, 2005).

Complications

Malignancy

Celiac disease carries an 80-fold greater risk of small bowel adenoma than the general population (Green & Jabri, 2003; Green et al., 2001). The major celiac disease lymphoma (T-cell lymphoma) responds poorly to chemotherapy and is rapidly fatal (Egan, Walsh, Stevens, Connolly, Egan, & McCarthy, 1995; Swinson, Slavin, Coles, & Booth, 1983). Evidence exists to suggest that treatment with a gluten free diet decreases mortality from small bowel adenocarcinoma making it comparable to the general population (Biagi, Campanella, Martucci, Pezzimenti, Ciclitira, Ellis et al., 2004; Corraro, Corazza, & Bagnardi, 2001). Unfortunately, this risk reduction does not seem to hold true for non-Hodgkin's lymphoma (Catassi, Fabiani, Corrao, Barbato, De Renzo, Carella et al., 2002). A nine fold increased risk of non-Hodgkin's lymphoma has been reported in celiac patients adhering to a gluten free diet over an average of approximately five years (Green, 2005; Green, Fleischauer, Bhagat, Goyal, Jabri, & Neugut, 2003).

Osteoporosis

Osteoporosis is an important complication associated with celiac disease due to calcium malabsorption. The associated decrease in bone density increases the risk for fracture (Alaedini & Green, 2005; Green & Jabri, 2003; Mendoza, 2005). Studies have shown that osteoporosis and low bone mineral density vary according to age and gender. Premenopausal women are least likely to be affected; however, postmenopausal women and men appear to be comparable in their susceptibility. Men appear to be more severely affected than women. In addition, postmenopausal women with celiac disease demonstrate bone mineral density a half standard deviation lower than normal postmenopausal women. Although improvement in bone mineral density has been noted with adherence to a gluten free diet, it may not be possible to restore mineral bone density to normal (Ciacci, Maurelli, Klain, Savino, Salvatore, Mazzacca et al., 1997; Meyer, Stavropolous, Diamond, Shane, & Green, 2001; Valdimarsson, Lofman, Toss, & Strom, 1996).

Fertility Problems

Fertility problems have been noted in both men and women with celiac disease. Women have presented with delayed menarche, premature menopause, amenorrhea, recurrent abortions, and fewer children. Low birth weight, increased perinatal mortality, and shorter duration of breast feeding have been described with patients with celiac disease. Men with celiac disease compared to men without the condition have been reported to have children with shorter gestation period and low birth weight (Ludvigsson & Ludvigsson, 2001).

Autoimmune Disorders

Patients with celiac disease are reported to have ten times the risk of developing an autoimmune disorder compared to the general population. When antibodies to gliadin are formed, the body treats those cells as a virus infection. This immune response damages surrounding tissue and establishes the potential occurrence for health problems throughout the body (Gluten Intolerance, 2007). Autoimmune disorders associated with celiac disease include type 1 diabetes, thyroid disease, cardiomyopathy, autoimmune liver disease, renal disease, and neurological disorders (Green & Jabri, 2003).

Immunologic mechanisms are implicated in the pathogenesis of celiac disease (Viljamaa, Kaukinen, Huhtala, Kyronpalo, Rasmussen, & Collin, 2005b). The common genetic predisposition shared by persons with celiac disease and autoimmune disorders is the HLA (human leukocyte antigen) alleles. Controversy exists as to correlation between gluten load and the development of autoimmune disease in celiac disease.

Untreated celiac disease is associated with increases in anti insulin antibodies and antibodies against thyroid peroxidase when compared to treated celiac disease (Toscano, Conti, Anastasi, Mariani, Tiberti, Poggi et al., 2000; Ventura, Magazu, Gerarduzzi, & Greco, 2002; Ventura, Magazzu, & Greco, 1999). Treatment with a gluten free diet has been associated with re-growth of hair in patients with alopecia as well as reversal of severe liver dysfunction (Barbato, Viola, Grillo, Franchin, Lo Russo, Lucarelli et al., 1998; Corazza, Andreani, Venturo, Bernardi, Tosti, & Gasbarrini, 1995; Kaukinen, Halme, Collin, Farkkila, Maki, Vehmanen et al., 2002). In contrast, however, a study conducted by Viljamaa et al.(2005b) did not support the association of gluten exposure to the prevalence of autoimmune disorders in celiac disease.

Neurological Manifestations

The endomysium is the fine connective tissue sheath enveloping a muscle fiber and nerve fibers. Patients with celiac disease produce endomysium antibodies that may cause an autoimmune response to muscles and nerves, which would weaken the defenses of nerves against other toxins (Gluten Intolerance, 2007). Neurological manifestations have been described for over 100 years with Cooke and Smith (1966) highlighting the severity of neurological disease with the description of 16 cases, 8 of which died from severe, progressive neurological irritation. Fortunately, due to an increase in recognition and efforts aimed toward earlier diagnosis and treatment of celiac disease, severe nutritional abnormalities that lead to progressive neuropathy are increasingly rare (Grossman, 2008; Muller, Donnelly, Smith, Grundman, Holmes, & Toghill, 1996). Neurological complications are estimated to occur in approximately 6-10% of patients with celiac disease. There are a number of neurological manifestations; however, ataxia and peripheral neuropathy seem to be the most common manifestations described (Green et al., 2005). Interestingly, Cicarelli et al. (2003) reported no celiac disease patients with ataxia. Findings indicated that headache ($p < 0.05$), dysthymia ($p < 0.05$), and peripheral neuropathies (cramps, paresthesia, weakness, and hyporeflexia) ($p < 0.001$) were the most common manifestations. Celiac disease patients, adhering to a strict gluten free diet, experienced less frequent dysthymia ($p < 0.05$), cramps ($p < 0.001$) and weakness ($p < 0.05$); however, there was no improvement in paresthesia or hyporeflexia (Cicarelli et al., 2003).

Diagnosis

The most important step in diagnosing celiac disease is recognition of the many clinical signs and symptoms of the disease. There is no single test for all individuals that can conclusively establish the diagnosis or negate its presence. Characteristic changes in small bowel mucosa and positive serologic tests are used in diagnosing celiac disease (Green & Jabri, 2003).

Endoscopy with Intestinal Biopsy

Proximal intestine biopsy is the major criterion for diagnosis of celiac disease (Libonati, 2007). Villous atrophy with crypt hyperplasia and intraepithelial lymphocytosis are the major histological characteristics of celiac disease. However, according to Marsh (1992), there is a range of histological abnormalities associated with celiac disease. Histological abnormalities range from normal villous mucosa with epithelial lymphocytosis all the way through partial villous atrophy to total villous atrophy. Confirmation of celiac disease is made when mucosal abnormalities improve once a gluten free diet is introduced (Green & Jabri, 2003; Marsh, 1992).

Serology Testing

Serology tests can be used to manage patients with celiac disease and to help establish the diagnosis of celiac disease. Antibodies against endomysium are nearly 100 % specific and highly sensitive, making their presence useful in diagnosing celiac disease (AGAI, 2006; Libonati, 2007). Celiac disease serology tests include total serum immunoglobulin A antibody (IgA), IgA anti-tissue transglutaminase antibody (tTG), IgA antiendomysial antibody (EMA), and IgA anti-gliadin antibody (AGA) (Green & Jabri, 2003; Libonati, 2007).

Antigliadin antibody is less accurate than the anti-tissue transglutaminase antibody; however, AGA is less expensive. Therefore, AGA can be used as a screening test for an indication of an immune reaction to gliadin. Anti-tissue transglutaminase antibody has 98 % sensitivity in adults with specificity between 95% and 99%. Because analysis is computer generated, tTG is more cost effective than EMA, which requires human evaluation (Libonati, 2007).

Sensitivity for EMA exceeds 90% with specificity over 95%. The AGA has sensitivity between 70 to 85% with specificity between 70 to 90% for celiac disease. Measurement of total IgA establishes whether a person has IgA antibody deficiency (Libonati, 2007). If an individual has an IgA deficiency, either the IgG EMA and/or the

IgG tTG can be performed because both have exceptional sensitivity and specificity; however, both are less sensitive and specific than the IgA tests in individuals with normal IgA levels (AGAI, 2006).

Additional tests can be performed with suspected celiac disease. Negative serology tests and ambiguous biopsy results can occur as a consequence of treatment with a gluten free diet prior to testing. Human leukocyte antigen (HLA) alleles., HLA-DQ2 or HLA-DQ8, are shared by over 98% of individuals with celiac disease (Green & Jabri, 2003). Unfortunately, these alleles are seen more commonly in populations with both type 1 diabetes and celiac disease. The genetic markers (DQ2 and DG8) have high sensitivity but poor specificity and are rarely useful clinically (Libonati, 2007).

Gluten Free Diet Trial

Individuals should maintain a regular diet until serology testing and biopsy are completed. Once a gluten free diet is introduced, individuals should note dramatic clinical improvement. Additionally, improvement should be noted in small bowel mucosal abnormalities and serology tests. If repeat serology and biopsy tests are inconclusive or if symptoms persist, a gluten free diet can be introduced. Gluten sensitivity would be indicated with reduction of symptoms (Libonati, 2007). The most common cause of failure of symptoms to abate, of histology to fail to improve, or of serology titers to decrease is dietary non-compliance.

Patient Classification and Diagnostic Testing

Although classifications of patients with common characteristics of celiac disease exist, their clinical significance has not been determined. The classifications are: (1)

classic celiac disease; (2) celiac disease with atypical symptoms; (3) silent celiac disease; and (4) latent celiac disease.

An individual with c*lassic celiac disease* presents with major clinical manifestations and resultant consequences of gastrointestinal malabsorption. Diagnosis is confirmed by serology testing, small bowel tissue biopsy indicating villous atrophy, and improvement of symptoms on a gluten free diet. Individuals presenting with *atypical celiac disease* have few if any gastrointestinal symptoms. Diagnosis is confirmed by serology testing, small bowel tissue biopsy indicating intestinal inflammation and villous atrophy, and improvement in histology on a gluten free diet (NIH, 2004).

Silent celiac disease is characterized by positive serology tests with inflammation or villous atrophy on biopsy and no noticeable symptoms. An individual with *latent celiac disease* has positive serology tests without villous atrophy on biopsy. Although these individuals are asymptomatic, they may develop symptoms, tissue abnormalities, or complications of chronic malabsorption of iron, calcium or folic acid at a later date (NIH, 2004).

Treatment

Management of Celiac Disease

Management of celiac disease requires life-long adherence to a strict gluten free diet. Wheat, barley, and rye need to be avoided (AGAI, 2006). Although oats are generally not toxic to individuals with celiac disease, liberal use is often avoided because of difficulty in guaranteeing that the oats have not been contaminated during processing by other grains (Janatuinen, Kemppainen, Julkunen, Kosma, Maki, Heikkinen et al., 2002). Although most individuals with celiac disease quickly respond to a gluten free diet, the rate of response can vary among individuals (Green & Jabri, 2003).

According to the National Institutes of Health (NIH) (2004), six key elements are essential in managing individuals affected by celiac disease. The key elements are as follows:

- **C**onsultation with a skilled dietitian
- **E**ducation about the disease
- **L**ifelong adherence to a gluten free diet
- **I**dentification and treatment of nutritional deficiencies
- **A**ccess to an advocacy group
- **C**ontinuous long-term follow-up by a multidisciplinary team.

Consultation with a skilled dietitian will help individuals with celiac disease identify foods to avoid and develop a diet plan. It is preferable that the dietitian be familiar with celiac disease in order to effectively advise individuals. Knowledge about celiac disease and a gluten free diet is related to improved self-management. Advocacy groups provide emotional and social support and may also serve as a valuable tool for augmenting adherence to a gluten free diet. Individuals need to be assessed and treated for nutritional deficiencies such as iron, calcium, phosphorus, folate, cobalamin (B12), and fat soluble vitamins (NIH, 2004).

After the initial diagnosis and treatment regimen, individuals need to follow-up, periodically, with their health care provider for assessment of symptoms, dietary adherence, and possible complications. Serial serology tests are used to monitor response (NIH, 2004). Dietary antibodies such as AGA IgG and IgA usually normalize within 2 to 6 months after starting a gluten free diet and increase with a gluten challenge. The auto-antibodies, EMA and tTG, may take up to a year to normalize after starting a gluten free diet. They also respond to a gluten challenge. The EMA and tTG auto-antibodies better correlate with the degree of villous atrophy. Individuals with proven celiac disease who do not respond to a gluten free diet need to be further evaluated for refractory celiac sprue, ulcerative enteritis, T-cell lymphoma, and other gastrointestinal cancers (Pietzak, 2005).

Dietary Compliance

A gluten free diet can be limiting because it requires exclusion of staple foods such as bread, pasta, and cereal, which must be replaced with gluten free substitutes. Substitutes consist of cereals made from rice, millet (*Panicum milaiceum)*, maize and buckwheat (*Fagopyrum esculentum* Moench). Additional grains, seeds, and starchy sources include amaranth (*Amaranthus caudatus* L.), teff (*Eragrostis tef*), quinoa (Chenopodium quinoa Willd.), soyabean, potato, plantains (*Musa paradisiaca* L.), nuts, and tapioca (made from cassava (*Manihot escu*lenta) root (McGough & Cummings, 2005).

Another barrier to adherence of a gluten free diet includes ambiguous labels on prepared foods. The label may not indicate if it contains wheat or if it could have been processed with wheat. The “Food Allergen Labeling and Consumer Protection Act” was signed by President Bush on August 2, 2004 requiring food manufactures, within the next 2 years, to clearly identify whether a product contained any of the top eight food allergens (milk, eggs, fish, crustacean shellfish, tree nuts, peanuts, soybeans, and wheat). Additionally, the FDA issued rules defining and permitting the term “gluten-free” on food labels (Allergen, 2004).

Multidisciplinary or regular follow-up of individuals with celiac disease can improve dietary compliance. Regular follow-up provides assessment for nutritional deficiencies and complications. It also provides an opportunity for reinforcing the need for strict adherence to a gluten free diet and for educating individuals in the avoidance of gluten containing foods (Pietzak, 2005).

Difficulties with dietary compliance, lack of disease and dietary education, and lack of support for individuals diagnosed with celiac disease are stressors that create barriers to an improved quality of life. Various coping strategies can be implemented by individuals in an attempt to deal with these stressors. Identification of coping strategies is essential for identifying nursing interventions and/or educational needs to aid in managing these stressors in order to improve quality of life. Therefore, this study assessed coping strategies of adults with celiac disease who are attempting to adhere to a gluten free diet. The strategies addressed included: 1) problem focused coping, 2) emotion focused coping, and 3) avoidance coping.

1.2 Purpose of the Study

This study examined: 1) factors and perceived causes that interfere with adherence to a gluten free diet for adults with celiac disease, 2) coping strategies of adults with celiac disease, and 3) the relationship between quality of life and coping strategies of adults with celiac disease adhering to a gluten free diet.

1.3 Research Questions

The research questions for this study were as follows:

1. What are the perceived causes that interfere with adherence to a gluten free diet?
2. What is the relationship between acceptance of the diagnosis of celiac disease and quality of life in adults with celiac disease on a gluten free diet?

3. What is the difference in acceptance between adults with celiac disease on a gluten free diet for 6 months to one year compared to adults with celiac disease on a gluten free diet greater than one year?
4. What is the relationship between coping strategies and quality of life in adults with celiac disease adhering to a gluten free diet?

1.4 Definition of Terms

The terms used in this study were defined as follows:

Diagnostic criteria for celiac disease: In order to define celiac disease as strictly as possible, thereby decreasing reporting errors, patients must self-report having had an initial endoscopy with a small bowel biopsy and / or a serum anti-tissue transglutaminase antibody (tTG), or both with a follow study that included a repeat endoscopy with a small bowel biopsy and or a serum tTG, or both.

Gluten free diet: Self-reported elimination of wheat, barley, rye, and oats from daily consumption of foods.

Quality of life: The worth, meaning, or satisfaction obtained from living (Venes, 1997). In this study, quality of life was measured by the dimensions of anxiety, depressed mood, positive well-being, self control, general health, and vitality with an overall index for general well-being in the Psychological General Well-Being Index (PGWBI), which was developed to evaluate perceived well-being and distress (Dupuy, 1984).

Psychological Stress: Is a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being (Lazarus & Folkman, 1984, p. 21), which interferes or threatens goal oriented efforts (Carver & Scheier, 2001). Strict adherence to a gluten free diet may be stressful; therefore, stress was measured on a four-point Likert scale from 1 to 4. Participants rated the amount (none = 1, 2 = minimal, 3 = moderate, and 4 = large) of stress relative to following a gluten free diet over the past month.

Coping: Constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person (Lazarus & Folkman, 1984, p. 141). The behavioral and cognitive efforts including self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame, may be used by adults with celiac disease adhering to a gluten free diet. Coping was measured in this study by the Brief COPE Inventory (Carver, 1997).

Problem focused coping: A process by which one actively attempts to eliminate or evade the stressor or to amend its effects (Lazarus & Folkman, 1984) through active coping, planning, and/or use of instrumental social support as measured by the Brief COPE (Carver, 1997).

Emotion focused coping: A process by which one actively attempts to regulate the emotional response to the stressor (Lazarus & Folkman, 1984) through use of emotional social support, positive reframing, acceptance, denial, and/or religious coping as measured by the Brief COPE (Carver, 1997)

Avoidance: A process of averting further contact with, or thought of the stressor through venting, self-distraction, and/or behavioral disengagement (Carver & Scheier, 2001), measured by the Brief COPE (Carver, 1997).

1.5 Assumptions

The assumptions for this study were as follows:

1. Adults with celiac disease adhering to a gluten free diet have the knowledge, skills, and experience to respond to questions related to celiac disease and adherence to a gluten free diet.
2. Adults with celiac disease adhering to a gluten free diet are willing to provide accurate information related to their celiac disease diagnosis and adherence to a gluten free diet.
3. Strict adherence to a gluten free diet may be a stressor.
4. Persons completing the internet survey are the actual patients with diagnosed celiac disease adhering to a gluten free diet.

1.6 Limitations

In this study, data was collected via three questionnaires that were linked to the Gluten Intolerance Group (GIG®) website on the Internet (GIG, 2007b). Because the questionnaires were completed online, there was a possibility that participants would not complete the entire compliment of questionnaires. In addition, the investigator was not able to encourage participants to complete all questionnaires entirely. Although specific instructions were included on the cover page and on each questionnaire that guided the participants, there was no control over the environment in which questionnaires were completed. Participants may have discussed their health or emotions prior to and/or while completing the questionnaires, which may have influenced their responses. An explanation or interpretation of questions may have been sought by participants from other individuals.

1.7 Significance to Nursing

The significance of this nursing research study lies in the potential for improving the quality of life for adults with celiac disease adhering to a gluten free diet by identification of useful coping strategies. Identification of coping strategies by adults with celiac disease adhering to a gluten free diet may provide categorization of coping strategies related to improved quality of life. Insight gained from learning about barriers to adherence to a gluten free diet and about how adults with celiac disease cope with adherence to a gluten free diet may help other adults with celiac disease and health care professionals to better understand how these barriers influence quality of life.

Findings from this study may help guide the advancement and testing of cognitive-behavioral interventions based on coping strategies of adults with celiac disease. Additionally, identification of coping strategies in relation to quality of life may help guide health care professionals to develop educational programs for adults with celiac disease adhering to a gluten free diet. The initiation of cognitive-behavioral interventions and educational programs may help to improve the quality of life for adults with celiac disease in managing the stressors associated with dietary adherence. Additional research may be inspired from this perspective and population foremost in discoveries into quality of life and coping strategies into adults not clinically diagnosed with celiac disease but adhering to a gluten free diet.

Chapter 2

REVIEW OF LITERATURE

2.1 Introduction

Within a relatively short period of time, the reported prevalence of celiac disease has increased in the adult population due to an increased awareness of celiac disease and advancements in serologic screening tests. This increased prevalence has brought to the forefront the recognition of numerous barriers related to adherence to a gluten free diet. Lifelong adherence to a strict gluten free diet requires major lifestyle changes. These changes in and of themselves have the potential of becoming significant stressors. Studies to date have indicated that strict adherence to a gluten free diet affects perceived well-being and is often considered to be a burden.

Although there has been discussion related to difference in coping styles, studies have focused on quality of life and not on coping strategies. The review of literature is a summary of the impact of disease on psychological well-being to address the burden related to dietary compliance, barriers related to dietary compliance, and coping. The perceived stress related to adherence to a gluten free diet for adults with celiac disease guides the coping response. For this study the strategies assessed were 1) problem-focused coping, 2) emotion-focused coping, and 3) avoidance coping. Barriers to dietary compliance are discussed in different contexts and disciplines with the conclusion of the discussion specifically related to one study addressing barriers to adherence to a gluten free diet. Because there are few studies specifically related to coping and celiac disease, studies of coping in different contexts and disciplines were presented. Finally, gaps in the literature precede the chapter summary.

2.2 Conceptual Framework: Theory Based Coping Strategies

The conceptual framework for this study was guided by the combination of two theoretical models as described by Carver, Scheier, and Weintraub (1989). The models were: 1) the Lazarus model of stress (Lazarus, 1966) and 2) a model of behavioral self-regulation (Carver & Scheier, 1981, 1983, 1985; Scheier & Carver, 1988). The theoretically based approach to assessing coping strategies as described by Carver et al. assesses various ways that people respond to stress, coping dispositions, and situation-specific coping tendencies. Although the theory shares conceptual similarities with other theories, specifically Lazarus and Folkman, it distinguishes among several distinct aspects of active coping and responses that may impede or interfere with active coping. It is the theory described by Carver et al. that served as the basis for assessing coping strategies in this study.

Model of Stress

According to Lazarus and Folkman (1984), the proposed meaning of stress is psychological in nature. Stress is a relationship between the person and the environment that is evaluated by the person as being exhausting or greater than one’s resources and jeopardizing one’s well-being. The underlying cause of psychological stress is based on two processes that intercede between the person-environment relationships. These processes are cognitive appraisal and coping. Cognitive appraisal is an evaluative process that determines why and to what extent a person-environment event is stressful (Lazarus & Folkman). Coping is the process by which the individual manages the person-environment relationship and the emotions generated by the appraised stressful event (Lazarus & Folkman, 1984, p.19).

Cognitive Appraisal

Cognitive appraisal is a continuous evaluative process that provides meaning or significance to a specific event. Although two main evaluative processes are identified as primary appraisal and secondary appraisal, it is important to understand neither is more important nor does one precede the other. Lazarus and Folkman (1984) identified three types of primary appraisal. They were identified as irrelevant, benign-positive, or stressful. Irrelevant appraisal occurs when one determines that a specific event with the environment has no repercussion for the individual's well-being. Benign-positive appraisals occur if the outcome of the specific event with the environment preserves or enhances well-being or has potential to do so. Threat relates to anticipated harm or loss, which manifests as untoward complications related to non-adherence to a gluten free diet, which threatens future well-being. Finally, challenge requires coping efforts similar to those of threat; however, it is characterized by positive emotions. Once again, it is important to note that threat and challenge can occur simultaneously. Secondary appraisal is a complex evaluative process in which the individual considers available options, determines whether or not the options will achieve the intended outcome, and considers whether a specific plan or plans can be effectively implemented.

Definitions of Coping

Coping has been defined in various ways by researchers. Researchers using the trait approach or psychodynamic conceptualizations define coping as routine problem-solving thoughts and actions (Vaillant, 1977). An example of trait measure is coping-avoiding in which coping is evaluated in the course of a single feature (Goldstein, 1973). Because trait conceptualizations and measures are unidimensional, they lack the ability to effectively reveal the multidimensional quality of coping applied in real-life situations (Lazarus & Folkman, 1984).

Researchers using the process approach to coping highlight a transactional experience with coping efforts continually changing in order to meet emergent demands of a stressor (Penley, Tomaka, & Wiebe, 2002). Lazarus and Folkman (1984) define coping as "*constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person"* (p. 141). It is believed that the process-oriented approach addresses limits of the traditional approach. Two major functions of coping are addressed in the process-oriented approach. Efforts to modify the stressful situation are referred to as problem-focused coping. Efforts to modify the emotional distress related to the stressful situation are referred to as emotion-focused coping (Folkman, 1984; Lazarus, 1993; Lazarus & Folkman, 1984; Penley et al., 2002).

First, it is process-oriented as addressed by *constantly changing* and *specific* demands. Second, there is a *distinction between coping* and *automatized adaptive behavior*. This is accomplished by limiting coping to demands that are appraised as taxing or exceeding a person's capabilities. Third, in an effort to avoid *confusing coping with outcome*, coping is defined as *efforts* to manage. Therefore, coping can include anything that a person does or thinks, regardless of the outcome. Fourth, the use of *manage* avoids associating coping with mastery. As a result, managing can involve minimizing, avoiding, and accepting the stressor as well as attempting to master the environment (Lazarus & Folkman, 1984). Because the dissertation study examined the relationship between quality of life and coping strategies for adults with celiac disease on a gluten free diet, the process approach was used. The assumption being that adherence to a gluten free diet may be stressful.

Coping

Coping is the process of implementing the appraisal response. The process has three main features. First, observations and assessments are concerned with what an individual actually thinks or how an individual acts. Second, the appraisal or action is analyzed within a specific context. Third, a process indicates change in coping thoughts and behaviors as the stressful event occurs (Lazarus & Folkman, 1984). The two main functions of coping are to manage or alter the problem within the environment causing the stress and to manage the emotional response to the problem. These two types of coping are identified as problem-focused coping and emotion-focused coping.

Coping Forms

Problem-focused coping and emotion-focused coping are two of the coping strategies examined in this study. Both coping strategies are recognized within the model of stress and the self-regulation of behavior. The third coping strategy (avoidance), which is described by Carver et al. (1989), is discussed later. Problem-focused coping is similar to problem-solving; however, it includes strategies that are directed inward and not solely on the environment. Emotion-focused coping is used to manage the emotional distress associated with a stressful event (Lazarus & Folkman, 1984). A stressful event usually brings forth both forms of coping. However upon appraisal of a stressful event, problem-focused coping is more likely when an individual determines that something constructive can be done; where as, emotion-focused coping is more likely when an individual determines that change cannot occur and the stressful event must be endured (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984).

Self-Regulation of Behavior

Carver and Scheier (2001), define stress in self-regulatory terms as a condition that exists when something interferes with attainment of a goal or causes one to move away from a goal. Threat is defined as doubt toward achieving a goal, while loss is defined as inability to achieve a goal. Because the stressful nature of challenge is considered to be questionable, it is disregarded in the self-regulation theory. Both problem-focused and emotion-focused coping are recognized in self-regulatory behavior; however, problem-focused coping is reflective of continued commitment to threatened goals by the stressor. The purpose of emotion-focused coping is to decrease the level of stress. Coping is the response to an individual's perception of stress, which is a consequence of negative appraisal (Carver & Scheier, 2001). Carver and Scheier identify three principles believed to be of importance in their theory of behavioral self-regulation. The first principle relates to feedback that is described as information gained as a consequence of behavior. In other words, the consequence of the behavior helps one determine whether to continue, change, or discontinue the behavior, which either leads toward a goal or away from an undesired end. The second principle is that of heirarchicality. This principle is based on the idea that behavior serves higher goals in order to achieve higher level principles and purposes. Finally, expectancy and confidence constitute the third principle. If efforts at achieving a goal are in doubt, avoidance behavior is noted (Carver & Scheier, 2001). The Brief COPE scale differs at this point by adding three additional less useful coping responses (focus on and venting of emotions, behavioral disengagement, and mental disengagement), which relate to avoidance (Carver et al., 1989).

Avoidance

Even though the theoretically based theory as described by Carver et al (1989) recognizes both problem-focused coping and emotion-focused coping, it also identified another category of coping referred to as avoidance coping. Avoidance coping is used to avert further contact with, or thought of the stressor (Carver & Scheier, 2001). It is suspected that focusing on emotions, especially for long periods of time, can become maladaptive when it delays adjustment or deters implementation of more useful coping strategies. Behavioral disengagement is associated with the expectation of poor coping outcomes and is identified with expressions such as helplessness. Numerous activities exist that prevent an individual from thinking about the goal with which the stressor is interfering. Thus mental disengagement is considered to be a variation of behavioral disengagement. Disengagement from goals for extended periods of time through avoidance coping has resulted in increased stress compared to other forms of coping (Carver, Pozo, Harris, Noriega, Scheier, Robinson et al., 1993). Due to the numerous activities associated with mental disengagement, it should not be considered as a unitary class of behavior. Mental disengagement is not suppression of competing activities; it is taking one’s mind off the problem. Graue, Wentzel-Larsen, Bru, Hanestad and Søvik (2004) used four items to evaluate mental disengagement. Following is an example used: “I turn to substitute activities to take my mind off things” (p. 1314). Exploratory factor analysis was used to present the most meaningful factor content from original coping subscales (denial and mental disengagement) in a study to evaluate coping styles among adults with type 1and type 2 diabetes (Karlsen & Bru, 2002). Variables from the subscales denial/mental disengagement ($\alpha = 0.78$) included:

1) I refuse to believe that it has happened.
2) I pretend that it hasn’t really happened.
3) I say to myself “this isn’t real”.
4) I turn to work or other substitute activities to take my mind off things.
5) I daydream about things other than this.
6) I act as though it hasn’t even happened.
7) I go to the movies or watch TV, to think about it less (p. 251).

Examples provided by Carver et al. (1989) included daydreaming, sleeping, and immersion in TV. An example of application of the theory to this dissertation follows.

Application of Theory to Study

For this study, the assumption was made that strict adherence to a gluten free diet may be a stressful event. The harm/loss occurs with the diagnosis of celiac disease or the experience of symptoms related to the diagnosis. For example, an individual may experience fear and anxiety with the symptoms associated with and/or the diagnosis of celiac disease and the need for strict adherence to a gluten free diet to manage symptoms and/or the disease. There is also the fear and anxiety associated with potential complications of celiac disease not managed by adherence to a gluten free diet. However, challenge may also be experienced when feelings of hopefulness and confidence are experienced upon identifying sources for obtaining gluten free foods and/or upon joining a support group. Another example of challenge may be experienced with feelings of hopefulness related to a decrease in symptoms following a diagnosis of celiac disease and treatment with a gluten free diet. Therefore, stress is reduced and one can continue to work toward achievement of an established goal. The conceptual framework used to guide this study is depicted in Figure 2.1.

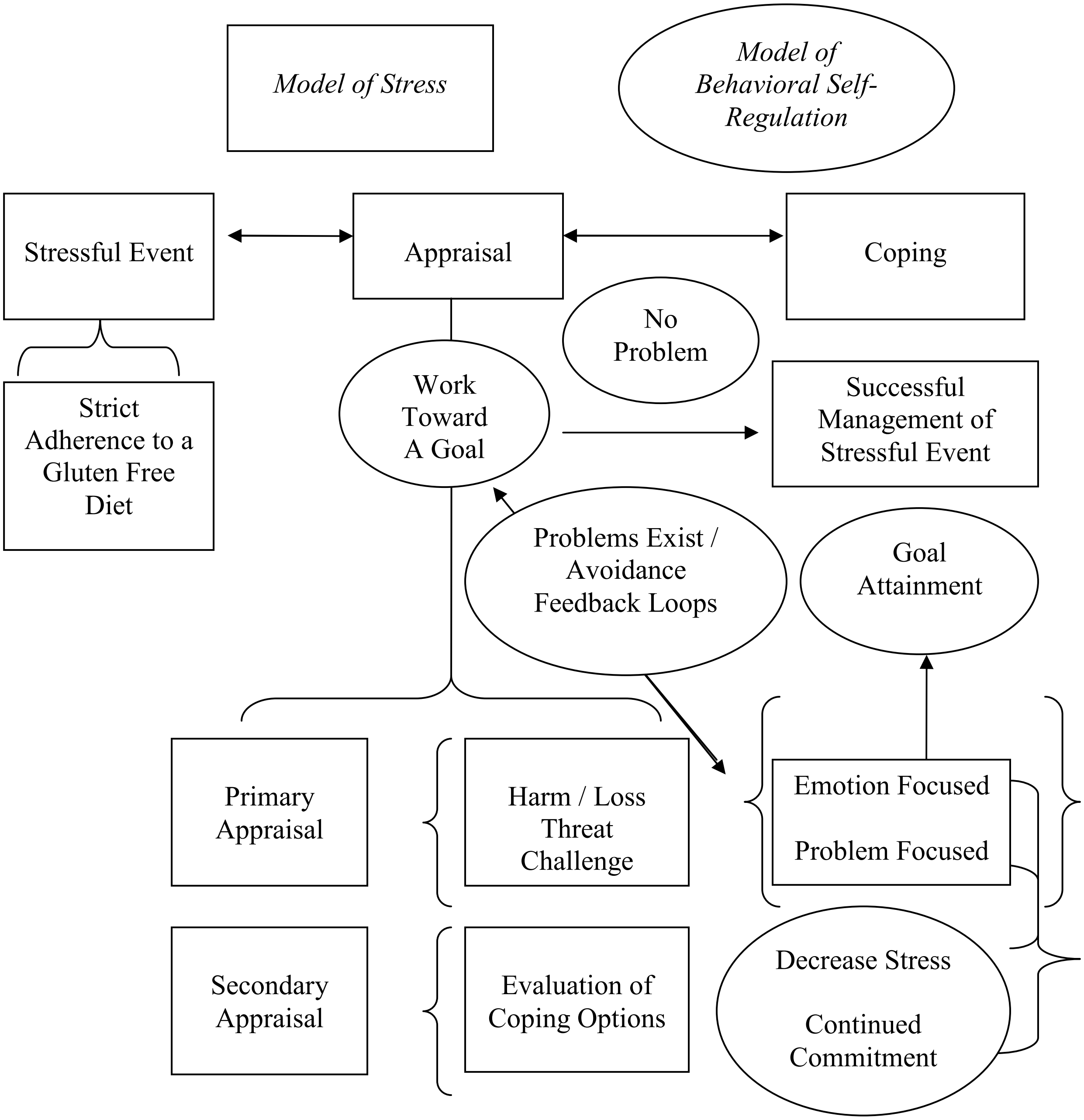


Figure 1. *Stress, Appraisal, and Coping of Adults Following Strict Adherence to a Gluten Free Diet*

The possibility also exists for an individual not to successfully manage the symptoms or disease due to dysfunctional coping behaviors. This is referred to as avoidance, which prevents attainment of a goal because the stressor is allowed to interfere. In this case, appraisal of adherence to a gluten free diet or a decrease of potential complications associated with celiac disease as hopelessness prevents an individual from achieving a goal. The hierarchical structure can be explained in the example that follows.

Lower level behaviors such as driving to a specialty food store serve higher goals such as purchasing gluten free food items. The higher level goals aid in achieving higher level purposes and principles such as taking care of one's self by adhering to a gluten free diet (Carver & Scheier, 2001). Therefore, psychological stress is a relationship between a person and the environment that through cognitive appraisal has been determined to affect one's well-being. Coping becomes the mechanism for managing the stressor regardless of the outcome (Lazarus & Folkman, 1984).

2.3 Quality of Life

With the exception of the first study, quality of life was reported to be poorer in the majority of studies that examined quality of life in patients with celiac disease especially when compared to the general population. A few studies also identified gender differences in quality of life, coping strategies, and social responsibility for adults with celiac disease adhering to a gluten free diet.

Johnson, Rodgers, and Watson (2004) conducted a study that indicated there was no significant difference ($p = 0.24$) in quality of life after one year on a gluten free diet. This study compared screen-detected celiac disease patients ($n = 14$) to a control group (n

= 23) comprised of symptom-detected celiac disease patients. In this study, general health and vitality, as measured by the Short Form – 36 Health Survey (Ware & Sherbourne, 1992), were significantly improved after one year on a gluten free diet for symptom-detected celiac disease patients ($p = 0.0004$).

Quality of life was assessed, by the Psychological General Well-Being Index (Dupuy, 1984) in screen-detected patients ($n = 19$) with reported signs and symptoms of celiac disease and in symptom-detected patients ($n = 21$) and then compared to healthy ($n= 105$) participants without known celiac disease. Significantly higher scores ($p < 0.01$) were detected at baseline for the control group and the screen-detected patients compared to the symptom-detected patients. PGWB index scores increased after one year on a gluten free diet for both groups of celiac disease patients. In the screen-detected group mean PGWB index scores increased from 108 (95% *CI*, 103 to 113) to 114 (95% *CI*, 110 to 118). In the symptom-detected group, mean PGWB index scores increased from 92 (*CI* 95%, 85 to 99) to 103 (*CI* 95%, 97 to 109). Follow-up scores for the symptom-detected group were equal to the healthy comparison group. Follow-up scores for the screen detected group exceeded baseline scores of the healthy comparison group (Mustalahti, Lohiniemi, Collin, Vuolteenaho, Laippala, & Maki, 2002).

Unfortunately this result was not always the case. Women ($n = 89$; 61 %) on a gluten free diet for 10 years also scored poorer on general health and vitality, measured by the Short Form-36 Health Survey (Sullivan, Karlsson, & Ware, 1995), when compared to the general population ($n = 5277$) (Hallert, Granno, Grant, Hulten, Midhagen, Strom et al., 1998).These researchers suggested that factors other than mucosal healing were significant for perceived health status of adult celiac disease patients. However, Midhagen and Hallert (2003) found that celiac disease patients, adhering to a gluten free diet for 8 – 12 years, demonstrated significantly increased gastrointestinal (GI) symptoms in comparison to the general population. Patients with celiac disease demonstrated a decreased quality of life compared to the general population. Continued symptoms and decreased quality of life may be associated with carelessness of dietary restrictions. Of course, celiac disease patients who become lax in dietary adherence place themselves at an increased risk for disease related complications.

Quality of life studies for adults with celiac disease have shown gender differences in regard to symptoms, coping strategies, and social adjustment (Hallert, Granno, Hulten, Midhagen, Strom, Svensson et al., 2002; Hallert, Sandlund, & Broqvist, 2003). A significant negative correlation ($p < 0.001$) was found between well-being, as measured by the Short Form 36 (Sullivan et al., 1995), and gastrointestinal symptoms, as measured by the Gastrointestinal Symptom Rating Scale (GSRS) (Svedlund, Sjodin, & Dotevall, 1988) of females ($n = 34$) and males ($n = 26$). Results were as follows: GSRS scores and general health ($r = -0.43$; $p < 0.05$; $r = -0.51$; $p < 0.01$) and vitality ($r = -0.38$; $p < 0.05$; $r = -0.40$; $p < 0.05$) for females and males, respectively. Because of these findings, a phenomenological study was conducted to explore differences in the understanding of health related quality of life. Five pairs of celiac patients were recruited from the previously discussed study. Hallert, Sandlund, and Broqvist (2003) reported that perceptions of health-related quality of life were poorer in women than men living with celiac disease. Despite adherence to a strict diet, bowel symptoms were reported to be greater in women than men. A reported increased demand in social roles contributed to a limited ability of women to deal with symptoms related to celiac disease. Women also reported a decreased acceptance of living with celiac disease, which may further increase their burden. Finally, women reported social consequences of feeling forced to plan daily activities due to controlling of foods. Men took advantage of problem-solving coping strategies while women used emotion focused strategies, resulting in less satisfaction with the outcome (Hallert et al.).

Quality of life, measured by the Psychological General Well-being Index (PGWB) (Dupuy, 1984), was assessed in adults with celiac disease in remission treated for ten years (Roos, Karner, & Hallert, 2006). Fifty-one (59% women) celiac disease patients diagnosed between 1984 -1988 were compared to 182 (57% women) participants from the general adult population of the same age (45-64 years). No significant difference was noted between celiac disease patients and the control group in relation to anxiety, depressed mood or distress 103 (95% confidence interval (*CI*) = 99-107) versus 103 (95% *CI* = 100-106). However, celiac disease men (71% (95% *CI* = 52-90) scored higher on the PGWB index than celiac disease women (33% (95% *CI* = 16-50) ($p < 0.003$) (Roos et al.).

Interestingly, women ($n = 410$), diagnosed before age 20, were found to adhere better than men ($n = 171$) with the gluten free diet and to be happier. However, they expressed increased embarrassment at sharing a table and anxiety associated with a sense of being different from the general population ($r = 0.20$; $p = 0.001$, for both). An unsatisfactory sex life was associated with feelings of depression ($r = -0.22$; $p = 0.001$) (Ciacci, D'Agate, De Rosa, Franzese, Errichiello, Gasperi et al., 2003). In another study, treated celiac disease patients (women, $n = 87$; men, $n = 27$) and untreated celiac disease patients (n = 25) were evaluated. The aim of the study was to evaluate the emotional impact of a celiac disease diagnosis in adults, how adults coped with the disease and the diet, and the relationship between the patient and the physician. Quality of life in relation to dietary adherence was also associated with anger ($F = 4.991$), which caused patients to lapse in regard to dietary compliance ($r = -0.330$; $P = 0.0005$). Anger was not determined to be a consequence of the general depressive-anxious condition but rather a primitive emotional reaction. Such reactions may lead to self-destructive behaviors (reduced adherence to a gluten free diet). This same study identified two factors related to the psychological dimensions of celiac disease, depressive-anxious and passive-adaptive attitudes (Ciacci, Iavarone, Siniscalchi, Romano, & De Rosa, 2002).

Celiac disease patients in the depressive-anxious group had a tendency to react with an exaggerated sense of dissatisfaction. It was hypothesized that this might lead to a more restricted life style with a propensity for decreased expression. Those patients in the passive-adaptive group accepted the disease; however, it seemed to be related to a passive negative attitude as opposed to active adjustment (Ciacci et al., 2002).

Lee and Newman (2003) examined the celiac diet and its impact on quality of life, measured by the Rand Corporation 36-item International Health Survey (Hays, Sherbourne, & Mazel, 1993). Of the 253 participants, 74% were females with 42% between 36 and 55 years of age and 46% being over 55 years of age. Areas related to having a negative impact were dining out (86%), travel (82%), and impact on family (67%). Interestingly, 21% rated the information from a dietitian as helpful; however, only 13% received information from a dietitian. Seventy-one percent of participants obtained dietary information from books, Internet, support groups, family, and friends.

Zarkadas et al. (2006) reported more positive results related to the impact of a gluten free diet on adults with celiac disease. They compared results from their study with those of Campbell, Molloy, Davidson, and Bankier (1991). Comparison indicated that not eating in restaurants had dropped from 93% to 79% and avoiding travel had dropped from 93% to 38%.

Emotions, relationships, and the management of daily life were the three main problem categories identified by 43 participants in a qualitative study that explored everyday lives of adults with celiac disease (Sverker, Hensing, & Hallert, 2005). Emotions experienced included isolation, shame, fear of becoming contaminated by gluten, and worries about being a bother. Problems identified in regard to relations with others included unwanted visibility, neglect, being forgotten, disclosure avoidance, and risk taking. Finally, problems associated with management of daily life included restricted product choice, double work, and constantly being on call.

Although the following study does not examine adults with celiac disease, it does examine effects of osteoporosis, which has the potential for being a complication of celiac disease. Coelho, Silva, Maia, Prata, and Barros (1999) evaluated the relationship between osteoporosis and depression measured by the Beck Depression Inventory (BDI) (Beck, Ward, Mendelson, & Erbaugh, 1961) and well-being, measured by the Psychological General Well-being Index (PGWB) (Dupuy, 1984). One hundred and two Portuguese white women participated. Women ($n = 48$) with osteoporosis compared to women ($n = 54$) with normal bone mineral density reported a significantly higher mean number of depressive symptoms (16 ± 9 versus 13 ± 10, $p = 0.045$). The overall prevalence of depression was 64.7%; depression in women with osteoporosis (77%) was significantly higher than in women without osteoporosis (53.7%, $p = 0.024$). Mean general well-being scores were not significantly different (62 ± 17 versus 64 ± 19, $p = 0.665$) (Coelho et al.).

The above findings, related to quality of life, merited inquiry into the manner in which adults cope with the stress related to being diagnosed and treated for celiac disease, a chronic illness. Therefore, the stress of coping with the required celiac disease dietary compliance is discussed.

2.4 Barriers Related to Dietary Compliance

To put this issue in context, the following disease processes are not managed by diet compliance alone. Medication, exercise, and lifestyle changes are significant factors in managing heart failure, diabetes, and end stage renal disease. Management of obesity is more closely related to management of celiac disease because diet and lifestyle changes are the most important issues associated with control and improved quality of life. A confounding factor was surgical interventions for weight loss as opposed to dietary management for weight loss and control. Thus, the following diseases, cardiovascular, diabetes mellitus, end stage renal, and obesity, are discussed in relation to dietary compliance. The discussion concludes with a recent study related to celiac disease and dietary compliance.

Cardiovascular Disease and Dietary Compliance

Heart transplant patients ($n = 94$), 80% being male, participated in a study that assessed predictors of dietary compliance (Grady & Jalowiec, 1995). Responses related to difficulty with dietary compliance to a low fat diet indicated that 47.9 % ($n = 45$) had no difficulty, 26.6% ($n = 25$) had little difficulty, 18.1 % ($n = 17$) had moderate difficulty, 6.4% ($n = 6$) had a lot of difficulty, and 1% ($n = 1$) did not respond. The mean level of difficulty was 1.8 ± 0.97, which equated to “a little difficulty.” Reasons stated for having little difficulty with dietary compliance were: 1) being away from home; eating out; finding it hard to select foods according to the diet and 2) increased appetite or hunger. Reasons stated for having moderate difficulty with dietary compliance were: 1) increased appetite or hunger and 2) missing foods eaten previously. Stated reasons for having a lot of difficulty with dietary compliance were: 1) increased appetite and 2) getting used to the diet and craving other foods (Grady & Jalowiec). Bennett et al. (2005) examined barriers to dietary compliance, measured by the Beliefs About Dietary Compliance Scale (Bennett, Milgrom, Champion, & Huster, 1997), in heart failure patients. Two studies (Study 1 $n = 101$; Study 2 $n = 162$) were performed. Although patients were knowledgeable about adhering to a sodium restricted diet with benefit scores ranging from 96% to 69%, barriers ranged from 76% to 14%, with comparable scores for each study. Examples of barriers to dietary compliance for Study 1 and Study 2 were 1) *food does not taste good on the low salt diet* (62 % and 76%, respectively) and 2) *I cannot go out to many places to eat because of the low salt diet* (49% and 44%, respectively).

Evangelista, Berg, and Dracup (2001) examined the relationship between psychosocial variables and dietary compliance in patients with heart failure. The sample consisted of 82 heart failure patients who were diagnosed for a mean of 5.72 years. Physical and mental health were measured by the Medical Outcomes Study Short Form-36 (MOS SF-36) (Ware & Sherbourne, 1992). Overall, dietary compliance was correlated with higher mental health and physical health, and lower neuroticism ($p < 0.001$) and higher health satisfaction ($p < 0.05$).

End Stage Renal Disease and Dietary Compliance

Katz, Ashmore, Barboa, Trueblood, McLaughlin, and Mathews (1998) examined disease knowledge and dietary compliance in 56 patients (30 men, 26 women) with end stage renal disease, identified as being compliant (n = 24) or noncompliant (n = 32). Patients had been on dialysis for an average of 2.5 years. A four-point Likert scale was used to assess psychological symptoms over the past month. The symptoms included feeling anxious, depressed, helpless, hopeless, irritable, tired, tense, angry, achy, lonely, worried, and afraid. Although difficult lifestyle changes are required of patients on dialysis, few psychological symptoms were reported. The mean number of symptoms was 3.8 (*SD* = 2.9). Participants reported a total distress score of 7.0 (*SD* = 6.8) out of a possible maximum score of 36. Thomas, Sargent, Michels, Richter, Valois, and Moore (2001) examined dietary compliance in older adults (N = 276) with end stage renal disease. Compliant patients compared to noncompliant patients felt that following their diet was one of the best things that could be done for their health (87.21% versus 73.08%, P = .003). Compliant patients compared to noncompliant patients felt that good nutrition decreased the severity of health problems including serious illness (85.47% versus 76.0 %, P = .054) (Thomas et al.).

Stress and social support were examined as predictors of dietary compliance in hemodialysis patients. The Weekly Stress Inventory (Brantley & Jones, 1988) was used to assess minor stressful events. Fifty-five persons participated in the study. Minor stress was significantly predictive of problems with control of potassium (partial r = .39, p < .01) and blood urea nitrogen (partial r = .34; p < .05) levels.

Diabetes and Dietary Compliance

Williamson, Hunt, Pope, and Tolman (2000) used an open-ended telephone questionnaire to interview registered dietitians (*N* = 75) to identify factors that contribute to barriers to dietary compliance in diabetics. Factors identified by dietitians as being barriers to dietary compliance were: 1) complications with lifestyle/competing demands, 2) denial/perception that diabetes in not serious, 3) poor understanding of the diet/disease relationship, 4) lack of self-efficacy, and 5) misinformation from unreliable sources. In general, the dietitians believed that most of the barriers could be overcome with additional and increased individualized education.

When type 1 diabetic persons (*n* = 51) were compared to nondiabetic persons (*n* = 47) quality of life, measured by the Diabetes Quality of Life Measure (DCCT, 1988), indicated that all persons were generally satisfied and not worried about their diabetes. Results from the SF-36 (Ware & Sherbourne, 1992) indicated no difference between scores from the diabetic and control group and the interim Australian norms (*n* = 6823) (Tahbaz, Kreis, & Calvert, 2006).

A two phase study was conducted to identify barriers to following dietary recommendation in type 2 diabetes (Vijan, Stuart, Fitzgerald, Ronis, Hayward, Slater et al., 2005). The qualitative phase consisted of focus groups to provide their views of barriers to following recommended interventions. The most common barrier was cost (14/14 reviews), followed by small portion sizes (13/14 reviews), support and family issues (13/14 reviews), and quality of life and lifestyle issues (12/14 reviews). The second phase consisted of a mailed survey. A total of 197 surveys were returned completed for a 54% response rate. The burden of diabetes was measured on a sevenpoint Likert scale (0 = do not dislike at all to 6 = dislike very much). Adherence to the recommended “moderate” diet was identified as a greater burden than oral agents (median 1 versus 0, $P = 0.001$); however, it was less of a burden than insulin (median 1 versus 4, $P < 0.001$). A “strict” diet, to aid in weight reduction, was rated the same as insulin (median 4 versus 4, P = NS) (Vijan et al.).

Obesity and Dietary Compliance

Help-seeking for weight control in a community sample of obese and overweight individuals ($N = 120$) appeared to be motivated by psychological factors of obesity as opposed to the physical and medical burden of obesity. The impact of obesity and weight reduction on quality of life was measured by the Impact of Weight on Quality of Life-Lite (IWQOL) (Kolotkin, Crosby, Kosloski, & Williams, 2001). The IWQOL Sexual Life subscale ($t(6, 101) = 2.68$, $p = .01$) was a significant predictor of help-seeking behaviors. Correlations among help-seeking predictors for all IWQOL subscales (Physical Function, Self-Esteem, Sexual Life, Public Distress, and Work) were significant ($p < .01$) (Annunziato & Lowe, 2007).

Obesity has been associated with binge eating, which is often accompanied by depression. Obesity accompanied by depression is most often seen in persons attempting to lose weight (de Zwaan, 2001; Smith, Marcus, Lewis, Fitzgibbon, & Schreiner, 1998). J. B. Dixon, M. E. Dixon, and O’Brien (2003) used the Beck Depression Inventory (BDI) (Beck et al., 1961) to assess predictors of depression in 487 consecutive patients before and at one to four years after gastric-restrictive weight-loss surgery. Cutoff values for BDI scores were: 0 to 9, reference group; 10 to 15, mild depressive symptoms; 16 to 22, moderate depressive symptoms; and 23 to 63, major depressive symptoms. Significant differences (*p* < .001) were assessed among BDI scores at each interval (pre-operative, one year, two years, three years, and four or more years). BDI scores were 17.7 ± 9.5 (*N* = 487), 7.8 ± 6.5 (*n* = 373), 8.0 ± 8 (*n* = 249), 9.0 ± 9 (*n* = 148), and 9.6 ± 7.7 (*n* = 134), respectively (Dixon et al.). The preoperative mean score (17.7 ± 95) was within the moderate range of symptoms for depression (16-22). Preoperative BDI scores for the SF-36, mental component summary were significant (p < .001) for the consecutive severely obese participants (*N* = 487). Reported scores for the cutoff values were: reference, 53.1 ± 6; mild 48.4 ± 8; moderate, 43.9 ± 6; and major, 38.1 ± 6 (Dixon et al.).

Celiac Disease and Dietary Compliance

Lee, Ng, Zivin, and Green (2007) examined the economic burden of a gluten free diet. Comparisons were made between products identified by name brand, weight or package size for both wheat-based products, and gluten free counterparts. Differences in costs were analyzed for various purchase locations and regions. Findings indicated variability in availability of gluten free products. The internet provided 100 % availability, with health food stores providing 94 %, upscale markets carried 41 %, and regular grocery stores carried 36 %. Although the internet was the most expensive, it was not statistically significant because data was collected from only four internet sites and four types of stores. Regions between states did not affect cost comparisons as strikingly as location except for bread and pasta. Availability varied more than cost when compared between regions. In the Portland and Rapid City areas, gluten free muffins and cakes were not available in health food stores or upscale markets. In general, gluten free products were 240 % higher in cost (*p* ≤ 0.05) with variance among different food types. There was no statistical difference in price for cereal and cake prices when comparing gluten free and regular products. Gluten free bread and pasta were twice as expensive as regular products (p = 0.00). Other costly gluten free items were snack foods such as pretzels (p = 0.01), crackers (p = 0.00), and cookies (p = 0.00) (Lee et al.).

Poor availability and increased cost of gluten free products, supported the need for further research into the impact of these findings on adherence to a gluten free diet and on quality of life and coping strategies used to deal with these potential barriers.

2.5 Coping Research

The human stress response has been described in terms of fight-or-flight as being a vital mechanism in the survival process. Taylor, Klein, Lewis, Gruenewald, Gurung, and Updegraff (2000) proposed that the human female stress response was more typically portrayed by a pattern termed "tend-and-befriend" rather than the fight-or-flight mechanism. They suggested that females maximize survival of self and offspring by caring for offspring and protecting them from harm, thus decreasing neuroendocrine responses that may compromise offspring health (tending pattern). Befriending behaviors are exhibited by associating with social groups to reduce stress (Taylor et al., 2000).

The proposed differences in human stress response support the need to investigate coping strategies of adults with celiac disease adhering to a gluten free diet. Common health care stressors are acute and chronic illness, pain, surgery, poor nutrition, disturbed sleep patterns, and grief and loss (Motzer & Hertig, 2004). For patients suffering from celiac disease, adherence to a gluten free diet and associated complications have the potential for being significant stressors.

There are various instruments used to assess coping. Although they differ in some aspects, they all assess problem-focused responses and responses related to characteristics other than the stressor itself. In addition, these instruments usually measure both functional and dysfunctional responses (Carver, 1997). Because studies specifically evaluating coping strategies of adults with celiac disease were not found, studies evaluating coping strategies of adults with chronic illness such as inflammatory bowel disease and hypertension as well as life-changing diagnoses such as HIV/AIDS and cancer are discussed.

Coping and Inflammatory Bowel Disease

Kinash, Fischer, Lukie, and Carr (1993) examined coping strategies and related characteristics in patients with inflammatory bowel disease using the Jaloweic Coping Scale (Jaloweic, 1988). Coping strategies of patients with Crohn's disease ($n = 77$) and those with ulcerative colitis ($n = 49$) did not differ significantly ($p > /05$). A significant difference ($p < 05$) was found by both groups indicating the use of problem-oriented strategies being used more often than affective-oriented strategies.

Another study investigated the presence of irritable bowel syndrome (IBS)-like symptoms and their impairment on quality of life. Participants consisted of patients with inflammatory bowel disease in remission ($n = 73$, ulcerative colitis and $n = 34$, Crohn's disease) and 66 healthy controls. Results indicated that the presence of IBS-like symptoms ($N = 37$) significantly affected quality of life ($P < .001$). However, no relationship was found between the presence of symptoms and task-oriented coping, emotions-oriented coping, or avoidance-oriented coping (Minderhoud, Oldenburg, Wismeijer, van Berge Henegouwen, & Smout, 2004).

In an exploratory study with a qualitative research design, Mukherjee, Sloper, and Turnbull (2002) examined coping difficulties of parents with inflammatory bowel disease

(IBD). Patients with inflammatory bowel disease experience signs and symptoms similar to those with celiac disease such as fatigue, malnutrition, diarrhea, and anemia. Results of the study revealed a variety of coping strategies to deal with the difficulties. The most commonly identified strategy by parents was turning to partners and members of the extended family for emotional and practical support. Other strategies specific to disease management included taking medications with an initial indication of a flare up or having surgery. Useful coping strategies identified were staying in shape, having only one child, or leaving a gap between children to avoid caring for more than one very young child. Positive thinking was another coping strategy along with using jokes; however, jokes were noted to be funny only to family members. Finally, some parents recognized that having children helped them to cope with IBD (Mukherjee et al.).

Smolen and Topp (1998) examined coping methods in persons (N = 46) between 16 to 95 years of age. They indicated that patients with IBD, a chronic illness, must learn to cope with recurrent symptoms as well as the possibility of complications associated with the illness, once again, similar to patients with celiac disease. It is also suggested that benefit may be gained by patients who learn to deal with life stressors that may exacerbate symptoms. Coping strategies were measured by the Jalowiec Coping Scale (Halstead & Fernsler, 1994). Participants (n = 33 with Crohn’s disease and n = 13 with ulcerative colitis) reported the most frequently used coping strategy as the optimistic style ($M = 2.10$) followed by self reliant ($M = 1.83$) and confrontive ($M = 1.82$) styles. Evasive and fatalistic styles were significantly correlated ($p < 0.05$) with perceptions of health, functioning, and well-being. Emotive coping was significantly correlated ($p < 0.05$) with health perception and well-being. Supportive coping correlated ($p < 0.05$) with the perception of functioning. Finally, a significant inverse predictive ability in health perception was demonstrated with the use of emotive coping ($R^2 = 0.20$) (Smolen & Topp).

Calsbeek, Rijken, Bekkers, Van Berge Henegouwen, and Dekker (2006) investigated the impact of coping, measured by the Coping Inventory for Stressful Situations (Endler & Parker, 1990), on performance in school and leisure activities in adolescents and young adults (12 to 25 years) with chronic digestive disorders (total n = 521) and healthy controls (n = 274). Chronic digestive disorder participants were: IBD (n = 190), chronic liver disease (n = 51), congenital digestive disorders (n = 122), celiac disease (n = 61), or food allergy (n = 97). Interestingly, the authors hypothesized that celiac disease and food allergy patients can be considered to be more controllable disorders; therefore, task-oriented coping as opposed to emotion-focused or avoidance coping would be more widely used. Results indicated no significant differences in the diagnostic groups and control group among the three meta coping strategies [task-oriented ($p = 0.26$), emotion-oriented, ($p = 25$) and avoidance (p = 76)]. However, significant differences were noted among several age groups. Significantly lower scores ($p \leq 0.01$) were found in the youngest group (12 -14 years) on all three coping strategies compared with the older groups. Adolescents (15-17 years) scored significantly lower ($M = 3.1$) on task-oriented coping than the older age groups (18-10 years and 21-24 years, $M = 3.4$). Positive correlations were noted with avoidance coping and going out, cultural activities, and friendship. In regard to educational level, task-oriented coping was found to be significantly related to higher education ($r = 0.232$; $p \leq 0.01$) (Calsbeek et al.).

In another study, seventy-two inflammatory bowel disease patients (n = 47 with Crohn's disease and n = 25 with ulcerative colitis) were evaluated for coping with the disease, measured by the Freiburg Questionnaire on Coping (Muthny, 1989). Results indicated that the most frequently used coping strategy was distraction / self-affirmation ($M = 2.91$, $SD = 0.79$) followed by active coping ($M = 2.84$, $SD = 0.88$) and depressive coping ($M = 2.03$, $SD = 0.37$). In addition, depressive coping was significantly associated with psychological distress ($\beta = 0.56$; P value = 0.000), self-rated health status ($\beta = 0.36$; P value = 0.003), and somatic complaints ($\beta = 0.35$; P value = 0.002) (Mussell, Bocker, Nagel, & Singer, 2004).

Coping and Chronic Illness

Specific coping strategies for illnesses with less control (rheumatoid arthritis and cancer, n = 77) and illnesses sensitive to individual and medical efforts at control (hypertension and diabetes, n = 74) were compared. Two coping indexes (information seeking and wish-fulfilling fantasy) from the Ways of Coping scale (Folkman & Lazarus, 1980) were used to assess coping efforts. Controllability was not found to be a factor; however, information seeking was associated with a decrease in negative affect ($\Delta R^2 = .02$), and wish-fulfilling fantasy was associated with a decreased acceptance of illness ($\Delta R^2 = .03$) (Felton & Revenson, 1984). Groarke, Curtis, and Coughlin (2004), in a follow-up study over one year that involved 52 Irish women with rheumatoid arthritis, reported results from correlational and hierarchical regression analysis that revealed statistically significant relationships ($p < 0.01$). Findings indicated that poor emotional adjustment was associated with higher perceived stress (assessed by the Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983)) and lower social support while the use of adaptive strategies, assessed by the COPE scale (Carver et al., 1989), and less frequent use of avoidant strategies was believed to be a factor in demonstrating a positive affect.

In a participatory action-oriented research study involving women living with type 2 diabetes (N =6), stress was identified as a major issue especially in regards to developing complications and increased mortality related to inadequate control of diabetes. Dietary management was perceived to be a problem, even though the basic principles (low fat, low sugar, high fiber and high carbohydrate) are generally advocated for healthy living. Women felt as though they were restricted and had lost their freedom to choose foods they wished to eat. Self-absorption was identified as a problem. Women perceived themselves as more self-focused due to consideration of diet, medication administration, physical and psychological well-being. Although the underlying source of depression was not identified, women felt that their depression (reported “ups and downs”) had worsened since their diagnosis (Koch, Kralik, & Sonnack, 2005).

Coping and HIV / AIDS

Strategies for coping have been examined in persons living with HIV / AIDS related to functional quality of life and coping strategies. Findings indicated that maladaptive coping strategies were associated with lower levels of energy and social functioning. Additionally, pain severe enough to interfere with activities of daily living was associated with a decrease in functional quality of life (Vosvick, Koopman, Gore-Felton, Thoresen, Krumboltz, & Spiegel, 2003). In a two year study of HIV + and HIV- gay men who were caregivers and HIV+ men who were not caregivers, goodness-of-fit was examined between appraisals deemed controllable and coping, assessed by a modified version of the Ways of Coping Questionnaire (Folkman & Lazarus, 1988). It was found that with different kinds of coping, the importance of fit between coping and controllability varied. Strongest support for goodness-of-fit was indicated with problem-focused coping in HIV+ caregivers ($p < .001$). Although there was no relationship between emotion focused coping and depressed mood, a relationship existed between emotion focused coping and better adjustment ($p < .001$). These results seem to indicate that researchers should consider context along with the type of emotion focused responses because they can be adaptive (Park, Folkman, & Bostrom, 2001).

Vosvick, Gore-Felton, Koopman, Thoresen, Krumboltz, & Spiegel (2002) measured psychological quality of life along three scales (mental health, cognitive functioning, and distress over health problems) from the Medical Outcome Study- HIV (MOS-HIV) among participants living with HIV and AIDS ($N = 141$). They reported improved cognitive functioning, such as memory and focus, in relation to being male ($r = .22$, $p < .01$), identifying as heterosexual ($r = .19$, $p < .05$), or Caucasian ($r = .20$, $p < .05$), household income greater than \$20,000 ($r = .32$, $p < .001$), and higher number of years of education ($r = .23$, $p < .01$). When compared to other ethnic groups, African Americans reported worse cognitive functioning ($r = .23$, $p < .01$). Other significant findings related to ethnicity included lower household incomes for African Americans ($r = .30$, $p < .00$) as well as lower years of education ($r = .31$, $p < .00$). The Brief COPE was used to assess the stress of living with HIV or AIDS. Multivariate regression analysis resulted in no significant relationships between demographic and AIDS-related variables and mental health scores as well as health distress. However, after controlling for household income, an increased use of behavioral disengagement as a coping strategy was significantly associated with poorer cognitive functioning (adjusted $R^2 = .22[F(6,134) = 7.39, p < .000]$).

Maladaptive coping strategies, among persons living with HIV/AIDS (N = 85), especially those that involve avoidant behaviors, have been associated with greater depression in adults with HIV at baseline and at 3 months. Coping, assessed by use of the Brief COPE, was found to be the most significant predictor of quality of life (accounting for over 41 percent of the variation) with negative coping behaviors resulting in a decreased quality of life. Quality of life, assessed with the MOS-HIV, was the most significant predictor of depression. Results indicated that depression scores, assessed by the Center for Epidemiologic Studies-Depression (CES-D), were close to the clinical cutoff (16 or higher) at baseline ($M = 14.73$, SD = 10.31) and at 3 months exceeded the cutoff ($M = 18.33$, SD = 12.10), which was statistically significant ($t(59) = -2.55, p < .03$, Cohen’s d = .32) (Gore-Felton, Koopman, Spiegel, Vosvick, Brondino, & Winningham, 2006).

In a study examining social support and maladaptive coping as predictors of HIV-related health symptoms (N = 64), venting as a coping strategy with a less satisfying social support demonstrated a greater increase in HIV-related physical health symptoms ($p \leq 0.05$) (Ashton, Vosvick, Chesney, Gore-Felton, Koopman, O'Shea et al., 2005). These findings support the need for screening for depression and developing improved methods for pain management, but, most importantly in relation to this study, the authors emphasize the importance of developing psychological interventions with a focus on decreasing maladaptive coping strategies related to chronic illness (Gore-Felton et al., 2006; Vosvick et al., 2002).

Coping and Cancer

Studies reviewed involved women (N = 117) with breast cancer. Stanton and Snider (1993) conducted a prospective study following women before breast biopsy and after diagnosis as well as those with cancer after surgery. Coping was assessed by the Ways of Coping Questionnaire (Folkman, Lazarus, Gruen, & DeLongis, 1986; Lazarus & Folkman, 1984). Predictors of prebiopsy affect revealed that women who reported prebiopsy vigor (partial $r = .34$, $p < .0005$) expressed more optimism and coped more by focusing on the positive. Predictors of postbiopsy affect indicated that women using cognitive avoidance (partial $r = .55$, $p < .01$) at prebiopsy were more distressed after receiving a cancer diagnosis. However, women who reported use of seeking social support ($r = .63$, $p < .001$), less cognitive avoidance ($r = -.47$, $p < .05$), and less positive focus ($r = -.59$, $p < .005$) expressed more vigor after diagnosis. Finally, Carver et al. (1993) assessed 59 breast cancer patients by the COPE inventory (Carver et al., 1989). Results indicated that cognitive avoidance was harmful for all assessment periods (1 day presurgery, 10 days postsurgery, and at 3, 6, and 12 month follow-ups). Coping was assessed for mediating effects of optimism on distress in women with early breast cancer. Acceptance was the only coping strategy found to be a significant predictor of postsurgical distress ($r = -.35$, $p < .04$). High levels of presurgical acceptance were correlated with decreased postsurgical distress. Presurgical distress was associated with increased levels of denial postsurgery ($r(56) = .36$, $p < .01$) and with higher levels of planning postsurgery ($r(56) = .28$, $p < .04$). At 6 months, distress predicted subsequent tendencies to suppress competing activities to concentrate more on the stressor ($r(42) = .30$, $p < .05$) (Carver et al.).

In a study conducted by Urcuyo, Boyers, Carver, and Antoni (2005), benefit finding indicated by responding to items with a potential positive contribution to one's life was measured and then related to simultaneous coping measures, assessed by the Brief COPE (Carver, 1997). A multi-ethnic sample of women (N = 230) was assessed. Positive reframing ($r = 0.33$, $p < 0.001$) and religious coping ($r = .28$, $p < 0.001$) were found to be positively related to benefit finding. Interestingly, there was a virtual lack of association with avoidance coping. Although a scarcely significant inverse relationship to substance use (r = -0.13, $p < 0.05$) was demonstrated, there was no relation to venting, denial, self-distraction, or behavioral disengagement. Speculation was that benefit finding had no useful function with negative coping traits (Urcuyo et al.).

In a study examining coping strategies, assessed by the Brief COPE, among minority women (African American (n = 26), Hispanic (n = 59), and non-Hispanic White women (n = 151)) with breast cancer, only two differences were identified. In a comparison among Non-Hispanic White women to African-American ($F(1, 170) = 3.94$, $p < 0.05$; $F(1, 170) = 9.25$, $p < .01$) and Hispanic women ($F(1, 203) = 5.13$, $p < 0.03$; $F(1, 203 = 9.97$, $p < 0.01$), both groups used humor-based coping ($F(2, 228 = 3.70$, $p < 0.03$) less and religion-based coping ($F(2, 228 = 8.49$, $p < 0.001$) more than non-Hispanic White women. In regard to distress, venting had a stronger relationship to elevated distress among Hispanic ($\beta = 0.58$, $p < 0.0001$) than among non-Hispanic White women ($\beta = 0.27$), $p < 0.002$) (Culver, Arena, Wimberly, Antoni, & Carver, 2004).

Harcourt, Rumsey, and Ambler (1999) investigated psychological impact and coping strategies, as assessed by the Brief COPE (Carver, 1997), of women undergoing the diagnosis of breast problems. The study compared women (n = 416) diagnosed in a “one stop” clinic to women (n = 375) diagnosed in a conventional clinic involving two appointments. Acceptance (58%), distraction (54%), emotional support (44%), planning (39%), and positive reframing (39%) were reported as being used most often by women prior to diagnosis by both groups of women. Women in the “one-stop” clinic reported higher levels of anxiety with the use of self-distraction ($F(1, 405) = 4.8, p < 0.05$), disengagement ($F(1, 404) = 9.251, p < 0.05$), alcohol/drug use ($F(1, 409) = 5.19, p < 0.05$), and venting ($F (1, 404) = 7.38, p < 0.05$). Additionally, significant interactions were noted with higher levels of anxiety being reported after diagnosis in the one-stop clinic when comparing effects between anxiety, type of clinic attended, and use of denial ($F(1, 303) = 9.30, p < 0.01$) and disengagement ($F(1, 303) = 5.93, p < 0.05$). Eight weeks after diagnosis, women with breast cancer reported using acceptance (60%), distraction (53%), positive reframing (35%), and emotional support (33%). Interestingly, women diagnosed with a benign condition used the same strategies but at a lower percentage: acceptance (42%), distraction (25%), positive reframing (20%), and emotional support (15%) (Harcourt et al.).

Coping and Health

Similar results have been found in studies involving healthy individuals when examining stress and coping, as assessed by the Brief COPE (Carver, 1997). Accident and emergency senior house officers (N = 37) reported increased anxiety ($r = 0.34, p < 0.05$) and depression ($r = 0.33, p < 0.05$) when the coping strategy, venting was used. However, decreased anxiety ($r = 0.38, p < 0.05$) and somatic complaints ($r = 0.46, p < 0.001$) were reported with the active coping strategy (McPherson, Hale, Richardson, & Obholzer, 2003). Undergraduate medical students (N = 260) demonstrated a significant association with immune function (hepatitis B vaccine) in relation to coping strategies, as assessed by the Brief COPE (Carver, 1997). Significant coping strategies included acceptance coping ($p = .04$), which was protective, whereas, substance use ($p = .005$) increased the risk of having an insufficient hepatitis B antibody count. When coping by substance use ($p = .006$), acceptance coping ($p = .05$), and self-blame ($p = .15$), substance use ($p =.02$) and acceptance coping ($p = .04$) were reported as significant predictors of antibody status (Burns, Carroll, Ring, Harrison, & Drayson, 2002).

Findings from these studies supported the need to investigate coping strategies of adults living with celiac disease. Identification of coping strategies can guide nurses practicing at all levels to develop cognitive-behavioral interventions and educational programs for patients living with celiac disease. The initiation of cognitive-behavioral interventions and educational programs related to effective coping strategies may help to improve the quality of life for adults with celiac disease by facilitating in the regulation of stressors associated with dietary management and chronic illness.

2.6 Gaps in the Literature

Review of literature revealed a significant gap in research on coping in adults with celiac disease adhering to a gluten free diet. Numerous studies were conducted on quality of life in adults with celiac disease on a gluten free diet. No studies were found that addressed coping strategies for adults exclusively with celiac disease on a gluten free diet. Two studies were found in which patients with celiac disease were included in the make-up of the total sample. Calsbeek et al. (2006) investigated coping in adolescents and young adults with chronic digestive disorders (total n = 521) and healthy controls (n = 274). Of the 521 participants with chronic digestive disorders, 61 were diagnosed with celiac disease. Results indicated no significant differences in the use of coping strategies between adolescents and young adults with various chronic digestive disorders and healthy controls, or among the diagnostic group. Johnson and Johnson (2006) conducted a qualitative study, which consisted of a convenience sample of 15 women with chronic ambiguous illness, five of whom were diagnosed with celiac disease. Ways of coping was one of the categories identified by the women interviewed. Multiple ways to deal with symptoms were shared by participants. One example specific to celiac disease was: "I stick to my gluten free-diet religiously and never go out to eat" (p.166).

Gaps in the literature may be related to the reported delay in diagnosis. Until recently, celiac disease was considered to be uncommon in the United States. However, prevalence has been found to be comparable to that in Europe. Because of the reported increased prevalence and the delay in diagnosis, researchers have focused on improving diagnosis and recognition of the disease. Additionally, management of the disease is by strict adherence to a gluten free diet. Because celiac disease was not considered to be common, measures to assist with compliance such as labeling of foods, availability of gluten free foods, etc., have not been a primary focus. Greater emphasis seems to be related to dietary restrictions and the underlying effects on nutritional status. Additionally, strict adherence to a gluten free diet has been related to a decrease in complications associated with untreated celiac disease. The small number of celiac disease patients, included in the two studies discussed, and the study results supported the need for further research. It appeared to be imperative that research into coping strategies for adults with celiac disease adhering to a gluten free diet may help improve quality of life through improved management of stressors related to dietary adherence.

2.7 Summary

To date the majority of research related to celiac disease focused on recognizing, diagnosing, and managing the disease. Physiological signs and symptoms as well as complications dominated the medical literature. Psychological factors have been addressed in relation to quality of life. Generally, nurses have addressed recognition along with dietary management.

The majority of literature specifically relates to celiac disease addressing quality of life in relation to stressors associated with dietary management. It appeared as though many studies identified a diminished quality of life; however, little research has been conducted as to improving quality of life. Because of the increase in reported prevalence of celiac disease, much research has focused on recognizing and diagnosing celiac disease. No research has been performed in relation to coping strategies for adults with celiac disease adhering to a gluten free diet.

Numerous studies have been conducted on stress and coping for healthy individuals as well as acute and chronically ill individuals. In addition, the healthcare disciplines conducting stress and coping research have been as varied as the individuals studied. With the increased prevalence of celiac disease, research should continue in the areas of recognition and management with an increase in areas related to coping with identified stressors associated with celiac disease.

This study sought to identify whether a relationship exists between quality of life and coping strategies of adults with celiac disease adhering to a gluten free diet. Gaps in the literature suggested the need to examine coping strategies. Findings from research may lead to the development and test of cognitive-behavioral interventions and/or educational programs that may improve quality of life.

Chapter 3

METHODS

3.1 Research Design

The research design for this study was a descriptive, correlational design using surveys to obtain information. Flexibility and broadness of scope were identified as the greatest advantage to survey research. Surveys are more suitable for extensive analysis and are generally used as nonexperimental studies. Self-report surveys can be used to acquire information related to psychological characteristics. The disadvantage tends to be that information is relatively superficial because they seldom explore complexities of human behavior and feelings, which allows for gaps. Because people have a tendency to present themselves in the best light, information provided may conflict with the truth (Polit & Beck, 2004).

3.2 Setting

Participants chose the setting for this study because the method of data collection was self-administered questionnaires. Potential participants were invited to participate in this study after accessing the Gluten Intolerance Group (GIG®) web site. A link was created from the GIG website to the survey questionnaires. The GIG® is a non-profit organization whose mission is to provide support to persons with gluten intolerances, including celiac disease, with the purpose of living healthy lives. Four levels of support and education are offered (the patients, health professionals, manufacturers, and the hospitality, and the public). Research projects are supported by making available information to patients about potential participation. GIG® also advocates for health reform measures that will be beneficial to persons with gluten intolerance. Some examples of advocacy include labeling reform, increased funding for NIH, and patient-rights issues (GIG, 2007a).

3.3 Sample and Recruitment Activity

In preparation for recruitment of participants, convenience sampling was anticipated through the recruitment of gastroenterologists, in order to gain access to patients diagnosed with celiac disease. In January of 2007, twenty-one letters (see Appendix I for sample physician recruitment letter) were sent to gastroenterologists in Ohio and one gastroenterologist in West Virginia covering three counties, overall. Return post cards (see Appendix B for sample post card) were included in the original mailing. Physicians were requested to return the post card if they were interested in helping with the dissertation study. Eighteen percent of the post cards were returned over a four month period. In regard to potential participants, total number of potential participants based on physician estimates was approximately 50. Because the opt-in method was used, follow-up calls were not made if post cards were not returned. With the opt-in method participants actively indicate willingness to participate in research. If no response is received, investigators are not able to contact potential participants for research. This method is believed to be more ethical than the opt-out method. With the opt-out method, potential participants are repeatedly contacted unless they specifically indicate an unwillingness to participate in research (Junghans, Feder, Hemingway, Timmis, & Jones, 2005; Willison, Keshavjee, Nair, Goldsmith, Holbrook, & Holbrook, 2003). Thank you letters (see Appendix C for sample physician thank you letter) were sent to each physician who returned the post card. Due to the low number of potential participants, it was necessary to develop a Plan B. Therefore, a second method to recruit participants was designed. The second plan, which follows, was used for the dissertation study.

Convenience sampling was used to recruit adults who accessed the Gluten Intolerance Group website. A link was provided from the Gluten Intolerance Group website to *SurveyMonkey®* (SurveyMonkey, 2007) where data was collected and later exported for analysis. *SurveyMonkey®* is an online survey tool that enables people to create their own surveys in a quick and easy manner. They are located in Portland, Oregon. Data collection was obtained by copying and pasting a link to the surveys. Analysis can be reviewed as collected and data can be downloaded for statistical analysis (SurveyMonkey).

Inclusion criteria required that participants were adults between 20 and 70 years of age who were able to choose their own diets. The age range for participants was based on increased prevalence in the United States as well the average length of time before a person is diagnosed with celiac disease. Green et al. (2001) estimated a period of eleven years for symptomatic persons to be diagnosed. Participants had to have been on a gluten free diet for six months or longer, sufficient amounts of time for individuals to make adjustments and benefit from a gluten free diet. Additional eligibility criteria included a self-reported celiac disease diagnosis based on standard tests used to confirm the diagnosis. These tests consisted of a small bowel biopsy and/or serum anti-human tissue transglutaminase antibody, or both, and a follow-up small bowel biopsy and/or a serum anti-human tissue transglutaminase antibody, or both.

Exclusion criteria included any person falling outside the established age range and having been on a gluten free diet for less than six months. Persons living in a facility that prepared and served meals to individuals were excluded. Persons not responsible for choosing or preparing for meals were not considered to be exposed to the documented difficulties such as shopping for foods, preparing meals, or disclosing the need for a gluten free diet to relatives and/or friends (Ciacci et al., 2003). Although there was no way of being absolutely assured of this happening, data from participants indicating that meals were prepared or delivered to them were excluded. Finally, diagnosis based on screening tests such as anti-gliadin IgA and anti-gliadin IgG antibodies, antireticulin IgA, and/or anti-endomysial antibodies were excluded.

Prior to performing power analysis, other studies were examined in reference to sample size (Hallert & Lohiniemi, 1999; Hallert et al., 2003; Johnston et al., 2004). Sample sizes ranged from 14 to 89 participants with data collection ranging from one to four years. One study (Lee & Newman, 2003) mailed a 29-item self-administered questionnaire to 404 members of the Westchester Celiac Sprue Support Group. A total of 254 completed questionnaires met eligibility requirements and were used in the study. Based on these findings from previous studies, sample size for multiple regression was used to estimate the sample size for this study.

Power analysis was used to estimate sample size. Power analysis requires an estimation of effect size. Effect size can be based on earlier research or calculated based on the principle that the effect size will be either small ($R^2 = .02$), moderate ($R^2 = .13$), or large ($R^2 = .30$). Effect size is an indication of the strength of the relationships among the research variables. Moderate effect size was used because it was estimated that the there would be a modest effect among the research variables. Application of the following formula, which is applied when using multiple regression analysis, was used to determine the estimated sample size.

$$N = \frac{L}{\gamma} + k + 1$$

N was the estimated number of participants needed for the study. L a tabled values was the function of Power and *u* at a specified alpha; *k* was the number of predictors, and γ was the estimated effect size. This study examined quality of life and coping strategies in adult patients on a gluten free diet using 20 predictor variables. With $R^2 = .13$, the estimated population effect size was .149 (.13 ÷ .87) with a power of 80 [probability that the test will lead to rejection of the null hypothesis and is directly related to sample size (Type II error- accept null when false)] and an alpha of .05 [the level of designating the probability of committing a Type I error (reject null when true)] (Polit & Beck, 2004). For this study, a two-tailed test of significance was used to determine improbable values and because there was no directional hypothesis. The purpose of the study was to examine the relationships between quality of life and coping strategies of adults adhering to a gluten free diet. Therefore:

$$N = \frac{20.96}{.149} + 20 + 1 = 161.6$$

Thus, a sample of approximately 162 adult celiac disease patients was needed to detect a population of R^2 of .13 with 20 predictor variables, with a 5 % chance of a Type I error and a 20 % chance of a Type II error (Cohen & Cohen, 1983; Polit & Beck, 2004).

A sample size of 156 achieved a power of 78, which was slightly below the power of 80, attributed to 20 variables with an alpha of 0.05 (Cohen, 1977). Recruitment was facilitated by the Gluten Intolerance Group website.

With the initial announcement of the study by the GIG®, numerous inquiries were received related to the study being limited to residents of the United States. Another encountered problem was documentation of an incorrect email address on the link created by the GIG® to the surveys. The problem was discovered after receiving an email message from the GIG® confirming the investigator email address. The GIG® reported having received approximately 300 email messages related to the survey; however, the messages were not forwarded to a corrected email address.

3.4 Measures

Demographic Information and Health and Diet History, a demographic tool, which was developed by the researcher, was used to collect data to describe the sample. The demographic tool was divided into four sections (see Appendix D for demographic tool). Section one was related to general information. General information included age, sex, marital status, geographic location, education, and income. Section two was related to health habits. Health habits included smoking, alcohol consumption, exercise, and sleep. Section three was related to the experience of signs and symptoms of celiac disease and how the celiac disease diagnosis was obtained. Section four was related to the gluten free diet. Gluten free diet included length of time on the diet, dietary instruction, dietary preparation, and obtaining gluten free foods. A final question in section four asked participants to rate the amount of stress over the past month relative to following a gluten free diet.

Psychological General Well-Being Index

One of the tools used was the Psychological General Well-Being Index (PGWBI) (see Appendix E for PGWBI©). A User Agreement from MAPI Research Trust (see Appendix F for user agreement) was received for permission to use the data collection instrument for this study and therefore, only a few sample questions are included. The PGWBI is a self-administered questionnaire, originally developed in 1970-71 to assess the health and quality of life of individuals in general and those with chronic illness (Dupuy, 1984). Significant results were obtained by use in the U. S. Health and Nutrition Examination Survey conducted from April 1971 through October 1975 (Fazio, 1977), and in the RAND Health Insurance Experiment in 1975 (Davies & Ware, 1981). The PGWBI consists of 22 items that include six dimensions: Anxiety, Depressed Mood, Positive Well-being, Self-Control, General Health, and Vitality (Dupuy, 1984; McDowell & Newell, 1996). It is estimated to take approximately 10 minutes to complete this self-reporting questionnaire, which is generally well-accepted.

Various scoring algorithms have been used. Originally, scores for each item ranged from 0 to 5 with a possible range of 0 to 110 for the global score, which was calculated by the sum of the six dimensions (see Appendix G for scoring of PGWBI©). Some investigators used scores for each item from 1 to 6 with a possible range of 22-132. For this study, the original scoring of items was used. Scores of 0 to 60 are reflective of "*severe distress*," 61 to 72 are reflective of "*moderate distress*" with scores of 73 to 110 being reflective of "*positive well-being.*" Weighting of scores is not used, and reversal of scores is not indicated because the direction of scores is the same for all items. In other words, direction is taken by the wording of options with higher scores always being positive (Chassany, Dimenas, Dubois, & Wu, 2004).

In a survey analysis, if the number of missing items is high, the dimension is judged to be missing. For Anxiety, Positive Well-being, and Vitality, if scores for 3 or more items are missing, the dimension as a whole is missing. If the scores for 2 or more items are missing from Depressed Mood, Self-Control, and General Health, the score of the dimension is missing. The global score is missing when one or more of the 6 dimensions is missing (Chassany et al., 2004).

Due to variations in PGWBI global scoring according to studies between 0 and 110 or 22 and 132, comparisons across studies may be difficult. Therefore, normalizing of the score range has been provided to facilitate comparisons of scores not only for the PGWBI but also for other quality of life instruments. To calculate a normal range (nr) of 0 to 100 for the global score and the 6 dimensions, the following adjustments are required: "for Anxiety, nr = (score / 25) x 100; for Positive Well-being or Vitality, nr = (score / 20) x 100; for Depressed Mood, Self-Control, General Health, nr = (score / 15) x 100; and for the global score, nr = (score / 110) x 100 (Chassany et al., 2004, p.24)."

Reliability has been reported to be quite high with Cronbach's alpha 0.96 (N=152), indicating some item redundancy. Based on factor analysis, there is no support for a six subscale structure as originally developed. However, there is support of the PGWBI total score (McMillan et al., 2006). Debate continues over the most useful way to score the PGWB because internal consistency has been reported with alpha coefficients ranging from 0.88 to 0.95. It is suggested that use of subscales would be redundant; therefore, the use of the total score is considered to be most useful. However, Fazio

(1977) reported PGWBI total score correlation of 0.47 with an interviewer's rating of depression, 0.66 with Zung's Self-rating Depression Scale and 0.78 with the Personal Feeling's Inventory.

Brief COPE Inventory

A second tool used was the Brief COPE Inventory (see Appendix H for the Brief COPE). This tool is available in the public domain, and investigators are free to use the Brief COPE as presented or can also choose selected scales for their studies (Carver, 1997). The Brief COPE consists of 28 items with 2 items per scale. It is based on the original COPE inventory (Carver et al., 1989). The 14 coping strategies that were evaluated included: active coping, planning, positive reframing, acceptance, humor, religion, using emotional support, using instrumental support, self-destruction, denial, venting, substance use, behavioral disengagement, and self-blame (Carver, 1997). Responses range from 1 (*I haven't been doing that at all*) to 4 (*I've been doing this a lot*). By changing verb forms, the items can be converted to a dispositional coping style format or a situational concurrent format. Cronbach's alpha for the different scales ranged from 0.50 to 0.90. All scales exceeded 0.60 except for venting, denial, and acceptance (Carver, 1997).

There is no overall score for this instrument. It is recommended that each scale be assessed separately in relation to other variables. In addition, no recommendation is provide for creating a dominant coping style for a particular person. An alternate method is to create second-order factors from the scales using collected data in order to determine the composition of the higher-order factors (Carver, 1997; Carver et al., 1989).

Computation of scales as well as scoring directions are provided in Table 1 without reversal of coding (Carver, 1997).

3.5 Procedures for Protection of Human Participants

Approval for the dissertation study was obtained from the Duquesne University Institutional Review Board. Potential participants, using the Gluten Intolerance Group website, were informed that by accessing the provided link to the questionnaires and answering the survey questions, they were giving consent to participate. Participation was totally voluntary. Risks were not anticipated from participation. Benefits included dissemination of findings to the multiple health care providers. There was no personal honorarium for participation and participation in the study did not require any monetary cost to the participants. A $500.00 honorarium was given to the Gluten Intolerance Group for research awareness and support in appreciation for providing a link in order to gather data for this dissertation study.

Because the data was collected from online questionnaires, security of the Survey Monkey® was obtained by accessing the Help Center from the website (SurveyMonkey, 2007). Additional security was added by purchasing secure sockets layer (SSL) encryption for the survey links and survey pages. SSL encryption provides 2 keys to encrypt data; one key is public and the second key is private or secret, known only to the recipient of the message. A secure connection was created between the participant and the server for securely sending any amount of information. The addition of this service provided compliance with HIPPA regulations and provided confirmation of security related to inquiries from the Gastroenterology Nurses and Associates Research Committee, who provided funding for this dissertation study.

Confidentiality and Anonymity

No identifying information appeared on the online questionnaires and no identities were revealed in the data analysis. None of the tools had any identifying characteristics that would allow for participant identification. All materials were stored in a locked filing cabinet in the researcher's home. In an effort to ensure confidentiality and anonymity, participants were instructed not to provide any identifying information in response to any questions on the tools completed. These instructions were provided in the introductory paragraphs inviting potential participants to partake in the study (see Appendix A consent to participate).

Several email messages were received from potential participants. Identifying characteristics were deleted from email messages forwarded from the dissertation chair. An anonymous note file was kept with information received from potential participants and/or participants. Although a few phone calls were received, there was no way to link the data with the caller. Survey Monkey® is designed to collect and to analyze data that can be exported for further analysis. Data was downloaded into a spreadsheet for further analysis. No identifying characteristics appeared in the data collected; therefore, data was not deleted for breach of anonymity or confidentiality.

3.6 Analyses

The Statistical Package for the Social Sciences (SPSS®) 14.0 Grad Pack was used to carry out data analysis. Systat 11 was used to confirm data analyses by the statistical consultant. Descriptive statistics including means and standard deviations were used to summarize data for all participants to describe independent socio-demographic variables of age, gender, marital status, educational level, and annual income (Polit & Beck, 2004).

Additional data summarized for all participants included factors related to smoking, alcohol consumption, hours of exercise per week, hours of sleep per night, present symptoms, and cooking and purchasing of gluten free foods. Frequency distributions and percentages were performed to assist in organizing the data for examination and to check for errors in coding (Burns & Grove, 2001).

Pearson's product-moment correlation coefficient (*r*) was to be used to measure the correlation between two variables of psychological well-being and coping strategies. The psychological variables were measured by the Psychological General Well-Being Index (PGWBI) and the coping variables were measured by the Brief COPE Inventory (COPE). Specific assumptions needed to be met in order to use Pearson's equation. These assumptions were: 1) interval measurements of both variables, 2) normal distribution of at least one variable, 3) independence of observational pairs, and 4) homoscedasticity (Burns & Grove, 2001). According to Polit and Beck (2004), interval or ratio scales can be used for variable measurement. With interval measurement, rank order with an assumed equivalent distance is used. Data from interval measurement can be averaged. Ratio measurement provides the highest level of measurement with a rational, meaningful zero. Normal distribution of variables is a theoretical distribution that represents frequency distribution of all possible scores. In a normal distribution, the mean, median, and mode are equal. Finally, homoscedasticity implies that data are evenly dispersed above and below the regression line, indicating equal variance of both variables (Burns & Grove). Preliminary data analysis indicated a violation of these assumptions; therefore, nonparametric tests were required.

The nonparametric equivalent of a Pearson's *r* is a Spearman's *rho*. Interpretation is similar to that of a Pearson's r with a value between -1.00 and + 1.00. A zero score indicates no relationship between variables. A – 1. 00 indicates a perfect negative score. A + 1.00 indicates a perfect positive score. When interpreting the Spearman's *rho* score, it was important to remember that the higher the absolute value of the coefficient, the stronger the relationship. Perfect relationships are rare with most relationships between psychological variables typically ranging between .10 to .40 (Burns & Grove, 2001; Polit & Beck, 2004). Weak relationships were not ignored in this research study. There is a tendency in nursing research to ignore weak relationships, which can create a significant likelihood of disregarding a linear relationship that may have meaning within nursing knowledge when examined in context with other variables (Burns & Grove).

Multiple regression analysis was to be used to understand the effect of two or more independent variables [14 subscales of the Brief COPE (see Table 1 for the Brief COPE)] on a dependent variable [global score of the PGWBI (see Table 2 for the PGWBI)]. Analysis is used to assess the degree to which two or more independent variables make predictions through multiple correlation coefficients. A multiple correlation coefficient or *R* has values ranging from 0.00 to 1.00. Values are indicative of strength but not direction of a relationship. The *R* value can be increased when independent variables have a relatively low correlation among themselves (Polit & Beck, 2004). Multiple regression analysis can determine that a set of independent variables explains a proportion of variance in a dependent variable at a significant level (R^2) and can determine the predictive importance of the independent variable by comparing beta weights (Garson, 2007). The accuracy of a prediction is evaluated by R^2 (Polit & Beck, 2004).

There are different strategies for entering predictor variables during regression analysis. For this study, hierarchical multiple regression was used. This particular strategy provided control of the order of entry of data into the model. Predictors were entered based on results from factor analysis. Hierarchical regression provided the researcher with the ability to determine the number of steps along with the number of predictors in each step (Polit & Beck, 2004).

Descriptive statistics including means and standard deviations were used to answer the first question. "*What are the perceived causes that interfere with adherence to a gluten free diet?"* Because assumptions for a normal distribution of data were violated, Spearman's *rho* was performed to determine whether or not there was a relationship between acceptance and quality of life in adults with celiac disease on a gluten free diet in order to address the second question. "*What is the relationship between acceptance of the diagnosis of celiac disease and quality of life (QOL) in adults with celiac disease on a gluten free diet?* To answer the third question, a Kruskal-Wallis test was conducted to determine if there was a difference between adults with celiac disease on a gluten free diet for 6 months to one year compared to adults with celiac disease on a gluten free diet for various lengths of time (1.5 – 3years; 3.5 – 5 years; 5.5 – 8 years; 8.5 – 12 years; and > 12 years). Hierarchical regression analysis was performed to answer the fourth research question. "*What is the relationship between coping strategies and quality of life in adults adhering to a gluten free diet?"* For this study, two models were used for hierarchical regression based on results from factor analysis. In the first model, the independent variable, emotion, was entered with the dependent variable, global score, which was the indicator for quality of life. In the second model, the dependent variable, global score, was entered with three independent variables, emotion, problem focused coping, and use of support. Analysis of results indicated a violation of collinarity and homoscedasticity. Due to the violations of assumptions and inability to generalize findings, additional analysis was performed. A Kruskal-Wallis test was conducted to compare the global score with the three factors that resulted from the factor analysis.

Chapter 4

Results, Analyses, and Discussion

4.1 Introduction

The chapter begins with a discussion of the recruitment of participants. An overall summary of the characteristics of the sample is presented and then followed by the results of the preliminary analysis conducted on the original data collected. Results and analyses of the data collected for the study sample in relation to each research question follows. A discussion of the findings concludes the chapter.

4.2 Recruitment of Participants

After receiving approval form the Duquesne University Institutional Review Board, the contact person for the Gluten Intolerance Group website was notified that approval was obtained and that the following announcement with the links created to access the surveys could be distributed to potential participants:

Quality of Life and Coping Strategies Survey
The purpose of this study is to examine whether or not there is a relationship between quality of life and coping strategies for adults with celiac disease adhering to a gluten free diet. Participation is voluntary and requires completion of three surveys, which can be accessed from the link provided. Voluntary completion of the surveys will confirm consent to participate. The estimated time to complete all three surveys is approximately 45 minutes.

Initially, the GIG® reported sending 11,000 emails, which included branch leaders. Approximately six weeks later, the GIG® reported issuing a reminder to 20,000 addresses on the GIG® major list serve. During this time, the GIG® reported that there were problems with their server, which accounted for approximately three weeks of downtime. The GIG® email list consisted of both active and inactive members. Members consisted of 98% consumers and 2% health care professionals. The contact person for the GIG® indicated that in general a 1% response was obtained from the email list. A total of 622 persons completed the demographic survey with 542 persons completing the PGWBI while 472 completed the Brief COPE averaging approximately a 2.5% response rate overall from the combined mailings. However, in several cases respondents did not complete all three questionnaires as directed. The overall response summary over approximately a four month period for each of the questionnaires is provided in Table 4.1.

Table 4.1

Survey Response Summary

Instrument	*Total Started*	*Total Completed*	*Percent*
Demographic Information and Health and Diet History	683	622	91
Psychological General Well-Being Index	562	542	96
Brief COPE	498	472	95

Note. This table represents originally collected data prior to filtering for inclusion / exclusion criteria. Percentages have been rounded to the nearest whole number.

Table 4.2

Frequency Distribution of Demographic Variables (N = 683)

Demographic Variable		*Frequency*	*Percent*
Gender			
	Male	103	15
	Female	580	85
Marital Status*			
	Never Married	102	15
	Now Married	470	70
	Separated	6	1
	Divorced	74	11
	Widowed	23	3
Annual Income*			
	< $10,000	36	6
	$10,000 - $14,999	13	2
	$15,000 - $24,999	19	3
	$25,000 - $34,999	58	10
	$35,000 - $49,999	81	14
	$50,000 – $74,999	145	24
	$75,000 - $99,999	100	17
	$100,000 - $149,999	76	13
	$150,000 - $199,999	38	6
	$200,000 or more	29	5
Smoker*			
	No	643	95
	Yes	27	4
Alcohol Consumption*			
	Not Applicable	274	41
	Yes	213	32
	Beer	81	12
	Wine	314	47
	Liquor	151	22

Note. All items were not answered by all participants from originally collected data prior to filtering for inclusion / exclusion criteria. Percentages have been rounded to the nearest whole number.

* = missing data. n = participants not answering (Marital Status, n = 8; Income, n = 88; Smoking & Alcohol Consumption, n = 9 each).

Table 4.3

Descriptive Statistics of Demographic Variables (*N* = 683)

Demographic Variable	*Range*	*M*	*SD*
Age in Years**	75 (18 - 93)	51.5	13.7
Education: Number of Years	38 (1 – 39)	15.5	4.0
Hours of Sleep per Night*	9 (3 – 12)	7.2	1.2
Hours of Exercise per Week*	100 (0 – 100)	4.9	6.8

Note. All items were not answered by all participants from originally collected data prior to filtering for inclusion / exclusion criteria.
* = missing data; n = participants not answering (Sleep & Exercise, *n* = 9 each);
** = cases eliminated due to ages ranging from 4 to 17 years of age

Results of the response summary for total number of surveys completed are provided in Tables 4.2 and 4.3 on demographic variables. Gender, marital status, smoking, and alcohol consumption are reported by frequency and percentage. Age, number of years of education, number of drinks per week, hours of sleep per night, and hours of exercise per week are reported by mean (*M*) and standard deviation (*SD*). Only one participant reported smoking one pack per day.

The third section of the first survey was related to whether or not participants were diagnosed with celiac disease, symptoms experienced by participants, and any follow-up care after being diagnosed with celiac disease. Overall results for the third section are provided in Table 4.4. Results are reported in response frequency and percent.

Length of time reported from the first symptoms until the diagnosis was made is reported in months and in years. Responses ranged from 0 to 11 months with a mean of 4.6 and a standard deviation of 2.7 and from 0 to 75 years with a mean of 15.0 and a standard deviation of 14.6. It seemed as though a few participants reported their age. This made it difficult to determine the length of time from first experiencing symptoms until a diagnosis was made. A total of 101 participants skipped this question.

Table 4.4

Celiac Disease Diagnosis

Question	*Frequency N = 683*	*Percent*
Diagnosed with celiac disease*		
Yes	571	89
No	70	11
Sign or symptoms before diagnosis*		
Gas	454	71
Abdominal Bloating and Pain	483	75
Weight Loss	280	44
Diarrhea	403	63
Anemia	326	51
Bone or Joint Pain	297	46
Difficulty Recalling Information	227	35
Missed Menstrual Periods	79	12
Pale Sores Inside the Mouth	126	20
Itchy Skin	231	36
None	18	3
Diagnosis*		
Endoscopy with Biopsy	438	68
CBC	107	17
Serum Ferritin	44	7
Anti-gliadin Antibodies	202	32
Immunoglobulin A (IgA)	229	36
Anti-tissue Transglutaminase Antibodies (tTG)	190	30
Anti-endomysium Antibodies (AEA)	61	10
Not Applicable	89	14
Additional Tests*		
Breath Hydrogen	19	3
Small Bowel Series	141	24
Colonoscopy	300	51

(table continues)

Table 4.4 (continued)

Question	*Count* *N = 683*	*Percent*
Bone Density	229	39
Bone Marrow	15	3
Iron Studies	155	26
Skin Biopsy	48	8
None	127	22
Follow-Up Test After Diet*		
Yes	354	55
No	287	45
Follow-Up Tests*		
Endoscopy with Biopsy	186	29
CBC	148	23
Serum Ferritin	82	13
Anti-gliadin Antibodies	158	25
Immunoglobulin A (IgA)	155	24
Anti-tissue Transglutaminase Antibodies (tTG)	152	24
Anti-endomysium Antibodies (AEA)	45	7
Not Applicable	262	41
Current Sign or Symptoms*		
Gas	201	31
Abdominal Bloating and Pain	183	29
Weight Loss	28	4
Diarrhea	117	18
Anemia	61	10
Bone or Joint Pain	192	30
Difficulty Recalling Information	141	22
Missed Menstrual Periods	16	3
Pale Sores Inside the Mouth	40	6
Itchy Skin	114	18
None	216	34

(table continues)

Table 4.4 (continued)

Question	*Count* *N = 683*	*Percent*
Current Sign or Symptoms*		
Gas	201	31
Abdominal Bloating and Pain	183	29
Weight Loss	28	4
Diarrhea	117	18
Anemia	61	10
Bone or Joint Pain	192	30
Difficulty Recalling Information	141	22
Missed Menstrual Periods	16	3
Pale Sores Inside the Mouth	40	6
Itchy Skin	114	18
None	216	34

Note. All items were not answered by all participants from originally collected data prior to filtering for inclusion / exclusion criteria. Percentages have been rounded to the nearest whole number.
* = missing data; *n* = participants not answering (*n* = 42).

The fourth section of the first survey was included to obtain information in regard to a gluten free diet. Overall responses are reported in Tables 4.5, 4.6, and 4.7 with response frequency and percentage being reported. Under the question related to how information was obtained after initial dietary instruction was received was an open ended choice "*Other*" in which participants could type in their response if it was different from the options provided.

Responses related to "O*ther*" numbered 181 for the open ended question of how dietary information was obtained after initial instruction. The majority of responses were names of individuals or institutions. The remaining "*Other*" responses included a nutritionist, naturopathy including one psychiatrist who was reported to use eclectic strategies, a dermatologist, and family and friends, especially those with celiac disease.

Table 4.5

Gluten Free Diet and Instruction

Question	*Frequency* *N = 683*	*Percent*
Length of time on a GFD*		
< 6 months	18	3
6 months to 1 year	47	8
1.5 to 3 years	143	23
3.5 to 5 years	142	23
5.5 to 8 years	111	18
8.5 to 12 years	68	11
> 12 years	94	15
Consultation with Dietitian*		
Yes	309	50
No	309	50
After initial instruction, how is information obtained?*		
Physician	118	19
Nurse	26	4
Dietitian	124	20
Library	171	27
Internet	558	90
Support Group	441	71
Other	132	21

Note. All items were not answered by all participants from originally collected data prior to filtering for inclusion / exclusion criteria. Percentages have been rounded to the nearest whole number.
* = missing data; *n* = participants not answering (*n* = 60).

Two participants reported receiving incorrect information. One participant reported receiving outdated information from a hospital dietitian. Another participant reported being told to gradually reduce gluten from the diet. Many responses included internet sites. The use of internet sites was not surprising given that participants used the internet to access the questionnaires for this study. In addition, the Internet was selected by 90% of the participants for this specific question.

Table 4.6

Oat Consumption and Diet Preparation

Question	*Frequency* *N* = 683	*Percent*
Are oats consumed?*		
Yes	255	41
No	368	59
Are meals prepared or served to you?*		
Yes	46	7
No	577	93
Are meals prepared at home?*		
Yes	616	99
No	7	1
Who prepares most meals?*		
Self	501	81
Spouse	84	14
Child	3	1
Significant Other	9	2
Other	21	3

Note. All items were not answered by all participants from originally collected data prior to filtering for inclusion / exclusion criteria. Percentages have been rounded to the nearest whole number.
* = missing data; *n* = participants not answering (*n* = 60).

Perhaps listing websites was provided because the questionnaires were accessed from a specific website dedicated to individuals with gluten intolerance and participants wanted to provide additional websites that were found to be beneficial for obtaining gluten free dietary information.

Responses to "*Other,*" an open ended response, in regard to who prepares meals were a) mother (10), b) parents (6), c) father-in-law (1), d) room mate (1), and e) coworker (1). The remainder of responses (7) was an ordering of multiple selections from the options listed or an explanation of self-preparation of meals.

Table 4.7 provides responses related to purchasing of gluten free foods and difficulty with adhering to a gluten free diet. Responses are reported in frequency and percentages.

Gluten Free Diet.

Participants were asked to estimate the percentage of purchased gluten free foods. Of the 69% of participants indicating gluten free foods were purchased, percents ranged from 0.5 to 100 with a mean of 17.4 and a standard deviation of 16.5. Additional responses to "*Other*" under where gluten free foods were purchased included an oriental food store, food co-ops and buyer's club, farmer's market, drug emporium, mail order, restaurants, bakeries, telephone orders, gluten free food fair, and visits to Canada.

Three participants indicated that foreign travel was less difficult than travel in the United States, especially when eating in restaurants. Foreign travel may be less difficult due to celiac disease being quite common in Europe with prevalence reported to be 1 percent of the population (Mendoza, 2005). In 2002, Australia declared that all potential food allergens such as *gluten*, peanuts, and other nuts, seafood, milk, *wheat*, eggs, and soybeans be identified on food labels. In 2005, the European Union Directive on product labeling required identification of 12 food allergens including dairy, eggs, celery, fish, *gluten*, mustard, peanuts, sesame seeds, shellfish, soy, tree nuts and *wheat*, and *derivatives*. On January 1, 2006 the US Food Allergen Labeling Consumer Protection Act went into effect. Food labels are required to identify eight allergens such as dairy, eggs, fish, peanuts, shellfish, soy, tree nuts, and *wheat*. Unfortunately, gluten was not included in the allergen labeling (Koeller & LaFrance, 2007). Foods stated to be gluten free were not always gluten free, as reported by one participant. Also, a chef stating that foods were gluten free was considered to be more acceptable as opposed to that of a waitress stating that foods were gluten free.

Table 4.7

Purchasing Foods and Dietary Difficulties

Question	*Frequency* *N* = 683	*Percent*
Are prepared foods purchased?*		
Yes	431	69
No	192	31
Difficulty obtaining GF foods?*		
Yes	175	72
No	448	28
Where are GF foods purchased?*		
Grocery Store	388	62
Specialty Food Store	426	69
Online	164	26
Other	54	9
Difficulties following a GFD*		
Do not understand what foods can and cannot be eaten	15	2
Do not like the taste	134	22
Expensive to buy	380	61
Do not understand labeling	40	6
Feel no different on a GFD	38	6
None	103	17
Problem outside my home	349	56

Note. All items were not answered by all participants from originally collected data prior to filtering for inclusion / exclusion criteria. Percentages have been rounded to the nearest whole number.
* = missing data. *n* = participants not answering (*n* = 60). GF = Gluten Free; GFD = Gluten Free Diet

Families were reported as being unaccepting and unsupportive with one participant indicating that her family had accused her of using food to reject them.

Table 4.8

Responses to dietary problems when outside the home were as follows:

Problem	*Frequency* *N* = 683	*Percent*
Restaurants	165	26
Other's Homes	37	6
Eating Out	34	5
Travel	31	5
Social Events	26	4
Business and School Functions	23	4
Potluck Dinners	8	1

Note. All items were not answered by all participants from originally collected data prior to filtering for inclusion / exclusion criteria.). Percentages have been rounded to the nearest whole number.
* = missing data. *n* = participants not answering (*n* = 60

One participant reported purchasing gluten free foods for her son, but not for herself due to the expense of gluten free foods. Another participant, who had reported being on a gluten free diet for 1.5 to 3 years, indicated that adherence to a gluten free diet was easier at the beginning of adherence to a gluten free diet as opposed to the present time.

Finally, the response rate to the amount of stress felt relative to a gluten free diet during the past month is reported in Table 4.9. The summary is from all participants from originally collected data prior to filtering for inclusion/exclusion criteria.

As data was being collected responses were periodically reviewed for inclusion and exclusion criteria. After approximately four months and a second two week period of no responses, data collection was closed. As noted, approximately 89% of participants indicated being diagnosed with celiac disease.

Table 4.9

Stress Related to a Gluten Free Diet

Level of Stress	*Frequency* *N* = 683	*Percent*
None	117	19
Minimal	315	51
Moderate	157	25
Large	34	6

Note. All items were not answered by all participants from originally collected data prior to filtering for inclusion / exclusion criteria. Percentages have been rounded to the nearest whole number.
* = missing data. *n* = participants not answering (*n* = 60).

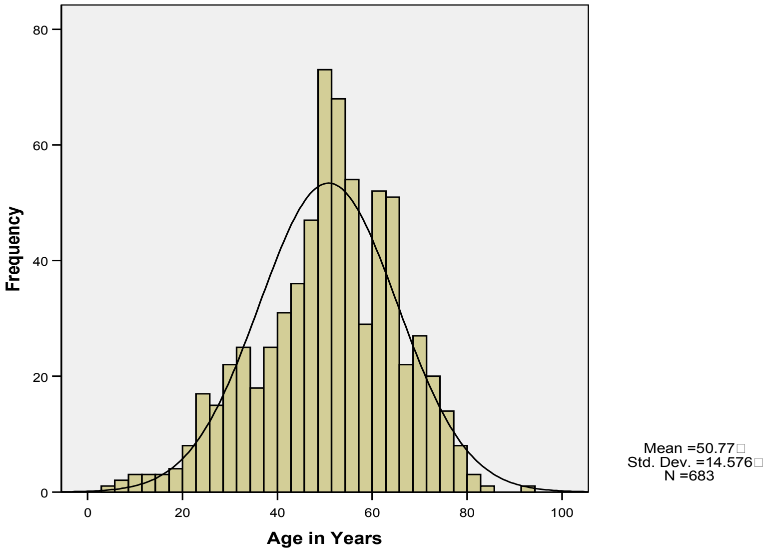
Responses were filtered to determine participants based on inclusion and exclusion criteria. Although the overall response rate was good, after filtering responses for inclusion and exclusion criteria, there were 156 eligible participants who had also completed both the PGWBI and the Brief COPE surveys. After talking with experts to examine inclusion and exclusion criteria for possible revisions, it was decided to continue as planned with diagnostic inclusion and exclusion criteria; however, the age range was modified from 20 to 70 years of age to 18 to 75 years of age. All participants reported that meals were prepared at home and after initiation of a gluten free diet, a follow-up study was performed. The final sample size for this study was 156 participants.

4.3 Preliminary Analyses

From this point on, statistical analysis is related to the sample population (*N* = 156) obtained after originally collected data was filtered for inclusion and exclusion criteria. Descriptive statistics including frequencies, percentages, means, and standard deviations were used to summarize demographic variables of age, gender, marital status, annual income, education in years, hours of sleep per night, hours of exercise per week, smoking habit, and alcohol consumption. Frequency distributions were constructed and examined for accuracy and consistency of data. For all major variables, histograms were generated to assess for data normality. Data normality was not identified in the major variables. Additional calculations were performed to check for skewness and kurtosis. Again, data normality was not identified. Figures 4.1 through 4.4 are included to demonstrate the comparison distribution of participants from the originally collected data (*N* = 683) with the sample study (*N* = 156) because neither data set demonstrated normality.

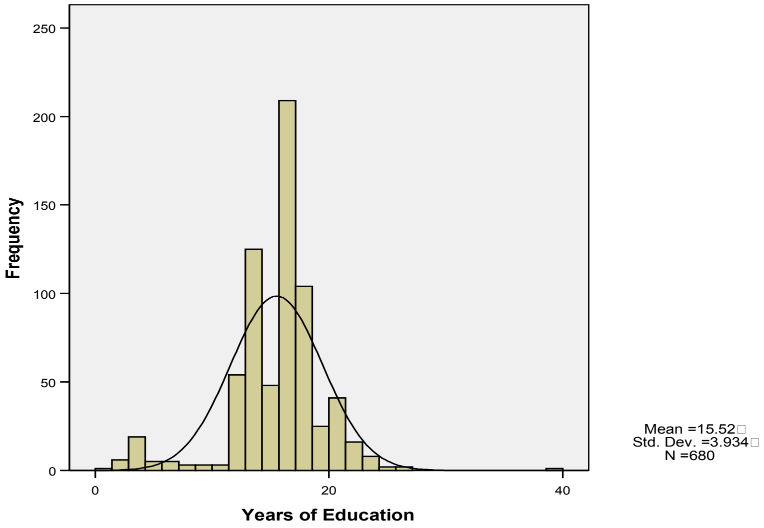
From the study sample (*N* = 156), the PGWBI and the Brief COPE were evaluated for internal consistency by calculating Cronbach's alpha. The normal range of values is between 0.00 to +1.00 with higher values reflective of a higher internal consistency (Polit & Beck, 2004). Cronbach's alpha for the PGWBI was 0.80, and Cronbach's alpha for the Brief COPE was calculated to be 0.77.

Figure 4.1. From originally collected data, age of participants in years (*N* = 683).



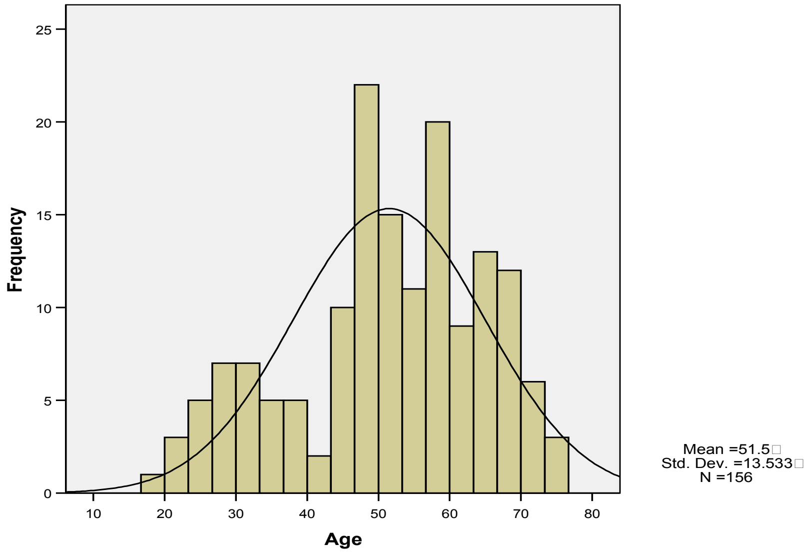
Note. Mean age in years of participants from originally collected data prior to filtering for inclusion and exclusion criteria.

Figure 4.2. From originally collected data, participants reported years of education (*N* = 680).



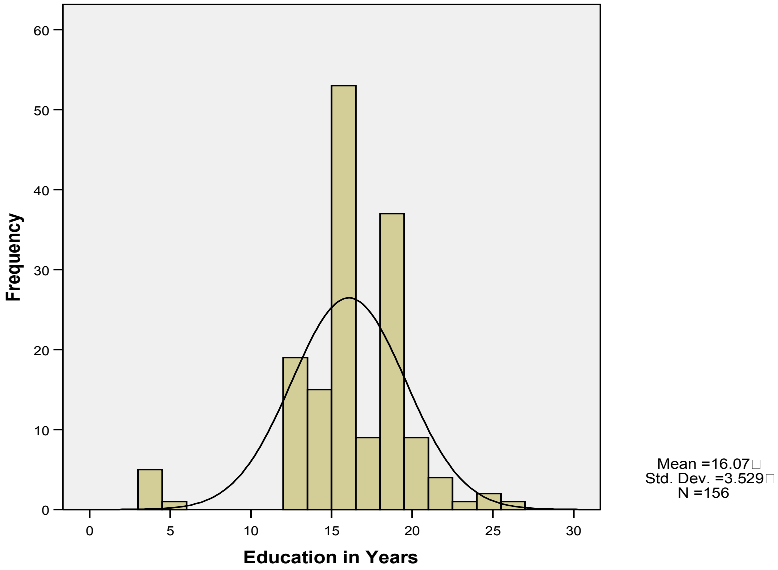
Note. Mean years of education for participants from originally collected data prior to filtering for inclusion and exclusion criteria. Not all participants responded.

Figure 4.3. Age of participants included in study (*N* = 156).



Note. Mean age in years of participants for the sample study.

Figure 4.4. Study participants reported years of education (N = 156).



Note. Mean years of education for the study sample.

4.4 Characteristics of the Sample

Results of the response summary on demographic variables of the sample population (N = 156) are provided in the Tables 4.10 and 4.11. Gender, marital status, smoking, and alcohol consumption are reported by frequency and percentage. Age, years of education, number of drinks per week, hours of sleep per night, and hours of exercise per week are reported by mean (M) and standard deviation (SD). Smokers did not report the number of packs smoked per day.

Geographic location, which follows, is reported by region. The District of Columbia and twelve states did not have participants in the study. The states that were not represented included: Arkansas, Delaware, Kansas, Louisiana, Mississippi, Montana, Nebraska, North Dakota, Oklahoma, Rhode Island, South Carolina, and South Dakota. California, Illinois, New York, North Carolina, Oregon, and Texas had participants numbering between 11 and 14. The remainder of states had participants in the single digits. With the exception of one participant from Hawaii, the number and percent from the five regions were as follows: Northeast [*n* = 34 (22%)], Southeast [*n* = 31 (20%)], Midwest [*n* = 33 (21%)], West [*n* = 38 (25%)], and Southwest [*n* = 19 (12%)].

Prior to performing statistical analyses to address research questions, examination of univariate indices of skewness and kurtosis was performed for all major variables. Results revealed a sample data set that did not meet requirements for normality. The skewness statistic in a normal distribution is about zero. It is probable that absolute values of 2 standard errors of skewness (*ses*) or more are skewed to a significant degree. The following formula was used to calculate the *ses*: $\sqrt{6/N}$. Kurtosis demonstrates the peakedness or flatness of a distribution compared to the normal distribution. In normal distributions, the kurtosis statistic (mesokurtic) is about zero. As values depart from zero, values that are positive indicate the possibility of a leptokurtic distribution (too tall) and values that are negative indicate the possibility of a platykurtic distribution (too flat).

Again, absolute values of 2 standard errors of kurtosis (*sek*) or more probably differ from mesokurtic to a significant degree. The following formula was used to calculate the *sek*: $\sqrt{24/N}$ (Brown, 1997). Figures 1 through 4 also illustrate the skewness and kurtosis of analyzed data. Calculated skewness and kurtosis values are reported in Table 4.12.

In an effort to bring data closer to a normal distribution, transformation of data was performed. Because data was negatively skewed with heterogeneous variances, square root transformation was used. Transformation of data did not result in a data set with a normal distribution. Skewness and kurtosis statistics were unchanged.

Table 4.10

Frequency Distribution of Demographic Variables

Demographic Variable		*Frequency* $N = 156$	*Percent*
Gender			
	Male	23	15
	Female	133	85
Marital Status			
	Never Married	22	14
	Now Married	109	70
	Separated	0	13
	Divorced	20	3
	Widowed	5	
Annual Income*			
	< $10,000	10	7
	$10,000 - $14,999	1	1
	$15,000 – $24,999	4	3
	$25,000 – $34,999	11	8
	$35,000 - $49,999	18	13
	$50,000 – $74,999	29	21
	$75,000 - $99,999	32	23
	$100,00 – $149,999	22	16
	$150,000 – 199,999	8	6
	$200,00 or more	4	3
Smoker			
	No	147	94
	Yes	9	6
Alcohol Consumption*			
	Not Applicable	98	63
	Yes	58	37
	Beer	19	14
	Wine	75	56
	Liquor	41	30

Note. All items were not answered by the study sample.
* = missing data. n = participants not answering ($n = 18$).

Table 4.11

Descriptive Statistics of Demographic Variables (*N* = 156)

Demographic Variable	*Range*	*M*	*SD*
Age in Years	57 (18 – 75)	51.50	13.53
Years of Education	23 (4 – 27)	16.07	3.53
Hours of Sleep per Night*	7 (5 – 12)	7.28	1.08
Hours of Exercise per Week*	28 (0 – 28)	3.84	3.91

Note. All items were not answered by the study sample.

* = missing data. *n* = participants not responding (*n* = 41, Sleep; *n* = 19, Exercise).

Performance of Kolmogorov-Smirnov(a) statistics resulted in a p < 0.005 for all variables. Examination of data indicated that departure form normality was due to both skewness and kurtosis. A significant K-S statistic was indicative of a problem with the data set because of the calculated difference between scores for each variable. Therefore, parametric tests, as originally planned, were not used for data analysis because data normality was not demonstrated with original or transformed data.

A Spearman *rho* correlation coefficient was performed to identify relationships among the dependent variable, quality of life (measured by the global score of the (PGWBI) and / or major socio-demographic variables, independent variables. A positive weak relationship was found between the global score and hours of sleep per night (*rho* (113) = .25, $p < 0.01$) with a two-tailed test of significance, indicating a significant relationship between the two variables. Quality of life improved with increased hours of sleep per night.

Table 4.12

Skewness and Kurtosis Statistics (N = 156)

Variable	*ses x 2 / skewness*	*sek x 2 / kurtosis*
Demographic Variable		
Age	0.39 / -0.50	0.78 / -0.46
Income	0.41 / -0. 72	0.83 / -0.41
Years of Education	0.39 / 0.99	0.78 / 3.79
Hours of Exercise / Week	0.41 / 2.82	0.83 / 12.4
Hours of Sleep / Night	0.45 / 0.92	0.91 / 3.45
Number of Drinks / Week	0.54 / 2.30	1.08 / 5.98
Level of Stress	0.38 / 0.44	0.77 / -0.00
PGWBI		
Anxiety	0.38 / -0.84	0.77 / 0.54
Depressed Mood	0.38 / -1.64	0.77 / 3.17
Positive Well-Being	0.38 / -0.54	0.77 / -0.51
Self-Control	0.38 / -1.28	0.77 / 1.45
General Health	0.38 / -0.43	0.77 / -0.32
Vitality*	0.38 / -0.31	0.77 / 0.55
Global Score	0.38 / -0.81	0.77 / 0.402
Brief COPE		
Self-Distraction	0.38 / 0.35	0.77 / -1.047
Active Coping	0.38 / -0.46	0.77 / 0.78
Denial	0.38 / 3.31	0.77 / 12.60
Substance Use	0.38 / 3.41	0.77 / 13.55
Emotional Support*	0.38 / 0.08	0.77 / -0.70
Instrumental Support	0.38 / 0.39	0.77 / -0.44
Disengagement	0.38 / 2.76	0.77 / 7.533
Venting	0.38 / 0.60	0.77 / -0.33
Reframing	0.38 / 0.14	0.77 / -1.17
Planning	0.38 / -0.27	0.77 / -1.12
Humor	0.38 / 0.64	0.77 / -0.56
Acceptance	0.38 / -1.84	0.77 / 2.55
Religion	0.38 / 0.31	0.77 / -1.37
Self-Blame	0.38 / 1.68	0.77 / 2.52

Note. * = variable with a normal distribution.

A moderate negative relationship was found between the global score and reported stress over the past month in relation to adherence to a gluten free diet (*rho* (154) = -.46, $p < 0.01$) with a two-tailed test of significance, indicating a significant relationship between the two variables. Quality of life decreased with increased levels of stress. A negative weak relationship was found between years of education and number of drinks per week (*rho* (80) = -.22, $p < 0.05$) with a two-tailed test of significance, indicating a significant relationship between the two variables.

4.5 Interpretation of Findings

A Demographic Information and Health History questionnaire that was researcher generated and the Psychological General Well-Being Index and the Brief COPE instruments were used to collect data from participants. Participants willingly provided responses to the topics of interest in relation to a reported celiac disease diagnosis and reported adherence to a gluten free diet. Results of each research question are presented according to the specific statistical method used for analysis.

Research Question 1: What are the perceived causes that interfere with adherence to a gluten free diet?

Responses were obtained from the following question on the Demographic Information and Health History questionnaire: "*What difficulties do you have in following a gluten free diet?"* for which participants were required to provide an answer. Participants were to choose all responses that applied. Fifteen percent of participants reported no difficulty adhering to a gluten free diet. Results from the 85% of participants reporting difficulties are provided from least to most difficult. Responses were as follows: 1) "I do not understand what foods I can and cannot eat." (n = 3 or 2%); 2) "I feel no different on a gluten free diet" (n = 9 or 6 %); 3) "I do not understand labeling on foods." (n = 10 or 6%); 4) "I do not like the taste of gluten free foods." (n = 40 or 19%); 5) "Gluten free foods are expensive to buy." (n = 95 or 61%); and 6) "I have a problem when outside my home.” (*n* = 95 or 61%). Responses from the sample population specifying where the problem existed outside the home are reported in Table 4.13.

Table 4.13

Where Dietary Problems Exist Outside the Home (N = 156)

Problem	*Frequency*	*Percent*
Restaurants	52	57
Friends/Family/Social Events	19	21
Travel	11	12
Business	5	6
Potluck Dinners	4	4

Note. Participants reported all problem areas outside the home that presented difficulty adhering to a gluten free diet. Percentages have been rounded to the nearest whole number.

Examples of specific comments made in addition to the where problems occur were as follows:

> “Others seem troubled by my questions, so I am eating out hardly at all any more.”
>
> “I miss having some normal foods.”
>
> “Having others understand that it is not safe to just cheat a little on a gf diet”
>
> “Feeling left out or different”
>
> “I cannot eat at family or friends unless it's prepackage that I brought myself!”
>
> “Feel ill at ease being so picky”
>
> “Weight gain now that nutrients are being absorbed”

Participants were asked to evaluate stress relative to following a gluten free diet as experienced over the past month. Over half the participants [*n* = 84 (54%)] reported a minimal amount of stress. Results from the remainder of participants from next highest to lowest amounts of reported stress were: moderate [*n* = 35 (22%)], none [*n* = 28 (18%)], and large [*n* = 9 (6%)].

The most frequently reported difficulties related to adhering to a gluten free diet were the expense of gluten free foods and problems encountered outside the home with both being reported at 61%. The remaining difficulties were identified as not liking the taste of gluten free foods, not understanding labels, not feeling different on a gluten free diet, and not knowing what foods to eat and to avoid. A little more than half of the participants identified restaurants as the place participants had the greatest difficulty adhering to a gluten free diet. Other places identified as causing difficulty adhering to a gluten free diet were home / social events, travel, business, and potluck dinners. Although participants reported difficulties adhering to a gluten free diet, slightly over half the participants reported a minimal amount of stress relative to relative to following a gluten free diet. The remainder of participants reported stress as moderate, none, or a large amount. Although over half the participants reported a minimal amount of stress related to dietary compliance over the past month, a significant moderate correlation was found between quality of life and stress. Regardless of the reported level of stress, quality of life was negatively affected as measured by the global score of the PGWBI.

Research Question 2: What is the relationship between acceptance of the diagnosis of celiac disease and quality of life (QOL) in adults with celiac disease on a gluten free diet?

Because the data obtained on the two variables including acceptance of a celiac disease diagnosis and quality of life did not meet an approximate normal distribution of data, Spearman correlation coefficient (*rho*) was used to determine the strength and magnitude of the relationship between acceptance and QOL. The correlation is reported between -1.0 and +1.0. In general correlations > 0.7 are strong, correlations < .03 are considered weak, and correlations between 0.3 and 0.7 are considered to be moderate (Cronk, 2006).

A Spearman *rho* correlation was performed for the relationship between acceptance and quality of life. The score for acceptance, as measured by the Brief COPE (see Table 1 for Brief COPE scales), was obtained by combining questions 20 (*I have been accepting the reality of the fact that it has happened.*) and 24 (*I have been learning to live with it.*). Quality of life was measured by using the Global Score of the PGWBI. Although the relationship was found to be significant, the relationship was very weak (r (154) = 0.194, $p < 0.05$) between acceptance and quality of life. Acceptance was found to be minimally related to quality of life. To further explore the relationship between acceptance and QOL, a Spearman *rho* correlation was performed for each of the dimensions of the PGWBI that made up the global score. Although significant, a very weak relationship was found between acceptance and three of the dimensions of the PGWBI. The significant and weak relationships between acceptance and the three dimensions of the PGWBI were as follows: depressed mood (*rho* (154) = 0.23, $p < 0.01$), general health (r (154) = 0.21, $p < 0.01$), and positive well-being (r (154) = 0.17, $p < 0.05$).

The relationship between quality of life and each subscale of the Brief COPE was also explored. A significant but weak negative relationship was found between quality of life and substance use (*rho* (154) = -.23, $p < 0.01$). Substance use had a negative effect on quality of life. Significant, moderate negative relationships among quality of life and five subscales of the Brief COPE: denial (*r* (154) = -.30, $p < 0.01$); self-distraction (*r* (154) = -.36, $p < 0.01$); venting (*r* (154) = -.39, $p < 0.01$); disengagement (*r* (154) = -.45, $p < 0.01$); and self-blame (*r* (154) = -.49, $p < 0.01$) were found.

Strong significant relationships were found between the global score and each dimension of the PGWBI. Sperman *rho* correlations for each dimension, which is a subcategory of the entire index, were performed and found to be between 0.71 and 0.90 at the 0.01 level with a two-tailed test of significance. These findings were expected and supported the strength of the relationship between variables.

The mean global score of the PGWBI for participants ($N = 156$) was 74.27 with a standard deviation of 18.76. This average score was reflective of "*positive well-being*" because the score fell between 73 and 110. The minimum reported score was 12 with the highest reported score being 108. The number and percent for each category of the global score were as follows: "*severe distress*" [$n = 36$, (23%)], "*moderate distress*" [n = 21, (14%)], and "*positive well-being*" [n = 99, (63%)].

While on a gluten free diet, participants were asked to report all signs and symptoms presently being experienced. The frequency and percentages are provided in Table 4.14 as compared to reported signs and symptoms prior to diagnosis of celiac disease. Additional diagnostic tests to further evaluate participants (N=156) following a celiac disease diagnosis were reported as: 1) colonoscopy [$n = 89$ (57%)]; 2) bone density [$n = 81$ (52%)]; 3) iron studies [$n = 53$ (34%)] and small bowel series [$n = 53$ (34%)]; 4) no tests [*n* = 18 (12%)]; 5) skin biopsy [*n* = 12 (8%)]; and 6) bone marrow biopsy [*n* = 8 (5%)] and breath hydrogen [*n* = 8 (5%)].

Results indicated that a significant but weak relationship existed between acceptance of a celiac disease diagnosis, a problem focused coping strategy, and quality of life. Further exploration of the remaining subscales of the Brief COPE resulted in moderate negative relationships between quality of life and emotion focused coping strategies of disengagement and venting. Moderate negative relationships were also found between quality of life and avoidance coping strategies of denial, self-distraction, and substance use.

Table 4.14

Reported Signs and Symptoms (*N* = 156)

Sign or Symptom	*Frequency*	*Frequency**	*Percent*	*Percent**
Bone Pain	50	79	32	51
Gas	49	118	34	76
None	39	6	25	4
Difficulty Recalling Information	38	49	24	31
Diarrhea	33	98	21	63
Abdominal Pain/Bloating	51	116	33	74
Itchy Skin	31	51	20	33
Anemia	18	90	12	58
Mouth sores	12	41	8	26
Weight Loss	7	2	5	1
Missed Menstrual Periods	3	22	2	14

Note. Percentages have been rounded to the nearest whole number.
* = reported signs and symptoms prior to a diagnosis of celiac disease.

A paired-sample *t* test was conducted to compare the frequency of signs and symptoms prior to a celiac disease diagnosis and initiation of a gluten free diet (M = 61.09, SD = 41.80) to current signs and symptoms on a gluten free diet (M = 30.09, SD = 17.56). A significant decrease in reported signs and symptoms was found ($t(10) = -3.03$, $p < .05$).

Research Question 3: What is the difference in acceptance between adults with celiac disease on a gluten free diet for 6 months to one year compared to adults with celiac disease on a gluten free diet greater than one year?

For this question, a Kruskal-Wallis *H* test, which is the nonparametric equivalent of the one-way ANOVA, was conducted to compare acceptance of a celiac disease diagnosis for participants on a gluten free diet for various lengths of time. No significant difference was found ($H(5) = 6.42$, $p > 0.05$), indicating that the participants did not differ significantly from one another. Regardless of the length of time participants were on a gluten free diet, the average score for acceptance was 6 with scores ranging from 2 to 8. Length of time on a gluten free diet did not seem to influence acceptance of the celiac disease diagnosis.

Further examination of coping strategies revealed significant findings in regard to positive reframing. Positive reframing was measured by combining questions 12 (*I have been trying to see it in a different light, to make it seem more positive*.) and 17 (*I have been looking for something good in what is happening*.) of the Brief COPE (see Table 1). The participants dependent on the length of time since diagnosis and initiation of a gluten free diet significantly differed from one another in regard to positive reframing ($H(5)$ = 11.65, $p < 0.05$). Positive reframing, with scores ranging from 2 to 8, indicated that participants on a gluten free diet 8.5 – 12 years reported a mean score of 8, while participants on a gluten free diet for 6 months – 1 year reported a mean score of 6. Participants on a gluten free diet for 8.5 -12 years reported using positive reframing more than other participants on a gluten free diet for varying lengths of time. Frequency and percentage of varying lengths of time on a gluten free diet are included in Table 4.15.

Table 4.15

Time on a Gluten Free Diet

Time on Diet	*Frequency* 156	*Percent*
6 months - 1 year	10	6.4
1.5 - 3 years	29	18.6
3.5 - 5 years	38	24.4
5.5 - 8 years	31	19.9
8.5 - 12 years	21	13.5
> 12	27	17.3

Note. Reported lengths of time on a gluten free diet.

In regard to research question three, no significant difference was found in acceptance in adults with celiac disease on a gluten free diet for 6 months to one year compared to adults with celiac disease that had been on a gluten free diet longer than one year. However, further investigation found that a significant difference with the use of positive reframing when comparing adults with celiac disease and length of time on a gluten free diet ($H(5) = 11.65, p < 0.05$). Scores for adults with celiac disease on a gluten free diet for 8.5 – 12 years reported the highest score possible, which was two points higher than reported by participants on a gluten free diet for varying lengths of time.

Research Question 4: What is the relationship between coping strategies and quality of life in adults adhering to a gluten free diet?

Prior to examining the relationship between coping strategies and quality of life, each subscale of the Brief COPE was examined. Coping strategies as reported by study participants are provided in Table 4.16. Scores are reported by the most frequent score and percentage as well as the mean and standard deviation for each subscale of the Brief COPE. Each subscale combines two questions (see Table 1 for Brief COPE scales). Scores were obtained by adding the responses for each question included in the scale. Responses for all questions were as follows: 1) *I have not been doing this at all*; 2) *I have been doing this a little bit*; 3) *I have been doing this a medium amount*; and 4) *I have been doing this a lot.*

Reported scores from the dimensions of the PGWBI along with the global score are reported in Table 4.17. Scores are reported by mean and standard deviation for each dimension of the index along with the global score, which is the sum of all six dimensions.

After obtaining results of the global score of the PGWBI and reported use of coping strategies, factor analyses of the subscales of the Brief COPE were performed to determine a group or cluster of variables. By performing factor analyses, variables were reduced from 14 variables to 3 variables. The reliability of factor analysis is dependent upon sample size. A sample of 300 or more generally provides a stable factor solution. Unfortunately, in this study only 156 participants met the inclusion criteria and therefore, an alternative method, the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy was used to determine appropriateness of factor analyses.

Table 4.16

Coping Strategies (N = 156)

Coping Strategy	*Score*	*Frequency*	*Percent*	*Mean*	*Standard Deviation*
Acceptance	8	104	67	7.16	1.48
Active Coping	8	46	30	5.90	1.83
Denial	2	130	83	2.35	0.94
Disengagement	2	129	83	2.36	0.90
Emotional Support	5	35	22	5.13	1.64
Humor	4	31	20	3.87	1.79
Instrumental Support	4	50	32	4.49	1.66
Planning	5	24	15	5.48	2.01
Positive Reframing	8	36	23	5.40	1.99
Religion	2	49	31	4.53	2.25
Self Blame	2	73	47	3.08	1.45
Self Distraction	4 and 5	24 each	15 each	4.11	1.82
Substance Use	2	132	85	2.34	0.93
Venting	3 and 4	39 each	25 each	3.86	1.48

Note. Subscales of Brief COPE reporting the most frequently recorded score and its percentage as well as the mean and standard deviation for each score. Percentages have been rounded to the nearest whole number.

Table 4.17

Dimensions of the PGWBI (N = 156)

Dimension	*Mean*	*Standard Deviation*
Anxiety	16.41	4.97
Depressed Mood	12.36	2.76
General Health	9.40	2.90
Positive Well-Being	12.60	4.07
Self-Control	11.89	3.01
Vitality	11.60	4.41
Global Score	74.27	18.76

Note. Reported scores for each dimension of the PGWBI used to determine the global score.

The KMO varies between 0 and 1 with a value of 0 indicating diffusion in the pattern of correlations making factor analysis inappropriate; where as, values close to 1 indicate that factor analysis should yield distinct and reliable factors. Values between .7 and .8 are considered to be good. The KMO for the Brief COPE was .784. The determinant for this data set was 0.11, which is greater than the necessary value of .00001. Consequently, multicollinearity (two or more variables are very closely linearly related) was not a problem and therefore, none of the questions needed to be eliminated. Some relationship between variables was required for factor analysis to succeed. Bartlett's Test of Sphericity was used to determine whether or not a factor analysis could be performed on the Brief COPE data set. Bartlett's test was significant (p < .001) and it was determined that a factor analysis was appropriate (Fields, 2005). Results of the test are provided in Table

4. 18.

Table 4.18

KMO and Bartlett's Test

Kaiser-Meyer-Olkin Measure of Sampling Adequacy.		.79	
Bartlett's Test of Sphericity	Approx. Chi-Square		677.93
	df		91
	Sig.		.000

Note. Results from Brief COPE data set test for significance to perform factor analysis.

Eigenvectors determine linear components within the data set, which required calculation of eigenvalues. This process is used to determine which factors to retain and which to discard. Eigenvalues represent the variance of a particular component. Only those factors with eigenvalues greater than 1 were extracted. Rotation was used to optimize the factor structure and equalize the relative importance of the extracted factors (Fields, 2005). Prior to rotation, factor 1 accounted for considerably more variance than the other two factors (27% compared to 20% and 8%, respectively); however, after rotation, factor 1 was decreased with factor 3 gaining importance (21% compared to 19% and 14%, respectively).

The component matrix demonstrated the loading of each variable onto each factor with variables loading less than .4 being suppressed. As a result, all variables were included except for self-distraction. Suppression was done to ensure that all factors loading within ±.4 were not displayed in the output (Fields, 2005). Reproduced relationships contain differences between the observed correlation coefficients and ones predicted from the model. Most values should be less than .05. For this data set, there were 50 (54%) residuals greater than .05. There are no hard and fast rules about the proportion of residuals that should be below .05; however, as residuals move beyond 50% concerns are raised (Fields, 2005). Oblique rotation was conducted resulting in two matrices: the *pattern matrix* and the *structure matrix*. Both resulted in the manifestation of the same three factors. Factor 1 represents problem focused coping, factor 2 represents emotion focused coping and factor 3 represents use of support. The correlation matrix indicated dependence between factors, which did not cause concern. A relationship between problem focused coping and use of support was anticipated; however, a relationship between emotion focused coping, problem focused coping and use of support was not expected. Results of the both matrices and the component correlation matrix are provided in Tables 4.19 and 4.20.

After completing the factor analyses, reliability analyses were conducted for each of the factors. Values for each of the factors were at .8, indicating good reliability. When reviewing the Alpha if Item Deleted column, question 21 from the emotion focused coping factor was greater than the overall reliability for that factor. Although the value of α for question 21 is greater (.809) than the overall value of α (.806), a dramatic increase in the value of alpha would not occur by deleting this question. Results are provided in Tables 4.21 and 4.22.

Table 4.19

Pattern Matrix

	Component		
	Factor 1 Problem Focused Coping	Factor 2 Emotion Focused Coping	Factor 3 Use of Support
Active Coping	.77		
Positive Reframing	.77		
Humor	.70		
Planning	.68		
Acceptance	.62		
Disengagement		.81	
Self Blame		.77	
Denial		.69	
Substance Use		.62	
Venting		.52	
Self Distraction			
Religion			-.83
Emotional Support			-.74
Instrumental Support			-.71

Note. Three factors resulting from oblique rotation of the Brief COPE subscales in which the influence of the variable to the factor with the influence of other variables was partialed out. Significance was not identified.

Structure Matrix

	Component		
	Factor 1	Factor 2	Factor 3
Active Coping	.82		-.42
Positive Reframing	.79		
Planning	.74		-.44
Humor	.66		
Acceptance	.62		
Self Distraction			
Disengagement		.79	
Self Blame		.78	
Denial		.70	
Substance Use		.61	
Venting		.54	
Emotional Support	.40		-.79
Instrumental Support	.41		-.78
Religion			-.76

Note. Three factors resulting from oblique rotation of the Brief COPE subscales, indicating the variables were correlated with the factors. Significance was not identified.

Table 4.20

Component Correlation Matrix

Component	Factor 1	Factor 2	Factor 3
1 Problem-focused Coping	1.000	.018	-.370
2 Emotion-focused Coping	.018	1.000	-.135
3 Use of Support	-.370	-.135	1.000

Note. Correlation of the three factors reduced from the original 14 variables of the Brief COPE.

Table 4.21

Cronbach's Alpha For Each Factor

Factor	Cronbach's Alpha	Number of Items
1. Problem focused Coping	.863	10
2. Emotion focused Coping	.806	10
3. Use of Support	.805	6

Note. This represents reliability analysis for each of the factors.

The third analysis performed was hierarchical regression analysis. Results are provided in Table 4.22. Although, it appeared as though the model was fairly accurate for the sample, it did not appear to be generalizable to the population. The first regression analysis indicated concern of three cases including 75, 79, and 153 that may have biased the results. The three cases were removed and the analysis was repeated. Results from the second regression analyses are provided in Table 4. 22. Two major assumptions including collinearity and homoscedasticity were violated and prevented the model from being generalizable. Results from collinearity diagnostics indicated multicollinearity for two major variables under study including problem focused coping and use of support. Heteroscedasticity was noted in the partial regression plot for emotion and the global score (Figure 4.5). A multiple regression was performed to predict quality of life based on emotion focused coping, problem focused coping, and use of support. A significant regression equation was found ($F(2, 152) = 102.56$, $p < .001$), with R^2 of .40. Participants predicted global score, measuring quality of life, was 110.90 – 3.02. Again, participants decreased the global score by 3 points when using emotion focused coping strategies. However, hierarchical regression analysis was not generalizable and therefore, a Kruskal-Wallis test was conducted comparing the global score with each factor. Participants differed significantly on emotion focused coping ($H(18) = 56.67$, $p < .001$). Participants who reported less use of emotion focused coping had higher global scores on the PGWBI, which indicated a better quality of life. The Kruskal-Wallis test for comparing the global score with problem focused coping and use of support was conducted. No significant differences were found for problem focused coping ($H(25) = 28.05$, $p > .05$) and use of support ($H(18) = 19.70$, $p > .05$).

Table 4.22.

Cronbach's Alpha if Item Deleted for Each Factor

Problem-Focused Coping Factor

Subscale	Question	Cronbach's Alpha if Item Deleted
Active Coping	2. I have been concentrating my efforts on doing something about the situation I am in.	.845
	7. I have been taking action to try to make the situation better.	.845
Positive Reframing	12. I have been trying to see it in a different light, to make it seem more positive.	.844
	17. I have been looking for something good in what is happening.	.841
Planning	14. I have been trying to come up with a strategy about what to do.	.848
	25. I have been thinking hard about what steps to take.	.846
Humor	18. I have been making jokes about it.	.855
	28. I have been making fun of the situation.	.859
Acceptance	20. I have been accepting the reality of the fact that it has happened.	.861
	24. I have been learning to live with it.	.845

Emotion-Focused Coping Factor

Subscale	Question	Cronbach's Alpha if Item Deleted
Disengagement	6. I have been giving up trying to deal with it..	.780
	16. I have been giving up the attempt to cope.	.784
Self Blame	13. I have been criticizing myself.	.766
	26. I have been blaming myself for things that happened.	.782

(table continues)

Table 4.22 (*continued*).

Emotion-Focused Coping Factor

Subscale	Question	Cronbach's Alpha if Item Deleted
	8. I have been refusing to believe that it has happened.	.788
Denial	3. I have been saying to myself "this is not real."	.793
	8. I have been refusing to believe that it has happened.	.788
Substance Use	4. I have been using alcohol or other drugs to make myself feel better.	.797
	11. I have been using alcohol or other drugs to help me get through it.	.786
Venting	9. I have been saying things to let my unpleasant feelings escape.	.797

Use of Support Factor

Subscale	Question	Cronbach's Alpha if Item Deleted
Emotional Support	5. I have been getting emotional support from others.	.774
	15. I have been getting comfort and understanding from someone.	.779
Instrumental Support	10. I have been getting help and advice from other people.	.783
	23. I have been trying to get advice or help from other people about what to do.	.772
Religion	22. I have been trying to find comfort in my religion or spiritual beliefs.	.778
	27. I have been praying or mediating.	.766

Note. * = value greater than the overall alpha value of .806 for the emotion focused coping factor and indicates a slight increase in the value of alpha if that specific question were eliminated from the questionnaire.

To answer the fourth research question that examined the relationship between coping strategies and quality of life required the use of various statistical analyses. Initially, coping strategies were examined to determine the most frequently recorded score. After examining the subscales of the Brief COPE, factor analyses were performed to create second-order factors as predictors (Carver, 1997).

Table 4.23

Summary of Initial Hierarchical Regression Analysis of Three Factors Reduced from 14 Variables of the Brief COPE (N = 156)

Variable	*B*	*SE B*	β
Step 1			
Constant (Global Score)	115.87	4.27	
Emotion focused Coping	-2.97	0.29	-.63*
Step 2			
Constant (Global Score)	110.90	6.55	
Emotion focused Coping	-3.02	0.30	-.64*
Problem focused Coping	0.08	0.95	.03
Use of Support	0.23	0.31	.05

Note. $R^2 = .40$ for Step 1; $\Delta R^2 = .39$ for Step 2. * $p < .001$

Factor analyses resulted in the reduction of 14 variables to three variables. Hierarchical regression analysis was performed; however, two major assumptions including collinearity and homoscedasticity were violated. As a result, the model was not generalizable. Finally, a Kruskal-Wallis test was conducted to compare the global score with each factor. Participants were found to differ significantly on emotion focused coping. The global score of the PGWBI, which measured quality of life, was higher for participants reporting less use of emotion focused coping.

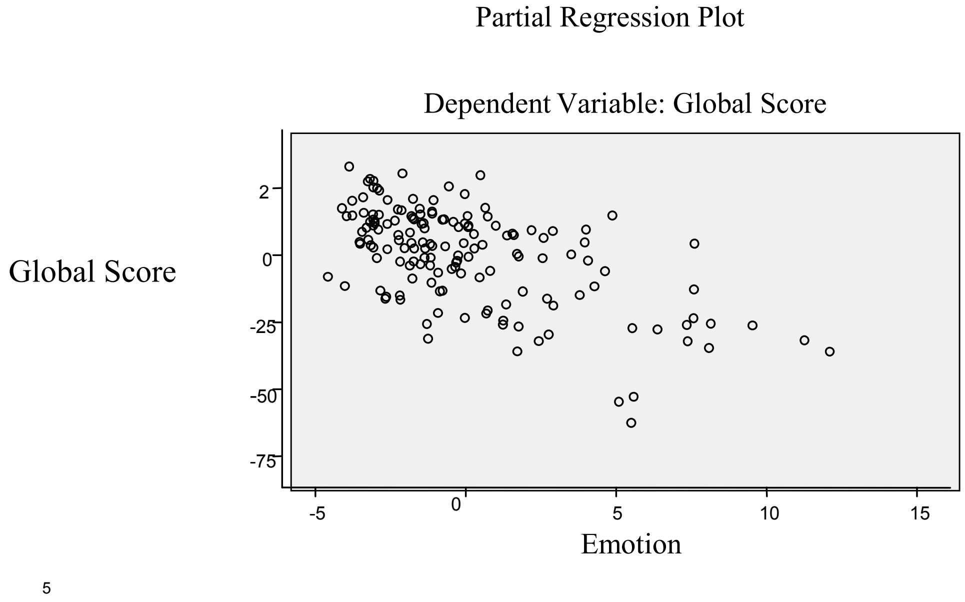
Table 4.24

Summary of Secondary Hierarchical Regression Analysis After Deletion of Items 75, 79, and 153 (N = 156)

Variable	*B*	*SE B*	β
Step 1			
Constant (Global Score)	119.01	4.98	
Emotion focused Coping	-3.26	0.35	-.60*
Step 2			
Constant (Global Score)	114.10	6.97	
Emotion focused Coping	-3.26	0.36	-.60*
Problem focused Coping	0.08	0.20	.03
Use of Support	0.23	0.31	.06

Note. R^2 = .35 for Step 1; ΔR^2 = .35 for Step 2. * $p < .001$

Figure 4.5. Heteroscedasticity of Emotion



Note. Illustration of heteroscedasticity from partial regression plot for emotion and the global score.

4.6 Discussion of the Results

The results of the findings are discussed in this section. This section is organized according to each research question. The conceptual framework that guided this study was guided by the combination of two theoretical models as described by Carver, Scheier, and Weintraub (1989). The models were: 1) the Lazarus model of stress (Lazarus, 1966) and 2) the model of behavioral self-regulation (Carver & Scheier, 1981, 1983, 1985; Scheier & Carver, 1988). Both theories recognized problem and emotion focused coping; however, a distinction was made among several aspects of active coping and responses that may impede or interfere with active coping, specifically avoidance (Carver et al., 1989). Problem focused coping is used when an individual actively attempts to eliminate or evade the stressor or to amend its effects. Emotion focused coping is used when an individual actively attempts to regulate the emotional response to the stressor. Avoidance is used when an individual attempts to avert further contact with or thought of the stressor. All forms of coping are used by individuals faced with real life stressful events.

Participants were recruited form the Gluten Intolerance Group website. As a result, the sample population included individuals who either had a computer or had access to a computer. Due to the nature of the website, individuals most likely used the computer as a tool for gaining information, which had the potential for creating bias in the sample given computer accessibility and ease with use for obtaining information. Analysis of demographic data indicated that the average age in years was 51.5 years with the majority of participants being female. The ratio of women to men was consistent with previous studies (Hauser, Stallmach, Caspary, & Stein, 2007; Mustalahti et al., 2002). A national survey in Canada examining the impact of a gluten free diet on adults with celiac disease reported 75 % of the respondents were female with a mean age of 56 years (Zarkadas et al., 2006). Lee and Newman (2003) examined the impact of a gluten free diet on quality of life. Ages ranged from 18 to more than 55 years with the majority (46 %) being 55 years or older. Seventy-four percent of the respondents were female with 26 % being male. A national survey in the United States resulted in women participants outnumbering men 2.9:1(Green et al., 2001). According to Bardell et al.(2005), women are diagnosed more often than men; however, health care practitioners recognition of gender differences in clinical presentations might improve diagnosis in men. The average years of education was reported to be 16.1. Based on results from the U. S. Census Bureau 2000 Summary, the sample study average years of education coincides with national statistics. Percentage of the population between 45 to 64 years of age graduating from high school or with higher educational attainment was 83%. In the same age group, 26 % earned a bachelor's degree or higher (Bureau, 2000). Geographically, regional participation for the five regions within the United States was between 20% and 25% for all regions except the Southwest, which was represented by 12% of the sample participants.

For this study, the assumption was made that quality of life was affected by individuals with celiac disease adhering to a strict gluten free diet, which had the potential to be a stressful event. The intervening processes used by individuals diagnosed with celiac disease adhering to a gluten free diet were problem and emotion focused coping as well as avoidance. The adaptation outcomes resulting from this process were problem focused coping and use of support with emotion focused coping having a negative effect on quality of life. Application of the conceptual framework that guided this study (see Figure 2.1) was integrated throughout this section.

Research Question 1: What are the perceived causes that interfere with adherence to a gluten free diet? The first research question inquiring about *perceived causes that interfered with adherence to a gluten free diet* was designated as a must answer question so that interfering factors could be identified by all participants (N = 156). Participants were to identify all interfering factors from the choices provided with an open ended option to provide interfering factors not listed. Responses from participants indicated that the greatest difficulties were encountered when outside the home (61%) and with expense of gluten free foods (61%). Problems existing outside the home were reported to be: restaurants, friends/family/social events, travel, business, and potluck dinners. Dislike of the taste of gluten free foods was reported next (19%) with not understanding labeling of foods (6%) following. A few participants reported feeling no different on a gluten free diet (6%). An even smaller percent (2%) of participants reported not understanding what foods could and could not be eaten on a gluten free diet. Interestingly, 15% of participants reported having no difficulty adhering to gluten free diet.

Analysis of data related to the first research question supported previous research on difficulties related to adherence to a gluten free diet. Lee, Ng, Zivin, and Green (2007) reported poor availability and increased cost of gluten free foods. In addition, Lee and Newman (2003) reported areas related to a celiac diet and its impact on quality of life. Areas related to having a negative impact were dining out (86%), travel (82%), and impact on family (67%). Participants said that moderate difficulties were experienced when sitting down to dinner or requesting gluten free foods (Ciacci et al., 2002). Several studies identified feelings of anger toward a celiac disease diagnosis and of hope that occasional ingestion of gluten as not being harmful as reasons for not adhering to a gluten free diet (Ciacci et al., 2003; Hallert et al., 2003). Sverker, Hensing, and Hallert (2005) interviewed individuals with celiac disease and identified five problems related to dietary compliance. Food situation at work, purchasing gluten free foods, traveling, eating meals at home, and eating meals with others outside the home were the identified areas related to dietary compliance, which were similar to those reported in the study sample. In a previous study, psychological barriers to adherence to a gluten free diet were identified as fear, anger, anxiety, and sadness. Depression, a common complication of celiac disease, might also affect dietary compliance along with lack of support, dietary education, and information (Pietzak, 2005).

However, other findings in the literature were not supportive. A comparison study indicated that the negative impact from dining in restaurants decreased from 93% to 79% as well as traveling, which decreased from 93% to 38% (Zarkadas et al., 2006).

Relative to this question was the amount of stress experienced over the past month related to adherence to a gluten free diet. Slightly over half the participants (54%) reported experiencing a minimal amount of stress. The remainder of participants reported stress at the following levels from next highest to lowest amounts of stress: moderate (22%), none (18%) and large (6%). Although difficulties related to adherence to a gluten free diet were reported, it did not appear to result in significant levels of stress. Interestingly, a moderate negative relationship was found between quality of life and stress even though slightly over half the participants reported a minimal amount of stress over the past month in relation to adhering to a gluten free diet.

Research Question 2: What is the relationship between acceptance of the diagnosis of celiac disease and quality of life (QOL) in adults with celiac disease on a gluten free diet? Analysis of data indicated a weak relationship (r (154) = 0.194, $p < 0.05$) between acceptance and the diagnosis of celiac disease. Over half the participants had an average global score of 74 (an indication of overall quality of life), which was reflective of "*positive well-being*" (63%). A lesser percent of participants reported experiencing "severe distress" (23%) with a smaller percent reporting "moderate distress" (14%).

Additional data collected to evaluate quality of life consisted of a report of all current signs and symptoms experienced. These signs and symptoms were the same as reported prior to being diagnosed with celiac disease. The most frequently reported symptom was bone pain (32%) which was followed by gas (31%). Twenty-five percent of participants reported having no present signs or symptoms related to a celiac disease diagnosis. Difficulty recalling information was reported by 24% of participants. Signs and symptoms such as diarrhea (21%), itchy skin (20 %), and anemia (12%) followed with mouth sores (8%), weight loss (5 %), and missed menstrual periods (2%) were also reported by participants.

The PGWBI score (74) was lower for this sample compared to scores from a study comparing screen-detected patients with symptom-detected patients after one year on a gluten free diet. In the screen-detected group, scores increased from 108 to 114. In the symptom-detected patients scores increased from 92 to 103 (Mustalahti et al., 2002).

In a phenomenological study, differences in understanding of health related quality of life were explored in five pairs of celiac disease patients. Women reported deceased acceptance of living with celiac disease with and increase in bowel symptoms (Hallert et al., 2003). Midhagen and Hallert (2003) also found that celiac disease patients adhering to a gluten free diet for 8 - 12 years demonstrated a significant increase in gastrointestinal symptoms in comparison to the general population. A study examining celiac disease and its impact on quality of life found that participants thought that physical health (87%) and emotion well-being (90%) did not effect social activities; however, they reported that adhering to a gluten free diet had a negative impact on their quality of life (Lee & Newman, 2003). Acceptance and control were two major coping strategies that emerged during interview sessions with patients diagnosed with celiac disease. The level of acceptance was reported to be higher for men than women upon recognition of having celiac disease. Control was more of a strategy used by women in that it was viewed as a behavior of *controlling* every meal. The behavior was associated with active information seeking by watching what foods were being offered to checking labels and to calling manufacturers when suspicious of foods containing gluten (Hallert et al., 2003). Although acceptance was not evaluated, quality of life in adults with celiac disease indicated that men (n = 25, PGWBI = 111) tended to score higher than women (n = 35, PGWBI = 97) ($p < .003$). In a 14 year follow-up study examining dietary compliance and quality of life, lower PGWBI scores were reported for untreated celiac disease indicating a decreased quality of life compared to treated screen detected celiac disease ($p = 0.004$) or non-celiac control group ($p = 0.004$) (Viljamaa, Collin, Huhtala, Sievanen, Maki, & Kaukinen, 2005a). Although a difference in acceptance of celiac disease diagnosis was not evaluated for men and women, a weak relationship was found between acceptance of a celiac disease diagnosis and quality of life. Because the questionnaires were accessed online from a website for individuals intolerant to gluten, it appears as though participants actively seek information related to a gluten free diet. Reported signs and symptoms were the same before and after starting a gluten free diet; however, a significant decrease in signs and symptoms was noted.

It appears as though the gastrointestinal symptoms continue while adhering to a gluten free diet. Although quality of life scores indicated "*positive well-being,*" for this sample population and the reported study (Mustalahti et al., 2002), scores fell at opposite ends of the range of scores. The sample population for this study was at the low end of the range, where as, the reported study scores were at the higher end of the range of scores for "*positive well-being.*" The differences in scores may be attributed to timing. In the reported study (Mustalahti et al.), participants completed the PGWBI before starting a gluten free diet and at one year follow-up. For this study participants completed the PGWBI once and at different lengths of time on a gluten free diet. In addition, participants reported being diagnosed with celiac disease. There were no screen-detected participants in this study.

Research Question 3: What is the difference in acceptance between adults with celiac disease on a gluten free diet for 6 months to one year compared to adults with celiac disease on a gluten free diet greater than one year? No significant difference ($H(5) = 6.416$, $p > 0.05$) was found when comparing acceptance of a celiac disease diagnosis for participants on a gluten free diet for various lengths of time. The length of time on a gluten free diet for participants was: 6 months to 1 year ($n = 10$), 1.5 to 3 years ($n = 29$), 3.5 to 5 years (*n* = 38), 5.5 to 8 years (*n* = 31), 8.5 to 12 years (*n* = 21), and > 12 years (*n* = 27).

The study by Hallert, Sandlund, and Broqvist (2003) indicated that women reported a decrease acceptance of living with celiac disease; however, it was not related to adherence to a gluten free diet for a specified amount of time. Interestingly, in this study, further exploration of coping strategies indicated a significant result ($H(5) = 11.650$, $p < 0.05$) when comparing positive reframing for participants on a gluten free diet for various lengths of time, indicating that participants differed from one another. Participants on a gluten free diet for 8.5 – 12 years reported using positive reframing more often than other participants for the same lengths of time on a gluten free diet as indicated for acceptance.

Findings appear to be contradictory. This sample population indicated no significant difference in regard to acceptance of a celiac disease diagnosis in relation to length of time on a gluten free diet. However, decreased acceptance of living with celiac disease was reported along with increased gastrointestinal symptoms after having been on a gluten free diet for 8-12 years (Hallert et al., 2003). Another contradiction in this study was the reported use of positive reframing for participants with celiac disease on a gluten free diet for 8.5 – 12 years. In this sample population positive reframing compared to acceptance was identified as a coping strategy used by participants in dealing with a celiac disease diagnosis after being on a gluten free diet for 8.5-12 years. Findings opposed previously reported findings that indicated participants, particularly women, had a decreased acceptance of celiac disease diagnosis. Differences may be attributed to the sample size. In this study, results were obtained from 156 participants completing the

Brief COPE Inventory. Findings from the reported study were obtained by open-ended questions in a conversational manner from 10 participants on a gluten free diet for 10 years. The five pairs of participants were recruited from a previous study with six participants scoring low and four high in the SF-36 General Health and Vitality scales (Hallert et al., 1998; Hallert et al., 2003).

Research Question 4: What is the relationship between coping strategies and quality of life in adults adhering to a gluten free diet?

According to the combined theory of Lazarus model of stress (Lazarus, 1966) and the model of behavioral self-regulation (Carver & Scheier, 1981, 1983, 1985; Scheier & Carver, 1988), individuals use cognitive appraisal to assess a stressful event. In this study, participants self reported the diagnosis of celiac disease. The participants were asked to identify ways they used or are using to cope with a celiac disease diagnosis. Stressors assumed to create barriers to improved quality of life for persons with celiac disease were identified as: 1) difficulty with dietary compliance, 2) lack of disease and dietary education, and 3) lack of support.

In an effort to analyze results, factor analyses of independent variables were performed. There is no overall score for this instrument and each scale was assessed separately. Factor analyses resulted in the manifestation of three factors from the 14 subscales in the Brief COPE. Factor 1 represented problem focused coping, factor 2 represented emotion focused coping, and factor 3 represented use of support. A comparison of the three factors with the 14 original subscales is discussed. Of the five subscales (active coping, positive reframing, planning, humor, and acceptance) that made up factor 1, *problem focused coping*, three of the five subscales (active coping, planning, and acceptance) were identified as problem focused coping. Positive reframing and humor were considered to be emotion focused coping strategies. In regard to factor 2, *emotion focused coping*, three of the subscales (disengagement, self blame, and venting) were identified as emotion focused coping while denial and substance use were classified as avoidance coping. All five subscales were identified as being dysfunctional and therefore, not conducive to moving toward necessary adjustments to deal with a chronic illness (Carver et al., 1989). Factor 3, *use of support*, included emotional support, instrumental support, and religion. With the exception of emotional support, instrumental support and religion were considered as relevant to problem focused coping. Although there is a distinction between seeking advise and praying or meditating (problem focused) and getting sympathy and finding comfort in spiritual beliefs (emotion focused), in practice, they tend to occur simultaneously (Carver et al., 1989).

In summary, individuals diagnosed with celiac disease continue to experience difficulties related to adherence to a gluten free diet. However, the reported stress level related to dietary adherence was minimal. A statistically significant but weak relationship was found between acceptance of a celiac disease diagnosis and quality of life as measured by the global score of the PGWBI. A statistically significant but weak negative relationship was found between quality of life and substance use. However, statistically moderate negative relationships were found among quality of life and denial, self-distraction, venting, disengagement, and self-blame. Length of time on a gluten free diet did not affect acceptance of a celiac disease diagnosis. A statistically significant positive result was found with the use of positive reframing. Participants on a gluten free diet for 8.5-12 years reported using positive reframing more than other participants on a gluten free diet for varying lengths of time. Finally, the use of emotion focused coping was found to have a negative effect on quality of life as indicated by a decrease in the global score of the PGWBI.

Chapter 5

Summary and Recommendations

This chapter begins with a summary and conclusions of this research study on quality of life and coping strategies of adults with celiac disease adhering to a gluten free diet. Limitations of the study are presented and the chapter concludes with recommendations for future research and implications for nursing practice and nursing research.

5.1 Summary and Conclusions

The purposes of this study were to: 1) examine factors and perceived causes that interfere with adherence to a gluten free diet for adults with celiac disease, 2) identify coping strategies of adults with celiac disease adhering to a gluten free diet, and 3) examine the relationship between quality of life and coping strategies of adults with celiac disease adhering to a gluten free diet.

The conceptual framework that directed this study was guided by the combination of two theoretical models as described by Carver, Scheier, and Weintraub (1989). The models were: 1) the Lazarus model of stress (Lazarus, 1966) and 2) a model of behavioral self-regulation as explained by Carver and Sheier (Carver & Scheier, 1981, 1983, 1985; Scheier & Carver, 1988). Adherence to a gluten free diet was the perceived stressful event for adults with celiac disease. Through primary and secondary cognitive appraisal, adults with celiac disease determine if adhering to a gluten free diet presents a challenge, harm/loss, or a threat. All forms of coping were identified by participant responses. Outcomes indicated that problem focused coping and use of support had a positive influence on quality of life, whereas, emotion focused coping had a negative influence on quality of life.

The research design for this study was a descriptive, correlational design using surveys to obtain information. After receiving approval from the Duquesne University Institutional Review Board, the Gluten Intolerance Group website was informed that approval had been granted to send email messages from their website to inform potential participants of the study. A link was created from the Gluten Intolerance Group website to Survey Monkey®, where a consent form and the three surveys were accessed for completion. Strict confidentiality and anonymity, along with security of surveys were maintained throughout the study. Overall, there was a 2.5% response rate (20,000 emails to active and inactive members with a second reminder) over approximately a four month collection period. From the overall completion, 25% of the participants met eligibility requirements and completed all three surveys.

This research study was the first to examine coping strategies in adults with celiac disease adhering to a gluten free diet. Descriptive statistics were reported for the entire study ($N = 683$) in the categories of demographics information and health and diet history. One-hundred and fifty-six participants met eligibility requirements and had completed both the PGWBI and the Brief COPE questionnaires. The PGWBI index assessed quality of life by obtaining a global score from dimensions that assessed anxiety, depressed mood, positive well-being, self-control, general health, and vitality. The Brief COPE assessed 14 coping strategies that included problem focused and emotion focused coping along with avoidance. Preliminary analyses were conducted on the data to determine whether or not assumptions of statistical tests had been met. Analyses and major findings were reported according to each research question.

Demographic findings were similar in some respects to previous studies in regard to gender and age of participants; however, the majority of studies were performed outside the United States, where celiac disease has been more readily recognized. More females (n = 133) compared to males (n = 23) participated in the study. The average age was 51.5 years. Additional demographic data obtained were related to marital status, education, income, alcohol consumption, smoking, hours of sleep per night, and hours of exercise per week.

Quality of life was measured by the Psychological General Well-Being Index (PGWBI). The PGWBI was originally developed in 1970-71 to assess the health and quality of life of individuals in general and those with chronic illness (Dupuy, 1984). Cronbach's alpha was 0. 804 for this research study, indicating a high internal consistency. Strong significant relationships between the global score and each dimension of the PGWBI were found (r = 0.709 - 0.894) at a 0.01 level of significance (2-tailed). In addition, acceptance of celiac disease diagnosis was minimally related to quality of life. Further exploration of the dimensions of PGWBI indicated significant weak relationships among acceptance and three other dimensions of the PGWBI: depressed mood (r (154) = 0.231, $p < 0.01$) general health (r (154) = 0.211, $p < 0.01$), and positive well-being (r (154) = 0.172, $p < 0.05$). Exploration of the remaining subscales of the Brief COPE revealed significant, moderate negative correlations among quality of life and five subscales of the Brief COPE: denial, self-distraction, venting, disengagement, and self-blame.

The average global score for participants ($N = 156$) was 74 with a standard deviation of 18.76. This score was reflective of "*positive well-being*"; however, it fell at the lower end of the range (73 to 110) for positive well-being. Scores ranged from 12 to 108. The percentage of participants ($n = 36$) in the "*severe distress*" range was 23. Participants ($n = 21$) in the "*moderate distress*" range made up 14% with the remaining 63% of participants ($n = 99$) in the "*positive well-being*" range.

Comparison of reported signs and symptoms prior to being diagnosed with celiac disease and beginning a gluten free diet with present signs and symptoms on a gluten free diet resulted in a significant decrease in reported signs and symptoms ($t(10) = -3.03$, $p < .05$). The coping strategy of acceptance in relation to the diagnosis of celiac disease was not influenced by the length of time a participant was on a gluten free diet. However, participants with celiac disease on a gluten free diet for 8.5 to 12 years scored higher for positive reframing compared to participants on a gluten free diet for 6 months to 1 year.

Although a significant regression equation was found ($F(2, 152) = 102.56$, $p < .001$) with R^2 of .40 to predict quality of life based on emotion focused coping, results were not generalizable due to the assumptions of collinearity and homoscedasticity being violated. Therefore, a Kruskal-Wallis test was conducted comparing the global score of the PGWBI with each factor. Participants differed significantly with emotion focused coping, indicating that less use of emotion focused coping improved the global score, thus improving quality of life.

In conclusion, this study provided research-based evidence that the use of emotion focused coping had a negative effect on quality of life as measured by the global score of the PGWBI. The Brief COPE subscales for factor 2, labeled as emotion focused coping, were disengagement, self-blame, venting, denial, and substance use. Coping strategies in factor 2 included three emotion focused coping strategies (disengagement, self blame, and venting) along with two avoidance coping strategies (denial and substance use). All five coping strategies have the potential to prevent participants from making adjustments toward dealing with chronic illness. Because over forty-nine percent of the participants in this study reported being on a gluten free diet for 3.5 years or longer, these findings were important especially because extended use of negative coping strategies have proven to interfere with patients making necessary adjustments for dealing with chronic illness. Identification of these coping strategies may benefit patients by helping them recognize the negative effects on their quality of life. Findings such as these provide the stimulus to further investigate coping strategies not only for patients with celiac disease but also for other patients with chronic illnesses.

Insight was also gained into the effect stress had on quality of life. Although over half the participants reported a minimum level of stress in relation to adherence to a gluten free diet, a significant relationship was found between quality of life and stress. A moderate, negative significant relationship was found between quality of life and stress. These findings are important because of the effect that minimal amounts of stress had on quality of life for this study sample.

5.2 Limitations to the Study

The following section consists of the identified limitations to this study. In future studies, it would be beneficial to take these limitations into consideration.

The sample used in this study may not have been representative of all patients with celiac disease for several reasons. First, the sample size ($N = 156$) was small and may not have been representative of the population under study. Only participants recruited from the Gluten Intolerance Group website were included in the study. Therefore, results of the study may not be generalizable to adults with celiac disease adhering to a gluten free diet.

Second, few males compared to females participated in this study. As a result, gender differences that may exist were undetected. Also, cultural backgrounds were not identified and therefore, any cultural differences that may exist were not examined.

Third, data was obtained via questionnaires completed online. The only way to track participants was via the Internet Protocol (IP) address, which is a numerical identification that serves as a unique identifier of a computer. It was noted that a few participants completed demographic surveys on more than one occasion. Their elimination was required for accurate analysis

Fourth, data was obtained via completion of three self-reported questionnaires. Based on the return, participant exhaustion may have occurred. A decrease in numbers from participants completing the demographic and health history survey to participants completing the second questionnaire (PGWBI) to participants completing the third questionnaire (Brief COPE) was noted.

Fifth, an additional limitation was deduced from comments received from participants via email messages. Comments were received suggesting the addition of lactose intolerance and weight gain to the signs and symptoms in the open ended response labeled "*Other.*" Another participant suggested assessment of whether or not support groups for patients with celiac disease were helpful. Finally, assessing "cheating" in relation to coping when feeling stressed and/or an inability to find gluten free foods when feeling hungry were suggested. These suggestions may demonstrate the compulsion some participants may feel to control their circumstances.

5.3 Future Research and Implications for Nursing Practice

The following is a discussion of the recommendations for future research based on the results of this study and the findings reported in the related literature. Recommendations are mainly related to the methodological design and variables studied.

Recommendations for Changes in Methodological Design

Because recruitment and accretion of participants was problematic, a more controlled method of recruitment may be beneficial. For example, knowledge of actual numbers of potential participants along with disease status prior to recruitment would be helpful.

The negative relationship between quality of life and stress should be further investigated. It is recommended that these variables be further examined with a more controlled sample population.

A secondary analysis could be conducted to investigate quality of life in relation to stress for participants from originally collected data prior to filtering for inclusion and exclusion criteria.

Recommendations for Changes in Measurement of Variables

Future studies should examine the relationship between cheating and stress of adults with celiac disease on a gluten free diet. The results might help to identify the effect of stress on cheating for adults adhering to a gluten free diet.

In this study, it was the assumption that adhering to a gluten free diet may be stressful. However, the perception of stress varies among individuals and therefore, the response to the perceived stress would also vary (Carver & Scheier, 2001; Carver et al., 1989). It is recommended that a reliable and valid instrument be used in future studies to measure perceived stress, and to use results to examine the relation between stress and quality of life.

According to Bardella et al. (2005) gender differences exist between men and women with celiac disease. Prevalence in ethnic minorities is unclear and therefore, prevalence within the United States needs to be determined as well as factors that influence dietary compliance in order to assess affects on quality of life (Brar et al., 2006). Future studies might also address gender differences, cultural differences, and ethnic minority differences in coping with dietary compliance and stress.

Another recommendation for future research would be the inclusion of objective data to confirm a celiac disease diagnosis and to obtain serology tests to identify any physiological effects of stress related to dietary compliance. It would also be beneficial to assess if cheating occurs and if cheating does occur, what is the extent.

Implications for Practice

The findings in this study indicate that minimal amounts of stress and the use of emotion focused coping negatively effect quality of life. These findings are important to health care professionals caring for adults with celiac disease adhering to a gluten free diet. Results would seem to be especially interesting to nurses working in gastrointestinal (GI) units or practices because of the frequent encounters with patients with celiac disease.

GI nurses also have the opportunity to establish a professional relationship with patients with celiac disease, which may promote free discourse of issues related to dietary adherence to a gluten free diet. Providing information that helps clarify dietary issues is a responsibility that should be freely and expertly provided. Nurses need to know and communicate that as of January 2006, labels were required to clearly state if a product contained any of the top eight food allergens, which includes wheat. The U. S. Food and Drug Administration (FDA) has also been charged with issuing rules defining and permitting the term “gluten free” on food labeling and then implementing a plan for labeling. In an effort to close existing knowledge gaps and create truthful and non-misleading labeling, the FDA scheduled a public hearing on food allergen labeling, September 16, 2008 (FDA, 2004). By referring patients to the Gluten Intolerance Group website, patients are able to view the Gluten-Free (GF) certification mark used to identify qualifying foods.

Nurses, especially GI nurses, can also investigate the use of cognitive-behavior interventions to decrease the negative effects of emotion focused coping. The identified negative affects of stress on quality of life creates an opportunity for nurses to implement and investigate cognitive-behavioral interventions to decease stress for adults with celiac disease adhering to a gluten free diet.

Figure 5.1. The New Gluten-Free Certification Mark

Note. Permission received from the Gluten Intolerance Group for reprint.

References

AGAI. (2006). Aga institute medical position statement on the diagnosis and management of celiac disease. *Gastroenterology, 131*(6), 1977-1980.

Alaedini, A., & Green, P. H. R. (2005). Narrative review: Celiac disease: Understanding a complex autoimmune disorder. *Annals of Internal Medicine, 142*(4), 289.

Allergen, F. (2004). Food allergen labeling and consumer protection act of 2004: Title 2 Pub. L. No. 118 Stat. 905.

Annunziato, R. A., & Lowe, M. R. (2007). Taking action to lose weight: Toward an understanding of individual differences. *Eating Behaviors, 8*(2), 185.

Ashton, E., Vosvick, M., Chesney, M., Gore-Felton, C., Koopman, C., O'Shea, K., et al. (2005). Social support and maladaptive coping as predictors of the change in physical health symptoms among persons living with hiv/aids. *AIDS Patient Care and STDs, 19*(9), 587-598.

Barbato, M., Viola, F., Grillo, R., Franchin, L., Lo Russo, L., Lucarelli, S., et al. (1998). Alopecia and coeliac disease: Report of two patients showing response to gluten-free diet. *Clinical and Experimental Dermatology, 23*(5), 236-237.

Bardella, M. T., Fredella, C., Saladino, V., Trovato, C., Cesana, B. M., Quatrini, M., et al. (2005). Gluten intolerance: Gender- and age-related differences in symptoms. *Scandinavian Journal of Gastroenterology, 40*(1), 15-19.

Bazzigaluppi, E., Roggero, P., Parma, B., Brambillasca, M. F., Meroni, F., Mora, S., et al. (2006). Antibodies to recombinant human tissue-transglutaminase in coeliac disease: Diagnostic effectiveness and decline pattern after gluten-free diet. *Digestive and Liver Disease: Official Journal of the Italian Society of Gastroenterology and the Italian Association for the Study of the Liver, 38*(2), 98-102.

Beck, A. T., Ward, C. H., Mendelson, M., & Erbaugh, M. J. (1961). An inventory for measuring depression. *Archives of General Psychiatry, 4*, 561-571.

Bennett, S. J., Lane, K. A., Welch, J., Perkins, S. M., Brater, D. C., & Murray, M. D. (2005). Medication and dietary compliance beliefs in heart failure. *Western Journal of Nursing Research, 27*(8), 977-993.

Bennett, S. J., Milgrom, L. B., Champion, V., & Huster, G. A. (1997). Beliefs about medication and dietary compliance in people with heart failure: An instrument development study. *Heart & Lung, 26*(4), 273.

Biagi, F., Campanella, J., Martucci, S., Pezzimenti, D., Ciclitira, P. J., Ellis, H. J., et al. (2004). A milligram of gluten a day keeps the mucosal recovery away: A case report. *Nutrition Reviews, 62*(9), 360.

Brantley, P. J., & Jones, G. N. (1988). Weekly stress inventory.

Brar, P., Lee, A. R., Lewis, S. K., Bhagat, G., & Green, P. H. R. (2006). Celiac disease in african-americans. *Digestive Diseases And Sciences, 51*(5), 1012.

Brown, J. D. (1997). Skewness and kurtosis. Retrieved July 4, 2008, from http://www.jalt.org/test/bro_1.htm

Bureau, U. S. C. (2000, 11/01/2008). Education attainment by sex: 2000. from http://factfinder.census.gov/servlet/QTTable?_bm=y&-qr_name=DEC_2000_SF3_U_QTP20&-geo_id=0

Burns, N., & Grove, S. K. (Eds.). (2001). *The practice of nursing research. Conduct, critique, & utilization* (4th
ed.). Philadelphia: W. B. Saunders.

Burns, V. E., Carroll, D., Ring, C., Harrison, L. K., & Drayson, M. (2002). Stress, coping, and hepatitis b antibody status. *Psychosomatic Medicine, 64*(2), 287-293.

Butterworth, J. R., Banfield, L. M., Iqbal, T. H., & Cooper, B. T. (2004). Factors relating to compliance with a gluten-free diet in patients with coeliac disease: Comparison of white caucasian and south asian patients. *Clinical Nutrition (Edinburgh, Scotland), 23*(5), 1127.

Calsbeek, H., Rijken, M., Bekkers, M. J. T., Gp, & Dekker, J. (2006). Coping in adolescents and young adults with chronic digestive disorders: Impact on school and leisure activities. *Psychology & Health, 21*(4), 447.

Campbell, J. A., Molloy, M., Davidson, A. G., & Bankier, L. M. (1991). Dietary aspects from national survey of persons with celiac disease and dermatitis herpetiformis. *Journal of Canadian Diet Association*, 5-8.

Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the brief cope. *International Journal of Behavioral Medicine, 4*(1), 92-100.

Carver, C. S., Pozo, C., Harris, S. D., Noriega, V., Scheier, M. F., Robinson, D. S., et al. (1993). How coping mediates the effect of optimism on distress: A study of women with early stage breast cancer. *Journal of Personality and Social Psychology, 65*(2), 375-390.

Carver, C. S., & Scheier, M. F. (1981). *Attention and self-regulation: A control-theory approach to human behavior*. New York: Springer-Verlag.

Carver, C. S., & Scheier, M. F. (1983). A control theory model of normal behavior, and implications for problems in self-management. In P. C. Kendall (Ed.), *Advances in cognitive-behavioral research and therapy* (Vol. 2, pp. 127-194). New York: Academic Press.

Carver, C. S., & Scheier, M. F. (1985). Self-consciousness, expectancies, and coping process. In P. M. McCAbe & N. Schneiderman (Eds.), *Stress and coping* (pp. 305-330). Hillsdale, NJ: Erlbaum.

Carver, C. S., & Scheier, M. F. (2001). *On the self-regulation of behavior*. New York: Cambridge.

Carver, C. S., Scheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology, 56*(2), 267-283.

Catassi, C., Fabiani, E., Corrao, G., Barbato, M., De Renzo, A., Carella, A. M., et al. (2002). Risk of non-hodgkin lymphoma in celiac disease. *JAMA: Journal of the American Medical Association, 287*(11), 1413.

Chassany, O., Dimenas, E., Dubois, D., & Wu, A. (2004). *The psychological general well-being index (pgwbi) user manual*. Lyon, France: MAPI Research Institute.

Ciacci, C., D'Agate, C., De Rosa, A., Franzese, C., Errichiello, S., Gasperi, V., et al. (2003). Self-rated quality of life in celiac disease. *Digestive Diseases and Sciences, 48*(11), 2216-2220.

Ciacci, C., Iavarone, A., Siniscalchi, M., Romano, R., & De Rosa, A. (2002). Psychological dimensions of celiac disease: Toward an integrated approach. *Digestive Diseases and Sciences, 47*(9), 2082-2087.

Ciacci, C., Maurelli, L., Klain, M., Savino, G., Salvatore, M., Mazzacca, G., et al. (1997). Effects of dietary treatment on bone mineral density in adults with celiac disease: Factors predicting response. *The American Journal of Gastroenterology, 92*(6), 992-996.

Cicarelli, G., Della Rocca, G., Amboni, M., Ciacci, C., Mazzacca, G., Filla, A., et al. (2003). Clinical and neurological abnormalities in adult celiac disease. *Neurological Sciences: Official Journal of the Italian Neurological Society and of the Italian Society of Clinical Neurophysiology, 24*(5), 311-317.

Coelho, R., Silva, C., Maia, A., Prata, J., & Barros, H. (1999). Bone mineral density and depression: A community study in women. *Journal Of Psychosomatic Research, 46*(1), 29.

Cohen, J. (1977). *Statsitical power analysis for the behavioral sciences* (Rev. ed.). New York: Academic Press.

Cohen, J., & Cohen, P. (1983). *Applied multiple regression/correlation analysis for the behavioral sciences.* Hillsdale, NJ: Lawrence Erlbaum.

Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior, 24*, 385-396.

Cooke, W. T., & Smith, W. T. (1966). Neurological disorders associated with adult coeliac disease. *Brain: a Journal of Neurology, 89*(4), 683-722.

Corazza, G. R., Andreani, M. L., Venturo, N., Bernardi, M., Tosti, A., & Gasbarrini, G. (1995). Celiac disease and alopecia areata: Report of a new association. *Gastroenterology, 109*(4), 1333-1337.

Corraro, G., Corazza, G. R., & Bagnardi, V. (2001). Mortality in pateints with celiac disease and their relatives: A cohort study. *Lancet, 358*, 356-361.

Cronk, B. C. (2006). *How to use spss* (4th ed.). Glendale, CA: Pyrczak Publishing.

Culver, J. L., Arena, P. L., Wimberly, S. R., Antoni, M. H., & Carver, C. S. (2004). Coping among african-american, hispanic, and non-hispanic white women recently treated for early stage breast cancer. *Psychology & Health, 19*(2), 157-166.

Davies, A. R., & Ware, J. E. (1981). Measuring health perceptions in the health insurance experiment. In P. N. R-2711-HHS) (Ed.): Santa Monica: RAND Corporation.

DCCT, R. G. (1988). Reliability and validity of a diabetes quality-of-life measure for the diabetes control and complications trial. *Diabetes Care, 11*, 725-732.

de Zwaan, M. (2001). Binge eating disorder and obesity. *International Journal of Obesity and Related Metabolic Disorders: Journal of the International Association for the Study of Obesity, 25 Suppl 1*, S51-55.

Dickey, W., & McMillan, S. A. (1998). Co-screening for primary biliary cirrhosis and coeliac disease. Association between primary biliary cirrhosis and coeliac disease. *Gut, 43*(2), 300.

Dickey, W., McMillan, S. A., & Hughes, D. F. (2001). Sensitivity of serum tissue transglutaminase antibodies for endomysial antibody positive and negative coeliac disease. *Scandinavian Journal of Gastroenterology, 36*(5), 511-514.

Dixon, J. B., Dixon, M. E., & O'Brien, P. E. (2003). Depression in association with severe obesity: Changes with weight loss. *Archives of Internal Medicine, 163*(17), 2058.

Dupuy, H. J. (Ed.). (1984). *The psychological general well being (pgwb) index. In assessment of quality of life in clinical trials of cardiovascular therapies.* New York: Le Jacq Publishing.

Egan, L. J., Walsh, S. V., Stevens, F. M., Connolly, C. E., Egan, E. L., & McCarthy, C. F. (1995). Celiac-associated lymphoma. A single institution experience of 30 cases in the combination chemotherapy era. *Journal of Clinical Gastroenterology, 21*(2), 123-129.

Endler, N. S., & Parker, J. D. (1990). Multidimensional assessment of coping: A critical evaluation. *Journal of Personality and Social Psychology, 58*(5), 844-854.

Evangelista, L. S., Berg, J., & Dracup, K. (2001). Relationship between psychosocial variables and compliance in patients with heart failure. *Heart & Lung: Journal of Acute & Critical Care, 30*(4), 294-301.

Fasano, A., Berti, I., Gerarduzzi, T., Not, T., Colletti, R. B., Drago, S., et al. (2003). Prevalence of celiac disease in at-risk and not-at-risk groups in the United States: A large multicenter study. *Archives of Internal Medicine, 163*(3), 286-292.

Fazio, A. F. (1977). A concurrent validational study of the NCHS general well-being schedule. *Vital and Health Statistics. Series 2, Data Evaluation and Methods Research*(73), 1-53.

FDA. (2004). Food allergen labeling and consumer protection act of 2004 (Vol. Title II of Public Law 108-282).

Felton, B. J., & Revenson, T. A. (1984). Coping with chronic illness: A study of illness controllability and the influence of coping strategies on psychological adjustment. *Journal of Consulting and Clinical Psychology, 52*(3), 343-353.

Fields, A. (2005). *Discovering staistics using spss (and sex, drugs, and rock 'n' roll0* (2nd ed.). London: SAGE.

Folkman, S. (1984). Personal control and stress and coping processes: A theoretical analysis. *Journal of Personality and Social Psychology, 46*(4), 839-852.

Folkman, S., & Lazarus, R. S. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behavior, 21*, 219-239.

Folkman, S., & Lazarus, R. S. (1988). *The ways of coping questionnaire*. Palo Alto: CA: Consulting Psychologists Press.

Folkman, S., Lazarus, R. S., Gruen, R. J., & DeLongis, A. (1986). Appraisal, coping, health status, and psychological symptoms. *Journal of Personality and Social Psychology, 50*(3), 571-579.

Gale, L., Wimalaratna, H., Brotodiharjo, A., & Duggan, J. M. (1997). Down's syndrome is strongly associated with coeliac disease. *Gut, 40*(4), 492-496.

GIG. (2007a). Gluten intolerance group of North America.

GIG. (2007b). Gluten intolerance group of North America. from http://www.gluten.net

Gluten Intolerance, C. D., Gliadin Sensitivity. (2007). Glossary (non-alphabetical). from http://members.cox.net/hal.kraus/glossary.htm

Goldstein, M. J. (1973). Individual differences in response to stress. *American Journal of Community Psychology, 1*(2), 113-137.

Gore-Felton, C., Koopman, C., Spiegel, D., Vosvick, M., Brondino, M., & Winningham, A. (2006). Effects of quality of life and coping on depression among adults living with hiv/aids. *Journal of Health Psychology, 11*(5), 711-729.

Grady, K. L., & Jalowiec, A. (1995). Predictors of compliance with diet 6 months after heart transplantation. *Heart & Lung, 24*(5), 359.

Graue, M., Wentzel-Larsen, T., Bru, E., Hanestad, B. R., & SÃ¸vik, O. (2004). The coping styles of adolescents with type 1 diabetes are associated with degree of metabolic control. *Diabetes Care, 27*(6), 1313.

Green, P. H. R. (2005). The many faces of celiac disease: Clinical presentation of celiac disease in the adult population. *Gastroenterology, 128*(4 Suppl 1), S74-78.

Green, P. H. R., Alaedini, A., Sander, H. W., Brannagan, T. H., 3rd, Latov, N., & Chin, R. L. (2005). Mechanisms underlying celiac disease and its neurologic manifestations. *Cellular and Molecular Life Sciences: CMLS, 62*(7-8), 791-799.

Green, P. H. R., Fleischauer, A. T., Bhagat, G., Goyal, R., Jabri, B., & Neugut, A. I. (2003). Risk of malignancy in patients with celiac disease. *The American Journal of Medicine, 115*(3), 191-195.

Green, P. H. R., & Jabri, B. (2003). Coeliac disease. *The Lancet, 362*, 383-391.

Green, P. H. R., Stropoulos, S. N., Panagi, S. G., Goldstein, S. L., McMahon, D. J., Absan, H., et al. (2001). Characteristics of adult celiac disease in the USA: Results of a national survey. *American Journal of Gastroenterology, 96*(1), 126-131.

Groarke, A., Curtis, R., & Coughlan, R. (2004). The influence of psychosocial variables and disease severity in patients with chronic illness: A one-year follow-up. *Psychology & Health, 19*, S68-69.

Grossman, G. (2008). Neurological complications of coeliac disease: What is the evidence? *Practical Neurology, 8*(2), 77-89.

Hallert, C., Granno, C., Grant, C., Hulten, S., Midhagen, G., Strom, M., et al. (1998). Quality of life of adult coeliac patients treated for 10 years. *Scandinavian Journal of Gastroenterology, 33*(9), 933-938.

Hallert, C., Granno, C., Hulten, S., Midhagen, G., Strom, M., Svensson, H., et al. (2002). Living with coeliac disease: Controlled study of the burden of illness. *Scandinavian Journal of Gastroenterology, 37*(1), 39-42.

Hallert, C., & Lohiniemi, S. (1999). Quality of life of celiac patients living on a gluten-free diet. *Nutrition, 15*(10), 795-797.

Hallert, C., Sandlund, O., & Broqvist, M. (2003). Perceptions of health-related quality of life of men and women living with coeliac disease. *Scandinavian Journal of Caring Sciences, 17*(3), 301.

Halstead, M. T., & Fernsler, J. I. (1994). Coping strategies of long-term cancer survivors. *Cancer Nursing, 17*(2), 94.

Harcourt, D., Rumsey, N., & Ambler, N. (1999). Same-day diagnosis of symptomatic breast problems: Psychological impact and coping strategies. *Psychology, Health & Medicine, 4*(1), 57-71.

Hauser, W., Stallmach, A., Caspary, W. F., & Stein, J. (2007). Predictors of reduced health-related quality of life in adults with coeliac disease. *25*(5), 569-578.

Hays, R. D., Sherbourne, C. D., & Mazel, R. M. (1993). The rand 36-item health survey 1.0. *Health Economics, 2*(3), 217-227.

Hoffenberg, E. J., MacKenzie, T., Barriga, K. J., Eisenbarth, G. S., Bao, F., Haas, J. E., et al. (2003). A prospective study of the incidence of childhood celiac disease. *The Journal Of Pediatrics, 143*(3), 308.

Howdle, P. (2002). Coeliac disease: A clinical update. In V. Emerton (Ed.), *Food allergy and intolerance. Current issues and concerns* (pp. 114-126). Leatherhead, Surrey, UK: Leatherhead International.

Jaloweic, A. (1988). Confirmatory factor analysis of the jaloweic coping scale. In C. F. Waltz & O. L. Strickland (Eds.), *Measurement of nursing outcomes* (Vol. 1, pp. 287-305). New York: Springer.

Janatuinen, E. K., Kemppainen, T. A., Julkunen, R. J. K., Kosma, V. M., Maki, M., Heikkinen, M., et al. (2002). No harm from five year ingestion of oats in coeliac disease. *Gut, 50*(3), 332-335.

Johnson, J. E., & Johnson, K. E. (2006). Ambiguous chronic illness in women: A community health nursing concern. *Journal of Community Health Nursing, 23*(3), 159.

Johnston, S. D., Rodgers, C., & Watson, R. G. P. (2004). Quality of life in screen-detected and typical coeliac disease and the effect of excluding dietary gluten. *European Journal of Gastroenterology & Hepatology, 16*(12), 1281.

Junghans, C., Feder, G., Hemingway, H., Timmis, A., & Jones, M. (2005). Recruiting patients to medical research: Double blind randomised trial of "opt-in" versus "opt-out" strategies. *BMJ (Clinical Research ed.), 331*(7522), 940.

Karlsen, B., & Bru, E. (2002). Coping styles among adults with type 1 and type 2 diabetes. *Psychology, Health & Medicine, 7*(3), 245.

Katz, R. C., Ashmore, J., Barboa, E., Trueblood, K., McLaughlin, V., & Mathews, L. (1998). Knowledge of disease and dietary compliance in patients with end-stage renal disease. *Psychological Reports, 82*(1), 331.

Kaukinen, K., Halme, L., Collin, P., Farkkila, M., Maki, M., Vehmanen, P., et al. (2002). Celiac disease in patients with severe liver disease: Gluten-free diet may reverse hepatic failure. *Gastroenterology, 122*(4), 881-888.

Kinash, R. G., Fischer, D. G., Lukie, B. E., & Carr, T. L. (1993). Coping patterns and related characteristics in patients with IBD. *Gastroenterology Nursing, 16*(1), 9.

Koch, T., Kralik, D., & Sonnack, D. (2005). Women living with type ii diabetes: The intrusion of illness. *Journal of Clinical Nursing, 8*(6), 712.

Koeller, K., & LaFrance, R. (2007). Gluten-free labeling regulations worldwide: Not all definitions are equal! Retrieved December 22, 2008, from www.glutenfreepassport.com/pdf/product-labeling.pdf

Kolotkin, R. L., Crosby, R. D., Kosloski, K. D., & Williams, G. R. (2001). Development of a brief measure to assess quality of life in obesity. *Obesity Research, 9*, 102-111.

Lazarus, R. S. (1966). *Psychological stress and the coping process*. New York: McGraw Hill.

Lazarus, R. S. (1993). Coping theory and research: Past, present, and future. *Psychosomatic Medicine, 55*(3), 234-247.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer Publishing.

Lee, A., & Newman, J. M. (2003). Celiac diet: Its impact on quality of life. *Journal of the American Dietetic Association, 103*(11), 1533-1535.

Lee, A. R., Ng, D. L., Zivin, J., & Green, P. H. R. (2007). Economic burden of a gluten-free diet. *Journal of Human Nutrition & Dietetics, 20*(5), 423-430.

Libonati, C. (Ed.). (2007). *Recognizing celiac disease, signs, symptoms, associated dsorders & complications*. Fort Washington, PA: Gluten Free Works.

Ludvigsson, J. F., & Ludvigsson, J. (2001). Coeliac disease in the father affects the newborn. *Gut, 49*, 169-175.

Marsh, M. N. (1992). Gluten, major histocompatibility complex, and the small intestine. A molecular and immunobiologic approach to the spectrum of gluten sensitivity ('celiac sprue'). *Gastroenterology, 102*(1), 330-354.

McDowell, I., & Newell, C. (1996). *Measuring health. A guide to rating scales and questionnaires* (2nd ed.). New York: Oxford University Press.

McGough, N., & Cummings, J. H. (2005). Coeliac disease: A diverse clinical syndrome caused by intolerance of wheat, barley and rye. *The Proceedings of the Nutrition Society, 64*(4), 434-450.

McPherson, S., Hale, R., Richardson, P., & Obholzer, A. (2003). Stress and coping in accident and emergency senior house officers. *Emergency Medicine Journal: EMJ, 20*(3), 230-231.

Meize-Grochowski, R. (2005). Celiac disese: A multisystem autoimmune disorder. *Gastroenterology Nursing, 28*, 394-401.

Mendoza, N. (2005). Coeliac disease: An overview of the diagnosis, treatment and management. *Nutrition Bulletin, 30*(3), 231.

Meyer, D., Stavropolous, S., Diamond, B., Shane, E., & Green, P. H. (2001). Osteoporosis in a north american adult population with celiac disease. *The American Journal of Gastroenterology, 96*(1), 112-119.

Midhagen, G., & Hallert, C. (2003). High rate of gastrointestinal symptoms in celaic pateints living on a gluten-free diet: Controlled study. *American Journal of Gastroenterology, 98*, 2023-2026.

Minderhoud, I. M., Oldenburg, B., Wismeijer, J. A., van Berge Henegouwen, G. P., & Smout, A. J. P. M. (2004). IBS-like symptoms in patients with inflammatory bowel disease in remission; relationships with quality of life and coping behavior. *Digestive Diseases and Sciences, 49*(3), 469-474.

Motzer, S. A., & Hertig, V. (2004). Stress, stress response, and health. *The Nursing Clinics of North America, 39*(1), 1-17.

Mukherjee, S., Sloper, P., & Turnbull, A. (2002). An insight into the experiences of parents with inflammatory bowel disease. *Journal of Advanced Nursing, 37*(4), 355.

Muller, A. F., Donnelly, M. T., Smith, C. M., Grundman, M. J., Holmes, G. K., & Toghill, P. J. (1996). Neurological complications of celiac disease: A rare but continuing problem. *The American Journal of Gastroenterology, 91*(7), 1430-1435.

Mussell, M., Bocker, U., Nagel, N., & Singer, M. V. (2004). Predictors of disease-related concerns and other aspects of health-related quality of life in outpatients with inflammatory bowel disease. *European Journal of Gastroenterology & Hepatology, 16*(12), 1273.

Mustalahti, K., Lohiniemi, S., Collin, P., Vuolteenaho, N., Laippala, P., & Maki, M. (2002). Gluten-free diet and quality of life in patients with screen-detected celiac disease. *Effective Clinical Practice: ECP, 5*(3), 105-113.

Muthny, F. A. (1989). *Freigburg questionnaire of coping with disease*. Weinheim: Beltz.

NIH. (2004). National Institutes of Health consensus development conference statement, celiac disease (pp. 1-14).

Park, C. L., Folkman, S., & Bostrom, A. (2001). Appraisals of controllability and coping in caregivers and hiv+ men: Testing the goodness-of-fit hypothesis. *Journal of Consulting and Clinical Psychology, 69*(3), 481-488.

Penley, J. A., Tomaka, J., & Wiebe, J. S. (2002). The association of coping to physical and psychological health outcomes: A meta-analytic review. *Journal of Behavioral Medicine, 25*(6), 551-603.

Pietzak, M. M. (2005). Follow-up of patients with celiac disease: Achieving compliance with treatment. *Gastroenterology, 128*(4 Suppl 1), S135-141.

Polit, D. F., & Beck, C. T. (2004). *Nursing research: Principles and methods* (7th ed.). Philadelphia: Lippincott Williams & Wilkins.

Roos, S., Karner, A., & Hallert, C. (2006). Psychological well-being of adult coeliac patients treated for 10 years. *Digestive And Liver Disease: Official Journal Of The Italian Society Of Gastroenterology And The Italian Association For The Study Of The Liver, 38*(3), 177.

Scheier, M. F., & Carver, C. S. (1988). A model of behavioral self-regilation: Translating intention into action. In L. Berkowitz (Ed.), *Advances in experimental social psychology* (Vol. 21, pp. 303-346). New York: Acedmic Press.

Smith, D. E., Marcus, M. D., Lewis, C. E., Fitzgibbon, M., & Schreiner, P. (1998). Prevalence of binge eating disorder, obesity, and depression in a biracial cohort of young adults. *Annals of Behavioral Medicine: a Publication of the Society of Behavioral Medicine, 20*(3), 227-232.

Smolen, D. M., & Topp, R. (1998). Coping methods of patients with inflammatory bowel disease and prediction of perceived health, functional status, and well-being. *Gastroenterology Nursing, 21*(3), 112.

Stanton, A. L., & Snider, P. R. (1993). Coping with a breast cancer diagnosis: A prospective study. *Health Psychology, 12*(1), 16-23.

Sullivan, M., Karlsson, J., & Ware, J. E., Jr. (1995). The swedish sf-36 health survey--i. Evaluation of data quality, scaling assumptions, reliability and construct validity across general populations in sweden. *Social Science & Medicine (1982), 41*(10), 1349-1358.

SurveyMonkey. (2007, February 2007). Surveymonkey. from http://surveymonkey.com

Svedlund, J., Sjodin, I., & Dotevall, G. (1988). Gsrs--a clinical rating scale for gastrointestinal symptoms in patients with irritable bowel syndrome and peptic ulcer disease. *Digestive Diseases and Sciences, 33*(2), 129-134.

Sverker, A., Hensing, G., & Hallert, C. (2005). 'controlled by food' -- lived experiences of coeliac disease. *Journal of Human Nutrition & Dietetics, 18*(3), 171.

Swinson, C. M., Slavin, G., Coles, E. C., & Booth, C. C. (1983). Coeliac disease and malignancy. *Lancet, 1*(8316), 111-115.

Tahbaz, F., Kreis, I., & Calvert, D. (2006). An audit of diabetes control, dietary management and quality of life in adults with type 1 diabetes mellitus, and a comparison with nondiabetic subjects. *Journal of Human Nutrition & Dietetics, 19*(1), 3.

Talal, A. H., Murray, J. A., Goeken, J. A., & Sivitz, W. I. (1997). Celiac disease in an adult population with insulin-dependent diabetes mellitus: Use of endomysial antibody testing. *The American Journal of Gastroenterology, 92*(8), 1280-1284.

Taylor, S. E., Klein, L. C., Lewis, B. P., Gruenewald, T. L., Gurung, R. A., & Updegraff, J. A. (2000). Biobehavioral responses to stress in females: Tend-and-befriend, not fight-or-flight. *Psychological Review, 107*(3), 411-429.

Thomas, L. K., Sargent, R. G., Michels, P. C., Richter, D. L., Valois, R. F., & Moore, C. G. (2001). Identification of the factors associated with compliance to therapeutic diets in older adults with end stage renal disease. *Journal of Renal Nutrition, 11*(2), 80.

Toscano, V., Conti, F. G., Anastasi, E., Mariani, P., Tiberti, C., Poggi, M., et al. (2000). Importance of gluten in the induction of endocrine autoantibodies and organ dysfunction in adolescent celiac patients. *The American Journal of Gastroenterology, 95*(7), 1742-1748.

Urcuyo, K. R., Boyers, A. E., Carver, C. S., & Antoni, M. H. (2005). Finding benefit in breast cancer: Relations with personality, coping, and concurrent well-being. *Psychology & Health, 20*(2), 175-192.

Vaillant, G. E. (1977). *Adaptation to life*. Cambridge, MA: Harvard University Press.

Valdimarsson, T., Lofman, O., Toss, G., & Strom, M. (1996). Reversal of osteopenia with diet in adult coeliac disease. *Gut, 38*(3), 322-327.

Venes, D. (Ed.). (1997). *Taber's cyclopedic medical dictionary* (19 ed.). Philadelphia: F. A. Davis.

Ventura, A., Magazu, G., Gerarduzzi, T., & Greco, L. (2002). Coeliac disease and the risk of autoimmune disorders. *Gut, 51*(6), 897; author reply 897-898.

Ventura, A., Magazzu, G., & Greco, L. (1999). Duration of exposure to gluten and risk for autoimmune disorders in patients with celiac disease. Sigep study group for autoimmune disorders in celiac disease. *Gastroenterology, 117*(2), 297-303.

Vijan, S., Stuart, N. S., Fitzgerald, J. T., Ronis, D. L., Hayward, R. A., Slater, S., et al. (2005). Barriers to following dietary recommendations in type 2 diabetes. *Diabetic Medicine: a Journal of the British Diabetic Association, 22*(1), 32-38.

Viljamaa, M., Collin, P., Huhtala, H., Sievanen, H., Maki, M., & Kaukinen, K. (2005a). Is coeliac disease screening in risk groups justified? A fourteen-year follow-up with special focus on compliance and quality of life. *Alimentary Pharmacology & Therapeutics, 22*(4), 317-324.

Viljamaa, M., Kaukinen, K., Huhtala, H., Kyronpalo, S., Rasmussen, M., & Collin, P. (2005b). Coeliac disease, autoimmune diseases and gluten exposure. *Scandinavian Journal of Gastroenterology, 40*(4), 437-443.

Vosvick, M., Gore-Felton, C., Koopman, C., Thoresen, C., Krumboltz, J., & Spiegel, D. (2002). Maladaptive coping strategies in relation to quality of life among hiv+ adults. *AIDS and Behavior, 6*(1), 97-106.

Vosvick, M., Koopman, C., Gore-Felton, C., Thoresen, C., Krumboltz, J., & Spiegel, D. (2003). Relationship of functional quality of life to strategies for coping with the stress of living with hiv/aids. *Psychosomatics, 44*(1), 51-58.

Ware, J. E., Jr., & Sherbourne, C. D. (1992). The mos 36-item short-form health survey (sf-36). I. Conceptual framework and item selection. *Medical Care, 30*(6), 473-483.

Williamson, A. R., Hunt, A. E., Pope, J. F., & Tolman, N. M. (2000). Recommendations of dietitians for overcoming barriers to dietary adherence in individuals with diabetes. *Diabetes Educator, 26*(2), 272-279.

Willison, D. J., Keshavjee, K., Nair, K., Goldsmith, C., Holbrook, A. M., & Holbrook, A. M. (2003). Patients' consent preferences for research uses of information in electronic medical records: Interview and survey data. *BMJ (Clinical Research ed.), 326*(7385), 373.

Zarkadas, M., Cranney, A., Case, S., Molloy, M., Switzer, C., Graham, I. D., et al. (2006). The impact of a gluten-free diet on adults with coeliac disease: Results of a national survey. *Journal of Human Nutrition & Dietetics, 19*(1), 41.

Appendix A

Physician Recruitment Letter

DUQUESNE
UNIVERSITY
School of Nursing

600 Forbes Avenue
Pittsburgh, PA 15282

January 22, 2007

Melissa M. Smith
2600 Sixth Street SW
Canton, Ohio 44710

Re: Dissertation Study

Dear Dr. _________________:

Thank you for taking the time to read this letter.

I need your help to complete my dissertation for a doctor of philosophy in nursing degree at Duquesne University in Pittsburgh, PA.

I am the primary investigator of a study examining the quality of life and coping strategies of adults with celiac disease. I hope to begin collecting data in the Fall of 2007.

I need to identify a cohort of adult celiac patients.

With your approval, I would like to propose sending a letter from you to your patients. I will do the work for you. The letter will introduce me to them. A stamped postcard will be included with the letter for return only if the individual is interested in participating in the study. After a two week waiting period, I will send a survey packet with a self-addressed stamped envelope. The packet will contain a HIPAA form. I will ask the potential participants to review their lab reports. In addition, I will ask patients to fill out multi-dimensional assessments of quality of life and coping strategies. Potential participants may be contacted to determine whether or not there is interest in learning more about the study and/or participating in the study.

I have enclosed a postcard for you to return if you may be interested in helping me recruit participants for my dissertation study. If you return the postcard, I will follow up with a phone call within the next few weeks to determine whether or not you have any interest in learning more about the study and/or participating in the study.

In conclusion, I wish to extend my gratitude to you for taking the time to read and to consider this request. I hope to gain your support in my dissertation study and I look forward to working with you.

Sincerely,

Melissa M. Smith, MSN, APRN, BC, CNS
Aultman College of Nursing and Health Sciences
Doctoral Student, Duquesne University School of Nursing

Appendix B

Physician Return Post Card

DUQUESNE
UNIVERSITY
School of Nursing

Yes, I may be interested in participating
in your dissertation study and would
like to further discuss this with you.

____
Signature

____
Date

Approximate number of patients in your practice
diagnosed with celiac disease.

____

Appendix C

Physician Thank You Letter

DUQUESNE
UNIVERSITY
School of Nursing

600 Forbes Avenue
Pittsburgh, PA 15282

May 16, 2007

Melissa M. Smith
2600 Sixth Street SW
Canton, Ohio 44710

Re: Dissertation Study

Dear Dr.:

Recently, I sent a letter requesting your support for my dissertation for a doctor of philosophy in nursing degree at Duquesne University in Pittsburgh, PA. This letter is being written to thank you for taking the time to read and to consider my request.

Based on information received, there does not appear to be a sufficient number of potential participants. I wish to extend my sincere thanks to you for returning the postcard and offering your support. Perhaps the future will provide an opportunity for us to work together.

Sincerely,

Melissa M. Smith, MSN, APRN, BC, CNS
Aultman College of Nursing and Health Sciences
Doctoral Student, Duquesne University School of Nursing

Appendix D

Demographic Information and Health History

Please complete the following survey by placing a checkmark in the area corresponding to the description that best describes you.

General Information	
Sex*	___ Male ___ Female
Age in Years*	___
Race or Ethnicity	___ White ___ Black or African American ___ American Indian or Alaskan Native ___ Asian ___ Native Hawaiian or other Pacific Islander ___ Hispanic or Latino of any race ___ Other: ________________________
Marital Status	___ Single ___ Divorced ___ Now Married ___ Widowed ___ Significant Other ___ Separated
Geographic Location*	___ AL ___ GA ___ MD ___ NJ ___ SC ___ WY ___ AK ___ HI ___ MA ___ NM ___ SD ___ AZ ___ ID ___ MI ___ NY ___ TN ___ AR ___ IL ___ MN ___ NC ___ TX ___ CA ___ IN ___ MS ___ ND ___ UT ___ CO ___ IA ___ MO ___ OH ___ VA ___ CT ___ KS ___ MT ___ OK ___ VT ___ DE ___ KY ___ NE ___ OR ___ WA ___ DC ___ LA ___ NV ___ PA ___ WV ___ FL ___ ME ___ NH ___ RI ___ WI
Education*	Number of Years of Education: _____
Annual Income*	___ < $10, 000 ___ $50,000 – 74,999 ___ $10,000 – 14,999 ___ $75,000 – 99,999 ___ $15,000 – 24,999 ___ $100,000 – 149,999 ___ $25,000 – 34,999 ___ $150,000 – 199,999 ___ 35,000 – 49,999 ___ $200,000 or more
Health Habits	
Smoker*	___ No ___ Yes Number of cigarette packs per day _____
Alcohol Consumption*	___ NA ___ Yes Number of drinks per week ___ ___Beer ___ Wine ___ Liquor
Hours of Exercise per Week*	_____
Hours of Sleep per Night*	_____

Celiac Disease Diagnosis	
Have you been diagnosed with celiac disease?*	___ No ___ Yes
If yes, how long after your symptoms began were you diagnosed?	___ Months ___ Years
What sign or symptoms did you experience before your diagnosis or before starting the gluten free diet?* (Select all that apply)	___ gas ___ hair loss ___ abdominal bloating and pain ___ weight loss ___ diarrhea ___ anemia (a low red blood cell count) ___ bone or joint pain ___ difficulty recalling information ___ missed menstrual periods ___ pale sores inside the mouth ___ itchy skin ___ none
How were you diagnosed? (Select all responses that apply)	___ Endoscopy with Biopsy Blood Tests: ___ CBC ___ Serum Ferritin ___ Anti-gliadin antibodies ___ IgA (immunoglobulin A) ___ tTG (anti-tissue transglutaminase antibodies) ___ AEA (anti-endomysium antibodies)
What other tests were done? (Select all responses that apply)	___ Breath Hydrogen Test ___ Bone Density ___ Small Bowel Series ___ Bone Marrow ___ Colonoscopy ___ Iron Studies ___ Skin Biopsy
Did you have a follow-up test after being diagnosed and starting a gluten free diet?	___ Yes ___ No (If no, please explain why):
After dietary therapy was started, what follow-up tests were done?* (Select all responses that apply)	___ Endoscopy with Biopsy Blood Tests: ___ CBC ___ Serum Ferritin ___ Anti-gliadin antibodies ___ IgA (immunoglobulin A) ___ tTG (anti-tissue transglutaminase antibodies) ___ AEA (anti-endomysium antibodies))
Please check any sign or symptoms you currently experience.*	___ gas ___ abdominal bloating and pain ___ weight loss ___ diarrhea ___ anemia (a low red blood cell count)

	___ bone or joint pain ___ difficulty recalling information ___ missed menstrual periods ___ pale sores inside the mouth ___ itchy skin ___ none
Gluten Free Diet	
How long have you been following a gluten free diet?*	___ < 6 months ___ 6 months - 1 year ___ 13 months – 2 years ___ 2 ½ - 4 years ___ 4 ½ - 6 years ___ 6 ½ - 8 years ___ 8 ½ - 10 years ___ > 10 years
Did you have a consultation with a dietitian? If not, please state who provided your initial dietary instructions.	___ No ___ Yes Other: ___________________________________
Since your initial instruction, how have you obtained information about a gluten free diet?	___ Physician ___ Nurse ___ Dietitian ___ Other: ___ Library ___ Internet ___ Support Group
Do you eat oats on your gluten free diet?	___ No ___ Yes
How often do you include gluten containing foods in your diet?	___ Never ___ Once a month ___ Once a week ___ Daily ___ Other: please specify: ___________________
Are meals prepared and served or delivered to you?*	___ No ___ Yes
If yes, who prepares your meals?	Identify: ___________
Are your meals prepared at home?*	___ No ___ Yes
If meals are cooked at home, who prepares the meals?	___ Self ___ Spouse ___ Significant Other ___ Child ___ If other, please specify: __________
Do you purchase already prepared foods?*	___ No ___ Yes If yes, please estimate the quantity of prepared foods purchased in percentage ___
Do you have difficulty obtaining gluten free foods?*	___ No ___ Yes
Where do you purchase gluten free foods?*	___ Grocery store ___ Specialty food store ___ Online If other, please specify: ___________

What difficulties do you have in following a gluten free diet?*	___ I do not understand what foods I can and cannot eat ___ I do not like the taste of gluten free foods ___ Gluten free foods are expensive to buy ___ I do not understand labeling on foods ___ I feel no different on a gluten free diet ___ I have problem when outside my home, please specify: _____________ ___ None
During the past month, rate the amount of stress you have felt relative to following a gluten free diet.*	___ None ___ Minimal ___ Moderate ___ Large

* Indicates a required response.

Appendix E

Psychological General Well-Being Index

General Well-Being Index (PGWBI): Quality of Life Instrument to measure self-representations of intra-personal affective or emotional states reflecting a sense of subjective well-being or distress. PGWBI© 1984 Harold J. Dupuy, All rights reserved.

This section of the evaluation contains questions about how you feel in regards to your general well-being. For each question check the answer that best applies to you. Please choose only one answer per question.

1. How have you been feeling in general during the past month?

In excellent spirits ☐ 5
In very good spirits ☐ 4
In good spirits mostly ☐ 3
I have been up and down in spirits a lot ☐ 2
In low spirits mostly ☐ 1
In very low spirits ☐ 0

2. How often were you bothered by any illness, bodily disorder, aches or pains during the past month?

Every day ☐ 0
Almost every day ☐ 1
About half of the time ☐ 2
Now and then, but less than half the time ☐ 3
Rarely ☐ 4
None of the time ☐ 5

3. Did you feel depressed during the past month?

Yes - to the point that I felt like taking my life ☐0
Yes - to the point that I did not care about anything ☐ 1
Yes - very depressed almost every day ☐ 2
Yes - quite depressed several times ☐ 3
Yes - a little depressed now and then ☐ 4
No - never felt depressed at all ☐ 5

4. Have you been in firm control of your behavior, thoughts, emotions or feelings during the past month?

Yes, definitely so	☐ 5
Yes, for the most part	☐ 4
Generally so	☐ 3
Not too well	☐ 2
No, and I am somewhat disturbed	☐ 1
No, and I am very disturbed	☐ 0

5. Have you been bothered by nervousness or your "nerves" during the past month?

Extremely so - to the point where I could not work or take care of things	☐ 0
Very much so	☐ 1
Quite a bit	☐ 2
Some - enough to bother me	☐ 3
A little	☐ 4
Not at all	☐ 5

6. How much energy, pep, or vitality did you have or feel during the past month?

Very full of energy - lots of pep	☐ 5
Fairly energetic most of the time	☐ 4
My energy level varied quite a bit	☐ 3
Generally low in energy or pep	☐ 2
Very low in energy or pep most of the time	☐ 1
No energy or pep at all - I felt drained, sapped	☐ 0

7 I felt downhearted and blue during the past month.

None of the time	☐ 5
A little of the time	☐ 4
Some of the time	☐ 3
A good bit of the time	☐ 2
Most of the time	☐ 1
All of the time	☐ 0

Appendix F

User Agreement for PGWBI

Dear Melissa,

Thank you for the User Agreement we received by regular mail.

I'm pleased to send you attached the Psychological General Well-Being Index (PGWBI) in US English together with the Scoring manual.

Contact information and permission to use is as follows:
MAPI Research Trust, Lyon, France. E-mail: contact@mapi-trust.org – Internet: www.mapi-trust.org

Kind Regards,

Katri

Katri Malte
Information Unit Assistant
Mapi Research Trust
Information Resources Centre
27 rue de la Villette
69003 Lyon - France
Tel: +33 (0) 4 72 13 65 75 - Fax: +33 (0) 4 72 13 66 68

Appendix G

Instructions for Scoring PGWBI

Dimensions	Item n	Item Cluster	Range
Anxiety (ANX)	5	5, 8, 17, 19, 22	0-25
Depressed Mood (DEP)	3	3, 7, 11	015
Positive well-being (PWB)	4	1, 9, 15, 20	0-20
Self-control (SC)	3	4, 14, 18	0-15
General health (GH)	3	2, 10, 13	0-15
Vitality	4	6, 12, 16, 21	0-20
Global Score	22		0-110

The 22 items of the PGWBI are grouped in 6 dimensions. A global score is computed as the sum of the scores on the 6 dimensions. No item score needs to be reversed because the direction of the score is the same for all, whatever the direction taken by the wording of the options (i.e., a higher score is always positive). Note that scores are not weighted. Calculation is simple. For each dimension, score is given by the sum of the relevant items. The ranges for each dimension have been provided. Similarly, the global score is calculated by the sum of the 6 dimension scores. It ranges from 0 (poor quality of life) to 110 (good quality of life), based on a 0-5 scaling item scaling range.

IQOD- Psychological General Well-Being Index Instruction Manual, pp.20, 24

Appendix H

Brief COPE

The items on the following page deal with ways you may have used or are using to cope with the diagnosis of celiac disease. There are many ways to try to deal with problems. These items ask what you have been doing to cope with your diagnosis of celiac disease. Obviously, different people deal with the diagnosis in different ways. I am interested in how you have tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you have been doing what the item says. In other words, how much or how frequently do you do what the item says. Do not answer on the basis of whether it seems to be working or not – just whether or not you are doing it. Try to rate each item separately in your mind from others. Make your answers as true FOR YOU as you can.

From the following scale, please indicate the number that best describes your answer for each question. Please use only these choices.

1 = I have not been doing this at all
2 = I have been doing this a little bit
3 = I have been doing this a medium amount
4 = I have been dong this a lot

ITEM	RATING
1. I have been turning to work or other activities to take my mind off things	
2. I have been concentrating my efforts on doing something about the situation I am in.	
3. I have been saying to myself "this is not real."	
4. I have been using alcohol or other drugs to make myself feel better.	
5. I have been getting emotional support from others.	
6. I have been giving up trying to deal with it.	
7. I have been taking action to try to make the situation better.	
8. I have been refusing to believe that it has happened.	
9. I have been saying things to let my unpleasant feelings escape.	
10. I have been getting help and advice from other people.	
11. I have been using alcohol or other drugs to help me get through it.	
12. I have been trying to see it in a different light, to make it seem more positive.	
13. I have been criticizing myself.	
14. I have been trying to come up with a strategy about what to do.	
15. I have been getting comfort and understanding from someone.	
16. I have been giving up the attempt to cope.	
17. I have been looking for something good in what is happening.	
18. I have been making jokes about it.	
19. I have been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	
20. I have been accepting the reality of the fact that it has happened.	
21. I have been expressing my negative feelings.	
22. I have been trying to find comfort in my religion or spiritual beliefs.	
23. I have been trying to get advice or help from other people about what to do.	
24. I have been learning to live with it.	
25. I have been thinking hard about what steps to take.	
26. I have been blaming myself for things that happened.	
27. I have been praying or mediating.	
28. I have been making fun of the situation.	

Table 1

Brief COPE Subscales

Subscales	Items
Self-distraction	1 and 19
Active coping	2 and 7
Denial	3 and 8
Substance use	4 and 11
Use of emotional support	5 and 15
Use of instrumental support	10 and 23
Behavioral disengagement	6 and 16
Venting	9 and 21
Positive reframing	12 and 17
Planning	14 and 25
Humor	18 and 28
Acceptance	20 and 24
Religion	22 and 27
Self-blame	13 and 26

Instructions to score the Brief COPE

It is not recommended that scales be combined into “problem focused” and “emotion focused”, or into an “overall” coping index. There is no such thing as an overall score on this measure, and there is no recommendation for a particular way of generating a dominant coping style for a given person. In general, each scale is considered separately to see what its relation is to other variables. An alternative is to create second-order factors from among the scales and use the factors as predictors. If the alternative method is chosen, it is recommended that ones own data be used to determine the composition of the higher-order factors.

Appendix I

DUQUESNE UNIVERSITY
600 FORBES AVENUE ♦ PITTSBURGH, PA 15282

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

TITLE: What Is the Relationship Between Quality of Life and Coping Strategies in Adults with Celiac Disease Adhering to a Gluten Free Diet?

INVESTIGATOR:
Melissa M. Smith, PhD(c), RN, ACNS-BC
Doctoral Candidate
Duquesne University
School of Nursing
Pittsburgh, PA 15282
(W) (330) 363-3930

ADVISOR:
Linda Goodfellow, PhD, RN
Associate Professor
Duquesne University School of Nursing
517 Fisher Hall
Pittsburgh, PA 15282
(412) 396-6548

SOURCE OF SUPPORT: This study is being performed as partial fulfillment of the requirements for the doctoral degree in nursing at Duquesne University. This study is supported by a grant from the Society of Gastroenterology Nurses and Associates, Inc.

PURPOSE: You are being asked to participate in a research project that seeks to investigate whether or not there is a relationship between quality of life and coping strategies for adults with celiac disease adhering to a gluten free diet and to determine if there are any perceived causes that interfere with adherence to a gluten free diet

These are the only requests that will be made of you.

RISKS AND BENEFITS: There are no risks greater than those encountered in everyday life. The benefit to you will be knowing that you will help in identifying coping strategies of adults with celiac disease adhering to a gluten free diet and that the results may eventually result in the development of cognitive-behavioral interventions and/or educational programs designed to improve quality of life in people just like you with celiac disease.

COMPENSATION: You are not required to pay to participate in this study and you will not be paid to participate in this study.

A $500.00 honorarium will be given to the Gluten Intolerance Group in gratitude for their assistance in creating the link for you to complete the questionnaires. This donation will be used by the Gluten Intolerance Group for further research.

CONFIDENTIALITY: Your name will never appear on any survey or research instruments. If any personal identification is provided, your responses to the questionnaires will be deleted.

No identity will be made in the data analysis. Your responses will only appear in statistical data summaries. All materials will be destroyed at the completion of the study after all data have been analyzed and the findings have been reported.

RIGHT TO WITHDRAW: You are under no obligation to participate in this study. You are free to withdraw your consent to participate at any time.

SUMMARY OF RESULTS: A summary of the results of this research will be posted on the Gluten Intolerance Group Website.

VOLUNTARY CONSENT: Voluntary completion of the surveys will confirm consent to participate. The estimated time to complete all three surveys is approximately 45 minutes.

I have read the above statements and understand what is being requested of me. I also understand that my participation is voluntary and that I am free to stop at any time, not complete the surveys and thus, withdraw my consent at any time, for any reason. On these terms, I certify that I am willing to participate in this research project.

I understand that should I have any further questions about my participation in this study, I may call Melissa M. Smith, Principal Investigator (330) 363-3930, Linda Goodfellow (412) 396-6548 Advisor, and Dr. Paul Richer, Chair of the Duquesne University Institutional Review Board 412-396-6326).

If you agree to participate in this study, please click on the link provided and complete the questionnaires.

Table 2

PGWB Index grouping of items by dimensions

Dimensions	Number of Items	Range of Scores
1. Anxiety	5	0-25
2. Depressed Mood	3	0-15
3. Positive well-being	4	0-20
4. Self-control	3	0-15
5. General health	3	0-15
6. Vitality	4	0-20
Global Score	22	0-110