Perspectives of Having Celiac Disease and Eating Disorders

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Perspectives of Having Celiac Disease and Eating Disorders

MSW Clinical Research Paper
Submitted by Heather M. Vargo
May, 2012

The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present their findings. This project is neither a Master’s thesis nor a dissertation.

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Abstract

The issue of eating disorders among individuals with celiac disease is a growing concern; yet, it receives little clinical research attention. The purpose of this project is to explore perspectives of individuals who have celiac disease and eating disorders. The research sought to learn more about the development of eating disorders and celiac disease for individuals, how individuals perceive the interaction between the two disorders, and what individuals think would be beneficial in treating these comorbid diseases? Using a qualitative design, nine individuals agreed to be interviewed about their experience of having celiac disease and an eating disorder. Data was analyzed using both inductive and deductive approaches which categories were first developed from the interview responses and linked to previous literature. The findings indicated that there is a significant interaction between celiac disease and eating disorders. The celiac disease often made it more “convenient” for participants to engage in their restrictive eating disorder symptoms. There is a continued need for ongoing research in this area of celiac disease and eating disorders.

Keywords: celiac disease, coeliac disease, eating disorders, anorexia, bulimia, EDNOS, gluten free diet
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# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>1</td>
</tr>
<tr>
<td>Literature Review</td>
<td>2</td>
</tr>
<tr>
<td>Conceptual Framework</td>
<td>15</td>
</tr>
<tr>
<td>Method</td>
<td>19</td>
</tr>
<tr>
<td>Findings</td>
<td>23</td>
</tr>
<tr>
<td>Discussion</td>
<td>44</td>
</tr>
<tr>
<td>References</td>
<td>54</td>
</tr>
<tr>
<td>Appendices</td>
<td>61</td>
</tr>
</tbody>
</table>
Perspectives of Having Celiac Disease and Eating Disorders

The issue of eating disorders among individuals with celiac disease is a growing concern, yet, it receives little clinical research attention (Leffler, Dennis, Edwards George, & Kelly, 2007). While we may be familiar with the eating disorders of Anorexia, Bulimia and Eating Disorder Not Otherwise Specified (EDNOS), celiac disease might be a more unfamiliar disease to some. Celiac disease is a lifelong autoimmune disorder in which a person’s body cannot tolerate gluten (Dowler & Shepard, 2008; Hasselbeck, 2009; Tessmer, 2009).

As many as 10 million Americans have a diagnosable eating disorder (National Eating Disorder Association, 2005). At one time celiac disease was thought to be rare, research now shows that one out of every 133 people in the United States has celiac disease (Celiac Disease Foundation, n.d.). Though there are few studies to document the cases of those who have an eating disorder and celiac disease, the conditions, at times, coexist (Jay, 2010; Leffler et al., 2007). There is no research indicating a correlation between celiac disease and a specific type of eating disorder.

Clients with these comorbid disorders face particular challenges; while eating disorders result in anxiety about eating food, celiac disease can compound this anxiety by introducing fear of eating foods that are unsafe. When faced with the comorbid disorders, these compounded challenges are even more difficult to manage (Leffler et al., 2007). While untreated eating disorders cause malnutrition, so too, does untreated celiac disease. Therefore, it makes dietary compliance to a gluten-free diet and strict meal plan even more vital to the individual who has celiac disease and an eating disorder. Similarly, eating disorders are often built on the need for control or the struggle with control (Costin, 2007). Following the dietary restrictions that are
necessary when an individual has celiac disease may further contribute to the predicament of control.

Social workers are involved in the treatment of eating disorders. Practitioners may not have a strong understanding of either diagnosis, which is central to delivering specialized care (Terence Wilson, Grilo, & Vitousek, 2007). In fact, practitioners may have a tough time distinguishing if the client really has an eating disorder, or if the celiac disease is causing an aversion to food (Jay, 2010). Conversely, the food restriction of the celiac disease may contribute to the psychological features of an eating disorder (Yucel, Ozbey, Demir, Polat, & Yager, 2006). Knowing that celiac disease and eating disorders both represent serious health concerns, understanding clients’ experiences may enhance practitioners’ work with individuals with this dual diagnosis. The purpose of this research is to learn about individuals’ experiences of having both celiac disease and eating disorders.

**Literature Review**

**Eating Disorders**

Eating Disorders include Anorexia Nervosa, Bulimia Nervosa, and Eating Disorders Not Otherwise Specified (EDNOS) (*Diagnostic and Statistical Manual of Mental Disorders: DSM-IV-TR*, 2000; Smith, 2008). Regardless of the eating disorder diagnosis, clients experience disturbances in body image (American Psychological Association, 2008; *DSM-IV-TR*, 2000). Other similarities across all eating disorders include extreme concern regarding weight and/or size and severe caloric restriction in order to attempt weight loss (Garner & Garfinkel, eds., 1997). Over time, as many as one-half of individuals can eventually be diagnosed with two or more of the different types of eating disorders (Lock & Le Grange, 2005; Striegel-Moore & Bulik, 2007).
Eating disorders do not discriminate based on age, gender, race or ethnicity (The Emily Program, 2011). While this is understood, the majority of eating disorders develop during adolescence and the early twenties (Striegel-Moore & Bulik, 2007). Also, up to 90% of eating disorders affect women and girls (American Psychological Association, 2008). Previously, eating disorders were primarily attributed to Caucasian women (Striegel-Moore & Bulik, 2007). Researchers now believe that there is a disparity in diagnosis, possibly due to clinician bias toward Caucasians being diagnosed (Striegel-Moore & Bulik, 2007).

Anorexia is characterized by refusal to maintain body weight at or above a normal weight, intense fear of gaining weight and absence of three consecutive menstrual cycles (DSM-IV-TR., 2000). Individuals with Anorexia tend to have perfectionistic personality traits (American Psychological Association, 2008). There are two subtypes of Anorexia: the restrictive type when individuals restrict their intake, and the binge/purge type when the person regularly engages in binge eating or purging behavior (Costin, 2007; DSM-IV-TR., 2000).

Individuals with Bulimia may experience recurrent episodes of binge eating (eating a larger amount of food, larger than most people within a two hour period of time) and a feeling of a lack of control over the eating episode (Costin, 2007; DSM-IV-TR., 2000). The binge behaviors are done along with compensatory behaviors, like using diuretics, laxatives, vomiting, enemas, excessive exercise and ipecac (DSM-IV-TR., 2000). One subtype of Bulimia is a purging type, and another is a non purging type (Costin, 2007; DSM-IV-TR., 2000). There is often a common character trait of being more impulsive (American Psychological Association, 2008).

The DSM-IV-TR places all other atypical eating disorders in a category referred to as Eating Disorder Not Otherwise Specified (EDNOS) (Costin, 2007; DSM-IV-TR., 2000). About one-third of all people with an eating disorder fall into this category (Costin, 2007). Research
indicates that EDNOS is more prevalent and as serious a problem as Anorexia Nervosa and Bulimia Nervosa (Smith, 2008). EDNOS includes several examples of atypical eating disorders. For example individuals who have met all criteria of Anorexia except when the individual does not have their regular menses, or has not met the weight criteria would fall under the EDNOS category. Similarly with Bulimia – all criteria is met except for duration or frequency of symptoms.

Another atypical eating disorder in the EDNOS classification of the DSM-IV-TR include Binge Eating Disorder. Individuals who binge eat and do not purge or restrict their intake fall under this category (Costin, 2007; *DSM-IV-TR*, 2000). Binge eating disorder is characterized by recurrent episodes of binge eating, marked distress regarding binge behavior and meeting three or more of five DSM-IV-TR criterion in the appendix (Costin, 2007; *DSM-IV-TR*, 2000). The DSM-IV-TR suggests further research to better classify this disorder. Similar to Binge Eating Disorder, compulsive overeating is another atypical eating disorder. Currently, there is no classification in the DSM-IV-TR for compulsive overeating, however, treatment programs have been established to treat both Binge Eating Disorder and compulsive overeating (Emily Program, 2011).

There are several proposed revisions to the diagnostic category of eating disorders in the DSM-5. Though revisions are not finalized upon the writing of this paper, the proposed revisions are significant and noteworthy. Specifically, the category of ‘Eating Disorders’ is posed to be renamed as ‘Feeding and Eating Disorders.’ The classification will include other disorders, such as Pica, Rumination Disorder and Avoidant/Restrictive Food Intake Disorder (classified in the DSM-IV-TR as Feeding Disorder of Infancy or Early Childhood). Binge Eating Disorder is set to be a new diagnosis and there will be a new category replacing Eating Disorder Not Otherwise
Specified. EDNOS is proposed to be broken down into two categories: Other Specified Feeding or Eating Disorder and Other Feeding or Eating Condition Not Elsewhere Classified. Other Specified Feeding or Eating Disorders include: Atypical Anorexia Nervosa, Subthreshold Bulimia Nervosa (low frequency or limited duration), Subthreshold Binge Eating Disorder (low frequency or limited duration), Purging Disorder and Night Eating Syndrome.

**Physical and Other Psychological Problems Associated with Eating Disorders**

Along with affecting the quality of life of the individual with the eating disorder, there are several health complications of eating disorders (National Eating Disorder Association, 2005; Smith, 2008). Some of the physical complications include reduction in bone density, heart attack, anemia, abnormally slow heart rate and low blood pressure, muscle loss, fainting, fatigue, dry hair and skin, hair loss, electrolyte imbalances, irregular heartbeats, potential of gastric rupture, tooth decay, and irregular bowel movements (American Psychological Association, 2008; National Eating Disorder Association, 2005). It is important to note, too, that one in 10 Anorexia cases end in death from starvation or medical complications making this the highest mortality rate of any mental illness (American Psychological Association, 2008; National Eating Disorder Association, 2005; Smith, 2008).

In addition to the physical problems that are associated with eating disorders, there are several psychological problems commonly associated with eating disorders (Smith, 2008). This includes mood and anxiety disorders, depression, impulse control, and substance use disorders (American Psychological Association, 2008; Smith, 2008). Research is unclear regarding whether or not eating disorders are symptoms of these problems or whether the problems develop because of social isolation, stigma, and physiological changes that are brought on by the eating disorder (American Psychological Association, 2008).
Risk Factors for Eating Disorders

There are several factors that may contribute to an increased risk for having an eating disorder, however, there is no single factor that causes an eating disorder (Schulherr, 2008). Risk factors include psychological, interpersonal, cultural, and biological factors (National Eating Disorder Association, 2005; Striegel-Moore & Bulik, 2007). Risk factors include several psychological factors like low self-esteem, feelings of inadequacy, depression, anxiety, loneliness, anger, and lack of control in life (American Psychological Association, 2008; National Eating Disorder Association, 2005; Striegel-Moore & Bulik, 2007).

There are also several interpersonal factors that are also risk factors of eating disorders (National Eating Disorder Association, 2005; Striegel-Moore & Bulik, 2007). Interpersonal risk factors that may contribute to eating disorders are troubled relationships, difficulty expressing emotions, an unbalanced family life, being teased based on size or weight, and a history of abuse (National Eating Disorder Association, 2005; Schulherr, 2008; Smith, 2008; Striegel-Moore & Bulik, 2007). Cultural factors also play a role in an increased risk for eating disorders (National Eating Disorder Association, 2005). There may be a higher social pressure to be thin, a narrow definition of beauty and cultural norms that value people based on physical appearance (National Eating Disorder Association, 2005; Striegel-Moore & Bulik, 2007). Lastly, researchers are exploring biological factors that may contribute to eating disorders (National Eating Disorder Association, 2005). In preliminary research, certain chemicals that control hunger and satiety have been found to be unbalanced, however, the implications of this imbalance is unknown (National Eating Disorder Association, 2005). What is known, is that eating disorders have a significant genetic component (American Psychological Association, 2008; National Eating Disorder Association, 2005; Schulherr, 2008).
Cultural Considerations for Eating Disorders

There are several cultural considerations in regards to eating disorders. Eating disorders are thought to affect western culture because of their standards of female beauty (Striegel-Moore & Bulik, 2007). Specifically, it has been thought that eating disorders affect predominantly young Caucasian females (Costin, 2007). Research shows that as populations are educated about eating disorders, individuals are more likely to develop them; the reason for this is unknown (Costin, 2007). Ultimately, eating disorders affect individuals of any age, gender, race or ethnicity (Costin, 2007; The Emily Program, 2011).

Historically, it was thought that eating disorders were rare among ethnic minorities (Striegel-Moore & Bulik, 2007). Researchers are finding that this is due to clinician bias. Clinicians believe that eating disorders are a disease of affluent Caucasian women (Striegel-Moore & Bulik, 2007). However, research shows that Hispanic women seem to have eating disorders at equal rates to Caucasian, while African Americans seem to have binge eating disorder rates equal to Caucasian (Costin, 2007). Also, ethnic minority women may be less likely to seek care for their eating disorder (Striegel-Moore & Bulik, 2007).

Treatment of Eating Disorders

Eating disorders are often undertreated. Research shows that eating disorders are one of the psychological problems least likely to be treated by mental health professionals (American Psychological Association, 2008). In fact, research shows that less than half of the individuals with Bulimia and Binge Eating Disorder sought treatment (Smith, 2008). Treatment for eating disorders is comprised of individual therapy and group therapy (The Emily Program, 2011; Park Nicollet – Melrose Institute, 2011; Stewart, Part 1, 2004).
Treatment for eating disorders varies in length according to the severity of the disorder. Treatment is often structured in several parts for eating disorders: Residential treatment, acute inpatient treatment, partial day hospitalization, intensive outpatient treatment, and outpatient treatment (The Emily Program, 2011; Park Nicollet Services - Melrose Institute, 2011; Stewart, Part 1, 2004). The level of treatment is determined based on the needs of the individual and the severity of their symptoms (Stewart, Part 1, 2004). Group therapies can include nutrition counseling, body image groups, relapse prevention, mindfulness training, creative therapies, exercise therapies, recovery skill building, and process groups (Stewart, Part 1, 2004; The Emily Program, 2011). Individual therapies often include a dietitian and therapist (American Psychological Association, 2008; The Emily Program, 2011; Stewart, Part 1, 2004). Individual treatment with a therapist typically focuses on psychiatric problems that need to be treated in order to understand how the eating disorder developed and continues to be present (Stewart, Part 1, 2004). Additionally, the therapist and client may work on reduction of symptoms, improving self esteem, working with negative emotional reactions, fear, anxiety, and maintenance of change (Stewart, Part 1, 2004). There is an improved chance of recovery from an eating disorder through early treatment and fewer comorbid disorders (Costin, 2007). If purging symptoms are infrequent or there is no purging behavior there is an increased chance of recovery (Costin, 2007).

Supportive loved ones is another consideration for improved chances of full recovery (Costin, 2007).

**Celiac Disease**

Celiac disease is a lifelong autoimmune disorder in which a person’s body cannot tolerate gluten (Dowler Shepard, 2008; Hasselbeck, 2009; Tessmer, 2009). An autoimmune reaction means that the body attacks itself when exposed to gluten (Dowler Shepard, 2008). Gluten is
CELIAC DISEASE AND EATING DISORDERS

found in wheat, barley, rye, and their derivatives (Dowler Shepard, 2008; Hasselbeck, 2009; Tessmer, 2009). Consuming small amounts of gluten, even 1/8 of a teaspoon, may lead to medical complications (Celiac Disease Foundation, n.d.; Dowler Shepard, 2008). When celiac disease individuals eat gluten, the villi in the small intestines are damaged (Celiac Disease Foundation, n.d.; Dowler Shepard, 2008). Villi are tiny carpet-like fibers in the small intestine that absorb nutrients from food (Celiac Disease Foundation, n.d.; Dowler Shepard, 2008). When the villi are damaged, this creates a malabsorption of nutrients which can mimic malnutrition (Celiac Disease Foundation, n.d.; Dowler Shepard, 2008).

There are several things that contribute to the development of celiac disease. Developing celiac disease requires a genetic disposition, an exposure to gluten and something to trigger this immune system response (Dowler Shepard, 2008; Tessmer, 2009). If an individual has been diagnosed with celiac disease, it is because there is a genetic predisposition already in place (Dowler Shepard, 2008). Researchers have found that individuals who have been diagnosed with celiac disease have HLA-DQ2 and HLA-DQ8 genes that interact with the gluten protein (Dowler Shephard, 2008). If someone does not carry this HLA typing, it is highly unlikely that they would develop celiac disease (Dowler Shephard, 2008; Celiac Disease Foundation, n.d.). Celiac disease may not become active, or symptomatic, until something initiates a celiac reaction in an already predisposed person (Dowler Shephard, 2008). It is important to note that even if a person does not have symptoms of celiac disease, the individual can still have celiac disease and there is still a risk of intestinal damage (Tessmer, 2009).

Many times the diagnosis of celiac disease happens after a long period of an individual experiencing months or years of a combination of symptoms. The process of diagnosis can be quite difficult as celiac disease is often misdiagnosed as irritable bowel syndrome, anemia,
chronic fatigue syndrome, intestinal infection, and Crohn’s disease (Dowler Shephard, 2008). According to Tessmer (2009), the first step in the process of diagnosis is to conduct a blood antibody test which is used to screen for gluten intolerances. If the result of the blood test reveals particular antibodies to be higher than normal, it shows that the individual’s body is responding negatively to gluten. The blood test, however, does not indicate celiac disease. If there are increased levels of antibodies, this suggests the probability of celiac disease. If there are symptoms of celiac disease, and the antibody levels are high, a biopsy of the small intestine is taken via an endoscopy, which checks for damage in the villi of the small intestine. If damage is present to the villi and symptoms improve with a gluten free diet, this confirms the diagnosis of celiac disease. Antibody levels and damage to the villi are only present in someone with celiac disease if the individual has gluten in their diet. For this reason, physicians advise individuals to not follow a gluten free diet before having the antibody blood test and endoscopy (Tessmer, 2009).

Physical and Other Psychological Problems Associated with Celiac Disease

Celiac Disease is associated with over 300 different symptoms - the most common include gastrointestinal symptoms, anemia, vitamin deficiencies, migraines, unexplained weight loss, and chronic fatigue (Dowler Shepard, 2008; Tessmer, 2009). Gastrointestinal symptoms are the most common symptoms, including abdominal pain, bloating, gas or indigestion, constipation and/or diarrhea, nausea, vomiting, and unexplained weight loss ("Celiac disease - sprue," 2010; Dowler Shepard, 2008; Tessmer, 2009). Ongoing lack of absorption of vitamins and minerals from food may lead to malnourishment with the following symptoms happening over time: bruising easily, depression or anxiety, fatigue, growth delay in children, hair loss, dermatitis herpetiformis, missed menstrual periods, mouth ulcers, muscle cramps, joint pain,
nosebleeds, seizures, tingling or numbness in the hand or feet, and unexplained short height ("Celiac disease - sprue," 2010; Dowler Shepard, 2008).

Celiac disease may involve several coexisting common diseases: asthma, osteoporosis, dermatitis herpetiformis, Down’s syndrome, Addison’s disease, rheumatoid arthritis, systemic lupus erythematosus, intestinal cancer or lymphoma, lactose intolerance, type 1 diabetes and infertility ("Celiac disease - sprue," 2010; Dowler Sherpard, 2009; Tessmer, 2009).

**Treatment of Celiac Disease**

Upon diagnosis of celiac disease, the individual is advised to learn about gluten free diets and to start adhering to the gluten free diet immediately (Pietzak, 2005; Tessmer, 2009). The only treatment for celiac disease is a lifelong strict adherence to a gluten free diet (Celiac Disease Foundation, n.d.; Dowler Shepard, 2008; Tessmer, 2009). No medication is necessary (Celiac Disease Foundation, n.d.; Dowler Shepard, 2008; Tessmer, 2009). As gluten is removed from the diet, the small intestine will start to heal and overall health will improve (Celiac Disease Foundation, n.d.). Newly diagnosed individuals are encouraged to get regular supervision from a physician, receive medical nutritional counseling from a dietitian and to consider getting involved in a support group (Pietzak, 2005). The follow up with the individual’s physician may entail screening for nutritional deficiencies, compliance with diet and monitoring of complications, and signs of other autoimmune diseases (Pietzak, 2005). The longer someone with celiac disease is undiagnosed and untreated, the greater chance there is for long term complications ("National Digestive Diseases Information Clearinghouse," 2008). After one year of a gluten free diet the celiac disease individual is advised to check serum antibodies (Pietzak, 2005). If the individual is doing well, antibodies are normal and there are no clinical symptoms; the individual should continue checking serum antibodies annually (Pietzak, 2005). If the celiac
individual has elevated antibodies, clinical symptoms and/or nutritional deficiencies, the individual is then advised to follow up with the dietitian, physician and support group (Pietzak, 2005).

**Celiac Disease and Eating Disorders**

Very little research considers the comorbid conditions of celiac disease and eating disorders (Leffler et al., 2007; Yucel, Ozbey, Demir, Polat, & Yager, 2006). Both diseases have been under diagnosed and have comorbid psychological conditions (Leffler et al., 2007). In a study of 10 cases of patients with celiac disease and eating disorders, the majority of cases showed that the diseases interacted significantly (Leffler et al., 2007). In a case study of 10 patients with celiac disease and eating disorders, researchers found four of five patients who exhibited fair to poor gluten free diet adherence did so specifically due to concern with weight gain following celiac disease diagnosis (Leffler et al., 2007). These four patients experienced weight gain following diagnosis, gaining between 15 and 40 pounds (Leffler et al., 2007).

Weight gain is a key fear of individuals with eating disorders and they will often sacrifice health to facilitate weight loss. Oftentimes the weight gain results from gluten free products being made of highly processed, unenriched flours with a lot of added sugar and fat (Lorrigio, 2010). In other words, a patient may lose weight as a result of undiagnosed celiac disease because of gastrointestinal problems and malabsorption of nutrients (Celiac Disease Foundation, n.d.). Therefore, weight gain on a gluten free diet may indicate that the body is, once again, absorbing key nutrients, however, may be considered a reason not follow an eating plan by a person with an eating disorder. Adolescents with celiac disease and eating disorders have reported that they have intentionally consumed gluten to facilitate weight loss (Leffler et al., 2007). It is believed that adults with celiac disease may be doing the same thing to lose weight (Leffler et al., 2007).
The intentional consumption of gluten is similar to the idea of insulin omission to facilitate weight loss in the comorbidity of diabetes and celiac disease (Criego, Crow, Goebel-Fabbri, Kendall, & Parkin, 2009; Smith, 2008). Similarly, another case report confirmed that the symptoms overlap and interact (Yucel et al., 2006). Ultimately, the cause and effect relationships between Anorexia Nervosa and celiac disease are unclear, and celiac disease may lead to confusion in the differential diagnosis of Anorexia Nervosa (Yucel et al., 2006).

Another consideration with celiac disease and eating disorders is cultural factors. Specifically, the highest proportion of individuals with eating disorders is Caucasian women (Stark, 1999). Similarly, high risk genes for celiac disease tend to be more prevalent in Caucasians who are of northern European descent ("Celiac disease - sprue," 2010; Lewey & Ford, 2007). It is important to note, too, that in addition to eating disorders, women are also more likely than men to have celiac disease ("Celiac disease - sprue," 2010; Costin, 2007).

**Learning from Other Comorbid Disorders: Eating Disorders and Diabetes**

The literature regarding eating disorders and celiac disease is limited; therefore, it may be beneficial to consider a similar comorbid disorder. One particular dual diagnosis to note is eating disorders and diabetes mellitus, or more commonly called, diabetes. Diabetes, like celiac disease, is an autoimmune disease characterized by high blood glucose levels. The high levels of glucose result from defects in the body’s ability to produce or use insulin. There are several types of diabetes: type 1 diabetes, type 2 diabetes and gestational diabetes. (American Diabetes Association, 2011). Type 1 diabetes is more commonly associated with the development of eating disorders. Type 1 diabetes is where the body’s immune system attacks the beta cells and prevents the production of insulin (Juvenile Diabetes Research Foundation International, 2011). Individuals must take insulin multiple times, by injection or a pump, to survive (Juvenile
It is likely that type 1 diabetes is more commonly associated with eating disorders due to the increased focus on weight management and the ongoing need to manage intake (Price, 2004).

There are 25.8 million people in the United States that have diabetes (American Diabetes Association, 2011). As many as 10% of girls with type 1 diabetes in their mid teens meet criteria for an eating disorder while 14% of girls demonstrate disturbed eating behaviors which could develop into an eating disorder given stressful environmental factors (Jancin, 2008). Bulimia and EDNOS are more commonly associated with type 1 diabetes (Juvenile Diabetes Research Foundation International, 2011). Research has found that individuals with diabetes had a significantly higher incidence of bingeing and compensatory behavior with a high level meeting psychopathological criteria for eating disorder (Smith, Latchford, Hall, & Dickson, 2008). It is clear in research that the diagnosis on diabetes often precedes the development of an eating disorder (Price, 2004).

Misuse of insulin was common in individuals with diabetes and eating disorders. Individuals may fail to take insulin, causing their blood sugar levels to increase. The increase in blood sugar causes the kidneys to work continuously to purge excess sugar from the bloodstream – resulting in rapid weight loss (Juvenile Diabetes Research Foundation International, 2011). The idiom used to describe this is “diabulimia” (Criego et al., 2009; Juvenile Diabetes Research Foundation International, 2011). There are several risks associated with insulin omission. Short term effects are dehydration, fatigue, and breakdown of muscle tissue, while long term effects include early onset of blindness, kidney disease, and heart disease (Juvenile Diabetes Research Foundation International, 2011). One study found that as many as 30% of adolescent type 1 individuals reported that they skipped or restricted insulin in order to lose weight (Juvenile
Diabetes Research Foundation International, 2011). While weight loss may be the reason for insulin omission, it is important to note that insulin omission can also result from distress of psychological symptoms or fear of hypoglycemia (Criege et al., 2009). Weight management is important to diabetes and initiation of insulin therapy may cause weight gain; in predisposed adolescent females the weight gain may trigger the onset of eating disorders (Price, 2004). Similarly, the increased focus on dietary regulation with the restraint of carbohydrates and weight management emphasized by caregivers and medical authorities may be contributing factors to the development of eating disorders in this population (Price, 2004; Smith et al., 2008). These factors are in addition to societal pressures for weight management that already exist (Smith et al., 2008).

Like diabetes, celiac disease is an autoimmune disease. There is an increased focus on dietary regulation with both diseases: diabetes is focused on dietary regulation due to insulin levels resulting from carbohydrate intake, while celiac disease requires strict adherence to a gluten free diet. This increased focus on dietary compliance may contribute to the development of eating disorders. Also, just as there is insulin omission with diabetes and eating disorders in order to facilitate weight loss, there is also intentional gluten consumption with individuals with celiac disease and eating disorders.

**Conceptual Framework**

**Biopsychosocial Model**

Systems theory focuses on the interaction of the client with the systems in his or her environment. The concept of the system is that the there are relationships with objects and their attributes. Problems of the client are not seen as property of the individual, but rather, as a
description of their interactions. (Rodway, 1986) A part of the systems theory is the biopsychosocial model (Adler, 2009).

The biopsychosocial model directs practitioners to simultaneously look at the biological, psychological and social systems (Frankel, Quill, & McDaniel, 2003). The model was developed by Engel (1997) who argued that mental disorders, like medical conditions, emerge in individuals who are part of a whole system – including the biological, psychological, and sociological systems. This model asks that practitioners to have a working knowledge of the basic principles of each system, but, not be experts. Essentially, the model draws practitioners to look at additional layers of what may be happening for the client. The relationship of the biological, psychological and social levels of the individual affect the process and outcomes of care. The biopsychosocial model has been integrated into psychiatry, social work, psychology and other professions within the past 20 years. This model has the intention of integrating physical and psychological treatments without undermining doctor’s diagnostic authority (Frankel et al., 2003).

The biopsychosocial model provides a lens in which celiac disease and eating disorders can be viewed comprehensively as both conditions have biological, psychological, and sociological aspects. The development of celiac disease is likely due to genetic and environmental factors that triggered the onset of the disease. The development of eating disorders may be due to a multitude of reasons including psychological, social, environmental, and genetic. Thus, this multifaceted approach emphasizes that there are genetic, neural, behavioral, familial, and social factors that are considered to be part of both conditions and allows for a myriad of ways that they might influence one another.
Crisis Theory

Crisis theory provides framework for examining stressful times and guidelines for interventions (Golan, 1986). The theory is rooted in psychodynamic personality theory, stress theory and learning theory with extended reach to systems theory, role theory, and gratifications theory.

Crisis theory operates under the framework that that individuals have periods of external and internal stress during their lifespan which interfere with their homeostasis. There may be one major event – called a ‘hazardous event,’ or an internal pressure that has built up overtime. The impact of the hazardous event puts the individual into a vulnerable state that is evidenced by increased anxiety. As a way of coping with the triggering event and heightened anxiety, the individual attempts to regain equilibrium through the already learned coping mechanisms, such as the disordered eating. If this does not help the individual gain a sense of peace, the tension increases (Golan, 1986). At this point, the affected person uses emergency coping mechanisms might this be active disordered eating. If these, too, fail the tension continues to rise to a peak. At this point, a precipitating factor may bring a release of tension, however, if this does not happen, the individual is in a state of active crisis, which could be a severe health response. Active crisis is marked by disorganization, followed by a period of reorganization where the individual creates a new state of equilibrium (Golan, 1986). As the situation develops, the individual may face threats. The threat can be met with a loss of needs or sense of autonomy, person, status or capacity or it can be met as a challenge to survive, grow and master. Each of these brings forth an emotional reaction that reflects the subjective meaning of the event to the individual, for example, loss may bring forth a sense of depression while challenges may kindle hope and expectation (Golan, 1986).
The crisis may be linked to an earlier experience that the individual has had. That experience could either be unresolved or partially unresolved which brings forth an exaggerated response. The time of crisis resolution varies widely, depending on the severity of the hazardous event, the temperament of the individual, and the available supports. According to Golan (1986), each crisis seems to follow a specific sequence and the person can be fixated at one particular point. As the crisis starts to resolve, the individual becomes more open to help because they have realized that their previous coping mechanisms were ineffective. Defense mechanisms are weakened and the ego is more open to outside influence and change. New ego sets may emerge as the crisis resolves which enables the individual to cope more effectively with future situations. If appropriate support is not available during the crisis, inadequate and/or maladaptive patterns may be adopted. The result of this is a weakened functionality (Golan, 1986).

The onset of an eating disorder can be viewed through the lens of the crisis theory. An eating disorder can be triggered by one hazardous event, for example, a coach telling a young girl that she needs to consider going on a diet to improve her athletic performance. Or, there can be internal pressure building overtime, like continuous body dissatisfaction, problems within the family, bullying due to weight concerns or dieting due to societal pressures to achieve a certain standard of beauty. If these events come to a full crisis and the individual does not receive adequate support, the individual may develop maladaptive patterns, like restricting food intake, binging or purging. Then, an eating disorder may develop and there is weakened functionality.

Within the eating disorder, too, there are various stages of crisis. Perhaps a crisis develops the first time an individual experiences a major physical side effect of the eating disorder. A first time side effect can be many things, including thinning hair, dizziness, abnormal lab results, passing out or an abnormal electrocardiogram. Or, a crisis develops the first time a
friend, parent or mentor notices the eating disorder as possibly interfering with the individual’s
day-to-day life. Once that crisis is resolved, the individual may be more open to change. Or, the
individual may experience another hazardous event. Oftentimes with eating disorders, the
hazardous events become more frequent and more severe as the disorder progresses. Also, there
may be times of improvement and times of set back (Costin, 2007).

**Research Question**

There is a lack of research that considers the interactions of celiac disease and eating
disorders. No research studies look at the client’s experience or what appropriate treatment
would be for these co-occurring conditions. The few research studies that have studied celiac
disease and eating disorders have stated that clinicians must be aware of both diagnoses to
properly treat the patient (Leffler et al., 2007; Yucel et al., 2006). Yet, no research studies have
looked extensively at the client’s experience of having celiac disease and eating disorders.
Therefore, the research questions are: 1) What does the development of eating disorders and
celiac disease look like for individuals, 2) How do individuals perceive the interaction between
the two disorders, and 3) What do individuals with the co-occurring disorders think would be
beneficial in treating these comorbid diseases?

**Methodology**

**Research Design**

The purpose of the research was to explore the development of eating disorders and
celiac disease, how individuals perceive the interaction between the two disorders, and what
individuals with the co-occurring disorders think would be beneficial in treating these co-morbid
diseases. This was a qualitative study involving interviews with individuals who have been
diagnosed with celiac disease and eating disorders. Through structured interviews, the goal was
to gain better insight into the respondent’s perspective and experience of having celiac disease and eating disorders and their perspectives on what is beneficial in treatment of each, and what may have worked in treating both. It was therefore, the hope of the researcher that the findings of this study would serve as a starting point for more specialized treatment of the comorbid disorders.

**Population and Sample**

The purpose of this study necessitates that individuals be diagnosed with celiac disease and an eating disorder. Agencies in the Twin Cities, Minnesota metropolitan area agreed to post recruitment flyers about the study. The agencies included eating disorder treatment facilities and support groups as well as celiac disease treatment support groups. Recruitment also took place by posting information online using Facebook on special interest groups for eating disorders, gluten free products and websites, as well as celiac disease interest groups. A celiac disease list serve was also used to recruit for the study.

The researcher interviewed nine individuals; one interview was removed from the study because the interviewee exhibited mild symptoms of dieting behavior and had not been diagnosed with an eating disorder. The interviewee did not consider herself to have an eating disorder. The sample was a convenience sample consisting of people who inquired about the study through the flyers either posted or passed out. Two individuals contacted the researcher through a friend who told them about the study.

**Protection of Human Subjects**

This research was entirely voluntary and the study did not proceed until the researcher obtained the approval of the University of Saint Thomas Institutional Review Board. Participants were required to read and sign an informed consent form (Please see Appendix B). Consent was
given upon the respondents’ understanding that participation would not affect their current treatment of their celiac disease or eating disorder. Additionally, participants were informed that their participation was confidential and any identifying characteristics were omitted from the final paper. Consent forms, interview audio files and transcribed interviews were kept on a password protected hard drive, only accessible to the researcher. The documents will be destroyed upon the completion of this study on July 1, 2012.

There was no known physical, social, or economic risks to the participants. There was risk of psychological harm in that the interview had the potential of bringing up the sensitive topic of having comorbid conditions. There may have been transitory feelings of stress in recollecting experiences of having eating disorders and celiac disease. Research respondents were provided with a crisis counseling phone number in the case that they experience feelings of stress in their recollections. Also, there was a listing provided of local support groups for individuals struggling with eating disorders. The interviewees were compensated with a gluten free care package and a $10 Target gift card.

Agencies that agreed to allow the research to take place in their agency will receive a Portable Document File (PDF) of this research to inform clinicians of the findings. If desired, the researcher can write a shortened version of the study for clinicians at the agency. Also, by allowing this research at an agency, the agency is furthering the knowledge of the comorbid conditions.

Data Collection

The research instrument used was a multi question interview (See ‘Research Questions’ Appendix A). Interviews were semi-structured and based on a series of questions developed by the researcher. The questions were a combination of closed and open-ended questions and
focused on past and present experiences of having celiac disease and an eating disorder. Interviews took place in a private room or via a phone line. The interviews lasted approximately 60 minutes. The interviews were audio taped and transcribed.

The researcher conducted a literature review prior to creating the multi question interview in order to gain better understanding of eating disorders, celiac disease, and the comorbidity of celiac disease and eating disorders. By examining the literature, the researcher used the information as a foundation for formulating interview questions. Also, the questions were vetted by two experts of eating disorders and the comorbid diseases.

The interview consisted of descriptive questions (i.e. age, gender, race, age of diagnoses), questions regarding the individual’s celiac disease diagnosis and treatment, questions regarding the development, diagnosis and treatment of the individual’s eating disorder and celiac disease, treatment of the comorbid conditions, and interaction of the comorbid conditions. Although the researcher had prepared questions for the interviews, the semi-structured interview format allowed the researcher to ask follow up questions, as appropriate, in order to gain greater depth and insight. Also, the questions were reworded when a participant did not directly answer the question.

Data Analysis

In order to analyze the data obtained through the interview, data reduction and content analysis were done. The researcher used the grounded theory technique, which is an interpretative approach of analysis through line-by-line analysis of the transcribed interviews, the researcher established words and content that emerged into greater themes. This is an inductive approach of analysis (Berg, 2009). The researcher approached the field with no pre-established coding schemes, but was sensitized by the literature. Coding categories were developed as they
emerged from the interview. The researcher went through transcripts twice once the coding scheme was established in order to increase reliability of coding.

**Findings**

There are eight interviewees included in this study. All eight of these individuals were females and considered themselves to be Caucasian, one individual reported that they were Caucasian and American Indian. Interviewees ranged in age between 21 and 43 with seven individuals between the ages of 21 and 30. Three participants were from Minnesota and there was one participant from each of these states: Wisconsin, Iowa, Washington, Pennsylvania and Texas (a summary of the findings are provided in the table on page 24).

**Onset of Celiac Disease and Eating Disorders**

The first theme found was that there were several similarities in regards to the age and time of the development of each disorder. All interviewees reported that their eating disorders developed prior to a celiac disease diagnosis. Interviewees reported the onset of their eating disorder to be primarily in their teenage years, ages 12 to 19, one exception being an interviewee who reported symptoms of her eating disorder as early as four years of age and stated that her eating disorder was fully present by age ten. Interviewees had been diagnosed with celiac disease between ages 18 to 28. All individuals in this study developed the eating disorder prior to their celiac disease diagnosis.

While they were not yet diagnosed with celiac disease, all interviewees stated that as they look back at their lives and could see how their celiac disease impacted their health throughout their life, stating: “It’s [the celiac disease] one of those things, honestly, that I think has been there forever” and, when asked how long the interviewee had celiac disease before diagnosis, stated, “Well, my whole life,” but had only sought a diagnosis for four years. Two interviewees
<table>
<thead>
<tr>
<th>CD Diagnosis</th>
<th>Ethnicity</th>
<th>Age</th>
<th>Age of CD Onset</th>
<th>Age of ED Onset</th>
<th>Age of ED Diag.</th>
<th>ED Diagnosis</th>
<th>Symptoms of ED</th>
<th>Treatment for ED*</th>
<th>Comorbid Conditions</th>
<th>Sequence of Diagnosis</th>
<th>Condition of ED at Interview</th>
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</thead>
<tbody>
<tr>
<td>1 Skin Test, Endoscopy</td>
<td>White</td>
<td>23</td>
<td>18</td>
<td>3</td>
<td>22</td>
<td>Anorexia</td>
<td>Restrict Intake</td>
<td>OP, IOP, IDP, IP, RES</td>
<td>OCD, Anxiety</td>
<td>ED --&gt; CD</td>
<td>Currently seeing dietitian, physician, therapist. Continued symptoms of eating disorder. ED fully present.</td>
</tr>
<tr>
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<td>White</td>
<td>21</td>
<td>18</td>
<td>17</td>
<td>20</td>
<td>EDNOS, Anorexic Tendencies</td>
<td>Restrict Intake, Binge</td>
<td>OP</td>
<td>Depression, Anxiety, Recurring Acid Reflux Problems, Lactose Intolerant, Vegetarian</td>
<td>ED --&gt; CD</td>
<td>Currently seeing dietitian, physician, therapist. Working toward recovery from ED.</td>
</tr>
<tr>
<td>3 Blood Test, Endoscopy</td>
<td>White</td>
<td>28</td>
<td>28</td>
<td>19</td>
<td>22</td>
<td>Anorexia</td>
<td>Restrict Intake, Overexercise</td>
<td>OP, IOP, IDP, IP, RES</td>
<td>No Conditions Reported</td>
<td>ED --&gt; CD</td>
<td>Currently seeing dietitian, physician, therapist. Working toward recovery from ED.</td>
</tr>
<tr>
<td>5 Blood Test</td>
<td>White</td>
<td>30</td>
<td>28</td>
<td>12</td>
<td>16</td>
<td>Anorexia, Bulimia</td>
<td>Restrict Intake, Binge, Purge</td>
<td>OP</td>
<td>Other Significant Allergies</td>
<td>ED --&gt; CD</td>
<td>Currently seeing dietitian, physician, therapist. Continued symptoms of eating disorder.</td>
</tr>
<tr>
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<td>Native American/White</td>
<td>27</td>
<td>26</td>
<td>15</td>
<td>21</td>
<td>Anorexia</td>
<td>Restrict Intake, Overexercise</td>
<td>NONE</td>
<td>Gall Bladder Problems, Bipolar Disorder</td>
<td>ED --&gt; CD</td>
<td>Currently seeing physician. ED is not prevalent, however, present in concern with weight.</td>
</tr>
<tr>
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<td>White</td>
<td>26</td>
<td>18</td>
<td>16</td>
<td>18</td>
<td>EDNOS, Anorexic Tendencies</td>
<td>Restrict Intake</td>
<td>One OP Appt</td>
<td>Anxiety</td>
<td>ED --&gt; CD</td>
<td>ED in remission.</td>
</tr>
<tr>
<td>8 Blood Test</td>
<td>White</td>
<td>26</td>
<td>22</td>
<td>17</td>
<td>20</td>
<td>EDNOS, Anorexic Tendencies</td>
<td>Restrict Intake, Overexercise</td>
<td>OP</td>
<td>Other physical problems with no diagnosis yet.</td>
<td>ED --&gt; CD</td>
<td>Currently seeing physician. ED is present in overexercising and restrictive tendencies.</td>
</tr>
</tbody>
</table>

* OP: Outpatient; IOP: Intensive Outpatient; IDP: Intensive Day Program; IP: Inpatient Treatment; RES: Residential Treatment
** ED: Eating Disorder; CD: Celiac Disease
All participants are female.
reported that their celiac disease symptoms were present during childhood, absent during adolescence and returned in young adulthood stating,

*Interestingly, it [the celiac disease] sorta went through this honeymoon stage. A lot of academic research has shown that there tends to be a period in puberty or the high school years that the symptoms [of celiac disease] would wax and wane. Mine did just that.*

Ultimately, individuals in this study felt as if they could look back and see that there were celiac disease symptoms throughout their lifespan, even prior to diagnosis of their celiac disease.

Individuals in this study reported that their eating disorder preceded their celiac disease diagnosis. This was the case though interviewees felt that they can look back at their life and see that there were symptoms of their celiac disease throughout their lifespan.

**Participants’ Development of Eating Disorders**

Each individual’s development of their eating disorder was unique. The common theme between all participants was that their eating disorder developed due to a stressful situation. Stressful situations were attributed to difficult relationships with parents, roommates and boyfriends. For example,

*As a teenager, life is not always perfect... It was a combination of having a difficult challenging time with my mother and step father combined with my boy friend at the time, we argued a lot, and it was something for me to control when I could not control anything else.*

Also, individuals discussed stressful situations that included being teased about weight and recognizing weight gain associated with puberty.
I was getting on the scale and realized that I had gained some weight. It was normal thing - I was going through puberty... I was getting a little bit of hips or something or whatever. I immediately freaked out and started cutting down my calories down to 600 calories a day.

Two individuals stated directly that there was a family history of eating disorders which attributed to the development of their eating disorder, stating, “There wasn’t really a before [my eating disorder] because I grew up in a very restrictive food environment. So, it wasn’t specifically my own eating disorder, it was my mom’s. Or, it was food rules at my house.” And another stated, “I don’t think it [the celiac disease] caused it [the eating disorder]. It’s been a family history thing with eating disorders.” The development of eating disorders is unique, however, the themes that presented was stressful situations. The stressful situations were interpersonal relationships, comments about weight and family history of eating disorders.

As interviewees discussed the development of their eating disorder, they also discussed their treatment history. Two individuals stated that they did not receive ongoing treatment for their eating disorder. One had gone to just one dietitian appointment and another stated that they never sought treatment for their eating disorder. Six participants of the eight received some type of ongoing treatment for their eating disorder at one point. All six had done outpatient clinic appointments at some point while three individuals received intensive programming, including inpatient treatment, intensive outpatient programs and intensive day programs. Two of these three individuals were also in residential treatment for six months or more for their eating disorder at least one time. One individual who participated in outpatient clinic visits also participated in group therapy at one point. Summing this up, people received different types of treatment, which may be due to different types of eating disorders and severity, but it also may
be due to chance. It became evident in the interviews that the level of treatment is not necessarily based on need, but what treatment was available to the individual, such as insurance coverage or availability of specialized treatment of the eating disorder. Also, what the individual is willing to undergo was also a factor (A summary of the participants’ level of treatment is provided in the table on page 24).

Interviewees that received treatment for their eating disorder stated that the length of time between the onset of their eating disorder and the time they were diagnosed and receiving treatment as between one and twelve years. In regards to those who sought treatment, with the exception of one individual, the majority of the participants were between one and four years between the onset of their eating disorder symptoms and the time that they were diagnosed with an eating disorder. Some interviewees reported that their symptoms were somewhat suppressed while living in their parents’ home, stating, “It was kinda hard cause living at home I couldn’t really exercise too much. I did it in secrecy, because my parents started getting on my case because of my eating.” Every participant stated that their eating disorder progressed to full-blown symptoms during their college years. In the end, the length of time between onset of eating disorder symptoms and being diagnosed and receiving help varied between each person. The common theme was that all participants experienced full-blown symptoms during college. Full-blown symptoms were different for each person, but each indicated that their symptoms were at an extreme point during their college years. This may be due to the participants feeling that their symptoms had to be somewhat repressed while living in their parents’ home.

Another theme that emerged from the data is that the majority of interviewees exhibited restrictive eating behaviors. Five interviewees were diagnosed with anorexia at one point in their history; two of these interviewees also had some symptoms of bulimia throughout their history.
The remaining three individuals were diagnosed with EDNOS and all exhibited restrictive tendencies, yet, did not meet the weight or body dysmorphia requirements for anorexia. It is significant to note that all individuals exhibited restrictive food tendencies regardless of their eating disorder diagnoses.

Five of the eight participants discussed their family and friends’ role in whether or not they obtained treatment for their eating disorder. One interviewee stated that her parents had her hospitalized at age 14,

*I did it in secrecy because my parents started getting on my case because of my eating. I was rebellious and just wouldn’t eat as much as they wanted me to. After I lost 20 pounds they said, “This is it. We can’t put up with this anymore.”*  So they had me hospitalized.

Another person stated, “*I saw a dietitian because my mom was worried that I wasn’t eating enough.*” While some parents helped in their child’s eating disorder, others deterred their child from getting treatment, for example: “*My mom didn’t really recognize it when I told her, ‘Mom, I think I have a problem.’ She was, like, ‘I think this is just a phase.’ So, I never really recognized it until I got to college.*” This same interviewee went on to say, “*My mom was kinda resistant to treatment centers and things like that. She had treatment for bulimia in the [19]80’s.*” Lastly, an individual stated, “*My boyfriend at the time and one of my college roommates, who is still one of my best friends, eventually confronted me about it [the eating disorder].*” Parents and friends played a significant role in whether someone sought treatment for their eating disorder and in the timing of their treatment.

Each person’s development of their eating disorder was unique, however, each individual experienced stressful situations to trigger their eating disorder. All individuals exhibited restrictive food tendencies regardless of their eating disorder diagnosis. All participants
experienced full blown symptoms during college, which may have been due to feelings that their symptoms had to be somewhat repressed while living in their parents’ home. All individuals experienced their own journey in treatment of their eating disorder based on their individual needs. Lastly, parents and friends played a significant role in whether someone sought treatment for their eating disorder. Also, they played a role in the timing of their treatment.

**Participants’ Development of Celiac Disease**

Participants in the study discussed their symptoms of celiac disease prior to diagnosis. Participants stated that they experienced symptoms such as fatigue, bloating, nausea, constipation, diarrhea, brain fog, rash, abdominal pains and cramping, severe joint pain, hair loss, weight gain, anemia and mouth sores. The most common recurring symptoms between participants were constipation, diarrhea and bloating.

All individuals stated that they had been to a doctor to confirm their diagnosis of celiac disease. Two individuals experienced mixed results from blood work, one individual had already started a gluten free diet prior to the blood test, and another went on to get a biopsy, which confirmed diagnosis. One individual experienced an inconclusive endoscopy, likely due to already being on a gluten free diet. The two individuals who adhered to a gluten free diet prior to diagnosis stated that they were not informed that they had to be eating gluten for the tests to be accurate. Both were asked to go back onto a gluten diet for tests and were unable to go back to the gluten diet due to extreme symptoms. The reaction to a gluten free diet was so strong that each doctor confirmed the diagnosis of celiac disease. Seven individuals were tested for celiac disease via blood work while three had blood work and an endoscopy. One individual only had an endoscopy and no blood work. Ultimately, the path to celiac disease diagnosis can be different and it is difficult to diagnose once an individual is on a gluten free diet.
The process of diagnosis for individuals with celiac disease can be long. Seven participants discussed the length of time they actively sought a diagnosis for their celiac disease symptoms. Three interviewees stated that they actively sought a diagnosis for their symptoms for two years. Two participants stated that they actively sought a diagnosis for less than a year. Two other participants stated they sought a diagnosis for four years and another stated they actively sought a diagnosis for ten years. In conclusion, interviewees experienced a lengthy process in regards to diagnosis.

A theme that emerged when discussing the development of celiac disease was the positive reaction to the gluten free diet. Though not explicitly asked about their reaction to a gluten free diet, seven individuals stated that they experienced a positive reaction. They stated: “I researched it and went ahead did the gluten free diet anyway and I felt so much better, it was insane, it was crazy.” “I feel about ten times better.” “Two weeks off of gluten, I’ve been pain free ever since.” In the end, interviewees experienced positive reactions to a gluten free diet.

Interviewees were asked to provide a number from 1 to 10 regarding their celiac disease dietary compliance. One meant that the participants don’t comply at all with their gluten free diet, five was, “Oh well, if I get gluten, it’s okay, I’ll just deal with it,” and ten meant, “If I can help it, I never have gluten in my diet.” Every interviewee stated that they were a ten – if they can help it, they never have gluten in their diet. There were only two of the eight participants who stated that they had ever intentionally eaten gluten. One was newly diagnosed and stated, 

One night I had a couple Christmas cookies, probably like two. I noticed that I did have symptom stuff from that. But, ever since then I’ve been really really careful. I didn’t know that I would be that sensitive, but, I guess I am.
Another stated, that she did intentionally eat gluten once when she was drinking alcohol and stated “it was definitely because I was drinking... I was hungry and there were no other options.”

Ultimately, all participants exhibited strong adherence to their gluten free diet.

The most common recurring celiac disease symptoms between participants were constipation, diarrhea and bloating. The interviews showed that the path to celiac disease diagnosis can be different and lengthy for each person and it is difficult to diagnose once an individual is on a gluten free diet. There was a positive reaction to a gluten free diet and all participants exhibited strong adherence to their gluten free diet.

The Cause and Effect Relationship between the Diseases

The majority of interviewees stated that they feel that their celiac disease contributed to the development of their eating disorder. One person stated,

*I think the pain was just the pain. I didn’t know what it was... Well, if I just don’t eat, then, I’ll be okay. So, I definitely feel like it probably contributed more than I was aware of at the time. Now that I kind of look back, I wonder if that was kinda why I was restricting that much. I’m not putting it all on the celiac or anything, but, I think it probably contributed to my general lack of appetite and desire to eat.*

And another individual reported:

*I think it [the celiac disease] was the underlying cause of it [the eating disorder]. I think it was because I wasn’t wanting instinctively – intuitively – my body wasn’t wanting to eat the carbs and what not. It turned my preoccupation into not wanting to eat and it just escalated into a full-blown eating disorder... I think that if I had not had celiac disease, I would not developed the eating disorder.*
Two participants looked back and attributed the beginning of their eating disorder to the beginning of their celiac disease symptoms, one of them stated:

*The eating disorder or disorder eating habits started my senior year in high school. It was around that same time that my celiac symptoms became very profound. And so it was almost became like dealing with two things going on at the same time.*

In the end, it may be difficult to know whether celiac disease was the underlying cause of the eating disorder, however, it is evident in these participants that they felt that their celiac disease, through experiencing pain or discomfort when eating, played a role in the development of their eating disorder.

Every participant stated that they had experienced increased symptoms of their eating disorder due to their celiac disease. Three individuals explicitly stated that their celiac disease made it more “convenient” to continue in their eating disorder symptoms because they could easily make excuses not to eat. For example:

*My celiac disease made it very convenient for my eating disorder to be active. I would just say, “I can’t eat this” and use it as an excuse to not eat something, when there were times I could probably eat it.*

Others alluded to the idea that, if there were no gluten free options available, they would be more likely to restrict their intake. Still others stated that, when they experienced cross-contamination, they would get ill and have a hard time eating afterward. For example, “If I would eat something that would make me have a reaction – the bloating from it and the rash tends to get me back into trying to avoid that reaction.” And another stated, “I have to be careful with the anxiety if I do have an accidental exposure, I start feeling really guilty and I will start controlling things and that will push me into more symptoms.” With this information, it would be accurate to say that
individuals may experience increased symptoms of their eating disorder due to their celiac disease.

Five individuals stated that they, at times, experience decreased symptoms of their eating disorder because of their celiac disease. One individual stated, “Seeing that what I am eating has been affecting my body in a very negative way has helped in being able to maintain a healthy weight has been huge for me.” Another interviewee who reported that her eating disorder was mostly about control went on to explain that she has experienced less eating disorder symptoms after being diagnosed with celiac disease: “being diagnosed with celiac helped to control things only because the gluten free diet is not something you can avoid. It is something that you have control over every day for the rest of your life.” Another person reported, “I feel like because I don’t have any symptoms, it’s much more easy to do what I need to do. I have an appetite so I’m able to listen to that a lot better.” Others stated that they are used to packing their meals and this helps them in meal plan compliance. Ultimately, eating disorder symptoms may decrease as a result of celiac disease.

The Comorbid Diseases and Practitioner Response

As we consider the interactions of celiac disease and eating disorders, seven individuals discussed the perceived knowledge and lack of knowledge of their practitioners. Four individuals stated their doctors lacked knowledge of their celiac disease: “They are the doctor and they are supposed to have the answer, but even though they don’t really have a clue, they try to pretend like they do.” “Especially for celiac disease, it’s astounding the lack of knowledge that doctors have.” And:
My doctor hasn’t been very helpful. Not very helpful at all. She doesn’t know anything about it... Uhm, yeah, my blood test results, she didn’t know anything about it. She just kinda let me go and I had to do a lot of the research myself.

Another individual discussed their experience of their outpatient treatment,

*I went a few times to a counselor at my school. I hated it. I thought it was horrible. I felt like he didn’t take me seriously. I felt stupid just talking about it. It just wasn’t a good experience.*

A notable experience that someone shared about their practitioners’ lack of knowledge was when she was given the incorrect feeding bag for her feeding tube:

*One time I was hooked up to a feeding tube and they gave me supplements that had gluten in it. I kept telling them that “I am feeling sick, are you sure that this doesn’t have gluten in it?” They’re like, “Oh no, it’s fine, you’re just afraid of the calories in the supplement, it’s in your head.” And they kept telling me that. I felt that I wasn’t being believed. Finally, after some major events went down that very hurtful to me, the celiac dietitian looked at the supplement and said, “Yes, there is gluten in it.” And, so then they finally believed me and switched formulas on me. Then I was okay, but, I had to really get sick before they believed me.*

Three individuals stated that they had good experiences with their doctors and practitioners. The similarities between these individuals were that they had received specialized treatment for their eating disorder. They stated: *“The eating disorder professionals have been great... like my therapist and nutritionist didn’t necessarily know everything about it the first time I saw them, but, by the next time I saw them, they had done some research.”* And *“Staff was really understanding.”* Lastly, *“The doctors were very skilled and very well known in the field.”*
Individuals who experienced their practitioners as not having knowledge of their diseases had this experience primarily with their celiac disease. Interviewees who had a different experience and felt supported in both diseases also received specialized treatment for their eating disorders.

**The Comorbid Diseases and the Gluten Free Diet**

A theme that emerged from the data was that individuals were concerned with the caloric density of the gluten free products that are available. Three individuals discussed this, stating:

> It’s really challenging because things that are gluten free generally have more fat than things that are not gluten free. And baking gluten free is a lot harder to bake, like, fat free. So, it’s hard because there really aren’t diet foods that are gluten free.

And “The breads usually contain more fats and stuff. So, there’s definitely a mental adjustment to like, okay, a grain is a grain despite that.” Lastly, one interviewee stated that it would be helpful to

> ...look at the gluten free food as regular food because a lot of our gluten foods are more calorie dense and have a lot more calories than the regular. And so, kinda to look at a slice of bread as a slice of bread rather than as more calories.

The similarity between these individuals was that those who mentioned the caloric density of foods had been chronically in and out of treatment programs in higher levels of care, including inpatient and residential programs. The nutrition density of gluten free foods may be a difficult adjustment for individuals who have celiac disease and eating disorders.

Many of the interviewees stated that their celiac disease makes them more cautious. This caution affects their eating disorder. For example, one person reported, “I’m cautious anyway with everything I eat. So when you’re adding another illness, it just makes me more hyper vigilant.” Another person stated,
I have to be careful with the anxiety if I do have an accidental exposure. I start feeling really guilty and I will start controlling things. And that will push me into more symptoms. I just have to be extra conscious.

Still another stated, “I have to be careful with what I eat... It affects my daily life for sure because I am very careful that I don’t potentially eat gluten.” And another stated,

You are automatically watching everything you are putting in your body. You start to think twice. Not just is there gluten in this? But, it’s like, wow, what’s the fat content? Is this a vegetable? Is this fruit? Is this meat? Is this dairy? Is this grain? How many calories? How much sugar? Fiber? You start to analyze it a little bit more than the average person would who doesn’t have a tendency toward disordered eating.

The two diseases interact in multiple ways; in this instance interviewees stated that they are careful and hyper-vigilant.

It may be difficult to know whether celiac disease was the underlying cause of the eating disorder, however, it is evident in these participants that they felt that their celiac disease played a role in the development of their eating disorder and possibly in the maintenance of the eating disorder. Individuals who experienced their practitioners as not having knowledge of their diseases had this experience primarily with their celiac disease. Interviewees who had a different experience and felt supported in both diseases also received specialized treatment for their eating disorders.

The nutrition density of gluten free foods may be a difficult adjustment for individuals who have celiac disease and eating disorders because gluten free foods are typically higher in fats and sugars. Another adjustment is the need to be careful about intake, because individuals with eating disorders are already conscious about their intake; however, they need to turn their
attention even more to getting in the proper foods that are gluten free. Interestingly, individuals may experience increased or decreased symptoms of their eating disorder due to their celiac disease. On the one hand celiac disease and the gluten free diet may make it more convenient to restrict intake, on the other hand individuals with celiac disease may be accustomed to packing meals and controlling their diet already.

Social Interactions around Food

A significant theme that emerged from the data was the need to pack and prepare food. One participant stated, “I just usually plan on not eating if I’m going to a barbeque or something and always pack a lunch.” And, “I don’t think twice about it [bringing food along] because I’m so used to taking my food with me.” Another stated, “I pack my lunch now and I didn’t used to do that as often...” This theme came up multiple times in every interview. In summary, individuals in this study found that they needed to pack and prepare their own food.

Many of the individuals stated that they would rather pack their own food than risk accidental exposure to gluten with someone else’s food or at a restaurant. For example:

*The majority of people, even though we’ve explained things to family members – but, if you have to live it – you don’t really get it – The extent of having to have pans and cook wear and all that stuff. I don’t trust other people’s food.*

Another interviewee stated, “I would usually always know that I prefer to eat my own foods and know that it’s safe than to eat what everybody else is eating.” It is significant to note that many individuals believe that it is better to be safe than sorry when it comes to their celiac disease and gluten free diet.

Many participants stated that they feel that their celiac disease takes away the convenience of eating while they are out. They stated, “I have to really prepare what I eat. I
can’t grab and go.” Convenience and dining out were topics that most of the interviewees discussed at some point in the interview. When asked about how celiac disease affects her daily life, one person stated, “The biggest thing. I would say has been not going out to eat. If we do, it’s very very rare. We used to go out to eat.... I loved to go out to eat.” One interviewee discussed going out to eat:

I don’t want anyone to think they have to worry about me when I’m eating over or when we’re eating out together or something like that. That’s why I don’t really enjoy eating out with people anymore. Or going over to people’s house for dinner, it becomes such an anxiety-causing event for me.

Another stated,

You don’t have the convenience of going out to eat or going out with family or friends and not thinking twice about being “in charge” of the restaurant you go to. Or wondering, should I eat something before I go or should I put something in my bag to eat. I think that’s the only thing that is hard and remains hard on a daily basis. Not always, but it is there.

Ultimately, participants stated, “It’s just easier to eat at home then go out and deal with it all.”

Participants in the study stated that there is little social interaction around food. The lack of social interactions is sometimes related to fear due to the eating disorder, but, the majority of the participants stated that social interactions are limited due to their celiac disease. One interviewee explicitly stated, “that is the biggest complication – is having a social life. Because it’s just not the same.” She continues,

Especially when you are in college, everyone wants to eat pizza and junk food and as a celiac – you can’t eat pizza and junk food. Well, you can – as long as its gluten free pizza
and junk food – but if you are going to school in a small town, let’s be real, gluten free food isn’t cheap. And in college, that’s what people eat is cheap food. So it really hinders that.

Another states that she would prefer to “do other things socially rather than eating.” And “eating has become much less of a social activity for me.” And another, “there isn’t a lot of social interaction around food and, if there is, I keep it to a minimum.” Individuals in this study found that their social interaction around food is minimal.

With having restrictive food tendencies, some individuals discussed their friends and family questioning their celiac disease diagnosis and gluten free diet, for example:

*The longer I’ve known people who were around me when I was going through a hard time, they are more apt to make comments, not negatively, but, I guess they are the ones who think that I am little bit more extreme when it comes to eating and different health life styles.*

Another individual stated, “I’ve had a couple people comment on it – one being my brother and saying, ‘this is just another one of your things.’ And I’m like, ‘no not really, I’m medically diagnosed.’” And another stated that it took a long time for her family to accept that it was a medical diagnosis and not a fad diet. Eating disorder treatment centers also have to question whether or not the eating disordered individual is truly diagnosed, one individual stated that something that has not been helpful,

*has been the people who say they are gluten intolerant and, then, eat gluten. Because, then, it gives, especially in residential [treatment], can give off, kinda the sense of that’s how all of us are... There is a difference between being [gluten] intolerant and having celiac. So, that was a challenge. And also, having to say to providers “No, I have celiac*
disease, this is not my eating disorder...” They are like, “We need to see those labs.”

And I’m, like, I have those labs somewhere, but I was 18 when I got those drawn and my mom was still keeping track of all of my medical records. She couldn’t find them when I asked her to look for them.

After exhibiting patterns of disordered eating, many individuals stated that family, friends and treatment centers may question their gluten free diet and celiac disease.

Individuals in this study found that they needed to pack and prepare their own food, likely because they believe that it is better to be safe than sorry when it comes to their celiac disease and their gluten free diet. Individuals in this study stated that their social interaction around food is minimal. This may be problematic when considering the eating disorder because social interaction around food is often helpful in working toward recovery from the eating disorder. After exhibiting patterns of disordered eating, many individuals reported that family, friends and treatment centers questioned their gluten free diet. After many years of exhibiting disordered eating patterns, the gluten free diet may come across to family, friends and treatment centers as being part of the latest fad diet.

**Promising Treatment of Celiac Disease and Eating Disorders**

The majority of the study participants stated that it was helpful in their treatment of their eating disorder and celiac disease to have an individualized approach to their treatment. An example of individualized treatment was when other patients and therapists would taste gluten free foods with the person:

*I was really close with people at my table and they would try things when I was, like, “This is disgusting.” Just to validate me. And that was really helpful. Or, like, my therapist would try it [a lemon cookie] and she was, like, “This tastes like lemon pledge.*
This is not a cookie.” She would come and eat. She would come down to the table. So, that was helpful.

Another individual stated, “The hospital had some [gluten free foods], they had some gluten free bread and gluten free cereal, but I wanted more variety of some of the things that I would eat when I was out of the hospital.” This individual was allowed to bring some of their own foods with them to the hospital. Yet another person gave another example of individualized treatment,

With the eating disorder, it’s so much of a secret thing... when I would ask where my body was at – where my labs were at and where my weight was at – and no one would tell me. And I was like, well, how is that? This is my body and I need to know what’s going on. I think that wasn’t helpful because it freaked me out even more. It felt like they were holding something against me... but, that is something that has been an open book recently at the [residential treatment center] and that’s been very good. Cause it’s like everyone’s on the same page. Everyone is open that this is your treatment.

In the end, it was helpful for interviewees to have an individualized and personal approach to the treatment of the celiac disease and eating disorders. Also, it is important to note that there is greater awareness of celiac disease in eating disorder treatment facilities and facilities are able to better accommodate individuals with celiac disease.

**Physiological changes.** While only two individuals commented on this, it is significant to note that a couple individuals stated that it is helpful to experience hunger queues again after their celiac disease was diagnosed, one reflected,

*When I am sick, I can’t tell how hungry I am. That’s why I was binging so bad and that is kinda why I restricted because I can’t tell... for years before being diagnosed, not being at able to tell. My hunger queues are not normal.*
This individual went on to state that it is helpful to experience hunger and fullness on a gluten free diet. Another individual stated, “I feel like I get hunger queues a little bit better now because I don’t get the discomfort and pain. Since that is not there I am able to listen to my body a little bit more.” These individuals also stated that they are unable to determine their hunger queues when they experience cross-contamination. In conclusion, individuals stated that hunger queues may be difficult to determine with the co-morbid diseases.

**Social interactions.** Numerous people mentioned that it is helpful to talk with others about their eating disorder and celiac disease, saying that it is helpful “just letting them [friends] know so they can kinda support me around that.” Another stated, “So I think the more open my friends and I are, the more helpful.” Yet another stated, “my family has been supportive and I have a really supportive boyfriend and that’s helped a lot.” Participants found it beneficial that some people were willing to cook and bake gluten free items for them and help them feel less alone, but, letting others know about both diseases was helpful.

While participants say that it is helpful to talk with others about their co-morbid disorders, they do not want people to “fuss” or “worry” about their diet. One person stated that it would be helpful for, “people to not, like, be so apologetic: “Oh my god, I feel so bad that you can’t eat.” Well, I would rather not eat, then eat and get sick – and I’m still here...” Another person stated, “I don’t want anyone to think they have to worry about me when I’m eating over or when we’re eating out together or something like that.” Another worries and says, “I don’t want to appear that I’m not easy going.” Individuals do not want people to go out of their way or “worry” about their gluten free diet.

**Internet and online social networks.** When asked about what has been helpful in treating celiac disease and eating disorders, the majority stated that the internet and social
networking sites have been helpful for them as they have worked with these comorbid diseases. One person reported, “*Facebook is a really helpful tool for many things. Especially finding out how other people deal with going out to eat and, where to buy things.*” And another said, “*A lot of places now will post menus on the internet and I can look at the menu ahead of time and decide what it is I’m going to eat.*” Yet another stated that it is helpful “*having communities online, uhm, like, on twitter, I’ve been using that a lot.*” Interviewees stated that social networks are helpful for them as they worked with eating disorders and celiac disease.

**Restaurants, grocery stores and safety.** While many of the interviewees agreed that gluten free food options at grocery stores and restaurants are getting better and this helps them cope with their celiac disease, five people cited the need for restaurants to be better educated. For example, “*A lot of places are coming onto the bandwagon for gluten free food, but, not necessarily the safety part behind it. I guess [there needs to be] more awareness in the food industry.*” Another stated something that is not helpful is, *Criticism.* *When people just roll their eyes, especially servers... When they say we have this gluten free menu and what they actually have on the gluten free menu has gluten in it – that’s not helpful. Or when their staff is not knowledgeable, they have this gluten free menu and they don’t know what they have to do. Those things are not very helpful.*

While it is helpful to have more gluten free options at grocery stores and restaurants, participants would like there to be increased knowledge on behalf of restaurants and staff.

There are several things that would be beneficial in treating celiac disease and eating disorders. Individuals stated that it is helpful to let others know about both diseases, however, they do not want people to go out of their way or “worry” about their gluten free diet. Letting others know about the comorbid conditions helps in coming against the social isolation that
comes with the eating disorder and allows others to consider the individual’s needs when dining out. Interviewees stated that it is helpful to have hunger queues again after being on a gluten free diet. The physiological changes helped the individuals learn to eat when they are hungry and stop when they are full which helps in the recovery of their eating disorder. Also helpful were online social networks, increased knowledge of safety for gluten free persons at restaurants and an individualized approach to treatment.

**Discussion**

As many as 10 million Americans have a diagnosable eating disorder (National Eating Disorder Association, 2005). Additionally, at one time Celiac Disease was thought of to be rare, however, now research shows that one out of every 133 people in America has Celiac Disease (Celiac Disease Foundation, n.d.). Though there are few studies to document the extent of cases of those who have an eating disorder and Celiac Disease, the conditions assuredly coexist to some extent (Jay, 2010; Leffler et al., 2007; Yucel et al., 2006).

No research studies have looked extensively at the client’s experience of having celiac disease and eating disorders. Therefore, the research questions were: 1) What does the development of eating disorders and celiac disease look like for individuals, 2) How do individuals perceive the interaction between the two disorders, and 3) What do individuals with the co-occurring disorders think would be beneficial in treating these comorbid diseases?

**Onset of Celiac Disease and Eating Disorders**

There were several similarities in regards to the gender, race, and age of the development of the eating disorder. The literature discussed that up to 90% of eating disorders affect women and girls (American Psychological Association, 2008) and eating disorders were primarily attributed to Caucasian women (Striegel-Moore & Bulik, 2007). All of the interviewees were
Caucasian women. Similarly, it was found in the literature that high risk genes for celiac disease tend to be more prevalent in Caucasians who are of northern European descent ("Celiac disease - sprue," 2010; Lewey & Ford, 2007) and woman are more likely than men to have celiac disease ("Celiac disease - sprue," 2010; Costin, 2007).

The majority of interviewees reported the onset of their eating disorder to be primarily in their teenage years, ages 12 to 19. This is similar to what is found in the literature, which states the majority of eating disorders develop during adolescence and the early twenties (Striegel-Moore & Bulik, 2007). Ultimately, the gender, race, and age of the development of the eating disorder reflected almost precisely with what was found in the literature. Interviewees had been diagnosed with celiac disease between ages 18 to 28. All individuals in this study developed the eating disorder prior to their celiac disease diagnosis.

As the literature states, celiac disease may not become active, or symptomatic, until something initiates a celiac reaction in an already predisposed person (Dowler Shephard, 2008). Furthermore, even if a person does not have symptoms of celiac disease, the individual can still have celiac disease and there is still a risk of intestinal damage (Tessmer, 2009). While they were not yet diagnosed with celiac disease, all interviewees stated that as they look back at their lives and could see how their celiac disease impacted their health throughout their life. Individuals in this study may have experienced intestinal damage prior to their celiac disease becoming symptomatic.

**Participants’ Development of Eating Disorders**

The development of eating disorders is unique, however, all participants commented on a stressful situation that triggered the development of their eating disorder. When comparing literature on the comorbid disorders of eating disorders and diabetes, as many as 10% of girls
with type 1 diabetes in their mid teens meet criteria for an eating disorder while 14% of girls demonstrate disturbed eating behaviors which could develop into an eating disorder given stressful environmental factors (Jancin, 2008). This could also prove to be the case when considering celiac disease. When adhering to a gluten free diet, individuals may demonstrate disturbed eating behaviors, which could develop into an eating disorder given a stressful event.

As interviewees discussed the development of their eating disorder, they also discussed their treatment history. The majority of participants received some type of ongoing treatment for their eating disorder at one point. The literature states that treatment for eating disorders varies in length according to the severity of the disorder, also the level of treatment is determined based on the needs of the individual and the severity of their symptoms (Stewart, Part 1, 2004). Summing this up, people received different types of treatment, which may be due to different types of eating disorders and severity, but it also may be due to opportunity. It became evident in the interviews that the level of treatment is not only based on need, but what treatment was available to the individual, such as insurance coverage or availability of specialized treatment of the eating disorder. The willingness of the individual to proceed with treatment is also a factor.

Five of the eight participants discussed their family and friends’ role in whether or not they obtained treatment for their eating disorder. Parents and friends played a significant role in whether someone sought treatment for their eating disorder and in the timing of their treatment.

**Participants’ Development of Celiac Disease**

Participants in the study discussed their symptoms of celiac disease prior to diagnosis. The most common recurring symptoms between participants were constipation, diarrhea and bloating. All individuals stated that they had been to a doctor to confirm their diagnosis of celiac disease.
The process of diagnosis for individuals with celiac disease can be long. The literature states that the process of diagnosis can be quite difficult as celiac disease is often misdiagnosed as irritable bowel syndrome, anemia, chronic fatigue syndrome, intestinal infection, and Crohn’s disease (Dowler Shephard, 2008). Seven participants discussed the length of time they actively sought a diagnosis for their celiac disease symptoms. The majority of individuals in this study sought a diagnosis for one to ten years. Nothing in the literature discussed the average amount of time it takes to obtain a diagnosis of celiac disease, however, it is clear that the path to diagnosis is lengthy and sometimes difficult.

Upon diagnosis of celiac disease, the individual is advised to learn about gluten free diets and to start adhering to the gluten free diet immediately (Pietzak, 2005; Tessmer, 2009). As gluten is removed from the diet, the small intestine will start to heal and overall health will improve (Celiac Disease Foundation, n.d.). This was confirmed in this study in that seven individuals stated that their overall health improved and they experienced a positive reaction to a gluten free diet.

In a case study of 10 patients with celiac disease and eating disorders, researchers found five patients who exhibited fair to poor gluten free diet adherence (Leffler et al., 2007). This is different from this study. Every interviewee stated that if they can help it, they never have gluten in their diet.

In the literature, adolescents with celiac disease and eating disorders have reported that they have intentionally consumed gluten to facilitate weight loss (Leffler et al., 2007). It was believed that adults with celiac disease may do the same thing to lose weight (Leffler et al., 2007). There were only two of the eight participants who stated that they had ever intentionally eaten gluten. One was newly diagnosed and unaware of side effects of consuming gluten while
the other was intoxicated. Both denied that they consumed gluten to facilitate weight loss. This is different than what might have been thought in the literature. The intentional consumption of gluten is similar to the idea of insulin omission to facilitate weight loss in the comorbidity of diabetes and celiac disease (Criego, Crow, Goebel-Fabbri, Kendall, & Parkin, 2009; Smith, 2008). Individuals with celiac disease experience painful side effects from consuming gluten. They report being ill for two to three days following the consumption. This painful side effect may deter those with celiac disease from consuming gluten to facilitate weight loss. Insulin omission has no direct immediate side effects that cause pain to the individual even though it has dangerous side effects long term.

The Cause and Effect Relationship between the Diseases

The majority of interviewees stated that they feel that their celiac disease contributed to the development of their eating disorder. In the limited literature available, the majority of cases of individuals with these comorbid diseases showed that the diseases interacted significantly (Leffler et al., 2007) and another case report confirmed that the symptoms overlap and interact (Yucel et al., 2006). In this study every participant stated that they had experienced increased symptoms of their eating disorder due to their celiac disease, some explicitly stated that their celiac disease made it more “convenient” to continue in their eating disorder symptoms because they could easily make excuses not to eat. Some of the same individuals stated that they, at times, experience decreased symptoms of their eating disorder because of their celiac disease. These individuals stated that they are used to packing their meals and this helps them in meal plan compliance. Ultimately, symptoms overlap and interact significantly.
The Comorbid Diseases and Practitioner Response

As we consider the interactions of celiac disease and eating disorders, seven individuals discussed the perceived knowledge and lack of knowledge of their practitioners. Many individuals commented that they felt the care they received was poor and, at times, even dangerous when professionals were not knowledgeable. The literature emphasized that it is important for clinicians to have an interdisciplinary approach to management of celiac disease and eating disorders (Leffler et al., 2007). Also, the literature states that clinicians must be aware of both conditions to provide optimum care (Leffler et al., 2007).

The Comorbid Diseases and the Gluten Free Diet

A theme that emerged from the data was that individuals were concerned with the caloric density of the gluten free products that are available. Three individuals discussed this, the similarity between these individuals was that those who mentioned the caloric density of foods had been chronically in and out of treatment programs in higher levels of care, including inpatient and residential programs. The nutrition density of gluten free foods may be a difficult adjustment for individuals who have celiac disease and eating disorders. This is confirmed by the literature that is available on these co morbid conditions. Weight gain is a key fear of individuals with eating disorders and they will often sacrifice health to facilitate weight loss. Literature states that weight gain results from gluten free products being made of highly processed, unenriched flours with a lot of added sugar and fat (Lorrigio, 2010). In the literature, some individuals in the study had poor adherence to a gluten free diet specifically due to concern with weight gain following celiac disease diagnosis (Leffler et al., 2007).

Many of the interviewees stated that their celiac disease makes them more cautious. This caution affects their eating disorder. A primary characteristic of anorexia is the intense fear of
gaining weight, which causes individuals to be cautious about what they eat. The celiac disease may attribute to individuals being even more cautious because the slightest amount of gluten can make an individual very ill. In this study interviewees stated they are careful and hyper-vigilant about their diets. This may be even more intense due to having both diseases.

**Social Interactions around Food**

As many people seek support for their eating disorder, they do so by eating with others. The individuals in this study all stated that there is significant difficulty in being able to dine out at a restaurant or someone’s house. This can be difficult as the literature states that social isolation, stigma, and physiological changes that are often brought on by the eating disorder (American Psychological Association, 2008). Ultimately, the combination of the eating disorder and celiac disease make this social interaction even more difficult, which likely reinforces the eating disorder. The individual is pushed by society, not just themselves, to eat alone because restaurants are unable to accommodate and others feel that they do not have the knowledge to cook safely for the individual.

Participants in the study stated that there is little social interaction around food. The lack of social interactions is sometimes related to fear due to the eating disorder, but, the majority of the participants stated that social interactions are limited due to their celiac disease. It is possible to conclude that the fear of food that takes place with eating disorders is even more exacerbated by the celiac disease.

Numerous people mentioned that it is helpful to talk with others about their eating disorder and celiac disease with friends and family. This is a good sign for the chances of recovery for those individuals. The literature states that supportive loved ones improves chances
of full recovery (Costin, 2007). While participants say that it is helpful to talk with others about their co-morbid disorders, they do not want people to “fuss” or “worry” about their diet.

**Promising Treatment of Celiac Disease and Eating Disorders**

The majority of the study participants stated that it was helpful in their treatment of their eating disorder and celiac disease to have an individualized approach to their treatment. This focus on an individualized approach is along the same lines as what the literature states. The literature reports that the level of treatment is determined based on the needs of the individual and the severity of their symptoms (Stewart, Part 1, 2004). Individuals with these co morbid disorders may need even more individualized treatment as they have to focus on maintaining a strict gluten free diet.

**Physiological changes.** While only two individuals commented on this, it is significant to note that a couple individuals stated that it is helpful to experience hunger queues again after their celiac disease was diagnosed. This individual went on to state that it is helpful to experience hunger and fullness on a gluten free diet. Increased awareness of hunger queues may reduce symptoms of over and under eating.

**Implications for Further Research**

The findings of this research indicate that there are many considerations when treating an individual with celiac disease and eating disorders. Future research is greatly needed in this area.

Having celiac disease predisposes an individual to have an eating disorder due to the discomfort that may be experienced when eating. Perhaps earlier detection of the celiac disease may prevent the eating disorder from developing. Research is needed on earlier interventions for celiac disease and the lifelong impact of that early intervention. Similarly, all of the individuals in this study had developed their eating disorder prior to their celiac disease diagnosis. It may be
advantageous for there to be increased testing for celiac disease in eating disordered individuals who experience abdominal discomfort when eating.

In celiac disease, what does the usual dietary compliance look like? When we take into account that this study had 100% gluten free dietary compliance, researchers may benefit from knowing whether this is based on perfectionistic tendencies of those diagnosed with eating disorders or possibly all those with celiac disease demonstrate a strong adherence to their gluten free diet.

More information is needed in regards to specific types of eating disorders and their interactions with celiac disease. Also, it may be helpful to look at the degree of eating disorder severity and the levels of treatment each individual experiences and how this may influence the level of interaction between the co-morbid disorders. For example, does the eating disorder and celiac disease interact on a more significant level when an individual is in an inpatient level of treatment? A logical conclusion would say that the co-morbid disorders would interact more significantly, however, it is not yet known.

It would be helpful to know how practitioners could improve the interviewee’s experience of having these comorbid disorders. Many reported that they were not satisfied with their practitioner; however, they did not have an opportunity to discuss what could be different to have a more positive experience during the interview. While practitioners are more knowledgeable about celiac disease in recent years, perhaps practitioners could research more about celiac disease and eating disorders. Practitioners should also consider studying more creative and individualized approaches treatment for the comorbid conditions. When a diagnosis is provided, perhaps more comprehensive education is needed about each disease. This also leads
to the need for individuals to communicate about both diagnoses with all of their practitioners so practitioners are better able to coordinate care for the individual.

**Strengths and Limitations**

Due to its exploratory nature, a strength of this research design is the possibility to guide future research in an area that is currently understudied. The results of this study may inform the practice of working with individuals who have celiac disease and eating disorders. This research could be a benefit to organizations and support groups that treat celiac disease and eating disorders. Finally, the study will allow individuals with these comorbid disorders to have their voices heard. It may be an empowering process for participants who may sometimes feel overlooked.

There were limitations in this design. The sample was small and drawn primarily from online social networking sites, and therefore, not representative of the general population. The interview questions were created by the researcher, and have not been used in previous studies, limiting the validity of this instrument. As a semi-structured interview, questions varied slightly among each participant, limiting the comparability of each respondent’s answers or interview experience.
References


experience of caring for a person with bulimia nervosa: Carer's needs and experiences of services and other support.

Appendix A

Research Questions

Thank you for coming to the interview. (Informed Consent and Confidentiality)

How long have you had celiac disease?

How did your celiac disease develop?
  What symptoms did you experience?
  How long did you have symptoms before you were diagnosed?
  How did it get diagnosed?
  What are your symptoms now when you eat gluten?
  Does your celiac disease affect your daily life? If so, how?

How did your eating disorder develop?
  When did it start?
  What symptoms did you experience?
  How long did you have an eating disorder before seeking help?
  Where are you at currently with your eating disorder?
  Maybe some discussion on history of eating disorder, including treatment.

What has been helpful for you as you have dealt with your celiac disease?
  Have you gone to a celiac disease support group?
  Any iPod/iPhone apps books that helped?

What has been helpful/not helpful for you as you have gone through treatment of celiac disease and eating disorders?

How have you addressed your eating disorder?
Some individuals experience complications in treatment with having celiac disease and eating disorders. Have you experienced complications in treatment settings with having these disorders? (i.e. Cross contamination, incorrect meal, lack of knowledge about comorbid conditions)

Has there been a time when the celiac disease lead you to have increased or decreased symptoms of your eating disorder?

What would be helpful in situations where you experience increased symptoms?

What are the effects of celiac disease on your eating disorder?
What are the effects of your eating disorder on your celiac disease?

Do you believe that your eating disorder developed due to your celiac disease? Vice versa?

Social experiences often revolve around food, how does celiac disease and eating disorders impact your social life?
What has been beneficial in social situations?
What could be more beneficial in social situations?
What does not help in social situations?

How did you feel eating different foods than others?

Name:
Age:
Gender:
Ethnicity/Race:
Age of celiac disease diagnosis:
Age of onset of eating disorder:
Age of eating disorder diagnosis:
Eating disorder diagnosis:

Celiac Disease Dietary Compliance
1 = I don’t comply at all with my gluten free diet
5 = Oh well, if I get gluten, it’s okay, I’ll just deal with it
10 = If I can help it, I never have gluten in my diet

Do you ever intentionally eat gluten?

Never    Once a week    Once a month    Once every six mos.    Once a year

How was your celiac disease diagnosed?
Blood Test    Endoscopy    Unsure    Other

Please rate the severity of your Celiac Disease symptoms:
1 = Mild, I don’t really feel anything at all
5 = Moderate
10 = Severe

Do you have any other comments or things you would like to share about celiac disease and eating disorders?
Appendix B

Informed Consent

CONSENT FORM
UNIVERSITY OF ST. THOMAS
GRSW682 RESEARCH PROJECT

Individual’s Perspectives of Having Celiac Disease and Eating Disorders

I am conducting a study about individual’s perspectives of having celiac disease and an eating disorder. I invite you to participate in this research. You were selected as a possible participant because of your diagnosis of celiac disease and an eating disorder. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by Heather M. Vargo, a graduate student at the School of Social Work, St. Catherine University /University of St. Thomas and supervised by Dr. Jessica Toft.

Background Information:
The purpose of this study is to answer the following questions: 1) What does the development of eating disorders and celiac disease look like for individuals, 2) How do individuals experience the two disorders together, and 3) What do patients with the co-occurring disorders think would be beneficial in treating these comorbid diseases?

Procedures:
If you agree to be in this study, I will ask you to do the following things: Participate in a 45 to 60 minute interview in a private location of your choice that will be audio taped and transcribed.

Risks and Benefits of Being in the Study:
There is some risk of emotional discomfort in that the interview has the potential of bringing up sensitive topics. There may be transitory feelings of stress in recollecting experiences of having eating disorders and celiac disease. Should you experience feelings of stress, here is a listing of local support groups and listing of programs to call for help:

Crisis Connection Minnesota (no cost)
612.379.6363
www.crisis.org

The Joy Project, Eating Disorder Support Group (no cost)
Mondays, 6:30 - 8:30 pm
University Lutheran Church of Hope
601 13th Avenue SE
Minneapolis, MN 55414
www.joyproject.org
The Emily Program (costs associated with services)
Various locations in Minnesota: Burnsville, Duluth, Saint Louis Park, Saint Paul and Stillwater.
www.emilyprogram.com
651.645.5323

The Melrose Institute (costs associated with services)
3525 Monterey Drive
Saint Louis Park, MN 55416
www.parknicollet.com/eatingdisorders
952.993.6200

Eating Disorder Anonymous (no cost)
Go to www.eatingdisordersanonymous.org for the most updated information on meetings.

You will be compensated with a gluten free care package and $10 Target gift card upon completion of the interview.

Confidentiality:
Consent forms and hard copies of transcribed interviews will be kept in a locked file cabinet at the interviewers home. Interview audio files and transcribed interviews will be kept on a password protected hard drive, only accessible to the researcher and transcriptionist. The documents will be destroyed upon the completion of this study on July 1, 2012.

Voluntary Nature of the Study:
Your participation in this study is entirely voluntary. You may skip any questions you do not wish to answer and may stop the interview at any time. Your decision whether or not to participate will not affect your current or future relations with St. Catherine University, the University of St. Thomas, or the School of Social Work. If you decide to participate, you are free to withdraw at any time without penalty. Participation will not affect your current treatment of your celiac disease or eating disorder. Even if a therapist or service provider told you about the study, they will not know whether or not you participated. Should you decide to withdraw, you have one week to withdraw.

Contacts and Questions
My name is Heather Vargo. You may ask any questions you have now. If you have questions later, you may contact me at XXX.XXX.XXXX or varg3050@stthomas.edu/heather.m.vargo@gmail.com. The professor supervising my research is Dr. Jessica Toft and she can be reached at 651-962-5803 or jetoft@stthomas.edu. You may also contact the University of St. Thomas Institutional Review Board at 651-962-5341 with any questions or concerns.
You will be given a copy of this form to keep for your records.

**Statement of Consent:**
I have read the above information. My questions have been answered to my satisfaction. I am at least 18 years old. I consent to participate in the study and to be audio taped.

______________________________  __________________________
Signature of Study Participant   Date

______________________________
Print Name of Study Participant

______________________________  __________________________
Signature of Researcher          Date
Do you have celiac disease and an eating disorder?

Are you interested in being part of a study that explores perspectives of those who have celiac disease and eating disorders?

If so, you are invited to participate in a study!

The purpose of this study is to explore the needs of individuals - like you - who have celiac disease and an eating disorder.

Interested in participating?
Please contact:

Heather Vargø, Master of Social Work Student, at 440.382.4445 or varg3050@stthomas.edu

The University of Saint Thomas & Saint Catherine University
You will receive a gluten free care package and a $10 Target gift card for participating!