

## Article 19

### **Celiac Disease: Depression, Anxiety, Social Stigma, and Implications for Counselors**

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#### **Abstract**

The National Institutes of Health estimate that up to 23.5 million Americans suffer from autoimmune disease and that prevalence is rising (National Institutes of Health, 2014). One type of autoimmune disorder is called celiac disease. It affects the gastrointestinal tract of those diagnosed. Celiac patients often show an increased level of psychological distress initially after diagnosis and during transition into a gluten-free lifestyle. Depression, social anxiety, and stigmatization often accompany diagnosis and need to be addressed by the medical and psychological community. The author's personal account of being diagnosed with celiac is provided to give an in-depth look into the transition to a gluten-free lifestyle. Counselors will gain awareness into this type of disease, how it affects many populations, and treatment ideas to use with clients who have been diagnosed.

*Keywords:* celiac disease, depression, social anxiety, stigma, implications

#### **Introduction**

Celiac disease is an autoimmune disease that affects approximately 1% of the population in the United States, equating to approximately 2.3 million people. The disease rates in Europe vary from approximately 0.3% in Germany to approximately 2.4% in Finland (Barbero, McNally, Donohue, & Kagnoff, 2014). Celiac disease is characterized by the atrophy of intestinal villi when gluten is ingested. Many of the

common symptoms of celiac disease include abdominal swelling, bloating, abnormal bowel movements, weight loss, fatigue, weakness, and vomiting. Another symptom, dermatitis herpetiformis, is a blistering of the skin that is often itchy and painful (Barbero et al., 2014).

Aside from the physical symptoms, little research is being conducted on the psychological symptoms associated with celiac disease. The primary psychological symptoms include anxiety, depression, irritability, and difficulty with memory and concentration due to lack of nutrition (Addolorato, Capristo, & Ghittoni, 2001). The purpose of this article is to demonstrate the connection between a primarily medical diagnosis and the resultant mental health issues which accompany celiac disease. This paper focuses on the impact celiac disease has on depression, anxiety, and social stigma and the negative quality of life consequences. It will provide evidence that celiac disease affects rates of depression, both prior to and after diagnosis, anxiety in recently diagnosed patients, and the social stigma associated with this disease. A personal account of being diagnosed “celiac” in the United States from the author’s perspective will also be provided. The article will also discuss the implications and recommendations for counselors dealing with clients who are diagnosed with celiac disease.

### **Celiac and Depression**

To date, the strongest relationship found relating to the diagnosis of celiac disease was the presence of depression. According to a meta-analysis of depression and anxiety around celiac disease, “Depression was reliably more common and/or more severe in adult celiac disease than in healthy adults” (Gerdes & Smith, 2012, p. 191). Patients diagnosed with celiac often experience depression before diagnosis, and once the proper diet is achieved, it was seen from the meta-analysis study that “inspection of data indicates that a gluten-free diet was often unable to ameliorate depression” (Gerdes & Smith, 2012). Through the meta-analysis study it was found that there are two general ideas surrounding how celiac disease impacts depression in people. The first is that celiac disease may be specifically linked to depression through pathogenic mechanisms, and the second sees the link between depression and celiac as non-specific or chance events.

In particular, it is conceivable that depression, initially present as a consequence of the disease symptoms and malabsorption–malnutrition, is sustained by the reduction of the quality of life of these patients related in part to the decreased sensation of general well-being, and in part to dietary restrictions that lead to difficulties in daily social relationships. (Addolorato et al., 2001, p. 19)

In a study conducted by Central Queensland University, people with celiac disease that experienced depression were less likely to manage their illness effectively (Hughes, Stone, & Storey, 2012). This study was unique in that the researchers attempted to focus on what specifics they could add based on what was previously known from completed research. What was already known in this study included the high prevalence of depression in people with celiac disease, that people with depression are less likely to comply with medical recommendations, and that non-compliance with a gluten-free diet can result in serious illness and possible death (Hughes et al., 2012). This study chose to provide proof that stress and co-morbid medical illness are more strongly correlated in people with celiac disease. The study found that in people who were recently diagnosed,

there was a higher prevalence of depression but the level of depression decreases over time. This increased rate of depression was often associated with the abrupt change in lifestyle including giving up certain foods, reading ingredients of everything before purchasing, and ensuring accommodations when eating out (Hughes et al., 2012). Therefore, the most likely increase in depressive symptoms was immediately after the initial diagnosis of celiac.

According to a study conducted by Orfila and Black (2011), “A similar proportion felt depressed because of their condition, with 7% feeling depressed all of the time and up to 40% feeling depressed at least some of the time as a result of CD” (p. 9). There have been multiple studies that have tried to connect depression to celiac disease, but the reports of a relationship often ranged from 6% to 57%, which is often attributed to cultural and social differences that change from region to region (Garud et al., 2009). Most research conducted on the topic of Celiac disease is a combination of quantitative and qualitative methodology, therefore leading to broader ranges in percentages than purely quantitative studies would show. Future research needs to be conducted in order to determine if depression is directly related to a diagnosis of celiac disease or if depression is due to the chronic nature of the disease.

### **Celiac and Social Anxiety**

Along with depression, people diagnosed with celiac disease show symptoms of anxiety. The most common form of anxiety exhibited by people diagnosed with celiac is social anxiety. According to a study conducted by the Catholic University of Rome and St. Andrea Hospital “social anxiety is characterized by a marked fear of performance, an excessive fear of scrutiny and fear of acting in an embarrassing way” (Addolorato, Mirijello, & D’Angelo, 2008). This particular study found a high prevalence of the state reactive form of anxiety, in this case anxiety being triggered by social situations, and depression in people diagnosed celiac. This study found no differences in the prevalence of social phobia between newly diagnosed celiac patients and those on a gluten-free diet. This indicates that newly diagnosed patients are just as likely to suffer from social anxiety as patients who have assimilated the gluten-free diet. With the presence of these disorders, people with celiac often experience a reduced quality of life and poor social interaction as a result. People with celiac often will avoid social interaction, particularly when they are going to be observed eating such as eating in public places. This social phobia was categorized into generalized and non-generalized social phobia. In this study, it was found that people with “generalized anxiety usually present more severe social anxiety, greater depression, a significant impairment and reduced life satisfaction” (Addolorato et al., 2008, p. 5). It was also reported that people with celiac disease often show avoidant behavior mainly due to dietary restrictions and/or fear of giving their friends and partners an impression of an illness state (Addolorato et al., 2008). It was noted in this study that future studies with larger samples are needed to clarify the possible social anxiety risks in celiac patients.

## **Celiac and Stigmatization**

Along with the high prevalence of depression and anxiety symptoms for people diagnosed with celiac disease, there also is social stigma of being diagnosed with celiac as well. Social scientists define stigmatized persons as “any individual who possesses a characteristic, temporary or permanent, that other individuals view as unfavorable, negative, or unacceptable” (Schroeder & Mowen, 2014, p. 475). Stigmatized individuals are more likely to suffer from low levels of self-esteem, increased rates of depression and anxiety, alcohol use, and other psychological issues including increased feelings of anger and hostility. Related to health stigmas, studies have found that individuals with chronic diseases, such as cancer and epilepsy, become significantly more likely to develop depression and negative self-perception at the point their chronic disease becomes a dominant aspect in their life (Schroeder & Mowen, 2014). People with celiac disease often suffer from stigma, feelings of inadequacy, and exclusion from normal social roles. Stigmas also interfere with maintaining positive self-concepts, which tends to lead to reduction in social network and support systems.

In one study, a large number of interviewees reported knowingly consuming gluten containing foods to maintain a socially positive identity. Most interviewees reported consuming gluten knowingly due to wanting to maintain a normal identity, avoid embarrassment, and for convenience (Schroeder & Mowen, 2014). In this study, it was noted that respondents “experience disease-related stigma, mainly through the perception that they are different and treated as such because of celiac, and that the older and more celiac-experienced subjects reported fewer disease-related adjustment issues” (Schroeder & Mowen, 2014, p. 6). It was reported from this study that younger interviewees suffered more social consequences of being diagnosed celiac than older interviewees. Older interviewees viewed the diagnosis as another ailment to manage while younger interviewees saw the diagnosis as a limitation, and the need to adhere a strict diet was not common in their social circles.

### **Author’s Account of Being Diagnosed Celiac**

“Well it looks like you have celiac disease” was the first thing I remember as I woke out of anesthesia from having an upper endoscopy. It was a name for the symptoms I had been experiencing for most of my life. As a child, I began to believe that pain when eating was normal due to how doctors responded to my symptoms. I remember being told it was a stomachache and would get better with time. As my symptoms became worse in adulthood, it was by chance that my general practitioner tested for Tissue Transglutaminase Antibodies (tTG-IgA) in my routine blood work. The blood test showed that I had the possibility of celiac disease and led me to the upper endoscopy for final confirmation.

The upper endoscopy required anesthesia, and I was groggy as I heard my diagnosis. A packet describing the diagnosis was given to my father as the doctor described the basics of the diagnosis. The doctor conveyed that I showed signs of severe villi blunting and this was characteristic of celiac sufferers. I remember my father had a look of confusion about what villi were and what “blunting” meant. The doctor discussed that I was expected to read my handout, follow the change in diet, and everything would

be all right. I could live out the rest of my life in health, comfort, and without pain. The challenges that followed after the diagnosis and how every area of my life this disease would affect were not mentioned.

The information given to me about celiac disease was very simplistic and extremely medically oriented. The summary of the three-page handout I received instructed me to not consume any products containing gluten that is found in wheat, oats, barley, or rye, or it would cause an internal autoimmune response. This immune response would “blunt” the small intestinal villi used to absorb nutrients and cause my body to essentially starve itself. This basic information was straightforward and frightening, instilling an immediate desire to change in the person who reads it. I conformed to the new dietary regimen and implemented a gluten-free diet, expecting life to continue on better than before. The problem was that I had not been prepared for the long, bumpy road along the way.

There was constant explaining to family, friends, and strangers in the form of educating and questioning. It was emotionally exhausting. I was diagnosed as a young adult and was already experiencing massive transition from being an adolescent into becoming an adult. I was working full time and getting my bachelor’s degree while still living at home. The fast-paced lifestyle I was living, coupled with lifelong eating habits in my family, began to affect me negatively. I began to become less strict around my diet and often ate foods containing gluten to make life easier for those I cared about, particularly family and friends. I thought of myself as a burden to my family and friends. I was aware this was hurting my own body but the love of my family was greater and I knew how difficult it was for them to change for my disease. Depression began to show up more and more because I was so unprepared for the magnitude of changes surrounding this diagnosis and how much it would affect my social support, and I grieved for the way of life that I lost.

The more time I spent trying to talk to people about my disease, the more I realized I knew nothing about it. I began researching the disease trying to piece together how I had acquired it. I read through countless medical journals and public forums online. Through this new information, I started to realize how difficult it was for people diagnosed to implement the medical recommendations without help or guidance, and how many people did not follow these recommendations as advised, leading to lower quality of life. From the information I gathered, I began to formulate the idea that certain mental health issues could be tied to celiac disease and how little research was being conducted about this issue. Through my passion for mental health, along with my own personal experience, I realized that people suffering from celiac diagnosis needed to be heard and that I could provide that voice.

### **Implications and Recommendations**

The implications for counselors regarding clients diagnosed with celiac disease include becoming aware of the psychological distress this disease can cause. In a qualitative study conducted by Taylor, Dickson-Swift, and Anderson (2012), participants often spoke of their support systems and it was found that primary support systems including family and friends had the biggest impact on well-being. This study also supported the notion that support groups for those diagnosed and education surrounding

the disease to both the diagnosed and the primary support group for those diagnosed is invaluable. A different study (Addolorato et al., 2001) suggested that patients could benefit from psychological support after diagnosis and at the beginning of gluten-free diet treatment in order to correct psychological disorders and to improve the acceptance of the gluten-free diet. This psychological support and acceptance of the gluten-free diet could potentially increase compliance with treatment and related disease complications (Addolorato et al., 2001).

Counselors should also be aware of the stigma attached to the celiac diagnosis. Counselors should use treatment models that help people incorporate the diagnostic label and to help clients find empowerment regarding this diagnosis. Schroeder and Mowen (2014) reported that “The commonality the conditions [mental illness, sexually transmitted diseases, and celiac disease] share, however, is that celiac, STDs, and mental illness greatly elicit negative social reactions when exposed or revealed; importantly, and all three conditions can also be concealed in most circumstances” (p. 10). With these ideas in mind, counselors need to recognize that people diagnosed will selectively reveal their diagnosis only to those they trust and often will attempt to maintain pre-disease identities. Counselors working with these clients should try and integrate the diagnosis into a new identity where the client can experience acceptance of the disease and not feel the desire to hide the disease. This therapeutic work from medical professionals can help to increase the well-being of the client as well as empower the client to maintain the gluten-free diet that is required for treatment.

Most people experience the initial transition after being diagnosed with celiac disease as the most challenging. After the initial diagnosis, a person often needs to go shopping for all new food and dispose of any gluten containing foods that they already possess, while simultaneously balancing how to communicate with family and friends the magnitude of the diagnosis. Based on the research already noted and my firsthand account, it can be determined that services should be offered as soon as diagnosis occurs and continued throughout the first few years of treatment to provide support and coping skills. During this time period, the diagnosed will have support from professionals outside their primary support systems to help educate and provide a safe space for the client to explore the new diagnosis.

During this transition period, counselors can allow the client space to grieve the loss of their former lifestyle and provide coping skills for those newly diagnosed. Counselors can offer education surrounding mindfulness, stress reduction techniques, and role-play scenarios where communicating about their disease is needed. Every person diagnosed with celiac is different in regards to their experience and how much support they will need. It is the medical and counseling professional’s obligation to provide the services for these clients to help them attain a better quality of life and sense of well-being after being diagnosed.

## **Conclusion**

In summary, the celiac population is in need of psychological services ranging from support groups and psychological education to possible treatment for mental illnesses such as depression and anxiety. It is important for counselors and medical professionals to be aware of the negative emotional and psychological effects that

accompany being diagnosed with celiac disease and the recently diagnosed require support services. Being diagnosed with a chronic illness, such as celiac disease, changes so many aspects of a person's life and in ways that are not yet fully understood to counselors and medical professionals. It is the responsibility of medical professionals and counselors to gain insight into how this diagnosis is affecting individuals and to give light to the fact that a diagnosis of celiac disease can have far-reaching effects.

There are few known interventions and techniques for counselors and medical professionals to utilize. These interventions and techniques have not been widely studied or acknowledged. It can be assumed that early intervention will facilitate better transition into the gluten-free diet treatment often equating better management of treatment earlier on. Professionals should start by initiating interventions about grief, stigmatizations, and major life transitions. Depression, anxiety, and social stigma are often found in those diagnosed with celiac disease, though the severity of each is dependent on each person, and that awareness on the part of medical and counseling professionals can help lessen the severity of those negative psychological experiences. Celiac disease is a chronic medical illness that can cause physical, mental, and emotional suffering to those diagnosed. It is incumbent on the mental health community to understand this disease more fully and to treat its sufferers more effectively.

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