

Perspectives of Having Celiac Disease and Eating Disorders

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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.*

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). 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.

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).

Research Questions

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

Methodology was informed by a full literature review. 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. 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 research instrument used was a multi question interview. Interviews were semi-structured and based on a series of questions developed by the researcher. The field was approached no pre-established coding schemes, but the researcher 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 & Discussion

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.

Onset of Celiac Disease and Eating Disorders

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. 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 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.

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. Also, individuals discussed being teased about weight and recognizing weight gain associated with puberty. Two individuals stated a family history of eating disorders which attributed to the development of their eating disorder.

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 the end, the length of time between onset of eating disorder symptoms and being diagnosed

and receiving help varied between each person. 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.

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. 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. Interviewees experienced a lengthy process in regards to diagnosis.

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.

Every interviewee stated that 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 another stated, that she did intentionally eat gluten once when she was drinking alcohol. Ultimately, 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

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."* Another states that she would prefer to *"do other things socially rather than eating."* 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.

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. Increased awareness of hunger queues may reduce symptoms of over and under eating.

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."*

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.

If you would like to review the entire research study and/or a list of references, please email the researcher at heather.m.vargo@gmail.com.