

AN EXPLORATION OF DIAGNOSIS AND ILLNESS EXPERIENCES OF
WOMEN AND MEN LIVING WITH CELIAC DISEASE

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Introduction

The purpose of this research is to explore and investigate experiences before, during and after diagnosis as well as satisfaction with medical care from the perspective of women and men with Celiac Disease. Celiac Disease is an autoimmune disease that prevents individuals from tolerating and absorbing anything that contains gluten which is a protein found in grains such as wheat, oats, barley and rye (Catassi and Fasano, 2010). The consumption of gluten results in damages to the lining of the small intestine which can lead to malabsorption of nutrients and long-term health complications if not addressed (National Institute of Diabetes and Digestive and Kidney Diseases, 2015). Celiac Disease can manifest through typical gastrointestinal symptoms or through atypical symptoms such as anemia and neurological complications (Catassi and Fasano, 2010). At this time, the exact cause of Celiac Disease is still unknown. Certain individuals can develop this disease due to genetics while others can develop the disease based on exposure to environmental factors (Rubio-Tapia, Van Dyke, Lahr, 2008). However, as many as 1 in 141 Americans have Celiac Disease, but many of these individuals remain undiagnosed (Rubio-Tapia, Ludvigsson, Brantner, Murray, and Everhart, 2012). More recently, the percentage of adults in the United States that have been diagnosed with Celiac Disease is only .71% of the population and is more frequently diagnosed in women than men (Ludvigsson, et al, 2013).

Due to the varying symptoms of Celiac Disease, receiving a diagnosis is sometimes difficult despite serological screening, which tests for Immunoglobulin

Ig G and IgA antibodies, genetic testing and duodenal biopsy which is taken during an endoscopy (Hopper, Hadijvassiliou, Butt, and Sanders, 2007). Although typical symptoms of Celiac Disease such as gastrointestinal distress including bloating and diarrhea are more common, this disease is underdiagnosed in the medical community (Hin et al, 1999). Atypical symptoms such as neurological complications or anemia are often overlooked or confused with other diseases which can prolong receiving a diagnosis (Catassi and Fasano, 2010). Although there are ways to diagnose Celiac Disease, it also has characteristics of a contested illness which is a generally accepted condition among medical professionals that is not widely applied in medical practices (Brown, 1995). This is problematic because a diagnosable disease should not be stuck in limbo between two condition typologies. Additionally, this can lead to a prolonged period of time before a patient is diagnosed based on whether or not their symptoms are recognized as a manifestation of Celiac Disease.

Examining Celiac Disease through a sociological lens highlights the social construction of diagnosis and illness (Brown, 1995). By exploring the social construction of diagnosis and illness, patient's experiences with their diagnosis process can provide insight on what it means to have Celiac Disease and how gender shapes their experiences pre- and post-diagnosis. Additionally, this can help provide insight on the differences between women and men who receive this diagnosis and how it has impacted their lives.

Furthermore, applying a sociological perspective to Celiac Disease allows for a closer examination of illness experiences among those living with Celiac

Disease. To illustrate, the consumption of food is a highly social aspect of our society. When there are individuals who are unable to fully participate in an activity due to limitations, there is a possibility of stigma, loss of identity, and dissatisfaction with quality of life. By gaining a better understanding of the social implications of this disease, we could identify negative perceptions and experiences as well as make improvements to enhance our ability to care for this population.

This study used in-depth semi-structured interviews to explore and understand the experiences of individuals who received the diagnosis of Celiac Disease as an adult. In order to accomplish this, the following specific aims were investigated:

- Explore the diagnosis experiences of women and men who received the diagnosis of Celiac Disease as an adult and the meaning they place on these experiences.
- Investigate pre- and post-diagnosis experiences with healthcare professionals and their implications for patient satisfaction with an emphasis on gendered interactions
- Examine illness experiences outside the healthcare setting including stigma experiences among women and men living with Celiac Disease.
- Explore social support systems and how they impact chronic illness management (illness and everyday life) of Celiac Disease for women and men.

Significance

This is significant because food is a highly social aspect of our culture but some individuals might not be able to fully participate because of living with Celiac Disease. It is important to understand what their experiences are like before, during and after diagnosis so that as a society we can help educate others about this disease and the severity of it. This might also aid in improving our understanding of other chronic illnesses to better serve these populations. Additionally, it is important to understand the social construction of this illness so that it is not treated as a contested illness which can impact the meaning that individuals with Celiac Disease as well as others around them place on their interactions and experiences with this disease.

Background

Celiac Disease is an understudied condition inside and outside the medical field. Within the social sciences, it is even more overlooked. A literature review was conducted to identify gaps in previously conducted research. The majority of research that has been conducted has occurred in Europe and research in the United States is virtually non-existent. Additional research was collected from other conditions such as food intolerances to explore potential similarities in applicable concepts.

Illness Experiences of Living with Celiac Disease

Only one article used qualitative methods to understand adult experiences with Celiac Disease (Schroeder and Mowen, 2014). In this study, modified

labeling theory was used to explore initial reactions, the effect of living with Celiac disease as well as interpersonal and personal relations. It was not the lifestyle change that was difficult for these individuals in the study. Rather, it was being different (Schroeder and Mowen, 2014). Starting with their initial diagnosis, there were feelings of anger, depression and anxiety. The diagnosis did not necessarily make their lives easier because it introduced a new life style change that required far more work than they originally expected (Schroeder and Mowen, 2014). For their social interactions, certain participants reported that they felt like they were disappointing their friends because they did not want to engage in food related activities (Schroeder and Mowen, 2014). This study also investigated the methods in which participants managed their conditions. It was interesting to find that the participants were selective on who they disclosed their conditions to (Schroeder and Mowen, 2014). The themes from this study are important and valuable for my own study because they demonstrate how Celiac Disease is socially constructed through their experiences. This is an area of Celiac Disease that is still not widely understood and can help strengthen medical practices and procedures when it pertains to this disease for individuals in the future.

An additional study pertaining to adults takes a medical approach to Celiac Disease using quantitative research. According to Ciclitira and colleagues (2010), there is a lot of responsibility placed on a patient when it comes to Celiac Disease; however, this responsibility is often explained poorly to a patient when they receive a diagnosis and they are not provided with collaborative resources to help them manage and understand their disease. These findings raise a

question about whether the process in which one receives a diagnosis has an impact on how they perceive their disease based on the care that was provided.

Studies involving adolescents with Celiac Disease also proved to be useful. One recent study conducted a mass screening for the disease among adolescents to gain a better understanding about the impact that Celiac Disease had on their quality of life (Rosen, Ivarsson, Nordyke, Karlsson, Carlsson, Danielsson, Hogberg, and Emmelin, 2011). The results showed that girls were more pro-active in making changes to adhere to a gluten free lifestyle but also the first to abandon it. Boys experienced more difficulties dealing with the diagnosis. They often relied on a support system or were in denial of initial diagnosis. Within the group of adolescents that participated in the study, stigma of the disease did have an impact on individual choices (Rosen, et.al, 2011). Several participants shared experiencing feelings of loneliness and vulnerability in certain situations and would actively avoid having to participate if food was involved (Rosen, et.al, 2011). This is significant because it is another example of how someone can hide that they have Celiac Disease in order to prevent stigma and poor reactions in social interactions. Additionally, the gendered experiences were also interesting from an adolescent viewpoint. It will be interesting to see if adults have similar gendered experiences when adhering to a gluten free diet and coming to terms with their diagnosis.

Similarly Olsoon and colleagues (2009) also found interesting results on daily interactions of adolescents with Celiac Disease using small focus groups. This study focused on the visibility of the disease and the stigma that occurred

because of it. Stigma is a discrediting attribute that can be both visible and invisible (Olsson, Lyon, Hornell, Ivarsson, Snyder, 2009). Participants did not like that they were different and that this difference was potentially visible. They did not like the unnecessary attention they received. Additionally, this showed the struggle that the participants faced when trying to maintain their identities (Olsson, Lyon, Hornell, Ivarsson, Snyder, 2009). It will be interesting to explore the ways in which adults maintain their identities and to see if there are similarities between women and men.

Celiac Disease as a Contested Illness and Routinely Defined Illness

A contested illness is described by having the following characteristics: their status as a legitimate illness is highly controversial; their etiology is ambiguous; their existence has been linked to other diagnoses and co-morbid conditions; their treatment regimens are unclear; and their legal, medical and cultural classification is disputed (Swoboda, 2006). A routinely defined illness is usually accepted in the medical community and has biomedical definitions that are applied (Brown, 1995). Celiac Disease is diagnosable by blood work and has been established as a legitimate disease by the medical community. However, it is a highly complex disease and no real cause of this disease has been pinpointed. When compared to a routinely defined illness, an argument can be made that it is more conflictual than other diseases due to its complex nature and wide range of symptoms. This also raises concerns for the overall illness experience and diagnosis experience that a patient has if they have a disease that is stuck between two condition typologies. It is difficult to understand having

a disease and coming to terms with it when the diagnosis process is inconsistent and the way in which the medical community perceives this disease is inconsistent.

Stigma and Illness Experiences

Erving Goffman stated that the term stigma refers to “an attribute that is deeply discrediting”, (1963, pg 3). This can be a visible or invisible attribute which holds a negative perception. There are five components of stigma: Labeling, stereotyping, separation, status loss, and discrimination (Green, Davis, Karshmer, Marsh, Straight, 2005). Stigma can effect health in four ways: first is through psychological stress; second, the fear of being stigmatized may cause some individuals to delay seeking help from medical care professionals if they think they have a stigmatizing disease; thirdly, stigma may be experience adverse reactions from others in a healthcare setting by certain staff members; fourth, communities that are slow in providing infrastructure or facilities to provide services to a stigmatized group (Cockerham, 2010). Those with Celiac Disease may experience stigma if they experience adverse reactions in a healthcare setting when trying to pursue a diagnosis and in their personal lives if they are not able to fully participate in a social events due to their differences. This can cause difficulties with managing illness work and everyday life work. Illness work pertains to the regimen that is required by an individual to ensure that their illness does not get out of control to where it interferes with everyday work. Everyday work pertains to the daily routine that is required to keep a household functioning (Corbin and Strauss, 1985). For those with Celiac Disease, illness work pertains

to a strict gluten free diet which helps with prevention and symptom management. The importance of illness related work reflects on everyday work which can be interrupted if illness related work is not abided by. This can be further complicated by stigma if they do not have a good regimen in place to manage their illness work or attempt to maintain their status and identity through methods that compromise their ability to accomplish their illness work. This could include refusing to disclose their condition to others or failing to adhere to the gluten free diet.

An interesting area of stigma involving food pertains to the rise in the gluten free diet fad. While awareness of Celiac Disease is important, negative awareness only hinders the outcomes for individuals who have the disease. More recently the diet fad has become popular in the United States (Moore, 2014). However, the popularity of the diet has had a negative impact for those who are pursuing a diagnosis of Celiac Disease. It has been described as an “Illness you have to fight to get” (Moore, 2014). Additionally, research on food intolerance is often treated as a contested illness and grouped with Celiac Disease despite their differences (Moore, 2014). This is problematic because the medical community is inconsistent and this reflects on public knowledge and perception. We socially construct illness based on our experiences and if something is not treated as important or seems erratic, it is difficult to determine what is true or false.

At this time research on Celiac Disease in the social sciences is vague and there is a need for additional research so that we can gain a better

understanding of this disease. The diagnosis of this disease is inconsistent and is often treated as a contested illness which causes further problems when trying to understand this disease on a social level. We have barely scratched the surface when it comes to understanding this disease and in order to improve outcomes for individuals who are diagnosed, we need to gain a better understanding of experiences from the viewpoint of individuals who already live with Celiac Disease. Findings will shed insight on some of the challenges faced as people are diagnosed and receive care. This study will also provide insight towards any areas where changes can be implemented towards improving the perception of this disease and the diagnosis process.

Research Design

In order to address the specific aims for this study, qualitative research methods were utilized to explore the experiences of these individuals. In addition to this, an interpretive approach was utilized using semi-structured interviews in order to understand and interpret the meaning behind the participant's experiences as adults with Celiac Disease (Esterberg, 2002). This allowed participants to share their experiences and opinions in their own words and allowed for each interview to be tailored to the participants while still exploring this topic (Esterberg, 2002).

Reflexivity

Reflexivity is critical to address in qualitative studies because it allows researchers to acknowledge and share their own experiences that they bring to a

study (Creswell, 2016). As an individual who was diagnosed with Celiac Disease as an adult, I have an insider status in this population. This means that I have prior knowledge of the disease and have had my own experiences as an adult with Celiac Disease. This brought advantages and potential disadvantages to the study based on my insider status. Having knowledge of the disease and first hand experiences means that I am able to comprehend what participants are sharing and have the ability to build rapport with them. Having rapport with participants was also advantageous because it is possible they will feel more comfortable speaking with someone who is knowledgeable of the disease. A potential disadvantage of my insider status is that participant's responses in the interview might be skewed based on the knowledge of my diagnosis. To account for this, I disclosed my status prior to the interview but did not share my story or answer questions about my experiences until after the interview was concluded.

Participants and Recruitment

The initial goal was to recruit 10 participants which consisted of five women and men who received their diagnosis between the ages of 21 years of age and 55 years of age. However, a total of 11 participants were recruited which consisted of five women and six men. Recruitment was conducted through support groups that have been established for central Indiana through social media outlets such as Facebook. Snowball sampling was used in order to supplement recruitment for male participants. Snowball sampling involves identifying other potential participants with backgrounds through current

participants in the study (Atkinson and Flint, 2001). Compensation was provided in the form of a \$10.00 Target giftcard.

Interview

Prior to the interview questions, each participant completed a demographic survey. The purpose of the demographic survey was to collect general background information for each participant such as age, gender, and satisfaction with the diagnosis process. Additionally, this information complimented data collected during the in-depth interview which will be beneficial for data analysis. Interviews consisted of semi-structured questions in order to obtain information as it pertains to the specific aims. Participants were asked about their diagnosis experiences, interactions and experiences in restaurant establishments, their social interactions and relationships before, during and after their diagnosis, and what this has meant to them. The interview guide can be found in Appendix A. Semi-Structured interviews were the best fit for this study because it allowed for the exploration of additional topics outside of the specific aims (Esterberg, 2002).

I conducted the interviews myself in private settings, by Skype, and by telephone. At the beginning of the interview, I shared that I was diagnosed with Celiac Disease as an adult, but waited to answer any questions about my own experiences should the participants have them until the end of the interview so that the focus is placed on the participant's experiences. It was important that each participant understood that the purpose of the interview is to discuss their experiences verses my own. Each interview was recorded using an audio-

recording device and transcribed by me. Participant's names were kept confidential and any specific information relating to the medical practices or healthcare providers were also de-identified if mentioned during the course of transcription.

Techniques to Improve Data Quality

In order to improve data quality for this study, all interviews were recorded and transcribed so that they could be coded to pinpoint and determine common themes. This allowed for written data to be analyzed so that common themes can be pinpointed between all of the interviews. An additional measure to improve data quality was the use of peer review by my thesis committee members. This ensured that the final results of this study reflected the experiences of the participants and ensured reliability as well as the validity of this study (Merriam, 2002).

All interviews were recorded using a hand-held recording device and manually transcribed. After transcription was completed, corresponding notes were reviewed in tandem with each transcription. Any important themes that appeared within an interview were marked and later these themes were compiled into categories along with respective quotes of interest through the use of content analysis (Kavale, 2007).

Human Subjects

This study had little to no risk for participants as it was voluntary and participants could choose to not answer certain questions or end the interview at

any time. Additionally, this study received IRB approval. A study information sheet was provided to all participants. During transcription, no names were transcribed and any participant-specific information was omitted or changed to protect each participant's identity. Additionally, each participant was given an alternative name for additional protection. This information was also covered with each participant before the recording of the interview began and they were asked for their consent to record the interview. Lastly, at the end of this study, all recordings were erased.

Data Analysis

Female Participants

A total of five female participants were interviewed in person, through skype, or by telephone for this study. Background information for female participants can be found below in **Table 1**.

Table 1- Female Participant Background Characteristics

Code Name	Age of Diagnosis	Current Age	Race/Ethnicity
Anna	25	25	White
Betty	49	63	White
Claire	39	39	Hispanic
Diana	23	25	White
Elaine	47	53	Korean/White

While each interview was unique, there were noticeable and reoccurring themes present in each of the participant's experiences. Interviews ranged from

40 minutes to an hour and a half. For interviews that lasted a full hour and half, participants were typically willing to share information with little probing where other interviews required additional probing. Finding all five female participants proved less difficult through an electronic support group. There was a large response to the initial post and five participants were chosen based on response time to the initial post and their ability to meet criteria necessary to participate in the study. Additionally, among the five female participants, symptomology was diverse in that some had typical symptoms which lead them to a diagnosis of Celiac Disease where others experiences atypical symptoms. The common themes found among female participants are found below.

Receiving a Diagnosis

Among the women interviewed, it was often necessary for participants to attend multiple visits with multiple doctors before a diagnosis was obtained. Among the five female participants, four were misdiagnosed. Each participant had different symptoms which ranged from typical digestive responses to atypical symptoms such as severe joint complications or difficult pregnancies. Anna shares her experience with her doctor on the diagnosis process.

It was, well first of all when I went there, Celiac Disease was not on my radar at all for what could be the cause. So I just went in and talked to my doctor who I've had for years and years, so she has a really good background on me and when I told her my symptoms she was like "Ok, we are going to do some blood tests and I'm going to include Celiac". And I was like "What?", and she said "given these symptoms that you had", and she knew I had a history of constipation and such so she added that and then when it came back positive...

Although it took only one visit with a doctor, receiving the confirmed diagnosis was less formal and informative.

Oh yeah. It was awful because I was riding the elevator down from work with a bunch of coworkers with me and I get this phone call where they were like “Your lab results came back and you tested positive for a celiac disease diet”. And I was like “What?” “And they were like “Yeah, you need to stop eating foods with gluten”.

Betty’s diagnosis experience was different and she had to wait years before she received the correct diagnosis.

Well, let me think a minute....the way it went was that I probably didn’t start going to see a lot of doctors until I was up in to my 20’s. And the way it went through the years is that I would come up with some weird symptom, I’d go to the doctor and they would tell me that it was due to stress. Or that there was nothing wrong with me. And that happened so many times. Sometimes they would do a test or two and sometimes they wouldn’t even bother to do a test.

From there Betty began a long journey which included seeing many doctors. Towards her late 40’s, her health started deteriorating and she finally started doing some of her own research which lead her to believe that she had Celiac Disease. Unfortunately, her doctor refused to test her for it. From there she had to see several specialists until they finally got to the bottom of all of the problems she was having. This is when she received a positive test result for Celiac Disease. She was very angry and displeased with the medical care she had received because it was killing her. She explained,

But after my gallbladder surgery when I started to feel so much worse, I got every half way decent looking medical book and said “Well, I guess I’m going to have to read all of these until something fits”. So I was reading Mayo Clinic on digestive health. And what I thought to myself when all of this was happening was “Well, you know it could be wheat, but it happens with corn cereal and rice cereal...how could it be that?” So that was like a Saturday and Monday morning I called the doctor and tried to get in as soon as I

could... and I went in to see my primary doctor at the time and I asked to be tested for Celiac disease and she said “No”.

It took over 40 years to receive a diagnosis and she only received it after constant effort. Due to her experiences with doctors, she has lost a lot of faith in the medical community because of her experiences. Claire also had to visit multiple doctors before finally receiving a diagnosis. Although she did not have as negative of an experience as Betty, she still experienced frustration with the process.

Well, after I was diagnosed with thyroid disease. No one mentioned anything about getting tested for celiac. And after what happened with my pregnancy... I, myself, thought maybe I should in to celiac and so I went gastro.. I asked my endocrinologist treating me for thyroid about celiac and she said “I doubt it but I’ll send you/ I’ll refer you to a gastro. So I went to the gastro, he ran a blood test and um I was negative for IgA. So life went on symptoms gradually got worse. Then my daughter got diagnosed. That’s what lead me to get diagnosed. The final doctor who was actually willing to run blood tests, very thorough blood tests before automatically deciding an endoscopy was necessary. She was like “let’s just run a bunch of tests”. She also didn’t make me go off of the gluten free diet I had already put myself on. She was the one who pulled all the test results together and told me that I definitely had Celiac Disease. Before that I had not had a doctor do that.

Like Betty, Elaine also experienced symptoms for years that were never specifically attributed to Celiac Disease but impacted her life through terrible skin reactions and rashes.

I was the child who would come in with their eyes swollen shut and was told to lay down and not rub my eyes anymore. I remember wondering why none of the other kids had allergy symptoms like this and why it was just me. My mom also used every soap possible until she found one that finally worked for my skin as a baby and that was Dove soap.

In addition to these symptoms, there was an undiagnosed issue with malabsorption where she was very skinny and had terrible migraines but none of

these symptoms brought forth a diagnosis so she continued to deal and live with them. She also presented signs of arthritis and her doctor wanted to give her a drug as a ten year old. Eventually she was told that her iron was low. Eventually she grew used to these symptoms and managed to deal with them. However, as she got older things started to change.

I was married to someone who's main staple was bread. It seemed that every other weekend I had to stay in bed. I just felt horrible. I also had chronic narcolepsy. Then I developed problems with walking.

As she got older, a new symptom appeared in the form of reproductive difficulties which were coupled with abnormal liver test results that always seemed to correct themselves over time. However, the causes of the reproductive difficulties were not determined and it was not until later when Elaine discovered that it was likely Celiac Disease causing them. She was eventually diagnosed after mentioning that she constantly chewed on ice. Anemia is often coupled with Celiac Disease and wanting to chew on ice is attributed to Anemia. It was after this that she received a diagnosis of Celiac Disease. Despite this, she uses her experiences to help and educate others so that they can better understand their own health.

Feeling Overwhelmed/Lifestyle Changes

Celiac Disease can manifest in several different ways. Some are more easily pinpointed than others. However, receiving a diagnosis of Celiac Disease is often overwhelming as individuals discover their new limitations. For many female participants, they found it difficult to find safe food when initially

diagnosed because they did not know where to look or how to determine if something was safe to eat. Aside from a vague information pamphlet, no other guidance was given from healthcare professionals once a diagnosis of Celiac Disease was received.

Anna shares her experiences about changing her diet and keeping track of an additional chronic illness.

Probably the limitations in the foods that you can find that are gluten free. Because for my other chronic illness I have to ingest a lot of salt as a part of my treatment so salty snacks is a must for me. Finding gluten free snacks that have a good amount of salt and that are not ridiculously unhealthy for you was a bit of a challenge to start with.

Another area that Anna has found challenging concerns eating out. She often worries about situations and what other's think.

It's hard because it's so limiting because people don't quite understand like my lack of desire to go certain places or inability to go certain places to eat. And I think that something that bugs my friends is that I have to bring my own food everywhere and I think they might think it's kind of insulting that I don't want to eat their cooking or their parent's cooking or whatever. And I know it bothers my mom too for family gatherings that I bring my own food. Like for Christmas and Thanksgiving cause she wants me to be able to take part in the whole family experience, so that's been a little... she's gotten better about it and she does understand that I can't enjoy everything with them but still that's still hard.

Betty also had similar experiences. She didn't know what to eat at first aside from the basics. She found a dietician to be unhelpful because they did not have any knowledge of the disease.

Well, I think the biggest challenge was being able to figure out what the gluten free diet was fairly quickly. The dietician I went to didn't know anything about it at the time. I think if you are going to a

dietician it needs to be one that specializes in it. Because they still don't all know about it.

In addition to having to go gluten free, she eventually had to go dairy and egg free as well due to having developed sensitivities to them after being diagnosed with Celiac Disease. It is a common but over-looked result of going so long without being diagnosed that adds additional difficulties to determining if food is safe or not.

Diana also shared some interesting experiences on what all she had to do in order to remain completely gluten free. She no longer eats out at any restaurants even if they have a gluten free menu and even bought all new cookware to prevent cross contamination. While it is overwhelming, she is trying to maintain her health and prevent any health issues that could happen should she come into contact with gluten. Additionally, she mentioned that awareness in the Midwest of the United States made things difficult and that other areas of the world were more knowledgeable of Celiac Disease.

I've been on a restaurant ban for more than a year now so no eating out whatsoever. Just trying to be gluten free wasn't enough. I'm still not used to it. I also think it's really hard to be a Celiac in the Midwest of the United States. I travel. I went to Australia this past summer and it was actually very easy to get around because there is a much higher awareness there. Food is much cheaper and I just ate so much food when I was there because it was so easy to get. I find it in the US very hard. I still haven't gotten used to it. I still haven't quite stabilized in terms of blood work so I'm slowly getting there, but it's been a drastic life style change.

Of all the participants, Diana was the only one who went on a complete restaurant ban or mentioned how it was easier for Celiacs in other countries.

Despite this, other participants seemed worry of restaurant practices and

awareness due to a lack of education among staff. Once trust is misplaced or found untrustworthy, it is difficult to regain a sense of safety when other are involved in food preparation.

Having a Support System

After receiving a diagnosis of a disease that is not widely understood, it is beneficial to have a support system in place to help an individual acclimate to the changes they have to make. For individuals who were diagnosed with Celiac Disease as an adult, this was one of the more positive themes that appeared within their experiences. It was comforting to have someone who would take the time to research and ask about their specific needs.

Anna described a recent visit with her sister and how she helped make Anna's visit comfortable.

My sister has been very great. She actually, they live in California right now and I went and visited before my diagnosis but I still had food restrictions then. I just told her here's the rundown of what I can and can't eat, and she drew up a menu and said "how about this, we can make these things and go to these certain places". And that's what we did. She made some great meals every night I was there. If I said, oh I can't eat that or asked if we could go somewhere else, it was never a problem. For Christmas she asked questions and she cares about learning about what I got through with my illnesses. She's been great.

Additionally, having support from one's spouse helps with adapting to the gluten free diet. Claire described how supportive her husband was.

As far as my husband, he was totally supportive with me wanting to eat gluten free completely in the house. I didn't force him to and he eats gluten outside of the house but he's totally fine with me saying "hey, let me not eat this for 6 months and see if I feel better", so that was very supportive. My family was also supportive. They

didn't act like I was crazy or anything. At family gatherings they ask before they serve me or my daughter anything so they are on board with it.

Elaine's husband was also very helpful and support of the change due to having lost his parents early on due to health complications. This change was also easier to do with small children. However, her extended family was not as supportive. Elaine wanted to raise awareness about Celiac Disease based on what she went through in order to achieve positive change and there ended up being several Celiac Disease diagnosis that occurred within her family, extended family, and even close friends.

Additionally, support groups through social media were also found to be helpful, especially for individuals who were newly diagnosed. Anna explained that everything was very over whelming when she was first diagnosed. She didn't know where to turn for help but started with social media. After posting on Facebook about her new diagnosis, several individuals reached out to her to provide support.

Actually, I have a friend from high school that I didn't even know, two of them, who are Celiac. I don't keep in really close contact with them. One of them lives in Washington, but as soon as I said on Facebook "Oh, I just got a diagnosis for Celiac. I'm kind of overwhelmed", they posted, "Here are some tips that we have if you need any help with brands to look for foods and other stuff."

One interesting response concerning support systems came from Diana who was not in favor of support groups through social media. She explained how they were not helpful for her and also explained how she did not really have a support system. This is particularly interesting because it provides insight about individuals who do not respond well to support in a group setting which could be

significant in understanding this population and identifying other gaps in current research. However, one of her colleagues also was diagnosed with Celiac Disease, and she said that just having one person to ask advice from was helpful.

I don't really have a support system outside my boyfriend, but that's generally been it. I'm estranged from most of my family and only keep in contact with mom. My colleague told me "It does get better", and that was difficult at first because I was frustrated. Facebook Support Groups are not helpful. It's a lot of people complaining and a lot of negativity.

Lastly, Betty also had similar experiences due to multiple individuals having Celiac disease in her family.

My mother was officially diagnosed when she went back to the doctor and he was like "Oh I'm sorry". And then my sister had psoriasis and I went with her one day at work and said "you know what... you need to be tested". So she got tested and ended up being positive. It ended up that all my brothers and sisters got tested even though they had some difficulty being tested. Doctors wouldn't run it and things.. But they eventually all got tested. So it's my sister, my daughter and one of my nieces. And then extended family, one cousin definitely, one cousin probably and another cousin's child. So there is a lot. So when we have family get together, 3,4,5 of us have Celiac so it's not anything I have to explain to anybody or make a big issue about it. So hadn't really had that problem where I had family members who aren't understanding.

As a result, Betty formed a support group for her area because there were none and she wanted to create a way for others to be able to find information that they might not receive from a healthcare professional. Although Betty had a negative experience with healthcare professionals, she was able to use it constructively to help empower others who are diagnosed with Celiac Disease.

Summary

Each female participant received a diagnosis of Celiac Disease. However, their experiences and symptoms were all different—highlighting the complexities and potential difficulty of the diagnosis process for women with Celiac Disease. Additionally, female participants expressed frustration concerning interactions with healthcare professionals because they had to go to great lengths in order to be tested for Celiac Disease. Their diagnosis experience reflects that of a contested illness despite Celiac Disease being medically diagnosable (Brown, 1995). Having a support system seemed to be one of the more prominent themes among the interviews. Even if you did not have a large support system, having one person to rely on seemed to be helpful. Another interesting result from these participants is how awareness of Celiac Disease through other family members or friends has been helpful towards maintaining a gluten free diet. Most respondents reported frustration with having to make large lifestyle changes including having to conduct extensive research about their condition in order to better understand it as a result of the lack of information provided by a healthcare professional in addition to others, usually outside of their family, taking their condition seriously. Positive social relationships appeared to facilitate adherence to a gluten free diet through emotional support (e.g., providing encouragement), instrumental support (e.g., providing gluten free food), and informational support (e.g., discussing dietary restrictions and/or resources).

Male Participants

Male participants were recruited through the same support group as the women participants or through snowball sampling. In total, six men were interviewed for this study instead of five. Because Celiac Disease is less prevalent among men (Ludvigsson, et.al, 2013), it was challenging to find male participants that fit within the preferred age range that the study required. Therefore, it was necessary to expand the age parameter in order to complete the study. The ages of the male participants ranged from mid-twenties to late-seventies and duration of interviews ranged from 45 minutes to an hour and a half. However, two of the six male respondents acquired a diagnosis in their sixties, which fell outside the original sampling frame of age of diagnosis between 21-55 years. Age of diagnosis as well as race and ethnicity can be found below in **Table 2**.

Table 2- Male Participant Background Characteristics

Code Name	Age of Diagnosis	Current Age	Race/Ethnicity
Anthony	42	49	White
Ben	40	51	White
Daryl	33	64	White
George	62	72	White/Italian
Tim	19	26	White
Silas	62	73	White

Receiving a Diagnosis

Among the male participants, there were four who have been living with Celiac Disease for 10 or more years. In particular, one male participant, Daryl, was diagnosed when he was 33 years old, but received the diagnosis back in the 1980's. His doctor explained to him at the time of diagnosis that Celiac Disease was a rare disease. Daryl mentioned what it was like trying to work with the doctor that diagnosed him after the hospital stay that led to his diagnosis.

Then I continued to seek treatment because of the Celiac Disease and he was like "No, you're healthy now, just go see a family doctor and you'll be fine the rest of your life." And so he just kind of threw me away.

Daryl felt like he was brushed off and from that point on, he has not had a family doctor because he has had more luck finding resources on his own and with the help of his daughter who was also diagnosed with Celiac Disease. This was particularly interesting because he was actively seeking input from a healthcare provider but was not taken as seriously once he received a diagnosis. However, this led to a greater distrust in doctors. These experiences with healthcare providers that overlapped with gendered experiences impacted his overall health choices after his diagnosis. To illustrate, he does not meet with a specialist concerning management of Celiac Disease and he also did not understand the severity of his disease and continued to consume gluten verses strictly staying on the gluten free diet until his symptoms became too severe.

Daryl attempts at pursuing resources to practice healthy behaviors after his diagnosis were essentially shut down. This is concerning because even with

advancements, he has continued to have experiences where doctor's do not "want to make the insurance companies mad." This suggests that while this disease is diagnosable and can be managed, doctors may not have the knowledge to provide continuing care.

Other participants experienced situations where knowledge of Celiac Disease was either vague or non-existent further contributing to Celiac Disease being in a liminal state of a contested illness and a routinely defined illness. Ben explains his experience below.

You know, the GP (General Practitioner), nice guy but I don't think he knew where to start or even knew what Celiac was and I think he was just treating irritable bowel. I would go back and things had not improved. After that he referred me to a gastroenterologist. She didn't suspect Celiac at first either.

Despite the methods in which Celiac Disease can be diagnosed, it is not something that doctors initially consider or even rule out even in cases where patients are showing typical digestive symptoms. Given that men are thought to have a lower prevalence, this may be even truer for them. Additionally, Ben mentioned that instead of having blood work, he had a gastrointestinal scope. Similarly to Daryl, Ben tried to find resources to educate himself on his new condition. He went to a dietician in hopes of finding more answers.

I worked at a hospital at the time and went to the dietician. She helped lay out different things that I should eat and shouldn't eat. But there just wasn't a lot...cereals, pastas, things out on the shelves. You could go to the health food store and get a few things but primarily the diet was fruit, vegetables, meat, rice. There were poorly written handouts that weren't that great.

However, the available resources were just handouts with vague information that was not exceptionally helpful.

Tim did not have any bloodwork or gastrointestinal biopsies. His doctor did not have access to proceed with doing a blood panel to determine if he had

Celiac Disease. Instead he ran every other test he could to rule out those things and when they came back as negative he mentioned that in his own professional opinion that Tim likely had Celiac Disease. The extreme weight loss and joint pain stopped as a result of Tim going on a gluten free diet.

An additional aspect of the diagnosis process that was mentioned during several interviews pertained to the exchange of information from doctor to patient at the time of diagnosis. For Daryl, he did not understand the severity of Celiac Disease and would cheat often on the gluten free diet.

But since I didn't have the knowledge of what gluten did to you, I cheated an awful lot. We would go to Pizza king or wherever to get pizza and I would say "Oh, you know I'll cheat just this one night and I'll get sick but it won't be that bad so I'm ok in two days.", because the symptoms would go away."

Daryl was not equipped with the knowledge that by continuing to cheat, the symptoms would get worse and more severe because it took much longer for his body to heal from each consumption of gluten. However, after doing more research on his own, he discovered how damaging gluten consumption can be when you have Celiac Disease. Ben had a similar response.

And you know, in the beginning, I would cheat somewhat. I think all people do. Then of course you get sick and then get better. I knew I could eat two slices of pizza and I wouldn't get sick.

Feeling Overwhelmed/Lifestyle Changes

Making changes to one's lifestyle can be difficult depending on the degree of change that they must make. Going from eating gluten to not eating gluten might sound simple on the surface. However, given how prolific gluten is in the typical American diet (Specter, 2014), respondents often reported feeling

overwhelmed due to the perceived magnitude of this change. Participants were unsure of where to go for reliable resources that would aide in education on their new diagnosis as well as nutritional information to ensure they were remaining gluten free. Those who had a support system in place to help them through these changes often mentioned it being less stressful. They were also less inclined to cheat on their diets. However, for those who might not have this type of support or have to deal with other individuals that are not educated about Celiac Disease, it can become overwhelming.

Silas explained that it was very overwhelming to try and learn that on his own and that it would have been much easier if there was someone who could have acted like his guide through the beginning.

Find someone who will take you out and go around with you. Help you figure things out. The unknown is the greatest fear. When you have you find someone who can help you navigate through that with you.

The fear of the unknown was the most significant sentence of this quote. Not knowing what you can and cannot eat is significant and necessary for survival. He went on to explain how or what you needed in order to make gluten free bread. For him now it is fairly easy to do. However it was not always like this.

Learning to cook Celiac Style was not too hard. Understanding what you can and can't do is the big thing. Not being overwhelmed. Having someone to help you get started is the big thing.

This indicates that there is a greater need for patient education when they are diagnosed with Celiac Disease. Several who mentioned visiting a dietician reported that they were not exactly helpful and that the information was vague.

However, unless they had another relative who had been previously diagnosed, this was the only resource provided.

An additional source of change in life style pertained to eating out at restaurants. Some were unbothered by the change while others found it difficult to convey their dietary restrictions without being a nuisance. Anthony explained what was most difficult for him to get used to.

It took me a while to speak up for myself. If I didn't feel comfortable with what the server was telling me. I don't go as much as I used to. Explain my conditions to the server and sending something back. That was the hardest.

Being overwhelmed and acclimating to lifestyle changes overlapped with several themes from the interviews. Those who had a support system felt less overwhelmed. Those who were more comfortable with their condition had an easier time speaking up at restaurants to ensure that their food was safe. This topic would fit well into additional research conducted on the impact that Celiac Disease has on mental health.

Having a Support System

Having a support system was also a common and reoccurring theme among male participants in this study. One particular area of interest was the positive impact that having a support system had on a participant which helped them. Tim mentioned that having a group of friends who were health conscious made a difference.

I had a group of friends who were into the paleo diet. Through hanging out with them, it made things easier because there would always be something that I could eat. A lot of my friends outside of

this group were not as supportive. Many did not believe it was a real thing. It was at the time the gluten free fad was up and coming.

Daryl also had a positive experience from having a support group through his family. With this restriction, his wife began teaching herself how to prepare gluten free foods such as bread, cookies, etc., in an attempt to make things easier for him and later on their daughter. She was determined to make something that tasted good and eventually went gluten free herself even though she did not need to. As a family unit, it seemed that in doing this, it brought Daryl, his wife, and later his daughter closer together. They all had each other to rely on which made it easier and added strength to their family dynamic.

And it makes it easy not to cheat because even thinking about cheating...I get yelled at if I even think about eating something that isn't organic. "You can't eat that dad!", and I say "Hey, these chips are good to me and they say gluten free on them". My daughter has become my second mom. Yes, it has. It strengthens our relationships as a family and it makes it plain easier to not have any thoughts of cheating.

George also mentioned that his wife helped him with learning how to determine if something was not gluten free. He had previously seen a dietician but did not receive helpful information that allowed him to further learn about Celiac Disease.

My wife is good at that. She started printing stuff off. I just started learning as I went. If I had a reaction to it, I wouldn't eat it anymore. That's changed a lot though. I never used to read labels and she got me going on reading labels now.

Additionally, Anthony described how having a sister who was previously diagnosed helped with making changes as well as his wife who also had dietary concerns.

My wife was supportive in terms of figuring out what we needed to do in our household. It took us a few weeks to figure out all of the hidden gluten. My family was supportive. My sister also had Celiac. I had a lot of phone conversations with her.

Daryl expanded on the importance of having a support system in comparison to someone who does not have one.

Well, I had a support system, but if you have someone who is not willing, and you are male and you don't cook, and you have someone who is not willing to make two different things. If you don't have someone who is willing to work with you, mentally, I think you would come close to losing your mind.

Lastly, Silas explained that not having a support group starting out was extremely difficult. His children became his support group.

I would have very much appreciated at that time having a support group. I was just given a bunch of papers. My kids got involved. They were more conscientious of it than I was. My kids worked very hard to include me.

In general, the men interviewed emphasized the importance of having a support system. The role of wives and other female family members took on greater importance for a number of male participants. Yet, this research raises additional questions such as: What do people do if they do not have a support system? What happens in a same-sex relationship? Half of the participants recruited were a result of snowball sampling. They were not a part of the support group where initial recruiting had taken place. Furthermore, how do individuals cope with potential anxiety and depression? These are areas that this study does not cover and will need additional research.

Summary

Overall, male participants had more similar experiences and symptoms, compared with the women, which may have contributed to an easier diagnosis process, even though there was a diverse age range when participants were initially diagnosed. Unlike the female participants, male participants did not face problems with healthcare professionals believing that they had a legitimate illness. Their experiences were similar to that of a routinely defined illness (Brown, 1995). Despite this, the amount of time it took to receive a diagnosis was not shorter than that of female participants.

One topic that all male participants discussed and expressed their frustrations with pertained to resources available post-diagnosis. At the time of their diagnosis, many did not have any prior knowledge of the disease and follow-up care with specialists only provided vague information. As a result, support systems were also a major theme among male participants. For those who were married, having a spouse had a positive impact on a participant's overall experience with Celiac Disease because they helped research and assisted with food preparation. It was easier for participants to acclimate to lifestyle changes because they had this support from their spouse. For individuals who did not have a support system like this at the time of diagnosis, it was difficult to adjust to changes because they were unsure of how to find information to help them acclimate to the necessary lifestyle changes. Additionally, interviews with male participants showed that more research will be

necessary to understand the dynamics and roles that a support system plays when an individual is in a same-sex relationship, widowed, or single.

Discussion

Gendered Experiences with a Contested Illness and Routinely Defined Illness

Between female and male participants, there were some similarities and some differences in illness experiences after being diagnosed with Celiac Disease. In general, the women had a several atypical symptoms that were not present among the male participants such as nerve, reproductive issues. Four out of the five female participants were initially misdiagnosed before receiving a diagnosis of Celiac Disease. Additionally, female participants expressed more frustration about interactions with healthcare providers. Three out of the five female participants had difficulties with healthcare professionals believing that there was an issue and that it could be Celiac Disease. This prolonged the overall diagnosis process and even created mistrust for the medical community. Women utilized health care services more than men who usually utilize them during a more serious health issue (Courtenay, 2000). Despite this having a greater impact on overall health, utilizing doctors and healthcare resources are still damaging towards a woman's character as it is viewed as a weakness (Courtenay, 2000).

However, for male participants, the issue was not that doctors did not believe the participant, but that each individual doctor had varying levels of

knowledge that pertain to Celiac Disease. Additionally, male participants expressed more frustration with experiences post-diagnosis. They explained that not knowing where to go or who to ask for help was burdensome. This was more prevalent with male participants who were the first to be diagnosed in their family or if they did not have a support system initially post-diagnosis. Courtenay (2000) mentions that, for men, visiting the doctor less is seen as a sign of masculinity and strength which is valued. This is troubling because doctors should listen to their patients and then make a decision while working with the patient to achieve a certain outcome. If judgement is passed prior or based on previous history, patients will not receive consistent quality care and potentially be misdiagnosed or not diagnosed at all with an illness.

Lastly, it is problematic that among gendered diagnosis experiences, Celiac Disease is still stuck between two condition typologies: a contested illness and a routinely defined illness. Diagnosis experiences for female participants reflected that of a contested illness, which a legitimate illness that is questioned and controversial (Brown, 1995). In comparison, diagnosis experiences for male participants reflected that of a routinely defined illness which is generally accepted and diagnosable (Brown, 1995). This is concerning because by definition Celiac Disease should fall under the typology of a routinely defined illness.

Gendered Illness Experiences and the Meaning of Social Support

Additionally, one area of interest that resulted from the interviews pertained to the dynamic of those who were in relationships or married during the

time of diagnosis. Male participants valued the help that wives provided in terms of finding different ways to cook meals or education on the specific details that pertained to Celiac Disease. Some even mentioned that they would not know what someone would do if they did not have help acclimating to these changes. On the other hand, female participants sought out their own knowledge or formed a support group in order to learn more about Celiac Disease. This is particularly interesting due to the manner in which illness experiences can be co-constructed. Women in heterosexual relationships usually take on the role of the primary care-giver in a family unit in addition (Umberson, Thomeer, Reczek, and Donnelly, 2016). This means that in addition to managing their own health, they also monitor and provide care for other members in their households. Taking on this specific role, allows for women to take more of an authoritative approach to health which can impact the outcomes of their spouses health (Umberson, Thomeer, Reczek, and Donnelly, 2016). However, for men in heterosexual relationships, this is not necessarily mimicked. Men are more likely to brush off potential health concerns and postpone medical intervention which can impact care-giving for their spouse (Umberson, Thomeer, Reczek, and Donnelly, 2016).

All participants were recruited through an electronic support group which can be both empowering for a patient and create a safe space, but can also have negative implications depending on the individual. Electronic support groups can take on specially meaning and increase medicalization among those who have contested illnesses (Barker 2008). It allows for an individual to connect with others who may have been through similar situations at their own pace (Rier,

2010). However, depending on the atmosphere of the support group, any attitudes or environment that is perceived as negative can dissuade an individual from wanting to participate and seek help from those who have the same disease or condition. While Barker (2008) emphasizes the potential of electronic support groups to empower patients, it is also necessary to recognize that illness reification (i.e., viewing a collection of symptoms as a unified entity) may perpetuate misinformation and reaffirm in- and out- groups as represented in Diana's experience.

There is a connection that can be made between health or illness outcomes and social relationships (Umberson and Montez, 2010). Greater social involvement or interactions lead to more positive health outcomes. In taking an active role with food preparation and helping with education, it led to a more comfortable understand of Celiac Disease. This also helped those who initially wanted to cheat on their diets to stop cheating on them. Additionally, these findings echo previous research that observed that boys had a more difficult time coming to terms with the diagnosis or did not take it as seriously (Rosen, Ivarsson, Nordyke, Karlsson, Carlsson, Danielsson, & Emmelin, 2011). While there is a difference between adolescence and adulthood, it was still interesting that there were similarities despite a change in age. This indicates an additional area that needs to be explored in order to gain a better understanding of the illness experiences among men who are diagnosed with Celiac Disease.

It is possible that this dynamic exists due to the fact that women are usually the primary care givers in a family unit and may reflect the central role of

spouses for men's support networks, and the propensity of women to do "care" work (Lin, Fee and Wu, 2012). However, this does not take into consideration those who are in same-sex marriages or unions as well as those who are single or widowed. This would need more extensive research in order to gain a better understanding of individuals in these situations.

A final interesting outcome pertained to the absence of stigma among social interactions with family and peers. Experiences shared showed that most people do not understand or know about Celiac Disease which could explain the absence of stigma. There was only one small experience mentioned by a male participant that pointed towards potential stigma. It was a great example of how peers can impact an individual who has to make such a drastic change in their lifestyle. However, it also underscores that individuals in our society still doubt the legitimacy of Celiac Disease leading to experiences similar to those with contested illnesses including stigma (Moore 2014). For female participants, concerns for stigma pertained to eating at restaurants. Additionally, the issue of trust became apparent. The women reported being weary of going to restaurants or new restaurants because they were unsure that they could trust the staff. These findings reflect previous research exploring food allergies (Gupta, et al, 2011). However, this issue may take on particular relevance for women with Celiac Disease because the increase in gluten-free diets has led to greater stigma and skepticism within the public (Moore 2014). Additional research will need to be conducted in order to fully explore if individuals with Celiac Disease are stigmatized as society becomes more aware of its existence.

Limitations

There were a few limitations in this study. This study is difficult to generalize because each individual experiences their illness differently and was largely focused on those who live in the urban Midwest region of the United States. Although there are local support groups, it does not mean that the individuals in these support groups are interested in participating. Additional limitations that occurred pertained to recruitment of male participants through an electronic support group. As a result, three of the six male participants were recruited through the use of snowball sampling and required more time to complete data collection.

Conclusion

In conclusion, Celiac Disease remains as an understudied disease in the social sciences and medical community. In order to gain a better understanding of Celiac Disease, it is vital to conduct research and investigate how it impacts men and women who were diagnosed as adults. Through this study, several important themes emerged from participant experiences. For female participants, receiving a diagnosis was more difficult because they had to go to greater lengths to convince healthcare professionals that there was an issue after preliminary tests showed that nothing was wrong with them. This created distrust between female participants and healthcare professionals because they were treated as if they had a contested illness despite suggesting that they be tested for Celiac Disease. Male participants did not have this issue when seeking out help from healthcare professionals and their diagnosis experiences reflected that

of a routinely defined illness. Both male and female participants expressed frustration concerning resources available to them post-diagnosis. Female participants were more independent when it came to conducting their own research. However, for male participants, they found the lack of information provided post-diagnosis to be the most problematic. They did not know where to look for reliable information that would help them learn how to acclimate to a new lifestyle change. Support systems were also a major theme for both female and male participants. Several female participants turned to support groups or even family members who received a diagnosis of Celiac Disease after their own. For male participants who were married, spouses helped with research, food preparation, and provided assistance. This had a positive impact on the outcome of their diagnosis experience and several mentioned that they would not know what to do if they did not have a support system or someone to help them.

The emergence of these themes raises several questions and indicates areas where additional research needs to be conducted. Among the 11 participants for this study, there were inconsistencies present with diagnosis. Some participants only had blood work completed, others only had an endoscopy or colonoscopy. We need to better understand how healthcare professionals are educated about Celiac Disease and how they implement that knowledge when diagnosing patients to determine if additional training and awareness could improve misdiagnosis as well as under-diagnosis of this disease. The sample size of this study was small and was missing diversity among race and age. African Americans were absent from this study for both male and female

participants and will need to be further investigated to determine if Celiac Disease is prevalent or if it is underdiagnosed in addition to diagnosis experiences. Besides there being limitations with diversity among the participants, the majority of participants were in a committed heterosexual marriage. Additional research will need to be conducted to explore experiences and relationship dynamics of individuals who are single, in a same-sex relationship, or are widowed and how a diagnosis of Celiac Disease impacted their lives. Lastly, most individuals were diagnosed with Celiac Disease later in life. In order to gain a better understanding of how Celiac Disease is misdiagnosed or underdiagnosed, additional research will need to be conducted with added participants that represent a more diverse age range. Without a deeper understanding of Celiac Disease, we will not be able to continue to improve policies, practices, and attitudes as they apply to this disease and other chronic illnesses.

Appendix A:

DEMOGRAPHICS

- 1) Please select the gender you identify with
 - a. Male
 - b. Female
- 2) What is your racial/ethnic background?
- 3) What is your current age?
- 4) What is your current relationship status?
- 5) What is the highest schooling you have attended?
- 6) When were you diagnosed with Celiac Disease?
- 7) How many doctors did you visit before receiving a diagnosis?
- 8) How long did you experience symptoms before seeking medical treatment?
- 9) How long did it take for you to receive a diagnosis?
- 10) How old were you when you received a diagnosis?
- 11) Did you have any prior knowledge or experience with Celiac Disease?
 - a. Yes
 - b. No

12) If you answered “Yes” for question #7, could you provide more detail?

13) On a scale of 1 to 10, 1 being completely unsatisfied and 10 being completely satisfied, how would you rate the quality of medical treatment you received during the diagnosis process?

1 2 3 4 5 6 7 8 9 10

14) After your diagnosis, did you feel prepared by your medical care provider to manage your disease?

Strongly Disagree Disagree Neutral Agree Strongly Agree

SEMI-STRUCTURED INTERVIEW GUIDE

PRE-DIAGNOSIS

1. Could you share what your life was like before you started experiencing symptoms of Celiac Disease?
 - a. Can you provide details of what you considered your overall health to be like prior to Celiac Disease?
 - b. Can you describe any immediate changes in your health?
 - c. How about ways it affected your social interactions or daily tasks?
 - d. How long did you experience these symptoms before seeking help from a medical care provider?
 - e. Can you share any specific experiences that prompted you to seek medical treatment?

DIAGNOSIS

2. Can you describe what your diagnosis experience was like?
 - a. Can you describe any positive experiences with medical professionals?
 - b. How about any negative experiences with medical professionals?

SUPPORT

3. Can you describe what your support system was like during that time?

- a. What did they do to help you acclimate to this change?
- b. By having a support group, do you think it helped you come to terms with being diagnosed with Celiac Disease?

LIFESTYLE POST-DIAGNOSIS

4. Can you describe the changes you made, if any, to your lifestyle after your diagnosis?
 - a. What did you find most challenging about making these changes?
 - b. How long did it take for you to get used to this new life style?
 - c. Can you think of a time where you were tempted to cheat on the gluten free diet? If so, what happened?

SOCIAL INTERACTIONS

5. How did Celiac Disease impact your social interactions and relationships?
 - a. What changed, if anything, within family interactions?
 - b. Did anything change within friend interactions? How so?
 - c. What about more intimate relationships? Has living with Celiac Disease affected that in any way? How so?
 - d. Has this diagnosis had any positive impact on your relationships? How so?
 - e. Has this diagnosis had any negative impact on your relationships? How so?
6. Has Celiac Disease changed the way you interact with others in the way you socialize?
 - a. What are family gatherings/events like?
 - b. Which relatives are easier to work with in terms of compromise at family gatherings?
 - c. Do you have any relatives who make these gatherings difficult? If so, what difficulties have you experienced?

RESTAURANTS

7. What's it like going out to eat now compared to going out to eat before your diagnosis?

- a. Have you had positive experiences going out to eat? If so, could you share any that come to mind?
- b. Have you ever had a bad experience when going out to eat? If so, could you share what happened?
- c. Can you share any experiences with restaurant staff where it was difficult for them to understand the severity of your condition?
- d. What precautions do you take to ensure you are not exposed to gluten?
- e. Are there any criteria or resources that you use to determine if a restaurant is safe to eat at? If so, what are they?

RECOMMENDATIONS

8. Do you think any improvements can be made to the process of how Celiac Disease is diagnosed? How so?
 - a. What could doctors do to improve the outcome of this diagnosis?
 - b. Are there any changes that the FDA could make?
9. Do you have any recommendations for other people who receive a diagnosis as an adult and what kinds of things may be helpful?
10. Do you have any other experiences that you wish to share?

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Curriculum Vitae

Amanda J. Horn

Education

Ph.D. Philosophy

August 2017- Current

Wayne State University

M.A. Sociology

December 2017

Indiana University Purdue University Indianapolis

B.A. Sociology

December 2013

Indiana University Purdue University Indianapolis

Minor in Spanish

December 2013

Indiana University Purdue University Indianapolis

Minor in Medical Sociology

December 2013

Indiana University Purdue University Indianapolis

Publications

In Preparation

Horn, Amanda J. "An Exploration of Diagnosis and Illness Experiences of Women and Men Living with Celiac Disease".

Presentations

Paper Presentations

Horn, Amanda J. "An Exploration of Diagnosis and Illness Experiences of Women and Men living with Celiac Disease". Midwest Sociological Society Annual Meeting, March 2017, Milwaukee, WI. Accepted and Presented.

Awards

Dean's List	2012 - 2013
David C. Bell Theory Fellowship in Sociology	May 2017
Dean's Diversity Fellowship- Wayne State	August 2017

Professional Organization Memberships

Midwest Sociological Association	January 2017- Current
Alpha Kappa Delta	October 2016- Current

Work Experience

GP Strategies Corporation

LMS Data Processor & Course Curriculum Administrator May 2014- Current

- Astellas Pharmaceuticals: Quantitative data processing and analysis for individual, department-based, and system migration projects pertaining to learning management system
- General Electric: Provided troubleshooting and educational sessions for GE employees regarding company learning management system

Harger Farms Inc.

Administrative Assistant April 2014- July 2017

- Compiled and organized active farm accounts in addition to providing assistance with data entry to ensure that proper totals of crop were recorded and invoiced

Indiana University Purdue University- Indianapolis

TCC Supervisor

January 2012- May 2014

- Trained and supervised new computer lab consultants that provided technical support for computer labs across campus