



Women's Experience With Celiac Disease

A Phenomenological Study

ABSTRACT

The purpose of this qualitative study was to explore the lived experience of women who have been diagnosed with celiac disease. Celiac disease is a multisystem autoimmune disease and affects approximately 1% of the population. In addition, celiac disease is seen 1–2 times more often in women and they tend to have more severe disease and treatment burden. Quantitative research has been completed on celiac disease, but there remains a gap related to the implications of the disease from a qualitative perspective. The research tradition used for this qualitative study was phenomenology. Interviews were audio-recorded using a developed questionnaire. Saturation of the data occurred after 12 participant interviews. Following the analysis, 5 themes resulted: (a) Who am I? (b) medical aspects; (c) challenges; (d) daily living; and (e) facing the challenges. There remains a gap in the education, support, advocacy, and follow-up care of this population.

Celiac disease (CD) is an inherited autoimmune disease that causes chronic inflammation in the small intestine after ingestion of gluten. Celiac disease is characterized as a chronic disease with multisystem involvement. Even though there has been an increase in the numbers diagnosed, many adults with the disease remain undiagnosed (Allen, 2016; Ma, John, & Forbes, 2013; Rubio-Tapia, Hill, Kelly, Calderwood, & Murray, 2013). Celiac disease affects approximately 1% of the population and is seen 1.5–2 times more often in women (Bai et al., 2013; Dorn et al., 2010; Shah & Lefler, 2010; Sverker, Ostlund, Hallert, & Hensing, 2009).

Most qualitative research on CD has been completed in other countries, mainly Sweden. Qualitative research done in the United States (U.S.) has focused mainly on children and adolescents. Few qualitative studies were found in the literature looking at the adult experience of having and being diagnosed with CD in the U.S. (Sverker, Ostlund, Hallert, & Hensing, 2007;

Whitaker, West, Holmes, & Logan, 2009). The majority of research is quantitative and thus a gap exists related to the social, physical, financial, and psychological implications of the disease from a qualitative perspective. With the increased diagnosis of this disease, knowing how CD affects the quality of life is important to the health and well-being of women (Lee, Ng, Diamond, Ciaccio, & Green, 2012; Leet, Williams, Bradley, & Butcher, 2013; Shah & Lefler, 2010). In addition, this information can benefit family members and healthcare providers.

Background

Celiac disease previously was termed a rare childhood disease, but today, at least 20% diagnosed are older than 60 years, with an average diagnosis around 40 years of age (Leet et al., 2013). It is reported that diagnosis may be delayed, taking anywhere from 4–11 years or more (Green et al., 2001). Because there are more than 200 symptoms seen in CD, the symptoms that adults presents with may be numerous (Sansotta, 2017).

Symptoms

Adults who have classical CD generally present with symptoms that relate to malabsorption in the gastrointestinal tract. These symptoms may include chronic diarrhea, steatorrhea, bloating and pain, gas, weight loss, fatigue, and irritability (Celiac Disease Foundation; 2019; Dorn et al., 2010; Holmes, 2010).

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Adults diagnosed with nonclassical CD present with extraintestinal symptoms. Adults more often exhibit the nonclassical symptoms, which consist of few or no gastrointestinal symptoms. Common symptoms in this category are fatigue, bone pain, infertility, osteoporosis, anemia, and infertility (Dorn et al., 2010; Holmes, 2010).

Adults who have silent CD have no obvious gastrointestinal or extraintestinal symptoms. However, endoscopy with biopsy demonstrates damage to the intestinal villi (Celiac Disease Foundation, 2019).

Testing

Serological testing and biopsy of the small intestine are the gold standards for diagnosis. Adults with CD test positive for the antibodies on the anti-tissue transglutaminase and the anti-endomysium antibody. In addition, an endoscopic biopsy is performed in the small intestine to determine damage to the intestinal villi (Celiac Disease Center at Columbia University Medical Center, n.d.; Green, Lebwohl, & Greywoode, 2015; University of Chicago Celiac Disease Center, n.d.). There is generally chronic inflammation in the small intestine with damage to the intestinal villi when CD is diagnosed.

Treatment

The only treatment at this time for CD is a gluten-free diet. According to Rubio-Tapia et al. (2013), there are strong recommendations that once diagnosed, a registered dietitian should provide thorough assessment and education to the patient with CD. The patient may see a difference in his or her symptoms within a week, and healing of the small intestine generally occurs within 6 months. Once the diet begins, men have better symptom resolution than women and children have better resolution than adults; however, more research is needed in this area (Sansotta, 2017).

Methods

Purpose

The overall purpose of this qualitative study was to explore the experiences of women diagnosed with CD. Before the collection of data began, institutional review board approval was obtained. All individuals involved in the research study completed the Collaborative Institutional Training Initiative.

Research Tradition

The research tradition used for this qualitative study was phenomenology, which is embedded in the philosophical tradition by Husserl and Heidegger (Polit & Beck, 2017, p. 470). Phenomenology looks at the

specific lived experience of the individual, in this case, women living with CD. The researcher wants to understand their lived experiences.

Participants

Participants were recruited via convenience sampling from the local Celiac Sprue Association support group in a large metropolitan city in the Midwest. Inclusion criteria for participants to be part of the study were as follows:

- Speaks English;
- Female;
- 19 years of age or older;
- Positive blood work for diagnosis of CD (stated by the participant); and
- Positive biopsy of the small intestine for diagnosis of CD (stated by the participant).

Twelve participants who met the inclusion criteria were invited to a tape-recorded, semistructured interview. All interviews took place in an office at a college where one faculty member interviewed all participants. At the interview, the consent form was signed before participants answered any questions. In addition, the participants were informed that they could withdraw from the study at any time.

Table 1 provides the interview questions that were developed to prompt rich descriptions of the experience with the diagnosis of CD. The interview questions consisted of a general lead-in question, three questions related to diagnosis, eight questions related to coping after diagnosis, two quality-of-life questions, and four additional broader questions. At the end of the interview, the participants were asked whether they wanted to share any further information. Data were saturated after the 12 interviews. Each participant received a \$40 gift certificate to a local grocery store for food and a copy of the magazine, *Gluten-Free Living*.

Data Analysis

All interviews were audio-recorded and then transcribed verbatim by a medical transcriptionist. Once the interviews were transcribed, they were housed in a separate file on the researcher's password-protected computer at the college. The qualitative data were then loaded into NVivo 10. NVivo 10 is a software package for qualitative data analysis and produced by QSR International. This tool is designed for qualitative researchers working with rich text-based and/or multimedia information, where deep levels of analysis on small or large volumes of data are required. A modified Stevick-Colaizzi-Keen method for data analysis was used. An outside researcher hired to analyze the data had qualitative research expertise.

TABLE 1. Celiac Questionnaire

<i>General questions</i>
1. Tell me a little about yourself.
<i>Diagnosis questions</i>
In your own words, can you describe your diagnosis of celiac disease?
1. What was the approximate time frame between your initial symptoms of celiac disease and actual diagnosis?
2. How much research about celiac disease did you perform on your own prior to and after your diagnosis?
3. What role does celiac disease play in your personal identity?
<i>Coping</i>
What was your biggest life adjustment to the diagnosis of celiac disease?
1. What is the most significant challenge that stands out in your mind with the diagnosis of celiac disease?
2. Tell me about how you coped with celiac disease at the time of diagnoses.
3. Describe in your words how you felt when you were first diagnosed with celiac disease.
4. Describe the kind of support you received after your diagnosis of celiac disease.
5. How does the diagnosis of celiac disease affect your social life?
6. How does the diagnosis of celiac disease affect your family life?
7. How does the diagnosis of celiac disease affect your work life?
8. How does the diagnosis of celiac disease affect your relationships (work/marriage/family/friends)?
<i>Quality of life</i>
1. Can you tell me how celiac disease affected your life before diagnosis?
2. Can you tell me how celiac disease affected your life after diagnosis?
<i>Broader questions</i>
1. How does celiac disease make you feel now?
2. What role does celiac disease play in your personal identity?
3. Describe your overall experience with celiac disease.
4. Describe the kind of support you receive now.
<i>Is there anything else that you would like to add to this discussion?</i>

Results

Twelve participants volunteered for this qualitative research study related to women's experiences with the

diagnosis of CD. The women ranged in age from 24 to 67 years. The 24-year-old was diagnosed at 2 years of age; however, the majority (70%) of women were diagnosed in their late 40s to 60s. Following the analysis, five themes resulted: (a) Who am I? (b) medical aspects; (c) challenges; (d) daily living; and (e) facing the challenges.

Who Am I

The participants were trying to figure out who they were after their diagnosis of CD. One participant in particular provided the following insight:

Thinking about our conversation, I do not want to give the impression that I am some Pollyanna that just ignores the difficulties of dealing with celiac. However, age has made me appreciate the fact that as the Rolling Stones said, you can't always get what you want. We make compromises every day in the way we live our lives.

According to another participant, "being GF is simple—just don't consume gluten—it's not always that easy." Another participant noted, "In retrospect, this whole process has been an extremely positive one. It has helped clarify not only my thinking about having celiac disease, but many of the emotions that are connected with it." Another participant stated, "And so I went to my doctor and leaned over and said, do I really have celiac"? Finally, one participant explained:

I mean it's like a double-edged sword. I feel better and so that's great and I know what's wrong if I'm not like, you know, she's just crazy, but then again, it's like well, it kind of sucks because enjoying food is a part of life....

Medical Aspects

Under this major theme, one participant stated,

Because celiac has so many varied symptoms and I seem to be reactive to additional things that I wasn't before, I think there are many times when I will be the only one who can correlate what might be causing something and what helps.

Subthemes under the medical aspects theme included symptoms and diagnosis.

Symptoms

The range of symptoms was from none to many. Symptoms most talked about in the interview were gas, bloating, constipation, irritable bowel, weight gain, weight loss, fatigue, fainting, joint pain, headaches, and anemia. Some participants also had no symptoms. One participant, in particular, stated, "... but I can remember just feeling terrible one day and

like laying on the floor in the living room and just moaning.” Another stated, “My energy level has increased [since diagnosis] and my neighbor said, don’t you remember when we’d take our nightly walk that you would say, I’m so tired, I could just lay down in the grass here.”

Diagnosis

The other subtheme under medical aspects was the actual diagnosis. The diagnosis of CD many times occurred when the participants were seeing the doctor for other reasons such as irritable bowel, anemia, miscarriages, osteoporosis/osteopenia, and upset stomach. One participant felt that she had CD for 20 years before being diagnosed with the disease. Another mentioned that she had symptoms of CD since she was a teenager. Most of the participants were diagnosed within 2–4 months of seeing the physician. The mode of diagnosis was laboratory tests and endoscopy with biopsy.

Challenges

Another major theme described by the participants was challenges of diagnoses and living with CD. Under this main theme were the subthemes of eating, financial means, traveling, church, and work.

Eating

Participants felt that the most uncomfortable part or challenge of having to be gluten free was having to make separate meals for the family and eating socially with friends. One participant stated the main challenge was “staying on the diet.” Holidays, events, eating out, and meals with friends and family were seen as big challenges. As many participants noted, food is a big part of being social and therefore a challenge. Another participant felt,

The most challenging aspect of the disease for me is trying to explain to people why I am unable to go to certain restaurants or eat something at an outing such as a wedding. It is particularly challenging and depressing when I attend an event and I am the only one not eating.

Financial Means

All the participants stated that the cost for gluten-free options was expensive. One participant put it into perspective by saying, “...to spend \$5.00 on a 12-ounce box of spaghetti opposed to \$1.00 on a 16-ounce box, you know, that’s been tough. Yeah, it hurts the pocket a lot.” Many times participants had to replace everything in their kitchen. One participant stated, “...probably \$200.00 to \$300.00 we’ve had to spend to replace different foods. I did replace a couple of things [kitchen tools], but I didn’t go to the extent of replacing all my pots and utensils.”

Traveling

Traveling posed another challenge for those diagnosed with CD. Traveling and having access to gluten-free food were always difficult. As one participant described,

It is a struggle to travel, always having to plan ahead and prepare food to take with you. You can never just take a quick run through the drive-thru. I love to travel, but I don’t like the additional thought I have to put into it. I always wanted to take a cruise with my husband but now, I will have to put additional time and research into it to make sure the cruise line provides for a gluten-free diet.

Another participant who was invited to a wedding outside of U.S. had this response, “No, I am not going ... I can’t eat, I can’t drink, I’m just not going.”

Church and Work

Both church and work presented a challenge for those with CD. Participants commented about potlucks at church and work. They have learned to bring their food, which helps with control of the contaminated food [with gluten]. Quite a few of the participants mentioned problems with communion, even though there are now gluten-free hosts. One participant talked about being sick, “...I was sick for the next 6 days after one priest opened up the gluten-free communion wafer and contaminated it.”

Daily Living

As one participant stated, “Having celiac opens up a whole can of worms and I do not want it to define me, but at the same time, it can never be ignored.” Under this main theme were three subthemes of feelings, relationships, and food.

Feelings

There was an array of feelings articulated by the participants once they were diagnosed with CD. Participants were grateful they were diagnosed with an illness that could be controlled and managed with a gluten-free diet. Many of the participants talked about the pity party they had, feeling sorry for themselves that they could not eat what they wanted. One participant stated, “...it is a daily struggle to overcome the thoughts that I can’t have a Twinkie, even though I didn’t eat them before....” Selfishness was a big feeling, as one participant stated, “...everything kind of revolves around what I can eat....”

Relationships

On the contrary, relationships with spouses were not spontaneous anymore. As one participant stated, “... ”

we have to be careful, he has [my husband] to brush his teeth, you know, some sacrifices he has to make.” Another participant explained, “I always have to be prepared; there is no more spontaneity when it comes to ... kissing my husband.”

Food

One participant described food as “the center of my world.” Many of the participants talked about the possibility of food contamination or cross-contamination with gluten. One participant remarked, “Why would anyone put wheat in ketchup”? Another participant stated,

...we can just read a label and then you realize it's not just the labels you really need to know about the manufacturing process ... if it's not made in a dedicated factory or the lines are dedicated, that makes a difference.

Finally, one participant stated about eating out and feeling safe, “Honest to God, I almost cried thinking I can sit here and eat and not have to worry about staying gluten free.”

Facing the Challenges

Under this major theme, the participants felt there were challenges to face after diagnosis. One participant called the digestive system a “...mean machine but it can break down....” Under this theme, there were four subthemes of learn, adjust, advocacy, and support.

Learn

To learn about the disease, participants used the Internet, a dietician, the Celiac Support Association (CSA), and grocery stores. Participants felt that professionals had a lack of knowledge about this disease, and one participant, in particular, was “very disappointed with the lack of education and support from my doctor's office.” On the contrary, one participant noted that the local CSA “provided a good combination of research, physician presentations, sharing personal experiences, and providing helpful tips for this lifestyle.” Another participant stated, “I will never forget Celica's crew helping me over that mountain.” Finally, one participant explained, “Celiac Sprue Association, what a godsend they are....”

Adjust

Adjusting to the diagnosis, participants described binging on food that was not gluten free, trying to find balance in their life, trying to figure it out, and going through stages of grief. They talked about adjusting to the disease through the stages of grief, particularly denial, questioning, and finally acceptance. One participant noted, “I know I must simply do this for the

rest of my life.” Because of the diagnosis, one participant stated, “One has to learn to take food with you, be prepared and have the quick fixes.” Another participant stated, “It is particularly challenging and depressing and inconvenient and at times embarrassing ... I avoid certain foods and feel good, or I eat those foods and feel terrible....” Once the diagnosis occurred, following a gluten-free diet was not easy, as one participant noted, “Being gluten free is simple, just don't consume gluten. It's just not always easy.”

Advocacy

Advocacy was also a subtheme under the main theme of facing the challenges. Participants stated that they had to be an advocate for themselves and for others with the disease. They also felt that the encouragement from others was very important and well-intended.

Support

The last subtheme was support. One participant noted, “...support groups are an important resource. I think women in general are ... open to sharing and so they are more prone to take advantage of them [support groups].” The participants consistently mentioned family, husband, daughters, sisters, and friends as being very supportive as they were diagnosed with celiac. Words that were used to describe the support were phenomenal, understanding, supportive, awesome, saving grace, and accommodating.

Discussion

The purpose of this qualitative study was to explore the experience of women who have been diagnosed with CD. According to the literature, women with CD comprise approximately 70%–75% of newly diagnosed adults and they have more clinically severe disease (Ciacci, Cirillo, Savino, Sabbatini, & Mazzacca, 1995; Shah et al., 2014). Undiagnosed CD appears to affect the health and well-being of women and can lead to poor health outcomes and quality of life. According to Roos, Hellstrom, Hallert, and Wilhelmsson (2013), CD affects all parts of life: past, present, and future (p. 268). In addition, CD has a higher treatment burden than many other chronic diseases (Shah et al., 2014).

Five major themes resulted after analysis of the qualitative data that provided information about being diagnosed and experiencing CD as a woman. The five themes were as follows: (a) Who am I? (b) medical aspects; (c) challenges; (d) daily living; and (e) facing the challenges. Women in this study found that CD diagnosis is a challenge and affects many areas of a person's life psychologically, financially, socially, and physically. In 2005, Sverker, Hensing, and Hallert, explored the dilemmas that men and women experience in their everyday life after the diagnosis of celiac.

The three main categories of the dilemmas resulting from analysis were emotions, relationships, and management of daily living, which relate well to the results seen in this qualitative research study.

Little qualitative phenomenological research has been completed on the aspects of CD in adults, especially in the U.S. The results of this qualitative study will help bridge the knowledge gap that occurs when women are diagnosed with CD. Women in this study were trying to figure out who they were after diagnosis, as it changed so many aspects of their lives. These women were trying to deal with the medical aspects and challenges of the disease on a daily basis. The diagnosis of CD by these women resulted in psychological, financial, social, and physical changes and affected their quality of life. The women had a variety of emotions when they were diagnosed. Some of the women discussed that going through the process of acceptance of the celiac diagnosis was very similar to the stages of grief. These women were grieving over the challenges that eating gluten-free food brings personally and socially. As many of the participants stated, treatment of the disease is eating gluten-free food; however, it is not that easy. According to Rose and Howard (2014), in development of their grounded theory study of CD, one category/theme that resulted was grief. These authors found that their participants described a mourning period before acceptance of the disease, similar to how the women in this study described their grief.

Once diagnosed, the women had to learn about their disease. Some of the women talked about researching their disease to learn more about it. Many of the women mentioned how instrumental the CSA in the Midwest and the individuals associated with the grocery store were to their understanding and coping with the disease. It was very compelling that a dietitian was mentioned only once as being instrumental to learning about the celiac diet. As far back as 2013, Rubio-Tapia et al. provided strong recommendations that once diagnosed, a registered dietitian should provide thorough assessment and education to the patient with CD. One participant stated, "...disappointment with the lack of education and support from my doctor's office." This information relates well with the study results by Zarkadas et al. (2012). The CSA personnel in the Midwest where the women were recruited for this study were mentioned as very important in helping the women understand the disease. The personnel in the CSA are mainly dietitians, or women who have the disease. The CSA also had connections with the grocery store in the Midwestern city and many times held their meetings on the premises of the grocery store. In addition, the dietitians from the grocery store were very involved with the CSA and assisted newly

diagnosed adults and children with their disease and grocery shopping. According to Roos et al. (2013) and Rose and Howard (2014), women felt they had been neglected/ignored by the healthcare system, which mirrors the results of this study. Continued celiac education (physical, social, and emotional) and follow-up needs to be a priority for all those who are diagnosed with CD. Jacobsson, Milberg, Hjelm, and Friedrichsen (2016) found that education, advocacy, and support are needed for those diagnosed with CD. This qualitative study resulted in one main theme of a realigned sense of self in relation to the disease and three sub-themes: (1) togetherness creates strength, (2) comparing creates insight, and (3) knowledge enables reappraisal. Education, advocacy, and support are needed for those diagnosed with CD.

The themes that resulted from this qualitative study are very similar to the model developed in the grounded theory study by Rose and Howard (2014). This grounded theory model had as its center a changed identity, and in the current study, one of the major themes was 'who am I.' Rose and Howard (2014) also found similar themes to help women deal with challenges and everyday living such as the need for education and support.

Limitations

There are a few limitations to this study. Because this study used a convenience sample from the local CSA, the generalizability of this qualitative study will be limited. Verifying the qualitative statements from the participants was very difficult to do and therefore a limitation of the research. Because of the nature of qualitative research, replication of the study and the results may be very difficult. The researcher, who has CD, did not participate in the interviews of the participants or in the analysis or interpretation of the interviews, thus limiting the ethical problems with this type of research.

Implications for Practice

There are many implications for practice that have resulted because of this qualitative research study. According to the literature, support and education are provided for children, adolescents, and their families after the CD diagnosis. In addition, in some of the larger metropolitan areas in the U.S., there are hospitals that have celiac clinics/departments that provide the support, education, and follow-up for adult individuals who have CD. Women living in rural areas, however, may not be getting the support, advocacy, education, or follow-up care needed to deal with their chronic disease. The results of this qualitative study could provide the healthcare team with more compassion and understanding of the lived experiences of

these women and assist in their holistic care and education. Qualitative studies provide information that can help others be more sensitive to the lived experiences of individuals from different care aspects.

Nurses were never mentioned in this qualitative study. However, according to Holmes (2010), they should play a larger role in the support and education of patients with CD. Nurses could provide support, advocacy, education, and follow-up for recently diagnosed patients. In this study, the women provided support and advocacy for each other. In addition, they would seek out information from each other, the CSA, and the websites to educate themselves on the disease.

Celiac disease is considered a chronic multisystem disease that can be a threat to identity and self-esteem with a challenging reality (Roing & Sanner, 2015). In a recent study from Sweden, the researchers reported that women more than men with CD do experience a lower quality of life and report a greater burden prior to diagnosis (Nordström, Lindholm, Sandström, Nordyke, & Ivarsson, 2011). Women diagnosed with CD need to be educated about the disease, especially how it may affect the emotional, physical, and social aspects of their well-being. Support groups for these women may help increase their confidence and provide empowerment with control of the disease. Support groups may also assist with coping and adjustment to the diet and improving overall outcomes for these individuals. According to Jacobsson et al. (2016), providing education and support groups seem invaluable for the women diagnosed with CD. In addition, Peterson and Grossman (2016) agreed that education and guidance are needed for the individual diagnosed with CD.

Another area that was discussed in the literature was the need for yearly follow-up after the celiac diagnosis. The participants of this study felt that there was a lack of education and support from their doctor's office. A doctor's office may be the first point of contact for the women. Physicians, as well as nurses and dietitians, should develop a process for education, support, advocacy, and follow-up for their patients who have CD. Green et al. (2001) found that only 15% of their sample had follow-up care. Roos, Karner, and Hallert (2009) suggested the importance of nurse-led follow-up care for celiac patients. Recently, Allen (2016) reiterated the importance of a multidisciplinary team for education of the patient with CD and family along with follow-up care.

Conclusion

The purpose of this qualitative phenomenological research study was to explore the lived experience of women diagnosed with CD. Twelve women participated in this study. The analysis of the interviews resulted in the following five themes: (a) Who am I? (b)

medical aspects; (c) challenges; (d) daily living; and (e) facing the challenges. Participants provided rich descriptions of what it was like to be diagnosed and live with CD. There remains a gap in the education, support, advocacy, and follow-up care for this population diagnosed with CD. Analysis of the data revealed that the diagnosis of CD resulted in changes in women's social, physical, psychological, and financial aspects, affecting their quality of life. Women in this study provided support and advocacy for each other and would seek out information about the disease. Additional research is needed to determine ways to better educate, support, advocate, and provide follow-up care for these women. ★

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