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Sonya Patricia Quinlan-Jacob

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A WORLD WITHOUT WHEAT: THE JOURNEY TOWARD ACCEPTANCE OF A DIAGNOSIS OF CELIAC DISEASE

by

Sonya Patricia Quinlan-Jacob

A thesis submitted to the Faculty of St. Stephen's College
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I dedicate this thesis to my husband for all of his encouragement, and belief that I would finish this piece of work. I would like to thank him for his help with all of the aspects of our lives that I was unable to focus on during this writing process. I would like to thank my parents for believing in me. Also I would like to thank my program friend for all of her support and conversations about this writing process. I would also like to thank my parents for their faith in me. Without all of these people I have no idea how I would have made it through all of this work. The support of others helped to make my journey lighter.

Abstract

A medical diagnosis can change the life of a person forever. The purpose of this narrative inquiry was to explore how women in their twenties had been given a celiac disease diagnosis and their journey toward acceptance of the diagnosis. Three women were individually interviewed over a 40-65 minute period. The interviews were audio recorded. Following a close analysis of the interview transcripts, the related experiences of the women were placed in a story-map to better visualize their past and present experiences as well as their concerns about possible future complications and questions they had about the future. Six common themes were easily identified in all of the women's stories: 1) experiencing symptoms of undiagnosed celiac disease; 2) importance of communication in the diagnosis process; 3) concerns related to following a gluten-free diet; 4) emotional aspects of acceptance; 5) the role of supports in the journey to acceptance; and 6) changes in self-identity. The role of spirituality was considered as an aspect of the women's experience. This study helped to identify what made it possible for these women to journey toward acceptance of their celiac diagnosis.

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Chapter 1: Introduction

Life as I knew it ended for me on June 25, 2006 with the results of a medical test. During a follow-up visit, my family doctor confirmed that I had celiac disease. In response to hearing this news, my mind became numb. For a number of minutes, I was unable to absorb anything that the doctor shared with me. I knew very little about celiac disease. I was 27 years of age. I had considered myself a typical young woman. The shock of this moment ran through me like lightening, changing my life forever. The way in which I understood myself and how I fit into the world suddenly vanished. Numerous questions plagued my mind: What had I done to deserve this? How was I going to live my life after this diagnosis? I felt overwhelmed. How does one go on when you are told that the way you used to live your life is no longer feasible?

My situation was incomprehensible to me. I experienced a serious disconnect concerning God and my diagnosis. Why was I chosen from so many to be given this disease? I wanted to shake my fist at God. I felt that I had been a good person. How could I have been a better person to avoid this diagnosis? I felt that there should be answers to my questions somewhere. I struggled to find them.

I was referred to a dietician, but what was I to do in the meantime? I did not know anyone with the disease. I had no idea what I could eat or where to shop for food. I worried about the stigma of having a disease, and the odd looks I felt people would give me when I told them about my diagnosis. Most of my social interaction with people outside of work centered on food. I did not want to be different from others that I socialized with. I no longer felt like a person, but a disease instead. Was I going to lose friends over this, or were people going to be supportive? Was my partner going to stand by me through the life-altering changes that I was going to have to make? There were so many questions and so few answers.

My faith played a significant role in my initial response to my diagnosis. At the time of my diagnosis, God was a very important part of my life. I felt a need for spiritual guidance or support in my life in relation to my diagnosis, and was unsure where to turn for this support. I found comfort in the idea that God does not give us more than we are able to handle. According to 1 Corinthians 10:13: "… God is faithful; he will not let you be tempted beyond what you can bear. But when you are tempted, he will also provide a way out so that you can stand up under it" (The Holy Bible, 1984, p. 653). I understood this to mean that God believed I could handle this diagnosis and the hardships that I was going to have to endure. My faith in myself was not as firm. My faith community might have been able to relate to my crisis of faith, but I was unsure that they could relate to the health crisis I was experiencing.

Problem Statement

The Canadian Celiac Association (2010) estimates that "1 in 133 persons in Canada are affected by celiac disease." With respect to the United States, Green and Jones (2006) report that 97% of people with CD are undiagnosed (p. 3). There is evidence that celiac disease (CD) affects almost twice as many females as males (Megiorni, Mora, Bonimico et al., 2008). Dr. Alessio Fasano (2008), one of the leading researchers in this area, suggests that many cases of CD go undetected because "CD often presents in an atypical or even silent manner" (p. xii). In addition, many clinicians are unfamiliar with the condition, while relatively uncomplicated screening procedures can help diagnose CD including “specific blood tests and an intestinal biopsy” (Green, 2006, 44).

Many people with celiac disease report being misdiagnosed with many other conditions before being finally diagnosed with CD. The Calgary Chapter of the Canadian Celiac Association (2005) has provided information that outlines the difficulty of diagnosing CD:

> The symptoms of celiac disease can be vague and varied and often mimic symptoms of other diseases. Some people display no apparent symptoms of the disease. Diagnosis is frequently the result of identifying the cause of some seemingly unrelated condition. Symptoms can include: depression, learning difficulties, or severe irritability. (p. 3)

Many people with celiac disease report that they have waited a number of years for an accurate diagnosis. I experienced my initial symptoms in infanthood and it took 27 years for me to receive my CD diagnosis. The passing of so much time between the presentation of initial symptoms and a diagnosis of CD can lead to confusion and doubt. A person struggles with their health while the medical system is not able to determine what is happening to them. After receiving a diagnosis of CD, an appointment with a dietician can help patients become informed about a gluten-free diet and how this can help improve their health. Subsequent follow-up visits with family doctors and other specialists typically also occur. The focus is on the patient’s physical health, but what about their mental health and overall well-being?

Purpose of the Study

The journey toward acceptance can be a challenging one for those diagnosed with celiac disease. In this thesis, I explored the experiences young women have in relation to coming to accept a diagnosis of CD. I had wondered if my experiences following my initial diagnosis were similar to or different from those of other young women diagnosed with CD. I was curious as to what helped young women move forward toward acceptance following a CD diagnosis.

Choice of Methodology

Narrative inquiry allowed me to consider the stories of young women who were willing to share the experiences of their journey "across times, places, and situations" (Clandinin, 2007, p.77). The journeys that we take in our lives happen across time, in many places and in different situations. These journeys make us who we are. They contribute to the ongoing formation of our identity. Narrative inquiry, allowing for a close listening to personal stories, can be considered "a procedure for collecting and documenting a category of data or as a process through which data are collected around specific research questions" (Clandinin, 2007, p. 79). In conjunction with narrative inquiry, I used story mapping to outline and clarify the experiences that my participants shared (past and present), as well as their future-related concerns, hopes and aspirations. I identified excerpts from the transcripts in relation to identified themes to support inferences drawn from the data.

Definitions

Llewelyn Bower (2007) defines celiac disease[1] "as a multisystem disorder that causes the body's immune system to respond to protein in certain grains" (p. 2). The Canadian Celiac Association (2006) describes celiac disease as:

> a medical condition in which the absorptive surface of the small intestine is damaged by a substance called gluten. This results in

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[1] Two spellings for celiac disease are used in this thesis. In North America "celiac disease" is used, but in Europe it is spelt "coeliac disease." Throughout this thesis I will be using the two spellings depending on the author I am referring to, or citing.

> an inability of the body to absorb nutrients: protein, fat, carbohydrates, vitamins and minerals, which are necessary for good health. (para. 1)

Gluten is defined as "the term for storage protein of wheat" (Green and Jones, 2006, p. 22). Llewlyn Bower (2007) discusses the importance of a gluten-free diet: "making sure your food is gluten-free is the key to staying healthy" (p. 27). A person with CD must avoid eating wheat, rye, barley and oats in order to maintain or improve their health. The reason for the elimination of oats is that food companies that process oats typically also process wheat products.

In this study "coping" refers to a person's management skills as this relates to the process of adjusting to a celiac disease diagnosis. Markers of coping included functioning well in daily situations that include wheat, being able to express that they have the disease in social situations, and continuing to eat in social settings despite instances of unknowingly ingesting gluten. Green and Jones (2006) examined the importance of coping skills in adopting a gluten-free lifestyle. They state that "a person's reaction to illness or any other trauma is determined by their individual style and coping skills. Some immediately take control ...", while "others must develop these coping skills" (p. 263).

I defined having "acceptance" of a diagnosis of celiac disease as a change in mental attitude after resisting or denying a situation that should be accepted as true. Markers of acceptance included not only following the gluten-free diet but also having a positive attitude about having the disease. Another marker of acceptance was openly acknowledging one's diagnosis to others.

For the purpose of this study, I defined "spirituality" as the values, beliefs and meaning that people assign to their life, which inform and guide their daily lives. Coll

(1998) states that “spirituality has to do with the values people hold; it has to do with what is ultimate in people’s lives, it has to do with what meaning they assign to life. It has to do with how we relate-to ourselves, to other people, to all of creation” (p. 175).

Significance to Counselling

The significance of this study for those involved in the counselling field lies in the potential for increasing the understanding of the journey of young adult women as they come to accept a diagnosis of celiac disease. Much of the literature indicates that receiving a diagnosis of a serious illness or disease can be profound and life changing. Learning about what contributes to accepting a CD diagnosis, and living well with CD, can be used to help others who are newly diagnosed. Insights gained from this study about the journey to acceptance can help counsellors better understand and support newly diagnosed patients.

The literature suggests that people with celiac disease often struggle with depression. According to Llewelyn Bower (2007), “depression is common among people with CD and that a GFD (gluten-free diet) sometimes helps depression” (p. 41). They suggest that patients with CD “must be aggressive concerning improving all aspects of her life, including physical, psychological, and spiritual well-being” (p. 41). Increased awareness of the psychological needs of patients who receive a CD diagnosis will hopefully help this patient group obtain enhanced support and resources.

In addition, I hope that information from this study will help those who are newly diagnosed with celiac disease to better understand the disease, and the process of adjusting to a CD diagnosis. The findings from this study may also result in the medical community and other organizations in providing more supports and resources to CD patients.

Assumptions

Based on the literature in this area, as well as my own experiences, the following assumptions informed this study:

- Young adult women may have unique concerns and issues related to receiving a diagnosis of celiac disease, relative to other patient groups;
- Young adult women with CD have the ability to articulate their own experiences;
- Given their responses to a series of questions, it can be determined if young adult women have accepted their diagnosis of CD;
- Young adult women will be open and honest when asked about their experience of being diagnosed with CD.

The existing literature suggests the validity of these assumptions. For example, one of the women interviewed by Dowler Shepard (2008) asked “Who would fall in love with a twenty-four-year-old with so many health problems?” (p. 33). As another example, James Ahern (2007) described her experience of receiving a CD diagnosis, the struggles that she had, and how it was that she was able to move toward acceptance.

Summary

Accepting a diagnosis of celiac disease can be fraught with difficulties. Through this research I explored how young women came to terms with their diagnosis of CD. Specifically, I wanted to deepen the understanding of the experiences of young women who have received a CD diagnosis and all that entailed for them, including the spiritual dimension of this experience. In undertaking this study, I hoped to contribute to the information that practitioners in the field have available to them, so that they are better able to work with those who have been recently diagnosed.

Chapter 2: Literature Review

Much of the research on the experience of being diagnosed with a serious illness or life-threatening disease is relevant to celiac disease. Many people struggle to adjust to a serious medical diagnosis regardless of the specific condition they are diagnosed with, although aspects of a particular diagnosis will introduce unique challenges that patients need to face. Many of the studies in this area have investigated how people initially responded to their diagnosis, and the factors that helped them to cope with having a serious illness or disease.

Receiving a Life-Changing Medical Diagnosis

People experience strong feelings when they are given a life changing diagnosis, which can influence how they begin to process and cope with their diagnosis. Isaksson and Ahlström (2006) conducted an interview-based study that explored the diagnosis and illness experiences of 61 multiple sclerosis (MS) patients. Many of the patients in their study had difficulty believing the diagnosis they were given. There was a sense of being in shock and being unable to absorb what the doctor was telling them. Some wondered, “Why me?” (p. 234). They felt that their diagnosis was unfair. Some patients who were religious wondered if they were being punished because they had upset God in some way. These individuals experienced a lot of emotional turmoil as they struggled to understand their diagnosis.

The way in which a physician delivered “bad news” to patients also significantly impacted how they receive their diagnosis. Isaksson and Ahlström (2006) described how the participants felt vulnerable in relation to the care they received given “communication problems, long waiting times, or lack of kind treatment” (p 231). They found that most of their MS participants experienced distress and other strong emotional responses following their diagnosis, which influenced how they coped with their diagnosis. The emotional burden of an MS diagnosis included “anxiety, fear, uncertainty, sadness and sorrow, shame, mistrust, anger, confidence, repression, and wishful thinking” (p. 231-232). They found that a patient’s response to their diagnosis depended on their pre-existing understanding of MS, which “ranged from the negative image Disablement and Death to a Nuanced Picture of MS” (p. 230).

A longitudinal study into the experience of 55 adult women diagnosed with human immunodeficiency virus (HIV) was conducted by Stevens and Hildebrandt (2006). Asked about their diagnosis experience, many of the women in this study described their healthcare provider as being “uninformed, frightening, or flippant” (p. 213). Frequently, the women were told about their diagnosis over the telephone. Less than 10% of their informants (3 of 55 women) experienced their healthcare provider as being kind and helpful when they shared their diagnosis. In addition, few of the healthcare practitioners provided information and support in the weeks following their diagnosis.

Most of the women, feeling depressed and alone when they learned of their diagnosis, felt there was little support or hope for them. They “remembered the mortality statistics or flippant remarks instead of any kindness that might have been shown” (p. 218). The women in this study reported feeling devastated, shocked and outraged when they received their diagnosis. Many of the women suffered from depression that lasted months, and in some cases years. They reported escalating drug and alcohol use, they felt scared and ashamed, and some contemplated suicide. This study strongly suggests the need for ongoing post-diagnosis support.

Power, Brown, and Ritvo (2008) conducted interviews with 30 women diagnosed with ovarian cancer. Interviewees shared that their diagnosis was “often delayed due to lack of awareness of symptoms combined with misdiagnosis” (p. 371) on the part of their treating physician. Many described being shocked by their diagnosis. Still, most of the women described the physicians and nurses that treated them as “very approachable,” and felt that they “truly understood what they were experiencing emotionally as a cancer patient, in addition to being highly capable at their jobs” (p. 373). A smaller percentage of women felt that they did not receive information or support in a timely or adequate fashion. They also found that information was not readily available. Many spent a lot of time searching the Internet and other sources which given the nature of much of the information available, such as mortality rates, was anxiety-provoking. The women who experienced communication difficulties and limited availability of physicians shared that this contributed to their distress.

During the diagnostic phase of breast cancer, Boehmke and Dickerson (2006) found that women experienced “a range of emotional responses, including fear, shock, grief, anxiety, and anger” which influenced their ability to process their diagnosis (p. 1122). Not expecting the diagnosis, the women described being suddenly thrust into a world of illness when they received the results of their mammogram. Several aspects of the women’s lives were affected by their diagnosis, including their emotional well-being, physical health, their family and their work, as well as other support systems. Many of the women described their experience of diagnosis and treatment as contributing to “an ‘erasing of a former self’ because of physical and emotional alterations” (p. 1123). Their changed body image negatively influenced their sense of self in relation to their feminity. One of the women shared: “I don’t think the person in the mirror is me. I don’t look the same. Everything has changed. …. I’ll never be the same person again. I will always be different” (p. 1124). Over half of the women in this study viewed themselves as “fighters and survivors” (p. 1124). They did not complain about what they were experiencing; the cancer was something that “just had to be dealt with” (p. 1124). The women felt that there were other more important things in their lives that needed their attention. Once they got over their cancer they would be able to get back to their lives.

Robinson, Clarke, and Evans (2005) conducted a study with nine couples that explored the impact of receiving a dementia diagnosis. Some of the key themes identified in this study involved grief and loss and the impact of the diagnosis on their social identity. Robinson et al. concluded that the “social stigma of receiving a diagnosis of dementia has been revealed as a key issue for many resulting in some people with dementia attempting to cover up or minimise their difficulties” (p. 338). Even though people had not lost their partners, they still struggled with the knowledge of what the future held and grieved their past. This study showed that “a positive state of mind was emphasised by several couples as a crucial part of adapting” (p. 344). Robinson et al. recognized “a need for services to provide psychological and psychosocial interventions around the time of receiving the diagnosis” (p. 346).

How a diagnosis is shared with a patient can influence how they receive and ultimately come to accept their diagnosis, and can also influence the choices they make in relation to their health. Stevens and Hildebrandt (2006) found that “the degree to which providers were personally warm, respectful, and sensitive, was more important to test recipients” (p. 218) than many other aspects of their diagnosis. They recommended that newly diagnosed HIV patients receive supportive counselling after their diagnosis, and also suggested the need for ongoing support as may be needed in individual cases. Boehmke and Dickerson (2006) found that when supports were removed many of the women in their study felt “the sense of aloneness was profound and moving” (p. 1124).

The Experience of Being Diagnosed with Celiac Disease

As described in the preceding section, the way in which a medical diagnosis is shared with a patient can have a tremendous impact on their ability to accept their diagnosis. In addition, the lag between initial symptoms and receiving an accurate diagnosis, as well as the extent to which a diagnosis is expected or anticipated can also influence how a patient receives a medical diagnosis.

A variety of symptoms may present over many years before an individual receives a diagnosis of celiac disease. Dowler Shepard (2008) states that: “Because an unhealthy intestinal tract can affect virtually any other system in the body, celiac symptoms are often difficult to distinguish from the symptoms of many other conditions” (p. 5). Having to wait so long for a diagnosis can be trying and tiring for the patients. Over the course of numerous years, a patient may go to the doctor for many problems. Receiving multiple diagnoses can leave patients feeling confused and frustrated with the health care system, as well as concerned about their health. Dowler Sheppard (2008) believes that a more holistic approach to health care would help CD patients receive an accurate diagnosis sooner.

Green and Jones (2006) and Llewelyn Bower (2007) suggest that in the end, many people diagnosed with celiac disease suspect they have the disease. They report that people with CD ask their doctors to be tested after reading about it on the Internet or in books. Green and Jones recount the experience of one woman with CD:

> I finally looked in an old medical textbook and read the paragraph on celiac disease. I called the gastroenterologist and told him. My husband is a physician and I read him the paragraph. He said, ‘You would have lost a lot of weight. No one at forty-three has celiac disease.’ I was actually a typical case. (p. 58)

Coping with a Diagnosis of Celiac Disease

The adjustment that one faces after receiving a diagnosis of celiac disease is difficult for some, and easier for others. According to Griffiths (2008) “the impact of diagnosis depends not only on their symptoms but also on other factors such as age at diagnosis, family support, their role in society, relationships and even concomitant illness” (Griffiths, 2008, p. 127). Studies show that while the emotions experienced by people with CD are widely varied, emotional issues related to food and socialization are common. These issues present special challenges for coping with celiac disease.

In 2002, Hallert et al. conducted a study with 68 men and women who had been living with celiac disease for over 10 years. Following a gluten-free diet was a struggle for many of their study participants, particularly in relation to participating in leisure activities and social situations. Study participants reported a fear of being different from others. Sverker, Hensing and Hallert (2005) interviewed 43 women and men, aged 20-40 years, using a ‘critical incident technique’ to explore the types of challenges and dilemmas that the participants experienced as a result of having celiac disease. Managing emotions, relationships, and challenges of daily life were identified as the three main categories of difficulties that the participants faced. The emotions that the participants experienced as a result of CD included a sense of isolation, as well as "shame, fear of being contaminated by gluten, and worries about being a bother" (p. 175). Sverker et al. found that people with CD have a strong sense of being isolated from others because they are unable to eat gluten and they find it difficult to take part in social interactions with others. The women reported that their family and friends did not want to cook gluten-free food even when they knew they were on a gluten-free diet. They were offered glutinous food which they were not able to eat, so they felt excluded.

It has been suggested that post-diagnosis support can be of great benefit to patients recently diagnosed with celiac disease. Bebb, Lawson, Knight, and Long (2006) conducted a study that asked about the kind of support and follow-up people with celiac disease (who had been diagnosed on average 5.4 years earlier) would recommend post-diagnosis. What was most preferred by individuals with CD was long-term follow-up with a dietician, with access to a doctor if needed. However, findings described by Haller et al. (2002) and Sverker et al. (2005), also suggest that psychological and social aspects of CD need to be taken into account in terms of the support offered to CD patients, in addition to attending to dietary concerns.

Medical Complications Resulting from Celiac Disease

Llewelyn Bower (2007), among others, has identified that celiac disease is best treated by following a gluten-free diet. She has identified the following as key elements in the management of individuals affected by CD: 1) consultation with a skilled dietician; 2) education about the disease; 3) lifelong adherence to a gluten-free diet; 4) identification and treatment of nutritional deficiencies; 5) access to an advocacy group; and 6) continuous long-term follow-up by a multidisciplinary team (p. 80).

Regular medical check-ups are very important for people with celiac disease. Given that CD affects multiple systems of the body, it is not surprising that people with CD are at risk of osteoporosis, vitamin and mineral deficiencies, anaemia, and problems with folate (Llewelyn Bower, 2007). Difficulties in any of these areas could lead to further complications.

Problems with fertility have also been associated with having celiac disease. If a woman has undiagnosed or untreated CD, getting pregnant or maintaining a pregnancy can be problematic. Green and Jones (2006) state that "studies have demonstrated that women diagnosed with celiac disease are often able to get pregnant, but have an increased rate of spontaneous abortions (miscarriages), accounting for fewer children" (p. 148). Dowler Shepard (2008) states that "studies have shown that as many as 6 percent of infertile women are undiagnosed celiacs" (p. 132). If a woman has reproductive problems, Llewelyn Bower (2007) suggests that she should ask her doctor to test her for CD. Green and Jones note that studies have also found that males with CD also struggle with reproductive problems, suggesting that men who are trying to have children also ask fertility specialists how their CD may be presenting difficulties for them.

Theological and Spiritual Insights

Researchers have shown that elements of religion have influenced people's overall health and well-being throughout the ages. Thoresen and Harris (2002) state that "ancient wisdom, situated within major religions, echo much of the message voiced by Hippocratic medicine in ancient Greece, the notion that lifestyle (including beliefs, emotions, and behaviours) powerfully influences health and risk of disease" (p. 3). It is within this that people are able to connect the spiritual (with implications for meaning and purpose in life) with “a greater sense of inner peace, harmony, hopefulness, and compassion for others and oneself” (Thoresen & Harris, 2002, p. 4).

In a number of studies, it has been shown that being involved in a religious community has a positive impact on people’s physical health factors. A review of the literature by Thoresen and Harris (2002) found that “in the NIHR [National Institute of Healthcare Research] consensus report, Matthews, Koenig, Thoresen, and Friedman cited studies providing some evidence to link religious involvement, usually frequency of religious service attendance, with physical health factors” (p. 5). This review highlights the importance of religion/spirituality on physical health but does not address the psychological impact. Thoresen and Harris (2002) state that

> assessing for more psychological factors would permit examination of possible interaction effects of certain person factors with certain religious factors (e.g., how narcissistic personality characteristics interact with religious attendance or with a person’s beliefs about God, such as strict and punishing God vs. a loving and forgiving God. (p. 7)

As multiple factors, including “one’s RS [religious and/or spiritual] beliefs and practices” can influence health and disease risks, Thoresen and Harris (2002) believe that healthcare professionals need to consider “RS factors” in relation to their patients and health outcomes, and would benefit from training in this area (p. 10).

The way a person defines their sense of spirituality influences their values, beliefs and approach to life. For example, Lauver (2000) describes feminist spirituality in relation to "the ability to be self-affirming for life-enhancing mutuality" (p.79). Women develop their spirituality through connecting with one another. Lauver suggest that by “connecting with Spirit within oneself, other women, and community, women’s spirituality may be fostered” (p. 79). For women, being able to connect with themselves through their body provides a connection to the divine.

Lauver (2000) states that “over the last 10 years, women’s health increasingly has been recognized as an important focus among women and health care systems. Over the same period of time, interest and participation in women’s spirituality have grown dramatically” (p. 76). Women’s spirituality in health has also been recognized as an important area that requires increased study and focus. Lauver suggests that “(c)linicians can consider how ideas from women’s spirituality relate to their conceptualization of women’s health and guide their practice” (2000, p. 77).

The way in which women approach spirituality is different from men. The focus is on “women’s lived experience” (Lauver, 2000, p. 80). Women are creating rituals and sacred space for themselves. Lauver explains that “as women re-construct rituals, language, and symbols based on their experiences, they value and affirm these experiences” (p. 80). Within this re-creation, there is a stronger focus on the body and the inherent beauty of women’s bodies. “Woman-centered symbols serve to propose greater-meaning, to affirm women’s lived and spiritual experiences that are rooted in their bodies, and create a context for women’s empowerment” (Lauver, 2000, p. 81). Placing women at the center of their spiritual practices can help to empower them.

Empowering women in their spirituality carries over to other areas of their life, including their health. In the past, women were located peripherally at the margins of decision-making that occurred in regards to their own health. A caring and egalitarian experience with medical professionals is considered a requirement of acceptable health services (Lauver, 2000, p. 81-82). There is a need for a positive relationship between women and the health professionals that treat them. Lauver (2000) states that

> relationships are central to women's psychological development and integration, to women's empowerment, and to women's social roles. Contrary to other developmental theorists, contemporary feminist theorists have proposed that it is through relationships with others that many women learn who they are and what is of ultimate importance (p. 82).

The relationships that women create with others, including their healthcare providers, affect their overall well-being. If they do not have a positive relationship with their healthcare providers, especially during illness, their sense of self and the divine can be greatly impacted. Women are empowered in their health and well-being when they have positive, supportive, and connected relationships.

Spirituality, Coping and Chronic Illness

Research that has focused on the area of spirituality and health suggests that spirituality and religious faith can help people cope with disease and illness. Cooper-Effa, Blount, Kaslow, Rothenbery and Eckman (2001) have defined spirituality "as the capacity to rise above life experiences, to celebrate life, and to experience joy" (p. 117). They studied the role of spirituality in patients with sickle cell disease and found "a positive relation between existentialism and depression, and a direct association of spirituality with hope or future-oriented goal setting" (p. 117). Religious and spiritual forms of coping can help people who have received a medical diagnosis to move forward in positive ways. Spiritual well-being has been associated with positive coping and adjustment among those affected by disease and chronic illness.

Yanez, et al. (2009) explored the influence of spirituality in relation to adjustment to cancer with respect to two distinct components of spiritual well-being: meaning/peace and faith. The authors defined meaning/peace as one's sense of meaning and purpose in life. Faith was defined as "perceived comfort derived from a connection to something larger than the self" (p. 732). Patients who reported having achieved "meaning/peace", reported better adjustment to cancer, and an overall enhanced quality of life. Higher scores for meaning/peace, in combination with increased scores observed over time, were inversely associated with depression and positively associated with enhanced vitality over a one year period. Faith was found to be unrelated to most outcomes, except for perceived cancer-related growth. Yanez et al. (2009) describe their findings as underscoring "the greater adaptive value of finding meaning and peace" (p. 739) in relation to the experience of well-being when struggling with cancer.

Studies have also shown that spirituality and religious beliefs are associated with lower levels of depression among those living with HIV. For example, Peréz, Chartier, Koopman, Gore-Felton, and Spiegel (2009) studied the effect of "spiritual striving", defined as "the process of consciously trying to grow spiritually and pursuing a meaningful and fulfilling daily life" (p. 89), on depression as experienced by 180 adults with HIV/AIDS. They found that spiritual striving had both direct and indirect effects on experienced depression: "Higher levels of spiritual striving predicted lower levels of depressive symptoms, and acceptance as a coping style partially mediated this relationship" (p. 94).

Büssing et al. (2009) studied the role that spirituality and religiosity played in the lives of 580 patients who suffered with chronic pain conditions. They found that about one-fifth of the patients reported having "renewed interest in spiritual/religious issues because of their illness" (p. 332). Close to 60% reported searching for "grounding and meaning in their life," but distinguished this from "interest in spiritual/religious issues," which the researchers interpreted as meaning that they had not considered questions of meaning in the context of spirituality. Büssing et al. (2009) found that patients who identified as being spiritually oriented managed their lives differently than other patients. Spirituality/religiosity was associated with "positive disease interpretation" and "reappraisal: illness as chance" (p. 336). They also found a relationship between intrinsic religiosity and spiritual orientation and patients' positive interpretations related to their disease condition, such as viewing their condition as providing a valuable challenge in their lives.

Distinctions between spirituality, faith and religious involvement and affiliation are not always well addressed in studies that deal with the role of spirituality and religiosity in relation to illness, health and well-being (Tanyi, 2002). Nevertheless, there appears to be good evidence that spiritual and faith-based coping may affect a number of different psychological, and emotional, and also possibly physiological domains that influence adjustment to a number of different health conditions, including chronic pain. Waccholtz, Pearce, and Koenig (2007) reviewed the literature on the relationship between spirituality, coping, and pain and concluded that:

> R/S (religious/spiritual) coping correlates with feelings of spiritual support, spiritual connection, peace, calmness, and decreased anxiety and results in an improvement of mood. More positive mood has been correlated with decreased sensitivity to pain and increased ability to withstand the impact of negative situations. (p. 316)

They suggest that there is value in exploring the various pathways by which spirituality might influence positive health outcomes, including "meaning-making attributions, self-efficacy, distraction, spiritual support, and relaxation as potential mediators." They also suggest "there may be something unique to religion" (p. 316).

The Role of Spiritual Assessment in Healthcare

Recognition of the spiritual dimension of health has led to increased discussion of the potential role of spiritual assessment in healthcare. Many patients are interested in having their physician talk to them about their spiritual needs. Büssing et al. (2009) found that 37% of the chronic pain patients in their study wanted to talk to their doctor about their spiritual needs. Perez et al. (2009) also found that the participants in their study expressed an interest in having health care professionals assess their spirituality and spiritual supports. Hanson et al. (2008) cites a review that found "between 41-94% of patients want their physicians to inquire about spiritual needs" (p. 907-908). Variability across the studies reviewed was related typically to the disease that a person was diagnosed with, and where they were in their illness journey (e.g. if they are facing end of life issues or not). Those facing the end of life were more interested in being asked about spiritual concerns in relation to their health.

Assessing spirituality in connection with other standard assessments can help healthcare professionals provide or suggest additional supports and coping resources that can help patients in relation to their health concerns and challenges. Christina Puchalski, MD, of the George Washington Institute for Spirituality and Health, suggests another important contribution of heightening awareness of the spiritual dimension of the illness and healthcare experience. She states:

> Patients learn to cope with and understand their suffering through their spiritual beliefs, or the spiritual dimension of their lives. It is also through that dimension that I think the compassionate, caring part of the doctor/patient relationship is enacted. (Puchalski & Romer, 2000, p.129)

The variety of definitions and understandings of the role of spirituality in relation to health evident in the literature across researchers, and also individual patients, suggests that a spiritual assessment should not impose a particular view of spirituality, but seek to explore the views, thoughts, and experiences of individual patients. Based on their findings, Yanez et al. (2009) suggested that:

> it may be more important to discuss spirituality in terms of the patient's sense of meaning rather than religiosity, with the ultimate goal of establishing contentment and fostering purpose in life. … clinicians might wish to discuss how faith and other approaches can serve to promote a sense of meaning in life. (p. 739-740)

Spirituality is not an area that healthcare providers are comfortable discussing with patients, nor are they always comfortable in providing spiritual care to patients. Hanson et al. (2008) interviewed seriously ill patients and their family members about the people they identified as providing them with "spiritual care", extending from help with relationships and coping with illness, to religious ritual and intercessory prayer. The people that provided spiritual care for many of the patients were identified as being family and friends (41% of the identified spiritual care providers), health care providers (29%), and clergy (17%). While their findings support the importance of providing spiritual care, Hanson et al. suggest that more research is needed to determine how best to meet the expressed needs of patients and their families. They also suggest that "strategies to meet the demand for spiritual care could include expanding the presence of clergy in healthcare" (p. 912).

Patients that identify spirituality as playing an important role in their lives cope with their diagnosis differently than patients that do not identify with spirituality in their lives. Many patients in these studies reported a desire for their doctors to ask them about their spirituality. They are not looking for the medical community to impose a specific set of beliefs on them but rather explore their values, beliefs and spirituality with them. There was an expressed need for this kind of support from their doctors. Spiritual care reportedly helped people cope with their illness. Having spiritual support aids in coping with some of the psychological as well as physical effects of the disease. Addressing their spiritual needs can also assist in personal growth.

Spiritual Applications in Health

When exploring the psychological dimension of a person's experience of illness it is important to consider their spirituality. Counsellors have reported that spiritual interventions have been of value in working with clients. Harris, Thoresen, McCullough, and Larson (1999) discuss how "studies examining spiritually augmented cognitive-behavioural therapies, forgiveness interventions, different meditation approaches, 12-step fellowships, and prayer have provided some evidence, albeit modest, of efficacy in improving health under specific conditions" (p. 413). In this study they discuss how a person's thoughts and actions can impact their own health.

It is possible for a person to have an effect on the health of another without even knowing all of the details of that person's life. One of the studies that Harris et al. (1999) reviewed detailed a double-blind study which showed that with nominal information prayer improved the health condition of strangers: "Results showed that patients in the prayer condition did substantially better than control patients on a number of health-related outcome categories" (p. 422).

Harris et al. (1999) also examined the significant impact that meditation had on patients with confirmed heart disease and discovered that there were "dramatic reductions in physical symptoms and improved overall health" for patients in the experimental group (p. 419). They debated the impact that these therapeutic interventions have on the lives of people that are having health issues. It is important to note that Harris et al. do not view health as being “the absence of physical disease or illness.” Rather they define health as “the relative presence of positive characteristics, particularly the level of available energy that benefits the individual mentally, physically, spiritually, or otherwise in coping with the demands of daily living” (p. 414-415). The way that one defines ‘health’ will influence the approach that a counsellor uses to work with patients with health issues.

There is a strong relationship between a lack of spiritual practice and distress. In a study of the relationship between distress and spirituality conducted by Kohls and Walach (2007), “data revealed that the pathways to distress are different for spiritually practicing and non-practicing individuals” (p. 1311). This suggests that people in their study that practiced spirituality regularly “suppressed the pathways of experiences of ego loss towards distress” (Kohls & Walach, 2007, p. 1314). When a patient reports being in distress over their medical diagnosis, assessing their spirituality and connecting with their experience may help to decrease the patient’s distress.

Many patients report feelings of depression and a loss of meaning in their lives after receiving a serious medical diagnosis. Simonelli, Fowler, Maxwell, and Andersen (2008) conducted a study with 260 women who had survived gynecological cancer to explore their experience of meaning. Simonelli et al. (2008) concluded that “finding meaning in one’s life may benefit cancer survivors by providing fulfillment and satisfaction, new perspectives or life goals, and sense of peace or harmony with life or offering a spiritual presence” (p. 280). For the women in their study, they found a strong relationship between depression and lack of experienced meaning. This study also concluded that “the lifetime prevalence of any psychiatric disorder for those with chronic illness is higher - 42% - than is found for the general population” (p. 282).

According to this study, there is a strong connection between chronic illness, depression, and lack of meaning. They found that facing "the existential challenge of the cancer experience – challenging one's view of self, the world, and one's future" (p. 282) contributes to enhanced meaning in the lives of the people who survived their cancer diagnosis. Once they have clarified their sense of life meaning, they can direct their efforts toward realizing their hopes and aspirations for their relationships and their life.

Holistic and Narrative Therapy

When discussing religion/spirituality in healthcare, it is important to reference the holistic model of health care. Muldoon and King (1995) state that "the holistic model of health care also affirms that one should not simply treat a body in pain, but respond to the suffering of the whole person within his or her full life" (p. 329). The experiences of people and their spirituality are an integral part of their whole life. Muldoon and King state that people "may communicate their own respective experiences of what it means to become a whole or authentic person in relationship to self, others, society, environment, and the absolute" (p. 334). The experiences that a person has contribute to their sense of meaning and wholeness in their lives. Muldoon and King connect the spiritual with narrative and holistic therapies:

> Since these questions of wholeness, meaning, and purpose are answered in one's life more than one's words, and since the integration is an experiential reality that unfolds in one's life-story, the discussion of one's spirituality can be achieved in an important way by people conveying their own narratives. (p. 334)

As described by Muldoon and King, suffering is "experienced by persons, not merely bodies, and springs from threats to the wholeness of a person" (p. 338). To understand a person's spirituality we have to try to understand their story.

Muldoon and King (1995) further discuss the need for the stories of the patients to be heard in order for their core values and beliefs to be understood. They suggest that there "can be a valuable role for a language of spirituality that attempts to speak in experimental terms to basic human issues" (p. 330). Spirituality in their work is directly related to the "universal human questions concerning the meaning of life and how it is lived" (p. 333). A narrative approach provides an opportunity for patients to have their stories heard and to find meaning in their experiences. Muldoon and King believe that "all human beings have a spirituality insofar as they gradually give a shape and direction to their lives which reflect how they understand life and what they hold to be of most value" (p. 333).

Relationships with others may impact how a person views their life in light of a health crisis. Muldoon and King (1995) discuss the need for external supports including family, friends and community. It is within the "context of ultimate meaning" that a person is able to live through and make sense of "pain, sorrow and loss of one's life" (p. 338). They further suggest that

> …the concrete conditions of women's lives, along with strategies for constructive change and support for them to get in touch with their own stories, deeper experiences, and ultimate concerns, may be of more benefit to women than a narrowly medical response. (p. 339)

The sharing of their stories is an important aspect of an illness experience, and also of health and healing.

When working with patients it is important for the medical community to remember that "human persons cannot be divided into physical, emotional, and spiritual compartments" (Pembroke, 2008, p. 554). Pembroke states that "a person who is ill is certainly very aware of her physical disorder and distress, but no less significant for her is the impact on her emotional, interpersonal, and spiritual aspects" (p. 555). Although it might appear that the only part of a person to be suffering in illness is the physical body when in fact the whole person is suffering. Pembroke also concludes that "patients experience themselves as whole persons and they want a holistic approach from their healthcare team" (p. 555). When one is ill there are many aspects of their person that are suffering and it is important to examine all aspects before providing treatment. In this research, Pembroke concludes that although physicians are not pastors they can however "empathically engage with their patients' spiritual values and concerns" (p. 555). By examining all elements of the person, it is possible to treat more than just the physical illness. By doing so, health, healing and personal growth can be supported among patients, including enhancing strength, coping skills, and confidence in adjusting to their diagnosis.

Personal Growth following Adversity

Research suggests that significant personal growth can be experienced after receiving a life changing diagnosis. Patients describe experiencing various aspects of personal growth, including developing emotionally, deepening current relationships, establishing new relationships, and spiritual growth.

In relation to suffering and personal growth, Wittmann et al. (2009) explored the illness experiences of 12 women with systemic lupus erythematosus (SLE). They described personal growth following a medical diagnosis as the process of "giving less prominence to those aspects of Self, particularly as threatened by the illness, at the expense of other aspects of Self, that might have been hitherto neglected" (p. 363). The story of Mrs. T. (a 30 year old, married woman) is used to illustrate a pathway associated with significant personal growth. After being told she had less than five years to live, Mrs. T. made many changes in her life:

> She quit her job as a secretary in an insurance company ("Why should I sit around 5 years here just to die afterward?"), married her boyfriend, and decided rigorously on which activities and social encounters she wanted to pursue and which to stop. Some months later, at the age of 24, she became pregnant, and her first child was born after a very difficult pregnancy. A second child was born 2 years later. She also developed new interests. Formerly a committed atheist, she developed an interest in spirituality and became a religious person. She now feels much stronger and calmer than before the onset of SLE. … What is her attitude toward SLE? Mrs. T talks about SLE as if it were a friend: "SLE somehow shapes my life and has a marked impact on most things that I do. It is difficult to accept that sunlight does so much harm to me, and I also suffer from anxiety and have had several panic attacks. But, on the other hand, SLE has guided my life positively in the last 10 years. I would not know life and myself as well as I do, and would not enjoy life as much as I do. Life is a precious gift." (p. 369-370)

Mrs. T.'s reported level of current suffering was scored as moderate, which led the authors to conclude that "exchange or adaptation of threatened aspects of Self appears to reduce suffering, as predicted, but it does not necessarily alleviate it altogether" (p. 371).

Bellizzi and Blank (2006) studied 224 female breast cancer survivors to explore factors associated with positive growth in their relationships, sense of life purpose, and appreciation of life. The level of distress associated with receiving their diagnosis was associated with growth across all the dimensions they measured (e.g. marital, employment and educational status). Study participants who reported using active, adaptive approaches to coping experienced higher levels of post-traumatic growth. Employed participants reported higher levels of personal growth in all areas. However, "women who did not attend college reported more post-traumatic growth in their relationships with others and purpose in life," but not in the area of appreciation for life. Women in committed relationships reported relationship growth, and enhanced purpose in life, but not appreciation for life. Younger women were more likely to report higher levels of personal growth in all areas. Overall, when all factors were considered, adaptive coping explained the greatest amount of variance in all three domains of post-traumatic growth.

It is through the rebuilding of one's life in a positive way after prior assumptions and approaches to life are shaken to core, that one can grow and develop. Mrs. T's story (described above) illustrates how a medical diagnosis can throw into high relief what is important in one's life. In relation to the present study, when a person is diagnosed with celiac disease they are suddenly faced with a choice of following a gluten-free diet or not and to what degree. A CD patient will need to consider their priorities, their relationships and other available supports, including spiritual support, as they begin to focus on their health needs. A person may seek out others that they can relate to, who they are able to make a connection with in relation to the new values and ideals they want to follow. They may also connect with people with the same disease that have overcome or adjusted well to their condition. As has been found for other disease conditions, a CD diagnosis can provide an opportunity for ongoing personal and spiritual growth, as patients connect with an inner strength and resolve to ensure their physical health and well-being as they live with their chronic disease.

Summary

This chapter provides a review of literature related to the experience of receiving a life-changing medical diagnosis. It is clear that people struggle with accepting and living with a diagnosis of serious illness and disease. The literature also highlights the needs of patients with regard to their physical and spiritual health. Receiving a medical diagnosis can result in tremendous emotional distress and disruption across multiple facets of one's life, including social relationships. The process by which a medical diagnosis is shared with a patient can have an enormous impact on the patient's ability to accept and comprehend the diagnosis. Compassion and support on the part of the health care practitioner will help patients to accept diagnoses. Providing ongoing follow-up support, and referring patients to available resources in the community can also help a patient adjust to their diagnosis. The support of family and friends will influence the ability of the patient to accept their diagnosis as well.

Recognizing and adjusting to the spiritual dimension of a patient's experience can help moderate distress and help in the post-diagnosis coping process. Studies reviewed in this section suggest that it would be helpful for physicians and other health professionals to discuss spirituality with patients. Doctors do not always ask about this aspect of their life, and many patients wish that they did. There is a need for doctors and others to be more sensitive to the needs of patients when they receive a life-changing medical diagnosis of illness. Patients need to have many supports in place to help them journey toward acceptance of their diagnosis.

A holistic approach to therapy was highlighted as a necessity for dealing with and coping with life-changing medical diagnoses, recognizing that we are more than just a physical body. Spiritual, psychological and social elements all define a person and the life they lead. Incorporating all elements will lead to positive therapeutic supports. Narrative therapy is an extension of the holistic therapy, as the patient's story is integral to their whole person.

There is limited literature available on the experience of patients with celiac disease in relation to receiving their diagnosis, adjusting to and coming to accept their CD diagnosis. Although generalizations can be made to some extent across medical conditions, different illnesses and diseases have unique features that will influence the process of coping with a medical diagnosis. In the present study, I explored the journey toward accepting a CD diagnosis experienced by three young adult women. In the next chapter, I outline the methods that I followed in doing so.

Chapter 3: Methods

Narrative Inquiry

Narrative inquiry was chosen for this research project. Narrative methods offer a means for considering the stories of our lives and the lives of others. According to Kohler Riessman (2008) “the term narrative carries many meanings and is used in a variety of ways by different disciplines, often synonymously with story” (p. 3). According to Angus and McLeod (2004), the “central idea animating narrative-based approaches to theory and research in the behavioural and social sciences is that human beings make sense of their lives and their worlds through stories” (p. 160). Kohler Riessman states that “in everyday oral storytelling, a speaker connects events into a sequence that is consequential for later action and for the meanings that the speaker wants listeners to take away from the story” (p. 3).

Temporality is an important consideration when using narrative approaches. Our stories unfold referenced in relation to the past, present, and future. Clandinin (2007) writes: “narratives are the form of representation that describes human experience as it unfolds through time” (p. 40). This is particularly pertinent in this research as a diagnosis of celiac disease usually follows many years of unexplained illness. When using a narrative approach people tend to share their stories “chronologically, as the events occurred, but may also include elaborate descriptions of the people involved and any other connected circumstances” (Hardy, Gregory, & Ramjeet, 2009, p. 8).

A form of narrative inquiry that is most appropriate to this study is the illness narrative. Illness narratives examine the experiences of people who have an illness or disease. Clandinin (2007) states that “when illness is protracted, when there is no chance of return to the person one once was, or when there is no hope of being ‘normal,’ a person’s very sense of self is lived in a special way through the body” (p. 407). Many people given a medical diagnosis feel that their personal identity is impacted and the pain and suffering they have experienced is conveyed through their narratives (Clandinin, 2007).

Kleinman (1988) states that “when we speak of illness, we must include the patient’s judgements about how best to cope with the distress and with the practical problems in daily living it creates” (p. 4). Kleinman continues discussing the importance of investigating the impact that an illness has on the life of the patient, their family, and others in their lives. According to Kleinman, illness raises many questions for people who are suffering. These questions cannot always be answered, but it is important for people to come to some understanding or find meaning in their suffering. Examining the lives of people struggling with illness can add clarity, understanding, and meaning to the experiences of people given a diagnosis.

Sharing Stories

Narrative inquiry invites participants to share their stories with others. One of the foundational aspects of this method involves the relationship between the researcher and the research participants. Moen (2006) writes:

> Several researchers (Altork, 1998; Connelly & Clandinin, 1990; Heikkinen, 2002; Kyratzis & Green, 1997) have been interested in the collaborative, dialogic nature of the relationship between the researcher and her or his research subjects. What seems to be important when discussing this issue is the necessity of time and space to develop a caring situation in which both the researcher and the research subjects feel comfortable. (The narrative research process, para. 3)

In sharing their stories, the participants and the researcher are each influenced by the story of the other. Clandinin (2007) states that “narrative inquirers recognize that the researcher and the researched in a particular study are in relationship with each other and that both parties will learn and change in the encounter” (p. 9).

From a narrative perspective, relationships are central to the inquiry process. In narrative inquiry it is acceptable for the author to consider their own story, reflect on it, and include it in the research text. When choosing a research topic, narrative researchers often choose a topic that they are passionate about, and which they usually have experience with. Their passion for and experience with the topics they study often provide added depth to their inquiry. According to Conle (2000), “the quest for knowledge about one’s own life and identity is an ancient one and has motivated work in which self-narratives are not primarily literary pursuits, but fall into a tradition ‘grounded in the ancient project of self-knowledge’” (p. 191). This form of inquiry allows the researcher to better understand their own experience and to present it to others. In the present study, both the participants and I shared our experiences of being diagnosed with celiac disease. Narrative inquiry enabled me to closely consider the participants’ experiences of receiving a celiac disease diagnosis, including how they came to accept their diagnosis, through their stories. I considered my experience of celiac disease in relation to the participants’ experience when writing this research text.

Method Outlined

The research design for this study followed a narrative approach that involved personal interviews with three young adult women. In this section, I review the questions guiding this study. I also describe the participants, the interview process and analysis approach I followed.

Guiding Questions

I was interested in the following questions: What are the stories that young adult women share about their experience of being diagnosed with celiac disease? Was the diagnosis difficult for them to accept? What made it possible for them to move forward following their diagnosis? What role did the medical community play in their journey toward acceptance? What role did spirituality play in their journey? I also wondered how my experience of being diagnosed with CD compared to the experience of other young women with CD.

Participants

I followed a social networking approach to recruiting research participants. Eight potential participants contacted me after they read the recruitment notices I posted on the Internet in chat groups and blogs dedicated to celiac disease. Others heard about my research through friends and acquaintances that I knew. Fourteen women in total expressed their interest in being involved in this study. In the end, I identified three women diagnosed with CD in their twenties to interview for this study, as well as two other women who agreed to be reserve participants. I asked two women to be reserve participants as I was aware that individuals are sometimes unable to complete their participation in a study, and might also elect to withdraw from participating in a study for whatever reason at any point should the need arise. The reserve participants were willing to participate in the study on an “if needed” basis.

I selected the participants after considering the recruitment criteria that I specified for this research project (see Appendix A). It was important that the participants had received a medical diagnosis of CD based on results of a gastroscopy, biopsies, and other diagnostic measures. I chose to interview women in their twenties because early adulthood is a period of time when much change occurs in relation to learning, growth and identity formation. After completing high school, there are many questions to be answered: What job or career direction should I pursue? Where will I live? Will I get married? Will I have children? CD is a constant that is considered in all aspects of life, particularly so during the early formative years of adulthood. In addition, I felt that I would be able to relate to the experience of the participants as I had been diagnosed with CD in my twenties.

For the purpose of this inquiry, it was also important that the study participants had accepted their celiac disease diagnosis. Acceptance of a CD diagnosis was demonstrated by rigid adherence to a gluten-free diet (i.e. does not “cheat” on the diet by eating food containing gluten from time to time). Finally, participants were selected based on their interest in participating in this inquiry, and willingness to share their story.

Specific Methods

I asked the women about their experiences of being diagnosed with celiac disease by using a series of semi-structured questions (*see Appendix B*). I invited the participants to share their stories in their own words. Some of the questions I asked were not as well suited to some aspects of the stories that participants shared with me, and the flexibility of using open-ended questions allowed for a full exploration of their story. I respected that the participants may have wanted to focus on particular aspects of their story and play down other aspects, which was their choice. I conducted interviews with the participants over a 40-65 minute period in a location of their choice to ensure their comfort. A portion of time initially was devoted to developing rapport with the research participants. Some people find it relatively easy to share personal stories with a researcher. Others find this more difficult knowing that their story will be shared with many others through the final research text. I acknowledged this with the participants and offered assurances regarding the confidential and respectful way I would treat their stories (outlined in detail in the next section). For example, at no time would I include their name or other identifying information in interview transcripts or the research text. Together with each of the participants, I determined a unique pseudonym they wanted me to use to protect their identity and to maintain participant confidentiality.

To ensure the integrity of the research account I developed, I used an audio recorder while conducting interviews with the research participants. All interviews were subsequently transcribed. In addition to using an audio recorder, I also took notes during the interviews. I noted insights, observations and topics to consider following each interview. I found these notes helpful as I considered other avenues and directions to follow, as I worked my way through the post-analysis of the data.

I read, re-read and reflected on the interviews to develop an initial understanding of the stories that the women shared that led to their celiac disease diagnosis, and also their experiences of adjusting to their diagnosis. During this early phase, I began to explore patterns in the narrative data. As described by Thorne (2008), “initial phases [of] data analysis are very much a time of allowing ourselves to react to the initial pieces of data that seem to take on a life of their own and attract our attention” (p. 144). During this stage, I focused on my initial impressions, such as words that stood out for me, and began to consider the direction that I would take with my analysis by identifying recurring themes. I noted commonalities along with differences across my interviews with the research participants, as Thorne (2008) believes that "it is also possible for us to ignore or block out contrasting cases, simply because we don't hear or see them" (p.143). To prevent this, differences as well as the similarities between the participants' stories were closely reviewed to illustrate important aspects of the journey toward accepting a diagnosis of celiac disease. As noted by Richmond (2002), "No single story provides a full understanding … each provides pieces for a 'mosaic' or total picture of a concept" (the significance of repeated patterns, para. 1).

A content analysis of the interview transcripts was conducted with a view to identifying key themes. As Bingley, Thomas, Brown, Reeve, and Payne (2008) have described, content analysis "encompasses a range of methods concerned with 'what is said' and 'thematic' analysis" (p. 655). Frequently used words, themes and commonalities across the participants' stories were noted, as well as the distinctive aspects of the participants' stories. I considered both what was said by the participants, and also what was not said, and began to code the data. Thorne (2008) states:

> This idea of attaching a 'code' to a piece of interview transcript or field notes derives from assumptions that one knows what the element entails, what other kinds of things might be similar, and what it ought to be distinguished from. Essentially, coding represents the initial basket into which the laundry is being sorted –dark verses light, and various shades of color, for example. (p.144)

Coding helped me to develop a clearer understanding of the journey toward acceptance of a celiac disease diagnosis by the three participants. Initial common themes, as well as variations were identified.

As common themes were identified and coded, I placed them in a story map as a way of organizing the data. A story map is a chart that contains common themes, in point form, that have become apparent through data analysis. Richmond (2002) has found story maps as a way of organizing participants' stories into past and present experiences, while also considering where they hope their story will go in the future (narrative methodology, para. 3). I used story mapping as an approach to organize common themes that I identified through data analysis in time periods of past, present, and future.

I shared the story maps I developed with each of the research participants in person. In this way, I was better able to share the empathy I felt for their stories. In preparing the research text, I selected quotes from the interview transcripts to support the identification of these themes and to represent the unique and variable experiences of the participants. I shared my *Research Finding*s chapter with the research participants by email. Although a few editorial changes were suggested, the research participants commented that I had effectively captured their experiences in both the story map and *Research Findings* chapter text.

With respect to the influence of my own story as a woman who was diagnosed in her twenties with celiac disease, I kept a journal of my thoughts and reflections during data collection and analysis. Journaling allowed me to track my own process and experience during this research study. The types of questions that I asked of the three participants were influenced by my own experience with diagnosis. However, I encouraged the participants to share their stories in ways that felt most valid for them. While it was impossible to escape the influence of my subjectivity, I remained reflexively aware of my own story and its impact on the emergent understandings developed through this research study.

Ethics

Approval for this thesis study was obtained from the St. Stephen’s College Ethics Committee. Participation in this research project was voluntary. Participants reviewed an authorized Letter of Information (Appendix C), and completed appropriate documentation confirming their consent to participate in the study. Participants were invited, on an ongoing basis, to address any questions regarding the study, or decline to answer a question they were not comfortable with. In Appendix C, I specifically outlined that participants had the right to refuse to answer a question at any time. Appendices D and E display the confidentiality forms that were signed by the transcriptionist and editors who assisted with this study. Copies of these forms were given to the participants to keep for their own records.

Participation in this study did not involve physical risk. I shared that I did not want to extract information of an overly-sensitive or invasive nature from participants and that likely the greatest potential discomfort for participants would be minor, short-term fatigue. With regard to social risks of being involved with the project, I recruited some of the participants through the Calgary Celiac Association. I assured participants that the information they shared with me would be held in confidence, and the Celiac Association would not know of their participation in this project. As Glesne (2006) states, “Participants have a right to expect that when they give you permission to observe and interview, you will protect their confidences and preserve their anonymity” (p. 138). Following from this, I removed identifying information from all project materials, and replaced the name of each participant name with a pseudonym of their choosing.

Participants were offered an opportunity to comment on interpretative summaries of their narratives. They were invited to clarify any information that did not fully reflect their experience, and also had the right to request removal of any aspects that they did not feel comfortable sharing publicly. Participants were also given a copy of the final report of the study prior to formal submission to my examination committee. No reimbursement was offered to the participants for participating in this project.

The opportunity to reflect on their journey and share their story was a potential benefit to participating in this study. Often when people are attempting to understand their disease and diagnosis, they feel as if no one is listening to them. Kleinman (1988) states patients have the sense that their doctors do not always believe them and they feel pressured to prove that they are suffering. Having to battle against this disbelief can be tiring and frustrating for the patient. It can be a powerful validating experience if someone takes the time to listen to their story.

Reading the Research Text

I present the research text I developed on the basis of carefully considering the stories of young adult women diagnosed with celiac disease through narrative inquiry in the next chapter (Chapter 4). I present my interpretation of the women's stories, which has been enlightened by my own experiences as well as by what I have read in the literature. I am aware that each person that reads this research text will apply his or her own understanding to what I have shared here, as each reader draws on their own experiences and contextual understandings in interpreting the research text.

There is no single understanding of human experience but many understandings that are important to acknowledge. Narrative inquiry is generative in that what we learn and come to understand can provide a bridge or connection to new experiences and understandings, for the researcher, participants, and others who read the final research text. This includes others who have been diagnosed with celiac disease, and those who can support them in adjusting to their diagnosis.

Chapter 4: Research Findings

In this section I present insights regarding the experience of young women who have been diagnosed with celiac disease. In the current study I explored the stories of three women regarding their experience of being diagnosed with celiac disease. By way of introducing each of the women, I present each in turn.

“Jen” was 23 years old at the time of our interview, and 21 years of age when she was diagnosed with CD. At the time of our interview, Jen was employed as a counsellor, and was planning on moving in with her boyfriend. Although she was surprised and was initially distressed by her diagnosis, Jen had come to embrace living with CD. She shared that CD helped her feel more connected to herself,

“Pam” was 26 years old at the time of our interview. Pam shared that she was married and was a full-time university student. She was diagnosed with celiac disease when she was 25 years of age. She initially responded to her diagnosis with depression, but had a close and supportive family which had been helpful to her adjusting to having CD.

“Ebony” was 35 years of age at the time of our interview, and was 27 when she was diagnosed with celiac disease. At the time of her diagnosis she lived in a rural area, and did not know anyone with CD where she was living. Currently she lives in Calgary. She works in the field of animal medicine, and has a boyfriend. She shared that she has accepted her diagnosis, and is doing very well.

Using a narrative approach, I carefully considered the stories that the three women shared with me. Through an iterative process of working with the transcripts, I identified six key themes which characterized the women’s stories: a) Experiencing

Symptoms of Undiagnosed Celiac Disease; b) Receiving the Diagnosis: Importance of Communication; c) Challenges of Following a Gluten-free Diet; d) Journeying toward Acceptance: Emotional Aspects; e) Journeying toward Acceptance: The Role of Support; and f) Changes in Self-Identity. These themes revealed commonalities and differences between the experiences of the women in this study in coming to accept their diagnosis of CD. The story maps shown in Appendix F further illustrate the variability that can be found across the women's accounts, in relation to both similarities and differences between their stories.

Experiencing Symptoms of Undiagnosed Celiac Disease

Each of the women shared that they had experienced physical symptoms associated with celiac disease before they were diagnosed. The unexplained physical symptoms they had experienced for a long period of time were a struggle for all three of the participants. Two of the women identified stomach problems as their most significant symptom from early on. Jen said that she had horrible stomach aches, bloating, and pain for many years. She said that she passed it off as regular stomach problems. She convinced herself that all people had these stomach problems and that she was normal: "I really normalized everything. Like, I thought everyone felt this way all the time. Everyone felt bloated. Everyone felt really tired. Everyone, you know, had these gastrointestinal problems." Pam recounted a similar experience. She had stomach pain from a very young age and was unable to have breast milk as a baby. When she got older and complained of stomach aches people would say, "Well, it's just because you're a woman."

Ebony identified being tired all the time as one of her symptoms. She felt exhausted and unable to do anything outside of work most days. "I had no energy to go out and do things or even like clean the house or laundry." She did not feel like a lazy person but her body would not let her do more. As debilitating as this was, she identified her most significant symptom as anaemia. She suffered from anaemia for 11 or 12 years without receiving any satisfactory answers from doctors as to the cause of her anaemia. She was advised to take iron pills and eat lots of meat. She shared: "My doctor at home, when I was living at home with my parents, encouraged me to take iron tablets. Did that; there was no change." Instead, her anaemia kept getting worse with each test. Each doctor that she saw completed blood work, but did not order other tests to see if the anaemia was caused by a pre-existing condition.

All three of the women described unwillingness on the part of their doctors to explore other possible medical causes of their health problems until they requested it. Jen asked her doctor to test her for celiac disease because she knew someone that had the disease and she thought that she might have also have CD. Pam asked her doctor to test her for as many medical problems that he could think of that were related to stomach problems. Ebony went to her doctor and asked if her anaemia could be related to any other condition. He suggested that she could have CD.

The physical effects that they experienced as a result of gluten-intolerance caused significant problems for all three women. When they learned that they had celiac disease, all of them wondered how long they had the disease.

<u>Sonya:</u> *My physical symptoms started early in life. As a baby I would often vomit my milk out of my nose. Things gradually got worse as I got older. When I was fifteen months old I was unable to keep down any food or liquids. I was admitted to in the*

hospital and was diagnosed with gastroenteritis. The doctor took me off milk and said that this would help me to get healthy. As I grew older, I was always sick with colds and ear infections. In my teens it was discovered that I had hypoglycemia. One of the problems I had as a teenager was a very heavy menstrual cycle. I often experienced two periods in the course of a month and they would last for a week to ten days at a time. Once I entered my twenties I developed anaemia. I was on iron pills for a year and a half with no improvement. When my anaemia got worse, my doctor suggested other forms of iron might work better.

Then, when I was 27 years old, I had a new doctor who was interested in determining what was wrong with me. I kept going to him with colds, the flu, tonsillitis, strep throat, chronic fatigue, laryngitis, and other ailments. My doctor thought that there had to be something else wrong with me and he ordered a full blood work up looking for anything out of the ordinary. The blood work came back with high levels of tissue transglutaminase (tTG). He said the next step would be a referral to the gastroenterologist specialist. As it turned out, there were a few more steps in the journey to learning that I had celiac disease.

Receiving the Diagnosis: Importance of Communication

Each of the women wished that they had experienced clearer communication and support from their doctors as they were going through the diagnosis process. Once they had their blood work completed they waited for some time for an appointment with a specialist. Two of the women reported that they had not been informed that after their initial blood work they should continue to eat gluten until after their biopsy, or else their biopsy results would be affected. Aware that celiac disease was a possible diagnosis for them, they had eliminated glutens from their diet. They then had to go back to eating gluten which they found difficult. This lack of clear communication created a sense of uncertainty that they struggled with, and found distressing.

Pam shared that she was given the results of her blood test by a nurse: “I got off, like, wheat as soon as the nurse said 'we think you have celiac [disease]'.” The nurse described her as being a “latent celiac” which she did not understand, and which was not explained to her. She was not given information about the disease and what this would mean for her so she did her own research. When she finally saw the specialist, she asked him what it meant to be a latent celiac: “He said, like, I don’t know where the nurse got that word [latent] from.”

Pam stopped eating wheat for a month after the nurse gave her the results of her blood test that suggested that she had celiac disease. It was her brother-in-law who told her she should start eating wheat before seeing the specialist, as it could affect the outcome of the test. She had not realized that she might not test positive for celiac disease if there was no gluten in her body when she finally had the biopsy to confirm the blood test results.

Jen shared an account that was similar to Pam’s story. Once Jen was told the results of her blood test, she also stopped eating gluten:

> Nobody told me not to stop eating it. So I stopped eating it, and then I got a call one day saying that they had an opening to do the biopsy earlier. And they said like, “Have you been eating gluten [found in wheat]?” I was like, “No.” And they’re like, “Well, now you have to eat it for, like, what three months. [This] after not eating it for about five months.

Ebony was given her diagnosis on the phone. She had not done any of her own research. She said, “I should have asked him a few other questions,” adding, “it probably took me a month or so before I actually started the diet. It had to sink in for a while." During the early period following her diagnosis, she shared "It felt like I couldn't eat anything."

Sonya: *My family doctor told me that I should eat wheat until after my biopsy because it could impact my test results. Then I waited for the call from the specialist about my appointment. No one followed up with me while I waited to see the specialist. I finally got a call from the specialist's office, and my biopsy appointment was scheduled. During my initial appointment with the specialist he said that just because my blood work tested high for tTG that did not mean that I had celiac disease. He shared information with me about what to expect next in relation to the biopsy process. Later when he reviewed my biopsy results, he reiterated that I may or may not have the disease and walked out of the room. I was left feeling confused and shocked. I still had no idea if I had CD or not. I had a follow up appointment the next day with my family doctor. When I told him what the specialist had shared with me, he said that he was going order a copy of the results. The next week, when I went back to see my family doctor he told me that it was clear that I did have CD.*

Challenges of Following a Gluten-free Diet

After receiving their diagnoses from their specialists, the three women were all referred to a dietician. This was not experienced as being all that helpful. Jen said, "I guess that they set up every celiac that gets diagnosed with a dietician. But it was like eight months after I was diagnosed, and by that time I knew more than she knew." Pam said that her visit with a nutritionist was mixed:

> (It was) kind of unhelpful because she kind of brings out the food guide, you know, Canada's food guide and she's like make sure

> that you’re getting enough of these. But you know what was nice: they gave me, like, a sample kit of Kinnikinnick products [these are products that are gluten free and are one of the popular supplier of gluten free products], and there was, like, Oreos and cake mix.

Ebony said, “What I needed was, someone just to sit down and help me read labels and stuff like that. I already knew how to eat healthy.” All three women felt they needed more from their dieticians than simply a review of the food guide. As a result, the women did not find the appointments with dieticians all that helpful.

All three of the women found adhering to a strict gluten-free diet to be challenging at least some of the time. Ebony said that when she was first diagnosed, going into the grocery store was a struggle because she did not know what to eat. She said, “I didn’t buy any prepared products like salad dressings or anything like that at the grocery store once I actually started on the diet, ‘cause I was too afraid. I didn’t know enough yet, so [I] subsequently dropped about 20 pounds ‘cause I didn’t know what I could eat.” Ebony said, “switching over wasn’t that hard once I understood how to go about it, how to read labels, and, yeah, do research and stuff like that.” She thought that living gluten-free “was a challenge . . . (that) once I got into it, I was willing to take on.” She said that “one day it clicked for me as far as I knew what I was doing with food … I knew what I had to stay away from or what things I could eat.” Ebony said that once she got through all the holidays and a number of special occasions, she felt that she finally got the diet down. It took about a year.

Ebony had never cheated on her diet, but shared that she has been “glutened, whether at a person’s house because they didn’t understand or, you know, at a restaurant.” Explaining her condition to other people has been difficult for her: “I would say [it took] about a year [before] I was comfortable with talking about it, explaining to other people, you know, and having enough experience with it, too, in social situations." The social aspect of the disease was difficult for Ebony: "It was really hard; it made me not want to go out of the house." Having to explain celiac disease every time she went out was a struggle and it embarrassed her. Even now, many years after her diagnosis Ebony admitted that she still struggles with eating out especially if she is with new people.

One of Pam's earliest recollections after her diagnosis was "going in the store, reading ingredients, and being totally overwhelmed." She shared: "I remember one day I came home with, like, when I first got the diagnosis, I went to Safeway and I got, like, a big thing of mandarin oranges, yogurt, and bananas and that's all I could think about. I was so depressed and that's what I ate for, like, two days and then I was like, this is ridiculous, and I figured out some other stuff."

Pam said that when she was growing up she ate like a "normal" person. That changed when she was diagnosed with celiac disease. When she was diagnosed, she re-invented her kitchen, and her approach to food preparation. She said that "you have to wash everything. Some of the stuff you have to throw out. I mean, you can't eat normally. But now that I know what I can eat, it's a rhythm, you know." On the other hand, she found "Eating out kinda disappointing," adding, "but it doesn't affect whether or not I go out." Pam said that she found restaurant menus disappointing because "you look at the whole list of things to eat in a restaurant, and even the shrimp are, like, battered and the vegetables are deep fried." Additionally, "eating out at people's houses is hard." Pam prefers to have "people over to our house instead of going over to their house, 'cause it's just safer for me."

Pam noted the cost of gluten-free food. Due to the cost of the gluten-free products such as bread, cookies, and cakes, she buys less of these specialty items. She said that she mostly buys regular food without gluten: “Instead of, like, eating breads and stuff, I’ll just have, like, rice and potatoes for supper and, you know, so we just sort of do with the staples instead of trying to get the wheat products in a gluten-free variety.” In addition, she has started to make food, such as gluten-free bread, on her own.

The women shared that they faced challenges adhering to a gluten-free diet when they ate outside of their homes. Pam shared that she was always concerned about cross-contamination[2] when she visits with friends, or eats out. She has gotten sick while eating out a number of times at restaurants, and is now nervous about eating out at restaurants. Jen shared an instance where she was going on a hiking trip and stopped to eat at a restaurant that she did not know. She told the waitress that she wanted plain meat, a plain baked potato, and steamed vegetables, all cooked on foil so that she would not have to worry about getting sick. The end result was that she was sicker than any other time in her life.

It can be a struggle when a person has no idea if they are going to be sick from the food that they eat. When she does eat out, Jen makes sure to explain “very assertively, very clearly, what I cannot eat and why. I have celiac disease. I do not have a gluten allergy.” Jen is bothered by the attitude of the restaurant industry and how it appears that people working in it “don’t care.” She said that she enjoys eating out when

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[2] Cross-contamination is the passing of harmful substances indirectly from one surface to another through improperly cleaned surfaces and utensils.

restaurants have knowledge of CD: “It’s such a treat, though, when you find someone that really cares.”

In addition to cross-contamination outside the home, the participants also shared being concerned about cross-contamination within their homes. Jen has tried to decrease her chances of getting sick at home by buying “separate gluten-free pots and pans” for her kitchen to avoid cross-contamination. Pam reorganized her kitchen and threw out all of the items containing or possibly containing gluten. This included her getting rid of cutting boards which can hold trace amounts of food items that have been cut on them, including any gluten products. Ebony had to clean out her kitchen as well.

Jen felt that “being gluten-free is the answer to every health problem. Not every health problem, but many of them.” Since gluten is found in many products she believes that if people would stop eating it, their overall health would improve even if they do not have celiac disease. Jen also raised concerns about not knowing whether some medications contain gluten. She was sick for a long time and discovered that one of the factors was that one of her medications contained gluten. This was very upsetting to her because no one told her about it.

Similar to Pam, Jen shared: “I’m not eating gluten-free out of package either. I’m eating just normal food like vegetables, meat and, like, potatoes or rice.” She said, “I’m better on the diet right now than I was a year ago. ‘Cause I’ve learned more in the last [year], you know, I think that you get better at it as you go.” Jen stated that “it’s very easy to be gluten-free . . . and a healthy gluten-free.” She believes that “there’s so much food out there that is low in nutritional value, very expensive, and when I first started just feeling really, like, oh, God, this is so expensive and bad for you.” Jen finds that she eats “just normal food that you just buy at the grocery store.” She said that she eats a larger variety of foods since her diagnosis than she did before and she is happy about this. “I swear my taste buds have changed.” Jen said “I’m eating, like, quinoa and amaranth, and buckwheat.”

When asked about the advice she would give others about celiac disease, Jen said “I [would] put stuff about how easy it is to cook gluten-free and that the best thing to do is make a couple of litres of gluten-free chilli, spaghetti sauce, curry, casseroles, etc., and freeze little containers so if you are too tired to make something to eat, or too busy, you always have something. I always have to know where I’m eating.”

One of the areas mentioned by two of the women was travel. Ebony said that having food to eat is of concern to her when she travels. She said that she needs to be organized and bring food with her in her suitcase. Even when she is not travelling she needs to keep gluten-free food with her. She shared that she was “always making sure I have food with me in case I can’t eat somewhere.” Jen said that for her eating while travelling can be problematic. She said she took a trip and there was “no food on the airplanes. I was on two airplanes.” Now she makes sure that she has food with her all the time.

Jen identified travel to countries where people do not speak English as another concern. She said that the Celiac Association of Canada sells cards that talk about the disease in a number of languages that can be helpful when you are travelling. Both Ebony and Jen said that it was sometimes a struggle to travel to other countries because they were unsure of what food would be available to them. When they travelled, a significant portion of their luggage was food because they were never sure what would be available to them or what food situations they might find themselves in. It did not matter if they were travelling to a country that spoke the same language as they did or not. The participants had been made sick even in countries where people spoke English and they were able to explain their disease. This made them question people's understanding of what they were saying about the disease. Knowing they always had food with them made taking a vacation a more positive experience for the women.

Sonya: *Most of the concerns that I still have about adhering to a gluten-free diet are centered on eating out and travelling. It can be problematic to explain the disease to people and exactly what it means to have it. For example, it can be stressful to explain celiac disease to a server in a restaurant. Another concern that I have about the diet is having access to a variety of foods. When I was first diagnosed, I lived in a community that did not have a grocery store with a dedicated gluten-free section, or any easily identified gluten-free food. I struggled to adapt to eating gluten-free food on my own. I remember spending two hours shopping the first day and only ended up buying 10 grocery items. Once I moved to a city that had stores with identified gluten-free food items, shopping became easier. I believe that this really helped me on my journey of accepting my diagnosis.*

When I eat out I am always concerned about eating gluten. I try to go to restaurants that have gluten-free items on their menu. In the past I have gotten very sick from eating out. I feel like I go through the whole process of explaining the disease and all of the places that gluten can hide but I still get sick. I become very upset with the food industry and I wish that everyone would listen to what I share with them when I eat out. I still hope that one day I will be able to eat out without getting sick. Eating out is an important part of our social interaction with others. I want the same opportunities as other people have when it comes to dining out. Sometimes I remind myself that there are people that are worse off than I am, that there are people in the *world that are not able to control their disease with food like I am. When I recall this, I also remind myself about the need to persist in raising awareness about celiac disease.*

Journeying Toward Acceptance: Emotional Aspects

Each of the women reported experiencing a wide range of emotions as they journeyed toward accepting their diagnosis. Pam reported that initially she felt very depressed. She had no idea what she could eat, and felt confused about her diagnosis after her conversation with the nurse because "the nurse wasn't that helpful." At the same time, she shared that she felt relieved: "I was a little bit relieved because I kind of had this, like, feeling my whole life something was wrong with me." Still, she shared that "you kinda mourn the fact that, you know, you're not just a normal person and you can't just do what everyone else is doing." She was also concerned "about what it meant for (her) body." She was concerned because she had been eating gluten for so many years, and she was worried about the damage she may have done to her body.

Following her diagnosis, Pam responded with positive action: "I reacted positively, positively in that I followed them [the rules for not eating gluten]. I felt like celiac disease demanded some seriousness because it wasn't like an allergy, and I was quite concerned that my intestines were going to be healthy." Pam has accepted that she may never know the consequences of eating gluten before she was diagnosed, but is "content with it now." She is currently at peace with having celiac disease, an emotional state she felt would not change unless she developed other health issues or complications as a result of having CD. She said "that would probably make me feel disappointed. Probably a bit more so, probably even angry at the disease itself or something." Pam does feel that "if life continues and nothing huge changes, then I think the only thing that will change is that I will continue to be even more content with it. She did admit that “sometimes I feel sorry for myself.”

Initially when she was diagnosed, Jen experienced “fear, loss, sadness, and frustration.” When Jen stopped eating gluten after the results of her blood work, and then discovered that she was going to have to go back to eating wheat she was very emotional: “I hated, hated it. I hated eating something that I knew that was going to hurt my body.” With respect to her diagnosis, she described feeling “really surprised,” but also “really motivated.” Jen said that much of her motivation came from the fact that she hated hurting her body. She was also intent on not feeling sick any more, and this motivated her to follow a gluten-free diet. However, it was not always easy, and she sometimes experienced setbacks: “Then I would get sick and then I’d get frustrated. And then I’d get really motivated again, and then I’d get sick and get frustrated, and then I’d get sad, and then I’d get angry, and then I’d get motivated and, like, it was just horrible.”

One of the areas Jen said is still emotional for her is eating out at restaurants, especially if she eats out with friends: “I hate to tell them that I got sick from that meal. I hate that. I feel like I’m being, like, I’m such a problem for other people sometimes.” She shared that her friends tease her about asking for gluten-free food, saying that wait staff would probably sprinkle flour on her food or put something else in her food to make her ill because she was being a difficult customer. At this point, she takes the teasing in stride: “I think my friends are really great in how they kinda make it a joke which initially maybe it irritated me a bit, but now I kinda like it.”

Ebony shared that she experienced a wide range of emotions in relation to her journey. Before her diagnosis she felt frustrated and depressed about the fact that she was unable to get answers to her pain and suffering. She began to doubt herself and her self-confidence was beginning to be affected. When she finally received her diagnosis, she felt ignorant because she had no idea what she could eat, or where to shop for gluten-free food. Ebony lived in a rural area at the time of her diagnosis and had limited options available to her. She found following a gluten-free diet very stressful initially. Since that time, she has accepted her diagnosis and has acquired good knowledge of dietary restrictions associated with celiac disease. Ebony now lives in an area that supports following a gluten-free diet, but she still struggles at times with adhering to the diet, particularly in social situations, which is frustrating to her.

Another area that the women identified as being very emotional was infertility. Pam shared that when she was initially given her diagnosis and did some research, infertility was one of the issues that arose for her. She was concerned when she came across information on the Internet that stated that "celiac disease in women, will decrease your chance of getting pregnant." This was a concern for her because she did not have children. Pam does hope to have a family in the future and has since learned that "there's no less chance of fertility" if she follows a gluten-free diet. Because of this, she is no longer concerned about infertility. Jen and Ebony remain concerned about infertility. Ebony said that "I'm hoping that I don't have problems because I think there is a correlation." Jen expressed concerns about also raising children as a parent with CD. She had a lot of questions about whether or not she should include gluten in her children's diets.

<u>Sonya:</u> *When I was first diagnosed with celiac disease I was angry and depressed. I really did not want to have to face all of these changes in my life. I was also scared about getting sick from everything. There was also a level of intimidation because there*

was so much to learn with no one to teach me and trepidation knowing that there was not going to be anyone to guide me through the process of adjusting. Not knowing anyone else who had the disease was also frightening to me.

My initial research showed that women with celiac disease were unable to have children. I was devastated by this news. I was not sure if I wanted to have children but to suddenly face the possibility that I couldn't was very upsetting. As I investigated further I have learned that this is not the case. Following the gluten-free diet is the way to increase fertility in people with CD. In time, I have come to feel more confident about the prospect of having children.

Journeying Toward Acceptance: The Role of Support

Most of the support that the women in this inquiry had in journeying toward accepting celiac disease as part of their life came from their family and friends. Ebony lived on her own at the time of her diagnosis. Her major support was her "mother coaching [her] on the phone." Ebony's mother was her biggest support in trying to figure out the disease. She also identified having a special group of friends as another important source of support in her life. She described them as being very understanding, and having added a lot to her life. She felt that everyone could benefit from having a group of friends like she had in her life. Having these people in her life made it easier for her to adjust to her diagnosis and to understand what it meant to be a person with CD.

Jen's support came from her family, her boyfriend, and friends. She said her mom has "been a huge help." Her mother was involved in the culinary world and had a great understanding of food. She suggested other options for Jen to eat instead of gluten. Jen's boyfriend was also very supportive. He said, "I'll eat gluten-free with you." Jen shared that "a lot of my support people have been really helpful." The support and understanding of all of these people had made a big difference she felt in how she adjusted to having celiac disease.

For Pam, her support came primarily from her family. She said that her sister-in-law "gave me a laminated, like, sheet of, things I can and can't have which was so helpful." Her sister-in-law helped her to better understand her new diet, and was "one of [her] biggest supports, actually." There were many things that she did not know about the disease and the diet. She appreciated the knowledge that her sister-in-law shared with her because there was no one else who could do this for her.

For all three women, their spirituality was something that also featured as an important aspect of their journey of coming to accept and adjust to being diagnosed with celiac disease. Jen said that spirituality has "always been a really important part of my life. Spirituality is something that grounds me." Her spirituality allows her to connect to her authentic self which is the "…core of my identity and mind that goes beyond my ego, mind, and societal world view." Jen said that she feels connected to her authentic self when she meditates or spends time outdoors." Having a healthy lifestyle helps to ground her. She feels that if she were to cheat (which she has no desire to do) this would be "feeding the ego" because her authentic self would never want gluten. Her authentic self would not want her to be sick but her 'greedy ego' would. Jen said that she does not want to make herself sick. Jen uses this perspective to connect to her inner self, in her work and her relationships, and other important aspects of her life. Not surprisingly, this thread also informed how Jen talked about CD in relation to her sense of identity (of this theme as summarized in a later section at the end of this chapter).

Pam shared that her spirituality is at the foundation of her life and at the centre of all of the things that take place in her life. Her spirituality was an ongoing support to her when she struggled with having celiac disease. She shared, “My spirituality is core in all things in life. It was just a matter of trusting that no matter what, just like anything else in life, that, even if I died because of it, that it was going to be okay.” She “didn’t think that because I have faith in God that he would cure me of it.” Pam considered her spirituality as an integrated part of her life. When she discussed her diagnosis and the times she struggled with having CD she considered her spirituality in relation to these experiences.

Ebony shared that she did not believe in a God, but she had a sense of there being a force that was greater than herself, that she could connect with. She said that she could not provide a name or label that described experience, but that there was something there. In relation to the various health issues she had experienced, Ebony believed that what was going on with her would get figured out in the end. She believed that she would get “a diagnosis of something or I just had to hold on and things would get better as far as my health.” She had faith that her health would improve. She felt that things in her life would improve because they had to since her health had been so poor up to this point. Ebony had a strong faith that things in her life happen for a reason. This faith has helped to guide her through her diagnosis and the improvement that she has seen since. Her faith was strengthened again with the improvement of her health.

Sonya: *As I have journeyed to accept my diagnosis of celiac disease my most ardent supporters have been my husband and my family. My husband accompanied me to my specialist appointment. He said that he would also eat a gluten-free diet to support me, and encouraged me to research different aspects of gluten-free living. Having his support in my life reassured me that no matter what my diagnosis was I would have support after my diagnosis. Prior to his sharing this with me I was worried about being without the support that I was going to need after my diagnosis.*

When I was given my initial diagnosis I was very angry with God. I could not understand what it was that I had done to deserve this. I felt abandoned and punished by God with this diagnosis. I believed that we all have to suffer in our lives but I did not want this to be my cross to bear. I was thinking of myself like Jesus. He carried the cross on his way to crucifixion and I saw myself in him. I was carrying a tremendous weight with this diagnosis and I felt I just had to endure the suffering. I was unsure if it was going to kill me socially, emotionally, or psychologically. I was angry because I felt that I was a good person and only someone that had done something wrong would be punished with this disease. I was very confused and emotionally distraught at this time in my life. I did not understand how I got the disease. I wanted to eat gluten and not change my whole life. I wanted to be 'normal' which was how I saw people who could eat wheat.

As I moved toward accepting my celiac disease diagnosis, I decided to no longer be angry with God. This disease was not something He had done to me, but rather it was just a matter of how I was physically made. I understood that God was not punishing me. I had done nothing wrong to deserve this diagnosis. It took a long time for me to feel that I no longer had to endure the suffering that I felt. I felt that suffering *was something that we all did in our lives before this realization. The suffering was a part of who I was and my outlook on life in general. I decided to access the relationship that I had with God prior to this diagnosis. I felt that having God in my life was going to be another important support through the journey to acceptance. I began to change my attitude and accept that I had CD. I began to believe that I could positively meet the challenge of my diagnosis.*

Changes in Self-Identity

Jen's diagnosis of celiac disease led her to take time to reflect on her life, her health, and who she is, or her sense of self. Jen said, "I've come to love being a celiac." She has embraced CD and following a gluten-free diet as part of her identity. She shared, "eating gluten-free is something I do to nurture my body and . . . if I don't do that, I'm not honouring my body. I'm not honouring myself. I'm not honouring what it needs, and, therefore, like, really disconnecting from my spiritual self, my grounded self." She shared that "even if they found something for celiac [disease], so we could eat gluten, I don't think I ever would [take it]. Maybe I would if I was going out for dinner or something like that, I would take it just in case but I think it's just become so much a part of who I am." Jen said that she believes in "loving yourself and your body and being as healthy and grounded as possible."

Having celiac disease has helped Jen to feel more connected to herself. She said that she has learned a lot about herself on this journey:

> You learn to depend a lot on yourself, I think. Before I was always relying on the medical model or going to the doctor, whereas now, I can – I feel like I can – if I start to get sick, I gargle saltwater or eat a lot of garlic or ginger and usually I can fight it off – whereas before, I would never look to doing things

> like that to look after myself. I feel much more natural and much more healthy. Very much holistic.

Pam's experience was slightly different. Initially when she was diagnosed she was upset "because it's a name and you're, like, I'm a 'celiac'." She felt like there was something wrong with her in the beginning. Pam said that her diagnosis "sort of changed me but from day to day, no, I don't think much different." There are times she wishes that she was a 'normal' person.

Referring to her diagnosis, Ebony said, "I guess I feel it's really a part of my identity, and I don't know whether that's a good thing or a bad thing." The feeling that the disease is part of who she is fluctuates: "Certainly I think more of it when I'm out socially." Her family and friends know and understand the disease and the significance of it to her overall health. She feels like she stands out sometimes and this "goes back to being comfortable with it and speaking up and that sort of assertiveness thing."

<u>Sonya:</u> *Having celiac disease is a strong part of my identity. When people ask me about myself I tell them that I have celiac disease, especially if a meal is involved in our meeting one another. I believe that the way to bring more attention to the disease is to talk about it with others. Having this disease has made it possible for me to be more assertive. I still have some work to do about being even more assertive but it is getting better every time I meet new people and I am in new situations. I want people to understand this disease, so I share information about it with them. I see it as being important to educate others about my disease so that there is increased understanding of CD.*

Summary

In this chapter, I have related the six thematic aspects of the narratives of the participants, as well as different aspects of my experience of coming to accept a diagnosis of celiac disease. Excerpts from transcripts of the interviews I conducted with three volunteer research participants, women who had been diagnosed with CD in their twenties, were used to illustrate the key themes associated with this journey. The three participants provided insights into what made it possible to journey toward acceptance of a diagnosis of a CD diagnosis. They were able to share information about the physical effects of the disease before their diagnosis and how their life changed after the diagnosis. How they received a diagnosis from their doctors had a tremendous emotional impact on their lives. They all received support from family and friends during this difficult time. All three described their experiences in relation to various spiritual aspects of their lives. As they learned more about the disease, they came to accept and at times embrace being a ‘celiac’ as part of their identity. Each of the women shared that they at times struggled with their diagnosis, particularly in the early days following their diagnosis, and often found social situations challenging. They found that educating others has helped them with this struggle. They each shared different stories, but have all come to accept and positively adjust to having CD.

Chapter 5: Discussion

Celiac disease is becoming more commonly diagnosed as greater understanding develops and more people are being screened for it. In this narrative inquiry the journey of three women towards acceptance of a diagnosis of CD was explored. The participants had varied backgrounds, and varied experiences journeying toward acceptance of CD as part of their lives and their identity. Various stages were identified by the women, with each stage of the journey playing a significant role in making it possible for them to accept their diagnosis.

The role of the medical community, and health professionals, was significant. The journey began for each woman with the experience of seeking an accurate diagnosis, finally receiving a correct diagnosis of celiac disease, and the initial reaction that they all had. The second stage of the journey included gaining knowledge about the disease and the changes they would have to make in their lives. In the third stage of their journey, the importance of support and understanding from those around them were identified, in conjunction with the impact of their diagnosis on social interactions. The final element of their journey involved changes in their self-identity as a result of their acceptance of their diagnosis.

Other areas of growth and development that these women have experienced on their journey were also described, including personal spiritual growth. As they journeyed toward accepting their diagnosis, they began to see themselves in new ways as they explored what it meant to have celiac disease. The journey to accepting their CD diagnosis was both significant and meaningful for participants. Their journey gave them the opportunity to understand how they are able to positively cope with difficult situations about their health, including through their faith and their relationship to God.

This inquiry provides a synopsis of the experiences of three women on their journey to acceptance of their celiac disease diagnosis. While not the experience of all people diagnosed with CD, there is great value in the narratives and reflections that the three women shared as part of this inquiry. My hope is that this thesis sheds some light on different aspects of the women's experience as they journeyed toward acceptance of their diagnosis, and that it may also provide lessons for healthcare providers and insights for others on a similar path.

In the following sections, I reflect on the experiences of the women as they journeyed toward accepting a diagnosis of celiac disease in relation to the literature and other sources. In addition to this, I also consider my journey, and how my experience was similar or different from the study participants.

Impact of Symptoms and the Diagnosis

A diagnosis that confirms one's suspicions and serves to reduce a sense of open-ended worry and uncertainty will often be welcomed by patients. Hallert, Sandlund, and Broqvist (2003) reported that "both men and women felt great relief when eventually being diagnosed to have coeliac disease and experienced new-found vitality and health soon after starting on a gluten-free diet" (p. 303). Having a diagnosis helped people to know that they were correct in the knowledge that something was wrong with them after years of uncertainty. For others, knowing what one was facing was just as scary as not knowing. In addition, patients who had been mostly asymptomatic described experiencing “confusion, distress and anger when diagnosed” (Griffiths, 2008, p.127).

The women stated that they tried to normalize the symptoms that they were experiencing. They constantly asked their doctors about their health concerns, but typically their doctors only reassured them that there was nothing wrong with them. Family, friends and associates often told them the problems that they were experiencing were normal. Although the women had a sense that something was wrong with them, they also often doubted themselves. When a person is constantly told that there is nothing wrong with them they begin to wonder if there is something psychologically wrong with them instead. Self-doubt caused them to think that they did not know their own bodies. They wondered if they were imagining what was happening to them. A person needs answers when they are not feeling well and the fact that they were not getting these answers caused great doubt, frustration and anxiety.

There was a sense that they were different from other people because of the physical effects that they were experiencing from the disease. The women in this study discussed the impact of the physical effects of the disease on their bodies. They struggled with gastrointestinal pain for many years: their symptoms were ongoing with little relief. Something was wrong with their bodies but they had no answers; they continued to search for a diagnosis. Ebony said that “she felt like she was lazy but she knew that she was not.” Years of unchanging anaemia was taking a toll on her body. In literature on anaemia, Baccini et al. (2006) report “coeliac disease has been recognized as a likely cause of unexplained or refractory IDA (iron-deficiency anaemia)” (p. 919). According to Ebony, she had anaemia for many years before she was diagnosed with CD.

People with celiac disease struggle for many years with incorrect diagnoses which impact their overall health. They are often treated for health conditions that they do not have. There are a wide variety of symptoms associated with CD which makes it problematic for doctors to diagnose. The literature states that “the sheer number of potential symptoms is amazing to see, but look closely at the enormous variation in the celiac symptoms as well. These symptoms can occur individually, in combination, sporadically, or constantly” (Dowler Shepard, 2008, p. 5-6). It took a number of years for each doctor to correctly diagnose each woman. The literature suggests that doctors should test for CD, which due to the wide range of symptoms can cause misdiagnosis. Misdiagnosis can result in further physical complications and stress in patients (Dowler Shepard, 2008, p. 8).

There are a number of complications related to celiac disease which early diagnosis can prevent these include “anaemia, infertility, osteoporosis, and even cancer” (Dowler Shepard, 2008, p. 8). All three of the women in this narrative study wished that they had been diagnosed earlier. According to Hallert et al. (2002) “both male and female coeliac patients expressed bitterness over not being diagnosed earlier in life” (p. 41). The women in this study shared that they felt an early diagnosis would have eliminated years of suffering and would have allowed the women to begin their journey towards better health and acceptance sooner.

Although they wished they had been diagnosed earlier, a sense of relief is common among people given a celiac disease diagnosis even after years of suffering. Hallert, Sandlund and Broqvist (2003) concluded, “both the men and women felt great relief when eventually being diagnosed to have coeliac disease and experienced new-found vitality and health soon after starting on the gluten-free diet” (p. 303). A sense of relief was experienced by all three women in this inquiry when they finally received their diagnosis, which provided them with a new focus and perspective. Not having a correct diagnosis for many years can lead CD sufferers to question and doubt their knowledge of themselves and their bodies.

The women in this study wondered how or where they manifested the disease. They also expressed a sense of distress and loss. Grief is a common emotion identified by people given a celiac disease diagnosis. Llewelyn Bower report, “emotions common to CD patients as they struggle to adapt to a new way of eating include grief over the loss of lifestyle and food” (p. 48). There was a sense that life was changed forever because their social life and their diet were affected. The participants in this study knew that their lives had been forever changed. After receiving their diagnosis, they would have to make significant adjustments in their diet and lifestyle.

A person given a diagnosis of celiac disease often feels as though they are different from others, as they struggle to cope with their diagnosis in diverse ways. The impact on their social life can be a challenge where they have to deal with new situations, people they do not know, and food they cannot control. Literature on CD describes the importance of being clear about your needs as a person with celiac disease and to sometimes call ahead to make arrangements in social situations. Calling restaurants in advance to review menu options in relation to their dietary needs can relieve some of the potential stress. These strategies require more effort, but help to reduce the feelings of loss associated with a CD diagnosis. These methods also provide some control for people with CD.

The three women in this study expressed concerns about infertility when they were first diagnosed. They described experiencing a high level of distress when they initially read about celiac disease and infertility on the Internet, and discovered information that stated that women with celiac disease were unable to have children. This was upsetting to the women because they wanted to have children. The inability to have children impacted how they saw themselves as women. There was a sense of loss of meaning in their lives since they were no longer able to have children. It motivated them to further investigate their options. In fact, research in this area provides evidence that women with CD are able to have children. Green and Jones (2006) report that "studies have demonstrated that women diagnosed with celiac disease are often able to get pregnant but have [an] increased rate of spontaneous abortions (miscarriages), accounting for fewer children" (p. 148). As the women investigated further they learned that they had been misinformed by their initial research. While the literature indicates that women and men with undiagnosed CD are likely to have fertility problems, this problem is alleviated when women are diagnosed and follow a gluten-free diet, Llewelyn Bower (2007) reports that "many women have gone on a GFD [gluten-free diet] and delivered normal healthy babies" (p. 39). Through their research they realised that they could have the lives that they wanted with children. They were not going to have to suffer for having the disease and be punished by not being able to have children. The meaning that they felt that they had lost returned to their lives with the knowledge that they had obtained.

Despite this, two of the women (Pam and Ebony), admitted to still having concerns about their ability to have children. They have not yet tried to have children which has left them not knowing if it will be possible. This sense of uncertainty leaves them with a number of questions that cannot be answered until they try to have children.

According to Hallert, Sandlung and Broqvist (2003) “women more often described themselves as ‘victims’ and dwelled upon questions about [the] meaning of contracting coeliac disease” (p. 304). Hallert et al. (2003) report that the women in their study tended to have a negative outlook about their disease. In contrast, the women in the present study had a positive outlook. The women felt that they were lucky that this was all that was wrong with them, as there could have been a worse diagnosis than celiac disease. It is as though they were relieved to only have CD. This outlook took time to develop but all identified that it emerged within the first six months after receiving their diagnosis. Having answers to their heath questions helped them to move on and accept the current state of their health.

Acceptance of a diagnosis can be facilitated by knowing and understanding one’s self. All three of the women had a clear understanding of who they were, and this helped them in the acceptance of their diagnosis. The literature shows the importance of knowing one’s self in accepting a diagnosis. Llwelyn Bower et al. (2007) write that “when anything happens to our physical body, we remain the same” (p.94). By knowing themselves, these women were able to discuss their health in relation to their disease with others, and seek support when necessary.

All three of the women were happy to feel well again. It had been years since they had felt healthy so this was a benefit of the diagnosis, as part of following the gluten-free diet. Much of the literature reports that people feel much healthier and experience an improved quality of life after their diagnosis. Dowler Sheppard et al. (2008) describe an interview in which a woman shared her experience of how “celiac disease changed me in ways I never thought possible. It empowered me to take responsibility for my health and happiness” (p. 33). People with CD know that if they want to be healthy the key is to follow a gluten-free diet. Jen admitted to feeling in control of her health now. She said in the past she would have relied on the medical system but now she relies on herself. This is a tremendous shift in thinking for people that are used to going to doctor after doctor about their health problems.

Much of the literature on celiac disease emphasizes the importance of CD patients taking responsibility for their health. In encouraging CD patients to assume an internalized locus of power or control in relation to living with their diagnosis, Dowler Sheppard et al. (2008) suggest that people ask themselves, “how far am I willing to go to take care of myself and reclaim my health?” (p. 34). They suggest that one should “embrace the fact that your condition can be managed through diet alone, and adopt a positive outlook on your new future in which you are in control of your own health and happiness” (p. 34). The women in this study did this and experienced many positive changes in their lives. Ebony no longer felt exhausted all of the time and her iron levels returned to normal. Pam felt healthier than ever, and Jen no longer had the gastrointestinal problems that she had in the past.

Sonya: *For me the symptoms before diagnosis were painful and greatly impacted my life. I have a great appreciation and understanding of the women’s experiences of relief they felt once they heard their diagnosis. I too felt that sense of relief quickly followed by confusion. It has become clear to me through this inquiry process that people given an accurate medical diagnosis feel a strong feeling of relief.*

Working with doctors that have an understanding and awareness of the disease has tremendous impact on the lives of those given a celiac disease diagnosis. The women needed family doctors, dieticians, and specialists to give them relevant and accurate information in order for them to receive an accurate diagnosis. This was not *their experience however, and if it had not been for their families and friends they might not have known what to do to be sure that they were given an accurate diagnosis. Over the years, the women had been given a variety tests and diagnoses but nothing relieved their symptoms. Their ability to advocate for themselves led to their diagnosis. The Internet was helpful to these women in their diagnosis of CD. Having doctors recognize that CD is a common disease and testing for it more frequently is key to receiving and accurate diagnosis sooner for those with CD.*

The feelings of happiness that followed for these women were tremendous. They knew their bodies and that what the doctors were telling them they had prior to their celiac disease diagnosis was not accurate. The women all fought for the relief that they felt after their diagnosis. Finally having an accurate diagnosis that provided symptom relief was amazing. For me and the participants, being diagnosed with CD opened up a new chapter in our lives.

Significance of Health Care

The participants' experiences leading to their diagnosis of celiac disease were similar: no one had a positive experience with their doctors. The women reported having seen a number of doctors before receiving their diagnosis. This is consistent with research by Llewelyn Bower (2007) who found that "the typical individuals with CD may go to many doctors before being diagnosed" (p. 9). All of the women knew there was something wrong with them but were unable to find an answer to their problems. The women were given diagnoses for various conditions: anaemia, gastrointestinal difficulties, irritable bowel syndrome, and/or fatigue. Green and Jones (2006) reported that "young and old take drugs and numerous specialists for gastrointestinal complaints, anaemia, joint pain, itchy skin conditions, constant fatigue, or headaches. Their symptoms are treated, but no underlying causes can be found" (p. 1). There was a lack of understanding on the part of the doctors that their patients were suffering and seeking answers. Green and Jones (2006) state "celiac disease may not be diagnosed because even though the patients are complaining, the doctors do not take much notice" (p. 64). Often, doctors misdiagnose the symptoms that people with CD present with as being the result of another condition and they do not test further for CD. Pam and Jen shared that they requested being tested for CD, rather than their doctors recommending the test.

Many people with celiac disease report frustration with their doctors (Llewelyn Bower, 2007, p. 48). In addition to feeling frustrated when their doctors failed to provide them with an accurate diagnosis over a protracted period of time, the women in this study also shared that they were frustrated by the lack of support they received following their preliminary diagnosis. Once referred to testing, the participants shared that they were given little or no information about CD by their family doctor while waiting to see the specialist. None of the women had been told that they should continue to eat wheat until after their appointment with the specialist. Llewelyn Bower (2007) asserts that "the first step to a diagnosis begins with a laboratory test. [Continue] to eat gluten until tested. If you go gluten-free, the protein that causes the antibodies will not be present to indicate CD, even if you have it" (p. 9). All three women in this study stopped eating wheat after they were told by their family doctor that they had might have CD. For two of the participants, other people that they knew informed them that they needed to continue to eat wheat in order for their test results to be accurate. Not having this information provided by their family doctor could have meant that these women would not have received their diagnoses in a timely fashion, resulting in more suffering.

Even after some patients saw their specialist they reported that they had been given very little information about the disease or how to live with it. According to Green and Jones (2006), “after diagnosis, it is not uncommon for patients to be given dietary counselling by their doctor that consists of: Go to the Internet and find out what to eat, come back if you need to. Good luck” (p. 171). The type of information and support provided by physicians could have been of better quality.

Once the participants of this study had received their diagnosis they were referred to a dietician to help them to better understand a gluten-free diet. The wait time between diagnosis and seeing a dietician was another issue identified by the participants. In the weeks between referral and their appointments with the dietician, they had no idea what it was that they were able to eat. One of the participants reported only eating yogurt and oranges for a few days because she did not know what else to eat. However, the women also reported that the dieticians had little to no knowledge of the disease which meant they were unable to adequately help them with their diet.

There is a need for better education regarding celiac disease among health professionals. The three women in this study shared that they were not satisfied with their interactions with health professionals. For example, when Jen went for her yearly biopsy with her specialist she reported that he told her that “she must not be following the diet because she had not gained weight.” She said that he proceeded to lecture her about the importance of following the diet even though she told him that she was eating gluten-free. Jen was frustrated and felt unheard by her specialist when she continued to have to defend herself. Ebony stated that when she told a doctor at a walk-in medical clinic that she had CD, he said, “so, you can only eat rice, that must be tough.” She was shocked that this comment came from a doctor, believing that he would be educated about the disease. In interviews conducted by Green and Jones (2006), one participant stated, “there are many things that make me angry … misinformation being among the major support groups, the [high] price of gluten-free food…but, most of all, the lack of awareness of celiac disease among the medical profession” (p. 65). Many people find this lack of awareness frustrating.

In addition, throughout the diagnosis process, attention should be given to providing holistic care to patients with celiac disease. When a person is initially diagnosed by the doctor they have many questions as they struggle toward accepting their diagnosis. Patients benefit from seeing different health professionals as no one is able to answer all of their questions. However, the lack of harmonious cooperation or collaboration between health care professionals as described by the women in this study left them with increasing frustration and uncertainty.

In this inquiry, the participants shared many struggles that that they found challenging when they were first diagnosed, including not being referred for counselling. Their primary care providers did not ask about mental health issues, even though research reviewed in this study showed that two out of three women given a celiac disease diagnosis suffer from depression. Ciacci, Iavarone, Mazzacca and De Rosa (1997) state that depression in people with CD is not “influenced by age, sex and socioeconomic variables and may be considered a feature of the diseases affecting patients regardless to their demographic characteristics” (p. 249). Young women and others who receive a celiac disease diagnosis may well benefit from the assistance of a counsellor who can support all aspects their clients’ well-being while they journey to acceptance of the diagnosis. Addolorato et al. (2004) conducted a study in which they concluded that patients diagnosed with CD who received supportive counselling had lower percentages of depression than those that were not offered counselling.

Of the three women in this study, Ebony and Pam reported feelings of depression at different points in their journey. Ebony described that she felt depressed before diagnosis and Pam felt some depression afterward. For Ebony, once she was diagnosed with celiac disease, her depression decreased. Pam felt that her depression was the result of the lack of knowledge of the gluten-free diet and poor knowledge of the food that she was able to eat. It is clear that knowledge of the diet can improve a person's mental health and physical wellbeing, but in addition counselling may also be helpful after receiving a CD diagnosis.

In addition to helping patients adjust to their diagnosis, Fasano has suggested that collaborative multidisciplinary assessments involving professionals across different medical and health specialities would help physicians to recognize when patients present with celiac disease symptoms earlier (see Rooney, 2008). He states: "… the disease is not a problem that can be handled by a single discipline … Its complexity demands the collaboration of paediatricians, adult and paediatric gastroenterologist[s], epidemiologists, immunologists, geneticists, and molecular biologists" (cited in Rooney, 2008, p. 1). This is a point that has been previously made, but merits restating.

Significance of Supports

The women reported the importance of support as part of their journey toward accepting CD as part of their life. Some of the supports that they relied on included family, friends, and support groups. The ability to talk to others and to share their struggles made the adjustment easier. Sharing what they had learned with others was also empowering for the women. This helped them to have a clearer understanding of the changes that were taking place because of their diet. Jen reported that much of her support came from her family and close friends. Pam was supported by her husband and her in-laws. Ebony, on the other hand, initially received much of her support from her mother, and then later her support group. Although social networking sites were used in recruitment, none of the women reported having used these for support around the time of receiving, or following their diagnosis. They were not informed about any support groups at the time of their diagnosis and were not aware of any afterward. The only group discovered by any of the women was the Canadian Celiac Association.

According to Dowler Shepard (2007), "people cannot fully understand the challenges that face you or your children unless they have walked in your shoes - these groups have worn those shoes and can provide not only information but ideas of how to overcome temptation or to successfully speak to a celiac family member about his or her new lifestyle" (p.91). People who have the disease have a better understanding and can offer more support than others without the disease. Family members are often motivated to learn about and support their loved ones, including going so far as to follow a gluten-free diet themselves. All of the women had different people that supported them throughout their journey. It was important to find people to discuss experiences with, as well as the trials and tribulations of, accepting a CD diagnosis and following a gluten-free diet.

Local or national support groups can be helpful for people given a celiac disease diagnosis. Martin (2008) discusses the importance of support groups in the lives of those given a celiac disease diagnosis. She states that "local and national CD support groups also play a critical role for patients and families by providing emotional support along with practical resources, such as gluten-free friendly supermarkets, manufacturers, literature, and restaurants" (p. 246). Ebony struggled with the gluten-free diet until she became involved with a group of people that offered her support and gave her guidance about the options for people with CD. She did not join the group immediately so there was a period of time where she did not know about the range of gluten-free options available to her.

The support of health professionals would have made the acceptance of the diagnosis much easier for the participants. The literature focuses on the importance of having a dietician or nutritionist that has knowledge of celiac disease as a major support in understanding the diagnosis. Green and Jones (2006) state that "patients told to go on a gluten-free diet need to consult with a nutritionist who is aware of celiac disease, or with a support group counsellor in order to learn the basics as well as subtleties of the diet" (p. 172). The burden of diagnosis felt by the participants was around their lack of knowledge of the diet and a lack of support in trying to understand the diet. When researching the diet it is important to focus on local (i.e. home country and community) information to help better understand diet requirements, as dietary recommendations vary by different national bodies. Organizations in Canada, the United States, and Europe have developed different rules and guidelines regarding the foods that people with celiac disease should eat. People newly diagnosed with CD would benefit if given information about local resource supports and possible contacts, in addition to a list of available literature. If a person sees a dietician who has no knowledge of the disease, the dietician should refer clients to other nutrition specialists who do have knowledge of the disease as an option for better support.

Self-management is something that people with celiac disease are constantly engaged in because they need to be in control of their diet to maintain their health. Harvey (2009) states, "self-management of chronic illness consists of activities that people do to improve or maintain one's health and is based on day-to-day activities to reduce the impact of their disease" (p. 206). According to Harvey (2009), approaches to self-managing their health include, "but are not limited to, medication management, physical activity, and dietary compliance" (p. 206).

While following a gluten-free diet is an important approach that people with celiac disease use to control of what is happening to them, spirituality offers another approach to managing their condition. In one interview conducted by Harvey (2009), a woman discussed her perception of God: "…God gives you something to do. He gives you a problem. You need to solve it. He gives you a way to solve it, too, if you are looking" (p. 213). This perspective puts the person in control of what happens to them with the knowledge that God is there with them on their journey.

Spirituality was a strong element of support for the women in this study. All of the women accessed their spirituality while on their journey, although each participant had a different experience of their spirituality. Jen reported that her spirituality grounds her and she used this to help her on her journey. Ebony said that she had faith that she would get answers to her suffering and that it would happen eventually. Pam stated that she has faith that no matter what happened everything would be okay. Spiritual connections aid people with their adjustment to their diagnosis. According to the literature, part of the self-management process following diagnosis involves accessing spirituality. In Harvey's (2009) study it was concluded that "strong spiritual connections improved the participants' sense of satisfaction with life and enables them to adjust to their disability and illness" (p. 214).

A diagnosis can spark a desire within people to get in touch with their spirituality in its various forms. Llewelyn Bower (2007) believes that "healing is a state of mind that needs to be nourished and cultivated" (p. 95) and can help bring a light back into the lives of people diagnosed with celiac disease and help add to their sense of purpose. Conducting an assessment of an individual's personal and spiritual resources can help them adjust to their diagnosis. I would suggest that a spiritual assessment be included by the medical community when they are working with patients. The women in this study were not asked about their spirituality while on their journey to acceptance of CD, however, all discussed the role that their spirituality played.

Sonya: *In addition to the health ailments that patients' experience, many health professionals have a poor understanding of celiac disease, which creates difficulties for their patients. Supports make adjustment to the disease and the journey to acceptance much easier. It was important for the participants to have the people close to them on their side and willing to cook gluten-free for them in order to support their new diet requirements. Having these people in their lives made it easier to learn about and understand the disease. The literature shows the important role that support plays in the journey toward acceptance of a diagnosis. Not only having support from family and friends but the medical community as well is vital. It is important that medical professionals are informed about the diagnosis that they are delivering, and the post-diagnosis information that follows needs to be relevant and complete. A complete patient assessment needs to encompass the medical as well as the psychological and spiritual aspects. In addition, based on the interviews and the literature review, post-*

diagnosis care and support are important in helping to decrease the depression and stress of patients related to a diagnosis of CD. Very little informed support was offered after diagnosis to the women. The supports offered by the medical community were often poorly informed.

Gluten-Free Diet

Following a gluten-free diet is one of the greatest challenges that people diagnosed with celiac disease face. One of the struggles for Ebony in the beginning was being organized in her daily life in relation to food. She always had to know what she was doing in a day in order to plan her diet. The struggle to find gluten-free food is not limited to travelling outside of the country; it happens here as well. When Ebony was first diagnosed she lived in a rural community and had poor access to gluten-free options. Some of the literature discusses the difficulty of finding gluten-free food for people in Canada, especially in rural areas where the majority of "respondents reported difficulty finding GF food (83%)" (Zarkadas et al., 2006, p. 45). The difficulty in finding gluten-free food adds to the struggle of following the gluten-free diet.

The cost of gluten-free food is an issue for some people. Gluten-free food can be expensive and if a person is living on a budget, it can add to the difficulty of following the diet. Sverker, Hensing and Hallert (2005) found that "over the years gluten-free products became monotonous to eat, and they were expensive to buy" according to their study participants (p. 177). The cost of food can also place a strain on personal finances. Pam admitted her concern about the cost of packaged and prepared gluten-free food. Jen said that she rarely eats packaged gluten-free food, as she prefers to eat fresh food and gluten-free staples. Many foods exist that do not contain gluten can be found at the local grocery store, such as rice and potatoes, which can help with the financial cost.

Pam described feeling overwhelmed by the gluten-free diet, especially the first time she went to the grocery store she struggled with the unknown. She tried to gain a clear understanding of what she could eat and what to avoid. This involved not only understanding the diet but also how to have a gluten-free house. According to Dowler Sheppard (2008) ingesting even minimal amounts of gluten can be problematic. She states "never simply pick the croutons off a salad or eat just the filling removed from a prepared sandwich, and never risk using condiments and spreads; pots and pans; cutting boards and utensils; or appliances that may have even a trace of remains from a non-gluten-free food" (p. 74). All the changes that have to be made to eliminate residual gluten in the kitchen can be overwhelming to a newly diagnosed CD patient.

The women were concerned about social situations that included eating at other people's houses. There was concern that the food they were going to eat might contain gluten, or there might be remnants of gluten in the kitchen, as cross-contamination could also make them sick. It was important for the participants to educate their friends and family about their concerns, which resulted in them feeling demanding and of putting pressure on their friends and family. Nevertheless, it was important to do so because their health was at stake.

There was also fear related to unknowingly ingesting gluten despite their best efforts to educate others around them. Sverker, Hensing and Hallert (2005) describe that, "even if someone had confirmed that there was no gluten in the food, they were suspicious and checked once and twice to be sure" (p. 175). There was a need on the part of participants in the current inquiry to be sure that there was no gluten in their food and they were vigilant to ask more than once. People with CD have to place their trust in terms of their health in the hands of people that they do not know which impacts on their ability to socialize comfortably and to eat anywhere that they would like to.

The women were frustrated when discussing or sharing their diagnosis. Jen's frustration centred on explaining celiac disease to people only to discover that they did not fully understand it. People often pretend that they do understand rather than ask more questions, or they may feel that the person with CD is exaggerating or being untruthful about their disease. This results in a sense that others are not concerned about making them sick, or feel that celiac disease is not a serious condition.

Many social interactions take place around food which provides people with the opportunity to connect with one another. This can be complicated for people diagnosed with celiac disease as their ability to socialize is greatly impacted after diagnosis. Eating outside of their house can be one of the most daunting tasks facing a person with CD.

> While it's true you may have enough wheat and gluten-free food stashed in your kitchen to last through the next millennium, you can't stay home and munch rice crackers forever. Sooner or later you must sit down to a meal with other humans. How well you do is going to depend heavily on your attitude. (Lowell, 2005, p. 26)

For many people with celiac disease, eating out creates so much fear and uncertainty that they stay at home and avoid going out. Dowler Shepard (2008) reports "the isolation, embarrassment, and frustration that correspond with being different" has a tremendous impact on the lives of people with CD. Their social lives are greatly impacted by this and they are sometimes unsure of how to cope. A person's ability to share with others information about their dietary needs is a vital part of making their way in the world of CD.

One area that can be problematic for people given a celiac diagnosis is being assertive when they eat out. People diagnosed with CD struggle to explain the details of their disease when they are in social situations because others believe that they are being picky or are hypochondriacs. Jen said that there was lack of understanding in the restaurant community about CD and the impact that eating gluten has on the bodies of people with the disease. According to much of the literature there is a fear on the part of those who have CD that others will think they are crazy in relation to their food (James Ahern, 2007, p. 63). The women also feared exclusion from some social events because they are unable to eat the same foods as others.

All of the women reported struggling in social situations especially with people that they had just met. There was a feeling that they stood out in these situations because they were not able to order off the menu or eat everything that their host cooked. Being comfortable with discussing what they needed in social situations is one of the most difficult aspects of the journey identified by the women. The women did not want people to think that they were being aggressive when they were telling them about the diet restriction.

The participants described needing to take the extra time to organize and pack gluten-free food in order to enjoy a vacation. A great deal of the literature available to people with celiac disease provides tips on how to make travelling easier. James Ahern (2007) offers the following advice: “plan ahead, pack your lunch, look for gluten-free bakeries and restaurants, bring a cell phone for calling companies, and give yourself a treat” (p. 69-71). The women reported that by being prepared they decreased their chances for ingesting gluten while on their vacation. Jen mentioned the lack of options offered by airlines when travelling as being a problem. Due to security restrictions, a person is not always able to carry their own food on the plane. It is important for airlines to provide gluten-free food for people with celiac disease who are travelling long distances.

Learning the difference between being assertive and aggressive is important for a person with celiac disease (James Ahern, 2007, p. 64). It is important to distinguish between the attitude of “cater to me” and being “clear about what we need and ask for it simply, we save so much time” (p. 64). If people state what they need clearly then they are more likely to get what they want. There is, however, the chance that one can get glutenized-food regardless of how clear and assertive one is. The three women realized the importance of being assertive for maintaining a gluten-free lifestyle. They also felt that this was one of the most challenging things for them to adjust to. Certain social situations affect their ability to be assertive but it is important to them. Ebony and Pam said that they still struggle with it sometimes but they are much better than they were initially when they were first diagnosed.

Confidence in themselves in relation to the disease and the gluten-free diet was reported by all of the women in the latter stages of their journeys. In addition, they all felt that they would be comfortable sharing their knowledge with other people who had been newly diagnosed. Ebony reported a strong desire to help others diagnosed with celiac disease. She believed that anyone diagnosed with CD would benefit from meeting others with the disease to help them adjust to their diet. They all felt confident about understanding their needs and their own bodies.

The women in this study shared that their confidence increased as they learned new information about their diet and they were able to educate others and share their learning. All of the women felt that they had learned a great deal about following a gluten-free diet. With all of the information that they had learned they felt confident in answering questions and advising others about the diet. That confidence underlined how far they had come in their journey in accepting celiac disease as part of their life.

The women described their self-identity in relation to having celiac disease. The women all described being celiac as part of who they are. When they introduce themselves to others they explain that they have CD. Through the journey toward accepting celiac disease as part of their life, they know who they are, and have come to feel empowered in approaching aspects of their life differently since their diagnosis. They describe having “found their voice”, actively taking charge of their health, and planning for their future.

Pam initially resented being given the label of a celiac at the time of her diagnosis. When she was first diagnosed, there were times she wanted to be normal, and able to eat gluten. She has since come to accept the disease. Jen said she feels that being a celiac is part of who she is and she embraces it. She said she loves being a celiac. Ebony said being a celiac is part of her identity. Hallert, Sandlund and Broqvist (2003) state, “the way the women talked about themselves pinpointed that they identified themselves more as coeliacs than the men did” (p.304). Their identity in social situations was based on being a celiac.

Some of the literature states that people with celiac disease feel overlooked or forgotten in social situations when there is nothing for them to eat. According to Sverker, Hensing and Hallert (2005), “examples of such dilemmas were for instance, that there was no gluten-free food at coffee breaks at work or when they visited friends and at parties" (p. 176). The women in this study did not report running into these kinds of situations. In fact their experience was quite different. They were thankful they did not have to eat the food. Jen explained how sometimes people at her work bring in donuts. As she cannot eat them, she keeps treats for herself in her desk. She said by doing this she does not miss eating the donuts. She rewards herself with things that she really enjoys but rarely eats. According to the literature it is important to find ways to treat one's self. Green and Jones (2006) say to "find ways to gratify the urge to splurge without destroying the lining of your intestine" (p. 266). For Jen it is about keeping small amounts of the less healthy foods for rewards to make it special. Remaining as healthy as possible is more important to the women. Instead of looking at treats that contain gluten as a negative or feeling forgotten they appreciated the benefit of knowing that they are not able to eat gluten.

<u>Sonya</u>: *The gluten-free diet is complex and difficult to understand. It is important to have someone who is educated in the diet to work with people that are newly diagnosed. They need to be aware that not everyone has adequate knowledge of what is involved in following a gluten-free diet; easy access is also often taken for granted. There are many companies that offer gluten-free options or only sell gluten-free products but some people, especially those newly diagnosed, have little or no knowledge of them. Having access to economical and healthy gluten-free food is of concern to people with celiac disease. People need to be aware of the choices that exist that are affordable.*

Understanding the diet not only means shopping and how to eat but how to live in a gluten-free house. It is important to offer information, tools and resources to people who are newly diagnosed to help educate them about all that it means to live gluten-

free. There will be people in their lives that do not know the appropriate food to offer them or what it means to live with celiac disease. The willingness of others to understand what CD is all about is a key step on the journey. Being accepted socially is an important part of journey.

Another aspect of the journey that was identified by all of the women was creating a new identity for themselves. According to the literature and the experiences of the women in this study, creating a new identity represents a huge step on their journey. The journey involves numerous important steps, but being able to identify one's self as a person with celiac disease is a tremendous accomplishment and takes a lot of courage. All of the women in this study had the strength to accept for themselves, and share with others that they have the disease.

Summary

While there was great variation among the experiences of the women in this study, there were also a number of consistencies across their experiences. The physical impact felt by the women was generally the same even though their diagnosis process was different. All three of the women identified a need for better support from the medical community. They wanted their doctors to provide more information to them about celiac disease and what they should be doing while they waited to see the specialist they were referred to. The women reported that they wished they had been able to see the dietician much sooner after their diagnosis. By seeing a dietician sooner they would not have been left wondering about the diet for as long. Subsequent to this, the participants expressed concern about the lack of knowledge that dieticians possessed about the gluten-free diet. Two of the women reported feelings of depression at some point and it would have been helpful to have an assessment to determine if they needed to see a psychologist. If doctors provided an information package to their patients containing basic information related to CD, this would help to make the experience a more positive one.

Social issues were a struggle for the women in the current study. They shared that the need to explain their diet to everyone they interacted with socially was time consuming and impacted how they enjoyed their social interactions. Numerous times they had poor experiences with restaurant staff, whether it was having to explain the diet, trying to get information about the menu, or getting sick even after they asked these questions and were provided reassurance. Enhanced feelings of confidence, and learning to be assertive were identified as positive approaches the participants used to manage these situations.

When asked about supports, the women of the current study identified family, friends, spiritual support, and support groups as being the most important to them. They felt that this made the journey to acceptance easier at times. The women reported that when they were struggling they approached their loved ones for primary support.

One aspect of the journey that caused great turmoil for the women in the current study was struggling with the gluten-free diet. Their frustration was related to poor access to gluten-free information even from the dietician that they were referred to. The women had struggles in travelling, in social interactions, in access to gluten-free food, and affordability of gluten-free food. The women reported feeling frustration about explaining celiac disease to many people and their lack of understanding of the disease. As they began to gain a better understanding of their disease and share their knowledge with others their confidence in themselves grew. In my opinion, given all of the various struggles the women described, I found it amazing that these women were able to follow the gluten-free diet as well as they did.

Infertility was another area that all of the women expressed concern about at some point on their journey. Two of them identified having concerns and a lot of questions about their ability to have children, especially as they had not yet had children. There are many unknown questions for these women that they will want to investigate once they decide to have children.

Having celiac disease was an important part of the participants' identity. Two of the women, Jen and Ebony, expressed strong feelings about identifying themselves as being a "celiac" which seemed to correlate with positive changes they made in their life, and their overall well-being. Acceptance was identified by the women as an important part of their journey. They believed that their acceptance of their diagnosis made it possible for them to follow the gluten-free diet and maintain their health. Two of the women said that they were relieved to find out that they only had celiac disease and this made acceptance easier. Having a clear understanding of themselves, including spiritual aspects of themselves, helped with the acceptance of the CD diagnosis.

The information in this chapter provides an overview of the experiences the women in the current study shared about being diagnosed with celiac disease. Acceptance of their diagnosis consisted of many steps and a range of experiences, which can be related to the existing literature but also adds a unique view. These included positive, adaptive – often spiritually grounded – changes which young women diagnosed with celiac disease make in accepting their diagnosis.

Chapter 6: Conclusion

Summary of the Results

Through this research a number of points have been brought to light. The participants identified weaknesses in the medical and community systems and supports during the time leading to a CD diagnosis, as well as post-diagnosis. They reported a greater need for better and more detailed information from medical professionals. They expressed a desire for improved interactions with health professionals. Understanding what was entailed in following the gluten-free diet would have been initially easier if they had been provided some basic information about the diet. Adjusting to the diet was one of the greatest struggles that the women faced. The women in this study indicated that having a support system of family members, friends, and discussion groups was helpful to them on their journey to acceptance. The assistance and the information that the women were looking for came from their own support system not from the medical community.

The emotional component of the journey was where they experienced the greatest amount of change. Some of the women reported experiencing depression at some period during their personal journey related to receiving a celiac disease diagnosis and acceptance of their diagnosis. The women were not asked questions about their mental health or spiritual supports that should have been assessed after their initial diagnosis. With time the women reported more confidence and a higher level of acceptance due to the acquisition of greater knowledge through their own efforts.

Prior to diagnosis the women tried to normalize their experiences by comparing their health-related symptoms to the ailments of other women. Their experiences were often described by others as normal consequences of being female, and that problems such as cramps and anaemia were nothing to be overly concerned about. The women did not give up on their feeling that they were different and they held strong to this belief long enough until they finally received their diagnosis. Over time, they all accepted their diagnoses, and having met various challenges, have embraced their new identities with confidence.

Being empowered can help a person to cope with a chronic illness. It is important to do all that is possible to empower patients when giving them a life changing medical diagnosis. Part of the empowerment process is tapping into all resources that a person has available to them. In addition to other supports, this inquiry suggests the importance of the relationship between spirituality and chronic illness, and acceptance of a celiac disease diagnosis for all of the women.

Revisiting the Literature

The literature on celiac disease covers a wide range of topics from acquiring a proper diagnosis, struggling with a gluten-free diet, health concerns, struggles with family and friends, coping strategies, and a plethora of medical information. Much of the information focuses on the diagnosis process and the diet, but there is little on accepting the diagnosis with the exception of coping strategies.

According to Llewlyn Bower (2007) “celiac disease (CD) has gone from the depths of the darkest pits of ignorance into the light of knowledge within the last 5 years. ‘For wisdom will enter your heart and knowledge will be pleasant to your soul,’ according to Proverbs 2:10” (p. 1). Having knowledge of the disease and understanding the impact that it had on their health, knowing themselves, tapping into all their supports, and taking responsibility for their health and happiness, empowered the women in this study to accept their diagnosis.

Green and Jones (2006) discuss how “celiac disease is a significant medical condition” (p. 4). The impact that celiac disease has on the health and well-being of people is tremendous. Dowler Shepard (2008) reports that people should “embrace the fact that your condition can be managed through diet alone and adopt a positive outlook on your new future in which you are in control of your health and happiness” (p. 34). This puts the control for accepting the disease in the hands of the people that have been given the diagnosis.

The women in this study were all happy to receive a diagnosis of celiac disease and find resulting relief from their symptoms. This contributed to a positive attitude in coping with, and subsequent acceptance of, a celiac disease diagnosis. How one accepts the diagnosis, how one interacts with others about CD, how one educates others about their diagnosis, and how one uses their support systems, are all impacted by attitude. A patient’s attitude can make it possible for them to accept a diagnosis, or it can stand in their way of accepting it. According to Lowell (2005),

> …the attitudinal trick is to see yourself as perfectly healthy or, to be more precise, no longer sick, in spite of the fact that your plumbing is peculiar at best, your immune system so weird it sees an innocent chunk of bread as a deadly poison. (p. 26-27)

Developing a positive attitude toward celiac disease does not occur immediately but rather takes time, and can be promoted through information and support offered to newly diagnosed patients.

Areas of Potential Application

This study adds to the understanding of the journey to acceptance of a diagnosis of celiac disease. Information has been provided about the needs of patients given the diagnosis and aspects that they wish were better addressed. This study can be used by physicians and other health professionals to better understand the needs of patients when they receive a diagnosis of CD.

The need for spiritual and psychological assessment at the time of initial diagnosis has been indicated. The data collected in these assessments would aid physicians when they make referrals that support taking a holistic approach to the health and well-being of their patients. Supporting all aspects of patient health and well-being is vital for proper patient care.

Counselors can use information from this narrative inquiry to increase their understanding of patients who have received a life changing medical diagnosis. Information from the psychological assessment would provide counselors with a starting point in supporting patients adjust to celiac disease diagnosis. This information can help counselors when they conduct their initial assessment of the needs of new clients.

The information in this study can also be of benefit to the people who are facing a new diagnosis of celiac disease, those that suspect that they have CD, or those with connections to someone that has CD. This study can provide these people with a greater understanding of how people can journey toward accepting the diagnosis.

Having good, clear, and comprehensive information can help a person who has received a diagnosis of celiac disease move toward acceptance. Differing opinions presented on the Internet and across different texts and resources can cause tremendous confusion for patients newly diagnosed with CD. For example, dietary recommendations vary by different national bodies. Organizations in Canada, the United States, and Europe have developed different rules and guidelines regarding the foods that people with celiac disease should eat. This lack of consensus can make adherence to a good dietary regimen challenging. It may cause some patients to minimize the seriousness of CD. Others may begin to doubt the diagnosis of their disease and the advice of their medical professionals that they would normally trust.

I hope that this study will increase the understanding of the experience and will aid medical professionals when they prepare to share a celiac disease diagnosis that will fundamentally change the life of their patient. By taking the time to improve their understanding of the experiences of their patients, medical health professionals can provide better care.

Further Topics of Inquiry

Much of the research about celiac disease has considered the physical impact of the disease on those who have CD. Some research has also considered the difficulty of receiving a diagnosis and the impact of this on patients, although this has primarily been based on questionnaire data. The journey to accept the diagnosis of CD has been explored to greater depth in the current inquiry, however further study is needed. For example, more in-depth study of the nature of support that is found helpful to people with CD at various stages of their journey would be beneficial. Research that documents successful strategies for following a gluten-free diet would be a helpful contribution to the literature. In addition, studying approaches for helping to enhance awareness of celiac disease among the health professionals, including developing informational resources that could be distributed to health professionals and also newly diagnosed patients would be useful. Research that has considered the psychological well-being of patients given a celiac disease diagnosis, in western countries suggests that many patients experience depression at some point during their initial diagnosis. However, patients are rarely asked about their emotional well-being. It would be useful to create an assessment post-diagnosis to evaluate people's well-being, and assess the supportive resources they have in place, including spiritual resources. The spiritual aspect of coping with celiac disease was an important finding in this inquiry. Further study of the role of spirituality in coping with life changing medical diagnoses should be undertaken.

Considering ways to increase knowledge of, and approaches to supporting people with celiac disease in underserved areas, including rural or isolated areas and developing countries, would also be a helpful research contribution.

Personal Statement

Sonya: *I embarked on this research to enhance the understanding of the experience of women as they journeyed toward acceptance after receiving a celiac disease diagnosis. By learning about others' experiences, I am hopeful that people might gain a better understanding of the experiences they may face in relation to being diagnosed with CD. I found that the experience of others helped me to better understand my journey toward acceptance of my diagnosis.*

While writing this thesis I learned a lot about my own journey toward acceptance. I struggled greatly in the beginning and was not aware of how much so *until I began to reflect on the experience. I believe that if I had not had a doctor that believed that there was something more wrong with me that I would never had known that I had celiac disease. Having a doctor that was supportive and interested in my health was magnificent. I was fortunate enough to have my doctor test me for the disease without having to ask for it. I had never heard of celiac disease before he told me that I might have it.*

Once I was told that I did have the disease my husband, followed by my parents and a few close friends, were my greatest supports in my life. With the help of these friends and family members I was able to journey with greater ease than I first anticipated.

Learning about the diet and all of the life changes that I was going to have to make was a long process. It took some intense research on my own to learn about the disease. I had no one other than myself to depend on when it came to increase my understanding of the disease and the impact that it would have on my health.

My understanding of who I am and what I am capable greatly increased with my journey to acceptance of my diagnosis. I have a clearer understanding of my voice and speaking up for myself especially in social situations. Throughout this writing process I have learned that my journey toward acceptance has helped me to grow and change as a person. My relationship with God has gone through many transformations while I was on my journey. I believe that it plays a significant role in my life just as it always has. My journey has taken me to dark places but in the end the light that has entered my life as a result of having the gift of my health is priceless to me.

The journey to acceptance is complex, can be very long in duration, and requires a number of steps. All of the experiences of these women added so much to *increase my understanding of the experiences of others, as well as my own experience. The journey provided a number of opportunities for the women to learn about themselves and others in their lives.*

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APPENDIX A: Recruitment Notice

"Coming to Accept a Diagnosis of Celiac Disease"

- Are you a young woman who received a diagnosis of celiac disease in your 20s based on medical biopsy?
- Have you been following a strict gluten-free diet for at least one year?
- Would you be interested in sharing the journey you followed in coming to accept a diagnosis of celiac disease?

If you answered *YES* to these questions, you may be eligible to participate in a study I am conducting as part of my Master of Arts degree in Pastoral Psychology and Counselling at St. Stephen's College in Edmonton, Alberta. I live in Calgary and plan on conducting interviews in Calgary and Edmonton.

I am interested in how young women experienced receiving their initial diagnosis, how they responded to learning they had celiac disease, how the disease affected their lives, and how they moved forward.

My intention is to interview three women with regard to their experience of moving toward acceptance of celiac disease as a presence in their lives. I also hope to identify two additional women who would be willing to be part of a reserve pool for this research in case, for any reason, one of the three women that I initially choose decides to withdraw from my project.

I will conduct one 90 minute interview with each participant. Interviews will take the form of a conversation during which I will ask participants to share stories about how they experienced receiving a diagnosis of celiac disease. I will ask a series of semi-structured questions to facilitate this process. With the participants' permission, I plan on audio taping the interviews. All information will be kept anonymous and confidential. Participation in this project is entirely voluntary. All participants will be free to withdraw from this project at any time. There is no compensation for participating in this research project.

This study has been approved by the Ethics Committee of St. Stephen's College. Please contact Sonya Quinlan-Jacob at xxxxxxx or **(xxx) xxx-xxx** for more information. I will provide a detailed letter of information and will be able to answer any questions you may have.

APPENDIX B: Interview Questions

1. Tell me about your diagnosis process. What was your life like before you were diagnosed? Can you tell me about your initial reaction to your diagnosis?

2. How did you come to accept your diagnosis? What do you believe made it possible for you to accept your diagnosis?

3. What effect has the diagnosis had on your life?

4. Can you describe the emotions that you have experienced throughout your journey?

5. How did you react to all of the dietary changes?

6. What impact has your diagnosis had on your perception of self in relation to others?

7. What have been some of the most difficult aspects of the journey? Have there been positive aspects of the journey?

8. What role if any would you say spirituality played in your journey?

9. What advice would you share with others who had been recently diagnosed to make their journey easier?

10. Is there anything else you would like to share with me about your journey toward accepting that you have celiac disease?

APPENDIX C: Letter of Information and Consent Form

January 30, 2010

RE: "Coming to Accept a Diagnosis of Celiac Disease"

Dear Potential Research Participant

My name is Sonya Quinlan-Jacob. I am enrolled as a Master of Arts student at St. Stephen's College in Edmonton, Alberta. I am completing this research as a requisite for my Master of Arts degree in Pastoral Psychology and Counselling program at St. Stephen's College**.** I am conducting this research to understand the journey that young women follow as they move toward accepting a diagnosis of celiac Disease.

There is remarkably little information available to help health professionals and others understand the impact of a diagnosis of celiac disease. Little is known regarding how people respond to a celiac disease diagnosis and come to accept this life-altering diagnosis. In particular, I am interested in the experience of women diagnosed in their twenties as to how they receive their initial diagnosis, how it affects their lives, and how they move forward. This project aims to expand the understanding of this experience.

My intention is to interview three women with regard to their experience of receiving a celiac disease diagnosis in their twenties, and how they moved toward acceptance of the disease as a presence in their lives. I am also seeking two women to be in a reserve pool *in case, for any reason,* one of the three women that I choose initially decides to withdraw from this project.

I will conduct one interview with each participant. Each interview will take the form of a conversation during which I will ask participants to share stories about how they experienced receiving a diagnosis of celiac disease. I will ask a series of semi-structured questions to facilitate this process. With your consent, I will audiotape our interview. You will be free to refuse to answer any question that you would prefer not to answer. Each interview will take about 90 minutes, and be conducted in a venue that will ensure comfort and privacy.

I will use transcripts of the audio taped recording in my thesis work, as I attempt to identify common themes as well as variability in the accounts shared by the research participants. Your name or any other identifying characteristics will not be used in the final report. I will remove all information that could identify you from project materials. I will offer you an opportunity to comment on a preliminary summary of the narratives and stories you share with me once I have transcribed and reviewed our interview. You can clarify any information that I may not have accurately or completely understood. You will also have an opportunity to read the final version of my findings chapter. As a research participant, you will have the right to request removal of any information you share during your interview that you do not want to be included in the research report.

Your information will be kept anonymous and confidential and will be available to me and my thesis supervisor. All the project material will be kept in a locked cabinet to ensure it is kept safe and secure. Information from participant interviews will be used only for the purpose of preparing my thesis, and sharing my findings in a presentation and/ or short newsletter article (all data will be presented in a way that ensures that participants anonymous manner). Two years after the completion date of the thesis, September 1, 2010, I will destroy the interview recordings and transcripts. At the end of this project, I will give you a copy of the final report of the study prior to formal submission to my examination committee. Your participation in this project is entirely voluntary. You will be free to withdraw from this project at any time. There will be no compensation for participating in this research project.

To summarize, you have the following rights as a participant in this research study.

- You are free to refuse to answer a question at any time.
- You have the right to withdraw from the project at any time and all data will be returned or destroyed.
- Up until the time that I submit my final report to my examination committee you can request removal of any information related to you, or suggest a change in the research text that will more accurately represent your experience.
- You will be given a copy of the final report of the study prior to formal submission to my examination committee.

Throughout this study, I encourage you to raise any questions you may have about the research process. You can contact me at myaddress@email.com or xxx-xxx-xxxx. In addition, if you have questions or concerns about this research you can also contact Dr. Pamela Brett-MacLean (my research supervisor at The University of Alberta). Her number is xxx-xxx-xxxx.

If you have any concerns about your treatment or rights as a research participant, you may contact Dr. Julie Henkelman, Coordinator, Master of Arts in Pastoral Psychology and Counselling Program at St. Stephen's College by calling xxx-xxx-xxxx.

I ____________________________ understand that I have the above rights as a participant in this study as explained to me by the researcher and I consent to this interview.

______________________________ ______________________________

(Participant's Signature) (Printed Name)

______________________________ (Day/ Month/ Year)

APPENDIX D: Confidentiality Agreement

Transcription Services

I, ____________________________, transcriptionist, agree to maintain full confidentiality in regards to any and all audiotapes and documentation received from Sonya Quinlan-Jacob related to her master's study on A World Without Wheat: The journey toward acceptance of a diagnosis of celiac disease. Furthermore, I agree:

- To hold in strictest confidence the identification of any individual that may be inadvertently revealed during the transcription of audio-taped interviews, or in any associated documents.
- To not make copies of any audiotapes or computerized files of the transcribed interview texts, unless specifically requested to do so by Sonya Quinlan-Jacob.
- To store all study-related audiotapes and materials in a safe, secure location as long as they are in my possession.
- To return all audiotapes and study-related documents to Sonya Quinlan-Jacob in a complete and timely manner.
- To delete all electronic files containing study-related documents from my computer hard drive and any backup devices by February 12, 2010.

I am aware that I can be held legally liable for any breach of this confidentiality agreement, and for any harm incurred by individuals if I disclose identifiable information contained in the audiotapes and/or files to which I have access.

Transcriber's name (printed) ____

Transcriber's signature ____

Date ____

APPENDIX E: Confidentiality Agreement Editing Services

I, ____________________________, editor, agree to maintain full confidentiality in regards to any and documentation received from Sonya Quinlan-Jacob related to her master’s study on A World Without Wheat: The journey toward acceptance of a diagnosis of celiac disease. Furthermore, I agree:

- To hold in strictest confidence the identification of any individual that may be inadvertently revealed during the editing of her thesis or in any associated documents.
- To not make copies of any computerized files, unless specifically requested to do so by Sonya Quinlan-Jacob.
- To store all thesis related materials in a safe, secure location as long as they are in my possession.
- To return all thesis related documents to Sonya Quinlan-Jacob in a complete and timely manner.
- To delete all electronic files containing thesis related documents from my computer hard drive and any backup devices by September 2, 2010.

I am aware that I can be held legally liable for any breach of this confidentiality agreement, and for any harm incurred by individuals if I disclose identifiable information contained in the audiotapes and/or files to which I have access.

Editor’s name (printed) ____

Editor’s signature ____

Date ____

APPENDIX G: Story Maps

See pages 114-116.

Storymap: Jen

	Past Experiences	Present Experiences	Future Considerations
Experiencing Symptoms	Normalized physical difficulties Follow up important Fighting illness after diagnosis	Wishing doctors would diagnose CD. Eating GF nurtures her body Learning the difference between getting sick and getting gluten sick.	Fertility questions Regular check-ups with the specialist Would not eat gluten if she were able to with medicine
Importance of Communication	More understanding from doctors Felt her doctor minimized her illness	Feels like a problem to others People not understanding	
The role of Support	Lack of support from medical community	Family, Friends, and Partner support. Spirituality is part of who she is and is in everything she does. Connection between body and spirituality.	
Emotional Aspects	Surprised but motivated.	Emotional struggle with cross contamination Frustration of explaining CD Gets very upset when she gets sick	
Concerns With Following the GF Diet	Easy to eat GF Ingesting unknown wheat	Cross contamination Lack of education and caring from restaurants. Benefits of a GF diet. Works hard to be GF. Doesn't understand people cheating. Expanding her food tastes due to diet.	See lots of opportunity for GF food. Desire for GF restaurants. Having GF kitchen of her own.
Identity		Has become more assertive Loves being a Celiac Confident that she can answer her health questions Self-confidence increased	

Storymap: Pam

	Past Experiences	Present Experiences	Future Considerations
Experiencing Symptoms	Normalized physical difficulties. Follow up important. Fighting illness after diagnosis. Long wait time to see specialist. Sick of being sick. Getting diagnosis was hard. Concerned about infertility.	Now knows there is no less chance of her having a baby than any other woman. Gets a bad stomach and low energy whenever she eats gluten.	Will be concerned if there are complications to her health
Importance of Communication	Did her own research Family shared CD info.	Desire to be normal in social situations Friends increased knowledge of CD Spirituality is core in all things in her life.	
The role of Support	Family support Lack of support from medical community Dietician had no knowledge of GFD but gave GF samples	Appreciates people going out of their way for her Changed her social life	
Emotional Aspects	Confusion. Relief initially. Feels like a burden sometimes. Panicked and depressed about diet. Happy with the prognosis of CD. Mourned the loss. Worried about diagnosis	Emotional struggle with cross contamination Frustration of explaining CD. Gets upset when she gets sick. Research is an emotional rollercoaster Feels content. Feels sorry for herself sometimes.	Foresees herself becoming more content with the diagnosis.
Concerns With Following the GF Diet	Overwhelmed about GF diet	Cannot eat normally. Eating out is a concern and disappointing. Socializing at home is easier. Cost of diet a concern. Confident in sharing her knowledge of GF diet and new foods.	
Identity	Labelled with CD. Feels like she got a Celiac stamp.	Has become more assertive Loves being a Celiac Confident that she can answer her health questions Self-confidence increased	

Storymap: Ebony

	Past Experiences	Present Experiences	Future Considerations
Experiencing Symptoms	Took twelve years for diagnosis. Physical affects began with anaemia. Tested for CD. Specialist gave diagnosis. Started to feel better after six months.	Improved quality of life. Has normal energy levels. Getting diagnosis was challenging. No health issues and since diagnosis Has been asked about not having children.	Fertility questions. Hoping to have children.
Importance of Communication	Given little information by doctor. Did her own research. Trained family & friends about diet Had faith that her disease would get figured out	Has found her voice socially. Wants to educate others about the disease.	Wants to educate more people about CD
The role of Support	Family pushed her to find a support group Limited support Dietician had no knowledge of CD	A support group is helpful. Involved in Celiac community. Finding specialists with knowledge.	
Emotional Aspects	Frustrated by lack of energy. Felt ignorant Stressful trying to understand diet. Felt depressed before diagnosis.	Emotional struggle with cross contamination Frustration of explaining CD. Gets upset when she gets sick. In a good place with the disease.	
Concerns With Following the GF Diet	Needed to understand the diet before following it and it took one month. Struggled to find GF food so she lost weight. Willing to take on challenge of GF diet	Never cheats but has been glutened. Loves to cook and experiment. Does not think about not being able to eat wheat. Thinks about food a lot; has to be organized when travelling.	
Identity	She did not want to be known as a lazy person because she knew that she was not.	Feels that being a Celiac is part of her identity. Thinks more about the disease when in public. Being assertive is something new.	