“WHY DO I HAVE TO FIGURE ALL THIS OUT? WHY CAN’T I JUST EAT GLUTEN?” LEARNING THROUGH EXPERIENCE TO SELF-MANAGE CELIAC DISEASE

by

STACEY LENELL GABLE SOLOMON

(Under the Direction of Laura L. Bierema)

ABSTRACT

The purpose of this qualitative study was to explore the lived experience of individuals’ self-management of celiac disease, and the role experiential learning played in that lived experience. The study was guided by the research question: What was the lived experience of individuals’ self-management of celiac disease and what role did experiential learning play in that lived experience? For this qualitative study, a semi-structured interview protocol was utilized to collect data in the form of critical incidents which were viewed through the lenses of Clerx et al.’s (2019) stages of celiac disease self-management and Kolb’s (1984) experiential learning theory.

In-depth interviews were conducted with 12 participants who had lived with celiac disease for a minimum of three years. From these interviews, 70 critical incident narratives were obtained, of which 40 demonstrated the four phases of experiential learning and were further analyzed. Based on Clerx et al.’s stages, four prominent themes were found that focused on acquiring experience with the gluten free lifestyle; engaging in social challenges and self-advocacy; navigating challenges in the workplace; and self-managing a gluten free diet in unfamiliar settings. Conclusions drawn from the findings were: 1) Experiential learning provided a framework for future experiential learning; 2) The skill of self-advocating for one's needs in the self-management of celiac disease was derived from experiential learning; and 3) Experiential learning initiated the transformation of perception in the self-management of celiac disease. Future research studies should further explore Clerx et al.'s (2019) stages of celiac disease self-management to understand the necessity for each individual's stage in the self-management of one's disease. Also, the influence of culture and age on how individuals self-manage celiac disease and experience learning should be considered. Finally, future studies should address the multiple significant barriers that women face when self-advocating in the self-management of their disease.

INDEX WORDS: celiac disease, coeliac disease, chronic disease, self-management, experiential learning, adult learning, self-advocacy, gluten free diet

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Fulfillment of the Requirements for the Degree

DOCTOR OF PHILOSOPHY

ATHENS, GEORGIA

2024

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December 2024

DEDICATION

To my mom, who always loved learning and encouraged education. You were an example and inspiration of what perseverance can do.

To Isaac, the first person to encourage me to challenge my personal biases and frameworks. Thank you, son. You left this earth way too early. I love and miss you.

I know you both are cheering from up on high.

ACKNOWLEDGEMENTS

"For a seed to achieve its greatest expression, it must come completely undone. The shell cracks, its insides come out and everything changes. To someone who doesn't understand growth, it would look like complete destruction."

Cynthia Occelli

This quote has been on my personal desk since I began my doctoral journey at the University of Georgia (UGA). Many changes and surprises occurred throughout my journey, along with unexpected twists and turns. I feel that by obtaining this PhD I have become undone, spilling out, and overflowing. Everything has changed and I am not the same person as I was when I first began my journey. While this growth occurred in me, I was not alone. I am grateful to others who helped cultivate my soil, planted seeds, watered, and fertilized, and yes, pruned when it was needed. I am so thankful for each and every one who has been with me on this journey.

I am appreciative for the opportunity to earn a Doctor of Philosophy from the University of Georgia (UGA). I do not take this experience lightly. I have been blessed with so many faculty who have been a part of my time at UGA, specifically my major professor and committee. To my major professor, Dr. Laura Bierema, thank you for your encouragement when I was too timid to jump into the deep. Your encouragement of "You've probably written more than you realize" was such a catalyst for me. I was amazed that once you became my major professor, that within a very few short months I had completed my comps exam and moved forward towards prospectus. Thank you for your belief in me!

To my committee, thank you for giving your time to me, not just for my dissertation, but also for what I have learned from each of you. First, Dr. Mark Ebell, thank you for believing that my topic was important enough that it deserved your medical expertise, volunteering to serve on my committee. I was humbled by your willingness to give this your time. Dr. Aliki Nicolaides, the many classes I had with you were inspiring and challenged how I thought about things. I will always remember your excitement in lecturing and for your “whackadoodle” insights. Dr. Karen Watkins, you have always had a calming effect on me with your serene disposition. I appreciate your ability to point me to empirical literature off the top of your head and I was always amazed at that feat. Thank you for serving as my methodologist and for introducing me to one of your favorites, critical incident technique (CIT). Your encouragement has meant so much! I will be forever indebted to all of my committee, and I am grateful for their time, the hours they spent reading my work, and the challenging questions that each has had. The words “thank you” cannot express my gratitude.

I appreciate Erin Miller and Kate Avery at Beyond Celiac for partnering with me in my dissertation work. I appreciate your willingness to work with me to obtain participants from your membership. I am grateful for the opportunity to work with you both in my dissertation research, as well as being a research intern at Beyond Celiac. You guys are great!

I want to express my gratitude to my research participants. From our interviews I gained great insights into your experiences with celiac disease and came away feeling like I had made new friends. I appreciate your willingness to be transparent and share not only your experiences, but your thoughts and emotions about those experiences. Your stories have made a difference to me, and I believe they will make a difference to other celiacs, both new and veterans that can see themselves in them. Thank you!

To my friends in the PhD program, and coaching classes, thank you for being on this journey with me. We have celebrated each other's successes and encouraged each other through our setbacks. Thank you, Sara Jane for your gut-checks. A special thank you to Kevin for being such a good friend from workdays at KSU to our cohort and PhD journeys. We have commiserated, lamented, encouraged, and cheered for each other. You are a true friend, and I will always value our friendship! I look forward to what will happen in each of our futures. Keep cultivating, my friend!

I am grateful to Danielle Burns for creating the graphic that explained the results of my dissertation. As I have told you before, you have the patience of Job to go back and forth with me as you attempted to create an image of what was going on in my mind. It was perfect!

I especially valued the support of my sister Kathy who seemed as excited as I was to be on this journey. Dad, I appreciate your encouragement, support, and interest in my work – enough to read all 60 pages of my comprehensive exam. Then call to ask questions, inquiring as to why I believed what I did. Thank you! It meant so much that you were interested.

Thank you to my eldest son, Noah. Your love of learning is inspirational. You are an encourager and have cheered me on through all of my higher education endeavors, attending every graduation from my bachelor's onward. This one should be it! 😊 Thank you, son!

And the best is for last, Michael, my husband, soulmate, love of my love, confidant, and the man that I will always love! There are not enough words or volumes to fill that would express my gratitude and thankfulness for you. I could gush and go on and on about what you mean to me. Thank you for EVERYTHING!!! Thank you for your belief in me, for knowing (not just thinking) that I could do this. You have been my greatest cheerleader!! Thank you for your words of encouragement, telling me you had been there, and it would be okay, and validating what I felt was normal on this journey. You have listened to me talk about my research until you can now quote learning theories, reflect, and search for the appropriate lens through which to see situations. 😊 You have fed me and have become quite the chef (too many meals to count), being patient that dinner would always be late because I wrote best late afternoon into the late evening. You shared your shoulder (and your ears) when I felt overwhelmed, providing solace and comfort. I am thankful for our 41+ years together (39 hitched) and the integrity you have had to keep your promise of years ago when you told a 17-year-old-girl, “I’ll always be there for you.” That you have done! I love you forever! “You’re still [and always will be] ‘the one.’”

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CHAPTER 1

INTRODUCTION

Vignette

It was supposed to be a simple annual gynecological check-up. But the prick of a finger changed the course of my life. As my gynecologist looked at the results of that simple prick, she remarked to the nurse, "I hope this is wrong." To which the nurse replied, "I checked it twice." Then the questions.

Doctor: "How have you been feeling?"
Me: "A bit tired."
Doctor: "Well your hemoglobin level is abnormal [indicating low iron]. How are you getting out of bed in the morning?"
Me: "I just do. I have two children."
Doctor: "Well, you've had a hysterectomy [interpreted, you no longer have a period], so you're bleeding somewhere."

Bloodwork was ordered and completed. A few days later the results indicated I was anemic. My ferritin level [which measures the amount of iron in blood], showed a level of one compared to a normal result of 14. This confirmed that I was indeed anemic, but why?

In the meantime, my doctor telephoned a gastrointestinal (GI) specialist to request the first available appointment. Another week to wait. More questions.

GI specialist: "Let's talk about your symptoms. Do you have constipation?
Me: "Yes."
GI specialist: "Bloating?"
Me: "Yes."
GI specialist: "What was your family heritage?"
Me: "Irish, Scottish, Cherokee Indian."
GI specialist: "Well, I think that you have celiac disease."
Me: "What is that?"
GI specialist: "We'll cross that bridge when we get there."

I was sent to the physician's scheduler to set an appointment for colonoscopy and endoscopy procedures that would decide my future. A week later my new GI doctor beamed as his instincts were corroborated with the endoscopy, "I was right, it's celiac disease!" The reason for my iron-deficiency was finally known! What was unknown was how I would learn to live with celiac disease and just how it would change my life forever.

Background of the Study – What is Celiac Disease?

Buttorff, et al. (2017) stated in their analysis of multiple chronic conditions of individuals in the United States (U.S.), that chronic illness served as a leading driver of health care costs, being responsible for 90% of the $4.1 trillion spent annually. According to the Centers for Disease Control (CDC), chronic disease was also the leading cause of death and disability in America (CDC, Chronic Diseases in America, 2022). Boersma et al. (2020) found in their analysis of 2018 U.S. chronic disease data that 51.8% of adults (129 million) were diagnosed with 1 of 10 chronic illnesses (e.g. hypertension, coronary heart disease, stroke, diabetes, cancer, chronic obstructive pulmonary disease (COPD), arthritis, hepatitis, kidney disease, and asthma) from an original list of 20 identified by the US Department of Health and Human Services. Of those diagnosed, 24.6% (61 million) had 1 chronic condition, and 27.2% (68 million) had ≥2 chronic conditions. According to Buttorff et al. (2017), the most common chronic diseases were heart, cancer, chronic lung, Alzheimer’s, chronic kidney, and mental health (e.g., mood disorders and anxiety disorders). However, among these chronic illnesses, one does not make the list, although it could be a catalyst for other chronic health issues, celiac disease.

Celiac (or, coeliac, the European spelling) disease (CeD) was defined as an inherited systemic autoimmune disorder where genetically susceptible individuals physically reacted to the protein of dietary gluten that comes from wheat, barley, and rye-based products (Ciao et al., 2019; Catassi & Fasano, 2010; Fasano & Catassi, 2012). Once gluten was encountered, the body was triggered to react by producing inflammatory cells and antibodies to destroy the gluten, which resulted in damage to the small intestine mucosa (villous atrophy) and impaired the body’s ability to absorb needed nutrients (e.g., iron, folic acid, B12, calcium), resulting in nutritional deficiencies and complications such as iron deficiency anemia and osteopenia/osteoporosis (Caio et al., 2019). In layman’s terms, when an individual ingested gluten, their body reacted by attacking itself, leading to a myriad of symptoms that included, but were not limited to, indigestion, constipation, diarrhea, bloating, weight loss, itchy skin, nutritional deficiency, chronic fatigue, and neurological symptoms such as headache, anxiety or depression (Ciao et al., 2019, Fasano & Catassi, 2012) Presently, there is no cure for celiac disease and a gluten free diet is currently the only effective treatment.

Diagnosis and Treatment

Celiac disease was verified through serological (blood) tests that look for gluten antibodies (anti-tTG antibodies; anti-endomysium antibodies (EmA); and deamidated gliadin peptide (DGP) antibodies), or through an endoscopy procedure that looked for mucosal changes in the intestinal villi by passing a camera through the small intestine (Ciao et al., 2019). Both tests were used to verify if damage (flattening) had occurred in the intestinal villi which led to vitamin and mineral deficiencies (iron-deficiency anemia, low calcium, etc.). These deficiencies, if left untreated, have resulted in other autoimmune disorders such as osteoporosis, infertility, impaired splenic function, neurological disorders and, although rare, cancers such as Enteropathy-associated T-cell lymphoma and adenocarcinoma of the jejunum (Fasano & Catassi, 2012). Unfortunately, by the time many individuals were diagnosed with CeD in their later years, they had already been diagnosed with chronic illnesses such as these.

Celiac disease was most common in persons of North European descent, with a prevalence as high as 1/150 in Europe, especially in Ireland and Italy, and 1/250 in the United States (Ruiz, 2022). The American College of Gastroenterology (ACG, 2023) stated there could be as many as two-to-three million individuals in the United States, and 20 million world-wide, who had CeD, with only one-in-five persons being diagnosed. The disease was found predominately in females (1.5 to 2 times more than men to have the disease); and individuals with a first degree relative (parent or child) diagnosed with CeD had a 10-15% increased chance of developing the disease themselves (Fasano & Catassi, 2012).

While eliminating gluten from one's diet may sound simple, for many it was not. Gluten hides not only in food, but in lipstick, make-up, shampoos and conditioners, lotions, and even medications. It was a sneaky little thing, and individuals had to be diligent to read labels, especially if the product was new to them. A gluten free diet was also costly. Gluten free products were more expensive than their counterparts. For example, a regular loaf of wheat bread at Walmart may cost as little as $1.97 compared to a similar loaf of gluten free bread for $5.96 (Walmart.com, September 2024).

To cook gluten free, an individual with CeD created a gluten free kitchen, or at least had a gluten free area of the kitchen. Individuals dispensed of unsafe cookware, such as scratched non-stick cookware, cutting boards, plastic and wooden cooking utensils. They re-seasoned cast iron and stone cookware, purchased separate small appliances such as toasters due to cross contamination by non-gluten family members, and the list went on. Cross-contamination became the mantra of celiacs as they were required to be careful of shared butter, jellies, and mayonnaise, or any other product that became cross-contaminated as soon as a knife went from its container, was slathered onto gluten-laden foods, and returned to the container for another schmear. With the enormity of these types of required changes, embracing a gluten free lifestyle was challenging physically, financially, and emotionally, and left many celiacs feeling isolated, anxious, or depressed (Hallert, et al., 2003; Sverker, et al., 2005; Zingone, et al., 2015).

Living with Celiac Disease

To understand how others navigated the learning required to embrace and make meaning of their new gluten free lifestyle, I researched CeD and how individuals were affected by the requirements of living with their diagnosis. Most empirical research focused primarily on the individual's lived experience and quality of life (Black and Orfila, 2011; Taylor et al, 2013); burden of illness (Hallert et al., 2002); gender differences (Sverker, et al., 2009); social effects of CeD (Bouery, et al., 2022); and psychological disorders (Jacobsson, et al., 2012; Ludvigsson, et al., 2007). Rose and Howard (2013) found in their grounded theory study that CeD was described as a social disease due to the change it brought to individuals' social lives, namely in the social act of eating. Individuals stated they were "overlooked or rejected, and therefore, rendered invisible, including at business events, workplaces, churches, and hospitals" (Rose & Howard, 2013, p. 36) which caused them to feel isolated. Still, others perceived their disease to be burdensome emoting depressive symptoms, with women having more coping issues than men (Hallert, et al., 2002, 2003; Jacobsson, et al., 2011). Finally, Rodriguez-Almagro et al. (2019) demonstrated how the lack of information and education about a gluten free diet increased the risk of poor adherence to the diet which led to frustration and "increased health care costs because of patients seeking medical care for ongoing symptoms and/or complications" (p. 4).

However, while individuals' experiences and knowledge gained about CeD were the focus of these empirical studies, the research rarely addressed how individuals theoretically learned to live with their disease, nor did it indicate the process of how meaning was made about the changes that occurred in their lives after diagnosis. In Valeras' (2010) research about chronic disease and identity, individuals described CeD as a "hidden disability;" a disability not visible to the human eye; however, while the disease provided anonymity, it brought with it other challenges such as “learning strategic self-disclosure and impression management; when to disclose and make it visible; and when to ‘pass’ and give society the impression of ‘able bodiedness” (p. 1). Again, the learning process was left unanswered.

Adult Learning

While learning theories have attempted to explain the nature of learning as it related to the environment (behavioral), whole person (humanism), mental processes (cognitive), and observation (social cognitive), learning was described by Merriam & Bierema (2014) as “how people made sense of their experience – learning was the construction of meaning from experience” (p. 36). Learning was active as individuals constructed knowledge based on their own values, culture, and situational contexts (Merriam and Bierema, 2014; Mogashoa, 2014; Schcolnik, et al., 2006; Yilmaz, 2008). This constructivist-based definition of learning brought with it the understanding that meaning-making and knowledge were constructed individually. For learning to occur, prior knowledge needed to exist, which involved language, social activity, and reflection, to which the new knowledge could be integrated (Mogashoa, 2014; Schcolnik, et al., 2006). As an individual engaged with new knowledge and chose what would and would not be learned, this type of constructivist approach to learning was adaptive and flexible.

In constructivism, truth was not absolute, but instead, truth became relative to the individual as they defined it based upon their own experiences, values, and prior knowledge (Yilmaz, 2008). An important aspect of constructivism’s epistemology (theory of knowledge) was its values. “Epistemology contains values in that it was normative” and was the basis for explaining the rightness or wrongness, the admissibility or inadmissibility, of types of knowledge and sources of justification of that knowledge” (Carter and Little, 2007, p. 1322). Individuals evaluated new knowledge according to their internal values and made the choice of whether to include such knowledge within their learning schema. For example, when an individual was diagnosed with CeD, they might reject making dietary changes because breads and pastas were valued as comforting, choosing instead to continue the harmful diet instead of replacing them with gluten free alternatives.

According to Antlova, et al., (2015), “As we got to know and evaluate the world, we constructed the system of our knowledge together with our preferences and values” and values “became the important motives for our decision making” (p. 215). Such values were influenced by the culture from which one came, as well as the culture in which they presently lived or worked and determined what learning would occur. As the world changed, an individual reassessed their values accordingly, and chose again what was important, finding the motivation for constructing new knowledge that accommodated such change.

Meaning Making (Forming)

Robert Kegan (2018) stated that epistemology (our frame or lens through which we see) was “not what we know, but our way of knowing” (p. 38), and that attending to this concept involved two kinds of processes: meaning forming and reforming our meaning. One’s meaning scheme, or epistemology, was constructed from espoused attitudes, values, and beliefs which determined how one made meaning of an experience. These schemes were then utilized to develop meaning perceptions which served as the structure of one’s assumptions (perspective, or world view) through which one filtered their perceptions of a new experience (Dubouloz, et al., 2010b).

The concept of meaning-forming was constructivist in that a coherent meaning was shaped from outer and inner experiencing; while reforming our meaning was to change the actual form (our epistemologies, or frame of reference) by which we made meaning (Kegan, 2018).

These frames of reference were structures based on culture and language through which individuals made meaning, and the tendency was to reject ideas that do not meet these pre-conceptions. For instance, prior to a celiac diagnosis, based on their family culture (frame of reference), individuals may correlate holidays as joyous occasions of shared dining that featured family recipes. However, post-diagnosis, individuals may choose to reject the prior attitude towards holidays (changing form, or frame of reference) as now such events are overwhelming and stressful due to the increased anxiety of potentially becoming ill, or the possibility their dietary restrictions may not be taken into consideration.

Two Types of Learning in Meaning Making

Two types of learning informed the process of meaning-forming and reforming our meaning: informative and transformative learning. *Both* types of learning were needed as informative learning helped one to gain knowledge about their condition and how to live with its restrictions, while transformative learning changed how individuals thought about themselves and their experiences with chronic illness.

Informative learning was bound by concrete thinking and changed *what* we know *within* our pre-existing frame (Kegan, 2018). As individuals were confronted by a chronic disease diagnosis, such as CeD, they added to their knowledge through informative learning: reading information about the disease, what the treatments of the disease were, the disease's prognosis, and talking with, or observing how others learned to live with the disease.

Instead of *what* we learned, transformative learning changed *how* one saw themselves, reconstructed the form, or frame of reference, and reconstructed their thinking (Kegan, 2018). According to Mezirow (1978), there were challenges in life that could not be resolved by simply learning more about them or learning better coping skills; but were addressed through the reassessment of our assumptions about how we made meaning of our experiences (Mezirow, 1978). Transformative learning focused on such adaptation and personal growth and such a shift in perspective was central to the transformative concept. When these meaning perceptions no longer worked with a new situation, it brought about distortion which was the point at which transformation occurred (Dubouloz et al., 2010b; Mezirow, 1978). As an example, individuals diagnosed with a chronic disease faced the challenge of reconstructing their thinking such as when HIV-patients “took stock of their identity, and purpose for being here” (Courtenay, et al., 1998, p. 74); and attempted to “establish a sense of control” (Kessler, et al., 2009, p. 1061) within their lives. Such restructuring of thought served chronic disease patients well as they sought control over their lives through the self-management of their disease.

Patient Self-Management

Over twenty years ago, Holman and Lorig (2000) recommended the adoption of self-management by patients of chronic disease and posited that with the rise of chronic disease, “acute practices have proved increasingly inefficient and ineffective” and resulted in “uninvolved patients, unnecessary hospital admissions…expensive, indecisive technologies, and useless accumulation of clinical data all drove health expenditures higher…without evidence of improvement of health status” (p. 526). The World Health Organization (WHO) concurred as they asserted that “health care providers can do more to engage patients in managing their own conditions” (Epping-Jordan, et al., 2001, p. 947).

With a patient-physician partnership, there was a paradigm shift to a more collaborative state where patients’ expertise about living with their disease was viewed in similar importance to the physician’s expertise in the disease (Bodenheimer, et al, 2002). This patient empowerment meant that the patient was “de facto, their own health care provider” (Anderson, 1995, p. 412) and accepted the responsibility to manage their own condition and developed the competence to solve their own problems with information, but not orders, from the physician (Bodenheimer et al, 2002; Rotheram-Borus, et al., 2012). This empowerment replaced the feeling of being a victim of their illness, with the feeling that they were in control of their disease and provided a sense of order from the disorder imposed by illness (Kralik, et al, 2004; Rotheram-Borus et al., 2012). This empowerment was necessary to ensure that individuals remained responsible for their own health management (Liu and Kauffman, 2021).

As individuals continued to depend on themselves to solve problems, internal motivation enhanced their ability to make lifestyle changes, unlike the external motivation of making changes to please their physician (Bodenheimer, 2002). Whittemore and Dixon (2008) stated that "Self-management in chronic illness was a dynamic active process of learning, practicing, and exploring the skills necessary to create a healthy and emotionally satisfying life" (p. 178). Such learning processes occurred as individuals self-monitored their health, taking note of changes in bodily symptoms, daily activities, and cognitive processes (Rotheram-Borus, et al., 2014).

Celiac Disease and Self-Management

After an individual received the diagnosis of celiac disease, they were responsible for their health and wellness. With the only treatment for CeD being the adherence to a lifelong gluten-free diet, individuals with celiac disease automatically became self-managers of their own health, with the primary goal to avoid only one thing: gluten. Although this concept seemed relatively simple, "these changes in diet were substantial and have a profound effect on a patient's life" (Rodrigues-Almagro et al., 2019, p. 1).

According to Clerx, et al. (2019), individuals diagnosed with celiac learned a variety of self-management skills to safely manage living in a gluten free world. Clerx et al.'s study of the self-management skills of 137 adults with CeD showed that participants gained self-management skills from learning that occurred over a hierarchical progression of four stages: (1) life at home (six months), (2) social settings (one to two years), (3) the workplace (three to four years), and (4) unfamiliar settings (five-plus years) (2019). Again, this study's results identified self-assessed skills that had been acquired by the celiac individual but did not provide a theoretical basis for or indicate the type of learning that occurred.

Statement of the Problem

Most chronic disease literature focused on the common trait of being lifelong with each disease having its own unique characteristics that produced distinctive responses from patients (Jacobson, et al., 2015). Because of this, CeD should be researched independently to better understand its unique qualities and requirements that influenced a patient's lived, learning, and meaning-making experience.

While research of chronic disease provided findings that discussed patients' lived experiences and acquired knowledge, very few gave a theoretical basis for such learning. Specifically, research about the lived experiences of individuals with CeD focused on quality of life, but did not address how these individuals made meaning or theoretically learned from such experiences. Instead, research only focused on how individuals gained self-management skills over time. Therefore, the problem this study addressed was the dearth of theory-based research about the lived experience of patient self-management and the learning that occurred within the lived experiences of individuals diagnosed with CeD.

Purpose of the Study

The purpose of this qualitative study was to examine the lived experience of individuals' self-management of CeD, and the role experiential learning played in that lived experience.

The research question guiding this study was:

1. What was the lived experience of individuals' self-management of celiac disease and what role did experiential learning play in that lived experience?

Significance of the Study

The significance of this research was to provide a deeply rich narrative that informed not just about the experience of living with CeD, but individuals' own personal stories which "provide rich data that express movement, interpret ideas, and describe from the storyteller's perspective how things used to be and how they are, as well as how they should be" (Feldman, et al., 2004, p. 150). Obtaining an understanding of the lived experiences of individuals who self-managed CeD, and the role learning played, provided a knowledge-base on which health care and coaching professionals, health promotions, and educational programs could improve patient interactions, services, and education for patients with celiac disease.

The results of this study expanded the body of knowledge in both health sciences and learning as it combined both fields to broaden the understanding of living and learning that was experienced by individuals diagnosed with CeD. Based on this new understanding, future educative interventions can be developed that inform and educate potential and current celiac patients, health coaches, and health care professionals that improve patient interactions, leading to better self-management.

Chapter Summary

For this research, self-management and experiential learning theory were appropriate for developing an understanding of the “phenomenon of how people interpret their own change experience and explain the process of how adults learned,” and focused on the “adaptation and personal growth in context of health conditions” (Barclay-Goddard, et al., 2012, p. 218). By understanding the self-management and learning experienced by individuals with CeD, health care and coaching professionals, health promotions, and educational programs can improve their interactions with patients, develop new services, and create educational opportunities that assist patients with the self-management of the chronic illness of CeD. In turn, patients also benefit through enriched engagements with health care and coaching professionals, as well as the possibility to participate in new services and learning opportunities.

CHAPTER 2

REVIEW OF THE LITERATURE

The purpose of this qualitative study was to examine the lived experience of individuals' self-management of celiac disease (CeD), and the role experiential learning played in that lived experience. The research question that guided this study was:

1. What was the lived experience of individuals' self-management of celiac disease and what role did experiential learning play in that lived experience?

Because of the far-reaching consequences of chronic diseases such as CeD, combining both the effects of the number of individuals diagnosed and the exorbitant costs incurred, it warranted a theoretical look at the lived experience of adults who self-managed their CeD and the role that learning played. This data can be utilized by health care professionals to improve their understanding of the lived experience of individuals who self-managed their disease and the role that adult learning had in the process. By understanding the lived experience of individuals diagnosed with CeD, health professionals and coaches have a patient-centric lens through which applicable health promotions and educational programs can be developed. Such programming can help diagnosed individuals embrace necessary changes in behavior, providing long-term interventions that enable better self-management of their disease.

This chapter began with a brief overview of chronic disease, CeD, and self-management. Several approaches to self-management will be discussed in the context of chronic disease, including various care models such as the chronic care model. The chapter will conclude with an empirical assessment of adult learning theory, specifically, experiential learning, which was utilized in the self-management of chronic disease with a focus in CeD. From these studies it was determined there was a gap that laid the foundation for the proposed research methodology in chapter three; the research implementation in chapter four; and its data findings in chapter five.

Chronic Disease

In 1998, Velicer et al., stated that “At the beginning of the new century, the focus of medicine and public health was shifting to the prevention and treatment of chronic diseases” and considered human behavior to be a “unique characteristic of chronic disease” (p. 216). Buttorff et al. (2017) concurred 19 years later that chronic disease was still rampant in that individuals with “five or more chronic conditions make up 12 percent of the population but account for 41 percent of total health care spending” (p. 15). This group also spent twice as much as those patients with only three or four conditions with “the majority of that additional spending going to office visits, inpatient visits, and prescriptions” (Buttorff et al., 2017, p. 16). But exactly what was the definition of a chronic disease?

Chronic diseases differed from acute diseases due to their slow onset and lengthy prognosis. Acute diseases lasted only a short time and developed quickly. According to verywellhealth.com, acute diseases were defined as diseases that resolved in less than six months, while chronic diseases lasted more than six months (Whitlock, 2023). However, other health organizations defined chronic diseases differently, such as the Center for Disease Control (CDC) (2022) and Psychology Today (2022) who stated that chronic diseases lasted for at least one year, required ongoing medical care, and limited the activities of such individuals. The American Medical Association (AMA) (2022), which was the largest and only national association in the United States, consisting of 190+ states and specialty medical societies, does not specify the duration of a chronic disease, but simply stated it was of long duration; and, the

World Health Organization (WHO) (2022), an agency of the United Nations which was responsible for international public health, gave guidelines that chronic disease, was a noncommunicable disease.

The disparity in the length of time that defined a chronic disease, as well as whether a chronic disease was communicable (e.g. aids) or noncommunicable (e.g. heart disease) “created confusion and misunderstanding when speaking in generalities about the impact…cost…and overall measures to reduce chronic disease” (Bernell and Howard, 2016). These varying definitions positively or negatively influenced health organizations as they chose chronic diseases on which to focus their research. For example, the CDC (2022) focused on three main groups (heart disease, cancer, and diabetes), the WHO (2022) focused on four (cardiovascular, cancer, chronic respiratory disease, and diabetes), and the Centers for Medicare and Medicaid Services CMMS (2022) listed all 21 chronic diseases. Because of the inconsistency about which diseases were most significant, individuals who sought information about their own chronic disease may question the motives of such organizations as it appeared that some diseases were deemed more important than others. Bernell and Howard (2016) reframed how chronic disease was defined stating it was not to take the attention away from the most common chronic diseases (heart disease, diabetes, arthritis, and COPD), but to bring “more diseases (and conditions) under the umbrella, with the hope of increasing awareness, sharing knowledge, and creating a larger community of individuals working toward improving the health of those who suffer from chronic health problems” (p. 3).

In addition to the disparity in how health organizations defined and informed about chronic disease, there were challenges in research due to the lack of consistency in key definitions. According to Goodman et al. (2013), data from chronic disease research lacked homogeneity in how chronic disease was defined, its duration, and the disease's risk factors, and was in "stark contrast to the process of measuring infectious conditions using established case definitions," which led to compromised data in "characteristics such as occurrence, burden, and associated costs" (p. 2). Because of these variances, chronic disease research was hard to validate and difficult to generalize in other populations. For consistency in this literature review, the term chronic disease was aligned with the CDC's 2022 definition of chronic disease where such conditions "last one year or more and require ongoing medical attention or limit activities of daily living or both."

Types of Chronic Disease

There were multiple chronic diseases that individuals experienced such as heart disease, cancer, chronic lung disease, and those that affected one's mental state such as Alzheimer's disease, depression, schizophrenia, and other psychotic disorders. The most prominently addressed chronic diseases were heart disease and stroke, cancer, and diabetes due to their prominence and the number of deaths caused. According to Benjamin et al. (2018), more than 877,500 individuals die of heart disease or stroke (one in three) each year in the U.S. - the leading cause of death – and costs the health care system $216 billion per year.

Many of these deadly chronic diseases were negatively impacted by patient behavior such as smoking after a diagnosis of cancer or heart disease or continuing to be overweight and/or eating unhealthy food when one had diabetes. By continuing poor health behaviors, other diseases could present themselves after the initial chronic disease diagnosis and lead to comorbidity of diseases for these individuals. The CDC (2022) concurred, stating that complications could arise from continuing to smoke with diabetes, leading to heart disease, kidney disease and eye disease. Unfortunately, influential medical organizations such as the

CDC, AMA and WHO, whose primary goal was to educate individuals about their chronic disease, omitted one important disease, celiac disease.

Celiac Disease (CeD)

Celiac disease (CeD) is a “multisystem disorder whose primary target of injury is the small intestine” and today is the “most common – and one of the most underdiagnosed – hereditary autoimmune conditions in the United States (U. S.)” (Green and Jones, 2020, p. 2). According to the American College of Gastroenterology guidelines, CeD, also known as coeliac disease, or celiac sprue, has a “wide spectrum of clinical manifestations that resemble a multisystemic disorder rather than an isolated intestinal disease” (Rubio-Tapia et al., 2023, p. 59). Green and Jones (2020) stated that CeD was characterized by “chronic inflammation of the small intestinal mucosa, which led to atrophy of the intestinal villi and subsequent malabsorption” (Pelkowski and Viera, 2014, p. 99). In other words, when ingested, gluten (wheat, barley, or rye products) causes the body to attack itself which causes the intestines to not absorb necessary nutrients for healthy living. This can lead to other health conditions, and subsequent symptoms of the disease such as anemia (iron deficiency), lactose intolerance (lack of production of lactase) osteoporosis (calcium deficiency), diabetes, neurological disorders, infertility, and even cancers (Fasano and Catassi, 2012; Pelkowski and Viera, 2014; Turner et al., 2015). Currently, the only medical recommendation for CeD is adherence to a strict gluten free diet, which will usually result in complete remission and healing of the intestinal villi, which after three to five years, reduces increased risk for complications such as malignancies or death (Turner et al., 2015).

History of Celiac Disease

In the literature there were several descriptions of when CeD was first discovered. According to Turner et al. (2015), the first description of CeD was in the first century BC by the Greek physician Aretaeus Cappadocia who described a disease such as celiac that affected older female adults. Green and Jones (2020) suggested that the critical moment for CeD was the move from hunter/gatherers to a more agrarian society. They proposed that as grains and crops were grown for nutrition and their ability to be stored for future use, some of these "were not actually designed to digest" (p. 68). Thus, the digestive issues began for mankind. However, both researchers agreed that the first modern-day physician to identify the dietary component of CeD was Samuel Gee in 1888. Dr. Gee considered celiac to be a disease of childhood that at the time was life-threatening (Green and Jones, 2020; Turner et al., 2015).

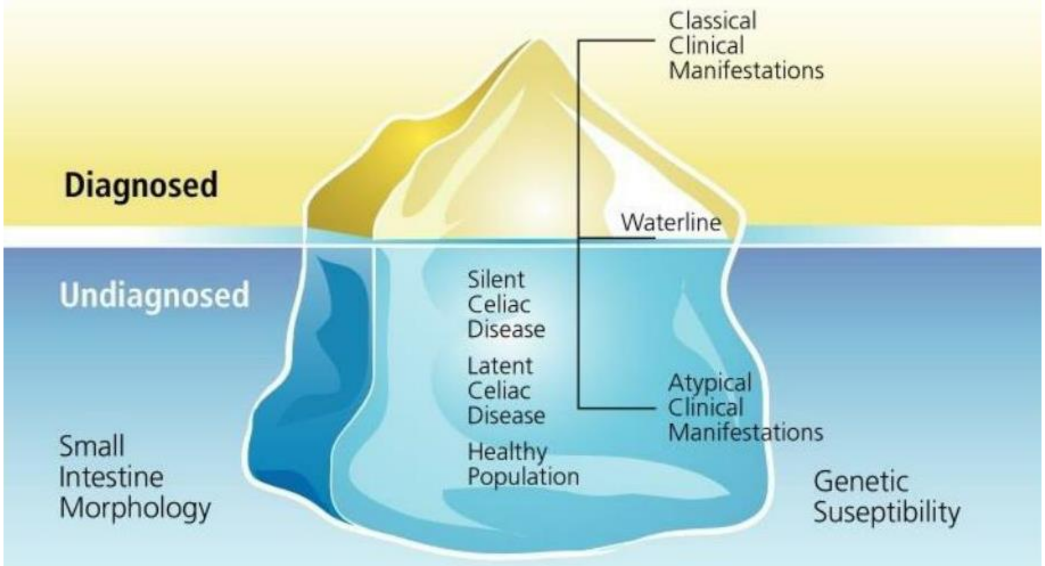
Years later, another physician, Wilhelm Dicke, identified the trigger of CeD to be wheat after the morbidity of the disease subsided during the bread shortage of World War II and returned once it was reintroduced (Green and Jones, 2020; Turner et al., 2015). Post war, technology such as intestinal biopsy became available in the 1950s and 1960s that provided a routine means of identifying CeD, followed by pediatricians in the United States finding a less invasive means of identification and treatment for children through exclusion diets that removed gluten grains (Green and Jones, 2020).

Symptoms of Celiac Disease

Celiac disease has been called the "celiac iceberg" because of the various types and manifestations of the disease which occurred outside of the classical clinical symptoms that led to a diagnosis (see Figure 2.1). While many diagnosed individuals displayed classical manifestations, there were others who were undiagnosed and unknowingly suffered from the atypical manifestations of silent, latent, and refractory celiac disease (see Chart 2.1).

Figure 2.1

Celiac Iceberg



Source: https://image.slideserve.com/702514/celiac-iceberg-l.jpg

Classical Clinical Manifestations of CeD (Symptomatic Disease)

Pelkowski and Viera (2014) stated that classical clinical manifestations of CeD varied and involved multiple organ systems and were either symptomatic or asymptomatic, and both manifestations could be intestinal (e.g., nutritional deficiencies), extraintestinal (e.g., osteoporosis), or a combination of both. When CeD was symptomatic, it exhibited classic or non-classic symptoms.

Classic Symptoms. Classic symptoms of CeD were chronic diarrhea, weight loss, iron deficiency with or without anemia, abdominal distention (bloating) or recurrent abdominal pain, chronic fatigue, aphthous stomatitis (mouth ulcers) and osteoporosis (Bai et al, 2017; Fasano and Catassi, 2012).

Non-classic Symptoms. Also known as atypical, non-classic symptoms included gastrointestinal symptoms without malabsorption, unexplained iron-deficiency anemia, chronic fatigue, unexplained infertility or miscarriage, migraine, and various skin disorders such as psoriasis, eczema, and the most frequent presentation, dermatitis herpetiformis, a pruritic (itchy) rash associated with CeD (Bai et al., 2017; Fasano and Catassi, 2012; Lebwohl and Rubio-Tapia, 2021).

Asymptomatic Manifestations of CeD (Silent Disease). Individuals with CeD who were asymptomatic had no symptoms of the disease, and many were diagnosed when screened due to a first-degree relative's diagnosis (Bai et al., 2017). While these individuals did not have symptoms, the villi of their duodenum were damaged due to gluten consumption. A concern about asymptomatic individuals was the possibility they may choose not to comply with a gluten free diet because they do not feel bad physically. If these individuals, or any diagnosed individual (symptomatic or asymptomatic) chose to not adhere to a strict gluten free diet, their risk increased for developing other complications such as neurological disorders or infertility; co-morbidities such as osteoporosis, thyroid, or pancreatic disease (diabetes); or malignancies and mortality (Fasano and Catassi, 2012; Bai, 2017). Because of these negative complications, it was very important that individuals continue to be assessed for their responsiveness to a gluten free diet "every 3-6 months during the first year and then every one to two years" (Raiteri et al., 2022, p. 166).

Latent Disease. Those who experienced latent celiac disease, had no signs, symptoms, or intestinal damage, but had inherited the genetic disposition for CeD. Again, this group, like those in the silent group, could have a difficult time adhering to a strict gluten free diet due to the lack of reaction to gluten, however, because of this, they may develop later co-morbidities.

Refractory Disease. Unfortunately, there were others who continued to be symptomatic despite strict adherence to a gluten free diet for at least a year and were diagnosed with refractory celiac disease, a form of celiac that was persistently active (Bai et al., 2017; Raiteri et al., 2022). Refractory CeD was categorized into subtypes I and II, of which type II was most severe due to being considered a low-grade lymphoma with a high rate of mortality (Bai et al, 2017; Raiteri et al., 2022).

Table 2.1

Manifestations of Celiac Disease (CeD)

Type of CeD	Manifestation	Symptoms
Classic	• Involving multiple organ symptoms • May be symptomatic or asymptomatic • May be intestinal (e.g., nutritional • deficiencies) • May be extra intestinal (e.g., osteoporosis), or both	• Chronic diarrhea • Weight loss • Iron deficiency with/without anemia • Abdominal distention (bloating) • Recurrent abdominal pain • Chronic fatigue • Mouth ulcers • Osteoporosis
Non-classic	• Involving multiple organ symptoms • May be symptomatic or asymptomatic • May be intestinal (e.g., nutritional • deficiencies) May be extra intestinal (e.g., osteoporosis), or both	• Gastrointestinal symptoms without malabsorption • Unexplained iron-deficiency anemia • Chronic fatigue • Unexplained infertility/ miscarriage • Migraine • Dermatitis herpetiformis or other skin disorders (psoriasis, eczema)
Silent	• Intestinal: damaged villi of duodenum	• No symptoms
Latent	• Genetic disposition for CeD	• No symptoms
Refractory	• Continued manifestation of symptoms	• Symptoms at diagnosis continue despite GF diet

Non-Celiac Gluten Sensitivity (NSGS)

Some individuals had symptoms like those of CeD (e.g., abdominal pain, diarrhea, bloating, eczema, anemia, and headaches) but did not have the autoimmune disorder and were diagnosed with non-celiac gluten sensitivity. However, while these symptoms were like CeD, they do not prompt the body to attack itself, causing damage and inflammation in the small intestine. Unfortunately, it was difficult to summarize how many individuals suffered with NSGS as many were self-diagnosed due to their symptoms subsiding when glutinous products were removed from their diets (Catassi et al., 2013).

Continuance of Symptoms

Not everyone diagnosed with CeD responded to a gluten free diet. This sometimes was due to an individual intentionally or inadvertently ingesting gluten. Some individuals continued to “cheat,” choosing to ingest glutinous foods while others encountered inadvertent ingestion of gluten. This may be due to hidden ingredients in food or products, encountering cross-contamination from foods prepared with “contaminated” utensils, pans, and shared fryers that were used to cook both gluten free and glutinous foods.

Diagnosis of Celiac Disease

Diagnosing CeD was important as individuals who were symptomatic improved their symptoms and quality of life, and with continued treatment of a gluten free diet over a lifetime, could reduce the possibility of malignant and nonmalignant complications such as cancers and other diseases which could lead to mortality (Bai et al., 2017). A genetic predisposition was considered a major factor for developing CeD as the *HLA-DQA1, HLA-DQB1,* and *HLA-DQ8* genes had a specific role in the presentation of gluten peptides (Bai et al., 2017). Therefore, blood tests were utilized as a first-line indicator of possible CeD. In addition to genetic testing, individuals can be tested for serological markers with two very sensitive serum antibody tests: IgA Endomysial Antibodies (EMA-IgA) and anti-tTGa-IgA. While the anti-tTGA-IgA test was the most sensitive test for diagnosing CeD, the EMA-IgA tests were nearly 100% specific for indicating villous atrophy (an indicator of CeD), but were less sensitive, and more expensive; however, they were still considered a good second-line test to anti-tTG-IgA, (Raiteri et al., 2022). In addition, a separate serum test, the IgA Tissue Transglutaminase (tTG), could also be administered to test for gliadin, known as the "offending agent," which, if positive, indicated CeD. By utilizing such blood tests, the number of unnecessary biopsies to determine CeD could be reduced (Bai, et al., 2016).

According to Caio et al. (2019), the gold standard of diagnosing CeD was via "duodenal biopsy and by positivity of serological tests" (p. 7) that tested for defining antibodies. However, Raiteri et al. (2022) stated there was not a gold standard, but, instead, a CeD diagnosis relied on elements of symptoms and serology (first-line antibody test in high-risk patients), followed by biopsy if necessary. This agreed with Caio et al.'s (2019) assessment that the current standard for diagnosing CeD was based on Catassi and Fassano's (2010) "four out of five" rule. This rule took into consideration that to be diagnosed with CeD, one must meet at least four of the following five criteria: (1) typical symptoms (e.g. diarrhea); (2) antibody positivity; (3) HLA-DQ2 and/or HLA-DQ8 positivity; (4) intestinal damage (e.g. villous atrophy); and (5) positive response to a gluten free diet.

Prevalence of Celiac Disease

Celiac disease was reported to affect approximately one percent of the U. S.'s population (331,453,741 x .01 = 3,314,537) with 50 percent (1,657,269) being undiagnosed (Caio et al., 2019; Green and Jones, 2020). More recently, in 2022, research conducted by the University of Chicago Celiac Disease Center (UCCDC) (2022) estimated that CeD was prevalent in one in 133 persons (334,828,463 x .008 = 2,678,628) with only one in 4,700 (570) being diagnosed. In a study by Choung et al. (2015), the prevalence of CeD in whites (P<0.0001) was shown to be higher (1.0%) than in non-Hispanic blacks (0.3%), and while the exact reason was unknown, Choung et al. (2015) theorized that it could be protective genetics, differences in diet, or socioeconomic status. When male and female diagnoses were compared, it was found that women were more frequently diagnosed than men at a ratio of 1.5:1 (Caio et al., 2019).

According to Lebwohl and Rubio-Tapia (2021), while CeD was thought to exist only in Northern and Western Europe, it was now prevalent worldwide due to improved recognition and testing of the disease, as well as a rise in incidence outside of detection. In a recent study about the global prevalence of CeD, Singh et al. (2018), conducted a systematic review and meta-analysis of celiac studies from 1991 to 2016. These studies indicated that of 138,792 individuals with biopsy-confirmed CeD, the disease was most prevalent in Europe (0.8%) and Oceania (0.8%), followed by Asia (0.6%), Africa and North American (0.5%), and was least prevalent in South America (0.4%) (Singh et al., 2018). It was also noted in Singh et al.'s study that this diagnosis was "1.5 times more common in females than in males, and approximately twice more common in children than in adults" (p. 827).

Under-Diagnosis of Celiac Disease

Bai et al. (2017) proposed that CeD was difficult to diagnosis due to the wide range of how it manifested, with symptoms that overlapped with other diseases, and a lack of testing in certain geographical areas. According to Green and Jones (2020), CeD was underdiagnosed due to the three P's: *perception, presentation, and practice.*

Until recently CeD was *perceived* to be a rare disease, which "can be self-fulfilling: if doctors think something was rare, they will not go looking for it" (Green and Jones, 2020, p. 58). So, if the disease was not looked for, then it remains a rare disease. Also, CeD has changed its *presentation,* or manifestation. Prior to 1991, studies showed that 91 percent of diagnosed individuals presented with diarrhea, and since 2001, that percentage was 37 percent. Symptoms were more diverse and included not only diarrhea, but osteoporosis, anemia, malignancies, infertility, migraines, and neuropsychiatric symptoms, making it difficult for doctors to diagnose and to know which individuals should be tested for the disease (Lebwohl and Rubio-Tapia, 2021; Green and Jones, 2020; Bai et al, 2017).

Finally, the *practice* of physicians was another reason for the under-diagnosis of CeD. Physicians should be better educated about CeD for their practice so they can accurately name their patients' disease; because, to give treatment, the disease must first have a name, or label so that the process can move forward (Green and Jones, 2020). Also, CeD was not a usual topic in educational programs that doctors attended. While the subject was now emphasized more in medical school curriculum, it could take years before change occurred as physicians and the public were not reminded by the pharmaceutical industry about CeD, as drugs were not utilized as a treatment (Green and Jones, 2020). Because of the lack of education about CeD, it was possible that without an intervention to educate health professions, CeD would be perceived as a condition that rarely occurred.

Celiac Disease Compared to Other Chronic Diseases

Like other chronic diseases, CeD lasted for more than a year. However, unlike most other chronic diseases, it was an autoimmune disorder. According to Martin (2023), autoimmune disorders resulted "when your immune system was overactive, causing it to attack and damage your body's own tissue," instead of it protecting you from "harmful viruses, cancers, and toxins" … the immune system "can't tell the difference between the invaders and healthy cells." While Martin (2023) found the focus of treating autoimmune disorders was to "reduce immune system activity," Catassi and Fasano (2010) contended that CeD was the only autoimmune disease that could be treated after correctly being diagnosed and following a strict gluten free diet. Similarly, CeD was unique among other autoimmune diseases in that "the trigger, dietary gluten, had been identified, and its removal resulted in resolution of symptoms and enteropathy in the majority of patients" (Lebwohl and Rubio-Tapia, 2021, p. 63).

Celiac Disease as Compared to Heart Disease and Type 2 Diabetes

Heart disease occurred when individuals encountered atherosclerosis that eventually restricted blood flow to the heart inducing a heart attack. According to the Center for Disease Control (CDC) (2022), heart disease was the leading cause of death (one in three) in the United States (U.S.) with 859,000 deaths each year. Like celiac disease, diet improved health in individuals with heart disease and should be changed to reduce foods that enhanced contributing risk factors such as cholesterol, blood pressure, and weight (American Heart Association [AHA], 2022). However, unlike CeD, individuals with heart disease could take medication to prevent the disease from worsening. Like CeD, heart disease led to other conditions such as stroke (the 5th leading cause of death) and heart failure (AHA, 2022).

According to the CDC (2023), one in ten Americans had diabetes, with 90-95% having type 2 diabetes mellitus, which occurred when cells do not respond normally to insulin. This caused insulin resistance, an inability to regulate sugar in the body, which could lead to comorbidities such as heart disease, kidney disease, and vision loss. Like CeD, there was no known cure for type 2 diabetes, however both diseases required individuals to consider how food and diet played a part in negating their disease's symptoms for improving their health. According to Green and Jones (2020), of the "1.25 million people with type 1 diabetes, eight to ten percent also have celiac disease" (p. 3)

Individuals diagnosed with chronic diseases of CeD, heart disease, and type 2 diabetes share similarities, one being that diet was a primary means of controlling the disease's progression. Additionally, all three diseases were caused by a genetic predisposition. Finally, all three diseases presented with psychological responses to their disease. Individuals with celiac experienced grief, fear, and anxiety about their disease, which led to a lower quality of life (Leffler, 2017; Rose and Howard, 2014). Similarly, patients with diabetes experienced anger, guilt, depression, and anxiety (Kalra et al, 2018); while individuals with heart disease had a risk of developing "mood disorders, such as anxiety and depression" (Kalantarzadeh et al., 2021, p. 844). While these three chronic diseases had many similarities, there was one vast difference among them. While self-management of heart disease and type 2 diabetes were assisted with prescriptive medications, the only way to self-manage CeD was through dietary intervention.

Section Summary

The purpose of this section was to give an overview of celiac disease, its diagnosis, and comparison to other chronic illnesses. The section began with an overview of chronic disease which served as the foundation for understanding the nature of celiac disease (CeD) and closed with a comparison of CeD, heart disease, and type 2 diabetes.

Celiac disease affected as many as one in 133 individuals and was “one of the most underdiagnosed – hereditary autoimmune conditions in the United States (U.S.)” (Green and Jones, 2020, p. 2). It was determined that the first occurrence of CeD was as early as the first century BC (Turner et al., 2015). Current research showed that a diagnosis of CeD was determined through genetic markers that indicated the presence of CeD, with or without duodenal biopsy (Catassi and Fassano, 2010). The many forms of CeD range from classical (typical) and nonclassical (atypical), to silent, latent, and refractory manifestations, which were treated and managed (not cured) through the adherence to a gluten free diet. When comparing CeD to other diseases such as type 2 diabetes and heart disease, diet was a primary means of controlling the progression of disease and each one had a genetic predisposition and psychological response(s). The primary difference between the three chronic illnesses was the use of prescriptive medications to manage the symptoms of heart disease and type 2 diabetes, while CeD was solely managed through dietary intervention.

Chronic Disease Patient Care – Chronic Care Models

In the mid-1990s, the staff of MacColl Center for Health Care Innovation, led by Edward Wagner, M.D., recognized the importance of addressing the different needs of patients with chronic disease within primary care practices (Wagner et al., 1996). Wagner et al. (1996) contended that primary care was designed for patients with acute and varied problems that were addressed by quick appointments, labs, prescriptions, and brief bouts of patient education. However, the needs and issues that patients with chronic disease experienced were unlikely to be met by primary care. Instead, Wagner (1998) believed that patients with chronic disease needed “planned, regular interactions with their caregivers, with a focus on function and prevention of exacerbations and complications” and such interactions should be “linked through time by clinically relevant information systems and continued follow-up initiated by the medical practice” (p. 2).

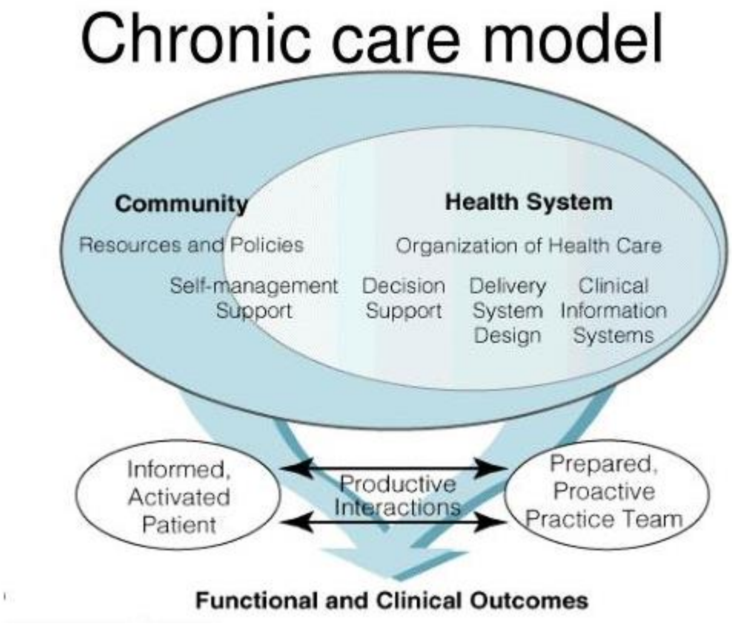
Based on the review of literature about the care of patients with chronic disease, Wagner et al. (1996) found when specialized clinics were utilized instead of primary care in larger systems such as the Veterans Administration and Mayo Clinic, low-income patients with chronic disease had better outcomes. These patients were treated by non-physician providers, working closely with physicians who utilized protocol-driven care that emphasized behavior change and adherence with assured follow-up. Additionally, the national health systems of Western Europe experienced better patient outcomes from hospital clinics than from general practitioners; however, they also proved to have greater cost and fragmented care which led an effort to change the way primary care practices engaged with chronic disease (Wagner, 1996). According to Wagner (1998), “the best approach to cost savings was to improve health status: that is, to ensure access to services that were proven to improve outcomes” (p. 3). This led to Wagner and colleagues’ development of an evidence-based, chronic care model (CCM) for improving primary care’s treatment of chronically ill patients as shown in Figure 2.2.

CCM took an organizational approach in its care for patients with chronic disease, and “operated within the context of the individual, community, provider organization, and the health care system” (Reynolds et al., 2018, p. 2). CCM’s guidelines consisted of six main categories:

(1) delivery system design (DSD) – the structure of the medical practice and its teams; (2) self-management support (SMS) – helped patients and families acquire skills and confidence to manage their disease; (3) decision support (DS) – integrated evidence-based guidelines within the practice; (4) clinical information systems (CIS) – computer information systems that provided patient reminders, patient feedback, and maintained patient registries; (5) community resources (CR) – patient education classes and community-based resources; and (6) health care organization (HCO) – structure, goals, and values of provider and its relationship with insurers and other providers (Wagner et al., 1996; Wagner, 1998). All aspects of the model were to promote productive interactions between informed, activated patients and proactive health care teams.

Figure 2.2

The Chronic Care Model



Note: Model for improvement of chronic disease. From "Chronic Disease Management: What Will It Take to Improve Care for Chronic Illness." By E. H. Wagner, 1998, *Effective Clinical Practice, 1*(1), p. 3. https://access.portico.org/stable?au=phwwtrq3nv

Wagner et al.'s (1996), review of the literature demonstrated substantial evidence that "structured self-management and behavioral change programs improved important outcomes" (p. 523) in diseases such as diabetes and heart disease, and the method of intervention was less important (class, counseling, online etc.) than the "ability to identify and respond to the individual needs and priorities of patients" (p. 523). CCM was utilized to bring about improvement in the quality of patient care in primary practices and was utilized in research and policy planning (Wagner, 2019).

Examples of Chronic Care Models

During the years of 1999 and 2007, CCM was more prominent in the improvement of patient care, in medical research, and within the development of policy. However, at the same time, the American primary care system faced a crisis as physicians became burnt out, new doctors avoided entering the primary care field, and patients became dissatisfied with their level of care (Wagner, 2019). In response, a new chronic care model was proposed by the American primary care professional societies, the Patient-Centered Medical Home (PCMH) that reaffirmed “continuity of care with a personal physician, comprehensive care, care coordination, and enhanced access” for patients seeing primary care doctors (Wagner, 2019, pp. 662-663). PCMH emphasized effective leadership, team building, and performance measurement in health care practices, and encouraged the development of care teams and work processes that ensured the delivery of consistent patient care. According to Wagner (2019), nearly “one-half of American primary care physicians now practiced in a PCMH” (p. 663).

Since 2007, additional chronic disease models were developed to focus on health care policymaking, information sharing, redesigned health care systems, and the development of self-efficacy in patients. These models are shown in Table 2.1. The World Health Organization (WHO) expanded CCM in 2002 with their Innovative Care for Chronic Conditions (ICCC) that included the management of the health care political environment, ensured shared information across multiple environments, settings, and times, and reoriented care around the patient and their families (Grover and Joshi, 2015). In 2004, the Transitional Care Model (TCM) was developed to provide more continuity of care for patients as they moved between different locations and levels of care such as hospital to home, home to hospital, chronic care to palliative care, and so forth (p. 219).

Wielawski’s model of Improving Chronic Illness Care (ICIC), developed in 2011, integrated “medical science with redesigned health care delivery systems so chronic patients in any setting can receive prompt diagnosis and care” (Grover and Joshi, 2015, p. 216), adding five additional themes of patient safety, cultural competency, care coordination in health and clinical systems, community policies, and case management. Since 2012, the Stanford Model of Chronic Disease Self-Management Program (CDSMP) became the most widely used chronic care model and emphasized and provided skills for patients to develop self-efficacy through six self-management tasks: problem solving, making decisions, utilizing resources, forming patient-provider partnerships, developing action plans to change behavior, and self-tailoring care to meet their individual needs (Grover and Joshi, 2015).

These various models provide medical professionals and health care staff with a roadmap for patients with chronic disease. While ICCC, TCM, and ICIC focused primarily on health care political environment, shared information, and continuity of care, including the integration of medical science in health care delivery systems, the Stanford Model of CDSMP and CCM were the only two models that sought to empower the patient. Patient empowerment was important, as Wagner (1998) indicated, “real improvement in outcomes will occur only when clinical systems reconfigure themselves specifically to address the needs and concerns of chronically ill patients” (p. 2). Such a reconfiguration included mutual goal setting with medical professionals, personalized health care planning, a plan for action, and the opportunity to provide feedback, and other aspects of patient self-management (Grover and Joshi, 2015).

Table 2.2

Examples of Chronic Care Models

Chronic Care Model	Description
Chronic Care Model (CCM)	Shifted focus from treatment of acute illness to chronic illness; proactive, patient focused. Six elements: health systems, clinical information systems, decision support, delivery system design, self-management support, community organizations and resources.
Patient-Centered Medical Home (PCMH)	Reaffirmed continuity of patient care with personal physicians, emphasizing effective leadership, team building, and performance measurement in health care practices; encouraged the development of care teams and work processes to ensure the delivery of consistent patient care.
Innovative Care for Chronic Conditions (ICCC)	World Health Organization (WHO) expansion created a structure for health care organizations. Broader policies that involved patients, families, health care organizations, and communities.
Transitional Care Model (TCM)	Set of actions that ensured continuity of care for patients with complex needs, ensuring coordination of comprehensive plan of care for patients transitioning between different locations/levels of care (e.g., hospitals, nursing facilities and home).
Improving Chronic Illness Care (ICIC)	Redesigned health care systems so chronic patients, no matter where, received prompt diagnosis and care; five additional themes were added: patient safety, cultural competency, care coordination in health and clinical systems, community policies, and case management.
Stanford Model (SM) of Chronic Disease Self-Management Program (CDSMP)	Most widely used model. Emphasized and provided skills for patients to develop self-efficacy through six self-management tasks: problem solving, making decisions, utilizing resources, forming patient-provider partnerships, developing action plans to change behavior, and self-tailoring care to meet their individual needs.

Patient Self-Management

As one of six essential parts of the Chronic Care Model, patient self-management has been utilized as a health care concept since the mid-1960s when Thomas Creer and his associates implemented it at the Children’s Asthma Research Institute and Hospital. As cited by Lorig and Holman (2003), Creer publicly introduced the term in his 1976 book, *Chronically Ill and Handicapped Children,* and he and his associates believed the term self-management indicated the patient was an active participant in treatment, a concept that became widely used mainly when “referring to chronic disease education programs” (p. 1). Schulman-Green (2012) defined self-management as a dynamic process that changed throughout the years of living with a chronic disease and was “neither an endpoint nor an outcome, but a process that affected and led to outcomes” (Miller et al., 2015, p. 3). For patients, such desired outcomes were improved health status, quality of life, and adherence, while system outcomes included lower health care costs and reduced use of health care services (Bodenheimer et al., 2002).

The concept of self-management was expanded and included social interventions, the psychosocial sequelae of illness, and adult learning (Barlow et al., 2002, Gallant, 2003), which emphasized it was “more than just strict adherence to a prescribed regimen,” but involved “a high level of control of the patient…autonomy…deliberate decision making, and problem solving” (Gallant, 2003, p. 171). Coleman and Newton (2005) broadened the definition stating simply, that self-management was “the ability of the patient to deal with *all* [emphasis added] that a chronic disease entailed” (p. 1503) which encompassed “the roles and responsibilities of the patient in managing his or her chronic condition” (Convery, 2019, p. 11). While self-management was defined in terms of patients’ ability to manage their disease, its definition has become complicated in empirical research due to the interchangeable use of similar terms such as self-care and coping.

Self-Care

Richard and Shea (2011) exchanged the term self-care for self-management. Self-care concepts were similar as one’s capacity to manage their own care was “situation specific and culturally influenced,” and involved “both the ability to care for oneself and the performance of activities necessary to achieve, maintain, or promote optimal health” (p. 256). However, Grady and Gough’s (2014) definition differentiated self-care from self-management stating self-care was related to “tasks performed at home by healthy people to prevent illness, rather than merely managing existing illness;” while self-management encountered the “the day-to-day management of chronic conditions by individuals over the course of an illness” (p. e26) and was not concerned with disease prevention. Such day-to-day management not only monitored symptoms, treatments, and lifestyle changes, but made decisions, developed health care partnerships, and managed the behavioral and emotional changes that dynamically changed with the progressions or cessation of disease (Lorig and Hofman, 2003; Richard and Shea et al., 2011; Convery et al. 2019).

According to Grady and Gough, self-care’s focus was to *prevent* [emphasis added] illness while self-management engaged in the daily management and partnerships needed *to live with* [emphasis added] a chronic disease. Matarese et al. (2018) concurred, adding that after such a diagnosis, the concept of self-care did not stop, but continued to be implemented in the areas that were not affected by the disease to keep the disease stable (self-care maintenance) and controlled (self-care monitoring). For example, patients with CeD self-managed their disease by eating only gluten free foods, while simultaneously implementing self-care by paying attention to the amount of salt they ate to prevent exacerbating their genetic history of heart disease.

Coping

According to Greenhalgh (2009), most self-management programs and policies focused on the biomedical view of living with chronic disease, “characterized by capacity and motivation to perform certain goal-oriented tasks expected by doctors and nurses;” however, an alternate way of viewing self-management was to “cope with the illness rather than managing it” (p. 630). In this sense, coping was interchangeable with self-management. Krakli et al. (2004) considered coping to be vastly different than self-management as coping was to tolerate a situation that could not be changed or mastered and bring about order in their lives. However, Ambrosio et al. (2015) believed that coping implied that one must "face the chronic condition and implement different strategies to deal with it" (p. 2361). Ambrosio et al.'s (2015) strategies were classified into two groups: emotion-focused and problem-focused. Emotionally focused processes helped individuals control emotional responses that occurred due to the disease, such as depression or anxiety; while problem-focused strategies were used to make changes in the situation presented by the disease, such as where to dine when eating gluten free.

Self-Management Defined

Because of its multiple definitions and myriads of interchangeable terms, self-management became a complex concept. However, Lawless et al. (2021) stressed that even though self-management was vastly complex, "distinguishing between the concepts was necessary to enable the synthesis of evidence, thereby facilitating the further development of coherent and consistent research, policy, and practice "(p. 2). Hence, for this research, self-management was distinguished from self-care and identified as the process by which an individual managed their chronic disease. It was defined as:

> "The individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition. Efficacious self-management encompasses the ability to monitor one's condition and to affect the cognitive, behavioural, and emotional responses necessary to maintain a satisfactory quality of life." (Barlow et al., 2002, p. 178).

Barlow's definition demonstrated that self-management was not only about the skills needed to manage one's disease, but "encompassed the broader range of knowledge, skills, and behaviors necessary to manage the effect of the chronic condition on all aspects of one's life" (Convery et al., 2019, p. 12).

Theoretical Perspectives of Self-Management

Clark et al. (1991) stated that the theoretical perspective for understanding self-management was derived from Bandura's (1986) social cognitive theory (SCT). Specifically, in self-management, individuals utilized the concept of self-regulation, which was grounded in SCT. Based on Bandura's principle of reciprocity, self-regulation was a triadic interaction between personal (cognitive and affective), behavioral (actions and reactions), and environmental (social and physical) factors which "gave rise to the acquisition and maintenance of behavioral patterns" (Convery, 2019, p. 12). Each factor (personal, behavioral, environmental) continuously and dynamically affected the other factors, known as reciprocal determinism, as individuals attempted to control these to reach a goal. Through self-observation, self-judgment, and self-reaction, individuals implemented strategies that were accepted or modified based on the individual's self-reflection or environment. Such strategies, or processes were not continued unless "they produced perceived benefits such as improved health or control over aversive events of illness" (Clark et al., 1991, p. 5).

Bandura (2004) stated that "Self-management operated through a set of psychological sub-functions" where individuals "learned to monitor their health, and the circumstances under which it occurs" and "used proximal goals to motivate themselves and guide their behavior" (p. 151). For individuals with CeD, a proximal goal would be to dine out safely. To do so, they may choose to join a GF Meetup group to gain confidence which increases their self-efficacy, motivating them to continue their GF lifestyle.

Self-efficacy. Another influence of self-management that stemmed from Bandura's social cognitive theory was self-efficacy. According to Bandura, individuals desired a sense of agency, or influence over important events in their lives (Schunk and DiBenedetto, 2019) and central to this desire was self-efficacy, the belief that they could accomplish their goal. Self-efficacy led individuals to set goals and strategies for achieving a behavior. As individuals pursued the goal, they measured their progress through self-reflection (a key internal motivator) and adjusted as needed to attain the goal.

Schunk and DiBenedetto (2019) posited that the more challenging the goal, and how strongly it related to the individual's values, the more motivated they were to achieve it. Shen et al. (2012) stated that for an effective behavior change to occur in self-management, self-efficacy toward that behavior should be enhanced and suggested four strategies: performance attainments through goal achievement and practicing behaviors; vicarious experience and learning from role models; verbal persuasion by described benefits of behavior change; and physiological feedback through discussions of the strategies to make behavior change. These strategies demonstrated that not only was self-efficacy an individual endeavor, but a team effort where others (role models) influenced and supported the individual through behaviors and feedback.

Cudris-Torres et al. (2023) determined that self-efficacy played an important role in "determining whether actions of self-care were initiated, how much effort was expended, and how long the effort was sustained in the presence of obstacles and failures" (p. 2), and those with higher levels of self-efficacy showed greater ability to cope with their disease and a sense of control over their lives. Not only did higher levels of self-efficacy indicate greater ability to cope with disease, Fueyo-Diaz et al. (2018, 2020) demonstrated that specificity of self-efficacy was also important. Validating Bandura's belief that evaluating self-efficacy for specific situations was a better predictor of future behavior, Fueyo-Diaz et al. (2020) measured self-efficacy of 271 celiac individuals for specific dining situations (eating gluten free while shopping, traveling, at home or restaurants, and at work). The results of better adherence to a gluten free diet were associated with high expectancy of specific self-efficacy (71.9% = 195 participants; ($p<0.001$)) than general self-efficacy ($p=.021$).

Self-Management Processes

Within self-management, individuals utilize multiple processes to manage their disease. According to Corbin and Strauss' (1985) seminal work, three lines of work, or processes, were utilized by individuals to self-manage their disease: illness work (taking medication or visiting the doctor); life work (everyday tasks that keep the household going); and biographical work (adapting to a new lifestyle or role) and its premise was based on the perception of how patients viewed their conditions. Clark et al. (1991) embraced Corbin and Strauss' work concept and described the process as self-regulation where individuals self-observed, self-judged, and self-reacted to the assessment of their own situation. According to Down et al.'s 2015 research about adhering to a gluten free diet, this type of self-regulatory self-efficacy was assessed in 212 adults with CeD and directly predicted accidental gluten consumption ($P < 0.001$) and indirectly predicted purposeful consumption ($P < 0.001$), indicating its importance in patient self-management.

Lorig and Holman (200) embraced patient perception, suggesting that a "detailed needs assessment must be done for each new topic and group of patients" (p. 2) so that patient education was individually based and contextual to their needs. They introduced five core self-management processes (skills) that individuals utilized when living with a chronic disease: problem solving, decision making, use of resources, partnerships with health care providers, and taking action. As individuals lived with their disease, they engaged in problem-solving and decision making, and gathered informative resources based on the changes in the condition of their disease. As an example, individuals with CeD receiving a new diagnosis of lactose intolerance would need additional information to know how to live with their newest diagnosis, which could include new physician partnerships or making additional changes to their diet.

In addition to patient perception, Loring and Holman (2002) added the core behavior of self-tailoring where individuals implemented all of the aforementioned five processes in a manner that was “based on personal evaluation of their own needs and not necessarily their health care providers’ evaluation of their needs” (Miller et al., 2015, p. 3). By making self-tailoring a priority, individuals learned specific methods for problem solving and decision making, gathering resources that were appropriate for meeting their own needs, while tailoring a relationship with their health care provider that would enhance their self-management skills. Unfortunately, Lewis et al. (2022) found self-tailoring was not the norm as health professionals took a flow-chart approach to self-management, focusing on “increasing patients’ knowledge, confidence, and skills…in order to achieve clinical outcomes” (p. 439) and focused on “time-bound self-management activities and goals…to produce measurable outcomes within set timeframes” (p. 441).

Self-Management Support

According to Lawn and Schoo (2010), there were many factors that influenced a patient’s capacity to self-manage their disease. These included individual attributes, social and cultural factors. In addition to these attributes, Lawn and Schoo, included three main elements of self-management support: 1) on going individualized assessments, 2) collaborative goals with health care providers, and 3) development of skills to meet goals, problem-solve and self-regulate their conditions (Convery et al., 2019, Lawn and Schoo, 2010). Like Lorig and Holman's concept of self-tailoring, such support was based on collaborative partnerships with health care professionals and emphasized that self-management support was not to implement uniformed standards but helped patients to reach their own self-defined goal to move toward better health, quality of life, and well-being (Convery et al., 2019).

Patient Education. Coleman and Newton (2005) defined patient education as a way to support patients in self-managing their disease through knowledge-based instruction. According to Lawn and Schoo (2010), effective learning occurred in group and/or individual interventions and the challenge was for health professionals to understand "which methods were best suited to support which patients in which contexts" (p. 206), indicating the need to be aware of patients' needs. Jacobsson et al. (2016) demonstrated this in their study of 14 women, who attended a patient education program for celiac women. It was found that women were strengthened by the ability to engage and compare themselves with others during the group class and realigned their viewpoint of their disease and sense of self, indicating that in a clinical setting of support, the type of knowledge needed by the patient (e.g. comparison with others) should be considered and not assume that the medical professional knows best (Jacobsson et al., 2016).

However, Grady and Gough (2014) countered Coleman and Newton's assessment that self-management occurred through knowledge-based instruction, stating self-management had "evolved beyond the practice of merely providing information and increasing patient knowledge" (p. e26) and instead, individuals self-regulated their cognitive behaviors having the "capacity to control and manage thoughts, emotions, or behavior" (e26), which recognized the "cyclical and reciprocal influence of personal, behavioral, and environmental factors on human functioning" (Clark and Zimmerman, 2014, p. 486).

Social Support. According to Grady and Gough (2014), self-managing chronic illness occurred in the context of other people and influences, and “fundamental to its success were the relationships among patients and their health care providers (primarily nurses), friends and community, and family members (p. e27). Rotheram-Borus et al. (2014) stated, “health-promoting decisions can be both supported and impeded by family and friends” (p. 6) and health providers were essential for encouragement of patients and provided emotional support. Unfortunately, relationships with family and friends could impede an individual’s self-management as some reinforced the diagnosed individual’s sick role instead of empowering the individual (Rotheram-Borus et al., 2014).

Peer support was found in disease-specific organizations. For instance, individuals diagnosed with CeD could obtain support from the Gluten Intolerance Group (GIG), National Celiac Association (NCA), or Beyond Celiac. Finally, health care professionals provided support for individuals who self-managed their disease through engagement and education about basic, instrumental, and advanced activities for various stages of life (Matarese et al., 2018).

Barriers to Self-Management

Coventry et al. (2014) found individuals’ barriers to self-management revolved around three factors: capacity, responsibility, and motivation. An individual may not have the capacity, physical and/or emotional, or access to social, economic, or material resources, to appropriately self-manage their disease. For patients with CeD, this barrier may be encountered by individuals with lesser financial means as gluten free products are, in most cases, more expensive than their glutinous counterparts.

The second barrier, responsibility, related to who (practitioner or patient) was responsible for managing the patient’s disease. Practitioners believed patients should share responsibility, but only as much as the patient was able to weigh the risks and benefits of self-management practices, which according to Coventry et al. (2014) were associated with lower literacy (knowledge for making decisions) and lower health status. Coleman and Newton (2005) believed health literacy could be enhanced by asking the patient to repeat information back from clear instructions given by the physician, which was associated with better self-management outcomes. Overall, regarding patient responsibility, most patients agreed they shared responsibility with their physician, however, "those in the most deprived areas tended to hold their doctor as responsible for managing and monitoring their health (Coventry, 2014, p. 8).

Coventry et al. (2014) found that motivation was also a barrier to self-management, and those who were not self-motivated were most likely to be unsuccessful in managing their disease. In addition to a lack of motivation, Cramm and Nieboer (2015) found an individual's lack of interest was not only a barrier to their ability to self-manage, but "negatively influenced professionals' willingness to continue self-management support interventions" (p. 250) with their patients. However, while professionals were affected by patient lack of interest, the patients encountered barriers from poor facilitation of support interventions due to the facilitators' "lack of continuity, commitment, knowledge or skills" (Lawn and Schoo, 2010, p. 210), which indicated that organizational changes were needed as to how individuals were trained to deliver patient interventions. Other barriers to self-management were depression, which kept individuals isolated and unable to cope; struggling with weight control; difficulty exercising due to joint pain or immobility; fatigue; pain; lack of family support; and financial problems that affected individuals' ability to be treated (Jerant et al., 2005).

Section Summary

The purpose of this section was to give an overview of chronic illness, specifically CeD, and the need for patient self-management. Because of the burden chronic illness placed on health care systems, it was important to develop a means for patient engagement to assist in the management of their disease. By utilizing chronic care models, health care became more patient-centric and gave a sense of autonomy to patients as they direct their own care with social support and partnerships developed with health professionals. Unfortunately, barriers such as lack of capacity, responsibility, and motivation negatively affected the success of self-management. Finally, to fully understand patient self-management, its definition should be considered as it has expanded from simply being a prescribed regimen of physiological care, to having a higher level of patient autonomy, decision making, and problem solving that encompassed social interventions, the psychosocial sequelae of illness, and adult learning (Barlow et al., 2002, Gallant, 2003).

What is Learning?

Merriam-Webster Dictionary (2023), defined learning in three ways: “the act or experience of one that learns,” “knowledge or skill acquired by instruction of study,” and the “modification of a behavioral tendency by experience” (Merriam-Webster, n.d.). In discussions of learning, the terms learning and education were used interchangeably as they were assumed to be the same concept. However, Knowles et al. (2020) made a distinction between the two concepts stating that education was an activity initiated by a change agent (educator) to effect change; while learning emphasized the experience of the one who engaged with learning to acquire knowledge, skill, or modification of behavior (Knowles et al., 2020). Essentially, education focused on the change agent, or educator while learning emphasized the learner.

According to Knowles et al. (2020) examples of other researchers' definitions demonstrated that learning involved individual change that included new habits or attitudes; that change was because of one's environment, an experience, or situation that occurred; or was an outcome of a process for attaining a given outcome as shown in Table 2.3 (Knowles et al, 2020).

Table 2.3

Definitions of Learning

Researcher	**Learning Defined**
Crow and Crow (1963)	Acquiring new habits, knowledge, and attitudes
Burton (1963)	Occurs due to an individual interacting with their environment
Haggard (1963); Cronbach (1963)	Reflected as individual change occurs from experience
Harris and Schwahn (1961)	Outcome of process that attains a given outcome, emphasizes motivation, retention, and transfer
Gagné (1965)	Change in disposition or capability outside of normal growth process
Hilgard and Bower (1966)	Development or change in activity after encountering situation
Skinner (1966)	Change due to experience or consequence (reinforcement)

Note: From: Knowles, M. S., Holton, E. F., Swanson, R. A., and Robinson, P. A. (2020). Exploring the World of Learning Theory. The Adult Learner (9th ed., pp. 12-16). Routledge.

To add new information to existing knowledge, constructivist researchers recommended that a learning environment should arouse a student's curiosity, and educators should guide students to discovery, instead of attempting to pour knowledge into an empty vessel (Mogashoa, 2014; Yilmaz, 2008). Schcolnik et al. (2006), suggested that students' work be viewed from the students' perspective, which allowed each student to build their own set of knowledge and led to "authentic learner authorship and ownership" (p. 14). Similarly, upon diagnosis of a chronic illness, adults became students of health as they learned to live with chronic illness, and as such, their unique perspective and knowledge were considered.

Learning Epistemology - Constructivism

The learning epistemology (frame or lens through which we see) of constructivism supposed the world constantly changed, and was not static, and preexisting truth did not exist. Therefore, knowledge was constructed, not transmitted, and ever evolved. For learning to occur, individuals constructed new knowledge by connecting their prior and present learning knowledge (e.g., language, social activity, and reflection) so new knowledge was integrated (Mogashoa, 2014; Schcolnik et al., 2006). In constructivism, truth was not absolute. Instead, truth was relative to the individual as they defined it based upon their experiences, values, and prior knowledge (Yilmaz, 2008).

Constructivism was adaptive and flexible, as when individuals engaged with new knowledge, they chose what they would and would not learn. Learning was active as individuals constructed their own knowledge based on their schemas that consisted of their values, culture from which they came, lived, or worked, and situational contexts that determined what was important to learn. (Merriam and Bierema, 2014; Mogashoa, 2014; Schcolnik et al., 2006; Yilmaz, 2008). Therefore, meanings were not objectively definitive and independent of the individual, but instead, were dependent on the individual's constant revision of new knowledge and new learning (Schcolnik, Kol, and Abarbanel, 2006).

Jean Piaget (1896-1980) influenced constructivism through his theory of cognitive development. Two key points of Piaget's work were assimilation and accommodation which compared human learning to an organism's development as it adapted to biological demands. When an individual was diagnosed with a chronic illness, they were faced with the new experience of how to adapt and engage with their diagnosis. This new experience caused perturbation (disruption) and a state of disequilibrium, or liminality for the individual, and by incorporating new information (assimilative learning), equilibrium returned.

According to Piaget, when individuals were presented with new knowledge, they had three choices: 1) disregard the information, 2) continue with their original thought processes, or 3) form a new learning schema (Yilmaz, 2008). With chronic illness, learning occurred when an individual desired to return to a state of equilibrium after their schema was disrupted by their new diagnosis. Piaget asserted that “learners use their cognitive structures to interpret the environment …assimilating new information into their existing cognitive schemas” and understood the new information “only to the extent allowed by the existing schemas” (Schcolnik et al., 2006, p.13). This assimilation resulted in learning as individuals incorporated new information into their already existing scheme such as individuals with one chronic illness being diagnosed with a second disease. While it may be a different disease, the individual had knowledge of living with chronic illness, thus the requirements of living with another diagnosis were added more easily to their existing schema.

Andragogy – The Learning of Adults

There were two theoretical models in learning theory: pedagogy and andragogy. Pedagogy was teacher-centric, with teachers making the decision as to what students should learn and students reciprocated by being dependent on others to know what needed to be learned, and were motivated by external motivators such as grades, approval, or parental pressure (Knowles et al., 2020). Pedagogical learning was based on what was considered to be traditional learning of behaviorism, humanism, cognitivism, social cognitivism, and constructivism (Merriam and Bierema, 2014). In andragogy, or adult learning, the focus was instead on the learners (adults) who were psychologically self-directed and responsible for their own lives.

While andragogy began with Thorndike (1928) and Lindeman (1926), who first wrote about adult learning as a separate teaching theory, it was not until Knowles was introduced to the term by the Yugoslavian adult educator, Savicevic in 1967, and promoted the concept of the differences between educating adults and children, that the theory was popularized (Knowles et al., 2020; Merriam and Baumgartner, 2020; Merriam and Bierema, 2014). Furthering the study were the works of Houle (1961) and Tough (1978) who classified three types of learners (goal-oriented, activity-oriented, and learning-oriented) and the concept of self-directed learning, respectively (Knowles et al., 2020; Merriam and Bierema, 2014). There were also six andragogic assumptions of adult learning:

1. *Need to know.* Adults need to know the reason they must learn something before choosing to do so.
2. *Learner self-concept.* As adults, they moved from a self-concept of dependency to self-directing.
3. *Learner experiences.* Adults had a wide range and quality of experience, which was a rich resource for learning.
4. *Readiness to learn*. Readiness to learn was closely related to developmental tasks or roles.
5. *Orientation to learn.* Adult learning was problem-centered and motivated by the extent learning would help them perform tasks or solve problems.
6. *Motivation to learn.* Adults were primarily motivated by internal pressures such as obtaining self-esteem, job satisfaction, and quality of life.

While these assumptions were applicable to many adults, there was criticism that the assumptions of andragogy were seen as fitting all situations, no matter the circumstance.

Knowles acknowledged his theory was adaptable to individual situations stating in 1990 that this meant “in practice that we educators now have the responsibility to check out which assumptions were realistic in a given situation” (Knowles et al., 2020, p. 78). Pratt (1988) embraced this concept and proposed a model that demonstrated an adult’s readiness to learn was affected by their life situation and, because of such situational influence, Knowles et al. (2020) suggested, “a learner may exhibit very different behaviors in different learning situations” (p. 79). As an example, an individual diagnosed with CeD, who was asymptomatic, may not be ready to learn how to change their behavior and eat gluten free while another individual with the same diagnosis, but symptomatic, was very willing to change their behavior to avoid the side effects of ingesting gluten.

Concepts that Influence Adult Learning

The following concepts were important to consider when adults were engaged in learning. Understanding what motivated adults to learn and factors of influence such as self-determination, self-regulation, and social context provided a foundation for engaging with patients living with chronic diseases, such as CeD. This knowledge, combined with an understanding of individuals’ possible resistance and barriers to learning, informed the health care community’s development of patient-appropriate materials and interventions to assist them in the self-management of their disease.

Motivation

Motivation was defined by Merriam and Bierema (2014) as the “drive and energy we put into accomplishing something we want to do” (p. 147) and was driven either intrinsically (internal factors) such as subject mastery, or extrinsically (external factors) for the attainment of recognition. When an individual was motivated to attain goals, they were more likely to engage in self-regulatory activities such as “self-generated thoughts, affects, and behaviors systematically oriented toward attainment of one’s goal” (Schunk and DiBenedetto, 2019, p. 5) for achievement of the goal. Such goals were learning-focused (obtaining skills and strategies that enabled learning) or performance-focused where tasks were accomplished and influenced through modeling behavior of others (observed motivation).

Adult learners were motivated more by things that helped them solve problems in their lives or provided internal payoffs and these served as a more “potent motivator” than extrinsic rewards (Knowles et al., 2023). In learning to manage one’s chronic illness, individuals were likely to engage in learning about their disease and its management if they deemed the learning process (and its materials) provided a solution to their problem of poor quality of life. Wlodowski (1985) discovered four factors that led to motivation in adults. Adults desired to:

(1) be successful at learning *(success)*
(2) feel a sense of choice, or autonomy *(volition)*
(3) learn something of value *(value)*
(4) experience learning as pleasurable *(enjoyment)*

As patients were more successful learning how to self-manage their disease, they not only improved their self-efficacy, but gained a sense of autonomy as they learned valuable content that informed them in the management of their disease. Finally, while it was important to undertake learning for the self-management of chronic illness, individuals who were diagnosed with such were living with daily stresses the disease brought. Therefore, ensuring the experience was pleasurable took away the drudgery about the process for them.

Self-Determination

To explain human motivation, Ryan and Deci (2000) developed the meta-theory of self-determination (SDT). Self-determination demonstrated the interaction of oneself with their environment. Through this interaction, the self constantly evolved and desired a sense of wholeness. This continuous development led individuals to “seek challenges and tasks in order to cope … and to reintegrate the experiences, new skills, and abilities into their self” (Kellenberg et al., 2017, p. 24). Ryan and Deci (2000) described the concept of self as an organismic process that had “innate tendencies of human beings to engage in interesting activities and to elaborate and refine their inner representation of themselves and their world” (p. 248).

Individuals were motivated by either intrinsic or extrinsic reasons and human needs “specify the necessary conditions for psychological health or well-being” (Deci and Ryan, 2000, p. 229). Conditions that were necessary to ensure an individual’s well-being were found in three innate psychological needs: Competence, autonomy, and relatedness (Ryan and Deci, 2000). As individuals sought to improve their well-being by learning how to self-manage their chronic disease, they gained competency by implementing what they had learned to master a new behavior; developed a sense of control, or autonomy; and felt a sense of belonging to others with whom they connected (relatedness), which enhanced the individual’s self-motivation to complete a goal, such as learning, for the mere satisfaction (Cherry, 2021, Find social support section; Ryan and Deci, 2000). Such self-determination influenced an individual’s interest in learning how to self-manage their health, and the more self-determined and in control one was in making changes for intrinsic reasons, the more likely an individual was motivated to engage in the behavior for satisfaction.

Self-Regulation

While an individual's self-determination encouraged motivation to enact change, according to St. Quinton and Brunton (2017), to turn motivation into action, "is dependent heavily on one's ability to self-regulate" (p. 2). Baumeister et al. (1994) defined self-regulation as the ability to "overcome obstacles, get back on track, and ward off distractions from tempting stimuli" (as cited in St. Quinton and Brunton, 2017, p.2). In health behavior, as individuals learned to maintain a behavior change for disease self-management, they first needed the ability to self-regulate their behavior (Mann et al, 2013). To do so, one needed to understand the factors that led to the development of self-regulation.

Self-regulation processes were initiated consciously, or automatically, and were categorized into either goal setting or goal striving (Mann et al. 2013). Latham and Locke (1991) first developed the theory of goal setting to answer the question of "why some people performed better on work tasks than others" (p. 213). Hence, the theory approached the issue of motivation from a first-level, individual perspective, and posited the reason some individuals performed better than others was due to their different performance goals (Latham and Locke, 1991).

Locke's theory was utilized in health behavior change and explained how a change was implemented and adhered to through the concepts of Bandura (1997) and Schunk (1995) such that "goals enhance self-regulation through their effects on motivation, learning, self-efficacy…and self-evaluations of progress" (Schunk, 2001, p. 2). A goal motivated an individual to exert effort to meet behavioral demands over time; however, according to Mann et al. (2013), one was not committed to that goal "until they were willing to invest affect, cognition, and behavior in attaining it" (p. 488). In the context of learning and patient self-management, a goal to maintain blood pressure or change one's diet was motivation to engage in learning to understand how to maintain their blood pressure or what foods were appropriate for a change in their diet.

Social Context

Social context was an important element to consider for adult learning. According to Merriam and Bierema (2014), context "refers to the social system that shapes the thoughts and actions of people within a particular setting" and "was equated with the history and culture of the learner" (p. 241). Understanding the characteristics and positionality of an individual provided a lens to know what influenced them and the potential biases they had in a learning context. For example, in managing chronic disease, were the perceived barriers the same for rural families attempting to prevent childhood obesity (Knol et al., 2016) the same as those who live in middle-class suburbs? Or how do social norms affect the responses as to quality of life of men and women living with CeD? (Hallert et al., 2003) Considering such influences spoke to how the types of education, programs, and assistance should be targeted to varying groups.

Barriers to Learning

Adult learners experienced barriers in their ability to learn. While adult learners had a wider range of experiential learning, prior learning interfered with current learning (Merriam and Baumgartner, 2020). An example was in Kozhakhmetova et al.'s (2022) study of doctors in Kazakhstan. While senior doctors were more aware of CeD because of their medical experience, they were unaware of atypical or asymptomatic versions of the disease, which was attributed to their old medical knowledge. In addition, as individuals matured, they had age-related factors such as slower memory response time, fatigue, and possible health problems; with family pressures and time limits presenting challenges for participation (Merriam and Baumgartner, 2020). An individual's geographic area presented a barrier as adult learners who lived in rural areas had fewer resources available, such as health care education, or online access for self-directed learning.

Cross (1981) identified three categories of barriers: situational (lack of time or money, work responsibilities), institutional (scheduling, location), and dispositional (attitude or self-perception). According to Merriam and Baumgartner (2020) the two most frequently cited reasons for nonparticipation were situational and focused on lack of time and money. Rubenson (2006) found in Nordic countries a lack of time was due to the care of children, which the countries addressed. They freed up time commitments for parents through a public-supported early childhood care system. Roosmaa and Saar (2017) found adults in Nordic countries were the least impeded among the 19 European countries studied; but Baltic countries encountered institutional barriers most often, with post-socialist countries in Southern Europe experiencing dispositional barriers due to the understanding that “education was acquired at school, completed at university, and adult only learning was only needed for work” (p. 271). In some international education systems, educational options were dependent on the individual’s initial level of education, and therefore access was not readily available for all individuals; however, such provision was found less in France and Mediterranean countries (Roosmaa and Saar, 2017).

Sociocultural elements such as race, class, and gender present barriers in adult learning. This was demonstrated by Sissel’s (1997) study of a Head Start education program that educated parents how to become involved in their child’s education. In the study, men participated more than women, and negative staff expectations (they “appeared to only want ‘good’ parents to get involved”) (p. 129) focused on class and personal background. A lack of program resources negatively affected how staff engaged with parents, as well as influenced parents’ lack of interest in learning. In addition to race, class, and gender barriers, Sissel’s study demonstrated how a lack of appropriate resources influenced the interest of parents' participation in the learning they offered. In Sissel's study, an example was a lack of childcare [resource] that made participation impossible for some parents who had other children at home.

Lack of participation in adult learning was not always due to a barrier but was considered resistance on behalf of the learner as they simply chose not to participate in formal learning (Merriam and Baumgartner, 2020). However, adults engaged in various types of learning, such as informal experiential learning, and it was still considered adult learning. Learning barriers for all populations should be considered as most providers who provided learning opportunities did so for similar others. As Rubenson (1989) pointed out, if the system of adult education assumed all individuals were capable and self-directed learners who self-selected and participated in learning, possessing the skills needed to participate in such learning, the system "will by necessity widen, not narrow, the educational and cultural gaps in society" (p.65).

Adults as Learners

Merriam and Baumgartner (2020) believed the more we knew about adult learners and the changes they experienced, and how these "changes motivate and interact with learning, the better we structure learning experiences that both respond to and stimulate development" (p. 345). Within this study's context of individuals diagnosed with CeD, the concept of understanding adults and the situations that motivated their learning had direct applicability in patient self-management. It also informed the health care industry and its professionals how best to engage in educating and partnering with patients of chronic illness.

As previously mentioned, adults were more inclined to participate in learning if they understood their need for participating, the extent the learning was problem-centered, and how the learning would help them perform tasks or solve problems (Knowles et al., 2020). Being diagnosed with CeD gave individuals an opportunity to learn about their disease and how best to self-manage their health. Such a diagnosis was an unanticipated transition that, while being stressful, had great “potential for stimulating learning and subsequent development” (Merriam, 2005, p. 5). According to a study of 2,000 adults, 25 years and older, 83 percent learned because of a transition in their lives, and only 17 percent learned for the sake of learning (Aslanian and Brickell, as cited in Merriam, 2005; Merriam and Baumgartner, 2020).

Life Transitions

Individuals experience many life transitions. Some are expected, others are unexpected, but both bring instability. In the context of a chronic disease diagnosis, such as CeD, individuals experienced stress and disruption of what was once seen as normal. However, it was necessary for the transition experience to be “discomforting, disquieting, or puzzling enough for us not to reject or ignore it, but to attend to it and reflect on it. It was then that learning took place” (Merriam, 2005, p. 8). As individuals attempted to make meaning of their transition, it was important to understand the meaning that was assigned to the transition and determine the type of learning that occurred. As an example, an individual who had severe symptoms prior to a celiac diagnosis chose the meaning that “diagnosis equals relief” and was happy to know what caused their health issue. However, if the individual was asymptomatic, they gave a negative meaning of “diagnosis equals nuisance” and ignored the diagnosis, continuing the same dietary behavior.

Bridges’ Transition Theory

According to Bridges (2001), change was different from transition in that change was something that happened to you (situational) while transition was a psychological process of coming to terms with the change by “letting go of the way things used to be and then taking hold of the way they subsequently become” (p. 2). Bridges’ theory had three phases that were experienced by an individual when presented with a change: ending, neutral zone, and new beginning. However, not all change caused transition as most transitions were equated with significant life events that required a restructuring of the individual's self and their world (Williams, 2008). Schumacher and Meleis (1994) theorized that transitions contained universal properties that helped one to know if the change was actually non-transitional or transitional (e.g. short-term illness versus chronic disease, respectively) in that they occurred over time; moved from one state to another in stages or phases; and the nature of change was either individual/familial (e.g. identity, roles, relationships) or organizational (e.g. structure, function, dynamics).

In Bridges' model's first phase, 'ending,' "individuals were emotionally uncomfortable and experience negative emotions such as "anger, sadness, anxiety, depression, and confusion" (Leybourne, 2016, p. 29) as they let go of old ways and bargained to remain or return to a state of homeostasis. To move forward to the second phase of 'the neutral zone,' it was necessary for individuals to obtain closure by acknowledging the past had ended (Leybourne, 2016, Selder, 1989). According to Selder's (1989) life transition theory, the new reality the individual constructed was based on the expectations they brought to the situation and their "experiences were structured in such a way as to find meaning in them in light of those expectations" (p. 439). Through this new construction, Bridges' third phase, a 'new beginning,' occurred as a psychological and behavioral change that took place within the individual and new identities and behaviors were embraced (Leybourne, 2016).

French and Delahaye Transition Theory

Expanding on Bridges' theory, French and Delahaye (1996) approached transition theory with a gap connection approach that looked at not only the content of the change but focused on the “recognition and fulfilment of individual needs as primary movement motivators” (p. 23). The model differed from Bridges linear approach to transition, as French and Delahaye (1996) believed change transitions were “discontinuous and vacillate” (p. 23) in and out, not in any set order, until the change was integrated into a new security for the individual. In this model, there were four phases: security, anxiety, discovery, and integration. The pre-change mode of security contained the conditions, or processes and habits that influenced how the individual responded to a change transition. In change literature, these familiar processes were known as schema which provided a level of comfort, but prevented the “flexibility, creativity, and experimentation” (French and Delahaye, 1996, p. 24) that were needed to break down boundaries preventing acceptance of a transition. When these familiar processes or habits were disrupted, individuals experienced the emotional discomfort of anxiety with feelings of doubt, anger, and confusion. This state of disruption and confusion was first identified as a state of “liminality” by Arnold Van Gennep in 1908 to explain the anthropologic experience or rites of passage.

Experiencing Liminality

Liminality derived from the Latin word limen, meaning threshold, doorway, or boundary, and denoted the middle of a transition, a place of ambiguity and uncertainty, a place of ‘betwixt and between’ (Wendling, 2008; Turner, 1966; Wels et al, 2011). For the individual experiencing a transition, such as a chronic disease diagnosis, it causes disruption in their lives and feelings of anxiety. To move beyond the liminal state, French and Delahaye (1998) stated, “It was the ability to learn that moves the individual away from the anxiety phase of change” (p. 25) toward a discovery period of uncertainty and stressful “chaos” that led to the development of new practices and eventually a new security. In other words, learning about one’s disease and required behavioral changes provided an opportunity for individuals to develop new ways of doing that provide security in their lives once again.

According to French and Delahaye (1998), “Maintaining a learner stance, was a very important part of the change transition process and for defining strategies of change management” (p. 25); and, if individuals do not have an attitude and willingness to learn, they had difficulty moving through the change transition process. However, consideration should be given to the amount of time it took to obtain an attitude and willingness to learn post-diagnosis. As Adili et al. (2013) found in their research of older women learning to live with diabetes, “Learning to take a chronic illness into one’s life takes time” and “we should not underestimate how long it takes to reorganize one’s lifestyle” (p. 153). Upon diagnosis, these women were not “ready to learn,” as they were preoccupied with incorporating the “technical and practical aspects” of self-managing their disease; however, in their second-year post-diagnosis, they were “learning to master activities to create order, discipline, and control in their lives” (Adili et al., 2013, p. 154).

Other research utilized transition theory to understand health behavior change as it related to the field of nursing, chronic disease, or spinal injury (Selder, 1989); individual change (French and Delahaye, 1996); and retirement (Schlossberg, 2022). An interesting aspect of French and Delahaye’s four-phase theory was their focus on the learning that occurred during individual transition, stating that “Maintaining a learner stance, was a very important part of the change transition process and for defining strategies of change management” (p. 25); and, if individuals do not have an attitude and willingness to learn, they had difficulty moving through the change transition process.

Meaning Making and the Adult Learner

Robert Kegan's theory of adult development identified four meaning-making epistemologies (lenses) through which individuals traversed their experience of development: instrumental, socialized, self-authoring, and self-transforming. One who had an *instrumental* lens saw the world to be navigated with rules, maximized the personal rewards, and minimized punishment (Lewin et al., 2019). In this mindset, as larger concerns arose, individuals reacted by making rules object (having control over it) and moved towards a more complex *socialized* lens where they became subject to (controlled by) social norms and subordinated their desires to those of others (Berger, 2003; Kegan, 2003; Lewin, 2019).

When competing norms were encountered, individuals made social norms object (they were no longer controlled by them) and made the transition to a *self-authoring* lens where, based on previous experiences, individuals chose their own values and directed their own actions, not being torn by others' conflict, and instead shaped a way of making sense of their own lives (Berger, 2006; Kegan, 2003; Lewin, 2019). Finally, the rarest lens for individuals to obtain was that of *self-transformation*. Individuals who utilized this lens made their own views object and realized they were incomplete and expanded their complexity perspectives that formerly were viewed as dissimilar (Berger, 2006; Lewin, 2019).

By having the ability to reflect on their prior experience, individuals reassessed the presuppositions on which their beliefs were constructed and developed new insights on which to base future actions (Kessler et al., 2009). This was an integral part of transformative learning, which led individuals to experience "an empowered sense of self, a critical understanding of how one's social relations and culture have shaped one's beliefs and feelings, and strategies for taking action" (Dubouloz et al., 2010a, p. 605).

Subject-Object

The subject-object of knowing formed the core of an individual's epistemology (the form/frame, or lens) that was used for making decisions. This concept expressed the difference between the "thoughts and feelings 'we have,' and the thoughts and feelings that 'have us'" (Kegan and Lahey, 2010, p. 434). According to Berger (2006) and Kegan (2003, 2018), things that were *subject* were unquestioned, and were simply a part of self, over which we have no control (it has us); however, those things that were *object* were those for which we take responsibility and have control over (we have it) (e.g., our diet). As we used a particular lens (frame) to make decisions (e.g., viewing life through the lens of "gluten free") we became subject to that lens, and it became normal and a part of us, and *[again]* we were unaware of its influence (Kegan, 2018; Lewin et al., 2019).

As a new challenge arose, such as chronic illness, individuals became aware that their current epistemology impeded their ability to navigate the new challenge and required a new lens that was more complex than the previous one (Kegan, 2018). This new lens allowed individuals to see how their "old lens shaped their understanding, including the blind spots, and distortions it introduced" (Lewin et al., 2019, p. 1300). In this capacity, the individual developed by moving the thing to which they had been "subject" to a place of "object," where they owned or had it. Because of this, the form, or container (worldview), became larger and more complex and individuals were able to see and act upon more things (Berger, 2006). An example of this would be newly diagnosed individuals who had CeD and chose to change their form (world view) of social norms, embraced new norms of gluten free living, and enlarged their view of the meaning of disability, accommodation, and inclusiveness.

In empirical studies about chronic disease, a common theme was the individual experience of poor quality of life. However, in searching for empirical studies that viewed chronic disease through the subject-object lens of transforming one's world view, none could be found. Instead, research participants viewed their diagnosis as burdensome, with a lower quality-of-life (Hallert, 2002); had negative social lives (Bouery et al., 2022); and experienced a sense of grief (Rose and Howard, 2013). According to Antonovsky's (1979) salutogenic model, "the way people viewed their life had an influence on their health" (Jacobbson et al., 2012, p. 3448). In essence, changing one's perspective about their disease from "subject" to one of "object" generated not only positive thoughts, but experienced a better quality of life. As Kegan (2018) quoted Huxley, "Our experience was less what happens to us, and more what we make of what happens to us" (p. 38).

Adult Learning and Self-Management of Disease

According to Merriam, Caffarella, and Baumgartner (2006), learning was defined as "a process that brought together cognitive, emotional, and environmental influences and experiences for acquiring, enhancing, and making changes in one's knowledge, skills, values, and worldviews" (p. 48). In self-management of chronic disease, each of these elements were experienced by individuals as they learned to live with their diagnosis. As individuals were faced with living with chronic illness, "learning and changing what we value and do can provide a powerful means to improve their quality of their life over time" (Zubialde et al., 2009, p. 195), which caused "a deep shift in perspective during which habits of mind become more open, more permeable, and better justified" (Cranton and Taylor, 2012, p. 201). Zubialde et al. (2009) stated, "Adult learning research repeatedly demonstrated that establishing good learning goals was critically important to good outcomes," and goals that correlated with improving "personal competence, social relatedness, and autonomy" (p. 196) created meaningful and lasting learning.

Adult learning was considered not only in the context of individuals who self-managed their disease, but also within the context of health care and its professionals that worked with adults diagnosed with chronic disease. According to Mukhalalati and Taylor (2019), it was important that health care professionals understood and utilized learning theory "in selecting and justifying the educational activities that they applied, so that these activities had a solid theoretical foundation based on the learning environment and setting" (p. 1). By using adult learning theory in patient education programs, it became an essential part of an evidence-based education practice that: helped educators select the best instructional strategies; improved learning by integrating learning theory with the subject matter and student understanding; and utilized such theory to explain the differences in how individuals learn (Mukhalalati et al., 2019). Unfortunately, important learning theories were not consistently implemented in the design and implementation of educational programs (Mukhalalati et al, 2019) as was seen in the following review of the literature.

Empirical Studies of Adult Learning and the Self-Management of Celiac Disease

For this research, to understand the relationship of adult learning and self-management within the specific context of CeD, an empirical literature review was conducted. Literature was obtained from CINAHL, EBSCO, MEDLINE, Gale, PubMed, Springer, and Google Scholar search engines for the years 2003-2023. The terms used for the search were a compilation of "celiac disease," "coeliac disease," "self-management or self management," "self-care or self care," "learning," "adult learning," and "learning theory," omitting the word "machine" to preclude machine learning. As adult learners were the primary focus of this research, articles were omitted that contained content based on child or adolescent learning. This yielded 76 empirical studies that were assessed for duplicates or chronic diseases outside of the scope of CeD focus, after which remained 28 articles. These were assessed for specific terms of celiac/coeliac disease, self-management/self-care, and learning/adult learning to ensure the relevancy of each article. The remaining 11 articles covered topics such as living with CeD, the difference in lived experiences of celiac men and women, and the assessment of doctors and medical students about their knowledge of CeD. As the future research of this study will group narrative findings thematically, I grouped the articles by common themes of learning: group learning, physician knowledge, and educational needs of celiac patients which were presented in Table 2.4.

Table 2.4

Celiac Disease and Learning

Study	Study purpose	Population	Location	Related learning
Group learning				
Hallert, C. et al. (2003)	Gender-related aspects of living with celiac disease	Ten men and women, mean age 57 yrs. on a GF diet 1-+ yrs.	Sweden	*Group learning* should be used as a coping strategy
Jacobsson, L. R. et al. (2012)	Coeliac School – patient education that utilized problem-based learning	Adult participants (106) with GF diet >5 yrs. Intervention group: 54, control group: 52	Sweden	*Problem-based learning* improved psychological well-being/*group learning* was needed for women
Jacobsson, L. R. et al. (2016)	Explored lived experiences of women after coeliac school	Fourteen adults, women who had previously participated in 2011 coeliac school	Sweden	*Group learning* was needed for women
Akbari Namvar et al. (2022)	Investigated effect of celiac patient group-based education on GI	Patients (n = 140) in education intervention	Iran	*Group learning* – group-based programming should

Study	Study purpose	Population	Location	Related learning
	symptoms/quality of life	group (*n* = 66) and control group (*n* = 74)		be added to individual education
Akbari Namvar et al. (2021)	Assessed group-based education among individuals with celiac disease	Patients (*n* = 130) in education intervention group (*n* = 66) and control group (*n* = 64)	Iran	*Group learning* – superior/ increased patient self-efficacy
Physician education				
Perlstein, R. et al. (2016)	Medical student knowledge about coeliac disease	Medical students (131/1st and 2nd yr.) and (66/3rd and 4th yr.)	Australia	*Knowledge*-medical students should be trained about nutrition in cancer/respiratory disease
Kozhakhmetova, A. et al. (2022)	Kazakhstan physician knowledge of celiac disease	Practicing physicians (110 primary care/122 specialists)	Kazakhstan	*Self-learning* should be utilized by physicians to increase knowledge about coeliac disease
Educational needs of celiac (coeliac) patients				
Clerx, E. et al. (2019)	Assessed the rate to acquire self-management skills post-diagnosis	Celiac patients (*n* = 137); 108 women and 39 men	United States	*Education* – celiac patients need targeted education/resources to facilitate adherence
Langarizadeh, M. et al. (2023)	Identified educational needs of coeliac patients	Twelve pundits in field of nutrition (*n* = 5), internal med. (*n* = 4), and gastroenterology (*n* = 3)	Iran	*Future education* – Celiac self-care system was developed to be used for creating educational materials/promotion
Garnweidner-Holme, L. et al. (2020)	Measured perceptions of living life with a gluten free diet	Twelve participants, varied gender	Norway	*Education* – patients need to learn more about coeliac disease post-diagnosis
Taylor, E. et al. (2013)	To understand the experience of living daily with coeliac disease	Ten women, diagnosed for two yrs.	Australia	*Education* – need more patient learning/educational materials

Theme 1: Group Learning

Five studies focused on the concept of group learning. These studies did not reference adult learning theory per se but embraced the concepts of Bandura's Social Learning Theory (SLT), also known as Social Cognitive Theory (SCT). Even though SCT was not mentioned in these studies, each one embraced the concept of group learning.

Both studies of Akbari Namvar et al. (2021, 2022) implemented group learning to assess its influence on celiac patients' knowledge and adherence to a gluten free diet. 130 patients were divided into two research groups, one control ($n = 64$) group that received routine education at the clinic, and the other an intervention group ($n = 66$) who received three one-hour group education sessions. At three months post-education, the intervention group gained more knowledge ($p = 0.03$) than the control group and there was a significant difference in the CeD adherence test (CDAT) scores between the two ($p = 0.02$).

Similarly, Akbari Namvar et al. (2022) utilized group-based education on gastrointestinal symptoms and quality of life in patients with CeD. As in the previous study, this study's 140 patients (66 intervention/74 control) participated in group or clinic education, respectively. Patients in the intervention group demonstrated fewer gastrointestinal symptoms ($p = 0.04$) and abdominal pain was significantly lower ($p = 0.04$). Both studies (2021 and 2022) found that group-education had a significant effect on those who participated. However, criticism of these studies was that they did not take into consideration socioeconomic issues and their possible influence on group-based education and its participants.

Jacobsson et al. (2012) utilized group-based learning in their studies. Jacobsson et al. assessed how attending an interactive Celiac School, a ten-session educational program, could improve the psychological well-being of women living with coeliac disease. The education program was situated in problem-based learning that encouraged its participants to utilize self-directed learning to find and implement solutions to issues experienced from living with coeliac disease. One-hundred and three women were divided into intervention (*n* = 51) and control groups (*n* = 52). The intervention group attended the Celiac School for ten-week sessions facilitated by female tutors (nurses and one behavioral scientist) while the control group received similar information from the doctor about CeD approximately every other week over a ten-week period. After ten weeks, the results indicated that the intervention group showed better psychological well-being ($p = 0.001$) and general health ($p = 0.002$). Comparatively, the control group was significantly worse in psychological well-being ($p = 0.006$) and general health ($p = 0.03$). After six months, an assessment noted that the only significant lasting change of the intervention group was that of vitality of life ($p = 0.009$). Overall, these results indicated that group learning and interaction had a positive effect on the psychological well-being of women and was the first randomized study to do so.

As a follow-up to their Coeliac School study, Jacobsson et al. (2016) conducted a phenomenological study about the lived experiences of women who had participated in the previous 2012 study. Fourteen of the 51 original participants agreed to share their experiences. It was found that the women did not trust all the information from the experts who tutored their groups, and what they did learn caused them to feel insecure about living with coeliac disease. Instead, the participants gained a better overview of life and understanding from interacting with others who had coeliac disease.

Hallert et al.’s (2003) phenomenological study of different perceptions of health-related quality of living (HRQoL) discussed the concept of learning from others but was not based on SCT or any other learning theory. Hallert et al.’s (2003) study assessed ten participants, five women and five men, to understand the gender-related aspect of living with CeD. Three dimensions were identified as they related to the quality of life living with CeD: bodily sensations, social consequences, and copying strategies. It was found that women experienced more bodily sensations such as reduced physical endurance and bowel symptoms than men. However, in all other aspects of social consequences such as food, identity, and their roles women experienced more stress and anxiety. Men and women also adapted to their diagnosis differently with men having greater acceptance of their disease than women; and women having greater dependence on connecting with others about their disease to accept it.

Theme 2: Physician Education

Because self-management changed the relationship between patient and physician, with the patient self-managing their disease, physicians should be knowledgeable of their patients' disease and appropriate strategies and methods for self-management. Two studies assessed the competence of medical professionals, both current and future doctors, to understand the importance they placed on being knowledgeable of strategies for treating disease.

Perlstein et al. (2016) assessed medical students' knowledge about nutrition and its effect on chronic diseases such as coeliac disease. The diseases selected for the study were based on chronic diseases from a medical course at the students' university and utilized diet as a primary treatment. It was found that of the 131 students, most first and second-year students agreed that physicians should know about nutritional issues in cardiovascular disease (99%), type 2 diabetes (94%), celiac disease (96%), and renal impairment (93%). However, most lacked confidence in their ability to demonstrate such knowledge with patients' individual medical conditions (1st year 26% and 2nd year 41%).

Third and fourth-year students had much higher confidence about their ability to demonstrate their nutritional knowledge in patients' individual medical conditions (3rd year 26% and 4th year 81%). Results showed that the majority of third and fourth-year students (>80%) had confidence in the dietary management of type 2 diabetes, cardiovascular disease, and coeliac disease. However, only 43% of third and fourth-year students felt confident in assessing a patients' nutrition habits and needs. This study demonstrated that as medical school students continued their studies, they became more confident in their confidence in demonstrating nutritional knowledge in individual medical conditions that had a direct correlation with diet as a form of treatment (type 2 diabetes, cardiovascular disease, and coeliac disease).

Kozhakhmetova et al. (2022) conducted a study to assess physicians' awareness of CeD in the Republic of Kazakhstan. The quantitative study was based on the international standards for CeD. 232 Kazakhstani physicians completed an online survey that assessed their knowledge about the etiology of CeD, its symptoms, diagnosis, and treatment, and inquired about their desire to know more about the disease. Results of the study revealed that most primary care physicians (63; 58.9%) had poor knowledge of CeD, and only nine physicians (8.4 %) had a good knowledge of the disease with females having a greater awareness of the disease than males ($p = 0.006$). Older physicians (50+) had the highest awareness of CeD ($p = 0.02$) followed by those under 30 years of age ($p = 0.138$) which the authors attributed to the experience of older physicians and latest medical knowledge for the younger. Unfortunately, the senior doctors were the least aware of the atypical or asymptomatic versions of CeD (the most prevalent), which was attributed to old medical knowledge.

There were also variances among physicians in their choice of a "gold standard" test for CeD. Most physicians surveyed chose to test for CeD using a gastroduodenoscopy with small intestinal biopsy (25.8%) while others, 20.5% chose a blood test for transglutaminase (TGA), a coeliac-specific antibody, followed by genotyping (20.5%). Regarding treatment of CeD, most physicians concurred that a gluten free diet (GFD) was the only pathogenic treatment (75%). However, the remaining 25% were ineffectively treating the disease by recommending a gluten-free diet temporarily, or only a dairy-free diet, or *H. pylori* (a bacteria found in the stomach) eradication therapy.

Theme 3: Educational Needs of Celiac (Coeliac) Patients

The third theme was the educational needs of celiac (coeliac) patients. Adult learning theories were not mentioned within these studies, but learning was assessed in the context of the needs of the patients, or the length of time to learn certain skills. However, the method and theory of *how* patients learned was not addressed.

According to Clerx et al.'s (2019) study of the acquirement of self-management skills for following a gluten free diet, individuals diagnosed with CeD must learn a variety of skills to safely manage living in a gluten free world. Because the timeline for learning how to live with CeD was unknown, Clerx et al. studied 137 adults (79% female, 21% male) with CeD to understand the process individuals go through to self-manage their disease. The research showed that participants gained self-management skills from learning that occurred over a hierarchical progression of four stages of time. The stages were considered hierarchical as they correlated with the individuals' (1) initial skills of learning how to navigate life at home (six months), followed by (2) social settings that required additional education or support (one to two years), (3) their workplace (three to four years), and (4) venturing out in unfamiliar settings (e.g. travel, five-plus years) (Clerx et al., 2019).

Langarizadeh et al.'s (2023) study sought to determine the educational priorities of patients living with CeD so that a minimum baseline set of data could be established. The study was conducted in two phases. The first phase in 2022 consisted of a literature review that identified categories and subcategories of educational needs of individuals living with CeD. In the second phase, a 105-item questionnaire was designed to cover nine topics such as demographic information, long-term complications, tests, dietary recommendations, and so forth. The questionnaire was distributed to twelve medical specialists in nutrition (*n* = 5), internal medicine (*n* = 4), and gastroenterology (*n* = 3) who ranked the importance and necessity of each item according to their own specialty. While this study provided an overview of the educational priorities found in the literature, there was no insurance of the validity of the data that was gathered and how it was gathered. The review considered all types of patients within the literature but did not specifically seek out patients from the country in which the chosen specialists worked (Iran), omitting a very relevant audience. In addition, the inclusion of socioeconomic information would have made the data more relevant.

Both the Clerx et al. (2019) and Langarizadeh et al. (2023) studies attempted to identify important information about individuals' self-management of CeD. While this information was pertinent to the future development of learning and support materials for celiac patients, the consideration of adult learning would have enhanced their findings by providing specific theories and methods that worked best with adult patients.

Garnweidener-Holme et al.'s (2020) social ecological study about individuals' experience and management of a gluten free diet addressed learning in the context of knowledge gathering. Twelve participants were interviewed in Norway about the challenges they experienced individually, interpersonally, in their community and with policies. It was found that obtaining knowledge about the gluten free diet took time, but the *how* of their learning was not addressed.

Taylor et al.'s (2013) study assessed how individuals lived with CeD and mentioned the term "learn" in the context of learning to read labels and how partners and friends were interested in "learning" about the disease. Results found that gaining more knowledge about the gluten free diet helped individuals cope with their disease and working with a dietitian who understood CeD provided extra support for them.

Discussion

In the studies that focused on group learning, none of the five referenced adult learning theory, or specified theories by name, but embraced the concepts of Bandura's Social Cognitive Theory (SCT). Even though SCT was not mentioned in these studies, each embraced the concept of learning within a group. From their investigations, researchers found that group-learning, especially for females, was an important aspect of learning that had a very positive impact on participants' ability to improve their knowledge and quality of life, especially psychological well-being, when self-managing their CeD. The interaction with others who had coeliac disease gave participants an overview of others' lives compared to their own lives and provided an opportunity for those having lived long-term with CeD to exchange the knowledge they had gleaned over time.

The importance of medical professionals having knowledge and understanding about the nuances and treatment of CeD, especially a gluten free diet, for a proper diagnosis was also a significant finding. The studies found that as medical school students continued their studies, they became more confident in demonstrating nutritional knowledge in individual medical conditions that utilized diet as a form of treatment. Unfortunately, there was a lack of confidence in assessing patients' nutritional habits. This was concerning because, as physicians, when there was a lack of such assessments, patients may not receive the diagnosis or treatment that led to better self-management of their health. There was also discrepancy among physicians about the "gold standard" of testing for CeD among physicians who differed in how extensive the testing should be. Physicians varied in their knowledge of treating coeliac disease, which again, could lead to patients not being properly diagnosed or treated.

Learning was used in the context of assessing the learning needs of patients and how long it took for them to learn to live with CeD. However, adult learning theory or methods were not utilized to explain *how* patients learned. Both Clerx et al. (2019) and Langarizadeh et al. (2023) studies attempted to identify important information about self-managing CeD. Clerx et al.'s study demonstrated the progression of learning of individuals in the self-management of their disease. Unfortunately, Clerx and associates missed the opportunity to ground their study in the literature of adult learning which provided a more substantial foundation for their work. Langarizadeh et al.'s (2023) study provided an overview of the educational priorities found in the literature; however, adult learning theory was not considered when assessing such priorities. In addition, the study was weakened as it did not take the opportunity to specifically seek out celiac patients from the country in which the study was conducted and did not include socioeconomic information that would have made the data more relevant.

The studies of Garnweidener-Holme et al.'s (2020) and Taylor et al.'s (2013) demonstrated researchers' lack of engagement with adult learning theory, as both studies addressed the "learning" that took place for individuals diagnosed with CeD. However, the learning addressed in the research was anecdotal in nature and does not incorporate the mental process or methodological "how" of adult learning theory.

These 11 studies demonstrated how adult learning theory concepts were omitted from the empirical literature of self-management of CeD. While the concept of learning was briefly mentioned, or utilized in “learning” about disease, empirical studies should have been grounded in adult learning theory as it serves as a means of reliability and validity for those in the health professions and provided an empirical basis for putting such research into practice. In addition, learning theory deepened and broadened the understanding of medical professionals as they partnered with individuals learning to live with the lifelong disease of celiac.

Experiential Learning Theory (ELT)

Because individuals diagnosed with celiac disease live with their disease for a lifetime, understanding how these experiences lead to learning to self-manage disease could benefit patients, medical and health care professionals, and enhance research in learning and patient self-management. These lived experiences and individual’s experiential knowledge “are closely interlinked, as the illness experiences were the basis upon which experiential knowledge was formed” (Jones et al., 2021, p. 562). Over time these individuals become experts at living with their illness as they learn to problem-solve and share their experiential knowledge with others in the hope of influencing systems of healthcare and education. The goal is to provide more holistic care, enriched learning, and greater understanding for improving patient self-management and quality of life. Therefore, for this study, experiential learning was chosen as the theoretical framework for providing an understanding of the role such learning played in the self-management of celiac disease.

Background

Experiential learning theory (ELT) was traced back to John Dewey (1859-1952), a major philosopher in education who proposed that learning was actively social. Learners reconciled changes that occurred within their regular world. Dewey believed that individuals did not do this learning alone, but through society and “its use of language and other artifacts” including engaging with “members of a discourse community to ‘carve out’ the world in similar ways” (Prawat and Floden, 1994, p. 44). According to Prawat and Floden (1994), Dewey’s philosophy was that knowledge was a relation of multiple things and could become complex, and with that complexity, meanings of things changed and grew accordingly, as learners reflected on new knowledge and applied it to their existing schema to create learning.

To learn from experience, Dewey (1938) believed there were two principles: continuity and interaction. According to Dewey (1938), “continuity of experience means that every experience both takes up something from those which have gone before and modifies in some way the quality of those which come after” (p. 27). This indicated that learning experiences were not just isolated events of time, but instead learners connected their current learning experiences with those of the past while seeing possible future implications for what they had learned (Merriam and Baumgartner, 2020). Dewey’s (1938) second principle of interaction indicated that an experience was “always what it was because of a transaction taking place between an individual and what, at the time, constitutes his environment” (p. 41). As these two principles of continuity and interaction interconnected and worked together, they provided the basis for experiential learning (Merriam and Baumgartner, 2020).

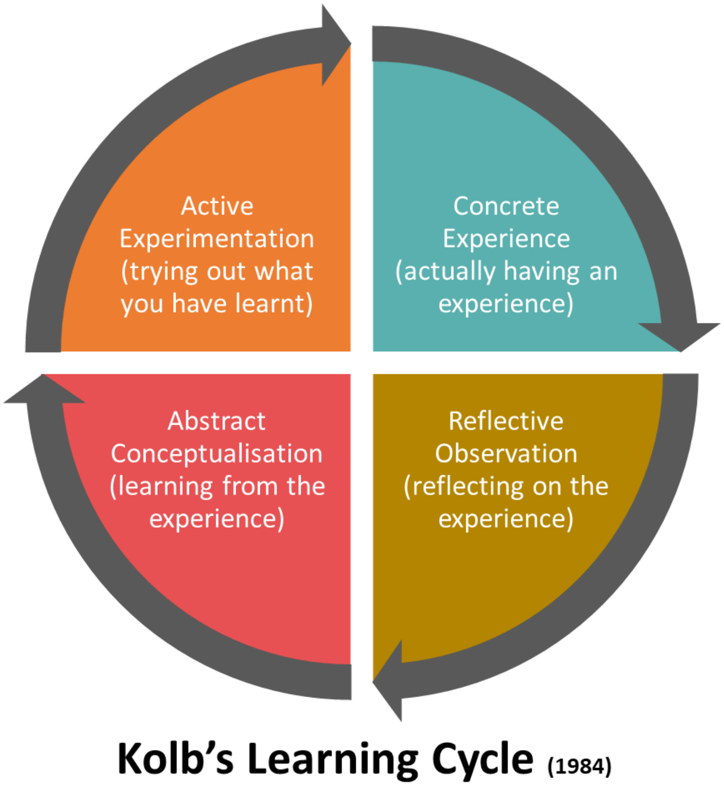
Kolb (1984) expanded on Dewey’s concept of experiential learning, adding, that “Learning was the process whereby knowledge was created through the transformation of experience” (p. 38). According to Kolb (1984), learners effectively engaged in and were effective learning experiences, as they went through a four-stage cycle of learning in which they possessed each of these four modes, or abilities:

- Able to fully involve themselves in new experiences (CE)
- Reflected and observed on the experience from many perspectives (RO)
- Created concepts and theories from the experience (AC), and
- Used these theories to make decisions and solve problems (AE) (Kolb, 1984).

Kolb believed that these concepts occurred cyclically and began with a concrete experience that was reflected on and analyzed so the concepts were learned and put into practice in the final phase, at which time they became a new set of concrete experiences on which to base new learning (Merriam and Baumgartner, 2020). To his theory of learning through experience, Kolb added four learning styles diverging, assimilating, converging, and accommodating, of which one would be an individual’s preferred method of learning.

Figure 2.3

Kolb's Experiential Learning Theory Model



Note: Kolb's Four Stages of Learning. From: [Kolbs-Learning-Cycle.png (1334×985) (inspiring.uk.com)]

Other theorists such as Tennant and Pogson (1995) built on Kolb's model and demonstrated how experience was a resource for learning by incorporating such experience into instruction: (1) prior experience (reflected upon and linked to new learning); (2) current experience (learning was connected to current experiences as a family member, worker, etc.); (3) new experience (created through instructional techniques such as simulation or internship); and (4) learning from experience (critical examination of prior experience) (Merriam and Bierema, 2014). However, Jarvis (1987) criticized Kolb's omission of context, recognizing "that the person brings his or her biography into the situation" (Merriam and Baumgartner, 2014, p. 203).

Boud and Walker (1991) approached context by indicating that “specific contexts shape an individual’s experience in different ways” and desired to understand how “differences among individuals—particularly past histories, learning strategies, and emotion, influence the sort of learning developed through reflection on experience” (Fenwick, 2001, p. 11).

Finally, Jarvis (2001) believed there were two main types of learning from experiences. These were either non-reflective, in which individuals “remember an experience and repeat it, or just doing what we were told to do (Merriam and Baumgartner, 2020, p. 203); or reflective learning where individuals “plan, monitor, and reflect upon our experiences” (Jarvis, 2001, p. 52). These concepts stemmed from Donald Schön’s concepts of reflection-in-action and reflection-on-action.

Reflection and Experiential Learning

In Schön’s (1987) reflection-on-action, individuals reflected after an experience occurred and assessed what they had learned about the action and what of that learning could be included in another situation (Merriam and Bierema, 2014). According to Schön (1987), when learners reflected-in-action, the reflection “reshapes what we were doing while we were doing it (p.26)”, and this was “what distinguishes the more expert practitioner from the novice” (Merriam and Bierema, 2014, p. 116). Benjamins et al. (2022) stated that “the partnership of these two forms of reflection [on-action and in-action] help practitioners and learners investigate and develop new conceptions of practice to be considered and operationalized” (p. 165).

In Benjamins et al.’s (2022) study of experiential learning and reflective practice in music performance studies, participants “became invested in and even began to crave this reflective process, noting the ways in which it impacted their current states of being, as well as their futures” (p. 173). Benjamins et al (2022) found that participants “often became more cognizant of issues related to professional expectations" (p. 173) and "highlighted the importance of knowing others were struggling with similar challenges, vulnerabilities, and insecurities" (p. 174). Additionally, the literature demonstrated that individuals reflected about their lived experience when they participated in a mindfulness study and assessed how the experience may help them live with their chronic illness (Mathews and Anderson, 2021). Individuals who participated in the study (concrete experience), followed by reflection (reflective observation), learned from the experience that mindfulness brought about therapeutic improvement in the management of their disease (Mathews and Anderson, 2021).

Experiential Learning and Patient Expertise

Experiential learning was holistic in nature and involved the "integrated functioning of the total organism – thinking, feeling, perceiving and behaving" (Kolb, 1984, p. 3). As experiential learning was seen as an adaptive process, "it provides conceptual bridges across life situations…portraying learning as a continuous lifelong process" (Kolb, 1984, p. 33). Because individuals diagnosed with celiac disease learned to live with their lifelong illness, it was suitable that experiential learning served as a theoretical basis for explaining how individuals learned to do so. As a point of clarification, within the literature the terms *experiential learning* and *experiential knowledge* were used interchangeably even though *learning* was defined as "the act of obtaining knowledge" while *knowledge* was defined as "understanding of or information about a subject that you get by experience or study" (Cambridge Dictionary, n.d.).

According to the seminal work of Borkman (1976), "the two most important elements of experiential knowledge were (1) the type of "information" on which it was based and (2) one's attitude toward that information" (p. 446). Borkman (1976) believed that the type of information in which an individual engaged was "wisdom and know-how gained from personal participation in a phenomenon instead of isolated, unorganized bits of facts and feelings upon which a person has not reflected" (p. 447). Borkman believed this wisdom was common sense, concrete, and specific because it was based on the individual's own unique experience.

Borkman (1976) described the *attitude*, or conviction of the individual, as directly related to the individual's "faith in the validity and authority of the knowledge obtained by being a part of the phenomenon" (Borkman, 1976, p. 447). In other words, individuals gained wisdom and insight from engaging in experiences and believed these would become knowledge. As individuals gained "competence or skill in handling or resolving a problem through the use of one's own experience," (Borkman, 1976, p. 447) they gained experiential knowledge. Caron-Flinterman et al. (2005) added to Borkman's definition, stating, "Experiential knowledge arose when these experiences were converted, consciously or unconsciously, into personal insight that enabled a patient to cope with individual illness and disability" (p. 2575).

For patients, experiential knowledge emerged from information acquired from others or by developing an understanding about their own body or illness which helped with coping and living with their illness (Caron-Flinterman et al., 2005). According to Borkman (1976), "the degree to which an individual integrated the information and became competent in applying it to a problem varies" (p. 447). It was only after individuals "made repeated observations and experiences explicit and have reflected on them, can patients acquire some propositional experiential knowledge" (Caron-Flinterman et al., 2005, p. 2577). Castro et al. (2018) added that in experiential knowledge, as individuals moved from novice to expert, their problem-solving evolved from "abstract towards more 'intuitive' and 'holistic' problem-solving actions" (p. 319). As individuals became experts in living with their illness, their expertise became explicit and transferable to others at the micro (direct care), meso (organizational), macro (healthcare system), and meta (research/education) levels (Castro et al. 2018).

Experiential Knowledge versus Professional Knowledge

According to Borkman (1976) experiential knowledge was pragmatic, focused on here-and-now action, and holistic while professional knowledge was theoretical and scientific, focused on long-term, systematic development, and segmented. Professional knowledge differed from experiential knowledge in that professional knowledge was limited to only those individuals who had obtained essential credentials, specialized education, and formal training (Borkman, 1976; Castro et al., 2018). Unfortunately, experiential knowledge was not considered robust enough and was given less credence among professionals. It was neglected because it was "considered to be subjective and individualistic and therefore not evidence-based nor scientific;" however, professional knowledge "seldom considers 'life with a condition or disease,' (Castro et al., 2018, p. 318).

Nonetheless, in Popay and Williams' (1996) seminal work, they expressed that if public health desired to be more robust in its research and its explanation of the patterns that occurred in health and illness, "then it must be utilized and built on lay [experiential] knowledge – the meaning health, illness, disability, and risk hade for people" (p. 760). This belief was based on the need for health care systems to understand the burden of living with chronic illness and disability and the "problem of how to evaluate the effectiveness of interventions in terms of multi-dimensional outcomes, including the patient's own assessment" (Popay and Williams, 1996, p. 760).

While there were differences between experiential and professional knowledge and their perceived importance, Castro et al. (2018) claimed the two forms of knowledge could be combined to bridge the gap between the two, leading to “a new and more balanced distribution of knowledge which better meets the needs of patients with long-term diseases or disabilities” (p. 319). For example, combining clinical knowledge about celiac disease with patient lived experience would give doctors a broader understanding about the unique holistic needs of their patient, thus providing a springboard for the development of new methods of treatment. Although the combination of the two types of knowledge would benefit both the patient and the doctor, there were challenges due to the hierarchy of importance which were directly related to the validity of knowledge.

Validity of Experiential Knowledge

Even though patients had experiential knowledge that could help individuals, as well as the overall health care community, it was often dismissed by professionals as invalid or illegitimate. In some circumstances, this dismissal was done in the name of science or “scientism,” which, according to Popay and Williams (1996), gave the impression that knowledge was valid only if it were scientific. Castro et al. (2018) concurred that such experiential expertise was considered to be “subjective and individualistic and therefore not evidence-based nor scientific” (p. 318). Such assessments demonstrated that the hegemony of science led to discounting “certain forms of knowledge from taking part in scientific discussion” and “disempowered groups of people working outside the dominate paradigm from making contribution” (Popay and Williams, 1996).

According to Blume (2017), one’s experience was treated as worthy of being considered knowledge “only to the extent that it appears compatible with medical knowledge and assumptions” (p. 99). Halloy et al. (2023) assessed that an individual’s influence of knowledge and expertise in living with illness, which justified their involvement in care, research, and education, was “also what disqualified them from contributing effectively to the health system” (p. 408). In addition, Blume (2017) stated that experience was treated as authoritative, or worthy of being knowledge, “only to the extent that it appeared compatible with medical knowledge and assumptions” (p. 99). Therefore, according to Blume’s assessment, if patients with CeD shared a different perspective gained from their personal experience than what medical practitioners thought to be true, the personal lived experience would be considered less valid than those of the medical community.

Although challenges existed in how experiential knowledge was viewed, Castro et al. (2018) found positives in the relationship between experiential and professional expertise. Patient interviews stressed that while professionals approached their physical health from a “purely theoretical or medical point of view,” those with experiential knowledge had the “expertise to support people living with a chronic disease or disability in various areas of life” (p. 315). However, Blume (2017) found there was a positive relationship between doctors (professionals) and patients (experiential knowledge), stating the doctors “respect their insights and their judgements” (p. 99). However, the reason for this was that the patient understood not only their own lived experience, but had been infused with medical thinking, and therefore their knowledge was treated as authoritative, “only to the extent that it appears compatible with medical knowledge and assumptions” (Blume, 2017, p. 99). While these examples did not permit experiential knowledge and expertise to stand on their own merit, it was a win in that they were acknowledged as part of a patient’s process of self-care.

Experiential Learning Theory and Patient Self-Management

For this research, to understand how experiential learning and self-management were utilized for celiac disease, a review of empirical studies was conducted. Literature was obtained from CINAHL, EBSCO, MEDLINE, Gale, PubMed, Springer, and Google Scholar search engines for the years 2003-2023. The terms used for the search were a compilation of "celiac disease," "coeliac disease," "self-management or self management," "self-care or self care," "experiential learning," omitting the word "machine" to preclude machine learning. Surprisingly, the search yielded zero empirical studies from all platforms. To ensure there was not an error in research parameters, I ran the search for a second time, reentering the same terms and criteria. Again, the results were zero for each search engine. It was then that I chose to expand the scope of my search criteria and replaced "celiac disease" or "coeliac disease" with "chronic disease" or "chronic illness" or "long term conditions" or "chronic conditions." This yielded 73 articles that were assessed for duplicates, systematic reviews, and how "experiential learning" was utilized within the study. Of the 73 articles, only 10 utilized the terms "experiential" and/or "experiential learning" throughout the article. However, four of the articles briefly mentioned the topic of experiential learning (once or twice) and did not discuss how experiential learning had occurred. Instead, experiential learning was addressed as a phenomenon (e.g., mindfulness; theoretical underpinning that was not proven in the study; patient experience (an action they did) without learning; and integrating new knowledge into existing experience). The remaining six articles demonstrated how experiential learning was utilized in individual and student learning in health care and focused on the self-management of chronic disease. These were presented in Table 2.4.

Theme 1: Individual Learning for Self-Managing Chronic Illness

Lasco et al. (2022) assessed 71 semi-structured interviews and 40 digital diaries in their study of patients with hypertension who lived in the Philippines. The goal of the study was to examine how patients self-managed their hypertension through embodied experience and the knowledge that emerged. According to Lasco et al., patients "co-constructed hypertension through diagnosis," meaning, as patients' embodied experiences (symptoms) were labeled by medical professionals, they adopted practices to self-manage their disease. Bodily sensations were relied upon for diagnosis and subsequent treatment of their disease. These bodily experiences prompted a type of co-diagnosing. As doctors inquired patients about their symptoms, patients framed their medical histories through that lens, even using the same medical terms of the doctor that they had used before to describe their illness.

Through their experience, patients' symptoms caused them to sense their hypertension. Known as "symptomology," patients became dependent on their symptoms to indicate how they treated their hypertension. If they did not feel "high blood" (hypertension) through symptoms such as headache, blurry vision, etc. they did not consider themselves to have "high blood" at that time discontinued the use of medicine prescribed for disease maintenance. However, the inverse was also true. If patients had symptoms, they "self-medicated" accordingly and ignored the orders that were initially prescribed by their physician. Finally, symptoms prompted a lack in medical consultations as patients ignored regular visits because they did not feel "high blood," and had the feeling the disease was no longer present.

Leyva-Moral et al. (2021) studied how experiential learning influenced the adherence to antiretroviral (ART) therapy for HIV patients who lived in northern Peru. Unstructured interviews were conducted with 18 participants (11 men, 7 women) at the regional hospital HIV unit where more than half of their 250 patients were non-adherent to taking ART. It was determined that "staying alive" was the core category of the interviews which represented the participants' adherence to ART as their life source. According to Leyva-Moral et al. (2021), "Appreciating ART as a life source requires experiential learning rather than obeying medical orders" (p. 7). As patients lived with HIV, they better understood it to be a chronic disease with the help of their medical team and significant people in their lives. Also, when patient's relationships with their medical team were positive and supportive, there was more adherence to ART. Individuals experientially developed their own strategies for self-care and changed habits of diet, exercise, alcohol consumption, drug intake, sex, and treatment adherence. Based on the results of this study, adherence to ART was not a spontaneous outcome, but instead a gradual transition through experiential learning.

Consumer health organizations (CHOs) (e.g., American Heart Association, American Cancer Society, Beyond Celiac) were organizations outside of the mainstream health care system that focused on supporting individuals in the self-management of their disease. Sav et al. (2014) desired to understand why some individuals do and others do not access CHOs. The study consisted of 97 participants in four regions of Australia and utilized in-depth, semi-structured interviews which assessed benefits and barriers to participation. Three themes were determined for the involvement in CHOs: knowledge and information, connection and support, and experiential learning. Individuals shared that through knowledge and information, they gained confidence in their ability to cope with and self-manage their disease. They also gained emotional, practical, and financial support and connection. These were important, especially for those who lacked a support system.

For others, CHOs provided a means for experiential learning with others. Individuals who openly discussed their experience found comfort and relief. By interacting with others, members were "experts in their illness, enabling them to engage in more constructive discussions with their healthcare providers" (Sav et al., 2014, p. 424). Lack of involvement in CHOs was determined to be due to limited access pathways where medical (e.g., GI doctors) and health care providers (e.g., diabetes educators) were more developed than a general practitioner who gave minimal or no encouragement to join. Also, some individuals believed that CHOs could not provide further assistance, or believed they were already experts due to self-managing their own health and found sharing with those with similar conditions depressing or a sign of weakness.

Theme Two: Student Learning in Health Care

Nursing students simultaneously engaged in experiential learning while providing care at a free clinic. An intervention utilized the chronic care model (CCM) and was implemented for 19 medically underserved, chronically ill patients from San Diego County with the goal to improve their care and overall patient outcomes (Saude, et al., 2020). While the primary focus of the study was to improve the care of underserved patients, there was the byproduct of experiential learning for nursing students who engaged in patient care. The experience of the students provided "experiential learning in delivering complex care to a vulnerable population" (Saude et al., 2020, p. 5) as their care of patients improved patient outcomes.

Mann et al.'s (2009) study implemented the "Seamless Care" model to develop medical students' interprofessional patient-centered collaborative skills through experiential learning. While working together at Queen Elizabeth II Health Science Center, teams of five interprofessional students from the fields of dental hygiene, dentistry, nursing, medicine, and pharmacy (*n* = 62) utilized the "Seamless Care" model to develop their patient-centered collaborative skills. Through small-group collaborations, which involved solving relevant problems, experiential learning occurred that induced a sense of self-efficacy and skill acquisition, which provided an opportunity for reflection about the content and process of the team's work and their own individual experiences.

Brand et al. (2015) evaluated the outcomes and experiences of medical students' (*n* = 60) who received palliative care instruction. The primary goal of the study was to provide insight into student learning outcomes and experiences that demonstrated their reactions and changes in knowledge/outcomes based on the teaching they received in palliative care. The students were asked to complete a multiple-choice pre- and post-knowledge test with validated attitudinal scales (*n* = 40), a student feedback survey (*n* =28), and two 45-minute focus groups (*n* = 6). Students participated in lectures, problem-based learning sessions, bedside/clinic tutorials, hospice center visits, and readings. Results from the pre- and post-tests found no significant improvement in the mean score of the student knowledge scores (pre-test: 11.9/20; post-test: 12.9/20). However, there was a statistically significant improvement in the score for helping patients manage symptoms (p=0.001).

Pre- and post-attitude tests indicated improvement in student attitudes toward communication, patient symptom management, and multidisciplinary team care (2-tailed significance 0.000). However, in individual subsets of attitudinal items, those that did not indicate significant change were talking to relatives of terminal patients (*p* = .0607) and discussing death with patient (*p* = .0619) correlated with specific areas where there was a lack of experiential learning. For instance, not having hands on experience in engaging with patients' families at the hospice unit affected students' ability to talk with family members of terminal patients. It was also noted that as experiential learning included reflection, which participating medical students did not receive from supervising medical staff/doctors, they turned to close others for support.

Table 2.5

Chronic Disease and Experiential Learning

Study	Study purpose	Population	Location	Experiential learning
		Individual Learning		
Lasco et al. (2022)	How experiential knowledge influenced the self-mgt. of hypertension	Patients (*n* = 40); 71 semi-structured interviews (40 initial 31 follow-up); 40 digital diaries	Low-income areas in Philippines	Patients relied on their own embodied experiences to define disease and self-care
Leyva-Moral (2021)	Develop a theory about the meaning of ART adherence from the experiences of patients	Patients (*n* = 18)	Northern Petru regional hospital	Experiential learning helped patients view ART as a life source which affected self-care
Sav et al. (2014)	Explored benefits of CHOs in self-mgt. and barriers that inhibit access of the chronically ill	Individuals with chronic illness (*n* = 97)	Four regions of Australia	Engaging w/others in experiential learning brought comfort, relief and became patient expert
		Student Learning in Health Care		
Saude et al. (2020)	Nursing students applied the chronic care model to improve self-mgt. in underserved population.	Patients (*n* = 19) in underserved population.	Student-run free clinic	By-product of actual study. Students gained medical experience from patient engagement.
Mann et al. (2009)	Developed inter-professional students' collaborative skills through the "Seamless Care" model	Medical students (*n* = 62) in teams of five (dental hygiene, dentistry, nursing, medicine, and pharmacy).	Queen Elizabeth II Health Science Center	Students engaged in experiential learning by gaining patient experience and through problem solving w/in their group
Brand et al. (2015)	Assessed outcomes and experiences of medical students w/in a palliative care education program	Medical students (*n* = 40)	Westmead Clinical School, Sydney AU	Students experienced lack of experiential learning/desired to engage more with doctors and patients

Discussion

In the review of the literature about the role of experiential learning in the self-management of chronic disease, two primary themes were found: (1) strategy development for living with the disease, and (2) reassurance and confidence. Strategies for self-managing chronic disease were developed in both Lasco et al.'s (2022) and Leyva-Moral et al.'s (2021) studies. In Lasco's (2022) study of hypertension, individuals' experiential learning informed the strategies they chose (e.g., identifying symptoms, adhering to medication, and doctor's visits) for the self-management of their disease. Similarly, Leyva-Moral et al. (2021) found that as individuals with HIV learned experientially about their disease, they saw ART as a life source. This, combined with the development of positive relationships with their medical team, helped promote their development of self-care that included lifestyle changes and treatment (ARV) adherence.

Individuals gained reassurance and developed confidence (self-efficacy) through experiential learning. As individuals utilized consumer health organization's (CHOs) to participate with others who shared their disease, they participated in experiential learning (Sav et al., 2014). Through this interaction, individuals found comfort and relief and became "experts," which gave them more confidence to engage with their own health care provider.

Future health care professionals developed on-the-job learning skills. In Saude et al.'s (2020) study, nursing students learned how to deliver care to underserved patients. Mann et al.'s (2009) interprofessional students learned how to collaborate with other future health care professionals which gave them not only skill acquisition, but a sense of self-efficacy.

Finally, an interesting theme came from Brand et al.'s (2015) study of students who engaged in learning how to give palliative care: the *lack* of experiential learning. While students improved in their attitudes for communicating and helping palliative patients manage their symptoms, there was a direct correlation with students' lack of attitude change and a lack of opportunity to participate in experiences with terminal patients and their families. For instance, discussing death with a patient was difficult due to a lack of opportunity to do so, this demonstrated that attitudes were changed if students had the opportunity to engage with the subject matter in an experiential nature.

These studies demonstrated the influence that experiential learning had on learning to self-manage one's disease. It also provided a platform for training medical professionals in how to help and support patients in their self-management. These studies demonstrated that experiential learning provided positive opportunities for individuals to learn how to self-manage chronic illness while obtaining comfort, relief, and self-efficacy about their skills to do so.

Empirical Gap

In comparing studies for how experiential learning was utilized in in the self-management of celiac disease, it was apparent there was a dearth of studies that utilized such learning in its management. Therefore, a gap was determined that demonstrated a need for additional study about the role of experiential learning in the self-management of CeD. To address this gap, this study examined the lived experience of individuals who self-manage their CeD, and the role experiential learning played in this experience.

Chapter Summary

This chapter gave an overview of chronic disease, celiac disease, and patient self-management. Several approaches to self-management were discussed in the context of chronic disease and celiac disease that included various care models such as the chronic care model (CCM). Empirical studies in which adult learning was utilized in the self-management of celiac disease were assessed and the theoretical framework of experiential learning was explained that demonstrated its relevance as a framework for this study. There were no studies to explain how experiential learning was utilized in self-managing celiac disease, therefore a review of the literature was conducted that utilized experiential learning in the self-management of chronic disease. Because of the dearth of research that existed about the role experiential learning played in the self-management of celiac disease, a gap was determined. This laid the foundation for the proposed research methodology in chapter three, the research implementation in chapter four, and its data findings in chapter five.

Chapter 3: Methodology

Purpose of the Study

The purpose of this qualitative study was to examine the lived experience of individuals' self-management of celiac disease and the role experiential learning played in that lived experience.

The research question guiding this study is:

1. What is the lived experience of individuals' self-management of celiac disease and what role did experiential learning play in that lived experience?

This chapter discusses the influence of constructivist theory on qualitative research to be conducted and how the critical incident technique was used to obtain rich narrative data from the selected sample of participants. Also included are the methods of data collection, how data was analyzed, and criteria that were met for the research to be considered relative and trustworthy.

Design of the Study

This research design for this study was based on the theoretical concept of constructivist research theory. Constructivism was based on the ontological assumption that "social reality was constructed by the individuals who participate in it" (Gall, Gall & Borg, 2007, p. 21). Social phenomena and their meanings were constructed by individuals who created meaning based on their social reality. This social reality was influenced by the individual's environment, social interactions, and cultural influence. What may be good or bad, right, or wrong were constructed based on the individual's interpretation and the meanings they gave to such concepts. Therefore, meanings were not objectively definitive and independent of the individual, but instead, were dependent on the individual's constant revision of new knowledge and new learning (Scales

2013; Schcolnik et al., 2006). Because this study sought to understand the nature of experiential learning that occurred in the lived, social experience of individuals with CeD, a constructivist theoretical framework allowed for each participant to bring their own social reality and meaning making about their experience into this research.

An important aspect of constructivism's epistemology (theory of knowledge) was its values. "Epistemology contains values in that it is normative" and "is the basis for explaining the rightness or wrongness, the admissibility or inadmissibility, of types of knowledge and sources of justification of that knowledge" (Carter & Little, 2007, p. 1322). In constructivism, the assumption was that individuals evaluated knowledge according to their internal values and made the choice of whether to include that knowledge in their learning schema, or stored memories, knowledge, etc. According to Antlova et al., (2015), "As we get to know and evaluate the world, we construct the system of our knowledge together with our preferences and values" and values "become the important motives for our decision making" (p. 215). As the world changed, an individual reassesses their values, accordingly, choosing what was important, and finds motivation to construct new knowledge to accommodate such a change.

Qualitative Research

Constructivist researchers "focus their investigations on the study of individual cases and by making 'thick' verbal descriptions of what they observe" (Gall et al., 2007, p. 27). According to Gall (2007), "Qualitative research was more flexible with respect to sampling techniques" and allowed "researchers to modify their research approach as data was collected" (p. 177). When utilizing qualitative methods, constructivist researchers considered the assumption that an individual's learning was an adaptable process where knowledge was formed as building blocks, building on top of other previously constructed learning. As researchers obtained data, they “found a way to get individuals to reveal their constructions of social reality” (Gall et al., 2007, p. 23), and for doing so, qualitative methods were the best choice for researching this topic.

Qualitative methods allowed individuals to share their personal values, schemas, and prior knowledge in open formats such as interviews or focus groups. Because constructivist researchers “assumed that people developed interpretations of the social environment that affects their subsequent actions” (Gall et al., 2007, p. 29), utilizing qualitative methods of data collection in this research, such as interviews, focus groups, and open-ended questions, best demonstrated a celiac individual’s personal reflections about the learning that occurred in their lived social experience and self-management. According to Patton (2015), qualitative methods allowed the researcher to inquire about selected issues “in great depth with careful attention to detail, context, and nuance” (p. 227) and were not constrained by predetermined categories. Because of this freedom, the researcher had the opportunity to obtain a deeper understanding of the learning that occurred for individuals and how it influenced the self-management of their condition.

Methodology

In selecting the methodology for this research study, the primary purpose of the study was considered. The primary purpose was to examine the lived experience of individuals’ self-management of celiac disease, and the role experiential learning played in that lived experience. To understand the learning that occurred for such individuals, the critical incident technique was utilized to recount stories of past and present experiences, allowing for all embedded meanings to emerge from the narratives.

Critical Incident Technique

Critical Incident Technique (CIT) was a qualitative research method that contained a set of procedures that were utilized to collect direct observations of human behavior incidents that had special significance and could be used to solve problems and develop psychological principles (Flanagan, 1954). According to Flanagan (1954), an incident was “any observable human activity that in itself allowed for inferences and predictions to be made about the person performing the activity” (p. 327). For such an incident to be considered critical, it made a “’significant’ contribution, either positively or negatively, to the general aim of the activity,” and what deemed the incident as significant “depended on the nature of the activity” (p. 338).

The development of CIT began as a task analysis tool utilized by psychologist John Flanagan for multiple studies in the Aviation Psychology Program of the United States Army Air Forces during World War II. The goal of these early studies was to develop procedures for selecting and classifying aircrews (Flanagan, 1954). Flanagan conducted multiple quantifiable studies such as analyzing why potential pilots failed learning to fly and reasons for failures in bombing missions. As research continued for Flanagan (1954), the methods became more systematic in an effort to “obtain first-hand reports, or reports from objective records, of satisfactory and unsatisfactory execution of the task assigned” (p. 329). Large-scale studies were conducted about the tasks in the United States Army Air Forces, specifically related to combat leadership, which gathered both effective and ineffective behavior activity with several thousand incidents being collected and given descriptive categories called ‘critical requirements’ of combat leadership.

Post-WWII, Flanagan joined several of his colleagues in developing the American Institute for Research (AIR). This nonprofit scientific and educational organization aimed to study human behavior through an extension of the systematic research principles developed while at the Aviation Psychology Program. This extension became known as the Critical Incident Technique (CIT) method. This method of research contained five primary steps: establish the aims, or objective, of the activity; identify plans and specifications; collect data; analyze the data; and interpret and report the findings (Flanagan, 1954).

CIT as Qualitative Research

As a researcher, Flanagan (1954) emphasized that CIT “does not consist of a single rigid set of rules governing such data collection” and “should be thought of as a flexible set of principles which must be modified and adapted to meet the situation at hand” (p. 335). Because of this flexibility, during Flanagan’s tenure at the AIR, CIT was utilized in many different fields for various research such as selecting personnel, training, creating operating procedures and determining leadership attitude. As it grew, it was utilized in multiple disciplines such as counseling, education, social work, and organizational learning (Butterfield et al, 2005; Butterfield, 2009).

As CIT evolved through the years, it theoretically moved away from its prior positivist nature of being grounded in behavioral-oriented, quantitative research to a more constructivist, qualitative approach that focused on actions, thoughts, and cognitions with participants determining which experienced incidents were critical (Butterfield et al., 2005; McConnell, 2013; Watkins et al., 2022). According to Butterfield et al. (2005), Flanagan’s description of CIT fits Creswell’s definition of qualitative research in that CIT “took place in a natural setting; the researcher was the key instrument of data collection; data were collected as words through interviewing, participant observation, and/or qualitative open-ended questions; data analysis was done inductively; and the focus was on participants’ perspectives” (p. 482).

Creswell added that each form of qualitative research had distinctive features in five major qualitative traditions: “Focus, origin, data-collection methods, data analysis, and narrative forms” (Butterfield et al., 2005, p. 483). Butterfield et al. (2005) agreed that the CIT model aligned with Creswell’s five dimensions which distinguished it from other qualitative methods. This included CIT’s *focus* as the critical events or incidents of a specific situation; its *origin* from industrial/organizational psychology and *data-collection* obtained primarily through interviews; while *data analysis* determined the frame of reference and emerging specific/general categories; and finally, CIT’s *narrative form*, were categories that had operational definitions and descriptive titles which were “necessary in order to be true to the method” (p. 483).

Although CIT had a very flexible set of principles that could be modified and adapted as the situation changed, Woolsey (1986) defined two basic principles of CIT as 1) factual reports of behavior were desired over opinions/general impressions and 2) only behaviors that made a significant contribution to the research should be included. When deciding which incidents to include, Flanagan (1956) stated that only simple judgments were required of the observer and those incidents that were included should meet the purpose of the activity.

Why Critical Incident Technique (CIT) For This Study?

Initially, CIT was utilized to obtain firsthand reports, or reports from objective records about how satisfactory or unsatisfactory a task was performed (Flanagan, 1956). However, since its inception, CIT expanded to health services research where it “was used to understand an activity, behavior, or experience…rather than what *helped* or *hindered* in undertaking that experience or activity” (Viergever, 2019). Because of this CIT was appropriate for this study as the goal was to understand the educative experience of individuals with CeD.

CIT was utilized to study a wide range of occurrences such as relationships, perceptions, decision-making, vocational choice, and group processes (Woolsey, 1986; Butterfield et al., 2005) over a long-time frame, allowing researchers to inquire about past events (Rosala, 2020; Christian, 2021). Being able to capture incidents over a period of time was beneficial to this research, as the participants to be interviewed were diagnosed with CeD for at least three years, and therein, accessed incidents of their past.

CIT was a flexible methodology that provided an opportunity for this study's participants to critically reflect on their lived experiences with CeD and share what type of learning transpired and the meanings that were made. To understand such lived experiences, CIT was known for its thick, information-rich data obtained through interviews that provided a means to record experienced behavior instead of focusing on anecdotal experiences based on opinion or hunch. Results from this type of data can be utilized by not only lay people who experienced the event, but for those in health professions (health coaches, medical doctors, and other healthcare personnel) who can utilize such facts to develop patient interventions.

CIT provided the opportunity to consider the respondent's personal perspective (Watkins et al., 2022). This was important to this research because the symptoms of CeD varied with each diagnosed individual, and CIT allowed for distinct, varying responses to be obtained. In addition, because CeD was not promoted as a common chronic disease in the United States (CDC.gov; CMS.gov), this research method was a good fit for this study as it provided a means to capture information about rare or uncommon events, and emphasized issues such as learning, meaning making, and identity development (Rosala, 2020; Christian, 2021).

As previously discussed, Flanagan's (1954) original version of CIT was enhanced throughout the years. One enhancement that was beneficial to this study was adding context, reasoning, and meanings to the incidents that were obtained (Watkins et al. 2022). Because the CIT method began with a question that encouraged participants to recall and reflect on past incidents that were deemed critical to them, it provided a means for understanding how meaning and learning developed over time. This afforded the individual a means for deeper involvement in the research process as the individual was the one to "unpack the meaning of the incident and to say what it was about the incident that made it meaningful to them" (Watkins et al., 2022, p. 723).

How meaning was made was of interest in this study because of its application to both an individual's learning and their social reality. Meanings of social phenomena, such as chronic disease diagnosis, were constructed by individuals based on their social reality. One's social reality was influenced by the individual's environment (context), social interactions, and cultural influences. What may be good or bad, right, or wrong was constructed based on the individual's interpretation (reasoning) and the meanings they gave to such concepts. Therefore, meanings were not objectively definitive and independent of the individual, but instead, were dependent on the individual's constant revision of new knowledge and new learning (Scales 2013; Schcolnik, Kol, & Abarbanel, 2006). This was an integral part of understanding how adult learning influenced one's ability to self-manage their chronic medical condition as individuals experienced "an empowered sense of self, a critical understanding of how one's social relations and culture shaped one's beliefs and feelings, and strategies for taking action" (Dubouloz et al., 2010a, p. 605).

Five Steps of CIT

The CIT methodology consisted of five steps and began with the first step of determining the aim of the activity. Once the type of study and research questions were chosen, the aim or objective of the activity, and what was to be accomplished by the persons participating was determined (Flanagan, 1954; Woolsey, 1986; and Butterfield, 2009). This provided the criteria for judging if the activity was successful and should be worded clearly and simply, choosing everyday language that communicated with little misinterpretation (e.g., appreciation, efficiency, development, etc.) (Flanagan, 1954; Woolsey, 1986). For this study, the objective was to obtain data, or individuals' stories about their lived social experience with CeD and the experiential learning that occurred from such experiences that influenced their ability to self-manage their health.

Step two of CIT was to set plans and criteria for the research. It was within this stage that many research decisions were made. The person(s), situation to be observed, and observers who were familiar with the situation and its relevancy were selected (Flanagan, 1954; Woolsey, 1986; Fitzgerald, 2008; Butterfield et al., 2009). Flanagan suggested that incidents of extreme behavior were more easily identified than those that were average and should be recorded as "critical incidents," thus defining an incident as critical if it "made a 'significant' contribution either positive or negative to the general aim of the activity" (p. 338). Instructions were to be as specific as possible and included the protocols to be used for evaluating and classifying the observed behavior (Flanagan, 1954; Butterfield et al., 2009). Also, during this step, participants were identified, including how they were obtained and the characteristics they had. Step two was detailed in this chapter in the section of Sample Selection.

After the plans and criteria were developed, data was collected in step three. This collection was primarily through interviews that utilized questions that “indicated exactly the kinds of incidents desired, or the data would have been diffused and difficult to categorize” (Woolsey, 1984, p. 248). To this, Flanagan (1954) added group interviews, mailed questionnaires, and written records. Interviewers asked the same questions of all participants, with the primary task being to “elicit sufficient data that the full story was clear and illustrates the incident” (Watkins et al., 2022, p.713). Observations were evaluated, classified, and recorded while the facts were still fresh to the observer (Butterfield.2009), as the more “full and precise details were given, the report was assumed to be accurate” (Fitzgerald, 2008, p. 301). In this chapter, step three was detailed under the section heading of Data Collection.

For step four, researchers analyzed the critical incident data. Many scholars found challenges and frustrations with this step of CIT (Woolsey, 1986; Watkins et al., 2022). After data was transcribed, it was reduced in analysis by extracting, and then categorizing the extracted elements to the level of specificity of the study’s aim, followed by a report of the findings (Flanagan, 1954; Woolsey, 1986; Butterfield, 2009; Watkins et al., 2022). According to Flanagan (1954), the goal of analyzing data was to “increase the usefulness of the data while sacrificing as little as possible of their comprehensiveness, specificity, and validity” (p. 345). To categorize data, a frame of reference was established as to how the data would be utilized, followed by inductive reasoning to subjectively separate incidents into groups based on context of the aim. The remaining steps of analyzing data and interpreting the data/reporting findings are detailed in the final two chapters, Chapter Four – Analysis and Chapter Five – Findings.

In the fifth and final step, data was interpreted, and the findings were reported. Flanagan (1954) posited that errors of CIT “were not made in the collection and analysis of the data, but in the failure to interpret them properly" (p. 346). As the data was interpreted, if there was a difference noted between the currently identified aim and the one originally intended, or if the individual being observed was not representative of the study, these issues were described as limitations in the findings. The amount of information that was provided in the report depended on its purpose and simplicity, brevity, and clarity which were essential as titles were developed for the data (Woolsey, 1986). All findings were reported transparently and clearly and included the limitations and values of the results (Flanagan, 1954; Woolsey, 1986; and Fitzgerald, 2008). According to Flanagan (1985), as judgements were made about such things, "the original investigator was best prepared to make the necessary evaluations" (p. 347).

Sample Selection

When designing a qualitative research study, one considers what type of method will be used to obtain their sample. According to Patton (2015), qualitative inquiry "typically focused on small samples…selected purposely" which allowed for "information-rich cases for study in depth" (p. 230) that were pertinent to the purpose of the study. Selecting such an information-rich sample produced greater insights and a deeper understanding of the subject to be studied (Patton, 2015). Woosley (1984) and Watkins et al. (2022) concurred with Patton and recommended that when a sample was obtained for critical incident research, the sample should be purposefully identified to ensure the participants had the characteristics to which the study would be generalized (Woolsey, 1984; Watkins et al., 2022). According to Woolsey (1986), because CIT was descriptive and exploratory and did not provide quantitative comparisons, it was more important that the selected participants possessed only *some* of the salient characteristics, rather than have a sample that represented *all* aspects. For example, not all participants had the same age, sex, or diagnosis story.

For this study, the sample was selected from the patient database of Beyond Celiac, a nonprofit organization located within the United States that funds research, advocates for, and supports members and others affected by celiac disease. Beyond Celiac had a well-established online presence and provided individuals living with CeD with online and in-person support for living with their disease and played a central role in promoting and developing empirical research about CeD. Beyond Celiac's members were national and international individuals who were males and females, had various ages, and had lived with CeD from one day to several decades. It is from these memberships that I obtained my sample.

Participants

Prior to obtaining a sample of participants, I, as the researcher, developed a relationship with the appropriate leadership from aforementioned gluten free organizations (e.g., executive directors, director of research) with the hope of obtaining participants for this study. One organization, Beyond Celiac, chose to partner with me in my research and approved my solicitation of their members for participation in this study. Beyond Celiac agreed to send an email to their members who met the participant criteria inquiring of their interest in participating. The email was written by me with the assistance of two of my committee members from the University of Georgia (UGA) my major advisor, Dr. Laura Bierema, and the study's methodologist, Dr. Karen Watkins. The email included information about the required criteria for participating, the objective of participating in the study (to understand the experiential learning that occurred after a diagnosis of CeD) and what would be accomplished by participating (better health care support in patient self-management). Upon Beyond Celiac's approval of the contents, the email was forwarded to their members who met the sample criteria.

Criterion sampling was used to “review and study all cases that meet a predetermined criterion of importance” (Patton, 2015, p. 238). By utilizing qualitative methods for obtaining data, individuals shared their personal values, schemas, and prior knowledge in open format interviews and informed about the experience of receiving a life-changing diagnosis. Participants needed to meet the following criteria:

1. Be an adult over the age of 18, as the Institutional Review Board (IRB) considers individuals over the age of 18 to be adults.
2. Formally diagnosed by a medical practitioner through either a blood serum test, an endoscopy procedure to ascertain flattening of duodenum villi, or both.
3. Lived with celiac disease, for a minimum of three years (including a strict gluten free diet). This timeframe was chosen based on Clerx et al.’s (2019) assessment that celiac individuals hierarchically progressed in their development of self-management skills, and it was at three years that individuals were able to navigate important areas of life such as home, education, and workplace.

Based on the above criteria and including all races and ethnicities, Beyond Celiac delivered the first batch of emails to 38 of their qualified members. Two individuals self-identified that they met the required criteria, and desired to be a part of the study. These individuals were required to participate in a pre-screening interview to determine their eligibility. The interviews took place via Zoom and served to establish a rapport with the participants by allowing them to share a brief story about their lived experience with CeD. During the screening, brief biographical data was obtained, and I inquired about their availability for an interview. As the researcher, I reiterated the email’s previously stated goals for the research and the objectives to be achieved from their participation. I informed the future participants about the semistructure of the in-depth interview questions and that their answers would be anonymous with pseudonyms being utilized instead of their actual identities.

Because only two members responded, I edited the previous email to clarify that the study was for a PhD dissertation and clarified that I was the primary contact and not Beyond Celiac. Beyond Celiac sent a second batch of emails to 122 participants that again included all races/ethnicities. I received eight more responses for a total of ten participants.

Regarding the number of individuals that were sought as participants, when utilizing CIT, the "sample is determined on the basis of number of critical incidents and not the number of people" (Woolsey et al., 1986, p. 246). The goal was to have between 15 and 20 participants to allow for the opportunity to reach a state of saturation where there are no longer any new incidents that arise from additional interviews. This saturation was utilized as a method of credibility that was covered in the trustworthy section of this chapter.

After completing the ten interviews, there was significant evidence of data saturation. At the suggestion of my methodologist, to ensure saturation had been reached, it was recommended that I obtain individuals who were ethnicities that were not non-Hispanic White. I asked Beyond Celiac to change their criteria to exclude non-Hispanic White individuals for the third batch. This batch was sent to 16 participants with two individuals responding (one Chippewa elder and the second, an individual who described herself as two or more races: Vietnamese and white). After these interviews were conducted, it was determined that saturation had, indeed, been reached. Therefore, it was not necessary to reach the original goal of between 15 and 20 participants.

Data Collection

CIT used many different qualitative techniques for recalling critical incidents such as direct observation, questionnaires, workshops, record forms, and interviews (Butterfield et al., 2005; Viergever, 2019). According to Merriam (2009), interviews were categorized by structure (highly structured, semi-structured, and unstructured/informal). Highly structured interviews were rigid, utilized predetermined questions and did not seek personal perspectives and understandings; while semi-structured interviews were flexible, asking questions that not only sought specific data from its respondents, but desired responses about particular issues that were explored (Merriam, 2009). The third structure of interviews, unstructured/informal, was used primarily to learn from the interview about a phenomenon that the researcher does not know so that questions can be formulated for future related interviews (Merriam, 2009).

Interviewing

Patton (2015) believed that the main purpose of an interview was to "obtain a special kind of information" such as "how people have organized their world and the meanings they attach to what goes on in the world" (p. 426). Interviews were an appropriate means of data collection when we "cannot observe the behavior, feelings, or how people interpreted the world around them" (Merriam, 2009, p. 88). Therefore, the purpose of interviewing "was to allow us to enter into the other person's perspective" and began with "the assumption that the perspectives of others were meaningful and knowable and could+ be made explicit" (Patton, 2015, p. 426).

Because this study focused on past incidents that were not observed by the researcher and because we sought to understand a special kind of information as to how patients learned and the meanings they made about their new gluten free world, I utilized semi-structured, individual interviews to obtain personal stories or critical incidents that "illustrated the phenomena of interest and that were significant" (Watkins et al., 2022, p. 713). According to Kemppainen (2000), the "face-to-face interview format was the most satisfactory data collection method for ensuring that all necessary details were supplied" (p. 1265). Therefore, the interviews for this study were conducted with individuals face-to-face via the use of Zoom video conferencing. These interviews were video recorded via Zoom, with individuals given pseudonyms for identification. The location for being interviewed was at a place chosen by the participant, while I, as the interviewer, utilized two locations to conduct the interviews: a private off-site setting and my personal office at my residence.

Utilizing a semi-structured style of interviewing for this research allowed me to "explore the experiences of participants and the meanings they attributed to them "(Tong et al., 2006, p. 351). This style of questioning provided me the opportunity to "cover a common set of themes but allowed for changes in the sequencing of questions and forms of questions," preserving "a natural conversation flow" (Suzuki et al., 2007, p. 311) which allowed me the freedom to engage in the natural flow of the interview. When utilizing the semi-structured interview, as the interviewer, I utilized a combination of a standard open-ended interview along with a guided approach because of the flexibility it offered for probing certain subjects in greater depth and the ability to ask new questions not originally anticipated (Patton, 2015). According to Patton (2015), a common strategy of this combination was to use the standardized interview format early in the interview which afforded the interviewer the opportunity to pursue in the latter half, new subjects that arose earlier in the interview. While this approach increased the comprehensiveness of the data and allowed for the interview to be done in a conversational manner, I was aware of the possible change of sequencing of questions and ensured that I made every attempt to explore the same content areas at the same level of detail with each participant, which was an important aspect of the CIT interview (Butterfield et al., 2009).

The Interviewer

According to Patton (2015), the premise of conducting a good interview was that "the quality of the information obtained during an interview was largely dependent on the interviewer" (p. 427). Interviewers should possess interview principles and skills such as asking open-ended questions, be clear, probe and make transitions when appropriate, be prepared for the unexpected and be present throughout the process (Patton, 2015, p. 427). To these Patton added that interviewers should not only know what types of questions to ask, but how to interact and engage with the participant which "involved the art of listening, and *really hearing*" (p. 427). Utilizing these skills enhanced the primary task of the CIT interviewer to "elicit sufficient data that the full story of the incidents was clear" … "that illustrate the phenomena" to be studied (Watkins et al., 2022, p. 713). As the interviewer for this study, I attempted to apply these skills, especially those of listening that demonstrated empathy, curiosity, respect, and that I fully understood the essence of what was being said (Butterfield et al., 2009; Patton, 2015; Woolsey, 1986).

Interview Protocol

Prior to the interview, I had the participant sign a consent form and forward it to me via email. Once the consent form was signed and returned, the next step was to proceed with the interview. Each interview began with a greeting and a thank you and included a review of the purpose of the study, its scope, and the general plan for how the interview would proceed. At the beginning of the interview process, I reminded the participant of how confidentiality was established using a pseudonym and who had access to their data. I asked if they were agreeable to me recording the interview through the Zoom application. Upon their agreement to be recorded, the interview proceeded.

For the critical incident interviews, I constructed an interview protocol (see Appendix A) that provided a guide for the interview process to ensure that the same basic inquiry was made of each participant. The protocol served as a guide for the interview process and included four primary questions based on the primary areas of interest for the study. For each of these areas, I included follow-up questions that I anticipated might arise from the participants' responses. To help the participants recall prior critical incidents, I began the interview with the prompt of "Think about a time when…] (Watkins et al., 2022, p. 713). By creating the protocol, I had a "greater likelihood that respondents would supply the answers that made sense – and were relevant, usable, and interpretable" (Patton, 2002, p. 365). It should also be noted that prior to conducting interviews, I sought IRB approval for this study.

The interview began with the interviewer obtaining basic demographic data from the participants, followed by a brief background about the problem the research would address. The participant was prompted with a question about the first critical incident. This process continued until all four critical incident questions were answered. After the interview was completed, the interviewer did a final wrap-up and asked the participant if there was anything more that they wanted to add or that should be known about the problem. This was followed by thanking the participant and ending the video recording.

Fieldwork Journal

During the interview, I took field notes that included my observations of the participant and key words, actions, and reactions that were heard or observed from the participant. While I attempted to be detailed during the interview, it was inevitable that I would be sidetracked or have the need to make abbreviated notes. Therefore, I developed a list of short-hand abbreviations that assisted with quick notetaking. For instance, CeD for celiac disease, GI for gastrointestinal doctor, and so forth. Post-interview, I transcribed my notes as quickly as possible, and prior to talking with others about their contents, because as Bogdan and Biklen (2007) suggested, there was poorer recall the more time passed between the interview and writing; and talking about the contents prior to writing diffused their importance (Merriam, 2009).

The observation notes were kept within a fieldwork journal. Within the journal I included my own analysis and interpretation of the interview field notes, as well as my personal assessment of the overall process of the research I was undertaking. I described the decisions I made and added reflective comments that included my “feelings, reactions, hunches, initial interpretations, speculations, and working hypotheses” and comments that were “over and above the factual descriptions of what is going on” (Merriam, 2009, p. 131). These field notes served as a form of validity for the research study and included information about the how I set the scene of the interview and assessed how I could make improvements for any subsequent interviews for this and future studies.

Data Analysis – The Literature

To make sense of the data that was collected, one must “immerse oneself in the data and consolidate the data, focusing on those segments that may provide insight” (Butina, 2015, p. 192) into the research questions of the study. For this research, to develop an understanding of the individual’s experience of living with CeD, utilizing CIT as a research method provided the researcher a means of identifying and categorizing the data inductively which allowed for non-scripted themes to develop that were based on the participant’s personal experiences and thoughts. By having the ability to reflect on their prior experience participants reassessed presuppositions on which their beliefs were based and developed new insights on which to base their future actions (Kessler et al., 2009, which for this research, was the self-management of their disease.

Over the years, CIT was enhanced using retrospective self-report; incorporating a constructivist approach and included aspects of Marsick and Watkins's (1990) informal and incidental learning that detected behaviors and their patterns of participants, and developed "rich narratives that captured context, reasoning, and meaning from the perspective of participants," (Watkins et al., 2022, p. 712). In 2005, Butterfield et al. added contextual and wish list questions and a list of nine credibility checks that were first used in counseling psychology research. These were believed to be consistent with Flanagan's intent for credibility and "enhanced the robustness of CIT findings" (p. 486). Other enhancements included the incorporation of action research and the inclusion of uncritical incidents (Watkins et al., 2022).

CIT and Data Analysis in Chronic Disease Studies

CIT has been utilized to study the lived experience of patients and individuals in the context of hospitalizations, self-management, information and education, and engagement with medical professionals (Bailey et al., 2016; Ivarsson et al., 2011; Kelo et al., 2012; Peltola, et al., 2018). While the use of CIT in such studies was consistent in its format (obtaining participants and data collection), studies utilized a variety of analyses to understand the data. For this study, I researched how CIT studies in chronic disease were analyzed. I found 12 studies. Of these 12, four authors duplicated their research design for two different types of participants. For example, one study by Sverker (2005, 2007) was conducted about the lived experiences of individuals diagnosed with celiac disease. He duplicated the exact research design with different participants, the relatives of coeliac individuals. Even though it was apparent that the results would be different due to having unique participants for each study, the focus of this literature search was not the results of the studies, but how the data was analyzed. Therefore, I chose to omit the four studies whose researchers had duplicated their design in other studies and kept those studies with more robust explanations of their data analysis. The remaining eight studies utilized various types of analyses to assess data from CIT narratives: qualitative, inductive, deductive, content, and descriptive (see Table 3.1).

Within each type of data analysis for the eight studies, there were common techniques that were utilized such as reading the transcripts multiple times to become familiar with their contents, reading the transcripts horizontally for context, and reading vertically to compare specific answers for research questions (Kelo et al., 2012; Sverker et al., 2009). Inductive analysis was another technique utilized to categorize data. Unlike deductive analysis where codes were developed from research questions or theoretical frameworks, inductive analysis was a more emergent strategy that allowed for codes and themes to develop as the researcher read the data (Bingham and Witkoswky, 2022).

Ivarsson et al. (2011) and Sverker et al. (2007) both utilized inductive analysis to categorize heart and lung transplant patients' experiences and to understand the perspectives of close relatives of coeliac individuals, respectively. Peltola et al.'s (2018) study about communication experiences of patients with type 2 diabetes also utilized inductive analysis to deduce themes but gave a deeper reasoning as to why. Peltola et al.'s (2018) group desired to utilize inductive analysis because it was proven to be beneficial in other studies as a way to "develop an understanding of the meaning of communication in the health care context by generating detailed, practical, meaningful information on communication phenomena …" (p.

1271). This was the only CIT research to address the need for developing an understanding about the meaning of a particular phenomenon.

Table 3.1

Critical Incident Theory (CIT) and Data Analysis in Chronic Disease Studies

Author	Disease(s)	Research description	Data analysis
Bailey et al. (2016)	Lung Cancer & COPD	Hospital care post emergency admission	Thematic Analysis
Holden, et al. (2018)	Heart Disease	Patient decision-making personas	Qualitative Analysis
Ivarsson et al. (2011)	Lung and Heart Disease	Patients' experiences of information and support	Inductive Analysis
Kelo et al. (2012)	Chronic Illness	Patient education of school-age children	Deductive Analysis
Ostlund et al. (2016)	Early Rheumatoid Arthritis	Managing participation restrictions among Swedish men	Content Analysis
Peltola et al (2018)	Type 2 Diabetes	Patient interpersonal communication	Inductive Analysis
Ravert et al. (2017)	Multiple Chronic Disease	Managing chronic conditions in college	Descriptive Analysis
Sverker et al. (2007)	Coeliac Disease	Perspective of close relatives	Inductive Analysis

Data Reduction and Re-Storying Incidents - A Constructivist Approach

Flanagan (1954) held that for CIT, the main purpose of analysis was to “summarize and describe the data in an efficient manner so that it could be effectively used for many practical purposes” (p. 345). Such data in CIT, were the stories that the participants shared about their incidents which provided “rich data that expressed movement, interpreted ideas, and described from the storyteller’s perspective how things were and how they are, as well as how they should be” (Feldman et al., 2004, p. 150).

Flanagan (1954) originally saw the purpose of data analysis to simply be a means of grouping and categorizing critical incidents “in an efficient manner so that they could be effectively used for many practical purposes” (p. 345). Flanagan (1954) stated that the procedures for analysis were not “concerned with improving on the comprehensiveness, specificity of detail, or validity of the statement of the requirements of the activity,” (p. 345) but, instead, were most interested in making the data easier to report, to draw inferences, and served as a comparison to other activities.

Over the years, other scholars desired to obtain more from their data and adopted a constructivist approach to analyzing CIT data. Such an approach was used by such as Ellinger and Watkins (1998) which analyzed the participant experience in their natural context (sociocultural and geographic) and reported data as stories or narratives that “captured the context, reasoning, and meaning from the perspective of participants” (Watkins et al., 2022, p. 712). This allowed for rich narratives that provided a greater understanding of the meanings participants made of their actions. Later, Watkins et al. (2022) added a two-part process of data reduction and re-storying of the incidents, and cross-incident analysis where participant stories illustrated “learning about the phenomena” and provided an opportunity for the researcher to “draw out the meaning from across all of the data to develop core themes” (p. 716).

Other researchers added more modifications such as the inclusion of contextual and wish list questions, credibility checks to enhance rigor, inclusion of uncritical incidents, and participatory action research (Butterfield et al, 2009; Chou et al, 2016; Ellinger and Watkins, 1998; Kamal, 2021). For this research, I chose to utilize a two-step process of data analysis that included Watkins et al.’s (2022) constructivist process of data reduction and re-storying of incidents and cross incident-analysis for asserting themes discovered in the data. Such an analysis provided for a deeper look into the learning and meaning-making that occurred for participants after a celiac diagnosis.

Data Configuration

During the interview, I took copious amounts of notes. Post-interview, I summarized the notes and highlighted what were considered to be salient points and themes. These summaries were emailed to the participants who were asked to read through them and agree, disagree, or make corrections to their content. Each participant read through their summaries and replied via email sharing their thoughts, corrections, and approvals.

The data from the interviews was transcribed by the TurboScribe transcription service. I read through each of the transcripts and (1) screened the narrative for incorrect grammar and phrasing, and (2) familiarized myself with the information and reflected about the overall meaning of the participants’ stories (Creswell, 2009). If it was determined that there were errors and/or confusing phraseology, I cleaned the data by making needed corrections, keeping as close to the original narrative as possible, so as to make the stories more understandable and the participants’ messages clearer.

Step One: Data Reduction and Re-Storying

In the first step of data reduction, I utilized the process of re-storying the data from individual transcripts. In the re-storying process, the individual transcriptions were re-storied as a form of data reduction where the "researcher extracts and rearranges elements to form stories" (p. 713). Critical incidents were then re-storied as closely to the participants' own words and given a headline to convey the essence of the story.

To re-story the data, I read each transcript individually from beginning to end, and upon completion, rearranged the elements of the narrative to form stories that were embedded in the narrative. This allowed me, as the researcher, to "capture the essence of the incidents" (Watkins et al., 2022, p. 713) prior to assigning categories that may bias the data. It also allowed the incidents to demonstrate how they related to the research purpose of understanding the learning and meaning-making that occurred for individuals with CeD.

According to Watkins et al. (2022), this may prove to be a challenge due to each participant possibly telling "stories within stories, and thus the researcher must first tease these out" (p. 714) in order to fully understand and capture the essence of the narrative. To counter this challenge, after re-storying the narrative using as much of the original narrative as possible, I determined the essence of the participant's story and designated a headline that demonstrated the important elements about the particular incident (Watkins et al., 2022). Once data was re-storied, a second process occurred that included a deep analysis of the critical incidents from which assertions developed from the data were bridged back to the research purpose of this dissertation.

Step Two: Cross-Incident Analysis

Analyzing data in CIT research was considered to be the most difficult step in the research process due to the number of incidents with which a researcher had to work, and the difficult task of inductively developing categories for those incidents (Butterfield et al., 2005; Flanagan, 1954; Watkins et al., 2022; Woolsey 1986). Because of these challenges, I utilized Erickson's (2012) technique of thematic assertion, coupled with deductive and inductive analysis, to assert themes that bridged between the purpose of the research and the obtained critical incidents (Watkins et al, 2022) as presented in Figure 3.1. According to Watkins et al. (2022) this secondary process was a "thematic rendering of what was learned about the research purpose" (p. 716). In addition, Erickson (2012) believed that by combining rich CIT data and cross-incident analysis, the recalled critical incidents were validated.

Figure 3.1

Thematic Assertion Analysis in Critical Incident Technique (CIT)

Note: Adapted from Watkins, et al. (2022).

Through this process, working assertions developed as the narrative implied answer(s) to particular research questions (Erickson, 2012). To prove these assertions, Erickson (2012) suggested that the initial search be exhaustive to “ensure that crucial evidence was not systematically ignored” (p. 1459). This deductive analysis entailed repeatedly assessing (comparing, organizing, and categorizing) each re-storied transcript for supporting evidence. According to Erickson, as researchers continued to work back and forth between their hunches and the data new insights were obtained. As the research constantly compared the data, categories that aligned with the study’s theoretical framework of experiential learning and research questions became apparent.

Once the coding of assertions was exhausted, the assertions were sorted according to how each related to learning after celiac diagnosis. Any remaining data that did not support the earlier defined assertions were inductively re-analyzed to determine other general themes as they related to experiential learning, self-management, and CeD. Table 3.2 is an example of the spreadsheet I created to organize the interview data from this study. The spreadsheet, in its entirety, can be found in Appendix B, and exhibits participant narratives as experiential learning utilizing the processes of experiencing, reflecting, thinking, and applying.

Table 3.2

Spreadsheet Example of Critical Incidents that Demonstrate Experiential Learning Theory (ELT)

		Concrete Experience	***Reflective Observation***	***Abstract Conceptualization***	***Active Experimentation***
Incident #	**Title of Incident**	**Incident**	**Meaning making**	**Learning**	**Application**
3	Learning from other mothers	So, I joined all of these celiac groups, and everyone was looking for community and tips.	You've got to keep searching because ... And I guess that the best thing that [learning from Facebook groups] taught me was just to keep moving forward, to not give up, and to not just accept, okay, that this is the way it's always going to be and trying to find people who knew things. I guess, stay humble enough to remember that there's got to be someone else out there who knows more than me.	And so, they were the ones who were on top of everything, and I made friends with all of these moms. And remember at the time, I'm like 25 and newly engaged, and all of these moms of 8, 9, 10-year-olds who had just recently been diagnosed…there's nothing like a mom protecting her kid…so, they're the ones that taught me pretty much everything.	And I am thinking in some ways it pushed me to not show when I accidentally got sick at her [mom's] house because I didn't want that [guilt] to happen [for mom].

After assessing the narrative stories, it became apparent that 70 studies demonstrated experiential learning. However, of those studies, only 40 included all four elements of Kolb's four-step cycle: experiencing, reflecting, thinking, and applying. The remaining 30 demonstrated a form of experiential learning (e.g., emulated behavior change) but lacked one or more elements of reflection (meaning-making), deep learning with thinking, and/or future application. Because this study sought to understand the role of experiential learning theory in the self-management of celiac disease, only 39 narratives were included in the findings of Chapter 4. The remaining 30 narratives were retained for future research. Table 3.3 presents the list of critical incidents that met these criteria.

Table 3.3

Critical Incidents Demonstrating Experiential Learning Theory

Participant Name	Incident #	Title of Incident	Assertion Quote (Meaning making)
Alice	1	A sudden change	It was just like all of a sudden you are no longer eating the way you've eaten your entire life.
	3	Learning from another mother	You’ve got to keep searching because ... And I guess that the best thing that [learning from Facebook groups] taught me was just to keep moving forward, to not give up, and to not just accept, okay, that this is the way it's always going to be and trying to find people who knew things.
	4	Becoming me again	I had options of leaving my house …. I had all of a sudden…I had this world of opportunities available to me.
	5	Thank you for your support	I learned that it helps when I have the support of the other people in the office, but there was, again, sort of a social hierarchy.
	6	Pure altruism	It's a fine balance to advocate for yourself while still respecting the hierarchy.
	7	Appeal to pity	So, I think this means that I care too much about what other people think and that's kind of not a nice thing to realize.
	9	I don't understand you	I just was like, okay, this is how the situation is going to be. I just need to be ready to roll with it … There really isn't any such thing as an impossible situation in terms of something this simple.
Betty	10	Gluten on the label, label, label	It was going to be a little harder than I thought it was going to be. You find out there's a lot more to it.
	14	All roads do not lead to gluten free	…and I am a little bit more - suspicious, you know? Don't assume that for something like that, don't assume that they understand at all.
Carole	19	Don’t make assumptions	Not just assume that things were still the same.
Callie	26	All grown up	I guess just moving out has really taught me that I need to think more about the little things … I would have paid more attention growing up and asked more questions
	28	The mental game between celiac and my identity	I think in my personal experience [celiac disease] has been just like a tough mental game to play with … I felt like celiac was my identity

Participant Name	Incident #	Title of Incident	Assertion Quote (Meaning making)
	30	Tell, even if they don’t ask	Even if they don't understand it, I've never encountered somebody that's given me hate for it either. Even if they didn't understand it. So, trust the people you surround yourself with. It’s okay to ‘be.’
	31	Don’t hold back	Sure, travel is scary travel, but that shouldn't hold you back. You should definitely still experience anything you want to.
Heath	33	Unknown preparation	So, again, as I said, it really was sort of an evolution, so it wasn't as big a deal to me once, I was officially diagnosed
	34	Be the change	So, I think as we're talking about learning, I think there's a lot more institutional and corporate learning going on, more than my individual learning
Holly	38	I didn’t realize that	There's gluten in a lot of things. A lot of unexpected places. It's also tricky whenever a product is not labeled gluten-free to determine is the product actually gluten-free or not.
	42	You should eat what is available	I felt like she did not take my dietary restrictions seriously at all. I felt isolated … it is juts easier to bring my own food.
	43	You take me seriously	I felt like my dietary needs were taken seriously. And I appreciated the compassion she had.
Joanna	48	This is the rest of your life	I realized how impactful this disease was going to be on the rest of my life. The time-consuming aspect of it. … I'm just like, this is what it is. I can handle it and, you know, move on to the next thing.
	50	Dr. Google	So, it was hard to know, well, is this real? Is this, you know, is this just Dr. Google being dramatic or what?
	51	Keep it simple	When it's like a work situation, that's another layer of challenge because you don't want to offend people pretty high up in your company or things like that.
	52	Pancake breakfast	You just have to take yourself out of that situation or be petty
	53	Please don’t eat the food	Even if people like to notice that you're doing something a little weird with your food, nobody's going to be talking about it a year after like, oh, my gosh, she brought her own food.
	54	Crying in Kroger	I think that's when it really hit me, how much of an impact on my lifestyle it would be.
Mary	56	Relatable nurse	The nurse practitioner gastroenterologist also has celiac, so she was able to give me a lot of pointers.

Participant Name	Incident #	Title of Incident	Assertion Quote (Meaning making)
	58	A family affair	But I think it was very much a learning experience for all of us, even just understanding the lengths I had to go to just keep myself safe.
	61	Clueless bosses	There's a lack of understanding from the bosses, as well as a lack of general knowledge about it.
Ryan	65	Cooking school	Over time I was able to distill down what I was uncomfortable with to get better at that.
	66	Cooking in Japan	I think I'm very happy to be able to produce food, not just any food, but many foods that I am happy to eat.
	69	Sailing away	You know there's certain scenarios where you realize that things are maybe possible but might be quite challenging.
Rosemarie	73	Gluten free country clubbing	That's kind of tiring at times, having to, on hot days, make sure that my food stays cool and not having the convenience of just walking into the restaurant and being able to order something.
Sarah	76	It's not you, it's me	With me, because it's all encompassing now, it's everything I buy. So, it's a constant awareness of where the gluten is and where it isn't.
	80	Sometimes I don't bother	You know, I give them my little speech. If they did not get it the first time, I think maybe it is not worth it.
	81	Learning from a celiac child	And it's so many. You just little by little, you realize, oh, this is a problem, too. And this is a problem, too.
	82	Gluten doesn't die in the freezer!	That kind of set the tone for how we handle things for me … ever since then I kind of just don't trust that anybody is going to prepare food safely.
Trevor	83	Team effort	In the beginning I felt sorry for myself and then I realized it's not that bad. When we were talking to our friend Jan and she was explaining 25 years ago, there wasn't a lot of food that was gluten-free and now there is a ton…
	93	Eating around gluten	As long as I communicate well, I won't get sick. A subset of that is that my friends are becoming more educated about my situation. And maybe a subset of that is, don't look for new friends…just kidding.
	95	Dining out after golf	You know, as long as I try to keep it simple and light and not foreboding, I find it works out just fine.
	96	Language barrier	It told me a little bit about language communication. In many countries, they're just trying to, to live day to day. So, a lot of those things are not as important, you know? So, you get sick for

Participant Name	Incident #	Title of Incident	Assertion Quote (Meaning making)
			a couple of days, no big deal. That was an eye-opener for me.

Trustworthiness

Merriam (2009) stated that trusting research results was "especially important to professionals in applied fields because practitioners intervene in people's lives" (p. 209). Because the goal of this research was to provide worthy data that enhanced the treatment of individuals diagnosed with CeD, it was imperative that the critical incidents of storied data were obtained, assessed, and reported in a trustworthy manner as such they were shown to be valid and reliable (Merriam, 2009). Validity of this research was shown internally through triangulation, member checks, and peer review; while external validity was concerned with the generalizability of the data and how well the research could be replicated (Cresswell, 2009).

Internal Validity (Credibility)

Internal validity ensured that the research findings were credible and matched what was considered to be reality by the interviewer and participants. Merriam (2009) stated that an assumption of qualitative research was that reality was "holistic, multidimensional, and ever-changing; it was not a single, fixed, objective phenomenon waiting to be discovered, observed, and measured as in quantitative research" (p. 213). Therefore, assessing validity of a qualitative study took into consideration the participants' "construction of reality – how they understood the world" and that there will be "multiple constructions of how people have experienced a particular phenomenon … have made meaning of their lives" (Merriam, 2009, p. 213). Therefore, what reality was deemed to be was more real when working with participants as an instrument of data collection, than in other forms of research. According to Merriam, when we view the rigor of a study with this in mind, internal validity was a strength of that study.

Exhaustiveness

To ensure the internal validity of this study, interviews were conducted for redundancy, or exhaustiveness. Butterfield et al. (2009) stated that “exhaustiveness determines when a sufficient number of participants have been reviewed” (p. 270). According to Flanagan (1956), the sufficient number to equate exhaustiveness was determined when adding 100 more critical incidents to the sample would only yield two to three new critical behaviors. For this research, data collection continued until no new categories emerged from each new interview.

Triangulation

I compared the transcripts of participant interviews with researcher field notes and summaries that were taken during and post-interview. These notes gave details about the researcher’s observations about the participant interviews and their interaction with the research participants. According to Cresswell (2009), triangulating two data sources (in this case, interviews, and field notes/summaries) would “build a coherent justification for themes” (p. 191) adding to the validity of the story.

Member Checks

Member checks were conducted to ensure internal validity. Member checks were utilized to solicit feedback from research participants, allowing them to determine if what was understood from the interviews was accurate or misinterpreted and needed correcting (Creswell, 2009; Lincoln and Gupta, 1996; Merriam, 2009). After the participant interviews were transcribed, cleaned and a re-storied narrative was generated, I contacted each participant via email, sending them a copy of the re-storied narrative and requested that they fully read the re-storied narratives for accuracy of how they reflected the incidents and stories they wished to convey. I requested that each participant respond to my request with an email that included their feedback to contain comments, suggestions, or corrections about the accuracy or misinterpretation of data. After receiving feedback from participants, the requested changes and comments printed from the participants' email, set with a time stamp, and placed into their physical file. Suggestions and corrections were made to the narratives at the participants' request.

Reliability

Merriam (2009) stated that reliability was the extent to which research findings could be replicated and was problematic in social sciences as "human behavior was never static" (p. 220), and therefore always changed. Unlike quantitative research, where the assumption was one reality, qualitative research had multiple interpretations based on the experiences of those participating whose behaviors were not static (Merriam, 2009). Therefore, even if the steps of this research were replicated exactly, they would not yield the same results. Instead, qualitative research focused on consistency instead of replicating exact results.

Audit Trail

To improve such consistency, I conducted an audit trail of my work that described in detail "how data was collected, how categories were derived, and how decisions were made throughout the inquiry" (Ruona, 2005, p. 248). This audit trail consisted of field notes and memos that I wrote that included my assumptions and biases, and the processes I utilized for making decisions regarding "problems, issues, or ideas I encountered in collecting data (Merriam, 2009, p. 223). These helped me "reconstruct and understand my research processes"

(Ruona, 2005, p. 249), and enhanced how I reported the methods that could be duplicated by others.

Peer Review

Peer reviews were utilized to assess how well the methodological process was utilized in this research. I worked with members of my committee, specifically my major professor and methodologist to obtain feedback about the accuracy and preciseness of steps I took throughout the research study, and if discovered themes and results were consistent with the data that was collected (Merriam, 2009). The expectation was that seeking such unique interpretations and debriefings allowed this research to resonate more with others, thus providing a sense of validity to what was discovered (Cresswell, 2009).

External Validity (Generalizability)

According to Merriam (2009), external validity was concerned with how well the findings of one study could be applied to other situations. For qualitative research, this definition was challenging as its value was in “the particular description and themes developed in context of a specific site” (Cresswell, 2009, p. 193). In other words, the results of qualitative research were based on the nuances and uniqueness of the site and its participants. Therefore, the results of qualitative research could never be exactly obtained should the study be replicated. According to Cresswell (2009), this meant that instead of how generalized research was, one should be most concerned with the particularity of the research process. To ensure that the qualitative processes could be utilized in other studies, I utilized thick descriptions that detailed the “description of the findings with adequate evidence presented in the form of quotes from participant interviews, field notes, and documents” (Merriam, 2009, p. 227). In these thick descriptions I provided detailed quotes from the interviews and/or re-storied narratives, as well as the field notes and summaries that I wrote during and post-interview.

Subjectivity

According to Given (2008), the purpose of a subjectivity statement was to help researchers "identify how their personal features, experiences, beliefs, feelings . . . affected their research" and to convey this information to other scholars for consideration as to the "study's credibility, authenticity, and overall quality or validity" (p.844). However, as researchers, we may not be aware of our subjectivity and its effect on how we approach and view our research. Peshkin (1988) stated that researchers "were not necessarily conscious of it [subjectivity]" and should "systematically identify their subjectivity throughout the course of their research" (p. 17). Doing so enables the researcher to become aware of how their subjectivity influenced what occurred within their research, avoiding skewed or misconstrued data.

As the researcher for this study, I addressed my subjectivity throughout the study to not tame it, but to "manage it-to preclude it from being unwittingly burdensome" (Peshkin, 1988, p. 20). To address this subconscious influence, I monitored myself by keeping a research journal. Through journaling, I conducted the reflexive work of writing short notes, memos, and thoughts about my subjective bias (hoping to make it object), continuing to do so throughout my research, which, according to Watt (2007) "was actually the beginning of analysis" (p. 83).

Ascribed Characteristics

I am a 57-year-old, middle-class, college-educated, married white female, and mother of two sons, one who is 32 and the other who will be forever 21. I have experienced multiple health issues, high levels of stress, and life-altering events such as the early deaths of my mother and several years later, my young-adult son at the age of 21. I live in the suburbs in the southern

United States with my husband of 39 years and ten-year-old black lab. We are empty nesters. My maternal ethnic heritage is Scottish, and my paternal ethnicity is Irish and Cherokee.

I hold a Bachelor of Science degree in Communications, a master's degree in Higher Education Administration, and I am currently working on my PhD in the College of Education's doctoral program of Learning, Leadership, and Organizational Development (LLOD) at the University of Georgia (UGA). My career path focused on education for almost 30 years: 20 years as a home-educator of my two sons and eight years in the field of higher education. At the university at which I previously worked, I was the director of the academic program of dual enrollment and worked with high school juniors and seniors who attended college simultaneously while in high school. I also have celiac disease.

Life as a Celiac

In 2010, while attending what was to have been a "normal" gynecological check-up, it was determined that I was anemic without a known cause. After a trip to a gastrointestinal specialist, bloodwork, and both a colonoscopy and endoscopy, I received the diagnosis of the autoimmune disorder celiac disease. Thus began my lifelong journey with an inherited chronic disease.

At first, I was glad to understand why I was so tired and fascinated that simply by changing my diet I was able to arrest my iron deficiency within just a few short months. Then, the reality and vastness of the diagnosis set in. I was still positive about the diagnosis because I desired good health. However, I realized that this disease was not just about food, it was about everything that surrounded food: my kitchen, shopping, eating out, holidays, and social life with family and friends. The first thing was to remove anything in the kitchen that could retain glutinous particles such as Teflon cookware (due to its inevitable scratches that retained gluten), cutting boards (especially wooden, again gluten retention), plastic/wooden spatulas and spoons, toasters, and re-seasoning cast iron skillets. No longer did we use jars of condiments. We now had to purchase squeeze bottles to prevent cross-contamination from schmearing their contents onto glutinous foods, especially within a mixed (celiac and non-celiac) household.

Trips to the grocery store were overwhelming for the first few months. Every label had to be read since the term “gluten free” was not always listed, even if the product did not contain glutenous ingredients. I became adept at calling companies about their products, locating their online FAQ, and Googling product descriptions to ensure they were gluten free.

Dining was another challenge. It became a dance of how to ask the right questions of the waitstaff and chefs without feeling I was imposing. Many staff had confused looks on their faces when asked about their procedures to avoid cross-contamination. They, too, asked questions of me: “Just how allergic are you?” or “If you just take the bread off the plate and place it in my hand, then it will be ok, right?” These issues did not only occur in restaurants, but also at family gatherings such as birthdays or holidays. Until you cannot eat, you do not realize how much an event is tied to food. I have been told by extended family that because I could not eat Thanksgiving dinner at their home (they would not prepare anything gluten free), that I was welcome to bring my own dessert for coffee after the meal; and another one stated, “You are invited, but I’m not sure what you can eat here.”

Initially, there were a few friends and family who included me by purchasing gluten free cupcakes for family birthdays or preparing a meal. However, after two or three times, the gluten free treats stopped and the invitations to get together for dinner, even to dine out, became nil. Still, even with these frustrations and disappointments, I moved onward and embraced gluten free living. My goal was to be healthy and live a happy life. So, I chose to focus on what I could control, and as disappointing as others' responses were to my condition, I chose to believe it was their loss if they chose to exclude me.

These situations would have been daunting had it not been for my immediate family of my husband and two sons. I am blessed to have them as my support system. Upon my diagnosis they took it upon themselves to ensure that cross-contamination did not occur in our shared kitchen. To this day, they check menus at restaurants and events to ensure that gluten free dining is available. My oldest son, on my behalf, has inquired as to the safety of meals that were brought to me because something seemed "off"; and I am very fortunate that my husband embraced the gluten free lifestyle by helping me to maintain a gluten free household, cooking for us, and contacting hotels and event organizers to inquire if gluten free options were available at their event. However, I know that this is not everyone's reality. I know that even when I am disappointed and frustrated with others' responses about my diet, or the fact that I, for the hundredth time, must ask how a chef avoids cross-contamination, that these issues may be trivial in comparison to other celiacs' stories.

Past and Present

"You must be the change you wish to see in the world." Ghandi

I became interested in advocating for others with CeD while I was employed at a university. The dining hall had won several awards for its culinary prowess and the students raved about it. Upon being invited to dine there, I noticed each food item was identified with little cards that stated known allergies. A very good thing. However, as I perused the food options, I noticed how nearby glutinous items could be dripped across the gluten-free items by the servers which would result in cross-contamination. There were also very few gluten-free offerings. So, the dining hall was not safe for all college students. This troubled me, and thus began my journey of advocating for individuals with CeD.

Because I desired to see the processes for allergy dining changed for college students, I volunteered to serve on the Food Committee. Sometimes I felt like a nuisance as I constantly brought allergy issues (not just gluten or CeD) to the forefront of the conversation. I was assured that things were good for the students and that the culinary department took my comments seriously. However, nothing seemed to change. They even rejected a suggestion for an allergy-free station to be added to the other meat-and-three and burger stations. To me, this suggestion seemed like a win-win (good press for the school and fewer illnesses), but the idea was rejected. Even with this rejection, I continued to advocate for students, encouraging the development of safe procedures for their dietary needs. Slowly over time I began to see university events for students and staff provide food for those with allergies, and the question “Are there any allergies?” became normal when ordering lunches for departmental meetings. I like to think that I had something to do with that.

Self-Reflexivity

In telling my story, I hope that it resonates with those who may have experienced similar challenges due to living with CeD. I want to assure the readers of this research that as the researcher, I do recognize the potential for my own experience to influence how I pursue this study. I realize that there are many circumstances that influence an individual’s experience of living with CeD which I may not have had but should take into consideration. Unlike me, many individuals who face a life-changing diagnosis may not have access to a good medical support system due to a rural location or lack of insurance. They may not have the opportunity to engage with gastrointestinal specialists, dietitians, health coaches or counselors. They may also have educational or socioeconomic challenges or barriers that I have not experienced. All of these can make implementing a gluten free lifestyle difficult. Also, as a white female, I will consider how other ethnicities and sexes may be affected differently and how their cultural lens influences their learning and meaning making of living life as a celiac.

As the researcher, although the practice is to keep bias in check, I acknowledge that having lived with CeD for the past 14 years, I cannot separate my assumptions and preconceptions from this research. However, I will practice self-reflexivity through journaling about my attitudes, thoughts, and opinions so that I become more aware of how these influenced the lens through which I perceived this study. By understanding my attitudes and opinions, and how these biased how I engaged with the interviewees, I can understand any blind spots I may have and be more purposeful in how I ask questions and obtain data. I will do this while being aware to not influence participants' responses through body language and nonverbal responses. Instead, I will remain neutral in my comments and emotional responses.

I will conduct person-centered interviews that incorporate empathic listening, while checking my own perceptions (Woolsey, 1986), reflecting in the moment, embracing everyone's story as unique and meaningful. As I bring my celiac experiences with me, I will remember that each celiac will have their own set of schemas and biases through which they interpret learning and meaning. Finally, I will share how my prior experience impacted and informed my interpretation of the research data, accounting for it in the discussion and conclusions of this research.

Chapter Summary

In this chapter, I described the theoretical and methodological approaches that were utlized for this qualitative study. The study detailed how the critical incident technique methodology was implemented, and utililzed open-eneded, semi-structured interviews to obtain narrative data. The data assessment was detailed as a two-step process that consisted of data reduction through restorying and cross-incident analysis that utilized inductive and deductive reasoning to determine assertions. The chapters discussed the trustworthiness of the study, addressed internal (credibility) and external (generalizablity) validity and reliability, as well as statements of the researcher's subjectvitiy and self-reflexivity which provided a sound grounding for the research narratives presented in Chapter 4 and the findings and conclusions presented in Chapter 5.

CHAPTER 4

DATA ANALYSIS

The purpose of this qualitative study was to examine the lived experience of individuals' self-management of celiac disease, and the role learning played in that lived experience. The research question guiding this study was:

1. What was the lived experience of individuals' self-management of celiac disease and what role does experiential learning play in that lived experience?

To answer this research question, I conducted semi-structured, open-ended interviews with 12 study participants who had lived with celiac disease for five-plus years and were diagnosed through bloodwork and endoscopy. The participants shared critical incidents in which experiential learning occurred in the area of learning to live with celiac disease at home, in a social setting, at work (or retirement), and in unfamiliar situations. These interviews were transcribed, and narrative representations were created from the raw data that yielded a total of 70 critical incidents, with 40 incidents being selected for presentation and analysis here (see Chapter 3 for a description of the incident selection process and Table 3.2 for a complete listing of the 40 incidents). Below is a brief biological description for each participant (with pseudonym) followed by the critical incidents they experienced, the meaning that was made, the learning that occurred, and how the learning would be applied to new incidents. All critical incidents were directly quoted from the participants' narratives and added clarification by the researcher shown within brackets [ ].Table 4.1 is a presentation of demographic data for each participant.

Table 4.1

Participant Demographic Data

Pseudonym	Gender	Age	Education	Employment	Years of symptoms	Age/ Year of diagnosis
Alice	F	40	PhD	Assistant Professor	17	Age 25 2008
Betty	F	75	M.L.S	Librarian; Sr. Database Administrator (Retired)	3+	Age 70 2018
Callie	F	25	Bachelor's degree	Graduate Assistant	9	Age 9 2010
Carole	F	72	Business major	Hospital Administrator/Co-owner of veterinary clinic (Retired)	10	Age 68 2020
Heath	M	73	M.D.	Pediatric Pulmonologist (Retired)	Intermittent GI issues for years	Age 68 2019
Holly	F	43	Bachelor's degree	Database Administrator for university	Diagnosed with wheat allergy as toddler	Age 36 2017
Joanna	F	31	PhD	Regulatory Affairs Manager/biotech company	1	Age 26 2019
Mary	F	40	Associate's degree	Full-time (did not share title)	Since her early 20's	Age 36 2020
Ryan	M	59	Bachelor's degree	Traded Japanese equities	7 months	Age 54 2019
Rosemarie	F	77	Business training	Executive Assistant	3+	Age 74 2020
Sarah	F	64	Bachelor's degree	Former Registered Nurse	Did not exhibit symptoms	Age 60 2020
Trevor	M	73	Bachelor's degree	Financial Planner (Retired)	20	Age 68 2019

Participants and Critical Incidents

Alice

Alice is a 40-year-old Palestinian-Swedish American female who worked as an assistant professor in Saudi Arabia. Born and raised in the United States, Alice suffered with breathing difficulties, hair loss, and digestive symptoms from the age of eight. In her teens, Alice attended school in Lebanon, returning to the United States in 2008, at the age of 25, to attend university to earn her doctorate. Upon her return, Alice was, at her father's request, seen by a friend who was a pulmonologist who inquired about her breathing and digestive problems. Based on her story, the doctor recommended that she immediately have bloodwork to determine if she had celiac disease and urgently told her to stop eating wheat. Three days after removing gluten from her diet she was shocked to wake up and not have her joints ache. The following were selected critical incident narratives provided by Alice.

INCIDENT #1 – "A sudden change"

Now I'm Palestinian. We use bread as silverware. I'm going to dip everything. Like beans, we eat with bread, like pita bread. So, when he [the doctor] said don't eat bread, I was like, then what do I eat? Like legitimately, I was like, well, what do I eat? And then he [said to] *use rice cakes instead, because … there was no gluten-free bread, unless you baked it* [and turned] *your kitchen into a chemistry lab. So, my dad and I went to the grocery store, and this was not when Walmart had a gluten-free aisle, and we looked for rice cakes. And we started reading the ingredients on everything and, okay, he said don't eat vinegar, so let's get rid of the balsamic vinegar. We just didn't understand what it meant. My dad was trying so hard to help me.*

But then we did things like … we took the rice cakes, and we didn't know that they weren't actually bread substitutes. Because I mean, keep in mind, I had just been living in Lebanon for *the past six years. We didn't have rice cakes there. We put them in the toaster and set the toaster on fire, because we thought they were bread. And it was just all this incredible, I mean, it [the change] was just very sudden. It was just like all of a sudden you are no longer eating the way you've eaten your entire life. Because I'm not joking, bread is a staple. So, it was just very sudden and shocking and extremely overwhelming. And my dad was with me, thank God, for those first two months. But I didn't actually really feel like I learned how to manage it until I was living on my own.*

I was just eating by myself and cooking for myself after I'd gone to grad school. And what I was doing was…I was just really restricting my diet to whole foods … fruits and vegetables, chicken breast, lots of tilapia fillets, because that's easy to cook. This was pre-Amy's mac and cheese. So, it was just lots and lots of whole food, which is great for me in general. But that was the main thing. I was just realizing I can't ever eat like I ate before. So, I'm just going to eat what I can. And I didn't really realize that would be, I guess, the healthiest kind of diet anyway. In general, for any person. But yeah, that was basically once I realized that as long as I cook for myself and I have at least one protein a day so [that] *I'm not starving, then I'd be fine.*

INCIDENT #3 "Learning from other mothers"

We didn't get any real-life resources. We weren't told to go see a gastroenterologist. Facebook groups, honestly, was how I was trying to learn. So, I joined all of these celiac groups, and everyone was looking for community and tips. The internet was a dumpster fire back then, it was the wild west. Everyone was just shaming other people, like, 'oh, you eat out, then you're going to get exposed to cross-contamination,' … 'I never eat out. I do all of this and I'm so wonderful and I'm sicker than you are.' It was just like, who are these people? It was just awful. I had to get out of those groups because they were so sanctimonious and condescending. Then I *remember finding a web page called something like Celiac Mommy Warriors or something like that. It was all of these moms of kids with Celiac. I was reading with them like, 'oh, if you're going to get Snickers, make sure they're not the ones imported from Russia. Because those are the ones that use wheat glucose instead of corn glucose.' And it's just like, wait, what? This is a thing? That's awesome! And so, they were the ones who were on top of everything, and I made friends with all of these moms. And remember at the time, I'm like 25 and newly engaged, and all of these moms of 8, 9, 10-year-olds who had just recently been diagnosed…there's nothing like a mom protecting her kid…so, they're the ones that taught me pretty much everything.*

Figuring out what those moms were going through gave me so much empathy for my own mom when I would go visit. Because she didn't have celiac diagnosis then, but she would literally scrub down the entire kitchen and she had a separate salt and pepper shaker that she kept in a cupboard upstairs that was just only used when I came because of course there's bread everywhere because we're Palestinians. I mean, seeing what these women [Celiac Mommy Warriors] *were going through and how deeply upset they got when their kids were sick and how much they blamed themselves. Oh my God, mom guilt. What the heck is mom guilt? Like I've never seen in my life. And it just gave me so much more empathy for my own mom. And I am thinking in some ways it pushed me to not show when I accidentally got sick at her house because I didn't want that* [guilt] *to happen.*

You've got to keep searching because…I kind of have this philosophy of life, if you don't ask, the answer's already no. I've got my PhD, but that doesn't make me THE expert, you know? And I guess that the best thing that [learning from Facebook groups] *taught me was just to keep moving forward, to not give up, and to not just accept, okay, that this is the way it's always going* *to be and trying to find people who knew things. I guess, stay humble enough to remember that there's got to be someone else out there who knows more than me.*

INCIDENT #4 "Becoming me again"

I was in my second semester of grad school and this Persian girl came up to me with like blue hair and a flower and little rockabilly style clothes and septum piercing and armpit hair like exactly the opposite type of person that you think would come up to someone in a headscarf and a skirt. And she just came up and she's like, 'I love your rusary and skirt. I'm originally Iranian. Where are you from?' And I was like, oh, my God, that was the nicest way anyone's ever asked me where are you from? And so, we started talking and she said, 'Let's go grab dinner.' I said, Oh, I can't. I have celiac disease. And I explained what it was. It's just like, [the friend said] oh, we'll go to Chipotle. And I was like, what's that? What's a Chipotle? And I don't know. I've been in the US for like five, four months at this point. We just walked there, and she told me what they had. And she's like, 'Yeah, you'll be fine. You'll be fine. It's just like rice and beans and chicken. And, you know, you can choose if you get the hot sauce and stuff, whatever.' And I was like, oh, no, I can't get hot sauce because it has vinegar. And she's like, 'Okay, don't get hot sauce.' And I was telling her like, yeah, but, you know, if they touch the tortilla and they touch my food, I could get sick, I don't know. And she's, okay, I'll just tell them to change their gloves. Oh, I guess I could do that, and she helped me order because I was overwhelmed. I was like, there are choices. I don't know. And she literally was like [to the staff], *'Was the chicken marinated in vinegar? What can she eat?' She was just like taking over, taking charge. And I kept waiting for my chest to hurt. It didn't. I almost cried because I was expecting it. Because usually within 20 minutes after eating something with gluten, my chest just really hurts, and it didn't. And I was like, oh my God, I can eat food. I just have to be careful. I can just ask questions and ask people to please* *change their gloves. If I'm polite, people will be polite back. There's no problem with this. So that was my big first entry back into the social world.*

It definitely reduced my anxiety. I had anxiety on so many levels because of the social aspect, because of the fact that I was always scared that I was going to get sick. Definitely, definitely decreased my anxiety. Definitely made me feel more secure. A lot more, you know, locus of control. That was great. I had options of leaving my house … I wasn't stuck on just this exclusive home cooked whole foods diet. I had all of a sudden…I had this world of opportunities available to me. It's like, oh my God, I can just ask questions. Do you know how much it changed my life to be able to stop at Chipotle on the way home instead of having to cook all the time or eat a potato for dinner? Like huge, huge change in my nutritional uptake. It goes back to learning from others…just to not be afraid. Because again, if you don't ask the answer's already no. It kind of taught me…okay, I can flow with it.

INCIDENT #5 "Thank you for your support"

My first graduate assistant position was basically as a receptionist in the graduate admissions department. And everyone was very understanding [about my diet] except for one person, and she would do things like bring in a cake. And I would say, oh, no, thank you. I'm allergic. And she'd be like, it's healthy. I made it with applesauce instead of fat. I'd be like, oh, no, I'm allergic to flour. And in my head, I'd be like, lady, we've had this conversation. She'd get super defensive, like so defensive. Like I was personally insulting her by not eating the cake. And she'd get this nasty tone, "Well, I cook healthy, and I cook whole, and I cook whatever, and I cook sustainable." And it's like, why are you throwing out these buzzwords? I don't care. I don't care if it's fat-free. I'm not allergic to fat. Olive oil is the best! Just stop it and back down.

It was very easy for me to be blunt and direct, and the rest of the office would back me … Why can't she just understand Molly has a nut allergy and Arifi can't eat gluten? And that took a lot of firm repetition. And that was very frustrating.

It was the first time that someone had not listened. Because usually when I'd say, oh, I'm sorry, I'm allergic, people would be like, oh, okay. And sometimes they'd be curious, and I'd explain what celiac disease is. I definitely learned that it helps when I have the support of other people in the office, but there was, again, a sort of social hierarchy.

INCIDENT #6 "Pure altruism"

This overlaps with me being Muslim. I had my boss, he's actually my PhD advisor. We went over to his house for a Christmas party. And he really excitedly handed me a gluten-free beer. And he was like, 'I couldn't believe it when I saw this, and I wanted to get it for you and I'm so excited.' And I had to just be like, thank you. And I just took it because he was so excited, and he was so happy, and he was my advisor and my boss. So, I'm holding this gluten-free beer, and he was so thrilled. He was so thrilled to have found this gluten-free find for me and gave this to me like this rare thing that he was sure I couldn't have. And yes, he was very correct that I couldn't have it. No, I didn't tell him. I took it.

I didn't [tell him] *because he was so excited, and he was my boss. It was just really nice of him. So, I took it, but it was like, oh God, you made this, you got this for me. Oh, it's so hard to say no to people's good intentions and it's so hard when people are happy, they're doing something for you. It was just true altruism. This was actually I'm so excited you get to be part of what we're all doing.' It's a fine balance to advocate for yourself while still respecting the hierarchy. It's a combination of I don't want to offend people. I don't want to call extra attention to myself in a negative way. I don't want to have them think that I'm rejecting something from* *them. If someone's offering you something in good faith, it's not a great look to reject it especially if they outrank you.*

INCIDENT #7 "Appeal to pity"

I would go to work events and people would tell me their food was gluten-free and I asked them about everything they put in it because they'd be pushing me to eat it. Because people push you to eat their food. I'd be like, no, no, listen, listen. Even if you use wooden spoons, there could be flour left in the cracks in the wood. Like I really, I don't want to risk it. I've got to drive home; I can't be sick. And they would be really insisting. 'No, I was so careful. I was thinking about you,' and so sometimes I would give in. And I remember one time someone had made something, and they left out the fact that they had put cream of mushroom soup in it. 'I had you in mind the whole time I was cooking this. I was so careful.' And then of course, I started throwing up; and of course, I had a migraine the next day; and of course, I'm still on campus the next day because you're in grad school and it's not like you get days off. I'm firm when it was clear that I could be, and then sometimes just giving in when people would get too, you know, the logical fallacy of appeal to pity where it's like, 'but you have to do this for me because you need to feel bad for me because of all the work I put in.'

With things like the appeal to pity, which has happened to me more than once at work events where I just kind of give in because they say, 'but I tried so hard and I was thinking of you the whole time and no, no really, I was so careful. I was so careful.' Yeah, I'd run out of reasons. I knew I would hurt their feelings…I knew that I wouldn't have the support of the people around me. So, I think this means that I care too much about what other people think and that's kind of a not nice thing to realize. Yeah, man I give in to social pressure. That's not great. That's not great at all.

INCIDENT #9 “I don’t understand you”

I left the U.S., moved to Saudi Arabia to be here for my aging in-laws. This was 2018. Oh my God. Advocating for yourself. First of all, Arabic is not one language. We have so many different dialects that have basically the same grammar, but the vocabulary is completely different. My Lebanese Arabic, useless … I would try and go out and we had no idea where I could eat or how to explain what I could eat and we were trying to re-navigate the whole situation. What foods are going to have hidden soy sauce in them?

What foods are going to have distilled vinegar outside the United States? It's not safe. Now I can't have salad dressing. That's right because I don't know where the vinegar in the salad dressing came from. All of these little hidden gluten things that had disappeared by the time I moved here because by 2018 we knew about stuff.

[Pre-relocation] I was just living my best celiac life. It was amazing. Life was great. Life was expensive but life was great. Just learning over again from zero and the convenience food didn't exist. All convenience food is imported. That was a whole new thing.

My poor husband is the most supportive person in the world when it comes to this. We found maybe five places where we can eat out. We just go to those same five places but adjusting to figure out those five places was so frustrating. Basically, our rule now is if we try someplace new, we're very careful. We have this whole thing that we tell them like a script but if I get sick, we don't go back. That's basically it. It's trial and error. It's like, ‘did I have a migraine for three days?’ Guess we're not going back.

My husband would need to ask for things for me all the time. Just a complete ‘starting from zero’ kind of situation. He was the one doing all of the talking instead of me. There goes *locus of control. Now it's better. It's been five years. Now I'm fine. Oh, my God. That was just so frustrating.*

[The move] *was another major life upheaval, and it was a complete readjustment, just like getting diagnosed was. It was not just a new readjustment, it was a major readjustment in a dialect of what should be my language, but that I don't understand. Now I do, but at that time, I barely understood it. Just a complete starting from zero kind of situation.*

This move really taught me how to approach travel with more readiness and more preparedness. I never really traveled a lot, but since we moved here, we've been able to... we went to Turkey in 2019 and there's not a lot of English there. There's even less Arabic. Google translated all of the things I'm allergic to. I took screenshots of them and put them in a separate folder in my photo album. I would just show them to people and then we'd communicate by gesture. I just was like, okay, this is how the situation is going to be. I just need to be ready to roll with it. I might just be hungry sometimes, but obviously I carry bars.

Coming here and learning, oh my God, this is a whole new situation. It helped me. Once I got it under control, I was like, okay, I can actually go do stuff. I can go new places. I just have to be really prepared and be aware that it might take time. There really isn't any such thing as an impossible situation in terms of something this simple. It all works out in the end. There's no such thing as a problem. There's just a situation we haven't found a solution for yet.

Betty

Betty is a 75-year-old white female who resided in Pennsylvania. She earned an M.L.S. degree in Library Science, working as a librarian for ten years, before retiring as a Senior Oracle Database Administrator. Betty was diagnosed with celiac disease at the age of 70, after her retirement. She did not have the typical digestive symptoms, but was misdiagnosed with age-related bone density loss, having related symptoms for at least three years. It was not until Betty fell and broke her left femur, which required a rod to be placed in her leg that connected her knee to her hip. Because Betty was not healing, her orthopedist sent her to a rheumatologist for an antigen blood test who thought Betty may have had celiac disease or some other type of allergy. Post-test, Betty was sent to a gastrointestinal doctor who diagnosed her with celiac disease based on the results of her endoscopy. After removing gluten from her diet, her bones began to heal. Below you will find Betty's most significant critical incidents.

INCIDENT #10 – "Gluten on the label, label, label"

The initial incident was when I got home. I just started going through all my cupboards looking for things that said anything about wheat, rye, or barley, and I was really surprised to learn that it was in some things I would never imagine. And so, I was just doing it on my own. I ended up throwing out a lot of stuff, giving a lot of stuff away and checking everything. That was my initial learning experience … the surprise it wasn't just cookies and bread. No, it was, in certain canned foods, certain brands of beans, certain brands of mayonnaise, soups…soups shouldn't have been surprising, but I guess it was at the time, because I didn't know what to expect.

I initially knew to look for wheat, rye, barley, and then go on the computer if I didn't [know]. *If I couldn't be sure I go on the computer and just kind of check and see if the item had gluten in it. And if it was some kind of canned potatoes and just potatoes and water, then I know offhand, well, that's fine. But if it had a bunch of other stuff that I'd never heard of, that was more difficult. So, I kind of erred on the side of just getting rid of it.*

I think it was just the whole idea of going through everything and seeing what I wasn't going to be able to eat and trying to figure out what brands I could buy. After that, every grocery *store visit was just reading contents. Then I was lucky enough to find this app so I could scan things and find out if they had gluten. It felt a little awkward in stores where I'd be scanning barcodes of stuff. I'd be standing in the aisle, and I'd pick something up and I couldn't tell. And I'd be scanning things and I thought, somebody's going to complain, you know? So that was a little bit awkward.*

It was going to be a little harder than I thought it was going to be. I mean, because initially you just think bread, some pastries, that kind of thing. But then you start getting into it. You find out there's a lot more to it.

INCIDENT #11 – "It's up to me"

I think we [neighborhood] had a party. And I took all my own food because I didn't know if there'd be anything I could eat and talking with friends there. I started noticing that I didn't go out with friends as much anymore. Because I think they would be planning to go to a restaurant, and they would know that there'd be stuff I couldn't eat. You know, which is a little, like I say, awkward.

It's gotten a little bit better with some of the people here and everything like that. It's gotten a little easier. Now sometimes when we go out to eat, they'll ask me where I want to go. But I noticed there was, like, we used to go a couple of times a year to this buffet. And I don't think I've gone in a long time, and I know they've gone quite a few times. It's just I don't think they feel comfortable. And I can understand that. You know, it's…that's just the way it is.

I learned that if I really want to go out to eat with some friends, it's really on me to say, let's go out and how about going to this place. And if I just sit back and wait, it becomes awkward for people. So, it's better for me to organize something with a few friends.

I am very much an introvert, but I have to initiate it if I want to go out, and a lot of social things revolve around food. So, if I want to go out someplace, it's up to me to organize something and pick a restaurant I know I can eat at. And then it makes it more comfortable for them too.

INCIDENT #14 – "All roads do not lead to gluten free" or "Glutened on the road"

It was a Road Scholar trip to Bar Harbor. A friend of mine and I go on vacation every year and they had boxed lunches, and they had offered gluten free. So, I had gotten it and there were two different times they had boxed lunches. So, the first time was fine. I didn't have any problem at all. The second time I got very ill, and I ended up spending several hours in the bathroom when everybody else was doing activities. I had actually gone to the tour guide and said I knew I was starting to get sick. So, I said, is there some way I can get back to the hotel? And unfortunately, from Bar Harbor, there was no way to get back to the hotel from where we were. So, I just took over the bathroom for several hours and just stayed in there. That's when my friend got really scared because I wasn't coming out of the bathroom. I did come out and I just said, you know, I'm just going to have to stay in there. And I think the tour guide got really scared, too. But it was no use calling any kind of doctor because there's nothing anybody could do. You know, you just have to ride it out.

It was not a good experience at all. I don't think she [the tour guide] *really understood until after that* [me getting sick]. *So, I don't think I want to go on any kind of trip anymore where it's not near a city where I know that there's transportation if I needed to have it. I never expected that. I guess I didn't really understand Bar Harbor being a little bit more isolated than I thought it was. If you've got Celiac and you go to Bar Harbor, it's different.*

But I'm going on another trip with Road Scholar. And like I said this time, I put on the thing I want to know what restaurant you're going to, what days you're going to have boxed *lunches so I can prepare. I can go someplace else, or I can bring something, so I know how much food to bring with me. I'll just bring granola bars that are good and that kind of stuff. Maybe some boiled eggs or something.*

I learned, don't believe it when they tell you something can be gluten free. If they are not specific, they probably don't understand the difference between celiac and gluten allergy/ intolerance. *So, I shouldn't assume - you can't assume anything. You can't assume that they'll understand it all, especially cross contact. I don't think they picked up on that at all.*
It was significant for me personally and I am a little bit more – suspicious, you know? Don't assume that for something like that, don't assume that they understand at all. You know, once again, you just have to be proactive, so you don't end up in that situation.

Carole

Carole is a 72-year-old white female who retired in 2023 as hospital administrator for a veterinary clinic that she and her husband co-owned. She resides in Nevada and was diagnosed with celiac disease at the age of 68 after incurring a problem with digesting wheat for ten years prior to her diagnosis, in addition to a lifelong issue of mouth sores and subsequent neuropathy. Below you will find the significant events that Carole shared in her interview.

INCIDENT #19 "Don't make assumptions"

One specific incident is my husband and I had been to dinner at a place several times and I had a specific dish that I was told is gluten free and I did not have any sickness with it. So, the next time we went to the same place, I had the same thing and almost immediately after I started eating it, I started having some bloating. They had a new chef, and he used flour for the thickening, whereas the other chef used cornstarch. So that was a learning experience in that I needed to ask every time. Not just assume that that that things were still the same.

Callie

Callie is a 25-year-old multi-race (white and Vietnamese) female research assistant who lives in Texas and works as a research area specialist in clinical trials. She has a master’s degree in biomedical science and is currently earning her second master’s degree in social work. She suffered with symptoms until the age of nine when she was diagnosed with celiac disease. Callie shared that it was not until she moved away from home to attend college that she experienced “a big learning curve,” realizing what a responsibility it was to self-manage her own health. Below you will find Callie’s most significant critical incidents.

INCIDENT #26 – “All grown up”

A lot of what I learned came a few years after I was diagnosed because growing up my mom pretty much took care of it for me. I just ate what she gave me. She cooked my meals. My dad packed my lunch for me. I just grabbed my lunchbox and went. I didn't really have to think about it. It was a really big learning curve when I moved out and I was on my own.

When I moved out, I wasn't with my parents at all. I lived in El Paso. I was 10-12 hours away from where I could be near them, and they could just come over and help. So, the hardest part with that was learning to cook, I guess, just in general, just learning how to cook and what ingredients I can have, down to the spices. I can have this brand of spices, but not this brand of spices. That was just a really big learning curve.

I think I just felt more alone. I knew I had a support system in the sense that I could always call my mom or my dad or call whoever. But it wasn't like they're right there and I can like ‘Mom like can you please just do this.’ It just felt more alone and a little bit more isolated in a sense.

Really, what I did was I called my mom. I was like, mom, what do I do? I don't know how to cook. What meal do I eat? And she taught me that I really needed to pay attention to the labels and pay attention to the small things. Don't eat maltodextrin. Don't eat this. Don't eat stuff like that. She sent me books. 'These are the books I read when I was learning about your disease when you were nine.' They [the books] *really helped her, and they helped me a lot too during that phase of my life. It gave me a lot of information that I didn't even think about.*

You can only be so prepared but if I could, I would have paid more attention to growing up and asked more questions. I never really thought to ask questions. I guess the conclusion is just try and ask as many questions as you can no matter when you're diagnosed. Be as informed as you can because I think the more informed I was the less intimidated or alone I felt.

INCIDENT #28 – "Celiac is not my identity"

I guess having to order in front of my friends. Like, 'Oh I want this and then I'd have to be like no,' then 'I need you to do this and this because I have this allergy,' and it would take me a little bit longer to order and figure out if I could even eat there in the first place. I think that a lot of what I dealt with in a social setting was more mental in that sense.

It can be really isolating in the sense that when you're at a birthday party maybe you can't eat the pizza that's provided and other kids are looking at you, 'why can't you eat this pizza that my mom brought' or 'why do you have your own cake' and 'why did you have to bring your own cupcake?' For a kid, I think that can be really hard because you don't have that answer. You don't know. So, having to grow up always kind of being on the outside, or not being able to be included in that pizza party, I think makes it a little tougher to feel included. Just trying to grasp that idea of I am like everybody else. I just can't eat that food.

And then having to go into high school where nobody knows what Celiac is. I barely know what Celiac is and having to sit down at a restaurant and order completely different than everybody else and not be able to laugh and giggle and be like yeah, I want the chicken parmesan. I think in my personal experience [it – celiac] *has been just like a tough mental game to play with.*

I think now I'm over it. The people I've surrounded myself with understand what Celiac is. So, it's very easy to be like yeah, I have this gluten allergy. I can't really have that, or I need you to change your gloves and stuff like that. But in high school nobody understood that. It just felt like they didn't understand that they didn't understand me.

It was eye opening in the sense that if my friends don't have a family member with celiac or they don't have it themselves they're not going to know what it is. And so, I'm going to have to teach them. And that was hard as a teenager because I didn't know what it was. I just knew I couldn't have certain foods. I didn't really know how to explain it and make them understand who I was because at the time I felt like Celiac was my identity. So, they didn't understand that they weren't going to know who I was … It was hard to teach them that. I think that what I noticed ... was the more informed I was the better I felt about myself ... the more I knew about my disease and about Celiac in general, the more comfortable I felt ordering at restaurants. It didn't scare me as much. I didn't feel embarrassed to do it in front of others or anything like that. … as I've gotten older [I've learned] *that Celiac is not my identity. I am a whole other person outside of my disease.*

INCIDENT #30 “Tell, even if they don’t ask”

The job I have now is my first real serious job. When I first started, I didn't know them [co-workers] *as well and they would go out for lunches. If it was somewhere I knew I couldn't eat I would be like oh no it's OK, I don't want to go. I brought my lunch. They would try and encourage me to go like oh it's not like you can eat your lunch tomorrow. No, it's OK. It's not a big deal. I think at the time I hadn't told them about my disease. That's probably why they continue to encourage me to come. I think it was just, I didn't want them to have to be forced to go to a place that does have gluten free options or is gluten free and they not be able to get what they actually wanted because I couldn't eat there.*

We did a little game, get to know your co-workers, and they're like what's one food you don't like. I put gluten. ‘What do you mean?’ [they asked]. *Well, I have this funny story…, ‘Oh my gosh why didn't you tell us? We wouldn't have gone to all these places that you could not eat, it's not a big deal.’*

You should just trust people, like, your disease is not something to be ashamed of. It's okay to tell people and more than likely they're going to be supportive of it. It's not some contagious disease that they're going to catch all of a sudden. Even if they don't understand it, I've never encountered somebody that's given me hate for it either. Even if they didn't understand it. So, trust the people you surround yourself with. It’s okay to ‘be.’

INCIDENT #31 “Don’t hold back”

Last summer I went to Cancun with my boyfriend and his parents. On that trip I was really nervous. I was like, I don't know what I'm going to eat. I guess I'm just going to wing it. If I get there and there's nothing to eat, then I guess I'm just going to starve. Who knows?

I don't know what's going to happen. So, I was pretty nervous going into it especially considering Cancun is Spanish speaking and I do not speak Spanish. I knew that whatever was going to be said was going to be through a middleman. Not that I don't trust my boyfriend, I do. Still, it was going to be through another person, not myself.

I was pretty nervous going into that. But once we got there it was okay. We stayed at a nightly resort that had gluten free options, but all the menus were in Spanish. Basically, the entire trip I couldn't leave my boyfriend because I can't read Spanish. He was great through it all. Whenever I needed to ask about certain options or what they had or anything like that he was really great and patient and helped me through that trip.

All the other trips that I've taken have always been with my parents and my parents have planned it out. This was the first trip that they weren't involved in the planning or the stay or anything like that. It was kind of intimidating to do on my own for sure.

Sure, travel is scary travel, but that shouldn't hold you back. You should definitely still experience anything you want to. If you want to travel to Europe, you should still be able to experience those things without the fear of not being able to eat. I think next time for a different trip or a different place I'd probably research more about the location I'll be at for sure. I'm not as scared or nervous going into it. Travel with people that understand your celiac disease and can also advocate for you if needed; or make you feel safe in a sense in terms of your celiac disease.

Heath

Heath is 73-year-old white male who resides in the state of Virginia, who earned a medical degree and retired as a pediatric rheumatologist. Heath was diagnosed with celiac disease at the age of 68 after suffering with gastrointestinal issues. In addition to celiac disease, he has lived with a shellfish allergy for over 30 years. Below are Heath's most significant critical incidents.

INCIDENT #33 "Unknown preparation"

I'm a doc…I have access to information. I think one of the other things is the last decade of my practice, my primary nurse and her daughter had celiac disease. So, I would find out stuff indirectly through them. What she would eat and what was around and what we didn't do and things like that. So, I sort of slid into it.

I mean, it was one of these things of, folks would bring lunches or things like that. She would have some things, she wouldn't have other things, and [I] *sort of paid attention to that. It was that kind of stuff that* [I] *just sort of noticed. I mean, knowing you don't do soy sauce. I learned that one before I was diagnosed, from my, from my nurse and things like that. So, again, as I said, it really was sort of an evolution, so it wasn't as big a deal to me once, I was officially diagnosed.*

You learn from your mistakes, and it was, again, oh damn, what did I eat two to three days ago that did this and I literally kept a notebook for a while of what I was eating up to when I was diagnosed, but again for a while afterwards, just trying to track what the hell was going on.

INCIDENT #34 “Be the change”

I go to a lot of professional meetings. What I do is I try to get there early and walk down the line reading what things I can have, what things I can't have. Over the years, if I’m not sure about things, I’ll ask all the servers. I've gotten now a number of organizations (and I'm on the boards over stuff like that) to make sure that they always have gluten free food available. It’s gotten to a point, when people are sending out invitations, ‘if you have any food allergies’ ... gluten free goes on all the time.

The American College of Rheumatology has a Washington Hill Day, every year, and they now have significant number of gluten free options. I like to think I helped make sure that happened. So that's been a change in the menus that they've had. There was a flourless chocolate dessert. It didn't ever used to be like that. At these buffets where you've got 100 people or something like that and the line goes on forever, [pre-diagnosis] *I would always walk over to the dessert table and eat one or two desserts and let the line go down. All of a sudden, I couldn't do that* [post-diagnosis] *because everything had gluten in it. And now I can. What I've been finding actually, which is interesting is that there's more and more of these buffets now that you've got adequate gluten free food you can fill yourself up on. If not, there's always coffee.*

So, again, I sort of had been primed for this, I think, over the years, in many ways. But I do think, as I said, people are much more aware now. If I'm in a situation where there's things going on, I'm much more open. I don't want to say aggressive, but I'm checking everything and figuring out which things [I can have].

So, I think as we're talking about learning, I think there's a lot more institutional and corporate learning going on more than my individual learning. As I've been at different hotels and restaurants and things like that, I'm noticing it's more GF on the on the menus. There are *people* [who] *know what you're talking about when you ask the question. And it's not a big deal to them to go find out for you as well.*

Holly

Holly is a 43-year-old white female, Pennsylvanian who earned a bachelor's degree and currently works as a systems administrator for a local university. She was diagnosed with celiac disease at the age of 36 after having symptoms for most of her life. After being diagnosed with a wheat allergy as a toddler, the allergist told her mother that she would outgrow the allergy and that she should be fed processed wheat instead of whole wheat. Years later when she was in college, she was diagnosed with irritable bowel syndrome (IBS) and upon her symptoms' digression, Holly was diagnosed with celiac disease. Below you will find Holly's most significant critical incidents.

INCIDENT #38 – "I didn't realize that"

At the time I was diagnosed, I lived alone. So that made it a little easier to know that I wasn't going to get cross contact in my home once I figured out what I was doing, which was a little bit of a learning curve. I ended up looking up a book on Amazon to help me, guide me through those first few weeks of what I needed to do to adapt my kitchen to be gluten free. It was the one by Jules Shepard about your first year living gluten free with celiac disease. I found the author's blog and read that as well.

I knew I had to read labels because the doctor told me I had to read labels, and I was used to reading labels because of having other allergies. But I didn't realize that on dried fruit, for example, when it said it may be processed on the same equipment as wheat and wasn't labeled gluten free, that didn't necessarily mean it was safe for me. I had to actually cut that out of my diet because I wasn't feeling well while still consuming that.

I also didn't realize that I needed to stop eating oats for a few months after diagnosis. I also had to clean out my kitchen, not only get rid of all the gluten containing products, but also just clean up all the crumbs, replace some cookware, replace my toaster. There's gluten in a lot of things. A lot of unexpected places. It's also tricky whenever a product is not labeled gluten-free to determine is the product actually gluten-free or not. At first, I didn't realize single ingredient products like a can of diced tomatoes didn't necessarily have to be labeled gluten free.

INCIDENT #42 "You should eat what is available"

There's about five other people (out of 50) in my office that also are gluten free. I and one other person are the only people that can't have dairy as well. The rest of the women, gluten is the only dietary restriction they have. So, for a holiday party, they were going to have food brought in from a Mexican restaurant and it could accommodate gluten free and dairy free. Well, when I went on the restaurant's catering website, I was looking to see if it could accommodate my other allergies. And I saw it could not. I had reached out to the HR rep and asked if they could get a meal brought in for me, separate from what everyone else was getting since I couldn't eat what was available. She was not willing to do that for me.

I called her out on it. I said, why should I be the only not allowed to get food from the outside paid for by the company when everybody else can? And she said, well, you should just be able to eat what's available. I was just very offended by this. And I just felt like she didn't take my dietary restrictions seriously at all. So, I ended up bringing my own food and keeping my mouth shut. Luckily, she's retired, and I don't have to deal with her anymore.

Well, another thing that had happened was some of the women that were gluten free had brought a dessert for all the gluten free people to eat, except it had dairy in it. And at the time I *was the only one who couldn't have gluten and dairy. And so I felt isolated from the gluten free group as well. It's just easier to bring my own food.*

INCIDENT 43 – "You take me seriously"

[At work] *they had an event and when they had the registration sent out, they actually asked what people's allergies were, which I was quite impressed because most of the time when they send a registration out like that, they don't ask for that information. So, I have to reach out to the contact and figure out, hey, can you provide a meal for me? Here are my restrictions. So, I put my information in and then whenever I got to the event, there wasn't a meal there for me. There wasn't anything I could eat there.*

I went and talked to one of the organizers and she was apologetic, and she made it right. She went and talked to one of the food service workers and said to the food service worker, this woman has a lot of dietary restrictions. Here's what they are. Can you please make her a meal and just charge it to the same account for the catering? And they did that.

I felt like my dietary needs were taken seriously. And I appreciated the compassion she had. She's like, don't apologize for something you can't control. I kept her contact information. It's okay to advocate for yourself and make sure that your dietary needs are met. I didn't feel isolated, it made it more enjoyable.

Joanna

Joanna is a 31-year-old white female who lives in Massachusetts, has a PhD in computational biology and is employed as a regulatory manager for a small biotech company. She was diagnosed with celiac disease at age 26 during the middle of her PhD qualification exams after having symptoms of exhaustion and disconcerting hair loss. She visited her primary care doctor who diagnosed the problem as stress due to graduate school and who recommended that she lose weight and stop eating out all of the time. After suffering with symptoms for a year, she found an endocrinologist who did bloodwork that indicated she had celiac disease. Joanna's most significant critical incidents are listed below.

INCIDENT #48 – "This is the rest of your life"

Before we really understood all the cross-contamination and that sort of thing, trying to make lunches was a really big challenge. A gluten free one for me and then whatever for my husband. But trying to make a gluten free sandwich for me and a gluten sandwich for him, I remember washing my hands ten different times and trying to remember, did I touch this? Did I touch that?

It was just so confusing. We've since moved on to like we both pretty much eat gluten free and I'm very thankful for that. I don't have to worry about it anymore. But just trying to manage the gluten shelf and the gluten free shelf and which bread goes where…I just remember being a really tough challenge.

I was frustrated. It's like, why do I have to figure all this out? Why can't I just eat gluten? I realized how impactful this disease was going to be on the rest of my life. The time-consuming aspect of it. Somebody without this type of disease or allergy or something like that would just never even have to think about that. They could just get up in the morning and make those sandwiches for lunch and just go about their day. There's no cure. It's like, this is the rest of your life.

I came to the conclusion that I can do it. It took some time and a lot of effort and making a process that would work for me and my family, but I can figure it out. And so, I think that was one of the earlier things that helped me realize, I can figure out other things like going to a restaurant or going to a family member's house who does not have a gluten-free kitchen.

Now I just feel more comfortable with it. I don't sit there and wonder anymore, oh, how am I going to do this for the rest of my life? I'm just like, this is what it is. I can handle it and, you know, move on to the next thing.

INCIDENT #50 – "Dr. Google"

I remember things would pop in my head and be like, am I going to get this because I have celiac disease? And so being really anxious until you go Google it. I knew I wanted to have kids, and I hadn't had kids at the time, but I remember I was in a meeting with my boss, and I was like, what if celiac disease has an impact on fertility? And I was like, oh, boss, I need to go look at something for work. And went back to my desk and was Googling it frantically because I had to know if that would be a challenge or not. So, learning about the other diseases, too. That was tough.

Just not having, like, you always hear oh, Dr. Google or WebMD, like those things or they just tell you that you're going to get cancer either way. So, it was hard to know, well, is this real? Is this, you know, is this just Dr. Google being dramatic or what?

I tried to look back at what the actual source was. I was lucky to be in a science grad school, so l felt really comfortable reading peer reviewed journals. I felt, maybe, you can trust those a little bit more than somebody's Facebook post. But I realize that's not everybody's situation. So, if you read something on Facebook, how are you supposed to know whether or not it's true? If you don't have that sort of background or you're not comfortable reading medical journals or articles, especially if your doctor is not really guiding you. I would imagine that would be really tough.

I think on the same day [I was googling] there was one post where they found evidence of celiac disease in Neanderthals. It's like an ancient disease. And then another post that was like, *it's brand new. They can't both be true. But they're both on this Facebook group that my doctor told me to join. This isn't helpful.*

INCIDENT #51 – "Keep it simple"

Somebody at my company that I've known for a really long time and who is quite a bit higher up than me in the hierarchy was having a couple people over for Thanksgiving, including myself and my husband. They're super nice and I think they really wanted to feed me. But it was really clear that they had no idea about the gluten situation. For grilling out, they wanted to toast sausages. I asked do you ever toast buns on your grill? He's like, 'Oh, yeah, but it gets so hot, it just burns off." And I'm like, oh, oh, no, it doesn't.

So, trying to educate somebody who really, really wants to help and who is pretty high up in my company and not wanting to offend them or make them feel like any type of way in their own home. That was something really challenging for me. When it's like a work situation, that's another layer of challenge because you don't want to offend people pretty high up in your company or things like that. I just ended up bringing like 100 percent of my own food and tried to eat it off to the side.

I don't know if I handled it the right way. I definitely felt so awkward, like trying to tell them, no I can't eat this because you used a sponge on all these gluten items, and you just wiped down this plate. I can't use it, especially when they're trying to be so accommodating. I think they even like bought gluten free food, but the way they served it just wasn't safe.

[There was] *a lot of guilt. I would say a lot of guilt and awkwardness probably were the two big words. I guess maybe it was more internal that I just felt really guilty about not being able to take advantage of the food that they had gotten for me. I learned to keep interactions about food simpler and not try to poke around and see if I could eat something to make* *somebody happy. Just tell them up front like I'm going to be bringing my own food. Please don't be offended or think that it's about you. It's about me. It'll keep me safe, and we can all have a good time and not worry so much about food.*

I think going forward, I would probably just do that, especially if there were other circumstances like a co-worker or like somebody, you know, not on my level at work, just because that's another layer of challenge.

INCIDENT #52 – "Pancake breakfast"

At work … they will occasionally make pancake breakfasts where they cook it on site. And there's a blender and it's just like the pancake batter and the mix everywhere all over the shared kitchen. So usually, I won't go into the office on those days and a couple of days after.

But there's been times where I will show up and there will be like pancake stuff everywhere. And I have a mask, like that N95, and just kind of do the best I can. But I don't want to be the person that stops pancake breakfast. I haven't said anything, even though it probably does make the kitchen really contaminated. The whole office is open plan, so, it probably wafts over to the desks. There's not like a wall or anything between the kitchen [and the rest of the office].

I mean, I don't want to be depressing, but it's just some situations are just not safe and there's nothing you can do. You just have to take yourself out of that situation or be petty. What's the right word? You can't be ashamed of wearing a mask or maybe taking a paper towel to touch the microwave and not be embarrassed about that because you have to keep yourself safe. When the situation is pretty serious, like flour all over the place, even though I was maybe a little too timid to go to the office manager and say, hey, can we not do pancake breakfast, or maybe can you make the batter outside and bring it in? You know, something I can do is wear a mask.

But whenever they say you missed the pancake breakfast I was like, oh, well, that's good, too. I'm going to head out of the kitchen because there's probably, you know, gluten in the air. They were a little confused. And I was like, yeah, it can hang in the air after you bake with flour. And if you breathe it in, you could get sick if you have celiac disease. So, I did some educating in that circumstance, and they had no idea, and they felt really bad. But that made me feel bad. I didn't want to ruin anybody's pancake breakfast.

I'm not private about it at work, but I just I don't want to be in the spotlight or have attention on me. But that was maybe one of the earlier times where I just told my co-workers, I was like, I've got to go. And here's why I have celiac disease. I guess the conclusion was it's okay to share it. Maybe not be as worried about if people will feel bad or not, especially when it's a safety issue.

INCIDENT #53 – "Please don't eat the food"

We had been invited to a friend's wedding and they were nice enough to tell us at the tasting we noticed there was some food, and they said it was gluten free, but it had a crust on it. And then the worker just came and took the crust off and left the food "gluten free." So, I'm sorry, please don't eat the food at our wedding.

I'm glad they noticed that that happened. I think that was one of the first times that I brought my own food to a wedding and just put it on the plate and ate it when everybody else went through the buffet or whatever it was. I felt a little bit awkward doing that, but I've done it a couple of times since and it's always been fine. And if people have questions, it's no big deal. You just kind of explain what you're doing and why and they accept it. Nobody's ever been rude about it.

Even if people like to notice that you're doing something a little weird with your food, nobody's going to be talking about it a year after like, oh, my gosh, she brought her own food. Even if people kind of look at you, that's what it is. They're going to move on. So, it doesn't really have to be anything embarrassing.

It's okay to ask for more information. I mean, in that case, they volunteered the information and I'm really happy that they did that. But there's been other times where I have no problem going up to the restaurant manager and asking, even in a buffet at an event, asking for details on how they prevent cross contamination. I think one of the last times I went to a buffet, I even asked, hey, can I go first? So that way nobody cross contaminates. And you feel rude doing that. But I did it and it was fine, and nobody was like, oh, my gosh, she's so rude. You can advocate for yourself.

INCIDENT #54 "Crying in Kroger"

Something really challenging that I had to learn was like my first grocery store trip after my diagnosis. I think I spent two hours in Kroger trying to buy food that was going to be for my new lifestyle. And that was huge. That was really tough. I think I was crying in the store.

You think something's gluten free, and you look at the label and you're like, oh, wait, no. So, I would say that was a massive learning undertaking was just how to shop with celiac disease. I was in grad school at the time, so we were on a pretty strict budget. So that was a little bit tough.

I think I tried to just find what I would normally eat, but just look for the gluten free version of it. I feel I've since learned that it's probably best from like a health standpoint, if you can do more produce as opposed to just try to find the gluten free version.

I mean, if somebody does just eat the gluten free version, that's fine. I would never judge them for that. It's really challenging and expensive to eat produce and stuff. But I guess I would try to encourage somebody to cook their own foods. Just from a health and cost standpoint.

I think that's when it really hit me, how much of an impact on my lifestyle it would be. I definitely was emotional in the store, picking up probably the 10th can and being, oh, this has to be gluten free. And it's like, may contain wheat. Well, got to find something else.

So, yeah, I just remember that is when it was kind of the impact, this is tough.

Mary

Mary, a 40-year-old, white female, developed minor food intolerances by the age of ten, also suffering from contact dermatitis on her hands in her 20's. Her symptoms continued to worsen, with more definite gastrointestinal symptoms, including chronic bloating. At the age of 36, Mary was finally diagnosed with celiac disease. She holds an associate's degree and works full-time while living in Virginia. Mary's most significant critical incidents are below.

INCIDENT #57 "Caring nurse"

When I had my tonsils out, I was so worried that they were going to give me medication that had gluten in it that I literally wrote it on my hand. Like, do not give medication that has gluten in it. I wrote it on my hand, on both sides. They are not going to miss this. And when I when I woke up from anesthesia, I asked the nurse first thing…my medication, does it have gluten in it? And she's like, this is the third time you've asked me.

But you were concerned. And she's like, I realize when people are asking multiple times as they're waking up, that is something they're really concerned about. So, I called the pharmacist after the second time you asked me to make sure your medication was safe for you, it was gluten free. I was like, this is amazing. This is special.

She talked with me about my experience of being diagnosed with celiac and that kind of thing. And asked more questions about, you know, my life, what it meant, how it impacted my life, that kind of thing. So that was really, really nice to be able to chat with her and just feel like there was a medical professional in the room who cared.

INCIDENT #58 "A family affair"

So, I think when I first got diagnosed, it was not only hard for me, but it was also hard for my family. My family goes to my parents' house every Sunday for lunch. And my mom is a very loving mom, and she loves to cook for people. I think it was really hard for her learning that it wasn't necessarily the type of thing where she could cook for me anymore in the same way. And so there were some instances of I think it was a grieving process for them as well as for me.

But even just learning to mitigate those kinds of situations, like to handle how do we do a meal as a family? How do we work around that? And I'm the first person to be diagnosed with celiac in my family and to be diagnosed with a gluten issue at all in my family.

But I think it was very much a learning experience for all of us, even just understanding the lengths I had to go to just keep myself safe. So, something we've done to mitigate that is my mom will still have things like carrots and things like that that I can peel and have for vegetables. My sister has also been diagnosed with gluten intolerance. So now there's two of us.

I have a box that has my own dishes. It has my own cutting boards, knives, that kind of thing, so that we can access that when we're cooking at my mom's house to have something that is safer for my sister and I to be able to use, which is a sealed box, too, so it's not something that gets easily contaminated. My mom now has two cooking areas in her house where one has a stove and has ovens with the other one has a microwave. It's the type of thing where one can be more designated gluten free and the other one can be more regular.

I feel like my family has come a very long way and are very much open to say [to visitors] Melissa has celiac. That's why her food's a little different. And I'm totally OK with that, too, because I feel since it is so rare and not known as well, the more people who have questions that I can answer, the easier it will be for not only myself, but other people down the road.

INCIDENT #61 – "Clueless bosses"

I work with children, but I don't give them snacks or anything of that nature. But during COVID, you know, all of the sanitizers that came out and I tend to be extra cautious about anything that I put on my hands because, you know, if it's on my hands, eventually it will get into my mouth in one form or another, whether it's because I'm eating food that's finger food or what. But I had to look at different sanitizers. I had to look at different things of that nature. I created a box of my own sanitizer, my own hand lotion. And it's Melissa's box, please don't touch it, that I had in my room. But since then, my bosses have been like we're not comfortable with you having that here when you're not here. So, you just have to make sure that you bring it in and take it out. I can appreciate that, but it also adds extra to me as well. Could just put it in a locker with a lock when I'm not here. They said, 'No, we don't even want it in the building if it's going to be that sensitive.'

I learned that some people don't necessarily understand, and you have to speak up for yourself. A lack of understanding on the bosses from the boss's standpoint, as well as a lack of general knowledge about it, which I mean, Celiac is not very well known anyway, but sometimes some of my coworkers will ask me about Celiac and I love that because then I can advocate for myself as well as advocate for the next person that they meet who has it. At the very beginning, there was a coworker who had Celiac as well, but we were not the closest of coworkers either. But it was nice to be able to have someone that was like, hey, look, this is gluten-free, you can *have this. I really enjoyed having these instances when people who are gluten-free can work together and to be like, we support each other.*

Ryan

Ryan is a 59-year-old white male who resides in Florida. After earning a bachelor's in mathematics, he continued learning within his career, obtaining multiple licenses, and ran a team at Deutsche Bank in Tokyo, specializing in trading Japanese equities. Ryan noticed gastric symptoms beginning in March 2019. In October 2019, at the age of 54, he was diagnosed with celiac disease through bloodwork and endoscopy. Ryan also suffers from the comorbidity of lymphocytic colitis. His most significant critical incidents follow.

INCIDENT #65 – "Cooking school"

Learning to improve my cooking skills, this was mostly a hands-on effort. Obviously, I was reading recipes, et cetera, but the key point was to actually do things. My wife is a Japanese national, certainly a significant portion of what we eat is at least derived from Japanese food or related to Japanese food. How do we interpret all this in the context of Japanese cuisine? Japanese cuisine uses a lot of soy sauce. That was right up there. But we also had lots of questions. You know, does miso ever contain gluten? The answer around miso is very, very complicated.

We had this problem that we both needed to understand what I could eat, what I could not eat, what foods contain gluten, maybe what kinds of risks there might be, even if food didn't obviously contain gluten, issues around fryers, cross-contamination, this kind of thing. Sometimes the names of ingredients are not obvious, right? Some things are obvious. Obviously, another important consideration is if you knock out bread, you knock out pasta, everything else, what are you doing to yourself nutritionally?

I'm presenting my wife with a very frustrating assignment to say the least. She's been cooking all her life and is very happy with how her style has developed and obviously it's like doctor's orders and it is biologically grounded commentary, but it is a significant monkey wrench. My wife recognizes that I need to get food. At some point we just, you know, knuckle under and deal with it.

I sort of think of like, you know, successively expanding circles. You start with the very basic things, and you keep adding. I was able to develop…really, my wife was not excited about being, a cooking teacher, shall we say, but she was certainly willing to answer questions. And I think over time I was able to distill down what I was uncomfortable with to get better at that. We got to be comfortable asking the right kinds of questions or asking a sort of a pointed and scope limited question that would help me.

INCIDENT #66 – "Cooking in Japan"

There was a very strange quirk in immigration rules during the pandemic where I could go to Japan and my wife could not. My children wanted to go to Japan. On two occasions for multiple months, I went to Japan with my children, and I did the cooking. That took the bar up quite a bit.

I needed to cook something, the whole meal, shop, and plan and cook the whole meal for myself, conforming to my diet…something that I enjoy eating and children would like it too. Children, just to be clear, currently 25 and 23 - adults at the time.

I think I'm very happy to be more able to produce food, not just any food, but many foods that I'm happy to eat. And I know that I'm producing something that is safe and nutritious and has good ingredients. And yeah, it's a very good thing.

INCIDENT #69 – "Sailing away"

I went to a sailing school and there we definitely needed to talk about diet and celiac because it was five nights on a boat, and we needed to cook for ourselves. I was very lucky there. One of my classmates was a very good cook and he basically did the whole thing. I think that made it much easier for me because I think I was confident cooking for myself. I wasn't necessarily confident cooking for a group of four people on a boat.

Clearly, when I signed up, I initially thought I couldn't take the course because it's a small space. You've got three students and an instructor. You're a week on the boat. And you learn how to cook in this crazy galley on the boat, which isn't very big. The cookware is limited and it's different. I thought that it would be kind of maybe too much of an imposition to need to impose my food restriction over the course of a week, but they were happy with this, and they were able to provision, subject to this.

They'd heard this before; they knew what to do. We figured it out as we figured out many things in the course of this weeklong experience. There're all kinds of things to learn, and in the sailing aspects of things, the instructor told us an awful lot that was in the book and all the rest. There wasn't really that much discussion around how to go back to cooking for yourselves, but we figured it out.

This guy was there who was just very good and enthusiastic about cooking. And he kind of went into the provisions and said, 'Oh, you know, I'm trying to think that I would make a few things.' Well, I told him what I needed to do. Well, you know, he accepted it. Remembering the whole provisioning has been somewhat tilted toward my request. We didn't write his ingredients, generally, there were a few exceptions, but largely were things I could eat.

It was much less of a problem than I had anticipated. Initially, I thought I couldn't take the course…I had a lot of apprehension about…I assumed that I was going to have to do much more of the cooking.

I was very lucky, as I say, to have this fellow participant on the course. That was a nice surprise. I realized that they did a good job of provisioning. I was grateful for that. You know there's certain scenarios where you realize that things are maybe possible but might be quite challenging. And sometimes they turn out to be harder than you had to say and sometimes they turn out to be easier. I think this one turned out to be easier.

Rosemarie

Rosemarie is a 77-year-old female who is an elder in the Chippewa (Ojibwe) tribe in her state of Michigan. She is a retired executive assistant who worked for the assistant superintendent of human resources at a local school district there. She was diagnosed with celiac disease at the age of 75 after three years of symptoms. She was very sick for six months pre-diagnosis, when she had the most difficulty eating and was losing weight. She was also diagnosed with osteoporosis. Rosemarie's most significant critical incidents follow.

INCIDENT #73 – "Gluten free country clubbing"

I golf with a group of ladies every week in the summer. And we're at a golf club and there is nothing there I can eat. So, I bring my own lunch and they're very nice at the golf club. They don't have an issue with me bringing my own lunch into the restaurant. That's kind of tiring at times, having to, on hot days, make sure that my food stays cool and not having the convenience of just walking into the restaurant and being able to order something. I have to go back to my car and get food that I can eat. It's inconvenient, but I have to prepare ahead of time. They do have salads there, which I did eat for a while. And I would bring my own salad dressing because they *didn't have any dressing that didn't have soy in it. But when I did that, I got very sick after being there and it lasted for three days. I think somehow it [the salad] was cross contaminated. So, I was afraid to eat.*

When I see everybody ordering things that I used to enjoy, I always think things could be worse. It bothered me a lot more at first than it does now. Now I look at it as something that's going to make me sick. I've been sick several times and it's not good. It's not a pleasant experience. So, it doesn't bother me now.

Sarah

Sarah is white 64-year-old female, who lives in Jordan, having moved from the United States in 1997. She is originally from Kansas (her grandfather was a wheat farmer) and worked as a registered nurse in hospitals, nursing homes and home care. Her journey with celiac disease began when she had to have a biopsy of a lump above her breast, which as negative, but led to further tests such as a dexa scan that showed she had osteoporosis. This diagnosis led to further blood work that tested the antibodies (tTg-Iga) that indicate celiac disease. Sarah's blood work indicated she was positive for antibodies despite not exhibiting celiac symptoms, and in 2020, at the age of 60, she was diagnosed with celiac disease. Her most significant critical incidents are below.

INCIDENT #76 – "It's not you, it's me"

OK, well, I have two sisters-in-law that live in Jordan and they're wonderful cooks, and I love their food. But I made a decision to just not eat it anymore. And I was very worried about how they were going to react to that. It's complicated because I don't want to interfere with my husband's socialization. You know, I want them to feel comfortable inviting us for lunch. I just bring a container of something to put in the microwave and I eat my food and they're okay with *it. They know that it's not about them because I used to eat their food. But it's been awkward a little bit. Then they'll be, what do I accept when I'm there? Okay, I will drink their tea, and I'll drink their coffee and then they bring the fruit and hopefully there won't be anything added to the fruit. My sister-in-law offered to be very careful and make food I could eat and she's making food for like thirty-five people and none of the rest of them are on the* [celiac] *diet. And like, please do not go to all this trouble. It's because I don't necessarily trust that it will be safe anyway, even if she does. And I don't want to hurt her feelings. I beg you to please just let me bring something and then I will be more comfortable. And it's not about you. You know, I love your cooking.*

I've come to the conclusion that it's safer for me to eat as little as possible of other people's cooking, you know, just in general, whether it's eating out and maybe I'm too careful. Maybe I overthink. I know I overthink. I definitely overthink. I think about it more than I want to think about it.

When you have celiac, it's like you have to expend energy thinking about your food a lot. I mean, not as much as some other people, because I have a lot of control most of the time. I mean, everything you eat, like when I go shopping, I read every single label, you know, of everything I buy. All the time. I mean, even things I bought before, sometimes I buy I'll read the label again because they change. I'm very reassured when I see the actual words gluten free and not just no gluten ingredients, because that doesn't necessarily mean it's safe.

With me, because it's all encompassing now, it's everything I buy. So, it's a constant awareness of where the gluten is and where it isn't. You know, as a nurse, I learned to think about sterile and not sterile, clean and dirty. And it's kind of the same kind of concept, knowing where gluten is all the time.

INCIDENT #80 “Sometimes, I don’t bother”

When I traveled on the Royal Jordanian airline last year. I mean, on the airplane, you have no choice, really, although I always bring something with me. They bring the little cart still with the cheese and crackers next to each other. It's like, really? You're doing that? It was just a 13-hour direct flight to Chicago. I don't know, I didn't want to try to educate them. So, I ate the food that they brought and set directly on my tray. I ate nothing off those carts. They need to be educated, but I didn't want that to be my responsibility. I didn't want to think about fighting with the staff.

Education is, you know, has been a priority of many people in Celiac. And you're talking about education. And here I'm saying, I don't want to do it. It’s just – it can be exhausting. I didn't know that I would really trust them, even if I did explain because I already made my general speech at the beginning: I'm on a gluten free diet. I always tell them first thing when I, you know, when they come around and introduce themselves, you have to make sure it's really gluten free, that there's no bread anywhere near it. You know, I give them my little speech. And if they didn't get it the first time, I'm thinking maybe it's not worth it. I'll just eat my bar and be quiet. And maybe it's not worth it. Because, if they haven’t gotten it, maybe they’re not really going to be listening anyway. Maybe it won’t be safe. Maybe I’m just – I don’t want to expend that energy right now because I have other things I’m thinking about.

INCIDENT #81 – “Learning from a celiac child”

I had spent 12 years learning about managing celiac before I was diagnosed because my daughter had celiac. I had to learn [to live with celiac disease], but I learned the most because of her. I watched her suffer years when we didn't know what was wrong. And we made mistakes at the beginning and tried to give her food that we thought was safe and it wasn't. You have to *find out that oats are not safe unless they say gluten free on them. And so many things. Well, I did not realize that, like most people who don't have celiac. I did not realize how pervasive gluten was. I had to learn how to be careful and not give her the wrong things. So there [was] some trial and error and making mistakes and then realizing she can't have this either and she can't have that either.*

Back then when, it was quite a few years ago, 15 maybe, it was hard to find good products that, you know, I mean, we eat like rice and chicken and, you know, all the things that are naturally gluten free unless you put in the bouillon cube that has gluten in it or, you know, you have to find that out too, if the soy sauce has gluten. And it's so many. You just little by little, you realize, oh, this is a problem, too. And this is a problem, too. I don't think they were even putting wheat on the list of allergens at that point, because I think at the beginning, even, you know, if it said natural ingredients or natural flavors or something . . . I was calling toll free numbers, and I was searching and checking so many things all the time.

INCIDENT #82 – "Gluten doesn't die in the freezer!" *(Learning to live with celiac disease as the parent of a child with celiac)*

I remember a specific time shortly after she [her daughter] *got married and we went to my sister-in-law's house for a meal. And I think my husband kind of pressured* [our daughter] *to go because, you know, it's a social thing to do. And he doesn't do that anymore.*

That was the time when my new son-in-law complimented her aunt on the chicken. And she's [the aunt] *explaining what she does with it. And she said she cleaned it with flour and his face turned white. And she's like, 'But no, it was in the freezer. It's fine!' No, no gluten doesn't die in the freezer! You know, and I'm like thinking, why did we make her? Why did we make her eat this food? You know, why did we do that? We can't do that to her. It's not fair. You know?*

She stopped eating it right then, but she'd already eaten some and she got sick. And yeah, of course, my sister-in-law was horrified because she's very sweet and kind and, you know, it's not about that. It's about gluten. Gluten doesn't care.

You’re still, we're learning, and that applied learning came, you know, because I understood. Yeah, people, you know that they're just giving you a good meal and don't realize. I realized that no matter how hard people are trying, they often just don't get it, you know? And that was eye-opening.

She [my daughter] *was an adult, but still, you know, parents put pressure on* [their children] *and their social situations and . . . that was, one time … it was kind of a, a turning moment. How we handle things for her. And then that kind of set the tone for how we handle things for me.*

That was kind of a moment where I, ever since then I kind of just don't trust that anybody is going to prepare food safely. In restaurants or anywhere. And I'm probably over cautious that way, but I don't trust that anybody is going to prepare food for me. I think that it … you really have to realize that nobody's going to think about it as hard as we're thinking about it.

Trevor

Trevor, a white 73-year-old male, retired to Arizona after a career as a financial planner. In addition to his four-year college degree, Trevor obtained career-specific education for securities and insurance licenses, along with completing continuing education (CE) requirements every two years. Trevor first met with a gastroenterologist (GI) in 1999 because of digestive issues and met with two additional GI doctors before his diagnosis in 2019 at the age of 68. Prior to his celiac disease diagnosis, Trevor experienced symptoms for 20 years and his doctors diagnosed him with irritable bowel syndrome even though he was never tested for it. His last doctor completed an endoscopy where his results showed that he was “double normal” the standard for celiac disease. Trevor’s most significant critical incidents are below.

INCIDENT #83 – “Team effort”

We have a friend that's celiac and got a hold of her and had multiple conversations with her. She'd had it for 25 years at that point. So, we learned, you know, about having my own cooking utensils, toaster, tubs of butter and things that you don't want to contaminate.

The learning part was really communication with our friend and, you know, understanding how to set up our kitchen. In the beginning I felt sorry for myself and then I realized it's not that bad. When we were talking to our friend Jan and she was explaining 25 years ago, there wasn't a lot of food that was gluten-free and now there is a ton and she goes, you know, you just have to go in the grocery store and just look around. And I did that. I went around to many grocery stores, Trader Joe's and Sprouts and our Safeway. And I found a lot of stuff and I recognize that there are some stores that really think about it and some stores that don't think about it at all.

INCIDENT 93 – “Eating around gluten”

And people think I can eat it around it. You know, that’s what they think. Right after I found out about it [being celiac], *we were invited over to somebody's house, and they had a certain kind of fish that’s apparently best if it's breaded and grilled. They suggested I eat around it. That I just take that thing* [the breading] *off and I go, I can't do that. And they said, no, come on. And they got a little snippy with me. And, and I said, look, it just takes just a tiny bit and I'm sick. And they said, okay. And they ended up grilling one with no breading. They put it inside some tinfoil, put it on the grill and it was delicious. And, so, you know, it's just kind of like slow education with a lot of my friends. A repetitive, slow education.*

Well, it was significant that, when those things happened and they happened quite a bit in the beginning after my diagnosis, is that I understand that I'm aware of what situations I have to stay out of. Also, aware that I have to educate others immediately and be clear. I guess, after a period of time, what's significant is that I realized that I've been pretty good at staying away from being sick. So, I guess the messages have been received. As long as I communicate well, I won't get sick. A subset of that is that my friends are becoming more educated about my situation. And maybe a subset of that is, don't look for new friends…just kidding.

INCIDENT #95 – "The process begins"

[I was] *invited to a golf match … I didn't know anybody but the guy who invited me. And then everybody wanted to go to a certain place. And then the process begins … me asking questions and they'll* [servers] *go, what are you talking about? And I go, I'm just allergic to wheat. And* [they respond] *'I've never heard of that.' I go, yeah, hang in there. You'll hear about it.*

It's like I have a little trigger in my brain that says, if I go into a restaurant and they're going to be preparing a meal that I am going to eat, I have to ask certain questions to understand, the [knowledge] *that they* [the restaurant staff] *have. So, a lot of times, my first question is, do you have a gluten-free menu, and I can tell from their response, even if they say no, that dead eye stare, if I get that, I'm like, oh no, I better just ask for a dinner salad. But most of the time I get a, 'oh yeah, yeah.' And I go, so you're the smart person that understands my options. 'Uh, I'll get the manager.'*

You know, as long as I try to keep it simple and light and I'm not trying to be foreboding. I find it works out just fine. And usually there's, the staff, if they've been around a while, they're educated, or they know somebody on the staff that is.

And, for me, the conclusion is, because in the beginning I felt sorry for myself when I was diagnosed and oh, I can't have that. Now it's like, I think of it…oh, that could hurt me. That's like poison. I have been in situations where I didn't know I was eating it [gluten] *and then I got sick, and it doesn't take long for me. It's like an hour. And I'm sick for about eight days. And I just hate it. So, I am not willing to go through it.*

INCIDENT #96 – "Language barrier"

We went to a wedding a year ago in the Dominican Republic. The wedding was at an all-inclusive resort. So, we stayed at an all-inclusive…like being on a ship, so you just belly up to the food bar and you're looking at, 'oh my God, that's so good.' I don't look at it that way. You know, I look at it as, that's poison, that could be non-poison, that's poison. So, you know, I'm looking at this array of beautiful food and we're also in the Dominican, so there are people who didn't understand my language, I didn't understand theirs. So, there was that lack of communication I had to deal with for five days.

Even at the wedding, when they rolled out the food, I waited because it was a whole setting of food, and they didn't bring it to you. You just picked what you wanted. So, I had to wait till everybody got done and the chef could come out and talk to me. And they had to have an interpreter come with the chef. I felt like, oh my God, there were like 150 people in the wedding, and I was the idiot that had to wait. And, you know, friends of ours, their child was getting married, they understood. So that wasn't all that bad. But those things, you know, I have to negotiate the language issue. And it turned out to be just fine, but you never know.

I spent a lot of time where, you know, on the grill, where they just made eggs. So that's where I go every morning. And I had to watch for a while to make sure they weren't putting bread on the grill, and they didn't do that. They always want to please you. So, they always nod yes, but *not sure that they really got it. But, you know, I didn't get sick on that trip. That's just how I do it. You just kind of have to sit back and watch what's going on.*

It told me a little bit about language communication. It also told me a lot about what happens in the United States in terms of education. I guess what I'm trying to say is that in the United States, for many things, we, drill down into the essence of issues. In many countries, they're just trying to, to live day to day. So, a lot of those things are not as important, you know? So, you get sick for a couple of days, no big deal. That was an eye-opener for me.

If I want to go outside the United States, I better be prepared to, ahead of time, educate myself in the language of what I'm trying to convey or find places that I already understand that have some understanding of celiac preparation. I think that preparation has been a big part of my life now, you know, just ready to walk into a restaurant.

Summary

In this chapter, I presented selected critical incidents from 12 individuals who were diagnosed with celiac disease. The critical incidents were selected from transcripts of semi-structured interviews that were conducted with each participant. The interview transcripts yielded a total of 70 critical incidents. A two-part analysis, described in Chapter 3, yielded 34 narratives which were derived from the words of the participants. This chapter also included a brief biological description of each participant followed by the selected narratives created from each participant's critical incidents. In Chapter 5, I used Kolb's experiential learning model and Clerx et al.'s (2019) hierarchical progress of self-management to identify themes and commonalities of how the participants utilized experiential learning in the self-management of their celiac disease.

CHAPTER 5

FINDINGS

The purpose of this critical incident study was to explore the lived experience of individuals' self-management of celiac disease, and the role learning played in that lived experience. The research question guiding this study was:

1. What was the lived experience of individuals' self-management of celiac disease and what role does experiential learning play in that lived experience?

In Chapter 4, I presented the stories of participants who had been diagnosed with celiac disease for a minimum of three years. This timeframe was selected based on Clerx et al.'s (2019) observation of a hierarchical progression of four stages of time (life at home, social settings, workplace, and unfamiliar settings), with the latter stage beginning at five-plus years post-diagnosis. For this research, I chose the timeframe of three years post-diagnosis as a participant requirement to ensure that I could explore how experiential learning affected participants during each of those four stages. Each theme is presented within Clerx et al.'s four stages of self-management.

The selected timeframe and self-management phases were combined with the theoretical framework of Kolb's (1984) four-phase experiential learning theory which provided the lens through which I analyzed the participants' stories (data) in Chapter 4. Each critical incident demonstrated what was experienced by the participant (concrete experience), their reflection on the experience (reflective observation), the learning that occurred (abstract conceptualization), and how they applied or planned to apply their learning (active experimentation). In Appendix B, I provide a table to demonstrate how the participants engaged with the four phases of experiential learning in each incident from Chapter 4 that led to the prominent themes.

Prominent Themes

Four prominent themes emerged from the analysis of the selected incidents from Chapter 4. These themes aligned with Clerx et al.'s (2019) stages of self-management and titles represented each phase which focused on learning to live with celiac disease at home, in social settings, in the work environment, and in unfamiliar settings. Theme 1 focused on how individuals acquired experience with the gluten free lifestyle incorporating learning from the media and others, as well as acquiring practical skills. Theme 2 centered on how individuals engaged in social challenges and self-advocacy to manage their celiac health, reclaiming a sense of self, and learning to self-advocate. Theme 3 showed how individuals navigated challenges in the workplace around their gluten free lifestyle and celiac disease by managing professional relationships and workplace hierarchies. Finally, Theme 4 revealed how individuals self-managed their gluten free diet in unfamiliar settings, experiencing a loss of locus of control and reconsidering their proactive preparedness. These themes and their subthemes are presented in Table 5.1. I conclude this chapter with an overview of the application of experiential learning in the context of the study's findings. Verbiage that was added to the incidents for clarification is shown in brackets [ ] and the words of participants are presented in italics throughout the narrative body of this chapter.

Table 5.1

Prominent Themes and Subthemes

Self-Management Stage Based on Clerx et al. (2019)	**Theme**	**Subtheme**
Adapting to Gluten Free Life at Home *(First six months)*	Acquiring Experience with the Gluten Free Lifestyle	○ Learning from the Media 　○ Scrutinizing Celiac Disease Data for Accuracy ○ Gaining Knowledge from Others' Experiences ○ Acquiring Practical Skills for Living Gluten Free 　○ Reading Product Labels for Gluten Ingredients 　○ Gluten Free Cooking at Home
Facing/Confronting Social Settings with Celiac Disease *(One to two years)*	Leveraging Social Challenges and Self-Advocacy to Manage Celiac Health	○ Reclaiming a Sense of Self in Social Settings ○ Self-Advocating in Social Situations 　○ Lack of Trust in Others 　○ Educating Others about Celiac Disease
Making Modifications in Workplace Settings *(Three to four years)*	Navigating Challenges in the Workplace around Gluten Free Lifestyle and Celiac Disease	○ Managing Professional Relationships Alongside Celiac Disease ○ Grappling with Workplace Hierarchy While Living with Celiac Disease 　○ Advocating for Others' Celiac Health
Chartering Unfamiliar Settings *(Five+ years)*	Self-managing the Gluten Free Diet in Unfamiliar Settings	○ Experiencing a Loss of Locus of Control when Traveling with Celiac Disease ○ Proactively Preparing for Gluten Free Travel

Stage 1: Adapting to Gluten Free Life at Home *(First six months)*

As a gluten free diet is the only effective treatment for celiac disease, upon diagnosis, individuals must master its requirements and nuances. This mastery begins at home with newly diagnosed individuals learning what foods are gluten free, how to make their kitchen safe by discarding or replacing cookware and appliances (e.g., toasters, air fryers), and if they live in a mixed household (gluten and gluten free) how to create a safe environment for cooking. It is essential that individuals learn to master such skills as adherence to a strict gluten free diet can bring about remission of the disease after three to five years (Turner et al, 2015).

Theme 1: Acquiring Experience with the Gluten Free Lifestyle

Theme one demonstrated how individuals learned how to self-manage their disease at home. Individuals employed various methods such as engaging in media, including books, blogs and internet searches, information from their doctors, and learning from others' experiences for how to self-manage a strict gluten free lifestyle. Through the application of knowledge and skills, individuals acquired experience, and an understanding of what behaviors would and would not work for self-managing their disease. Within this theme, three subthemes were found that individuals utilized as they gained experience with gluten free living: Learning from the media (online and print), learning from others, and implementing new skills.

Subtheme: Learning from the Media – Online and Print

The majority, seven out of 12 of the participants, mentioned utilizing media (print and online) to learn how others lived at home following their celiac diagnosis. The individuals shared that they read books and found information via online celiac support groups and gluten free websites and apps such as Beyond Celiac and Find Me Gluten Free, respectively. Many did not have any one particular incident but shared anecdotes about looking for information on the internet to manage their day-to-day lives. Two individuals, Joanna and Alice shared specific incidents.

Joanna utilized Google searches to learn more about celiac disease post-diagnosis and found that individuals with celiac disease are *more likely to develop certain diseases if you don't keep* [to a] *gluten free diet.* Joanna shared that she would have questions about other related conditions and complications that caused her anxiety,

> *I remember things would pop in my head and be like, am I going to get this because I have celiac disease? … I remember I was in a meeting with my boss, and* [I wondered] *what if celiac disease has an impact on fertility? And I said, boss, I need to go look at something for work and went back to my desk and was Googling it frantically because I had to know if that would be a challenge or not. So, learning about other diseases, too, was tough.*

Alice shared that she did not receive *any real-life resources* from the doctor who diagnosed her. *We weren't told to go to see a gastroenterologist. Facebook groups, honestly, was how I was trying to learn.* However, Alice found that in the gluten free world, there were conflicting opinions. *It was just awful. I had to get out of those groups because they were so sanctimonious and condescending.* Then she discovered an online group called Celiac Mommy Warriors (as a reminder, this was in 2008), stating,

> *They were the ones who were on top of everything, and I made friends with all of these moms. And remember, at that time, I'm like 25 and newly engaged, and all of these moms of 8, 9, 10-year-olds who had just recently been diagnosed … there's nothing like a mom protecting her kid … so, they are the ones who taught me pretty much everything.*

From these moms, Alice gained a sense of empathy for her own mother,

> *Figuring out what those moms were going through gave me so much empathy for my own mom when I would go to visit … I mean, seeing what these women were going through and how deeply upset they got when their kids were sick and how much they blamed themselves. Oh, my God, mom guilt … what the heck is mom guilt? Like I've never seen in my life. And it just gave me so much more empathy for my own mom.*

In addition to gaining a new understanding for her own mother, Alice said she felt that this group taught her to *keep moving forward, to not give up, and to not just accept that this is the way it is always going to be.* In reflecting about her experience Alice found,

> *you've got to keep searching because … if you don't ask, the answer is already 'no.' I have my PhD, but that does not make me the THE expert, you know? …* [I want to] stay *humble enough to remember that there has got to be someone else out there who knows more than me.*

Scrutinizing Data about Celiac Disease for Accuracy

Alice also found the internet to be a cause for concern. At the time of her diagnosis in 2008, she joined multiple online celiac groups but did not have a good experience until, as previously mentioned, she joined Celiac Mommy Warriors. Prior to that,

> *Everyone was looking for community and tips. The internet was a dumpster fire back then* [2008]*, it was the wild west. Everyone was just shaming other people … 'I never eat out. I do all of this and I'm so wonderful and I'm sicker than you are.'*

While Joanna found helpful information on the internet, she also found it to be frustrating because of the lack of accuracy of the information found online and said that it seemed "Dr.

Google" or WebMD *just tells you that you are going to get cancer either way* [eating gluten free or not]. *So, it was hard to know, well, is this real?"* She read one post that contradicted itself,

> *… one post where they found evidence of celiac disease in Neanderthals. It is like an ancient disease. And then another post that was like, 'it is brand new.' Both can't be true, but they were both on this Facebook group that my doctor told me to join. This is not helpful.*

To combat this, Joanna went to the actual source of the article and felt she *was lucky to be in a science graduate school, so I felt really comfortable reading peer reviewed journals. I felt maybe I could trust those a little bit more than somebody's Facebook post.*

Other participants shared their concerns about the quality of information available on the internet, as Carole stated,

> *there's quite a bit of information out there where people are saying that Celiac is not real … it's just you're missing something, and you need to have more of a certain supplement. It's interesting because you can go down a really long rabbit hole if you start following some of that.*

Ryan added,

> *In the early days, I think there was a "too much information problem." There was a massive amount of advice on the web for celiac patients. Some of that gets to what I would describe as sort of the neurotic level. Maybe the key is to have a guide or expectation settings or something like that. … There's a lot of things to learn. In the early days, it was very daunting. And there's a tremendous amount of information, but you don't necessarily have a good way of weighing the relative importance."*

Because of the amount of information on the internet and the need to investigate its validity, it becomes necessary for individuals to be adept at understanding what is correct. According to Carole, *you're going to have to find really good online or print material that has been vetted, that is real work. It's research that has been proven and … you can't just take the first website that pops up.*

Subtheme: Gaining Knowledge from Others' Experiences

Just as an individual reflects on and learns from their own experiences, they also learn from others' experiences. Participants in this study learned from others who had self-managed their celiac disease. These included not only individuals who themselves had been diagnosed with the disease, but also relatives with the disease with whom they lived and visited.

Mary had information offered to her by her gastroenterologist's nurse practitioner who had celiac disease herself. The nurse practitioner created a packet that included information she had gleaned from her own experience. Examples of the information were a list of ingredients/key chemicals, etc. that individuals with celiac disease should be cautious, may not be okay, and should be avoided. The packet also listed *restaurants that were celiac friendly … just everyday life kinds of things. I think she probably put that together from her own experience.*

Heath learned pre-diagnosis from a nurse with whom he worked who had celiac disease. Heath said he paid attention and learned about her diet indirectly by observing *what she would eat … she would have some things; she wouldn't have other things … I mean, knowing you don't do soy sauce. I learned that one from my nurse before I was diagnosed.* So, learning how to live gluten free for Heath was *sort of an evolution, so it wasn't as big a deal to me once I was officially diagnosed.*

Trevor and his wife had multiple conversations with a friend who had lived with celiac disease for 25 years. Trevor learned not only practical applications but was also encouraged.

> *So, we learned about having my own cooking utensils, toaster, tubs of butter, and things that you don't contaminate … The learning part was really communication with our friend and understanding how to set up our kitchen. In the beginning I felt sorry for myself and then I realized it's not that bad … when we were talking to our friend, she explained 25 years ago there was not a lot in the grocery stores and now there is a ton!*

Because of his willingness to integrate his friend's experiences into his own life and reflecting about how self-managing celiac disease had progressed over time, Trevor changed his perspective about the requirements for his own dietary changes and became more positive about what was being required of him in order to live a healthy life.

Callie and Sarah both learned how to manage their celiac disease from their families. Callie, diagnosed as a child, learned from her parents when she became an adult; and inversely, Sarah was a parent diagnosed later in life who learned from her celiac daughter. Both discovered that even though they understood the elements of self-managing celiac disease, it was not until they became responsible for the self-management of their own disease that they realized how overwhelming the change could be.

Callie was nine years old when she was diagnosed and as a child, her parents took care of everything. She ate what they gave her, not giving thought about what it took to maintain a gluten free lifestyle. Callie's first experience of maintaining her own diet was when she left for college.

> *When I moved out, I wasn't with my parents at all. I was 10-12 hours away … so the hardest part with that was learning to cook … and what ingredients I could have, down*

> *to the spices. I can have this brand of spices, but not that brand of spices. That was a really big learning curve.*

Callie indicated that she felt more alone and isolated because, even though her parents were a big support system, they were not “right there” to immediately help. She said she *didn’t think about makeup having stuff* [gluten], *or hairspray, I guess just moving out has really taught me that I need to think more about the little things because that never really crossed my mind*. To understand what was needed for self-managing her disease, Callie contacted her mom to ask what she needed to do. Her mom instructed her to pay attention to labels and the small things such as product ingredients.

> *She sent me books. ‘These are the books I read when I was learning about your disease when you were nine.’ They really helped her* [mom], *and they helped me a lot too during that phase of my life. It gave me a lot of information that I did not even think about.*

After reflecting on how different self-managing her health was as an adult, compared to being a child, Callie shared that even though you can only be so prepared,

> *If I could, I would have paid more attention to growing up and asked more questions. I never really thought to ask questions. I guess the conclusion is to just try and ask as many questions as you can, no matter when you are diagnosed. Be as informed as you can because I think the more I was informed, the less intimidated or alone I felt.*

Sarah first learned about managing celiac disease from her adult daughter when she came to visit her in Jordan post-diagnosis. In her role as a mother, she would scrub her home to ensure that gluten was not present with the hope of avoiding cross-contamination. When purchasing products for her daughter’s visits, she was also diligent to read product labels. However, Sarah had not engaged in visiting extended family with her daughter and what that would entail.

> *That was the time when my new son-in-law was complimenting her aunt on the chicken. And she's explaining what she does with it. And she said she cleaned it with flour and his face turned white. And she's like, 'But no, it was in the freezer. It's fine.' No, no gluten doesn't die in the freezer!*

Of course, Sarah's daughter became ill, and her sister-in-law was horrified *because she is very sweet and kind and, you know it's not about that. It's about gluten. Gluten doesn't care.*

Sarah recognized that as parents, she and her husband were still learning. Reflecting in the moment, she said that *applied learning came, you know, because I understood. I realized that no matter how hard people are trying, they often don't get it, and that was eye-opening*. Sarah said that the learning from this incident was *a turning moment … that kind of set the tone for how we handle things for me*.

Sarah also found that managing her own disease was very different than what she had learned to do for 12 years (prior to diagnosis) for her daughter. When Sarah was diagnosed, she applied the experience of what she had learned in keeping her daughter safe to her own life.

> *When you have celiac, it's like you have to expend energy thinking about your food a lot … I mean, everything you eat, like when I go shopping, I read every single label of everything I buy. All the time. I mean, even things I bought before, sometimes I'll read the label again because they change.*

However, Sarah found taking care of her own self-management was very different to shopping and cleaning when her daughter visited.

> *With me, because it's all encompassing now, it's everything I buy. So, it's a constant awareness of where the gluten is and where it isn't. You know, as a nurse, I learned to think about sterile and not sterile, clean, and dirty. And it's kind of the same concept, knowing where gluten is all of the time.*

Subtheme: Acquiring Practical Skills for Living Gluten Free

According to Bandura (2004) individuals utilize proximal goals to motivate themselves and guide behavior as they self-manage their conditions. For individuals diagnosed with celiac disease, such proximal goals are discerning gluten free items, shopping for gluten free food, and cooking safely at home. Upon diagnosis, individuals first begin their self-management journey by implementing practical skills.

Reading Product Labels for Gluten Ingredients

One of the first things an individual encounters upon their diagnosis of celiac disease is to understand which foods do and do not contain gluten. This entails vast amounts of label reading and product research. Immediately following her diagnosis, Betty went home and

> *... just started going through all my cupboards looking for things that said anything about wheat, rye or barley, and I was really surprised to learn that it was in some things I would never imagine it to be ... I ended up throwing out a lot of stuff, giving a lot of stuff away, and checking everything. That was my initial learning experience…the surprise that it wasn't just cookies and bread. No, it was, in certain canned foods, certain brands of beans, certain brands of mayonnaise, soups…soups shouldn't have been surprising, but I guess it was at the time, because I didn't know what to expect.*

Holly's doctor informed her that she would need to read labels. While she had learned to read labels because of her other food allergies, Holly *did not realize that when it* [the label] *stated the warning 'may be processed on the same equipment as wheat' and was not labeled gluten free, that did not necessarily mean it was safe for me.* This demonstrated the due diligence that individuals who are diagnosed with celiac disease have to incorporate into their assessment of labels in order to eat safely.

Holly also had to clean out her kitchen and *not only get rid of gluten containing products, but also just clean up all the crumbs, replace some cookware, and replace my toaster.* Like Betty, Holly found *there's gluten in a lot of things. A lot of unexpected places.* Betty added that she discovered her new gluten free diet was *… going to be a little harder than I thought it was going to be. … initially you just think bread, some pastries, that kind of thing. Then you start getting into it. You find out there's a lot more to it.*

Not only was reading labels at home difficult, learning to shop for gluten free items was a major challenge for newly diagnosed celiacs. Joanna shared that her first experience of grocery shopping post-diagnosis was overwhelming.

> *Something really challenging I had to learn was my first grocery store trip after my diagnosis. I think I spent two hours in Kroger trying to buy food that was going to be for my new lifestyle. And that was huge. That was really tough. I think I was crying in the store. You think something's gluten free, and you look at the label and you're like, oh, wait, no. So, I would say that a massive learning undertaking was just how to shop with celiac disease.*

Learning these practical skills was a bit overwhelming for Alice as well, as she shared, *it was just very sudden. It was just all of a sudden you are longer eating the way you have eaten* *your entire life … it was just very sudden and extremely overwhelming.* Alice told of her first experience of shopping for gluten free bread in light of being Palestinian and, in her culture, using bread as their silverware:

> *I'm going to dip everything; we eat with bread … So, when he* [the doctor] *said don't eat bread, I was like, then what do I eat? … And, then he said, you use rice cakes instead … My dad and I went to the grocery store … not like when Walmart had a gluten free aisle, and we looked for rice cakes … and we didn't know that they were not actually bread substitutes … We put them in the toaster and set the toaster on fire because we thought they were bread.*

For her shopping, Betty found help through an online application that reads labels so she could scan products to find out if they contained gluten.

> *It felt a little awkward in stores where I'd be scanning barcodes of stuff. I'd be standing in the aisle, and I'd pick something up and I couldn't tell* [if it was gluten free]. *And I'd be scanning things, and I thought, somebody's going to complain, you know? So that was a little bit awkward.*

These individual incidents of learning practical skills for living daily with celiac disease demonstrated Barlow et al.'s (2002) concept that self-management not only included learning skills to manage, but also the individual's ability to "monitor one's condition and to affect the cognitive, behavioral, and emotional response necessary to maintain a satisfactory quality of life" (p. 178). An example of such an emotional and behavioral response was Joanna's crying while grocery shopping and her realization of the impact her disease would have on her life:

> *I think that's when it really hit me, how much of an impact on my lifestyle it would be. It definitely was emotional in the store, picking up probably the tenth can and being, oh,*

> *this has to be gluten free, and it* [says] *'may contain wheat" … So, yeah, I just remember that was when it was the impact that this is tough.*

Alice also chose to change her cognitive and behavioral response, after realizing that she could not eat the way she did before, deciding *I'm just going to eat what I can … that was basically once I realized that as long as I cook for myself, and I have at least one protein a day, so I'm not starving, then I would be fine.* This change in her behavior provided the beginning of new thought processes for handling the self-management of her disease.

Gluten Free Cooking at Home

After diagnosis, cooking at home can be challenging, especially if the household is both glutinous and gluten free. Joanna experienced this as she made lunches for herself and her husband who was not gluten free. Joanna found that before she and her husband really understood about cross contamination that making lunches was a really big challenge.

> *I remember washing my hands ten different times and trying to remember, did I touch this? Did I touch that? It was so confusing … I was frustrated. It's like, why do I have to figure all this out? Why can't I just eat gluten? … I realized how impactful this disease was going to be on the rest of my life. The time-consuming aspect of it. Somebody without this type of disease … would just never even have to think about that. They can just get up in the morning and make those sandwiches for lunch and go about their day. There's no cure. It's like, this is the rest of your life.*

Joanna found through this experience that there were workarounds for living in a combined household. When asked about her workarounds, Joanna shared,

> *I guess doing a process multiple times and then figuring out what the most efficient way … like preparing food, the process of cutting boards you should and shouldn't use … educating other people on how best to keep cross-contamination from occurring.*

In reflecting on her experience of living in a mixed household, Joanna came to the conclusion that she can do this and she's more comfortable in self-managing her disease. *I don't sit there and wonder anymore, 'Oh, how am I going to do this for the rest of my life?' This is what it is. I can handle it and move on to the next thing.*

While Ryan was not the primary cook in his family, he desired to improve his cooking skills so he could help manage his diet due to his celiac diagnosis. Ryan asked his wife to help him, and they both found unique challenges in cooking as his wife is a Japanese national. They both had to learn to interpret the dietary changes in the context of Japanese cuisine. He felt he had presented his wife with a frustrating assignment,

> *… a significant monkey wrench. My wife recognized that I needed to get food. At some point we just, you know, knuckled under, and dealt with it. Really, my wife was not excited about being a cooking teacher … but she was certainly willing to answer questions.*

Over time, Ryan felt that he was able to get more comfortable with his cooking skills and likened his experience of improving his skills to expanding one's circles. *You start with the very basic things, and you keep adding … I was able to distill down what I was uncomfortable with to get better at that.* Ryan was able to apply these new skills on trips he took to Japan with his adult children during Covid.

> *I needed to cook something, the whole meal, shop, plan, and cook the whole meal … conforming to my diet … I think I'm very happy to be more able to produce food, not just any food, but many foods that I am happy to eat … and yeah, it's a very good thing.*

Stage 2: Facing/Confronting Social Settings with Celiac Disease *(One to two years)*

According to Clerx et al. (2019), at the point of one to two years post diagnosis, individuals with celiac disease become more comfortable in social settings. The following section provides critical incidents that demonstrate how participants utilized the self-efficacy they gained from practical learning to self-advocate for their dietary needs in social settings.

Theme 2: Leveraging Social Challenges and Self-Advocacy to Manage Celiac Health

After learning how to navigate the practical skills of self-managing celiac disease, individuals continued their learning by actively engaging in self-managing their celiac disease in social settings. Through individuals' experiential learning, they reclaimed their social lives and independence through the self-efficacy gained from implementing new practical skills. Individuals also advocated for themselves in multiple settings which involved family and friends, and with that, the need to educate others about their disease.

Subtheme: Reclaiming a Sense of Self in Social Settings

As participants developed self-efficacy from their practical experiences, they became more comfortable with their new gluten free lifestyle and were able to reclaim their independence and social lives. However, individuals faced anxiety and discomfort as they navigated what it meant to socialize in the context of a strict gluten free diet. Being diagnosed as a child, Callie experienced the angst of feeling different due to her celiac disease. As a child, Callie felt like she was just like everyone else, but just could not eat the same food.

> *It can be really isolating in the sense that when you are at a birthday party, maybe you cannot eat the pizza that's provided and other kids look at you, 'Why can't you eat the pizza that my mom brought?' or 'Why do you have to have your own cake?' and 'Why did you bring your own cupcake?' For a kid, I think that can be really hard because you do not have that answer. You do not know. So having to grow up always kind of being on the outside, or not being able to be included in the pizza party, I think makes it a little tougher to feel included.*

Callie continued to feel different from everyone else when she entered high school, and no one knew about celiac disease.

> *I barely knew what Celiac was*. *But in high school, nobody understood* [what celiac was]. *It just felt like if they did not understand that then they did not understand me. I think in my personal experience* [it – celiac] *has been just like a tough mental game.*

Callie felt that what she dealt with most as a teenager was the mental pressure and isolation of being different [from others] due to her celiac disease. She now feels she has grown beyond the situation and has chosen to *surround herself with people who understand* [or would like to understand] *what celiac is.* She also finds it easier to advocate for herself and tell servers, *Yeah, I have this gluten allergy. I cannot have that, or I need you to change your gloves and stuff like that.*

Callie said it was eye opening that when she encountered individuals who did not have someone close to them who had celiac disease or did not have the disease themselves, they were not going to know what it was. *And so, I was going to have to teach them.* However, as a teenager, Callie found it difficult to do this because she did not even know what it [celiac disease] was.

> *I just knew I could not have certain foods. It was hard to teach them that. I didn't really know how to explain it and make them understand who I was because, at the time, I felt like Celiac was my identity. As I have gotten older,* [I have learned] *that celiac is not my identity. I am a whole other person outside of my disease.*

Instead of Callie focusing on her social identity and how she did not belong to a group, being categorized as part of the out-group due to her dietary constraints (Stets and Burke, 2000), she became more proficient in her ability to self-manage her disease. As she gained greater self-esteem and self-efficacy in her ability to self-manage her disease, she increased both, which led to her embracing her own individual identity.

Alice also gained a new sense of self while she was in graduate school. Post-diagnosis, Alice ate only food that she cooked at home. This was very unlike her prior self in that she was a self-declared "fearless foodie" who tried new foods for novelty and challenge.

> *I have eaten lizards. I ate grasshoppers, just because they were there to try them. I have never ordered the same thing off a restaurant menu twice … and* [post-diagnosis] *I did not know how to have a social life without food. I did not know how I was going to make friends without food … how was I going to have anyone in my life because what do you do that isn't either alcohol* [she is Muslim] *or food-based?*

After her celiac diagnosis, Alice stopped trying new foods and kept to a standard of cooking fresh whole food at home. While Alice embraced the positive effect of her gluten free diet on how she felt physically, mentally she felt isolated as she chose to not go out with other graduate students due to her dietary restrictions. She said she experienced *depression and loneliness at first because I was in a new area, and again, I did not know how to make friends without food or alcohol.*

In her second semester of graduate school, Alice was greeted by a young Persian girl who introduced herself and after exchanging pleasantries the young woman asked Alice to go to dinner. After Alice explained to her new friend about her celiac disease, the young woman told her they would go to Chipotle for dinner. For every excuse Alice made to not go to dinner, the young woman countered with a solution: Cross-contamination – the staff can change gloves; the hot sauce may have vinegar [which can be made from a glutinous source] – so don't get the hot sauce. Alice was amazed how her friend navigated the requirements of her diet with the restaurant staff, asking them what Alice could and could not eat.

> After Alice ate, she *kept waiting for my chest to hurt. It didn't! Oh, wow! I almost cried because I was expecting it. Because usually within 20 minutes after eating something with gluten, my chest really hurts, and it didn't! I was like, 'Oh, my God! I can eat food* [out]. *I just have to be careful. I can just ask people to please change their gloves … So, that was my BIG first entry back into the social world.*

This experience of trying something that was socially uncomfortable opened up a whole new world for Alice.

> *It definitely reduced my anxiety. Definitely made me feel more secure. A lot more locus of control … I had this world of opportunities available to me … Do you know how much it changed my life to be able to stop at Chipotle on the way home instead of having to cook all the time or eat a potato for dinner? It goes back to learning from others … just to not be afraid. Because again, if you do not ask, the answer is already 'no.' It taught me … okay, I can flow with it … So, yeah, in a way it gave me my power back.*

Alice and Callie both reflected on the sense of agency they gained over the impact that celiac disease has had on their lives. From her situation, Callie learned that she is not her disease, and similarly, Alice gained back her sense of power. They both learned to not only educate themselves by asking questions when more information was needed, but to educate others when the situation presented itself.

Subtheme: Self-Advocating in Social Situations

Individuals with celiac disease utilize one skill in particular in the self-management of their disease, and that is self-advocacy. As the participants in this study learned more about themselves after their diagnosis, understanding how to appropriately self-manage their disease, all became adept at advocating for themselves with regard to their gluten free diets.

Some social situations can be more uncomfortable than others for individuals self-managing celiac disease. Joanna was invited to attend the wedding of friends. The friends understood Joanna’s dietary restriction and inquired of the caterer about offering gluten free food. After their meeting with the caterer, out of their kindness, Joanna’s friends contacted her to let her know that they were concerned that the staff did not fully understand how to prepare safe gluten free food. ‘*So, I’m sorry, please do not eat the food at our wedding.’* So, for the first time, Joanna brought her own food to a wedding, putting it on a plate to eat along with everyone else.

> [I] *felt a little bit awkward doing that, but I have done it a couple of times since and it has always been fine. And if people have questions, it is no big deal. You just explain what you are doing and why and they accept it.*

In learning how to explain her behavior to others utilizing practical skills, Joanna gained confidence in how she self-managed her disease and even when she may have felt uncomfortable bringing her own food, she determined that

> *even if people notice that you are doing something a little weird with your food, nobody is going to be talking about it a year after like ‘Oh, my gosh, she brought her own food.’*

> *Even if people kind of look at you, that is what it is. They are going to move on. So, it does not have to be anything embarrassing.*

From this event, Joanna learned how to explain her diet to others and has gained the confidence to approach restaurant managers, or even ask to go first in line at buffeted events. *You feel rude doing that, but I did it and it was fine. You can advocate for yourself.*

However, sometimes being in social situations where one has to bring one's own food in order to participate can be tiring, as Rosemarie shared,

> *I golf with a group of ladies every week in the summer, and we are* [dining] *at the golf club and there is nothing there I can eat. So, I bring my own lunch … that is kind of tiring at times, having to, on hot days, make sure that my food stays cool and not having the convenience of just walking into the restaurant and ordering something. I have to go back to my car and get food that I can eat. It is inconvenient, but I have to prepare ahead of time.*

While she manages her gluten free diet and stays healthy, even with the inconvenience, Rosemarie reflected positively on her situation:

> *When I see everybody ordering things that I used to enjoy, I always think things could be worse. It bothered me a lot more at first than it does now. No, I look at it as something that is going to make me sick. I have been sick several times and it is not good.*

Lack of Trust in Others

Family situations can be difficult to navigate with celiac disease. Even though the disease is a hereditary autoimmune disease, in most cases among the participants, there was only one individual who had been diagnosed within the family. If preventive screening had been done within the family, there may have been two, but no more. In Sarah's family, there were two, her daughter and herself. Her daughter, Alice, was also a participant in this study.

Sarah shared that she, like others who have celiac disease, made the decision to no longer partake in meals cooked by extended family, in particular her sisters-in-law, but to bring her own celiac-safe food. She was also very worried about how they would react to her decision.

> *It's complicated because I do not want to interfere with my husband's socialization. You know, I want them to feel comfortable inviting us for lunch. I just bring a container of something to put in the microwave and I eat my food, and they are okay with it. They know it is not about them because I used to eat their food.*

However, not eating the food was not the only decision that Sarah had to make when considering how to socialize with family. *Okay, I will drink their tea, and I will drink their coffee and then they bring the fruit and hopefully there will not be anything added to the fruit.* While Sarah's sister-in-law offered to make gluten free food for her, offering to be very careful as she was also making a meal for thirty-five people, Sarah declined because

> *It is because I do not necessarily trust that it will be safe … even if she does* [make the meal] … *And I don't want to hurt her feelings. I beg you to please just let me bring something and then I will be more comfortable. And it is not about you. You know I love your cooking.*

For individuals like Sarah, it is difficult to put one's health as a priority, especially when it may hurt another's feelings. However, individuals with celiac disease think about food and eating safely more often than they wish. It sometimes seems like their primary focus, as Sarah shared,

> *It is safer for me to eat as little as possible of other people's cooking … maybe, I am too careful. Maybe, I overthink. I know I overthink. I definitely overthink. I think about it more than I want to think about it. When you have celiac, it is like you have to expend energy thinking about your food a lot … I mean, everything you eat, like when I go shopping, I read every single label of everything I buy. All the time.*

Sarah feels like she has to *know where the gluten is all the time … it is a constant awareness of where the gluten is and where it is not.* This constant vigilance has brought about an anxiety that is built on a lack of trust.

> [Having to know where the gluten is all the time] *was kind of a moment where, ever since then, I kind of just do not trust anybody is going to prepare food safely. In restaurants or anywhere … I'm probably overcautious that way, but I do not trust that anybody is going to prepare food* [that is] *safe for me … You have to realize that nobody is going to think about it as hard as we are thinking about it.*

Similar to Sarah's family situation, Carole found that she could not trust food made by someone else was safe. Carole and her husband had a favorite restaurant at which she felt safe to dine. They had eaten at the establishment multiple times before and she had never gotten glutened. There was one particular meal that Carole knew for sure was safe, so she would order it each time she visited. However, on an outing with her husband, Carole began to experience symptoms of being glutened. It turned out that the restaurant *had a new chef, and he used flour for the thickening, whereas the other chef used cornstarch.* From that experience Carole shared she discovered that *I needed to ask every time. Not just assume that things were still the same* [as the last time she visited].

Educating Others about Celiac Disease

As individuals with celiac disease become more comfortable with themselves and their disease, they usually find themselves in situations where they need to educate others about their disease. This may be with family, friends, co-workers, restaurant staff, and even new individuals they meet. Just as Joanna found at the wedding, because of the strict dietary requirements of celiac disease, individuals with the disease may appear very unusual to the norms of regular dining. This usually prompts the need to educate others.

A diagnosis of celiac disease not only affects the individual, but also their family. Mary's family gathers at her parents' house every Sunday for lunch. Mary said that her mother loves to cook for people and so it was hard for her when she learned that she would not be able to cook for Mary like she always had.

> *There were some instances I think it was a grieving process for them* [her family] *as well as for me. It was very much a learning experience for all of us, even just understanding the lengths I had to go to just to keep myself safe.*

Mary's sister has since been diagnosed with gluten intolerance so their mother created a sealed box specifically for them to have their own cutting boards, knives, and dishes so they can participate in preparing their portion of the family meal.

> *I feel like my family has come a very long way and are very much open to say* [to visitors] *that Melissa has celiac. That's why her food is a little different. I'm totally okay with that because I feel since it is so rare and not known as well, the more people who have questions that I can answer, the easier it will be for not only myself, but other people down the road.*

Trevor had an incident where friends invited him to their home for dinner soon after his diagnosis. They planned to grill fish and insisted that it needed to be breaded and then grilled. Trevor requested that the breading be omitted, and the hosts balked, suggesting that he *eat around it and take the breading off*. Trevor took the opportunity to educate his friends by informing them that *it takes just a tiny bit, and I am sick*. The hosts relented, grilling his fish on a piece of foil*, and it was delicious, and so you know, it is just kind of like slow education with a lot of my friends. A repetitive, slow education.*

For Trevor, this incident was significant because through these many experiences with his various friends, he has become aware of what situations he needs to stay away from and that,

> *I have to educate others immediately and be clear … what is significant is that I realized that I have been pretty good at staying away from getting sick. So, I guess the messages have been received. As long as I communicate well, I won't get sick. A subset of that is that my friends are becoming more educated about my situation.*

When it comes to educating others, sometimes Sarah just does not bother. She travels frequently on Royal Jordanian between Jordan and the United States, and on one flight in particular, after going through the initial "I have celiac disease" speech, the attendants rolled out the cart with cheese and crackers and offered them to her.

> *It's like, really? You're doing that? It was a 13-hour direct flight to Chicago. I don't know I didn't want to try to educate them … They need to be educated, but I didn't want that to be my responsibility. I didn't want to think about fighting with the staff.*

Usually, when individuals with celiac disease are presented with the opportunity to educate others about their disease, they leap at it. Sarah iterated this:

> *Education has been a priority for many people in celiac. And here I am saying, I don't want to do it. It's just – it can be exhausting. I didn't know if I could really trust them, even if I did explain* [again] *because I already made my general speech at the beginning. And if they did not get it the first time, I am thinking maybe it is not worth it.*

Educating others can be rewarding for those who have been diagnosed with celiac disease. It gives them a platform to discuss the requirements and effects of the disease. In many cases, like Mary and Trevor, family and friends are willing to learn and provide a solution so those who are diagnosed can participate socially. Unfortunately, there are times when individuals feel unheard and that it is useless to continue trying to help others understand. For those with celiac disease, educating others can take a lot of effort and time, and it is okay when they become overwhelmed at the prospect of doing so and choose not to.

Stage 3: Making Modifications in Workplace Settings *(Three to four years)*

Clerx et al. (2019) found that between years three and four post-diagnosis, individuals become able to self-manage their disease at their workplace. It was found from this study that navigating celiac disease at work brought with it challenges similar to those of engaging with the disease in social settings. Of the 12 participants, only five were currently employed, with the remining seven being retired. The five employed individuals navigated work relationships, which were similar to social ones, as they educated others and advocated for themselves. In addition to these common themes, there were also challenges such as a lack of understanding and consideration from co-workers, as well as engaging with social hierarchies. The following summarizes the experiential learning of how these individuals navigated the self-management of their celiac within the workplace.

Theme 3: Navigating Challenges in the Workplace around Gluten Free Lifestyle and Celiac Disease

In any type of career or job, individuals navigate their employment culture, which includes understanding relationships and hierarchies. However, those who are diagnosed with celiac disease must add another stressor to this learning, their gluten free diet. While this may be thought to be a simple task, these individuals negotiate relationships that can bring both understanding and condescension from their leaders and coworkers. Within these workplace relationships, participants of this research found conflict, disregard, and surprising encouragement. These individuals desired to be understood by those with whom they worked, with some choosing to be more open than others in sharing about their disease.

Subtheme: Managing Professional Relationships Alongside Celiac Disease

Mary worked with bosses whom she considered to be “clueless” when it came to taking her gluten free needs seriously at work. During the COVID pandemic, she worked with children at a gymnasium and because hand sanitizer was deemed necessary during that time Mary investigated which ones were gluten free. Once she found which products were safe, Mary created a box she brought in from home that contained her own gluten free hand sanitizer and lotion and printed on the box, ‘Mary’s box, please do not touch.’ Unfortunately, Mary’s bosses were not sympathetic or supportive of her disease and were very uncomfortable having the box at the worksite while she was not there. They told her she had to ‘*make sure that you bring it in and take it out.’* Mary asked, *Could I just put it in the locker with a lock when I’m not here?* They responded, ‘*No, we don’t even want it in the building if it’s going to be that sensitive.*’ The meaning Mary made from her experience was that *some people don’t necessarily understand, and you have to speak up for yourself.* Even though she was disappointed by her “clueless” bosses' reaction to her needs, Mary appreciated the times her other co-workers inquired about her illness: *I love that because then I can advocate for myself as well as advocate for the next person …"*

As a master's student, Callie's first "grown-up job" was as a full-time graduate research assistant. She chose to not disclose her "hidden disability" and had to learn "strategic self-disclosure management; and when to disclose and make it visible" (Valeras, 2010, p. 1). When asked to dine out with her co-workers, Callie would make excuses, such as she brought her lunch, convincing them that it was not a big deal. She *did not want them to have to be forced to go to a place that has gluten free options … and them not be able to get what they actually wanted because I could not eat there.* Callie shared that one day in an icebreaker game she took the opportunity to share. Everyone was asked what food they did not like, and Callie answered *gluten*. When asked what she meant Callie shared her story, to which the response was *'Oh my gosh! Why didn't you tell us? We wouldn't have gone to all those places that you could not eat. It's not a big deal!'* From this experience Callie discovered

> *You should trust people, like your disease is not something to be ashamed of. It's okay to tell people and more than likely they are going to be supportive of it … so, trust the people you surround yourself with. It's okay to 'be.'*

Like Callie, Alice was a graduate assistant while she obtained her PhD. From the beginning, Alice decided to share with her co-workers about her disease. While Alice knew her co-workers were supportive of her situation, there was a newly hired employee who was very unsupportive. Alice shared that *she* [the co-worker] *would do things like bring in a cake* and when Alice would turn down the food, stating that she was allergic, the co-worker became defensive stating *… it is healthy, I made it with applesauce instead of fat … I cook healthy, and I* *cook whole … and I cook sustainable.* Unfortunately, it was difficult for Alice to educate her co-worker about celiac disease, and she became frustrated. *Why can't she just understand? … and the rest of the office would back me up … Why can't she understand that Molly* [another employee] *has a nut allergy and Alice cannot eat gluten? That took a lot of firm repetition …and that was very frustrating*. For Alice, *it was the first time that someone had not listened* [to her explain about her disease].

In her prior experience, when Alice mentioned that she had celiac disease to people, they would be okay with the circumstance and be curious, prompting Alice to educate them about the disease. She learned that, especially in difficult situations with her diet, like the one with her co-worker, *it helped when I had the support of the other people in the office.* Alice had learned to self-manage her chronic disease in the context of other people and influences, and relationships among community (Grady and Gough, 2014). Unfortunately, Alice's experience demonstrated that not everyone with whom an individual with celiac disease works will be understanding, even with a disease that is beyond their control.

In Joanna's work incident, she did not want to inconvenience her co-workers. At her place of work the employees make pancake breakfasts onsite. This was a challenging situation for Joanna as her workplace had an open floorplan and flour and batter were everywhere. Even with this challenge, Joanna did not

> *want to be the person that stops pancake breakfasts* [so I] *haven't said anything even though it probably does make the kitchen really contaminated … but it's just that some situations are just not safe and there's nothing you can do. You just have to take yourself out of that situation or be petty.*

So, Joanna chose to take herself out of the situation and scheduled her work at home days on pancake days. When she missed breakfast, her coworkers were aware and commented how she missed it which gave Joanna an opening to educate them on her circumstance,

> *Flour can hang in the air after you bake with flour. And if you breathe it in, you could get sick if you have celiac disease. I did some educating in that circumstance, and they had no idea, and they felt really bad. That made me feel bad. I didn't want to ruin anybody's pancake breakfast.*

Joanna eventually chose to disclose her situation and, in her experience, learned that *it was okay to share and maybe not be as worried about whether people feel bad or not, especially when it's a safety issue.*

Much like Joanna, many individuals with celiac disease who engage socially with others feel guilty that they may inconvenience them. They worry it may make others uncomfortable when placing a food order takes longer because of all the cross-contamination questions; or you have to question cooking procedures when food is prepared for you, or people simply forget and feel bad when they forgot to consider your illness and subsequent dietary requirements.

Alice found that she, too, might be too concerned about what others thought of her refusal to partake in glutinous food. At work events, individuals would tell Alice that their food was gluten free, and she would ask them

> *everything they put in it because they would be pushing me to eat it. I would be like, 'No, no, listen, even if you use wooden spoons, there could be flour left in the cracks in the wood. Like, I really do not want to risk it. I have to drive home; I cannot be sick. And they would be really insisting. 'No, I was so careful. I was thinking about you.' And so sometimes I would give in.*

Unfortunately, Alice did give in at an event and became very ill, followed by a migraine the next day. *And, of course, I'm still on campus the next day because you are in grad school, and it is not like you get days off*. In reflecting on these types of situations, Alice said that she found she was firm when it was clear she could be, but sometimes she would give in *because of the logical fallacy of appeal to pity*, as individuals insisted, *'But you have to do this for me because you need to feel bad for me because of all the work I put in' … 'I was thinking of you the whole time' and 'No really, I was so careful.'* Upon running out of reasons, Alice would give in when she knew that she would hurt their feelings and that the co-workers around her would not support her.

> *So, I think this means that I care too much about what other people think and that is kind of a not nice thing to realize. Yeah, man. I give in to social pressure. That is not great. That is not great at all!*

Holly had mixed experiences when attending work events. At a work event, she was pleased to find that her gluten-free diet could be accommodated. However, as with many individuals with celiac disease, Holly also had other food allergies, about which she asked.

> *I reached out to the human resources representative* [the organizer] *and asked if they could get a meal brought in for me, separate from what everyone else was getting since I couldn't eat what was available. She was not willing to do that for me. I called her out on it. I asked, Why should I be the only one not allowed to get food from the outside paid for by the company when everybody else can? And she said, 'Well, you should just be able to eat what's available.'*

Much like Alice's frustration of interacting with the co-worker who refused to understand the needs of a gluten free diet, Holly was offended by the organizer's response and lack of understanding the additional dietary requirements that sometimes accompany a celiac diagnosis. *I felt like she didn't take my dietary restrictions seriously at all. I ended up bringing my own food and keeping my mouth shut … It's just easier to bring my own food.*

Holly shared that there were also kind individuals who planned events for her office. Upon receiving the registration notice, the organizers inquired about the allergies of the attendees. *I was quite impressed because most of the time when they send a registration out like that, they don't ask for that information.* Instead, Holly would have to contact the organizer, inquire if a meal could be provided and then share her dietary restrictions. So, Holly completed the registration form and listed all of her dietary restrictions. *Whenever I got to the event, there wasn't a meal there for me. There wasn't anything I could eat there.* Holly talked to one of the organizers and she apologized for the oversight.

> *She made it right. She went and talked to one of the food service workers and said, 'This woman has a lot of dietary restrictions. Here's what they are. Can you please make her a meal and just charge it to the same account for the catering?' And they did that!*

Holly felt that the organizers took her dietary needs seriously. *I appreciated the compassion she had, and she's* [the organizer] *like, don't apologize for something you can't control.* This event demonstrated to Holly that advocating for herself could lead to positive outcomes. *It's okay to advocate for yourself and make sure that your dietary needs are met. I didn't feel isolated, it made it more enjoyable.*

Subtheme: Grappling with Workplace Hierarchy While Living with Celiac Disease

While individuals in the workplace navigate social hierarchies, those who are diagnosed with celiac disease may experience discomfort when trying to fit into their company's culture in the context of their dietary restrictions. Joanna and Alice both found challenges when attending events hosted by their work superiors that left them feeling uncomfortable.

Joanna was invited, along with another couple, to an individual's home that she had known for a long time at her company. The individual was higher in the hierarchy than she was, *they're super nice and I think they really wanted to feed me, but it was really clear that they had no idea about the gluten situation.*

[Prior to the event Joanna asked about food.] *For grilling out, they wanted to toast sausages. I asked, 'Do you ever toast buns on your grill?' He's like, 'Oh, yeah, but it gets so hot, it* [the gluten] *just burns off,' and I'm like, oh, oh, no, it doesn't.* This situation was very challenging for Joanna as she desired to educate her host, because she felt very awkward trying to educate someone who was higher up the hierarchy, especially

> *not wanting to offend them ... when it's a work situation, that's another layer of challenge because you don't want to offend people pretty high up in your company. I just ended up bringing 100 percent of my own food and tried to eat it off to the side.*

Joanna was not sure if she had handled the situation correctly.

> *I definitely felt so awkward, like trying to tell them, 'No I can't eat this because you used a sponge on all these gluten items, and you just wiped down this plate. I can't use it,' especially when they're trying to be so accommodating. I think they even bought gluten free food, but the way they served it just wasn't safe.*

The dinner became an educational experience for other co-workers who attended. They became aware of the lengths Joanna had to go to simply to enjoy a meal without cross-contamination. Joanna felt awkward and experienced a lot of guilt due to the situation:

> *I would say a lot of guilt and awkwardness probably were the two big words. I guess maybe it was more internal that I just felt really guilty about not being able to take advantage of the food that they had gotten for me.*

From this awkward experience, Joanna learned that she had to put her health first and decided how she would apply this to possible future situations:

> *I learned to keep interactions about food simpler … not try and see if I could eat something to make somebody happy. Just tell them up front, I'm going to be bringing my own food. Please do not be offended or think it is about you. It is about me. It will keep me safe, and we can all have a good time and not worry so much about food.*

In a similar situation, Alice was invited to attend a Christmas party at her PhD advisor's home. Not only was he her advisor, and therefore her boss in the hierarchy, but he was also a little intimidating. Alice found herself not only navigating her gluten free diet, but also dietary restrictions because of her Muslim beliefs. At the event, Alice's advisor excitedly handed her a gluten-free beer and excitedly told her,

> *'I couldn't believe it when I saw this, and I wanted to get it for you, and I'm so excited!' And I had to just be like, thank you, and I just took it because he was so excited, and he was so happy, and he was my advisor and my boss. He was so thrilled to have found this gluten-free find for me and gave this to me, like this rare thing that he was sure I couldn't have. And yes, he was very correct that I could not have it. No, I didn't tell him. I took it.*

Alice found herself in an awkward situation because, while she appreciated her advisor's thoughtfulness about recognizing her gluten free diet, she needed to also respect her religious beliefs.

> *It's so hard to say no to people's good intentions and it's so hard when people are happy, they are doing something for you. It was just true altruism. This was actually 'I'm so excited you get to be a part of what we are all doing.'*

In the midst of another's altruism, sometimes those with celiac disease have to weigh the options of keeping oneself safe, saying something that negates the kind gesture, or graciously accepting the gift. While Alice's advisor did accommodate her gluten free restrictions, and the beer was about cultural beliefs, as mentioned earlier, celiacs usually have more than one dietary restriction. It is difficult to turn down someone's kind gesture, such as purchasing gluten free cookies made with dairy when the celiac individual's diet is even more restricted due to a dairy allergy. Does the gluten free person accept or reject the kind gesture? Alice chose to accept, but not drink, the kind gesture and carried around the bottle of gluten free beer at the party. *It's a combination of I don't want to offend people, and I don't want to call attention to myself in a negative way. I don't want to have them think that I'm rejecting something from them.*

Alice was also concerned with her place in the hierarchy of student and PhD advisor. *If someone's offering you something in good faith, it's not a great look to reject it, especially if they outrank you.* She also knew that she wouldn't have the support of her peers around her. *I mean my engagement with others is* [that] *I'm more likely to* [say something] *if I'm more comfortable* [with] *people to explain to them, Oh, I'm really sorry. I can't take that … again, it comes down to the level of comfort.*

Advocating for Others' Celiac Health

As prior incidents have demonstrated, advocating for oneself was essential for engaging with others in social and work relationships. Within these relationships, individuals with celiac disease navigated hierarchies in the context of their gluten free diet. However, others used their positionality to advocate not only for themselves, but for others in order to bring about change.

According to Test et al. (2005), once individuals have gained an understanding of themselves and their rights and have communicated these in an effective manner in advocating for themselves, they are in a position where they can utilize their experiences to be leaders in advocating on behalf of others. Heath chose to utilize his experience of living with celiac disease to not only advocate for himself but engaged with others on a larger scale in order to make bigger changes for individuals with celiac disease. As a doctor, Heath attended many meetings for his profession and continued to do so even in his retirement. By serving on the boards of a number of these organizations, Heath used his positionality to ensure that gluten free food was available for everyone.

> *It's gotten to a point, when people are sending out invitations,* [they ask] *'If you have any food allergies ….'* [One particular group now has] *a significant number of gluten free items. I like to think I helped make sure that happened … there's more and more of these buffets that you have adequate gluten free food you can fill yourself up on … a lot more people have got options now as compared to a few years ago, certainly 10 years ago.*

Heath said that he has found that people are now more aware [about the gluten free diet] and if the food is questionable, he is *much more open, I don't want to say aggressive, but I'm checking everything and figuring out which things* [I can have].

While vigilant individuals have learned to advocate for dietary inclusion at the individual level when attending company events, Heath shared his perspective about the learning and responses that have occurred at the institutional/corporate level:

> *So, I think as we are talking about learning, I think there's a lot more institutional and corporate learning going on, more than my individual learning. As I've been at different hotels and restaurants … I'm noticing there are more gluten free* [items] *on the menus. There are people* [who] *know what you are talking about when you ask a question, and it's not a big deal for them to go find out* [the answer] *for you as well.*

In light of Heath's experience with engaging in institutional/corporate advocacy on behalf of the gluten free diet, it appears it had an effect on his gluten free population at large. While individuals desire to have their voices be heard, in circumstances such as these large group functions, it appears that an individual with positionality has more influence to enact change by advocating on behalf of the masses.

In addition, as great as it was that Heath could use his positionality, there may be an issue of gender bias, as Hutchens et al. (2023) demonstrated that women "who self-advocate are viewed as less likeable and not as warm" (p. 9). While it is important for those with positionality and influence, who have the experience of self-managing celiac disease, utilize their gravitas to enact change, it is also important that ALL [emphasis mine] voices be heard.

Stage 4: Chartering Unfamiliar Settings *(Five+ years)*

As individuals with celiac disease (CeD) become more adept at self-managing their health, many venture beyond their comfort zones and into the unfamiliar. According to Clerx et al. (2019), this venturing occurs five+ years post diagnosis. By the time patients with CeD have self-managed their disease for five or more years, they have gained high levels of self-efficacy in their ability to manage their disease, including how they manage their social lives and work environments. These individuals have solved problems and made decisions about their health, expect a locus of control over their lives, extend a level of trust, and have prepared for the unexpected.

Theme 4: Self-managing the Gluten Free Diet in Unfamiliar Situations

Five individuals participated in unfamiliar situations that included international travel, a relocation to a foreign country, and experiential/educational travel. These individuals engaged in experiential learning through concrete experiences via new, unfamiliar events and in reflecting on these experiences, realized new skills that needed to be learned for application to future unfamiliar events.

Subtheme: Experiencing a Loss of Locus of Control When Traveling with Celiac Disease

Three individuals traveled internationally. Alice made a life-changing decision to move with her husband to Saudi Arabia to care for his elderly parents, while Callie and Trevor had trips of leisure to Cancun, Mexico, and the Dominican Republic, respectively. For all three individuals, the destination country's language presented a significant barrier to their locus of control in the self-management of their disease.

In 2018, Alice moved from the United States to Saudi Arabia so she and her husband could care for her in-laws. The relocation was challenging. *Oh my God, advocating for yourself. First of all, Arabic is not one language … my Lebanese Arabic, useless.* She felt it was a *complete 'starting from zero' kind of situation.* Prior to moving, Alice was *living my best celiac life. It was amazing. Life was great. Life was expensive, but life was great*. However, when she moved, she had to implement her label reading skills to vet new products, asking questions about them:

> *What foods are going to have hidden soy sauce in them? What foods are going to have distilled vinegar outside the United States? It's not safe. Now I can't have salad dressing.*

> *That's right, because I don't know where the vinegar in the salad dressing came from. All of these little hidden gluten things that had disappeared by the time I moved here because by 2018 we knew about stuff.*

Much like a newly diagnosed celiac, having to learn how to navigate stores, restaurants, and products, Alice had to utilize her experience gained through the years to engage with a new country and all that entailed, to include its people, customs, and language. She felt this move was

> *another major life upheaval, and it was a complete readjustment, just like getting diagnosed was. It was not just a new adjustment,* [but a] *major adjustment. It was a major readjustment in a dialect of what should be my language, but that I don't understand. Now I do, but at that time, I barely understood it. Just a complete 'starting from zero' kind of situation. I was back to cooking on a hot plate in the basement* [of her in-laws] *for myself.*

She found that when she

> *… would try and go out and we had no idea where I could eat or how to explain what I could eat, and we were trying to re-navigate the whole situation … my husband … the most supportive person in the world when it comes to this … would need to ask for things for me all the time. He was the one doing all of the talking instead of me. There goes locus of control!*

As Alice reflected on her experience, she found that because of her move, she had learned to be better prepared:

> [The] *move really taught me how to approach travel with more readiness and more preparedness.* [If this] *is how the situation is going to be. I just need to be ready to roll*

> *with it. I might be hungry sometimes, but obviously, I carry bars. Once I got it under control, I was like, okay, I can actually go do stuff. I can go to new places.*

Prior to the move, Alice had not traveled a lot. She has since tried out her learning as she *went to Turkey in 2019 and there's not a lot of English there … Google translated all of the things I'm allergic to.*

Callie also had a loss of locus of control due to a language barrier when she traveled with her boyfriend to Cancun.

> *So, I was pretty nervous going into it especially considering Cancun is Spanish-speaking and I do not speak Spanish. I knew that whatever was going to be said was going to be through a middleman. Not that I don't trust my boyfriend, I do. Still, it was going to be through another person, not myself.*

Without a locus of control for ordering her meals, she, like Alice, was left with a sense of unwanted dependence on her significant other. Callie shared that *basically, the entire trip I couldn't leave my boyfriend because I can't read Spanish*. Both women were required to be dependent on someone else to converse on their behalf in a language they did not know, in order to obtain food that was presumed safe for them.

Callie admitted that all of the other trips she had taken prior to this one had been with her parents, who planned the trip and food.

> *It was kind of intimidating to do on my own for sure. Next time for a different trip or a different place, I'd probably research more about the location I'll be at for sure. I'm not as scared or nervous going into it.*

In Trevor's travel to a destination wedding, he had a lack of locus of control as he experienced a lack of communication about the Dominican resort's gluten free food due to a language barrier and was required to depend on interpreters for the wait staff and chefs so he could understand what he could eat:

> *So, there are people who didn't understand my language, I didn't understand theirs…so there was that lack of communication I had to deal with for five days ... so, I had to wait till everybody got done* [getting their food from the buffet] *and the chef could come and talk to me … So, they always nod yes, but I'm not sure that they really got it. But, you know, I didn't get sick on that trip. That's just how I do it. You just kind of have to sit back and watch what's going on*.

While these three individuals experienced language barriers, they saw these barriers as being helpful and prompting new learning because of their experience in self-managing their disease. Trevor reflected on the Dominican Republic's culture and how its residents dealt with food allergies,

> *It told me a little bit about language communication … in the United States, for many things, we drill down into essence of issues. In many countries* [like the Dominican Republic]*, they're just trying to live day to day. So, a lot of those things are not as important, you know? So, you get sick for a couple of days, no big deal. That was an eye-opener for me*.

When going out of the United States, he learned that *I better be prepared to, ahead of time, educate myself in the language of what I'm trying to convey, or find places that I already understand that have some understanding of celiac preparation*.

Callie added that individuals should *travel with people that understand your celiac disease and can advocate for you if needed; or make you feel safe in a sense in terms of your celiac disease… Sure, travel is scary, but that shouldn't hold you back.*

While the move to Saudi Arabia was challenging, it taught Alice *how to approach travel with more readiness and more preparedness*. Much like Coleman and Newton's (2005) expanded definition of self-management to encompass "the ability of the patient to deal with **ALL** [emphasis added] that a chronic disease entailed" (p. 1503), individuals desiring to live full lives with celiac disease deal with all it entails, including being appropriately prepared as Alice learned,

> *I just have to be really prepared and be aware that it might take time. There really isn't any such thing as an impossible situation in terms of something this simple. It all works out in the end. There's no such thing as a problem. There's just a situation we haven't found a solution for yet.*

Subtheme: Proactively Preparing for Gluten Free Travel

Individuals with celiac disease are known for being ready for any event or situation and make preparations to bring their own food, whatever that may entail. These are road warriors who travel with ice coolers full of food, pack multiple types of snacks, and let us not forget the infamous power bars. Those protein-packed, high caloric "meals" have saved every celiac at one time or another. They are the staple for those whose dietary restrictions are forgotten at events and who "do without when in doubt."

Ryan and Betty were both prepared for unfamiliar events. Ryan chose to attend a sailing school, a five-day course on the open water, all meals included. Betty's trip was also experiential, as she and a friend chose to take a road trip with Road Scholar to Bar Harbor. Both Ryan and Betty inquired about the gluten free food that would be provided and proceeded to be "ready" for the trip by obtaining fill-in gluten free options. Ryan was afraid that,

> *It would be kind of maybe too much of an imposition to impose my food restriction over the course of a week, but they were happy with this, and they were able to provision. We figured it out as we figured out many things in the course of this weeklong experience. There really wasn't that much discussion around how to go back to cooking for yourselves, but we figured it out.*

Ryan said the provisions were *tilted toward my request*, and that he *also brought along some things like camping meals and that kind of thing*. He also found camaraderie among his three other shipmates, with one choosing to be the primary cook. *This guy was there who was just very good and enthusiastic about cooking … Well, I told him what I needed to do* [to cook gluten free]. *Well, you know? He accepted it.*

Betty also inquired about the provision of her meals. The trip included gluten free boxed lunches:

> *The first time was fine … The second time I got very ill, and I ended up spending several hours in the bathroom when everybody else was doing activities. I had actually gone to the tour guide and said I knew I was starting to get sick. So, I asked if there is some way I can get back to the hotel. And unfortunately, from Bar Harbor there was no way to get back to the hotel from where we were. So, I just took over the bathroom for several hours and just stayed in there … there's nothing anybody could do. You know, you just have to ride it out.*

While both of these individuals prepared themselves by doing research to understand what provisions were provided and what they needed to bring to self-manage their diets, they were left with two very different outcomes. Ryan found that his trip was,

> *much less of a problem than I anticipated … I had a lot of apprehension about it … I mean I was glad. I was very lucky to have this fellow participant in the course* [the cook]. *That was a nice surprise. I realized that they did a good job of provisioning. I was grateful for that.*

Unfortunately, Betty did not have the same experience. While she had attempted to be ready for her trip, asking the right questions, and planning accordingly, she lost confidence in her ability to trust others' promises and learned that she had to be even more proactive:

> *I learned don't believe it when they tell you something can be gluten free … So, I shouldn't assume – you can't assume anything. You can't assume that they'll understand it all, especially the cross contacting. I don't think they pick up on that at all … and I am a little bit more – suspicious, you know? … Once again, you just have to be proactive, so you don't end up in that situation.*

Betty shared that she does not think she wants to *go on any kind of trip anymore where it's not near a city where I know that there's transportation if I needed to have it. I never expected that*. With that in mind, she does plan another road trip with Road Scholar and this time, she will apply the lessons learned from this trip:

> *I put on the thing* [application] *I want to know what restaurant you're going to, what days you're going to have boxed lunches so I can prepare. I can go someplace else, or I can bring something, so I know how much food to bring with me.*

In addition to her own learning experience, Betty believed the tour guide found the event to be significant,

> *I think that the guide on the trip learned a few things from that because I don't think she really understood or took it seriously … It wasn't good for me. It was a bad incident for me. But I think the tour guide learned something from it. So, you know, I mean, I learned from it, but I think some others did, too.*

Results: Experiential Learning in Self-Managing Celiac Disease

Based on the first phase of Clerx et al.'s (2019) self-management model, life at home, I presented an overview of incidents that were experienced by participants as they learned to navigate their new celiac diagnosis at home. The experiential learning process began with the initial diagnosis and centered on how individuals obtained information about celiac disease and the skills needed to self-manage their disease. Individuals utilized media, both print and online; learning from the self-management experiences of others diagnosed with celiac disease; and engaged in practical skills such as label reading, shopping, and cooking.

At first, some of the newly diagnosed individuals were stunned by their new lives as they attempted to locate accurate information about how to manage their disease. They felt alone or were overwhelmed due to a big learning curve and frustrations conducting routine tasks such as grocery shopping. Other individuals, who had learned from other celiac's experiences, felt less overwhelmed but noted the effort they had to put into self-managing their own diagnosis; like Sarah who, upon her own diagnosis, had to have a *constant awareness of where the gluten was and where it wasn't.* These diagnosed individuals reflected on the information they obtained from these experiences and applied their new knowledge (e.g., how to eliminate cross-contamination) to their daily lives.

These reflections brought with them changes in perception of their situations, such as Trevor realizing that his diagnosis *wasn't that bad* as he discovered from his friend just how much gluten free products had evolved, or Joanna's belief that she *can handle it* [living in a mixed household] *and move on to the next thing.* Individuals learned that they needed to take charge of their situations, such as Callie discovering *the more informed* [she] *was, the less intimidated or alone* [she] *felt.* These examples demonstrated how participants gained self-efficacy from their experiences of learning how to live with their chronic diagnosis. As described by Schunk and DiBenedetto (2019, individuals desired a sense of agency or influence over events such as the self-management of their disease and such self-efficacy led these individuals to set goals and strategies for changing their behaviors.

In social situations, the second phase of Clerx et al.'s model, individuals reclaimed a sense of self and enacted self-advocacy. Due to the self-efficacy gained from learning practical skills, individuals became more comfortable with their new lifestyle and were more willing to ask that their dietary needs be met. However, social situations brought about anxiety, such as a young Callie feeling left out at children's events and on the outside of peer groups as a teenager. Individuals felt a sense of loss as they became less of the person they knew, such as Alice trading her "foodie" days for those of a restricted diet. However, as individuals reflected and accepted their disease, applying the learning they obtained from their experiences, they were able to reclaim their identity, albeit a different one.

Individuals became more comfortable advocating for themselves as they utilized what they had learned and applied this knowledge. To eat safely Joanna brought her own meal to a wedding and in reflecting gained more confidence in her choice and that it really did not matter what others thought because *nobody was going to be talking about it a year after*. However, in other social situations, particularly with family, bringing one's own food in order to be safe was challenging. For Sarah, there was a pervasive sense of a lack of trust that others would be able to take care of her dietary needs. This demonstrated the difficulty that individuals have in attempting to be safe while maintaining social decorum or family relationships.

Finally, in social situations, it was found that one can educate others from their own learning. In many cases individuals found themselves in social situations in which they appeared odd due to bringing their own food or abstaining from eating, which presented an opportunity to educate. While this was generally seen as a good thing by most, sometimes the burden of teaching others became too great, and like Sarah, some diagnosed individuals would rather keep quiet and not engage.

Phase three covered the challenges of individuals diagnosed with celiac disease as they navigated workplace relationships and hierarchies. The incidents in this section demonstrated how individuals who were diagnosed with celiac disease sometimes shared their needs, while others chose not to do so, mainly because they did not want to be responsible for interfering with others' desires (e.g., Callie's coworkers and Joanna's company's pancake breakfast). Others were required to navigate the hierarchy of their work environment and instead of providing "teaching moments" chose to stay quiet and either bring their own food to the event or like Alice, accept the food or drink item and just not partake of it.

As individuals navigated workplace relationships, they learned not only how to navigate relationships such as Callie choosing to trust others with the knowledge of their diagnosis, but also about themselves as Alice learned that she cared more about what others thought of them than she realized. In navigating work relationships and hierarchies, individuals experienced discomfort, guilt, and isolation, as Holly felt when the event organizer responded that Holly should *just be able to eat what was provided*. Finally, while most individuals experienced the need to advocate for their own needs, one participant took advocacy a step further, utilizing his positionality to enact change for others attending medical events who may need dietary accommodation.

Section four presented an overview of critical incidents that individuals encountered when self-managing their disease in unfamiliar settings. These settings ranged from international destinations to experiential travel for educational purposes.

Three individuals (Alice, Callie, and Trevor) discovered that language was a major barrier which caused them to have less locus of control. However, with reflection, these individuals learned that to travel they needed to be more prepared to understand the language, and possible other barriers, to ensure their ability to eat gluten free. Alice shared that her relocation *really taught me how to approach travel with more readiness and more preparedness* and she actively experimented with traveling abroad, utilizing online translators to help her dine safely.

Callie and Trevor both learned that they needed to plan better for future travel by doing more homework about the countries they planned to visit and understanding their language and customs as they related to self-managing their gluten free diet. In addition, Callie recognized that although she had a loss of locus of control by depending on her boyfriend to translate for her, she felt that celiacs should *travel with people that understand your celiac disease and can advocate for you if needed; or make you feel safe in a sense in terms of your celiac disease.*

While individuals with celiac disease understand the necessity to prepare, Betty and Ryan demonstrated that preparedness may or may not ensure a pleasant experience. While Ryan reflected on the camaraderie he found among others on his trip, he appreciated how accommodating they were and their willingness to accommodate his diet, it was *much less of a problem than* [I] *anticipated.* Betty had a different experience and learned that even when one is prepared and proactive about gluten free dining, sometimes you can still have issues. Because of her experience of being glutened on her trip, she had become *a little bit more – suspicious … Don't assume that for something like that, don't assume that they understand at all*, which greatly influenced Betty's preparation for her next trip.

Through each of these experiences of self-managing celiac disease in an unfamiliar setting, the participants demonstrated significant reflection and learning that led them to actively experiment and apply what they had learned to new unfamiliar settings.

Chapter Summary

In this chapter, I presented findings derived from the analysis of selected critical incident narratives. Flanagan's (1954) critical incident technique was combined with Erickson's (2012) technique of thematic assertion to develop themes and subthemes associated with the selected critical incident narratives. The prominent themes were organized according to Clerx et al.'s (2019) stages of celiac disease self-management in the home, social life, at work, and in unfamiliar settings. Prominent themes were practical learning, social challenges and self-advocacy, challenges in the workplace, and continued learning. In chapter six I will discuss the conclusions, significance of the study, and its implications for future research and practice.

CHAPTER 6

CONCLUSION

In this chapter I summarize the study and make general conclusions regarding the research findings. I also discuss the implications of the study as it pertains to theory and practice, the limitations of the study, and future research.

Summary of the Study

The purpose of this critical incident study was to examine the lived experience of individuals' self-management of CeD and the theoretical role that experiential learning played in that experience. The research question guiding this study was:

1. What was the lived experience of individuals' self-management of celiac disease and what role did experiential learning play in that lived experience?

I designed this qualitative study to be exploratory; therefore, I used the Critical Incident Technique with semi-structured interviews to obtain recounted stories of past and present experiences of the participants. Participants were purposefully obtained from members of the nonprofit organization, Beyond Celiac. These participants were required to meet the criteria of being an adult over the age of 18; formally diagnosed with celiac disease by a medical practitioner through either blood serum test, endoscopy, or both; and had lived with celiac disease for a minimum of three years. The selection process is presented in detail in Chapter 3.

All interviews were conducted via Zoom, with follow-up online meetings conducted as needed for content clarification. The interviews were transcribed through the TurboScribe transcription service. Out of 70 total critical incidents, 40 included all four elements of Kolb's experiential learning theory: experiencing, reflecting, thinking, and applying. The data was analyzed by first cleaning and re-storying the transcripts, utilizing the participants' own words. Each story was then given a headline to convey the essence of the story. Second, the data was analyzed via Erickson's (2012) technique of thematic assertion, coupled with deductive and inductive analysis, to emphasize pertinent meaning-making and themes that were related to the research purpose and critical incidents (Watkins et al., 2022). The re-storied incidents appeared in Chapter 4, and a presentation of the findings of how experiential learning was utilized in the self-management of disease was given in Chapter 5.

Conclusions of the Study

In this section, I will discuss the conclusions I drew from the study according to the theoretical framework of experiential learning and in the context of self-management of celiac disease. Based on this framework, three main conclusions were made about experiential learning and patient self-management:

- **Conclusion 1:** Experiential learning provided a framework for future experiential learning in the self-management of celiac disease.
- **Conclusion 2:** The skill of self-advocating for one's needs in the self-management celiac disease was derived from experiential learning.
- **Conclusion 3:** Experiential learning initiated the transformation of perception in the self-management of celiac disease.

These three conclusions are discussed below and include key literature and narratives (in italics) from the critical incidents shared during the participant's interviews.

Conclusion 1: Experiential Learning Provided a Framework for Future Experiential Learning in the Self-Management of Celiac Disease

Combining the four phases of Kolb's (1984) experiential learning with Clerx et al.'s (2019) four stages of self-management of celiac disease provided a framework for new experiential learning within each stage. This process was demonstrated as post-diagnosis, individuals moved through each of the four stages (e.g., at home, social life, in the workplace, and unfamiliar settings) as they learned to self-manage their disease, adding new learning at each stage. This new learning was influenced by experiential learning from prior stages. For example, individuals combined the learning they acquired from Stage 1 (adapting to a gluten free life) with learning they gained in Stage 2 (social challenges), which provided a framework for new learning in Stage 3 (workplace), as well as in unfamiliar settings in Stage 4. See Figure 6.1.

This aligns with Dewey's (1938) philosophy that knowledge could become complex, and with that complexity, meanings change as learners reflect on new knowledge and apply it to their existing schemas; in this case, gained from stages of self-management. As discussed in Chapter 2, Dewey believed that "continuity of experience meant that every experience both took up something from those which have gone before and modified in some way the quality of those [experiences] which come after" (p. 27). This meant that experiential learning was not isolated, but individuals connected their current learning experiences (from the self-management stage they were presently in) with those of the past (prior stages) and saw future implications (the next stage) for what they had learned (Merriam and Baumgartner, 2020).

Figure 6.1

Framework for New Experiential Learning in the Self-Management of Celiac Disease

Experiential learning from Stage 1 is utilized for experiential learning in Stage 2.

Experiential learning from Stages 1, 2, and 3 provide a framework for new experiential learning in Stage 4.

Experiential learning from each individual Stage influences the next Stage. For example, Stage 1 influences Stage 2, Stage 2 influences Stage 3, and Stage 3 influences Stage 4.

Experiential learning from Stages 1 and 2 provide a framework for new experiential learning in Stage 3.

Note. Based on Kolb’s Four Stages of Learning and Clerx et al.’s (2019) Stages of Self-Management of Celiac Disease. Figure designed by Danielle Burns.

In addition, within their learning, as individuals reflected on their experience, they assessed what they had learned (Kolb’s abstract conceptualization), and how it could be included in other situations (Kolb’s active experimentation). As they reflected-in-action, they learned, and reshaped their thoughts in the moment of their experiences (Merriam and Bierema, 2014). In this study, both types of reflection occurred as individuals shared their reflections about their past experiential learning, as well as recalled reflections in the moment which occurred during the learning experience.

While most individuals in the study moved from Clerx et al.’s (2019) Stage 1 through Stages 2 and 3, only five (Alice, Betty, Ryan, Trevor, and Betty) shared critical incidents in

Stage 4 (unfamiliar settings). Each of these individuals had lived with celiac disease for five-plus years and during that time had experienced critical incidents that led to experiential learning in Stages 1-3 that was combined and utilized in Stage 4 as they experienced unfamiliar situations when self-managing their disease.

Alice utilized the learning from experiences she gained from navigating her disease at home (Stage 1) when engaging in social relationships (active experimentation), *you've got to keep searching … to not give up, and to not just accept, okay, this is the way it's always going to be.* By not giving up, Alice found a way to reenter the social world by learning how to advocate (abstract conceptualization) for herself through her social interactions (Stage 2) with a new friend, *I had options of leaving my house … all of a sudden … I had this world of opportunities … it goes back to learning from others – don't be afraid.* The experiential learning she gained from self-advocating was then utilized in her workplace (active experimentation) as she engaged in hierarchical situations while attempting to maintain her gluten free diet (Stage 3).

> *It's a fine balance to advocate for yourself while still respecting the hierarchy … in my engagement with others, I am more likely to* [say something about my gluten free needs] *if I am more comfortable with people to explain.*

Alice also found that in an unfamiliar setting (Stage 4), she once again felt uncomfortable and utilized the knowledge she had gained from Stages 1-3 (active experimentation). Upon moving to a new country with her husband, she lost her locus of control due to the language barrier and had to depend on her husband to interpret her gluten free needs to servers and others. Similar to her critical incident in Stage 1, Alice realized that she could not give up, *it was okay, this is how the situation is going to be. I just need to be ready to roll with it. I just have to be really prepared* (Stage 2) *and be aware that it might take time.* Alice found that being adaptable

(Stage 3) *taught me how to approach travel with more readiness and more preparedness … I can go to new places* (abstract conceptualization). As this example demonstrated, experiential learning served as the framework for moving from one self-management stage to the next. The theory of experiential learning proved to be an essential component for Alice as she built the necessary skills to successfully self-manage her disease in all stages.

Being diagnosed as a child, Callie primarily learned how to live with her disease after she became an adult and moved out on her own. She learned in this experience that you should *be as informed as you can* (Stage 1 – at home) *… just try to ask as many questions as you can no matter when you're diagnosed* (abstract conceptualization). Knowing the necessity of understanding her disease helped Callie navigate social and work environments as she learned the importance of others learning about her celiac disease, *the people I've surrounded myself with understand what celiac disease is* (Stage 2 – social life) *… You should just trust people. Your disease is not something to be ashamed of.* This experience led Callie to trust others more at work (Stage 3 – at work), which in turn positively affected her ability to trust her boyfriend (active experimentation) to be the middleman for explaining her gluten-free dietary needs because of a language barrier during her unfamiliar travel (Stage 4). This experience had Callie circling back to her original need to be informed, *I think next time, for a different trip … I'd probably research more about the location.*

The remaining three individuals, Ryan, Trevor, and Betty were different than Alice and Callie for two reasons. First, they were all diagnosed at retirement age (54 years, 68 years, and 70 years, respectively). Second, because they were diagnosed in retirement, these individuals did not follow Clerx et al.'s (2019) prescribed four-stage model. Instead of engaging in Stage 3 (at work), these individuals expanded their social lives and became involved with social groups such as Betty attending dinners and teas at her 55+ residence; Trevor volunteering at church or golf outings; or, as Ryan shared, his activities had been restricted because covid *cut down that kind of social activity massively for two and a half years.*

Although these individuals did not engage in Stage 3 through work experience, they did engage in Stage 4 (unfamiliar settings). Because of this, one can question if Stage 3 (at work) is a necessity for all individuals. This question will be discussed further in the section of Future Research.

Ryan, Trevor, and Betty each found that their experiential learning from Stages 1 and 2 combined to inform the learning in Stage 4's unfamiliar settings. As an example of Kolb's active experimentation phase where new learning was applied, Ryan's new learning of how to cook (Stages 1 and 2) informed his experience of attending sailing school by ensuring he had the necessary skills to cook meals for himself. Trevor's experience of learning not to feel sorry for himself, but instead to advocate for himself (Stages 1 and 2), gave him the confidence to engage with a language barrier when expressing his dietary needs at a destination wedding. Finally, Betty, who unfortunately became glutened in her unfamiliar setting, through her experience, doubled down on her skills of preparedness and advocacy (from Stages 1 and 2) to be even more prepared for her next adventure. Table 6.1 demonstrates how the experiential learning from Clerx et al.'s (2019) Stages 1-3 connected together and were applied to Stage 4's unfamiliar settings (Kolb's phase of active experimentation).

Table 6.1

Experiential Learning from Clerx et al.'s (2019) Self-Management Stages 1-3 as Applied to Stage 4

	Experiential Learning			
Participant	Stage 1 At home	Stage 2 In Social Settings	Stage 3 In the Workplace	Stage 4 In Unfamiliar Settings
Alice	Learned GF life skills from experienced individuals	Gained confidence to self-advocate when dining out	Self-advocated for GF lifestyle in a hierarchical setting	Gained understanding that *I just need to be ready to roll with it … I just have to be really prepared* **Applied Learning (Kolb) from Stages 1-3:** *You've got to keep searching … to not give up … learn from others - don't - be afraid*
Callie	Gained more understanding about celiac disease as an adult. Learned to be informed about her disease	Found that she needed to surround herself with others who understood her disease. CeD did not define her	Encountered others who were more supportive than anticipated	Discovered that *next time … I'd probably research more about the location* **Applied Learning (Kolb) from Stages: 1-3:** *Be as informed as you can … ask questions … be surrounded with people who understand … trust people*
Trevor	Gaining control of life post-diagnosis	Educating friends about CeD and how to cook safely for him	Retired – volunteer/golf outings/tourneys	*If I want to travel outside the U.S.,* *I better be prepared to educate myself … many countries* **Applied Learning (Kolb) from Stages 1-3:** *I realized it's not that bad … if I communicate well, I won't get sick … I*

	Experiential Learning			
Participant	Stage 1 At home	Stage 2 In Social Settings	Stage 3 In the Workplace	Stage 4 In Unfamiliar Settings
				have to educate others and be clear
Ryan	Learned how to cook for himself from his wife post-diagnosis	Cooked for family in Japan over a two-month period	Retired – pandemic affected social life	Learned that *others would be supportive of his diet* **Applied Learning (Kolb) from Stages 1-3:** *You start with the basic things, and keep adding … I'm very happy to be able to produce food … that I am happy to eat*
Betty	Became adept at reading labels and shopping	Being social with others depends on her invitation	Retired – retirement social groups	*I learned don't believe it when they tell you something can be gluten free … I am a little bit more suspicious* **Applied Learning (Kolb) from Stages 1-3:** *It was going to be a little harder than I thought … If I really want to go out … it's really on me … it's better for me to organize something*

Conclusion 2: The Skill of Self-Advocating for One's Needs in the Self-Management of Celiac Disease was Derived from Experiential Learning

According to Schmidt et al. (2020), self-advocacy was the ability for an individual to represent their interests when managing a disease or disability. There are four components to self-advocacy that include (1) knowledge of self, (2) knowledge of rights, (3) communication, and (4) leadership (Test et al., 2005). In this study, participants learned to self-advocate from their experiences of self-managing celiac disease at home, in social settings, at the workplace, and in unfamiliar settings. Test et al. (2005) asserted that the knowledge of self and knowledge of one's rights, were "viewed as the foundations of self-advocacy, because it was necessary for individuals to understand and know themselves before they could tell others what they wanted" (p. 2). For individuals with celiac disease, once they have an understanding of themselves and their rights, in and out of the context of their disease, they have a better foundation for being able to communicate the needs they desire to have met.

However, upon a chronic disease diagnosis such as celiac disease, as discussed in Chapter 2, newly diagnosed individuals may experience a sense of liminality, a place of ambiguity and uncertainty that is 'betwixt and between' (Wending, 2008; Turner, 1966; Wels et al., 2011) and desire to gain a sense of control. According to French and Delahaye (1998) for such individuals, it was the ability to learn that helped them move towards accepting the change.

Self-Efficacy and Self-Advocacy in Experiential Learning

To gain a sense of agency over their diagnosis, a central element for individuals was self-efficacy and the belief that they could learn to live with celiac disease at home. As individuals worked toward the goal of understanding their disease and the self-management of it, they gained self-efficacy. As individuals engaged in experiential learning, they engaged in strategies and goals for self-managing their disease. Within their experiential learning these individuals self-reflected on what occurred in their learning and adjusted their behavior accordingly to meet self-management goals. From their experiential learning, individuals had higher levels of self-efficacy as they gained a better understanding of themselves and their rights, and in turn, were able to self-advocate their needs.

The influence of self-efficacy on self-advocacy was seen throughout the study. For example, Joanna gained self-efficacy in her ability to self-manage her disease at home as

> *I came to the conclusion that I can do it … I can figure it out … I can figure out other things like going to a restaurant or going to a family member's house who does not have a gluten-free kitchen. I just feel more comfortable with it.*

From experiences like this, Joanna had the confidence to advocate for herself and communicate her needs to others, *just tell them up front I am going to be bringing my own food*, even though she felt awkward and a lot of guilt, Joanna persevered for her health's sake.

Others experienced similar situations of angst. Holly understood that she had the right to ask for food accommodations at work events. When it was not provided, she *called her* [the event coordinator] *out on it* and asked her, *why should I be the only one not allowed to get food from the outside paid for by the company when everyone else can?* While the coordinator had a negative response, Holly still knew she should, and could, communicate her dietary needs. Mary also experienced a negative reaction from her co-workers about bringing in her own box of gluten free supplies, *I learned that some people don't necessarily understand, and you have to speak up for yourself.*

According to Test et al. (2005) and Williams and Shoultz (1984), after individuals learn about themselves, their rights, and communicate these in an effective manner, they utilized this experience to be leaders and take on the role of leader as they advocated on behalf of others to ensure individuals with similar concerns about their own disease could have their voice heard as well. One individual in this study was able to do this, Heath, a medical doctor who was able to utilize his positionality to speak to event staff regarding dietary needs with the hope of not only helping himself, but others at the event and subsequent other attendees,

> S*o, as we're talking about learning, I think there's a lot more institutional and corporate learning going ono more than my individuals learning …* [an organization he belongs to] *has a Washington Hill Day year, and they now have a significant number of gluten free options. I like to think I helped make sure that happened.*

While this result was great for many and a very positive thing to occur, Hutchens et al. (2023) brought to light that women who attempted to self-advocate were deemed to be viewed as more unlikeable. This negative perception of women who advocated could limit the number of opportunities for women to engage in making changes on behalf of celiac disease. As previously mentioned, women were diagnosed with celiac disease 50% more frequently than men, and therefore, this negativity could limit their ability to reach their core constituency.

Conclusion 3: Experiential Learning Initiated Transformation of Perception in the Self-Management of Celiac Disease

Making meaning of one's experience is based on attitudes, values, and beliefs. In light of being diagnosed with celiac disease, individuals' perceptions may no longer fit the new situation, causing a transformation of that perception (Dubouloz et al., 2010a; Mezirow, 1978). For this to occur, thoughts, viewpoints, and attitudes must be changed, or transformed. This transformation included the process of meaning-forming (making) and reforming meaning. Because meaning making was a key component of experiential learning, it was necessary for individuals to have a clear understanding of how they see themselves (an essential part of self-advocacy) and consider their situation, making changes if necessary.

To make meaning from their experiential learning, individuals restructured their frame of reference and reconstructed their thinking (Kegan, 2018). According to Mezirow (1978), some challenges in life (such as a celiac disease diagnosis) cannot be resolved by knowledge alone but have the need for individuals to reassess their assumptions about their situation. For this study, that would indicate that individuals should focus on adapting to their disease and personally growing within its context (Barclay-Goddard et al., 2012). Such adaptation, personal growth, and shift in perspective (changing an old viewpoint for a new one) were central to this transformative concept.

In this study, individuals demonstrated through their experiential learning that they underwent a transformation of self and how they perceived their disease. As Alice found that she could navigate eating out again, she reflected on how she became herself again,

> *Actually, having that one person show me that I could reenter the world basically helped me … I really do think that being able to be myself again, I really feel like in some ways it unlocked me. It unlocked who I really am. I became myself again.*

Similarly, Callie found that she had transformed her viewpoint about her disease and herself as she reflected on how she had changed since becoming an adult,

> *In high school nobody understood that* [celiac disease]. *It just felt like if they didn't understand* [my disease] *that they didn't understand me … they didn't understand that they weren't going to know who I was. I felt like celiac was my identity.*

However, she found that her perspective transformed after she left for college.

> *I think it's gotten easier as I've gotten older … the more informed I was the better I felt about myself …* [I've learned] *that Celiac is not my identity. I am a whole other person outside of my disease.*

It seems common to assume that all changes in perspective will be positive. However, in light of living with celiac disease, this is not always the case as demonstrated by Sarah and Betty. Both individuals had negative transformations in their perspectives as it came to trusting others. Sarah shared about the moment her perception changed about trusting others to keep her safe from gluten,

> *I realized that no matter how hard people are trying, they often just don't get it, you know? That was kind of a moment* [after her daughter was glutened at a family member's home] *where I, ever since, just don't trust that anybody is going to prepare food safely … I'm probably over cautious that way, but I don't trust that anybody is going to prepare food for me … you really have to realize that nobody's going to think about it as hard as we're thinking about it.*

Similarly, when Betty was glutened on a Road Scholar trip, her perspective was transformed to not assume a trusting attitude towards others as it related to her diet. Even though she self-advocated for gluten free meals, she still was glutened.

> *I don't believe it when they tell you something can be gluten free. They probably don't understand the difference between celiac* [and gluten allergy/intolerance]. *So, I shouldn't assume – you can't assume anything. You can't assume that they'll understand at all, especially the cross contacting. I am a little bit more suspicious … Don't assume that they understand at all.*

As each of these individuals have shown, experiential learning can lead to both positive and negative perceptions of one's situation. While most individuals desire a positive perception, as Sarah and Betty have shown, sometimes a negative experiential learning incident, even though it brings about a negative perception, could be a means of protection, as these individuals become more diligent in assessing others’ knowledge of celiac disease and appropriate preparation of gluten free food.

This study demonstrated how individuals’ learning schemes were challenged when they made meaning of their celiac diagnosis. As they engaged in experiential learning they gained new perceptions about their experience that included recognition of their new self (e.g., I am me again; I am no longer identified by celiac; I do not trust, or I am more suspicious). In these perceptions from experience, individuals transformed their outlooks towards not only themselves, but also towards others’ response to their disease.

Implications

The Influence of Experiential Learning on Self-Management

Previous scholarly work indicated that experiential learning was an essential part of patient self-management in chronic disease. However, for celiac disease, it was found there was a dearth in the number of studies that demonstrated how experiential learning was utilized in self-management. According to Kolb (1984), experiential learning was an adaptive process that provided “conceptual bridges across life situations … portraying learning as a continuous lifelong process (p. 33). By combining Kolb’s (1984) experiential learning theory with Clerx et al.’s (2019) stages of self-management of celiac disease for this study, it was determined that experiential learning was utilized in each life situation, or stage (e.g. at home, social life, workplace, and unfamiliar situations) and that learning from each stage was applied to the next stage. See Figure 6.1 and Table 6.1. These results demonstrated that experiential learning was an essential component of self-managing celiac disease and served as a conceptual bridge between life situations (stages).

In addition, as discussed in Chapter 2, Borkman's (1976) seminal work indicated that individuals gained wisdom and insight from engaging in experiences, and as individuals gained competency in resolving their problems through their own experience, they gained experiential knowledge. Castro et al. (2018) added that as individuals moved from novice to experts in living with their illness, their expertise became transferable at the micro (direct care), meso (organizational), macro (healthcare system), and meta (research education) levels. This was demonstrated in this study as individuals gained experiences from learning to live at home and socially (micro) to engaging with others at work (organizationally), worked with their own medical care as they could (macro), and participated as contributors in celiac disease research (meta).

Understanding the trajectory of experiential learning, as it relates to the stages of self-management (life stages) prompted several positive outcomes. Health coaches and healthcare professionals could create supportive education programs that explain experiential learning and how it provides a framework for future learning and that each life phase builds on the prior one. This type of education would provide newly diagnosed individuals with reassurance that the self-management of their disease is a life-long process, thereby providing a more positive outlook on their diagnosis. For physicians, understanding the trajectory of experiential learning in which their patients engage can provide a new lens through which they can view their patient's diagnosis and needs, which may lead to a transformative experience.

Applying Self-Efficacy in Self-Advocating about Celiac Disease

This study demonstrated the influence of Bandura's concept of self-efficacy within experiential learning. According to Schunk and DiBenedetto's (2019) assessment of Bandura's work, individuals desire to have control and influence over important events. For this study, the important events were the diagnosis of celiac disease and learning through experience of how to self-manage the disease. In prior work by Cudris-Torres et al. (2023) about the influence of self-efficacy in determining which individuals participated in their own self-care, those who had higher self-efficacy showed a greater ability to cope and gain control over the self-management of their disease.

In this current study, it was found through experiential learning that as individuals gained more confidence in their ability to self-manage the dietary requirements of their disease, the more likely they were to advocate on behalf of their needs when engaging with others personally, socially, or in the workplace. By advocating for oneself, individuals made personally meaningful decisions, and communicated with health providers, improving their "perceptions of person-centered care, symptom burden, quality of life, and health care utilization" (Hutchens et al., 2023; Thomas et al., 2021) as it related to their disease. This research demonstrated several examples of how individuals had self-efficacy in their abilities to self-advocate when in personal, social, workplace, and unfamiliar situations.

The desire for these findings is to encourage individuals who may be introverted or have difficulty advocating for their needs. Two individuals who participated in this study shared that they were introverts, and although they found it difficult to speak up, they both had self-efficacy and belief that they could self-advocate. According to Betty,

> *I am very much an introvert, but I have to* [initiate] *if I want to go out, and a lot of social things revolve around food. So, if I want to go out someplace, it's up to me to organize something and pick a restaurant I know I can eat at.*

When Holly was asked what encouraged her to advocate for herself, because she was a quiet and reserved person, she shared that she talked with her mother, who used to work in the food service industry, and was encouraged to self-advocate: *'You need to tell these people what you need, and they will provide it for you. You just need to open your mouth.'* Holly took the advice to heart and was one of the more vocal self-advocates within the study.

Another goal for this research is to share informative lived experiences of learning so that coaches and healthcare professionals understand how individuals with celiac disease are influenced by these experiences when advocating for themselves. With this information, Coaches and healthcare professionals could develop programs or social experiences in which individuals who are diagnosed with celiac disease could participate. One example is group meetings such as Meet-ups, supper clubs, or group sessions that provide a way for individuals to practice and engage in events that can build their self-efficacy, encouraging self-advocacy.

Transforming the View of Celiac Disease

How one sees themself, as well as their disease, has an influence on how they self-manage their disease. Again, as Kegan (2018) shared, the learning of transformation changed *how* one saw themselves, and in this change, individuals reconstructed their thinking. To manage one's disease well, individuals not only needed to learn about their disease or how to cope with it, but also needed to reassess how they made meaning about their experiences (Mezirow, 1978). In this study, as several individuals confronted their loss of self, felt sorry for themselves, or became more fearful, they learned to adapt to their shift in perspective, which influenced how they approached the self-management of their disease.

In light of how individuals make meaning of their experiential learning, it is important for them to self-reflect and consider how they are coping, and through what lens they see their disease. This study provided narrative stories that described not only the struggles, angst, and frustration of a celiac disease diagnosis, but it demonstrated how self-reflection and introspection provided a means for participants to change their lens:

> *I came to the conclusion I can do it. This is what it is. I can handle it (Joanna); Celiac is not my identity. I am a whole other person outside of my disease (Callie); It bothered me a lot more at first than it does now. Now I look at it as something that's going to make me sick (Rosemarie);* and *It's okay to advocate for yourself and make sure that your dietary needs are met. I didn't feel isolated. It made it more enjoyable (Holly).*

Much like Courtenay et al.'s (1998) study of HIV-patients who reassessed their purpose for being here, desiring to take control of their lives, doing so through the self-management of their disease, it is important for celiac patients to do the same. For this to happen, it is important that health coaches and health professionals provide opportunities for these individuals to reflect on their circumstances and how their current lenses influence the meaning they are making of their learning experiences. In addition, the findings from this study about the transformation of individuals' perceptions can help physicians better understand the mental shift that occurs for celiac patients throughout the self-management of their disease.

Using Critical Incident Technique (CIT) for Medical Research

Critical incident technique (CIT) has been utilized to qualitatively study a wide range of topics such as relationships, perceptions, decision-making, vocational choices, group processes (Butterfield et al., 2005; Woolsey, 1986), and in the case of this study, application of adult learning theory. Because of its ability to study topics over an extended period of time, CIT was also deemed an appropriate choice for this study as participants' diagnoses ranged from four to 16 years. CIT also provided a platform for obtaining rich, thick narratives about the lived experiences of individuals self-managing celiac disease. This method did not disappoint but provided 40 critical incidents that were rich with detail, emotion, and transformation.

Because of its ability to obtain deep meaningful stories of lived experiences through its interview format of open-ended questions, CIT provides a platform for obtaining meaningful patient data within the medical profession, specifically for celiac disease research. According to Renjith, et al.’s (2021) review article of the use of qualitative methods in health care research, the utilization of qualitative research is “widely used to understand patterns of health behaviors, describe lived experiences, develop behavioral theories, explore healthcare needs, and design interventions” (p. 1). Each of these aforementioned subjects is not only one that can be utilized in celiac disease research but is one in which CIT can be used for gathering rich data as a means to inform these topics and develop materials for patient education and patient interventions for the self-management of celiac disease.

Limitations of the Study

There were several limitations associated with this study. First, while participants varied in age, they were not very diverse in sex, race, or ethnicity, and did not embody underrepresented populations. Second, all participants, except for one, had a form of advanced education which may have influenced the outcomes of experiential learning in self-managing celiac disease. Third, due to the interviews being conducted via video, there was a loss of body language and non-verbal cues that may have added to the depth of the interviews. Fourth, because the study was specific to celiac disease and its patients it prevents generalizability to other chronic illnesses.

Recommendations for Future Research

This study provided a rich, thick description of the role that experiential learning played in the lived experience of self-managing celiac disease. The themes and subthemes that emerged provided insight into these experiences and the role of experiential learning in stages of self-management of celiac disease, the influence of self-efficacy on individuals' ability to self-advocate, and how it initiated transformation of perspective in individuals diagnosed with the disease. However, further exploration of Clerx et al.'s (2019) stages of self-management in celiac disease should be conducted to understand the necessity of individuals following each stage and timeline to ensure meaningful self-management of their disease. In particular, in this study, there were three individuals who shared critical incidents in unfamiliar situations that had not met the criteria of navigating the disease in the workplace (Stage 3) due to them being retired. This calls into question the necessity of individuals needing to engage in each prior stage in order to be comfortable with unfamiliar situations.

Additionally, while culture was briefly mentioned as a characteristic of some participants (Muslim, Mennonite, Middle Eastern, and Japanese), this topic was not specifically researched in the context of its influence on the self-management of celiac disease. I recommend that future research take into account culture as it relates to and influences individuals' self-management of their disease.

Also, the role that age plays in experiential learning, as it relates to the self-management of celiac disease, should be considered. In this study, five individuals were diagnosed at the age of 36 or younger, with seven being diagnosed during post-retirement, 54 years and older. It was noted that the five individuals who were diagnosed at a younger age engaged in work-related challenges and hierarchies where those who were retired did not. It was also noted that those who were younger were more concerned with how they were perceived by others in social and work settings. Those who were retired had less concern for what others thought about them and had less expectations about what others should do for them with regard to their dietary requirements. Considering that individuals can be diagnosed with celiac disease at any age, studying how age affects individuals' self-efficacy and approach to living a gluten free lifestyle could be informative for medical professionals and health coaches as they develop programs for varying age groups.

Unfortunately, in recent studies, it was found that self-advocacy has challenges for one particular group, women (Hutchens et al., 2023). In a study of Australian women who advocated for their personal healthcare, it was found that women had multiple significant barriers in their ability to self-advocate. It was demonstrated that despite women being articulate and educated, they experienced low efficacy in self-advocating and felt silenced as they attempted to engage in relating their symptoms and needs. In addition, other factors influenced women's ability to self-advocate that included their previous experiences or current expectations of "backlash against assertiveness or self-advocacy," and it was theorized this was a "retribution for violating gender norms" (Hutchens et al., 2023, p. 8) where women were deemed less likeable when they asserted themselves.

In light of these findings and knowing that women are diagnosed with celiac disease 1.5:1 more frequently than men (Caio et al., 2019), it seems imperative that these barriers should be addressed. As reflected in Schmidt et al.'s (2020) scoping review of self-advocacy education interventions, self-advocacy can be taught, and therefore can be improved to ensure that individuals, especially women, are better heard. To better understand the lived experience of women with celiac disease who wish to self-advocate, I recommend further studies be conducted utilizing the critical incident technique to obtain personal narratives about self-advocacy. This type of knowledge could counter paternalistic norms that view a patient’s experiential knowledge as lacking credibility. In addition to focusing on the development of the patient’s ability to self-advocate, health care professionals and health care systems should “recognize the broader health socio-political context” (Hutchens et al., 2023, p. 10).

Conclusion

In this chapter, I presented findings and conclusions derived from the analysis of selected critical incident narratives. I utilized Flanagan’s (1954) critical incident technique combined with Erickson’s (2012) technique of thematic assertion to develop themes and subthemes associated with the selected critical incident narratives in the context of Clerx et al.’s (2019) self-management of celiac disease and Kolb’s experiential learning theory. Prominent themes included acquiring experience with the gluten free lifestyle; engaging in social challenges and self-advocacy for managing celiac health; navigating challenges in the workplace around a gluten free lifestyle; and self-managing the gluten free diet in unfamiliar settings.

It was concluded that experiential learning was utilized in each stage of Clerx et al.’s (2019) stages of self-management and learning from each stage was combined to encourage future learning in new stages. Individuals also utilized their sense of self-efficacy as a catalyst for self-advocating for their gluten free lifestyle, and individuals experienced transformation in their perceptions about their disease. Finally, limitations of the study were discussed as well as, future research that suggested assessing the necessity of all four stages of Clerx et al.’s stages of self-management and the barriers women face when advocating for their health.

It is hoped that the contributions of this study will encourage interest in these and other potential areas of research about the self-management of celiac disease. It is the desire for this research to serve as a catalyst for the development of future educative interventions that inform and educate potential and current celiac patients, health coaches, health care professionals, and physicians to improve patient interactions and lead to better patient self-management.

Reference List

Akbari Namvar, Z., Mahdavi, R., Shirmohammadi, M., & Nikniaz, Z. (2021). The effect of group-based education on knowledge and adherence to a gluten-free diet in patients with celiac disease: Randomized controlled clinical trial

Akbari Namvar, Z., Mahdavi, R., Shirmohammadi, M., & Nikniaz, Z. (2022). The effect of group-based education on gastrointestinal symptoms and quality of life in patients with celiac disease: Randomized controlled clinical trial. *BMC Gastroenterology, 22*(18), 2-7. https://doi.org/10.1186/s12876-022-02096-1

American College of Gastroenterology. (2023). *How common was celiac disease?* https://gi.org/topics/celiac-disease/

American Medical Association. *Chronic disease.* https://www.ama-assn.org/topics/chronic-diseases

Anderson, L., Thompson, D. R., Oldridge, N., Zwisler, A. A., Rees, K., Martin, N., & Taylor, R. S. (2016). *Cochrane Database of Systematic Reviews, 1,* 1-198. https://doi.org/10.1002/14651858.CD001800.pub3

Anderson, R. M. (1995). Patient empowerment and the traditional medical model. *Diabetes Care, 18*(3), 412-415. https://diabetesjournals.org/care/article/18/3/412/19212/Patient-Empowerment-and-the-Traditional-Medical

Antlova, A., Chudy, S., Buchtova, T. & Kucerova, L. (2015). The importance of values in the constructivist theory of knowledge. *Social and Behavioral Sciences, (203),* 210-216. https://doi.org/10.1016/j.sbspro.2015.08.284

Antonovsky, A. (1979). *Health, Stress, and Coping*. Jossey-Bass Inc.

Bai, J. C., Ciacci, C., Corazza, G. R., Fried, M., Olano, C., Rostami-Nejad, M., Gonzalez, A., Green, P. H., Gutierrez-Achury, J., Schultz, M., Verdu, E. F., Barada, K., Gibson, P., Koletzko, S., Coton, T., Mulder, C. J., Makharia, G., & LeMair, A. (2017). World Gastroenterology Organisation global guidelines: Celiac disease *Journal of Clinical Gastroenterology, 51*(9), 755-768. http://doi.org/10.1097/MCG.0000000000000919

Bailey, C., Hewison, A., Karasouli, E., Staniszewska, S., & Munday, D. (2016). Hospital care following emergency admission: a critical incident case study of the experiences of patients with advanced lung cancer and Chronic Obstructive Pulmonary Disease. *Journal of Clinical Nursing, 25*, 2168-2179. https://doi.org/10.1111/jocn.13170

Bandura, A. (2001). Social cognitive theory: An agentic perspective. *Annual Review of Psychology, 52,* 1-26. https://doi.org/10.1146/annurev.psych.52.1.1

Bandura, A. (2004). Health promotion by social cognitive means. *Health Education & Behavior, 31*(2), 143-164. https://doi.org/10.1177/1090198104263660

Barclay-Goddard, R., King, J., Dubouloz, C. J., & Schwartz, C. E. (2012). Building on transformative learning and response shift theory to investigate health-related quality of life changes over time in individuals with chronic health conditions and disability [Special communication]. *Archives of Physical Medicine and Rehabilitation, 93*, 214-220. https://doi.org/10.1016/j.apmr.2011.09.010

Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: A review. *Patient Education and Counseling, 48*, 177-187. doi: 10.1016/s0738-3991(02)00032-0

Baumgartner, L. M. (2011). The role of adult learning in coping with chronic illness. *New Directions for Adult and Continuing Education, 130*, 7-16. https://doi.org/10.1002/acc.406

Benjamins, L., Roland, S. L., & Bylica, K. (2022). The complexities of meaningful experiential learning: Exploring reflective practice in music performance studies. *International Journal of Music Education, 40*(2), 163-176. doi: 10.1177/02557614211043224

Berger, J. G. (2006). Key concepts for understanding the work of Robert Kegan. https://www.wellcoach.com/memberships/images/BergeronKeganConcepts.pdf

Berkowitz, A.D. (2003). *The social norms approach: Theory, research, and annotated bibliography.* http://alanberkowitz.com/articles/social_norms.pdf

Bernell, S. & Howard, S. W. (2016). Use your words carefully: What was a chronic disease? *Frontiers in Public Health, 4*(159), 1-3. https://doi.org/10.3389/fpubh.2016.00159

Black, J. L. & Orfila, C. (2011). Impact of coeliac disease on dietary habits and quality of life. *Journal of Human Nutrition and Dietetics, 24*, 582-587. https://doi.org/10.1111/j.1365277x.2011.01170.x

Blume, S. (2017). In search of experiential knowledge. *Innovation: The European Journal of Social Science Research, 30*(1), 91-103. http://dx.doi.org/10.1080.13511610.2016.1210505

Bodenheimer, T., Lorig, K., Holman, H., & Grumbach, K. (2002). Patient self-management of chronic disease in primary care. *The Journal of the American Medical Association, 288*(19), 2469-2475. https://doi.org/10.1001/jama.288.19.2469

Bodenheimer, T., Wagner, E. H. & Grumbach, K. (2002). Improving primary care of patients with chronic illness The Chronic Care Model, Part 2. *Journal of the American Medical Association, 288*(15). doi: 10.1001/jama.288.15.1909

Boersma, P., Black, L. I., & Ward, B. W. (2020). Prevalence of multiple chronic conditions among US adults, 2018. *Preventing Chronic Disease, 17*(E106). doi: http://doi.org/10.5888/pcd17.200130

Borkman, T. (1976). Experiential knowledge: A concept for the analysis of self-help groups. *Social Service Review, 50*(3), 445-456. https://www.jstor.org/stable/30015384

Boud, D., & Walker, D. (1991). *Experience and learning: Reflection at work.* Deakin University Press.

Bouery, P., Attieh, R., Sacca, L., & Sacre, Y. (2022). Assessment of the social quality of life and the physical activity of adult Celiac Disease patients following a gluten-free diet in Lebanon, *Nutrition and Health, 1-11.* https://doi.org/10.1177/0260106221095685

Brand, A. H., Harrison, A., & Kumar, K. (2015). “It was definitely very different”: An evaluation of palliative care teaching to medical students using a mixed methods approach. *An Evaluation of Palliative Care Teaching, 31*(1), 21-28. doi: 10.1177/082585971503100104

Brewer, M. B. (1993). Social identity, distinctiveness, and in-group homogeneity. *Social Cognition, 11*(1), 150-164. https://doi.org/10.1521/soco.1993.11.1.150

Bridges, W. (2001). *The way of transition: Embracing life’s most difficult moments.* Da Capo Press.

Butterfield, L. D., Borgen, W. A., Amundson, N. E., & Maglio, A-S. T. (2005). Fifty years of the critical incident technique: 1954-2004 and beyond. *Qualitative Research, 5*(4), 475-497. doi: 10.1177/1468794105056924

Butterfield, L. D., Borgen, W. A., Maglio, A-S. T., & Amundson, N. E. (2009). Using the enhanced critical incident technique in counselling psychology research. *Canadian Journal of Counselling, 43*(4), 265-282. https://cjc-rcc.ucalgary.ca/article/view/58863/44332

Buttorff, C., Ruder, T. & Bauman, M. (2017). Multiple chronic conditions in the United States. Rand Corporation. https://www.rand.org/content/dam/rand/pubs/tools/TL200/TL221/RAND_TL221.pdf

Caio, G., Volta, U., Sapone, A., Leffler, D. A., De Giorgio, R., Catassi, C., & Fasano, A. (2019). Celiac disease: a comprehensive current review. *BMC Medicine, 17*(142). 1-20. https://doi.org/10.1186/s12916-019-1380-z

Cambridge Dictionary. (n.d.). *Cambridge dictionary*. Retrieved May 4, 2024, from https://dictionary.cambridge.org

Caron-Flinterman, J. F., Broerse, J. E. W., & Bunders, J. F. G. (2005). The experiential knowledge of patients: a new resource for biomedical research? *Social Science & Medicine, 60,* 2575-2584. doi: 10.1016/j.socscimed.2004.11.023

Carter, S. & Little, M. (2007). Justifying knowledge, justifying method, taking action: Epistemologies, methodologies, and methods in qualitative research. *Qualitative Health Research, (17)*10, 1316-1328. https://doi.org/10.1177/1049732307306927

Castro, E. M., Regenmortel, T. V., Sermeus, W., Vanhaecht, K. (2018). Patients' experiential knowledge and expertise in health care: A hybrid concept analysis. *Social Theory & Health*, *17*, 307-330. https://doi.org/10.1057/s41285-018-0081-6

Catassi, C., Bai, J. C., Bonaz, B., Bouma, G., & Antonio, C. (2013). Non-celiac gluten sensitivity: The new frontier of gluten related disorders. *Nutrients, 5*(10), 3839-3853. doi: 10.3390/nu5103839

Catassi, C. & Fasano, A. (2010). Celiac disease diagnosis: Simple rules were better than complicated algorithms. *The American Journal of Medicine*, *123,* 691-693. https://doi.org/10.1016/j.amjmed.2010.02.019

Centers for Disease Control and Prevention (CDC). (2022). *Chronic diseases in America*. National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP). https://www.cdc.gov/chronicdisease/resources/infographic/chronic-diseases.htm

Centers for Disease Control and Prevention (CDC). (2023). *Diabetes: Type 2 diabetes.* https://www.cdc.gov/chronicdisease/resources/infographic/chronic-diseases.htm

Centers for Medicare and Medicaid Services (CMMS). (2022). *Chronic conditions.* CMS.gov. https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Chronic-Conditions/CC_Main

Cherry, K. (2021, March 15). Self-determination theory and motivation. *Very Well Mind.* https://www.verywellmind.com/what-is-self-determination-theory-2795387

Choung, R. S., Ditah, I. C., Nadeau, A. M., Rubio-Tapia, A., Marietta, E. V., Brantner, T. L., Camilleri, M. J., Rajkumar, V., Landgren, O., Everhart, J. E., & Murray, J. A. (2015). Trends and ration/ethnic disparities in gluten-sensitive problems in the United States: Findings from the National Health and Nutrition Examination surveys from 1988 to

2012. *American Journal of Gastroenterology, 110*, 455-461. https://doi.org/10.1038/ajg.2015.8

Christian, B. (2021, February 16). *Everything about critical incident technique – method, example, steps [guide]*. Openxcel. *https://www.openxcell.com/blog/critical-incident-technique/*

Clark, N. M., Becker, M. H., Janz, N. K., Lorig, K., Rakowski, W. & Anderson, L. (1991). Self-management of chronic disease by older adults: A review and questions for research. *Journal of Aging and Health, 3*(1), 3-27. https://doi.org/10.1177/089826439100300101

Clark, N. M., & Zimmerman, B. J. (2014). A social cognitive view of self-regulated learning about health. *Health Education & Behavior, 41*(5), 485-491. doi: 10.1177/1090198114547512

Clerx, E. M., Silverster, J., Leffler, D., DeGroote, M., & Fishman, L. N. (2019). Sequence of acquisition of self-management skills to follow a gluten-free diet by adults with Celiac disease. *Digestive and Liver Disease, 51*, 1096-1100. https://doi.org/10.1016/j.dld.2019.02.008

Coleman, M. T. & Newton, K. S. (2005). Supporting self-management in patients with chronic illness. *American Family Physician, 72*(8), 1503-1510. https://www.aafp.org/afp/2005/1015/p1454

Courtenay, B. C., Merriam, S. B., & Reeves, P. M. (1998). The centrality of meaning-making in transformational learning: How HIV-positive adults make sense of their lives. *Adult Education Quarterly, 48*(2), 65-84. https://doi.org/10.1177/074171369804800203

Coventry, P. A., Fisher, L., Kenning, C., Bee, P., & Bower, P. (2014). Capacity, responsibility, and motivation: a critical qualitative evaluation of patient and practitioner views about barriers to self-management in people with multimorbidity. *BMC Health Services Research, 14*(536), 1-12. http://www.biomedcentral.com/1472-6963/14/536

Convery, E., Hickson, L., Keidser, G. & Meyer, C. (2019). The chronic care model and chronic condition self-management: an introduction for audiologists. *Seminars in Hearing, 40*(1), 7-25. doi: 10.1055/s-0038-1676780

Cranton, P., & Talor, E. W. (2012). Transformative learning theory: Seeking a more unified theory. In E. W. Taylor & P. Cranton (Eds.) *The handbook of transformative learning Theory, research, and practice* (pp. 99-115). Jossey-Bass.

Cudris-Torres, L., Alpi, S. V., Barrios-Nunez, A., Arrieta, N. G., Gutierrez, J. M., Barranco, L. A., Rios-Carlys, G., Cuenca-Calderon, S. E., Bermudez, V., Hernandez-Lalinde, J., Zuleta, C. A. R., Bahamon, M. J., & Herrera, J. S. A. (2023). Quality of life in the older adults: The protective role of self-efficacy in adequate coping in patients with chronic diseases. *Frontiers in Psychology, 14*, 1-13. doi: 10.3389/fpsyg.2023.1106563

Dewey, J. (1938). *Experience and education.* Collier Books.

Dubouloz, C-J., King, J., Asje, B., Paterson, B., Chevrier, J., & Moldoveanu, M. (2010a). The process of transformation in rehabilitation: What does it look like? *International Journal of Therapy and Rehabilitation, 17*(11), 604-615. https://search.ebscohost.com/login.aspx?direct=true&AuthType=ip,shib&db=edb&AN=55052669&site=eds-live&custid=uga1

Dubouloz, C. J., King, J., Paterson, B., Ashe, B., Chevrier, J., & Moldoveanu, M. (2010b). A model of the process of transformation in primary care for people living with chronic illnesses. *Chronic Illness, 6*, 282-293. https://doi.org/10.1177/1742395310383340

Epping-Jordan, J., Bengoa, R, Kawar, R., & Sabate, E. (2001). The challenge of chronic conditions: WHO responds. *British Medical Journal, 323*(7319), 947-948. https://doi.org/10.1136/bmj.323.7319.947

Feldman, M. S., Skoldberg, J., Brown, R. N. & Horner, D. (2004). Making sense of stories: a rhetorical approach to narrative analysis. *Journal of Public Administration Research and Theory: J-PART, 14*(2), 147-170. https://www.jstor.org/stable/3525867

Fenwick, T. J. (2001). *Experiential learning: A theoretical critique from five perspectives.* Information Series No. 385. Columbus, OH. ERIC Clearinghouse on Adult, Career, and Vocational Education, Center on Education and Training for Employment.

Fitzgerald, K., Seale, N. S., Kerins, C. A, McElvaney, R. (2008). The critical incident technique: A useful tool for conducting qualitative research. *Journal of Dental Education, 72*(3), 299-304. https://doi.org/10.1002/j.0022-0337.2008.72.3.tb04496.x

Flanagan, J. C. (1954). The critical incident technique. *Psychological Bulletin, 51*(4), 327-358. https://doi.org/10.1037/h0061470

French, E. & Delahaye, B. (1996). Individual change transition: Moving in circles can be good for you. *Leadership & Organization Development Journal*, 17(7), 22-28. https://www.emerald.com/insight/content/doi/10.1108/01437739610148349/full/html

Gall, M. D., Gall, J. P. & Borg, W. R. (2007). *Educational Research.* Pearson.

Garnweidner-Holme, L., Sende, K., Hellmann, M., Henriksen, C., Lundin, K. E. A., Myhrstad, M. C. W., & Telle-Hansen, V. H. (2020). Experiences of managing a gluten-free diet on multiple levels of society: A qualitative study. *BMC Nutrition, 6*(65). https://doi.org/10.1186/s40795-020-00390-3

Given, L. (Ed.). (2008). *The SAGE Encyclopedia of Qualitative Research Methods.* (Vol. 1). Sage.

Gluten Intolerance Group (GIG). (2022). *Support Groups.* https://gluten.org/community/support-groups/

Goodman, R. A., Posner, S. ., Huang, E. S., Parekh, A. K. & Koh, H. K. (2013). Defining and measuring chronic conditions: Imperatives for research, policy, program, and practice. *Preventing Chronic Disease: Public Health Research, Practice, and Policy, 10.* doi: http://dx.doi.org/10.5888/pcd10.120239

Grady, P. A. & Gough, L. L. (2014). Self-management: A comprehensive approach to management of chronic conditions. *American Journal of Public Health, 104*(8), e25-e31. doi:10.2105/AJPH.2014.302041

Green, P. H. R. & Jones, R. (2022). *Celiac disease. A hidden epidemic.* HarperCollins Publishers.

Greenhalgh, T. (2009). Chronic illness: Beyond the expert patient. *BMJ, 338*(7695), 629-631. https://www.jstor.org/stable/20512333

Grover, A. & Joshi, A. (2015). An overview of chronic disease models: A systematic literature review. *Global Journal of Health Science, 7*(2), 210-227. http://dx.doi.org/10.5539/gihs.v7n2p210

Hallert, C., Granno, C., Hulten, S., Midhagen, G., Strom, M., Svensson, H. & Valdimarsson, T. (2002). Living with Coeliac Disease: Controlled study of the burden of illness. *Scandinavian Journal of Gastroenterology, 37*(1), 39-42. https://doi.org/10.1080/003655202753387338

Hallert, C., Sandlund, O., & Broqvist, M. (2003). Perceptions of health-related quality of life of men and women living with Coeliac disease. *Nordic College of Caring Science, 17*, 301-307.doi: 10.1046/j.1471-6712.2003.00228.x

Halloy, A., Simon, E., & Hejoaka, F. (2023). Defining patient's experiential knowledge: Who what and how patients know. A narrative critical review. *Sociology of Health & Illness, 45,* 405-422. doi: 10.1111/1467-9566.13588

Holman, H., Lorig, K. (2000). Patients as partners in managing chronic disease: Partnership was a prerequisite for effective and efficient health care. British Medical Journal, 320*(7234*), 526-527. https://www.jstor.org/stable/25187260

Hutchens, J., Frawley, J., & Sullivan, E. A. (2023). Is self-advocacy universally achievable for patients? The experiences of Australian women with cardiac disease in pregnancy and postpartum. *International Journal of Qualitative Studies on Health and Well-Being, 18,* 1-15. https://doi.org/10.1080/17482631.2023.2182953

Ivarsson, B., Ekmehag, B, & Sjoberg, T. (2011). Recently accepted for the waiting list for heart or lung transplantation – patients' experiences of information and support. *Clinical Transplant, 25,* E564-E671. https://doi.org/10.111/j.1399-0012.2011.01511.x

Jacobsson, L. R., Friedrichsen, M., Goransson, A., & Hallert, C. (2011). Does a Coeliac school increase psychological well-being in women suffering from Coelia disease, living on a gluten-free diet? *Journal of Clinical Nursing, 21*, 766-775. https://doi.org/10.1111/j.1365-2702.2011-03953.x

Jacobsson, L. R. Hallert, C., Millberg, A., & Friedrichsen, M. (2012). Coeliac disease – women's experiences in everyday life. *Journal of Clinical Nursing, 21*, 3442-3450. https://doi.org/10.1111/j.1365-2702.2012.04279.x

Jacobsson, L. R., Milberg, A., Hjelm, K., & Friedrichsen, M. (2016). Gaining perspective on own illness – the lived experiences of a patient education programme for women with treated coeliac disease. *Journal of Clinical Nursing, 25*, 1229-1237. https://doi.org/10.1111/jocn.13123

Jerant, A. F., von Friederichs-Fitzwater, M. M., & Moore, M. (2005). Patients' perceived barriers to active self-management of chronic disease. *Patient Education and Counseling, 57*, 300-307. doi:10.1016/j.pec.2004.08.004

Jones, M., Jallinoja, P., & Pietila, I. (2021). Representing the 'voice' of patients: How third sector organisations conceptualise and communicate experiential knowledge in health service development. *Voluntas, 32*, 561-572. https://doi.org/10.1007/s11266-020-00296-5

Kalantarzadeh, M., Alavi, M., Yousefi, H., Maghsoudi, J., Hungerford, C., & Cleary, M. (2021). Coping with chronic cardiovascular disease in Iran: A qualitative study. *Nursing & Health Sciences, 23*, 843-851. https://doi.org/10.1111/nhs.12869

Kalra, S., Jena, B. N., & Yeravdekar, R. (2018). Emotional and psychological needs of people with diabetes. *Indian Journal of Endocrinology and Metabolism, 22*(5), 696-704. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6166557/

Kegan, R. (2003). Hidden Curriculum of Adult Life: An Adult Developmental Perspective. *Adult Development in Post-Industrial Society and Working Life, 2*, 21-48.

Kegan R. (2018). What "form" transform? A constructive-developmental approach to transformative learning. In K. Illeris (Ed.), *Contemporary Theories of Learning* (pp. 29-45). Routledge.

Kegan, R. & Lahey, L. (2010). From subject to object: A constructive-developmental approach to reflective practice. In N. Lyons (Ed.), *Handbook of Reflection Inquiry: Mapping a Way* *of Knowing for Professional Reflective Inquiry* (pp. 433-449). Springer Science. https://doi.org/10.1007/978-0-387-85744-2_1

Kelo, M., Eriksson, E., & Eriksson, I. (2012). Perceptions of patient education during hospital visit – described by school-age children with a chronic illness and their parents. *Scandinavian Journal of Caring Sciences, 27*, 894-904. https://search.ebscohost.com/login.aspx?direct=true&AuthType=ip,shib&db=pbh&AN=91615345&site=eds-live&custid=uga1

Kessler, D., Dubouloz, C-J., Urbanowski, R., & Egan, M. (2009). Meaning perspective transformation following stroke: The process of change. *Disability and Rehabilitation, 31*(13), 1056-1065. https://doi.org/10.1080/09638280802509512

Knol, L. L., Myers,H. H., Robinson, D., Awololo, Y., Clark, D., Parker, C. L., Douglas, J. W., & Higgenbotham, J. C. (2016). Development and feasibility of a childhood obesity prevention program for rural families: Application of the social cognitive theory. *American Journal of Health Education, 47*(4), 204-214. https://doi.org/10.1080/19325037.2016.1179607

Knowles, M. S., Holton, E. F., Swanson, R. A., & Robinson, P. A. (2020). *The adult learner: The definitive classic in adult education and human resource development* (9th ed). Routledge.

Kolb, D. A. (1984). *Experiential learning: Experience as the source of learning and development.* Prentice Hall.

Kozhakhmetova, A., Aidossov, S., Kapassova, A., & Borsoldayeva, K. (2022). Current knowledge and "myths" about disease among physicians in the Republic of Kazakhstan:

A countrywide cross-sectional study. *Frontiers in Public Health, 10,* 1-10. https://doi.org/10.3389/fpubh.2022.956135

Kralik, D., Koch, T., Price, K., & Howard, N. (2004). Chronic illness self-management: Taking action to create order. *Journal of Clinical Nursing, 13*(2), 259-267. https://onlinelibrary.wiley.com/doi/abs/10.1046/j.1365-2702.2003.00826.x

Langarizadeh, M., Rahmati, P., Yousefpour Azari, S., Sarpourian, F., Sayadi, M. J., Langarizadeh, M. H., & Fatemi Aghda, S. A. (2023). Identifying and validating the educational needs to develop a Celiac Self-Care System. *BMC Primary Care, 2,* 1-8, https://doi.org/10.1186/s12875-023-02076-8

Lasco, G., Renedo, A., Mendoza, J., Seguin, M. L., Palafox, B., Palileo-Villanueva, Balabanova, D., & McKee, M. (2022). 'Doing' hypertension: Experiential knowledge and practice in the self-management of 'high blood' in the Philippines. Sociology of Health and Illness, 44, 1167-1181. doi: 10.1111/1467-9566.13503

Latham, G. P. & Locke, E. A. (1991). Self-regulation through goal setting. *Organizational Behavior and Human Decision Processes, 50,* 212-247. https://reader.elsevier.com/reader/sd/pii/074959789190021K?token=1D9158E60ABFC7B2AAEBB7F8CA921B899053F04209C7C256320591C78D9C7CD42DE52B54E4F8BBC7130149C21F595395&originRegion=us-east-1&originCreation=20220613215441

Lawless, M. T., Tieu, M., Feo, R. & Kitson, A. L. (2021). Theories of self-care and self-management of long-term conditions by community-dwelling older adults: A systematic review and meta-ethnography. *Social Science & Medicine, 287,* 1-16. https://doi.org/10.1016/j.socscimed.2021.114393

Lawn, S. & Schoo, A. (2010). Supporting self-management of chronic health conditions: Common approaches. *Patient Education and Counseling, 80,* 205-211. doi: 10.1016/j.pec.2009.10.006

Lebwohl, B. & Rubio-Tapia A. (2021). Epidemiology, presentation, and diagnosis of celiac disease. *Gastroenterology, 160,* 63-75. https://doi.org/10.1053/j.gastro.2020.06.098

Leffler, D. A., Acaster, S., Gallop, K., Dennis, M., Kelly, C. P., & Adelman, D. C. (2017). A novel patient-derived conceptual model of the impact of Celiac Disease in adults: Implications for patient-reported outcome and health-related quality-of-life instrument development. *Value in Health, 20*(4), 637-643. https://doi.org/10.1016/j.jval.2016.12.016

Lewin, L. O, McManamon, A., Stein, T. T. O., Chen, D. T. (2019). Minding the form that transforms: Using Kegan's model of adult development to understand personal and professional identity formation in medicine. *Academic Medicine, 94*(9), 1299-1304. https://doi.org/10.1097/ACM.0000000000002741

Leybourne, S. A. (2016). Emotionally sustainable change: Two frameworks to assist with transition. *International Journal of Strategic Change Management,* 7(1), 23-42. https://doi.org/10.1504/IJSCM.2016.10000308

Leyva-Moral, J. M., Palmieri, P. A., Loayza-Enriquez, B. K., Linden, K. L. V., Elias-Bravo, U. E., Guevara-Vasquez, G. M., Davila-Olano, L. Y., & Aguayo-Gonzalez, M. P. (2021). 'Staying alive' with antiretroviral therapy: A grounded theory study of people living with HIV in Peru. *BMJ Global Health, 6,* 1-11. doi: 10.1136/bmjgh-2021-006772

Liu, N. & Kauffman, R. J. (2021). Enhancing healthcare professional and caregiving staff informedness with data analytics for chronic disease management. Information and Management, 58(2), 1-14. doi: 10.1016/j.im.2020.103315

Lorig, K. R. & Holman, H. R. (2003). Self-management education: History, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine*, *26*(1), 1-7. doi: 10.1207/S15324796ABM2601-01

Ludvigsson, J. F., Reutfors, J., Osby, U., Ekbom, A., & Montgomery, S. M. (2007). Coeliac disease and risk of mood disorders – A general population-based cohort study. *Journal of Affective Disorders, 99,* 117-126. https://doi.org/10.1016.j.jad.2006.08.032

Mann, K. V., McFetridge-Durdle, Martin-Misener, R., Clovis, J., Rowe, R., Beanlands, H. & Sarria, M. (2009). Interprofessional education for students of the health professions: The "Seamless Care" model. *Journal of Interprofessional Care, 23*(3), 224-233. doi: 10.1080/13561820802697735

Mann, T., Ridder, D., & Fujita, K. (2013). Self-regulation of health behavior: Social psychological approaches to goal setting and goal striving. *Health Psychology, 32*(5), 487-498. doi: 10.1037/a0028533

Marsick, V. J. & Watkins, K. (1990). *Informal and incidental learning in the workplace*. Routledge.

Matarese, M., Lommi, M., De Marinis, M. G., & Riegel, B. (2018). A systematic review and integration of concept analyses of self-care and related concepts. *Journal of Nursing Scholarship, 50*(3), 296-305. doi: 10.1111/jnu.12385

Mathews, G. & Anderson, C. (2021). The lived experience of learning mindfulness as perceived by people living with long-term conditions: A community-based longitudinal phenomenological study. *Qualitative Health Research,* 31(7), 1209-1221. https://doi.org/10.1177/1049732321997130

McConnell, I. M. (2013). *"You never stop learning": Informal and incidental workplace learning and women city managers' career development*. [Doctoral dissertation, University of Georgia]. https://getd.libs.uga.edu/pdfs/mcconnell_ilka_m_201312_phd.pdf

Merriam, S. B. (2005). How adult life transitions foster learning and development. *New Directions for Adult and Continuing Education, 108*, 3-13. https://doi.org/10.1002.ace.193

Merriam, S. B. (2009). *Qualitative Research: A Guide to Design and Implementation*. Jossey-Bass.

Merriam, S. B., & Baumgartner, L. M. (2020). *Learning in adulthood* (4th ed.). Jossey-Bass.

Merriam, S., & Bierema, L. (2014). *Adult learning.* Jossey-Bass.

Merriam, S. B., Caffarella, R. S., & Baumgartner, L M. (2006). *Learning in adulthood: A comprehensive guide* (3rd ed). Jossey-Bass.

Merriam-Webster Dictionary. (2023). *Learning. https*://www.merriam-webster.com/dictionary/learning

Mezirow, J. (1978). Perspective transformation. *Adult Education, 38*(2), 100-110. https://doi.org/10.1177/074171367802800202

Mezirow, J. (2018). Transformative learning theory. In K. Illeris (Ed.), *Contemporary Theories of Learning* (pp. 29-45). Routledge.

Miller, W. R., Lasiter, S., Ellis, R. B. & Buelow, J. M. (2015). Chronic disease self-management: A hybrid concept analysis. *Nursing Outlook*, *63*(2), 154-161, doi:10.1016/j.outlook.2014.07.005

Mogashoa, T. (2014). Applicability of constructivist theory in qualitative educational research. *American International Journal of Contemporary Research, (4)*7, 51-59. http://www.aijcrnet.com/journals/Vol_4_No_7_July_2014/7.pdf

Ostlund, G., Thybert, I. Valtersson, E., Bjork, M. & Sverker, A. (2016). The use of avoidance, adjustment, interaction, and acceptance strategies to handle participation restrictions among Swedish men with early rheumatoid arthritis. *Musculoskeletal Care, 14*, 206-2018. https://search.ebscohost.com/login.aspx?direct=true&AuthType=ip,shib&db=a9h&AN=119880047&site=eds-live&custid=uga1

Patton, M. (2015). *Qualitative designs and data collection.* SAGE.

Pelkowski, T. D. & Viera, A. J. (2014). Celiac disease: Diagnosis and management. *American Family Physician, 89*(2), 99-105. https://www.aafp.org/pubs/afp/issues/2014/0115/p99.html

Perlstein, R., McCoombe, S., Shaw, C., & Nowson, C. (2016). Medical students' perceptions regarding the importance of nutritional knowledge and their confidence in providing competent nutrition practice. *Public Health, 140,* 27-34. http://dx.doi.org/10.1016/j.puhe.2016.08.019

Peshkin, A. (1988). In search of subjectivity-one's own. *Educational Researcher, 17*(7), 17-21. https://www.jstor.org/stable/1174381

Popay, J. & Williams, G. (1996). Public health research and lay knowledge. *Social Science Medicine, 42*(5), 759-768. doi: https://doi.org/10.1016/0277-9536(95)00341-X

Prawat, R. & Floden, R. (1994). Philosophical perspectives on constructivist views of learning; *Educational Psychology, (29)*1, 37-48. https://doi.org/10.1207/s15326985ep2901_4

Psychology Today. (2023). *Chronic illness.* https://www.psychologytoday.com/us/basics/chronic-illness

Raiteri, A., Granito, A., Giamperoli, A., Catenaro, T., Negrini, G., & Tovoli, F. (2022). Current guidelines for the management of celiac disease: A systematic review with comparative analysis. *World Journal of Gastroenterology*, *28*(1), 154-154-175. https://doi.org/10.3748/wjg.v28.i1.154

Renjith, V., Yesodharan, R., Noronha, J. A., Ladd, E., & George, A. (2021). Qualitative methods in health care research. *International Journal of Preventive Medicine, 12*(20), 1-7. doi: 10.4103/ijpvm.IJPVM_321_19

Reynolds, R., Dennis, S., Hasan, I., Slewa, J., Chen, W., Tian, D., Bobba, S., & Zwar, N. (2018). A systematic review of chronic disease management interventions in primary care. *BMC Family Practice, 19*(11), 1-13. doi: 10.1186/s12875-017-0692-3

Richard, A. A., & Shea, K. (2011). Delineation of self-care and associated concepts. *Journal of Nursing Scholarship, 43*(3), 255-264. doi: 10.1111/j.1547-5069.2011.01404.x

Roosmaa, E-L., & Saar, E. (2017). Adults who do not want to participate in learning: A cross-national European analysis of their perceived barriers. *International Journal of Lifelong Education, 36*(3), 254-277. https://doi.org/10.1080/026013720.2016.1246485

Rosala, M. (2020, January 26). *The critical incident technique in UX*. Nielsen Norman Group. https://www.nngroup.com/articles/critical-incident-technique/

Rose, C. & Howard, R. (2014). Living with Coeliac disease. A grounded theory study. *Journal of Human Nutrition and Dietetics, 27,* 30-40. https://doi.org/10.1111/jhn.12062

Rotheram-Borus, M. J., Ingram, B. L., Swendeman, D., & Lee, Adabel. (2012). Adoption of self-management interventions for prevention and care. *Primary Care Journal, 39*(4), 649-660. https://doi.org/10.1016/j.pop.2012.08.006

Rubenson, K. (1989). Sociology of adult education. In S. B. Merriam & P. M. Cunningham (Eds.), *Handbook of adult and continuing education* (pp. 51-69). Jossey-Bass.

Rubenson, K. (2006). The Nordic model of lifelong learning. *Compare, 36*, 327-341.

Rubio-Tapia, A., Hill, I. D., Semrad, C., Kelly, C. P., Greer, K. B., Limketkai, B. N., & Lebwohl, B. (2023). American College of Gastroenterology guidelines update: Diagnosis and management of celiac disease. *The American Journal of Gastroenterology, 118*. 59-76. https://doi.org/10.14309/ajg.0000000000002075

Ruiz, A. R., Jr. (2022). Celiac disease (gluten enteropathy). *Merck Manual.* https://www.merckmanuals.com/professional/gastrointestinal-disorders/malabsorption-syndromes/celiac-disease)

Ryan, R. M. & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist, 55*(1), 68-78. doi: 10.1037//0003-066X.55.1.68

Saude, J., Baker, M. L., Axman, L. M., & Swider, S. M. (2020). Applying the chronic care model to improve patient activation at a nurse-managed student-run free clinic for medically underserved people. *SAGE Open Nursing, 6*, 1-6. doi: 10.1177/2377960820902612

Sav, A., McMillan, S. S., Kelly, F., Whitty, J. A., Kendall, E., King, M. A., & Wheeler, A. J. (2014). Consumer health organisations for chronic conditions: Why do some people access them, and others don't? *Primary Health Care Research & Development, 15,* 418-429. doi:10.1017/S1463423614000036

Schcolnik, M., Kol, S. & Abarbanel, J. (2006). Constructivism in theory and practice. *English Teaching Forum, 44*(4), 12-20. https://files.eric.ed.gov/fulltext/EJ1107896.pdf

Schön, D. A. (1987). Educating the reflective practitioner. Basic Books.

Schmidt, E. K., Faieta, J., & Tanner, K. (2020). Scoping review of self-advocacy education interventions to improve care. *OTJR: Occupation, Participation and Health, 40*(1), 50-56. https://doi.org/10.1177/1539449219860583

Schumacher, K. L. & Meleis, A. I. (1994). Transitions: A central concept in nursing. Journal of Nursing Scholarship, 26(2), 119-127. http://doi.org/10.1111/j.1547-5069.1994.tb00929.x

Schunk, D. H. & DiBenedetto. (2019). Motivation and social cognitive theory. *Contemporary Educational Psychology, 60,* 1-9. https://doi.org/10.1016/j.cedpsych.2019.101832

Selder, F. E. (1989). Life transition: The resolution of uncertainty. *Nursing & Health Care: Official Publication of the National League for Nursing, 10*(8), 437-40, 449-51. https://www.researchgate.net/publication/20357747_Life_transition_The_resolution_of_uncertainty

Shen, H., Edwards, H., Courtney, M., McDowell, J. & Wu, M. (2012). Peer-led diabetes self-management programme for community-dwelling older people in China: study protocol for a quasi-experimental design. *Journal of Advanced Nursing, 68*(12), 2766-2777. doi: 10.1111/j.1365-2648.2012.06059.x

Siemens, G. (2005, January). Connectivism: A learning theory for the digital age. *International Journal of Instructional Technology & Distance Learning*. Retrieved from http://er.dut.ac.za/bitstream/handle/123456789/69/Siemens_2005_Connectivism_A_learning_theory_for_the_digital_age.pdf

Singh, P., Arora, A., Strand, T. A., Leffler, D. A., Catassi, C., Green, P. H., Kelly, C. P., Ahuja, V., and Makharia, G. K. (2018). Global prevalence of celiac disease: Systematic review and meta-analysis. *Clinical Gastroenterology and Hepatology, 16,* 823-836. http://dx.doi.org/10.1016/j.cgh.2017.06.037

Sissel, P. A. (1997). Participation and learning in head start: A sociopolitical analysis. *Adult Education Quarterly, 47*(3/4), 123-137. https://doi.org/10.1177/074171369704700301

St. Quinton. T. & Brunton, J. A. (2017). Implicit processes, self-regulation, and interventions for behavior change. *Frontiers in Psychology, 8*(346). doi: 10.3389/fpsyg.2017.00346

Stets, J. E. & Burke, P. J. (2000). Identity theory and social identity theory. *Social Psychology Quarterly, 63*(3), 224-237. doi: 10.2307/2695870

Sverker, A., Hensing, G., & Hallert, C. (2005). ‘Controlled by food’ – lived experiences of coeliac disease. *Journal of Human Nutrition Dietitian, 18,* 171-180. https://doi.org/10.1111/j.1365-277x.2005.00591.x

Sverker, A., Ostlund, G., Hallert, C., Hensing, G. (2007). Sharing life with a gluten-intolerant person – the perspective of close relatives. *Journal of Human Nutrition Dietitian, 20,* 412-422. https://doi.org/10.1111/j.1365-277X.2007.00815.x

Sverker, A., Ostlund, G., Hallert, C., Hensing, G. (2009). ‘I lose all these hours…’ – exploring gender and consequences of dilemmas experienced in everyday life with coeliac disease. *Scandinavian Journal of Caring Sciences, 23,* 342-252. https://doi.org/10.1111/j.1471-6712.2008.00628.x

Taylor, E., Dickson-Swift, V., & Anderson, K. (2013). Coeliac disease: The path to diagnosis and the reality of living with the disease. *Journal of Human Nutrition and Dietetics*, *26*, 340-348. https://doi.org/10.1111/jhn.12009

Test, D. W., Fowler, C. H., Wood, W. M., Brewer, D. M., & Eddy, S. (2005). A conceptual framework of self-advocacy for students with disabilities. *Remedial and Special Education, 26*(1), 43-54. https://doi.org/10.1177/07419325050260010601

Tough, A. (1978). Major learning efforts: Recent research and future directions. *Adult Education*, *28*(4), 250-263. https://doi.org/10.1177/074171367802800403

Turner, V. (1966). Liminality and communitas. *The Ritual Process: Structure and Anti-Structure* (pp. 94-130). Cornell University Press. https://womrel.sitehost.iu.edu/Rel433%20Readings/SearchableTextFiles/Turner_RitualProcess_chaps3&5.pdf

Turner, G. D., Dunne, M. R. & Ryan, A. W. (2015). *Celiac disease: Methods and protocols* (A. W. Ryan, Ed.). Springer. https://doi.org/10.1007/978-1-4939-2839-2_1

University of Chicago Celiac Disease Center (UCCDC). (2022). *Celiac Disease Fact Sheets.* http://www.cureceliacdisease.org/fact-sheets/

Valeras, A. B. (2010). “We don’t have a box”: Understanding hidden disability identity utilizing narrative research methodology. *Disability Studies Quarterly, 30*(3/4). https://doi.org/10.18061/dsq.v3013/4.1267

Wagner, E. H., Austin, B. T., & Von Korff, M. (1996). Organizing care for patients with chronic illness. *The Millbank Quarterly, 74*(4), 511-544. https://www.jstor.org/stable/3350391?origin=crossref

Wagner, E. H. (1998). Chronic disease management: What will it take to improve care for chronic illness? *Effective Clinical Practice, 1*(1), 2-4. https://yearofcare.co.uk/sites/default/files/pdfs/What%20will%20it%20take%20to%20improve%20care%20for%20chronic%20illnesses%20Aug-Sept%201998.pdf

Walmart (2024). https://www.walmart.com/browse/food/whole-wheat-bread/976759_976779_8399244_9908730

Watkins, E. E., Ellinger, A. D., Suh, B., Brenes-Dawsey, J. C., & Oliver, L. C. (2022). Further evolving the critical incident technique (CIT) by applying different contemporary approaches for analyzing qualitative data in CIT studies. *European Journal of Training and Development*, *46*(7/8), 709-726. http://doi.org/10.1108/EJTD-07-2021-0107

Watt, D. (2007). On becoming a qualitative researcher: The value of reflexivity. *The Qualitative Report*, *12*(1), 82-101. http://www.nova.edu/ssss/QR/QR12-1/watt.pdf

Wels, H., van der Waal, K, Spiegel, A., & Kamsteeg, F. (2011). Victor Turner and liminality: An introduction. *Anthropology Southern Africa, 34*, 1-2, 1-4. https://doi.org/10.1080/23323256.2011.1150002

Wendling, G. (2008). Understanding change through the rites of passages framework. https://artandstory.typepad.com/files/understadning-rites-of-passages.pdf

Whitlock, J. (2023, February 3). The difference between chronic and acute conditions. In *verywellhealth.com*. https://www.verywellhealth.com/chronic-definition-3157059

Whittemore, R. & Dixon, J. (2008). Chronic illness: The process of integration. *Journal of Clinical Nursing, 17*(7b), 177-187. https://doi.org/10.1111/j.1365-2702.2007.02244.x

Williams, D. (2008, January). *Life events and career change: Transition psychology in practice* [Paper Presentation]. British Psychological Society's Occupational Psychology Conference, UK. https://www.eoslifework.co.uk/transprac.htm

Williams, P. M., Harris, L. M., & Odom, M. R. (2022). Celiac disease: common questions and answers. *American Family Physician, 106*(1), 36-43, https://search.ebscohost.com/login.aspx?direct=true&AuthType=ip,shib&db=mnh&AN=35839368&site=eds-live&custid=uga1

Williams, P. & Shoultz, B. (1984). *We can speak for ourselves: Self-advocacy by mentally handicapped people.* Indiana University Press.

Wlodowski, R. J. (1985). *Enhancing adult motivation to learn.* Jossey-Bass.

Woolsey, L. K. 1986. The critical incident technique: An innovative qualitative method of research. *Canadian Journal of Counselling, 20*(4), 242-254. https://cjc-rcc.ucalgary.ca/article/view/59733/45123

World Health Organization (WHO). (2022, September 18). *Noncommunicable disease.* https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases

Yilmaz, K. (2008). Constructivism: Its theoretical underpinnings, variations, and implications for classroom instruction. *Educational Horizons (86)*3, 161-172. https://files.eric.ed.gov/fulltext/EJ798521.pdf

Zingone, F., Swift, G. L., Card, T. R., Sanders, D. S., Ludvigsson, J. F. & Bai, J. C. (2015). Psychological morbidity of celiac disease: A review of the literature. *United European Gastroenterology Journal, 3*(2), 136-145. doi: 10.1177/2050640614560786

Appendix A

Critical Incident Interview Protocol

Introduction

Interviewer: *"Good afternoon (morning, evening). Thank you for being willing to participate in this study."*

Review Purpose of Study

Interviewer: *"As a reminder, the purpose of this interview is to understand the learning that is utilized by individuals after being diagnosed with celiac disease; the meaning(s) made from such learning; and how these experiences affect the individuals' ability to self-manage their celiac disease."*

Confidentiality

Interviewer: *"Your personal information will be kept confidential, and your identity will be anonymized by using a pseudonym to avoid personal identification. If you agree with this process, please take a moment to read over the consent forms I have given to you about participating in the study and ask me any questions you may have about the forms or study."*

Begin the Interview

Interviewer: *"First, I would like to ask you for verbal confirmation that you are willing to participate in this research, and to note that we will sign the official consent form after the interview. So, do you give your consent for this interview?"* Wait for response.

Interviewer: *"With your permission, I will be recording the interview, which will be transcribed for analysis and used for my class assignment. I will send you a copy of the transcript results and ask that you review it for discrepancies. Do you give permission for the recording?"* Wait for response.

Interviewer: *"Once again, thank you for taking your time to assist me in this endeavor. I look forward to hearing more about your story. Please relax, take a deep breath, and let's begin our conversation."*

"For this study, I am trying to understand the learning that occurs for individuals in their self-management of celiac disease. I would like to ask you some questions about a few of your most significant experiences related to learning in the self-management of your celiac disease. I would also like to ask you about how you interpreted, or gave meaning to, these experiences, and finally what results occurred from the learning."

CRITICAL INCIDENTS

Critical Incident #1: Learning to navigate life at home after diagnosis of celiac disease.

Prompt: Tell me about a time when you engaged in learning initial skills for self-managing your disease at home after being diagnosed with celiac disease. What was the situation? What happened? What did you do? What, and or who, was involved in the process? What were the results? What was it about this incident that made it seem significant? What conclusions did you draw from this incident?

1. If a physician was part of the event:

   At the time of the event, what information did your doctor provide about celiac disease?

   a. If your doctor's office gave you information, how did this assistance help you learn?

   b. What more could your doctor have done?

Critical Incident #2: Learning in social settings.

Prompt: Tell me about a time when you engaged in learning to self-manage your celiac disease in a social setting. What was the situation? What happened? What did you do? What, and or who, was involved in the process? What were the results? What was it about this incident that made it seem significant? What conclusions did you draw from this incident?

Critical Incident #3: Learning in the workplace.

Prompt: Tell me about a time when you engaged in learning to self-manage your celiac disease in the workplace. What was the situation? What happened? What did you do? What, and or who, was involved in the process? What were the results? What was it about this incident that made it seem significant? What conclusions did you draw from this incident?

What made this incident significant – stand out to you?

Critical Incident #4: Learning in unfamiliar settings.

Prompt: Tell me about a time when you engaged in learning to self-manage your celiac disease in an unfamiliar setting. What was the situation? What happened? What did you do? What, and or who, was involved in the process? What were the results? What was it about this incident that made it seem significant? What conclusions did you draw from this incident?

What made this incident significant – stand out to you?

FINAL QUESTIONS

Interviewer: *"In light of what you have now talked about, is there anything else you wish to share with me, or that you think I should know about the learning you have encountered in self-managing your celiac disease?"* At this point answer any questions.

"Thank you very much for participating in this study. Please do not hesitate to contact me should you have any questions."

Interviewer: Speaking into recorder: *"This ends the current interview"* and press STOP on the recorder.

Appendix B

Experiential Learning in Critical Incidents

The tables below demonstrate the four stages of experiential learning (experiencing, reflecting, thinking, and applying) that occurred in the critical incidents shared by participants of the study. The meaning that was made, learning that occurred and how the learning could be applied in the future are supported by quotes made by the individuals, which are italicized.

Table 1

Phase One: Life at Home (six months)

Participant name	Title of Incident	Experiencing (Incident)	Reflecting (Meaning making)	Thinking (Learning that occurred)	Applying (Future application)
Alice	A sudden change	Learning to shop after diagnosis	*It was just like all of a sudden you are no longer eating the way you've eaten your entire life.*	*I was just realizing I can't ever eat like I ate before. So, I'm just going to eat what I can.*	*I realized that as long as I cook for myself and I have at least one protein a day so I'm not starving, then I'd be fine.*
Ryan	Cooking school	Learning to cook gluten free	*You start with the very basic things, and you keep adding.*	*And I think over time I was able to distill down what I was uncomfortable with to get better at that.*	*We got to be comfortable asking the right kinds of questions and scope that would help me* [learn to cook]
Mary	A family affair	Learning about celiac disease as a family	*But I think it was very much a learning experience for all of us, even just understanding the lengths I had to go to just keep myself safe.*	*But even just learning to mitigate those kinds of situations, like to handle how do we do a meal as a family? How do we work around that?*	*I feel like my family has come a very long way and are very much open to say* [to visitors] *Melissa has celiac … the more people who have questions that I can answer, the easier it will be.*
Trevor		Setting up kitchen post-diagnosis	*In the beginning I felt sorry for myself and then I realized it's not that bad.*	*We have a friend that's been celiac for 25 years, so, the learning part was really communication with our friend and, you know, understanding how*	*I went around to many grocery stores, and I found a lot of stuff – some stores really think about it, and some stores that don't think about it at all.*

Participant name	**Title of Incident**	**Experiencing (Incident)**	**Reflecting (Meaning making)**	**Thinking (Learning that occurred)**	**Applying (Future application)**
	Team effort			*to set up our kitchen.*	
Joanna	This is the rest of your life	Making lunch for family in a mixed (non-GF) kitchen	*I realized how impactful this disease was going to be on the rest of my life.*	*I came to the conclusion that I can do it. It took some time and a lot of effort and making a process that would work for me and my family, but I can figure it out.*	*I can figure out other things like going to a restaurant or going to a family member's house who does not have a gluten-free kitchen.*
Sarah	Parenting a Celiac	Learning about celiac disease when daughter visited	*Well, I did not realize that, like most people who don't have celiac, how pervasive gluten is*	*I had to learn [to live with celiac disease], but I learned the most because of her.*	*I had to learn how to be careful and not give her the wrong things. You just little by little, you realize, oh, this is a problem … and this is a problem, too.*
Sarah	Gluten doesn't die in the freezer	Cross-contaminated food at family member's home	*I realized that no matter how hard people are trying, they often just don't get it, and that was eye-opening.*	*That was kind of a, kind of a moment where I, ever since then I kind of just don't trust that anybody is going to prepare food safely.*	*And that kind of set the tone for how we handle things for me.*
Betty	Gluten on the label, label, label	Cleaning out kitchen by reading labels post-diagnosis	*It was going to be a little harder than I thought it was going to be. You find out there's a lot more to it.*	*I was really surprised to learn that it was I some things I would never imagine it to be.*	*After that, every grocery store visit was just reading contents.*
Joanna	Crying in Kroger	Grocery shopping post-diagnosis	*I think that's when it really hit me how much of an impact on my lifestyle it would be.*	*So, I would say that was a massive learning undertaking was just how to shop with celiac disease.*	*I've since learned that it's probably best from like a health standpoint, if you can do more produce as opposed to just try to find the gluten free version.*
Holly		Living at home	*There's gluten in a lot of things. A lot of unexpected places.*	*I ended up looking up a book on Amazon to help me, guide me through those first few weeks of what I needed to do to adapt my kitchen to be gluten free*	*But I didn't realize that on dried fruit, for example, when it said it may be processed on the same equipment as wheat … and wasn't labeled gluten free, that*

Participant name	Title of Incident	Experiencing (Incident)	Reflecting (Meaning making)	Thinking (Learning that occurred)	Applying (Future application)
	I didn't realize that				*didn't necessarily mean it was safe for me.*
Heath	Unknown preparation	Learning about CeD from former employee	*It really was sort of an evolution, so it wasn't as big a deal to me once, I was officially diagnosed.*	*I would find out stuff indirectly through them. What she would eat and what was around and what we didn't do and things like that.*	*So, I literally kept a notebook for a while of what I was eating up to when I was diagnosed, but again for a while afterwards, just trying to track what the hell was going on.*
Callie	All grown up	Learning to live with celiac disease as an adult.	*I guess just moving out has really taught me that I need to think more about the little things … I would have paid more attention growing up and asked more questions.*	*Be as informed as you can because I think the more that I was informed, the less intimated or alone I felt.*	*Just try and ask as many questions as you can no matter when you're diagnosed.*
Alice	Learning from other mothers	So, I was joining all of these celiac groups, and everyone was looking for community and tips.	*You've got to keep searching ... to not give up, and to not just accept, okay, this is the way it's always going to be and trying to find people who knew things.*	*They were the ones who were on top of everything. So, they're the ones that taught me pretty much everything.*	*And I am thinking in some ways it pushed me to not show when I did accidentally get sick at her house because I didn't want that [guilt] to happen.*
Heath		Advocating for others	*I've gotten now a number of organizations to make sure that they always have gluten free food available....and they now have a significant number of gluten free options.*	*So, I think as we're talking about learning, I think there's a lot more institutional and corporate learning going on more than*	*That there are enough people who think it's a big deal that they've got to adapt for the customers. And again, whether it's celiac or gluten tolerance the variations and the ability to, to be in social settings and not have to worry about either going home hungry, or*

Participant name	**Title of Incident**	**Experiencing (Incident)**	**Reflecting (Meaning making)**	**Thinking (Learning that occurred)**	**Applying (Future application)**
	Be the change			*my individual learning.*	*having a problem is really nice.*
Joanna	Dr. Google	Using Dr. Google for information about celiac disease	*So, it was hard to know, well, is this real? Is this, you know, is this just Dr. Google being dramatic or what?*	*If you don't have that sort of background* [education] *or you're not comfortable reading medical journals or articles, especially if your doctor is not really guiding you, I would imagine that would be really tough.*	*… I tried to look back at what the actual source was. I was lucky to be in a science grad school, so I felt really comfortable reading peer reviewed journals.*
Mary	Relatable nurse	Nurse practitioner provided celiac literature	*It was so* nice [the nurse had celiac disease] *when I had questions from a medical standpoint, or even a life standpoint, just to say, 'Hey, how do you handle this?'*	*I don't think she could have done more. I have encountered other medical professionals that don't necessarily understand it* [celiac disease] *as well.*	*I have some life experience now that helps me to weed some of those things out* [non gluten free items].
Sarah	Sometimes I don't bother	Deciding not to educate flight crew	*They need to be educated, but I didn't want that to be my responsibility. I didn't want to think about fighting with the staff.*	*I don't want to do it. It's just – it can be exhausting. I didn't know that I would really trust them, even if I did explain because I already made my general speech at the beginning*	*I give them my little speech. And if they didn't get it the first time, I'm thinking maybe it's not worth it. I'll just eat my bar and be quiet. Because, if they haven't gotten it, maybe they're not really going to be listening anyway.*

Table 2

Phase Two: Social Settings (one to two years)

Participant name	Title of Incident	Experiencing (Incident)	Reflecting (Meaning making)	Thinking (Learning that occurred)	Applying (Future application)
Joanna	Please don't eat the food	Bringing her own food to a wedding	*Even if people kind of look at you, that's what it is. They're going to move on. So, it doesn't really have to be anything embarrassing. I did it and it was fine. You can advocate for yourself.*	*It's okay to ask for more information. And if people have questions, it's no big deal. You just kind of explain what you're doing and why. They accept it.*	*But there's been other times where I have no problem going up to the restaurant manager and asking, even in a buffet at an event, asking for details on how they prevent cross contamination.*
Alice	Becoming me again	Learning from a new friend how to self-advocate	*I had options of leaving my house …all of a sudden … I had this world of opportunities.*	*I was like, oh my God, I can eat food. I just have to be careful. I can ask questions. So that was my first big entry back into the social world.*	*Do you know how much it changed my life to be able to stop at Chipotle on my way home instead of having to cook all the time? Huge nutrient uptake. It goes back to learning from others – don't be afraid.*
Callie	Celiac is not my identity	Eating out with friends as a teenager with celiac disease	*In my personal experience celiac has been just like a tough mental game to play with ... I felt like celiac was my identity… It just felt like* [if] *they didn't understand that they didn't understand me.*	*I didn't really know how to explain it and make them understand who I was because at the time I felt like celiac was my identity. I think what I have learned … is not everybody is going to know everything. And it's okay. That is completely ok.*	*I think now I'm over it. The people I've surrounded myself with understand what celiac is. So, it's very easy to be like, I have this gluten allergy … But in high school nobody understood that.*
Carole	Don't make assumptions	Ordering her usual GF meal and getting sick	*Don't assume that the meal is still the same.*	*So that was a learning experience in that I needed to ask every time* [about the way a meal is prepared].	*Ask every time how a meal is prepared.*
Alice		Individuals using guilt to encourage the	*I knew that I wouldn't have the support of the people around me.*	*Yeah, man I give in to social pressure. That's not great.*	*I'm firm when it was clear that I could be, and then sometimes just giving in when*

Participant name	**Title of Incident**	**Experiencing (Incident)**	**Reflecting (Meaning making)**	**Thinking (Learning that occurred)**	**Applying (Future application)**
	Appeal to pity	consumption of their food	*So, I think this means that I care too much about what other people think and that's kind of a not nice thing to realize.*	*That's not great at all.*	*people would get too, you know, the logical fallacy of appeal to pity where it's life, 'but you have to do this for me because you need to feel bad for me because of all the work I put in.'*
Rosemarie	Gluten free country clubbing	Bring food to a social event	*That's kind of tiring at times, having to, on hot days, make sure that my food stays cool and not having the convenience of just walking into the restaurant and being able to order something.*	*It's inconvenient, but I have to prepare ahead of time … When I see everybody ordering things that I used to enjoy, I always think things could be worse.*	*It bothered me a lot more at first than it does now. Now I look at it as something that's going to make me sick.*
Sarah	It's not you, it's me.	Dining at my sister-in-law's home	*So, it's a constant awareness of where the gluten is and where it isn't. You know, as a nurse, I learned to think about sterile and not sterile, clean and dirty. And it's kind of the same kind of concept, knowing where gluten is all the time.*	*When you have celiac you have to expend energy thinking about your food a lot. It's all encompassing now … I kind of just don't trust that anybody is going to prepare food safely.*	*I've come to the conclusion that it's safer for me to eat as little as possible of other people's cooking, you know, just in general … It's because I don't necessarily trust that it will be safe anyway.*
Trevor	Eating around gluten	Eating dinner at a friend's house	*As long as I communicate well, I won't get sick. A subset of that is that my friends are becoming more educated about my situation.*	*And, so, you know, it's just kind of like slow education with a lot of my friends. A repetitive, slow education.*	*I have to educate others immediately and be clear.*
Ryan	Cooking in Japan	Cooking GF in Japan	*I think I'm happy to be more able to produce food, not just any food, but many meals I can eat.*	*I know that I'm producing something that is safe and nutritious and has good ingredients.*	[I can] *cook the whole meal conforming to his diet.*

Table 3

Phase Three: Work Settings (three to five years)

Participant name	**Title of Incident**	**Experiencing (Incident)**	**Reflecting (Meaning making)**	**Thinking (Learning that occurred)**	**Applying (Future application)**
Alice	Thank you for your support	Individual at work does support GF diet	*It was the first time someone had not listened* [and took to heart GF restrictions.]	*It helps when I have the support of the other people in the office.*	*It was very easy for me to be blunt and direct, and the rest of the office would back me up.*
Holly	You should eat what is available – cont'd below	Event staff would not supply meal to meet *all* dietary restrictions	*I felt like she didn't take my dietary restrictions seriously.*	*It was easier to bring my own food. I felt so isolated.*	*It's okay to advocate for yourself and make sure that your dietary needs are met.*
Holly	You take me seriously/part two	Work event where staff met *all* dietary restrictions	*I felt like my dietary needs were taken seriously. And I appreciated the compassion she had.*	*It's okay to advocate for yourself and make sure that your dietary needs are met.*	*Advocate for self.*
Heath	Be the change	Advocating for celiac at large	*I've gotten now a number of organizations (and I'm on the boards over stuff like that) to make sure that they always have gluten free food available … I like to think I helped make that happen.*	*So, I think as we're talking about learning, I think there's a lot more institutional and corporate learning going on more than my individual learning.*	*But I do think, as I said, people are much more aware now. If I'm in a situation where there's things going on, I'm much more open. I don't want to say aggressive, but I'm checking everything and figuring out which things* [I can have].
Mary	Clueless bosses	Lack of understanding from bosses at work	*There's a lack of understanding from the bosses, as well as a lack of general knowledge about it* [celiac disease].	*I learned that some people don't necessarily understand, and you have to speak up for yourself.*	*Sometimes some of my coworkers will ask me about Celiac. I love that because I can advocate for myself as well as advocate for the next person.*
Joanna		Pancake breakfast at workplace	*So, I did some educating in that circumstance, and they had no idea, and they felt really bad. But that made me feel bad. I didn't want to ruin*	*You just have to take yourself out of that situation or be petty.*	*I guess the conclusion was it's okay to share it. Maybe not be as worried about if people will feel bad or not, especially when it's a safety issue.*

Participant name	Title of Incident	Experiencing (Incident)	Reflecting (Meaning making)	Thinking (Learning that occurred)	Applying (Future application)
	Pancake breakfast		*anybody's pancake breakfast.*		
Alice	Pure altruism	Party at advisor's home	*It's a fine balance to advocate for yourself while still respecting the hierarchy.*	*I think this means that I care too much about what other people think and that's kind of a not nice thing to realize. I give into social pressure. That's not great. That's not great at all.*	*In my engagement with others, I am more likely to* [say something] *if I am more comfortable* [with] *people to explain to them 'Oh, I'm really sorry, I can't take that.'*
Callie	Tell even if they don't ask	Explaining celiac disease to coworkers	*It's okay to tell people and more than likely they are going to be supportive of it.*	*You should just trust people. Your disease is not something to be ashamed of.*	*It's okay to tell people and more than likely they are going to be supportive of it.*
Joanna	Keep it simple	Thanksgiving with the boss	*So, trying to educate somebody who is pretty high up and not wanting to offend them was something really challenging for me. When it's a work situation, that's another layer of challenge because you don't want to offend.*	*I learned to keep interactions about food simpler and not try to poke around and see if I could eat something to make somebody happy. Just tell them up front like I'm going to be bringing my own food.*	*Just tell them up front that I am bringing my own food. I would probably do that, especially if there were other circumstances like a co-worker or somebody not on my level at work, just because that's another layer of challenge.*

Table 4

Phase Four: Unfamiliar Settings (Five+ years)

Participant name	Title of Incident	Experiencing (Incident)	Reflecting (Meaning making)	Thinking (Learning that occurred)	Applying (Future application)
Alice	I don't understand you	Move to Saudi Arabia/husband had to interpret for her	*It was okay, this is how the situation is going to be. I just need to be ready to roll with it.*	*It taught me how to approach travel with more readiness and more preparedness.*	*Once I got it under control, I was like, okay, I can actually go do stuff. I can go to new places. I just have to be really prepared and be aware that it might take time.*

Participant name	**Title of Incident**	**Experiencing (Incident)**	**Reflecting (Meaning making)**	**Thinking (Learning that occurred)**	**Applying (Future application)**
Betty	All roads do not lead to gluten free	Glutened on Road Scholar trip to Bar Harbor	*…and I am a little bit more - suspicious, you know? Don't assume that for something like that, don't assume that they understand at all.*	*I learned don't believe it when they tell you something can be gluten free.*	*Asking more questions and bringing on food for next Road Scholar trip.*
Callie	Don't hold back	International travel to Cancun	*I knew that whatever was going to be said was going to be through a middleman.*	*Travel with people that understand your celiac disease and can also advocate for you if needed; or make you feel safe in a sense in terms of your celiac disease.*	*I think next time for a different trip or a different place I'd probably research more about the location I'll be at for sure. I'm not as scared or nervous going into it.*
Ryan	Sailing away	Sailing class and eating gluten free	*Well, I told him what I needed to do. Well, you know, he accepted it!*	*Learned others would be open and supportive to his gluten free diet. Has less apprehension.*	*You know there's certain scenarios where you realize that things are possible but might be quite challenging. Sometimes they turn out to be harder than you had to say, and sometimes they turn out to be easier. I think this one turned out to be easier.*
Trevor	Language barrier	Destination wedding - language barrier	*So, a lot of those things are not as important, you know? So, you get sick for a couple of days, no big deal. That was an eye-opener for me.*	*It told me a little bit about language communication. In the United States, for many things, we, drill down into the essence of issues. In many countries, they're just trying to, to live day to day.*	*If I want to go outside the United States, I better be prepared to educate myself in the language of what I'm trying to convey or find places that I already understand.*