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The Lives and Stories of Celiac Disease

Ella Frazee

SOAN 370: Disability, Identity, and Power

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I. Introduction

Eleven years ago, I sat on my living room couch reading the third book of the Harry Potter series. I was deeply enveloped by another world of wizards and witchcraft, spells and magic, when the phone rang. I looked up from my book to watch my mother walk over to answer. It was my doctor, with news of my most recent bloodwork. Pretending to read, I leaned towards the phone to try and pick out words from the muffled voice coming through the speaker. My mom left the room to curl up on an armchair. I followed and hid behind a corner. A few beats of silence, and she began to sob into the phone. I listened to her cry for a few minutes, trying to control herself to hear the doctor's advice for what to do next. The call finished, and I watched as she hid her face in her hands.

This was not my first experience having to do with celiac disease, but it will forever be my most vivid. Having a close friend who had been diagnosed a few years prior, I had a brief understanding of what celiac was. I knew that it entailed a gluten-free diet and that I had to be careful around people who had it, but not that it could affect me beyond my friend's situation. Shortly after the above phone call, I was officially diagnosed in 2009 and received preliminary answers for why I hadn't grown in a year and why my bone age was two years younger than my nine year-old body. Beyond that, I had experienced no other conventional celiac symptoms and, if it weren't for my mother's persistent commitment to her intuition, could have gone years or even a lifetime without receiving a diagnosis.

Eleven years after that phone call, I am armed with a purpose and drive to write my disability studies paper on the experiences of people with celiac disease in both the medical and social worlds. The goal of this paper is to shed light on the collective and unique life stories that exist within the reality of celiac disease, an invisible disability surrounded by cultural stigmas and resilient individuals. Although I first explain the background and medical definition of the disorder, this paper will shift the focus away from the medicalized arena which frames much of

the chronic illness experience. Through the lens of narratology, this paper seeks to understand celiac disease as an impicator of cultural, emotional, and spiritual stories. After explaining what this condition is recognized as, I will move to express and analyze the narratives shared by my subjects and in the online realm.

Following my original goal to bring awareness into the world of this autoimmune disease, I have collected four personal stories from individuals who have either been diagnosed with or affected by celiac disease. Three of the narrators have the condition (including myself), and one is my mother. While she does not have celiac disease, my mother was responsible for getting me successfully diagnosed despite a plethora of roadblocks and loopholes presented by the American medical system. During the process of recording people's stories, I encountered the ethical issue of confidentiality and feared I might include a quote in this paper that was not to be publicized. To handle this, I fully transcribed each interview and emailed participants a copy so they could delete anything they did not want included. I have also given pseudonyms to my two celiac sources, but use me and my mother's public identities.

II. Background

Celiac disease is a genetic autoimmune disorder that affects the small intestine's ability to digest food, specifically gluten proteins. In the words of Italian medical professionals Antonio di Sabatino and Gino Corazza, "When a person who has celiac disease consumes gluten, a protein found in wheat, rye and barley, the individual's immune system responds by attacking the small intestine and inhibiting the absorption of important nutrients into the body."¹ In other words, gluten prevents the small-intestine from properly functioning and puts it into attack-mode against the rest of the body. This results in an extensive list of possible symptoms including but not limited to brain fog, malnutrition, seizures, indigestion, and delayed puberty.²

This condition affects 1% of all Americans, but our population is most likely underdiagnosed as people will usually only receive a test if they are experiencing traditional symptoms of celiac, such as gastrointestinal pain.³ However, there are many studies by medical professionals as well as institutions of medicine which have found high numbers of celiac patients (myself included) to be asymptomatic before being diagnosed.⁴ Asymptomatic celiac does not mean the disease has no negative affect one's body, as the small-intestine will have a similar level of damage to that of a symptomatic case. However, damage will not present itself until other issues arise as a result, such as other autoimmune diseases or even cancer.⁵ Although the condition is relatively rare, celiac tends to have a ripple effect which requires other people to be aware of the disease and manage their actions around food accordingly. The prevalence of this invisible disability means that the person diagnosed must often publicize the condition for their own safety in certain settings.

The most common path of diagnosis in America contains two steps: a blood test and a biopsy. The initial blood test screens for higher levels of certain antibodies in your blood, an indicator of a celiac reaction to gluten. The endoscopic biopsy is done in order to officially

¹Di Sabatino, Antonio, and Gino Roberto Corazza. 2009. "Coeliac Disease." *The Lancet* 373 (9673): 1480–1493. [https://doi.org/10.1016/S0140-6736\(09\)60254-3](https://doi.org/10.1016/S0140-6736(09)60254-3).

²³ *Ibid* .

Prashant Singh et al., "Global Prevalence of Celiac Disease: Systematic Review and Meta-Analysis," *Clinical Gastroenterology and Hepatology*⁴ 16, no. 6 (March 15, 2018), <https://doi.org/10.1016/j.cgh.2017.06.037> .
 "Celiac Disease Facts and Figures" (University of Chicago Medicine, 2016), https://www.cureceliacdisease.org/wp-content/uploads/341_CDCFactSheets8_FactsFigures.pdf. And Alessio Fasano et al., "Prevalence of Celiac Disease in At-Risk and Not-At-Risk Groups in the United States," *Archives of Internal Medicine*⁵ 163, no. 3 (October 2003): p. 286, <https://doi.org/10.1001/archinte.163.3.286> . "Symptoms of Celiac Disease," Celiac Disease Foundation (Celiac Disease Foundation), accessed December 17, 2020, <https://celiac.org/about-celiac-disease/symptoms-of-celiac-disease/>.

diagnose celiac in the patient, as it can observe the state of the patient's small-intestine in more detail than the blood test.¹ One challenge with these testing methods is that the patient must

¹ Abdulbaqi Al-Toma et al., "European Society for the Study of Coeliac Disease (ESsCD) Guideline for Coeliac Disease and Other Gluten-Related Disorders," *United European Gastroenterology Journal* 7, no. 5 (2019): pp. 583-613⁷ , <https://doi.org/10.1177/2050640619844125>.

continue to eat gluten until they have received their biopsy results. This way, the tests can measure the effects of gluten in your system without the diet change normalizing your antibody numbers or restoring the health of your small-intestine.⁷ For many, this means maintaining and often worsening symptoms until an official diagnosis is confirmed.

Due to its cause and incurable nature, the only way to manage celiac is to adhere to a strict gluten-free diet, where even a crumb could cause a reaction. As a result, people with celiac are often hyper-aware before, during, and after all social gatherings where food is served. For children with celiac, this often means their parents must keep a close watch on them at all times. There can be hesitation and fear to allow their child to attend events such as birthday parties, playdates, or in school holiday celebrations because of potential accidental cross-contamination or a decision to eat something regardless of the ensuing consequences, a choice especially prevalent for an adolescent who is tired of restriction or feeling different from their peers.² Living with celiac means you have to step on people's toes, be adamant about respecting your needs, as well as requiring others to respect you.

This brief overview of celiac's cultural and social implications is not widely shared and is often given little to no weight in comparison with the physical effects or symptoms of the disease. I and my sources shared this experience, recalling that we mainly talk about our condition within the walls of a doctor's office or explaining our symptoms to others. Much of the scholarly resources available surrounding celiac disease are concerned with an experience-far, detached and objective approach to describe or analyze the condition. As such, there is an available space and need to denaturalize the medical aspects of celiac disease through the sharing and recognition of personal narratives. This process allows an individual to construct their

² *Ibid.*

Kate, "Coeliac Parenting – How to Manage Play Dates and Parties," *Gluten Free Alchemist*, November 12, 2019, <https://www.glutenfreealchemist.com/p-friends-how-to-manage-play-dates-and/>.

experiences within their own life history, without the limitations of an empirical label, and to generate a sense of solidarity within a community that is easily invisible to the outside world.

Social psychologists George Rosenwald and Richard Ochberg characterize the narratology approach as one wherein, "...the object of study is not the 'true event,' but the construction of that event within a person's personal and social history."⁹ In other words, the emphasis of this paper will not be on the diagnosis or physical symptoms of celiac, but the surrounding implications and messages resulting from those events. Information will be filtered through the narrator's process of identity-construction, an aspect of human existence that is both stunted and progressed by their life experience.¹⁰ For these reasons, I focus on the experience-near accounts that I have recorded from my sources as well as my own personal life story to illustrate an interpretive account of this disability.

III. Social Conflicts and Identity Construction

Based on my experience as well as those of others living with celiac, most of the social conflict surrounding this disability results from a lack of knowledge among the mass population and spaces which lack dietary accessibility. One of the most common areas of social conflict occurs when people doubt the severity or misinterpret the meaning of celiac, often mistaking it for a diet trend rather than a serious chronic illness. While gluten-free diets have rapidly increased in popularity, there is still a knowledge gap among the general population

⁹ George C. Rosenwald and Richard L. Ochberg, *Storied Lives: the Cultural Politics of Self-Understanding* (New Haven, CT: Yale University Press, 1992). 3.

¹⁰ *Ibid.* 2.

surrounding celiac and gluten in general.¹¹ A 2017 study by the Mayo Clinic found that non-celiac related gluten-free diets tripled between 2009 and 2014, despite an unremarkable increase in cases of celiac disease.¹² These findings corroborate the conventional wisdom of a gluten-free diet being a "fad" or a personal choice, rather than a necessity of one's physical needs and health.

A 2015 study done by NSF International found that although gluten-free diets are increasingly common, 54% of non-celiac participants were unsure of what gluten actually was or incorrectly identified its substances.^{1 3}

The cultural misunderstandings which link celiac disease, a gluten-free diet, and the substance of gluten itself contribute to many social conflicts experienced by those who have celiac. My sources and I shared the frustrating yet common experience of being asked questions such as, “Is it *really* that serious?” or having people wrongfully assume your restrictions are the result of the newest diet trend. This is not meant to criticize those choosing to live gluten-free, but to point out the condition-specific hostility that results from such an association. This notion is exacerbated in food-centered spaces, such as restaurants or family gatherings, and can lead to many forms of social conflict.

My first source, known as Elizabeth in this paper, was diagnosed with celiac in 2006 at the age of five after experiencing symptoms of extreme indigestion and food sensitivity since she began to eat solid foods. In the first few years after her diagnosis, Elizabeth recalls the limited availability of gluten-free substitutions and frustration she experienced in food-centered spaces:

It was hard, you know? I was a little kid and all of a sudden food was a source of stress and fear for me. Shopping for [food] was a nightmare, I thought something was wrong with me because there was nothing I could eat anymore. Looking back, it shouldn't have been that big of a deal to

¹¹Rok Seon Choung et al., “Less Hidden Celiac Disease But Increased Gluten Avoidance Without a Diagnosis in the United States,” *Mayo Clinic Proceedings* 92, no. 1 (January 1, 2017): pp. 30-38, <https://doi.org/10.1016/j.mayocp.2016.10.012>¹²

¹³ *Ibid*.

“How Much Do You Know About Gluten?,” NSF International (NSF International, July 2020), <https://www.nsf.org/knowledge-library/how-much-do-you-know-about-gluten>.

give up things like bread or pasta, but it [translated to] a huge dive in my self-esteem. I saw my body as weak... incapable of, just, living right.

Elizabeth had similar experiences in restaurants, where attempting to order a meal often resulted in hostility from her server, and later an allergic reaction after the restaurant had either ignored or had accidentally failed to adhere to her requests.

Restaurants were embarrassing. No one knew what gluten was... they thought I was just [a] picky little girl. I started to get anxiety before ordering food from places, and then it kind of imploded from there. My doctor told me what to say, and I said it everytime, but for those first few years I'd always get blown off by servers or even managers. As a kid, you're learning about yourself and your place in the world. Those experiences told me I didn't have a space there, or there, or there... because I was different. And kind of like the grocery store thing, it became another reason to think bad things about myself.

Although we are the same age, my diagnosis was a few years after Elizabeth's and as such, I adjusted to the gluten-free diet with more food availability due to the diet's increasing prevalence in America while also being three years older than Elizabeth's age in the above story. These two factors placed me in a slightly more accessible cultural space than the one first encountered by Elizabeth, and also at a different point in my childhood development. Despite these differences, my own initial experiences with celiac in food-centered spaces were similar to those of my first source. As a nine year-old, grocery stores became unsafe, frightening places where I had more potential to slip up and poison my body. In restaurants, I felt vulnerable and exposed to others' opinions. Eating became a very stressful, high-risk undertaking. Each effort to explain my needs to the server was a reminder of the chaos and trauma which accompanied my diagnosis. When someone doubted or questioned my needs, those experiences felt invalid, invisible, and unrecognized, leading to a confusing and contradictory formation of self-identity. Food was a necessity, but it was also an enemy. As a child, one is not necessarily aware that mealtimes can be both social gatherings and opportunities to refuel the body. Meals are a dynamic event to serve and nourish the body, mind and spirit, meaning higher levels of stress around food in a social setting took a toll on my nine-year-old sense of self. Additionally, my body felt fine, but being so small for my age, my body also looked wrong. I yearned for others to

understand my condition but was uncomfortable and reluctant to share my experience and situation in its entirety.

Social distress with celiac is also prevalent in other social spaces, such as birthday parties or family reunions. As children with celiac, Elizabeth and I had common experiences at celebratory gatherings where the presence of food meant the need to be extremely vigilant of what you were eating. This vigilance often raised questions from parents, who wondered why a child was being so stingy with their meal or refusing to eat what had been offered to them. When I asked Elizabeth to tell me about a memorable interaction at a celebration, she recalled an all-too-familiar reaction from a classmate's parent:

It was third grade, we were having a big party for the kids with summer birthdays. There was cake and all kinds of snacks, but most of it wasn't gluten-free... I stayed at my desk to keep myself from eating anything. My mom made me a cupcake the night before, you know, to eat when they brought the big cake out. So it was cake time, and one of the moms had made it herself. She seemed super proud and excited for us to eat it... [She] handed me a piece and I said "No thank you, I brought my own." Well, that really offended her I guess. She said I was rude and being inconsiderate, and I tried to explain that I was allergic to the cake. I said... and I'll never forget this... I said to her, 'I have celiac disease, I can't eat your cake.' She immediately gasped like I'd spit on her or something... [and] pulled her daughter behind her, away from me. The lady thought I was contagious! I was confused for a long time. And then I felt sad. Really sad, and embarrassed too, because the whole class saw her do that. And then my mom, she was so mad... [she] had to send another email to the rest of the parents explaining what my allergy was, and how it wouldn't spread to other kids... That was the first time that I actually googled celiac disease, like, am I really dangerous to other kids? Do I have to worry about being too close to people?

Now that story just makes me so mad, because the mom had no right to react that way. The whole thing was so unnecessary, but when I think about it, kinda scarring. Under my anger I still feel sad, and pretty scared to be honest.

The lack of awareness and misconceptions surrounding celiac disease leave room for others to reach their own conclusions about the condition, which can be incorrect and harmful to the celiac community. I had a similar experience to Elizabeth's birthday party event which occurred with an extended family member when, in an effort to explain my condition to her friend, she said, "It's not always contagious, but when she eats gluten that changes and other people can get it, so we have to be careful around her." Not only was that statement incorrect in

many ways, but also very difficult to hear from someone who I expected to know the details of celiac. After all, it had been five years since I had been diagnosed. I sat next to this adult family member silent and frozen, not ready to speak up and advocate for myself in the ways I am able to now. The combination of her sharing my diagnosis without my permission, in front of me, and doing so with false information infuriated, paralyzed, and violated my now teenage body with the same feeling of otherness Elizabeth and I shared in food-centered spaces.

The doctor's office is another social dimension of celiac disease, a space which can present many challenges to individuals who experience the invisible and complicated nature of autoimmune disease. Medical spaces can often dominate the celiac experience, placing a focus on the physical aspects and symptoms of the condition. Until this paper, this was the case for me and each of my sources, either talking about celiac out of necessity or when asked to do so by a medical professional. While medical interaction is necessary and can help one's condition, there are social limitations present within the power dynamic between the doctor and their patient. The authority held by medical professionals has the potential to lead to harmful and common experiences when one presents a chronic illness within a medical space.

My second source, known as Megan in this paper, dealt with a series of social conflicts and doctor-initiated roadblocks throughout her twenty-year journey on the road to a celiac diagnosis. When symptoms of fatigue, bloating, and migraines began in high school, Megan went to her physician at the time in an attempt to find a cure. In her words, the first few years of searching for answers went like this:

I went from healthy, playing sports, energetic... to irritable and sick all the time. My doctor tried in the beginning, when there felt like there was a possibility for an answer. He was receptive to my symptoms at first and ordered all kinds of tests. They drew my blood, did allergy testing, and even tested me for ADHD when my brain fog started to get really bad. Well, everything came back normal so I was told I was fine. But I thought, no, I'm not fine. When nothing showed up on the tests [the doctor] said more appointments would just be a waste of money, so I stopped going. So then my symptoms got worse, and I started going to another doctor, a woman this time because I thought maybe she'd know more about the female body... At this point, I was twenty years old, tired all the time, had a horrible case of post-nasal drip and a night cough, night sweats, and crazy anxiety along

with my pre-existing symptoms... It was bad. She thought it was a hormone issue so we did all of those tests... everything was normal except for my thyroid, so I went on medication for thyroid problems. That didn't help. So [my doctor] said to give it time, and I did, but nothing changed. She asked me, 'Is it really that bad?' I was like, yes, it's that bad or else I wouldn't be here. But then, I would question myself after that hesitation from her... I went to another doctor, this one was a man, who said I didn't need my Hashimoto's medication, so I went off of that... and it actually relieved some of my fatigue, so I trusted him. He didn't run any tests though, and said that my symptoms couldn't be explained [and] they were probably just the result of my 'unique body.' He said that! A medical professional telling me I have a unique body, and that's why I can't walk down the stairs! ...So fast forward, I'm forty years old with two kids. I thought I had rheumatoid arthritis, because my kids would grab my hands and my fingers would sprain themselves. I was that weak... I couldn't get out of bed some days, I could hardly talk to others. I really lost myself in my symptoms and my whole world revolved around them. That doctor's reasoning really stuck with me though... about my unique body. I thought, oh, this is normal for people. This is aging. It's what happens... I gave up trying to find out what was wrong with me. I remember... [pretending] to float outside of myself to try and get through my day without pain. I thought, if I can just stay up here by the ceiling for a minute, I can get out of bed. I can drive. I just have to stay out of the pain.

Megan's experiences with medical professionals, from doubting the severity of her symptoms to misdiagnosing the latter, incorporated a traumatic, emotional side to her journey with celiac. This aspect went beyond her physical ailments to bring feelings of self-doubt, insecurity, and shame into her daily life. When I asked her to simplify what she went through for those years into descriptive terms, she answered, "I lost myself. I felt worthless, like nothing. Ashamed. A burden on others. A bad mom, I couldn't be present with my kids. A failure." The lack of recognition and social conflict endured in the medical space took away many things from Megan, leaving her at an emotional and physical low point.

I started seeing a therapist, because I figured if there was nothing wrong in my body, it must be my mind, right? And I was honestly losing the will to... not to live... but to do little things. Like shower. Get out of bed. I was depressed. This [therapist] was amazing. She heard me, I was validated for the first time... for the first time ever. And it wasn't my mind, there was something off in my body. She helped me trust myself, to listen to my body and not try to escape it. She helped me find a doctor who believed me, who slowed down to hear the timeline of my symptoms. My new doctor asked me about my diet... I was confused like, what does food have to do with it? [My doctor] said, 'Well, maybe everything.' So I got more blood tests, and she screened for celiac. I didn't even know what celiac was, no one had ever considered that as a possibility. I was sitting outside of my son's school when I got the results, which were basically off the charts showing that I had it. All those years, all those tests searching for answers, and here it was.

Q: How did the diagnosis make you feel?

A: Well, you'd think I'd be all happy to finally know what was wrong with me. But I was so angry Ella. I wanted to scream at the doctors before her who said I was fine. Who brushed me off. Who left it at "my unique body". Half of my life had been spent suffering and blaming myself for it, and now I hear that it didn't have to be that way? Yeah, I was furious. I cried in my car, I lost control of my body... I was shaking... my body was convulsing, like it was shaking out all of the toxicity, all of the shame. It was liberating... almost like... no, it was... it was spiritual really.

Megan's narrative of celiac, illustrating the depth of her life story through the struggle of her conditions, is similar to that of Laura Hillenbrand. A renowned American author, Hillenbrand spent years bedridden with a wide range of symptoms and encountered many frustrating, belittling experiences as a patient seeking help. As she recounts "disappearing" inside her illness, doctors attributed Hillenbrand's chronic symptoms to everything from Epstein-Barr syndrome to her psychological well-being, yet none of the attempted cures did any good.¹⁴ Her physical state began to be written off as laziness, weight-loss, or her need for attention.¹⁵ Although she was eventually diagnosed with Chronic Fatigue Syndrome and not celiac disease, Hillenbrand's story draws many parallels with others who bring irrational physical symptoms into the overwhelmingly rational world of Western medicine.

Medical spaces contain a power structure between the doctor and patient which if exercised in a certain manner, can strip patients of their autonomy within the walls of a doctor's office. As the objective observer operating out of knowledge and fact, doctors are viewed as the experts in their space rather than the patient who is experiencing their situation firsthand. As a

¹⁴Laura Hillenbrand, "A Sudden Illness," *The New Yorker*, June 30, 2003, <https://www.newyorker.com/magazine/2003/07/07/a-sudden-illness>¹⁵

Ibid

result, chronic illness patients can be dismissed and have their symptoms reduced to subjective assumptions made by a medical professional, hence Megan's "unique body" and Hillenbrand's laziness alongside suspected mental health issues. When the medical establishment possesses the authority and the ability to name what is valid and what is not, the result produced for many

patients suffering from chronic illness can be a sense of powerlessness and shame against the prevailing knowledge of institutionalized medicine. Megan's narrative, even with its own unique details, echoes common social conflicts encountered by celiac patients in medical spaces of hitting dead ends, not being taken seriously, or being written off by doctors who determine your case to be at the least unsalvageable and at the worst, fabricated or imagined.

I experienced this loss of autonomy and powerlessness in the first few years after my diagnosis, having a series of negative experiences during visits with my pediatric gastroenterologist. Shortly after receiving my official celiac diagnosis, I began to experience emotional turmoil surrounding my physical self that completely transformed the way I saw and related to my body. Through my eyes, my body was genetically impaired and inhuman. My identity had been turned on its head and shaken out, leaving me disoriented and discouraged by my new reality. The word "disease" began to trigger me, and hearing people refer to me through that label sent me into a spiral of anger and confusion. I was extremely sensitive to the underlying cultural meanings of the word "disease", watching it lead people to see me as sickly, contagious, and weak. To my nine-year-old self, disease conveyed a sense of shame and abnormality. It said I was one of nature's mistakes. However, my emotional reactions could not dissuade the fact that celiac, by definition, is a disease. According to the eleventh edition of the Merriam Webster dictionary, a disease is "a condition of the living animal or plant body or of one of its parts that impairs normal functioning and is typically manifested by distinguishing signs and symptoms."¹⁶ This definition does not include sickly, contagious, or weak, but the cultural assumptions and weight given to the word implied those meanings through a series of social conflicts I encountered.

My first gastroenterologist was a big fan of factual definitions and objective labels. To her, there was no issue with the word "disease" and she seemed to gain confidence with every chance she had to tell me about my celiac *disease*. The word stuck out to me like a sore thumb,

and I immediately dreaded returning to that space. When I asked my mom, Susan, to talk about her perspective of this situation, she recounted a frustrating series of events with my doctor:

The word disease really set you off... it made you angry and... sink inside of yourself. So I met with [your doctor] before you came in the room and I said, 'Here's the bottom line. You are not to use the word disease...' and I told her that it hurt you in a lot of silent ways. I was very clear. But [you got] disrespect from that doctor's office. You felt violated... Throughout the appointments she kept saying disease, and the way she said it... so proudly after I asked her not to use that word. She told me 'Well that's just what it is, there's nothing wrong with it! It's celiac disease!' And I was like, just don't use that word. Call it something else. Call it celiac, leave it at that. She was so concerned with using the right label. I remember thinking, it's not about being right or wrong here, it's about empowering your patient, my child, by removing the disempowering things.

In his book *Medicine, Rationality, and Experience*, American anthropologist Byron Good illustrates the ways in which Western medicine constructs its patients and their illnesses or conditions through language. The distinctly objective, distanced manner of patient analysis taught in American medical schools focuses the illness or condition at the center of discussion, making the body the location of impairment.¹⁷ Through the objectification of my physical body, the actions of my doctor were based in a stunted understanding of her patient. To her, my body was the location of the disease which was relevant to her work. At nine years old, I understood my body, emotions, and thoughts to be enmeshed as one single entity. There was no distinction from the physical, emotional, or mental states that made up my whole self and constituted my

¹⁶"Disease," Merriam-Webster (Merriam-Webster Dictionary), accessed December 17, 2020, <https://www.merriam-webster.com/dictionary/disease>¹⁷.

Byron J. Good, *Medicine, Rationality, and Experience* (Cambridge, MA: Cambridge University Press, 1994). 78. human experience. As a result, the word disease attacked my entire sense of self for which I was unable to compartmentalize facets of my identity. My trigger from the word "disease" was deemed irrelevant next to the prevailing reality of my physical diagnosis. Disease was the correct label for my body's physical condition, even if its implicit meanings seeped into other areas of my identity: crumbling my sense of self, distorting the body I saw in the mirror, and sparking a cycle of shame and anxiety that is still present for me today.

While it is perceived and used as a strictly empirical method of factual interpretation, medical language is just like any other human dialect: subjective, exclusive, and foreign to those who do not practice it. The language of medicine swept aside my mother's holistic presentation of my needs, making way for, as Good describes, "numbers and lab values" to define my human condition and characterize my disability.¹⁸ Good's work allowed me to further understand and explore the ways in which medical culture structures and decides what is of value from a patient's narrative and what is not. I became "...the site of disease rather than... a narrative agent" and felt the mechanics of medicine's "formalized hierarchy" descend upon me.¹⁹ In this medical space, my doctor's use of the word "disease" accurately constructed her patient in a way that concerned her knowledge of and need for relevant information. Her language also constructed me within the implicit, interpretive meanings carried by the word "disease" in my surrounding culture and language, leading to personal turmoil and social conflict in the world beyond that examination table.

I do not denounce the value and incredible feats accomplished by
the institution of

Western medicine. However, the language of medicine demonstrated above and analyzed by Byron Good is flawed in its commitment to remain objective and distant from the patient's

¹⁸¹⁹ *Ibid.*

Ibid. 80, 82.

experience. My doctor's refusal to take my situation into account with a simple change in wording resulted in each visit with her being a traumatic experience of powerlessness that largely shaped the ways in which I identify with my diagnosis. In my life story, that doctor amplified and validated the negative cultural meanings surrounding disability, disease, and impairment that I already feared would be applied to me by others. These messages quickly seeped into other areas of my identity, and I felt lost within the label of "disease" by way of my doctor's inability to stray from her medical language or acknowledge the broader cultural forces at play in her position of authority.

IV. Narrative Analysis

The narratives of celiac disease presented above share experiences of social conflict but are also distinct and individual stories that highlight areas of struggle and emancipation. Using the categories of narrative analysis developed by medical sociologist Arthur Frank, I will continue to present the life stories of celiac disease in a way that examines the source's characterization of their journey with this condition. Although Frank defines these categories in terms of illness, their traits can be applied to autoimmune disease as both a disability and chronic condition. From my own experience, that of my sources, as well as online stories, celiac narratives tend to be a dynamic mix of Frank's restitution, chaos, and quest narratives.^{2 0} The restitution narrative places the storyteller as a "hero" figure, overcoming the limitations of their illness or disability to live without the confines of their diagnosis. This narrative also "...protects memory from disruption" meaning the time experiencing symptoms or pain in one's journey will be reduced to a "...blip in the otherwise normal passage of time."^{2 1}

²¹ Arthur W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago, IL: Univ. of Chicago Press, 2013).
 Arthur W. Frank, *The Wounded Storyteller...* 90.

While celiac is chronic and as of now incurable, the restitution narrative is still present in people's accounts of overcoming the physical and mental limitations experienced as a result of their symptoms. Food must always be a consideration, but the restitution narratives include those who no longer view that need as a burden or restriction over their ability to live life to its fullest potential. I consider my own story to contain aspects of restitution, as my strictly gluten-free lifestyle has become my norm and I have worked to heal my gut from the damage it incurred during the first decade of my life. Before writing this paper, I did not recognize the length and depth of my experiences pertaining to the condition, and reduced my memory of those initial years with celiac to a "blip" in the larger image of my life story. My mom described my diagnosis as having improved the quality of life for our family, making us more aware of what we put into our bodies and how to eat better, healthier foods.

There is also an abundance of restitution-like celiac narratives online, which are mostly centered around conquering your symptoms, returning to health, and becoming liberated from the initial feelings of confinement and restriction that follow a gluten-free diet. For example, an article by Anne Hoyt, a mother with two daughters who all have celiac, is titled "Gluten freedom" and emphasizes the journey to restoring, and even improving their health after the challenges leading up to their diagnosis.^{2 2} Overcoming the struggles and pain from their incessant and unexplainable symptoms, this family used their celiac diagnosis to start a business and live as limitless as possible in spite of their dietary needs. However, the presence of restitution does not dissuade from the inherent chaos present within and around the celiac experience.

Frank's chaos narrative is the kind that nobody likes to hear. The opposite of restitution,

²²Anne M Hoyt, "Gluten Free-Dom: My Journey to Becoming an Unintentional Expert," Proceedings (Baylor University. Medical Center) (Baylor Health Care System, July 27, 2014), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4059589/>.

this narrative contradicts the modernist notion of rational healing. The narrator is trapped in a cycle of pain and struggle, unable to be fixed or cured. Furthermore, the chaos story is nearly impossible to put into words by those experiencing the latter. In this way, this is an "anti-narrative" with no comprehensible plot or end in sight.^{2 3} In the case of celiac, the chaos narrative is present throughout individual life stories and at varying moments in time. I identify the first two years after my diagnosis as my time in the chaos narrative. I lacked control over my own bodily autonomy, felt as though days were concaving into themselves, and was unable to verbalize my experiences until nearly a decade had passed and the chaos subsided. I also demonstrated an, "...incapacity to receive comfort" from others, making the simple process of my mother ordering food for me at a restaurant humiliating, vulnerable, and exposing the trauma that was synchronous with my condition.

This anti-narrative is also present for those who did not have their symptoms relieved with a gluten-free diet despite the positive result for celiac. My first source, Elizabeth, falls under this category. Her gluten-free diet has lessened brain fog and skin rashes she once experienced, but not her struggles with indigestion, fatigue, and malnutrition. She has since been diagnosed with IBS, or irritable bowel syndrome, and has struggled to find a manageable diet to accompany the gluten-free regimen already prescribed. Living without gluten has not noticeably fixed or healed her as it was supposed to, and she continues to perplex her traditional doctors who remain convinced that her prevailing symptoms are somewhat imaginary.

Elizabeth's interview was difficult to hear and challenging to understand. It lacked a chronological order of events, as her list of symptoms often overlapped with her timeline and

circled back to other instances in her life. Frank describes the chaos narrative as the most challenging yet necessary one to hear. Anyone, including the listener, is vulnerable to begin

²³ Arthur W. Frank, *The Wounded Storyteller...* 98.

experiencing a struggle with no end in sight.²⁴ Listening to Elizabeth's continued challenges was frightening and uncomfortable, as it drew me into the feelings of helplessness and struggles that I experienced within the chaos narrative. However, those with more restitution or quest narratives have an obligation to honor the pain and suffering within chaos stories, and to humbly recognize their struggle as valid even when empiricism lacks the ability to properly characterize their nature.

An aspect of the chaos narrative that is particularly applicable to the celiac experience is that of bodily dissociation.²⁵ In a chaos story, Frank claims that the individual must disconnect from their body in an act of survival, as the body is the agent and source of the pain.²⁶ Myself and Megan both experienced this process, but at different points in our journey with celiac. I recall dissociating from my body not from physical pain, but from the emotional confusion and chaos that surrounded my body image in the first two years after my diagnosis. As I spoke of previously in this paper, I began to see my body as distorted, diseased, and inhuman, with actions taken by authority that did not exactly help this situation (enter pediatric gastroenterologist). I did not accept that celiac was a part of my body and refused to give power to the label. Still, my body no longer felt like my own, and I preferred it that way. As time passed, I embarked on an individual journey of body-reclamation that was both spiritual and physical. The chaos subsided

for me, and I was able to integrate back into my body not in spite of, but in tandem with my celiac diagnosis.

When Megan described her bedridden days of severe fatigue and pain, she spoke of “floating” above her body in an effort to get through her responsibilities for the day. In doing so, she characterized her body as something outside of and other than herself. This time in her life

²⁴ Arthur W. Frank, *The Wounded Storyteller...*
109. *Ibid.* 103. ²⁶ *Ibid.*

was a very accurate depiction of the chaos narrative, as her world was unmade by pain and her body was “it” rather than “me.” The dissociative experience within the chaos narrative of celiac disease is often one of silence and loneliness. This could be the result of a general lack of public awareness surrounding the condition itself, its limitation to food-spaces or doctor’s offices, as well as the word-less nature of the chaos story. Either way, chaos narratives deserve to be heard and validated by those who are not currently experiencing the wind-tunnel nature of these stories.

I find Frank’s third and final category, the quest narrative, to be the most common celiac experience despite each story being a unique combination of all three. In the quest narrative, the storyteller is on a continuous journey with their illness or disability. Unlike the restitution that overcomes and the chaos that stays in pain, the quest narrative moves between the realms of health and sickness after one’s initial departure into their new illness reality. On this continuous journey, the narrator goes through a series of challenges rooted in both pain and suffering and triumph and joy. They are rewarded with “different experiences [and] different knowledge” than an average person, as each tribulation requires a journey into a world untraveled by those outside of the quest narrative.²⁷ This story has three parts: the calling, the initiation, and the return. The first are the initial experiences or symptoms related to your condition, the second being the moment you cross the “threshold” into the community of your condition, and the third is the

return to your previous normal, not necessarily impacted by the condition but remaining “marked by the illness.”²⁸

Celiac is a lifelong condition, meaning those who live with it must always be responsive to the needs required by their bodies. The calling can be understood as the moment in which your

²⁷ Arthur W. Frank, *The Wounded Storyteller...* 130

. Arthur W. Frank, *The Wounded Storyteller...* 118.

symptoms began or were recognized in terms of the condition. The initiation is the moment of diagnosis, and the return is when your symptoms become manageable once more. Still, you are “marked” by the chronic needs of celiac, must adhere to the gluten-free diet, and endure the challenges that accompany accidental diet mix-ups and gluten ingestion.²⁹ While the quest narrative does not place a heroic emphasis on “overcoming” the totality of your condition, each challenge and aspect of your journey contributes to the larger image of your identity.

As time passes, people with celiac often gain confidence and assurance with themselves to live with “gluten free-dom.”³⁰ Self-advocacy becomes less of a burden with each need to do so, and wisdom is gained through the struggles presented by your condition. For example, Megan’s description of her diagnosis as a “spiritual” moment of liberation and relief would not be possible without the years and tribulations brought on by her symptoms. Elizabeth’s confidence to advocate for herself in food-centered spaces was borne out of experiences similar to those of the overreactive cake mom in the third-grade classroom, at first painful but then transformed into self-assurance and an opportunity to further educate people. Numerous experiences and stories surrounding a condition I once refused to speak about slowly repaired my

ability to write an academic paper on the latter. And still, there is a lifelong journey to go. This is the quest narrative, and this is why it takes up the majority of celiac life stories.

V. Emancipation and Final Thoughts

While there remains a long way to go in regard to sharing the narratives of celiac disease and educating the general public about the condition, there has been a noticeable increase in the online resources available. From blogs and personal stories to The Celiac Disease Foundation

²⁹³⁰ *Ibid* .

Anne M Hoyt, "Gluten Free-Dom: My Journey to Becoming an Unintentional Expert," Proceedings (Baylor University. Medical Center) (Baylor Health Care System, July 27, 2014), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4059589/>.

and financial education, the celiac community has a vibrant online presence to connect with at any stage of the celiac journey. These sites target an array of individuals affected by the celiac experience, from surrounding parents and family members to children and adults who have been diagnosed. These acts of emancipatory action provide a sense of solidarity and a space of recognition to present a personal narrative, regardless of into which category your experiences fall. Through my time spent in the online space before and during the process of writing this paper, I found this realm of emancipatory consciousness to fall into two primary categories of daily life: finance and social interactions.

Along with social-conflict in certain environments, the requirements of a gluten-free diet can often be more financially demanding than a “normal” diet, as gluten-free substitutions are both less common and more expensive than their gluten counterparts.^{3 1} The enlarged economic burden of gluten-free products inhibits some from accessing the food required by their bodies and medical diagnosis. While price gap has slightly closed as the demand gluten-free substitutions is increasing, this financial requirement remains a challenge for anyone who cannot afford the expenses demanded by a gluten-free diet. To combat this issue, there are numerous online resources which offer advice and potential solutions to overcoming the problem of affordability. An article by Mary Herrington, published through Gluten Free Living, gives the reader “7 Tips for Eating Gluten Free on a Tight Budget.”^{3 2} The Celiac Disease Foundation has also dedicated an entire section of their website to providing information on the “Federal Benefits” available for individuals with celiac, such as a tax deduction to cover the extra costs of living gluten-free.^{3 3}

³¹Anne Lee et al., “Persistent Economic Burden of the Gluten Free Diet,” *Nutrients* 11, no. 2 (2019): p. 399, <https://doi.org/10.3390/nu11020399>³²

Mary Herrington, "7 Tips for Eating Gluten Free On a Budget - Gluten-Free Living," *Gluten*, May 17, 2018, <https://www.glutenfreeliving.com/gluten-free-savings/tips-saving-gluten-free/gluten-free-tight-budget/>³³

"Tax Deductions," Celiac Disease Foundation, accessed December 17, 2020, <https://celiac.org/gluten-free-living/federal-benefits/tax-deductions/>.

Along with financial information and advice, there are also many celiac-centered blogs sharing personal journeys and tips for managing your gluten-free needs in and around the world. One of my personal favorites in this category is "The Nomadic Fitzpatricks" blog by Jen Fitzpatrick.^{3 4} After being diagnosed with celiac in 2007 as a college student, Jen became gluten-free before there were available gluten-free substitutes in the surrounding grocery stores and significantly less public awareness surrounding the condition. Drawing from firsthand experiences and knowledge gained through the latter, Jen shares advice on how to self-advocate in difficult spaces and travel the world while still adhering to a strict gluten-free diet.^{3 5} These acts normalize common but challenging situations brought on by the reality of celiac, and also empower individuals who might be struggling to feel welcome in a space that refuses to cater to their dietary needs. Whether it be financial or social roadblocks, the online celiac community has allowed me to gain confidence in carrying myself through the world and strengthened my ability to make spaces safe and healthy for myself and others with the condition.

My experience writing this paper is quite challenging to put into words. Before taking a class on disability studies, I did not consider celiac or autoimmune disease to be a disability. However, characterizing it as such has allowed me to grow in my understanding of this condition without putting myself at the center of pity or focusing on the restrictions I face. Listening to and transcribing other personal narratives surrounding celiac was a cathartic experience to say the least. It provided me with a platform on which to look back at my own personal journey, recognizing the pain and struggle while also acknowledging the incredible growth and self-assurance I regained through each hardship.

³⁴ Jennifer Fitzpatrick, "Welcome!," The Nomadic Fitzpatricks, December 2, 2020, <https://www.thenomadicfitzpatricks.com/35>.

Jennifer Fitzpatrick, "How To Self Advocate With Celiac Disease," The Nomadic Fitzpatricks, May 1, 2020, <https://www.thenomadicfitzpatricks.com/how-to-self-advocate-with-celiac-disease/>.

This process has allowed me to recognize the ways in which celiac is more than just an allergy or diet plan, but an active, dynamic conduit of social experience and cultural events. One of my original goals, to increase awareness and knowledge of celiac disease, was at first focused on educating others and the rest of the world rather than myself. Including and analyzing my own narrative in this paper transformed that goal to be incredibly personal and introspective. It led me to focus on and share aspects of my life story for which I once lacked the words to describe and access a community of resources that I did not know existed. I hope that this paper has given you, the reader, access to experience-near insights on a condition that is easy to overlook and at times difficult to diagnose, but radically life changing in many ways. Thank you for taking part in the emancipatory action of learning about an invisible disability such as celiac disease, and listening to the restitution, quest, and chaos narratives held by those who live with the condition.

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