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Social Aspects of Food-Sensitive Adults

Abstract

People living with food-related illnesses find themselves subjugated by commonly held ideologies causing awkwardness in social situations. The current study is a qualitative analysis addressing how people with celiac disease (CD) navigate social situations in light of dominant beliefs that influence behaviors. Initially, I identify macro-level patriarchal, religious, sexist, ableist and etiquette-related commensality ideologies that disadvantage those with CD. Drawing from the communication narrative sense making (CNSM) theory that supports storytelling and memorable messages as a sense-making tool for individuals diagnosed with chronic illness and their family members, this work highlights retrospective stories and memorable messages from 20 randomly selected interviews (out of 66 conducted). Further, I discuss how individual identity evolves while redefining "truths" in light of having a disease.

Three overarching themes emerge from the analysis: 1) questioning ideologies to form revised "truths," 2) familial adaptation or non-adaptive responses, and 3) identity transformation. The first theme contemplates what is considered "true" depending on dominant ideologies on food-related expectations. The second theme examines social stigma that can result when a person in a given social group no longer conforms to these basic, assumed beliefs; or conversely, familial compassion that occurs when family and friends do conform. Finally, the third theme traces the evolution of an individual's transformation when faced with redefining his or her identity, standing with courage and fortitude to influence those around him/her to align with new "revised truths" that may yield compliance or resistance.

This study expands the current knowledge by associating how those with food sensitivities (FS) or CD find themselves subjugated by dominant ideologies that permeate behavior. The dissertation adds to the communication studies conversation by illuminating a seldom-studied population of adults living with the hidden disability of FS or CD, and expands the CNSM by contributing a concept I am calling a "homeostatic shift," or the process where rituals are disrupted, causing the person with CD to enter into a state of liminality or transition, reforming "truths" and eventually shifting to a new state of equilibrium living with the realization that all experiences thereafter are shrouded with the veil of disease.

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of the Requirements for the Degree

Doctor of Philosophy

by

Jean Elizabeth Duane

June 2019

Advisor: Dr. Christina R. Foust

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Advisor: Dr. Christina R. Foust
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CHAPTER ONE: STUDY OVERVIEW / LITERATURE REVIEW / THEORY

SUMMARY

Jean's Story –The Diagnosis

In 2003, I was on a business trip in New Hampshire when my skin blossomed into an itchy, burning rash. During the daylong meeting, I could feel it spreading under my clothes. I delivered a presentation to 20 people, while wondering what was happening to me. After the presentation, I went to the bathroom and opened my blouse. One look at my reflection in the mirror, and I fainted.

At the emergency room, I was confronted with seven different doctors, asking me if I had taken illicit or pharmaceutical drugs, or been exposed to fertilizer or dioxin. They told me I was having a systemic chemical reaction. They prescribed steroids and antihistamines. They said the rash exposed my body to bacteria and instructed me to buy a thick sweat suit to wear on the plane ride home. The rash itched unbearably for ten days and took six weeks to heal. This was the first of many full-body rashes that erupted unexpectedly over the next few years.

Back home, I searched Google, studied journal articles, and secretly feared I had leprosy. I visited specialists who did colonoscopies, endoscopies, barium enemas, and x-rays. They prescribed histamine blockers, antihistamines, Valium, Dapsone, and phenobarbital. I went to dermatologists who performed skin-prick allergy tests and biopsies; prescribed Valtrex, off-label anti-depressants, and steroid creams. None of the

doctors could diagnose the cause of the rash. Though some drugs quieted the symptoms, they caused terrible side effects, and no one monitored potential interactions.

Meanwhile, the shame around my rash caused me to become antisocial. I hid at home, mostly, but when I did venture out, I wore long sleeves, pants, and gloves to hide my skin—even in the heat of summer. My hands were the worst. They swelled with inflammation and itchy sores. One summer afternoon on the light rail, I was too hot to wear gloves. A woman sat across from me, took one look at my hands, and found another seat.

The intensity of the skin affliction was an extension of my childhood malaise. I grew with up with chronic stomachaches and bloating. I thought it was normal to feel sick after eating. Loose pants in the morning were tight against my waist by the evening. Every day at 4:00 PM, I would have gas and a bad stomachache. My life was scheduled around stomach pain and intestinal problems. Tests revealed that my intestines were anatomically correct albeit twisted, and I was told again and again there was “nothing wrong” with me. I ate a healthy and wholesome diet, following the nutritional advice of the day. Plus, restrictive diets were part of my family’s culture. My mother and sister were always counting calories or on Weight Watchers, and after my father had a heart attack, the whole family followed his restrictive heart-healthy regimen. No doctor ever asked me about my diet, and it didn’t occur to me that food might be the cause of my issues.

After suffering a series of painful and humiliating rash cycles between 2003 and 2005, my husband found a doctor who promised to find the cause. I endured more scopes down the throat and up the anus, ninety-eight needle sticks on my back, and

twenty-six bubble-tests on my forearms. Still, no diagnosis. Finally, the doctor arrived at the last three tests: Hashimoto's thyroiditis, rheumatoid arthritis, and celiac disease. My symptoms suggested I could have one or all of them. After a lifetime of stomach issues, years of painful rashes, and three months of exhaustive testing, he concluded that I was reacting to gluten. My symptoms were conducive to "a rare form of celiac disease called dermatitis herpetiformis," he said. He didn't tell me what gluten was, other than it was found in food.

The first rule of war according to Sun Tzu: "Know your enemy." Learning that a protein called gluten was wreaking havoc on my body, I determined to fight it with dietary changes. I wasn't sure what foods were safe and giving up gluten was an overwhelming proposition. Gluten wasn't part of the lexicon at the time and the so-called "gluten craze" was years away. Once again, I was left to research on my own.

I learned the scores of synonyms for gluten, so I could parse labels on foods, cosmetics, and pharmaceuticals. I discovered that virtually every food I consumed contained hydrolyzed vegetable protein, caramel color, glutamate, and many other ingredients with hidden gluten. Even with this knowledge, I'd be rash-free for a while, only to have another devastating surprise outbreak. This lasted several years after diagnosis, in spite of vigilantly controlling my diet. Seven years into my gluten-free life, I broke out in another full-body rash. I couldn't figure out what caused it. I purchased gluten test strips at \$11 per test and tested everything I could think of in my kitchen, my bathroom, and my bedroom. Forty-four tests later, one revealed that aspirin's binder was gluten. I had taken a single aspirin tablet for a headache ten days prior. The label said, "starch."

Over the years, the rashes have become fewer, as I've learned the constraints of my condition. Every bite of food I don't carefully scrutinize puts me at risk; even the tiniest infraction causes a reaction. I have zero resistance. Explaining my food idiosyncrasies to others is a challenge. My family members support me, though I've been accused of "trying to get attention," and my childhood stomach issues have never been fully acknowledged. I trust almost no one to cook for me. Too many times I have believed loved ones who said that a food is "Jean friendly," only to be sickened and suffer another rash-cycle. Social politeness isn't worth the damaging physical ramifications. Food is subsistence for me, now. I limit my diet to the few foods I know will not make me sick. With these strategies, I have learned how to live and thrive with celiac disease, but it has been a long and painful journey.



Figure 1.1. Gluten Sensitive

Introduction

Roughly 95 million Americans react negatively to gluten (Fine, 2003). Yet, “going gluten free” is considered a fad, ridiculed in contemporary culture, denigrated by culinary luminaries, and refuted by the Pope. My story is one of many that illustrate the

challenges of the illness, the struggle for diagnosis, and the daily battle to suppress ideological pressures to discount it. Celiac disease (CD) is an autoimmune reaction to gluten, a protein found in wheat, barley, rye, oats, and spelt. Grain derivatives containing gluten such as malt, Brewer's yeast, soy sauce, baking powder, dextrin, flavorings, stabilizers, and emulsifiers may not seem threatening, but they can cause weeks of illness for those with CD, and they are ubiquitous in processed foods, pharmaceuticals, cosmetics, and other products.

CD affects one in every 100 people in the United States (celiac.org). Despite these high incidence rates, American physicians often perceive it as a rarity (Fasano et al., 2003). While three million Americans have CD (Fasano, Sapone, Zevallos, & Schuppan, 2015), another three million have non-celiac gluten sensitivity (NCGS), also an autoimmune response to gluten (Uhde, et al., 2016). And one-third of Americans likely have gluten sensitivities, defined as illness from eating gluten that is not detected in current serological tests (Fasano, et al., 2015; Fine, 2003). Symptoms of CD and NCGS affect the intestine, including “gas, bloating, diarrhea, nausea, vomiting, fat in the stool, nutrient malabsorption, and constipation” (Fine, 2003, p. 1), and may manifest as autoimmune issues affecting the entire body, including “dermatitis herpetiformis, diabetes, chronic liver disease, multiple sclerosis, lupus, and osteoporosis” (Fine, 2003, p. 8). Some people with CD are asymptomatic. Despite these severe physical outcomes, the average period between initial symptoms and CD diagnosis is eleven years (Green & Jabri, 2003). CD has a roughly “2:1 to 3:1 predominance in women” (Goddard & Gillett, 2006, p.705) and is more prominent in people over the age of 55 (Vilppula, et al., 2009).

Many doctors continue to operate under the myth that CD presents mostly in white children and rule it out before testing adult patients (Fasano & Catassi, 2012). The lack of testing and awareness causes approximately two million Americans with CD to remain undiagnosed (Fasano, et al., 2003), and leads many others with NCGS and food sensitivities (FS) not to correlate their symptoms with consumption of gluten-containing foods (Wangen, 2009). Most adults are diagnosed at age fifty or older (Goddard & Gillett, 2006), and non-diagnosis of CD can result in lymphoma (Green & Jabri, 2003). NCGS affects at least the same amount of people as CD but there are no medical markers to confirm diagnosis at present; however, other autoimmune indicators are positive with the consumption of gluten in tests conducted by Uhde et al. (2016), suggesting that CD is not the only disease correlated with gluten. Though pharmaceuticals exist to address symptoms of intestinal discomfort and other physical manifestations, there is no medical cure for CD or NCGS. Only two treatment options exist presently: the drug Dapsone, which has hematological side-effects; or a strict gluten-free diet *for life* (Fasano & Catassi, 2012), which carries no risk on the “enteropathy” (Reunalda, 2001, p. 732).

The presence of gluten in myriad food products makes maintaining a gluten-free (GF) diet challenging. The Food and Drug Administration (FDA) determined 20 parts per million as the acceptable level of ingestion for those with CD (FDA, 2018). This means that the United States allows gluten to be present in packaged foods labeled as “gluten-free.” Many who live with CD feel this measure is not strict enough, and argue that *zero* parts per million should be the rule. Thus, a person with CD or NCGS must drastically alter his or her diet and understand how to read food labels in order to thrive.

Radical changes to one person's diet impact other household members in significant ways, as food is integral to daily life, celebrations, and cultural practices.

In Western cultures, eating represents a fundamental connection between a person and his or her environment (de Certeau, Giard, & Mayol, 1998). From garden to table, "food is forever bound to representation or culture" (Foust, 2011, p. 354). A brief review of Western celebrations and holidays confirms the centrality of gluten. In most American weddings, the bride and groom feed each other a piece of wedding cake to symbolize their unity. The cake is then distributed to guests who join the celebration (The Spruce, 2018). LeBesco and Naccarto (2008) note that when that cake is chocolate, it may even elicit "sexual desire and culturally ingrained fantasies of attainment through consumption" (p. 4), associating chocolate cake with intimacy.

Similarly, bread's symbolism far exceeds its function as a food source. Bread is often treated as a sacred food (de Certeau, et al., 1998), and purging it from one's diet can present a host of religious, spiritual, and cultural complications. For instance, weddings in Poland traditionally include a loaf of salted bread and wine for the couple to eat and drink, symbolizing a life of abundance (Wedding, 2018). At wedding receptions in Russia, the bride and groom take a bite of bread held by a third party. Whoever takes the biggest bite is deemed the head of the household (Wedding, 2018). In France, the bride and groom dance under a brioche and then eat it (French Today, 2018). In American Appalachia, guests bring stack-cakes (pancakes) and pile them on a plate, adding apple butter between each layer. The couple's popularity is determined by the height of the stack (History, 2018).

Individuals with food allergies or special diets disrupt family traditions, often triggering ridicule by other family members (Bentley, 2005; Masia, Mullen, & Scotti, 1998). For someone with a CD or NCGS diagnosis, this is particularly complicated, because sharing food reinforces ideologies that signify belonging in family, community, and religious contexts (Montanari, 2006). Indeed, individuals with CD or NCGS risk alienation if they do not participate in food festivities (Curtin & Heldke, 1992), or terrible health effects like autoimmune disorders (Green & Jabri, 2003), anaphylactic shock, and even death (Cummings, et al., 2010) if they do. Ideological truths such as *all in moderation* pervade family interactions and impact the reformation of the ill person's identity.

The present study centers on how individuals with food sensitivities navigate the disruption caused by CD diagnoses, as they attempt to live their “new normal.” Amplifying the voices of participants, I focus on how people diagnosed with disease assimilate new situations through the telling and retelling of stories, and retention of memorable messages. Ideologies, or common-sense taken-for-granted expressions influence what is considered “truth.” Surrounded by family members repeating common sense “truths” such as, *if it is made with loving hands, it will nourish your body*, a person diagnosed with CD finds herself on the marginalized end of an ideology and has to arrive at “new truths or redefined ideologies” with family and friends. This creates challenging scenarios, such as how to avoid poisonous food made by *loving hands*, while not offending the person who made it. Or, measuring the etiquette constraints of *clean your plate* against the scrutiny or judgment that often attends a CD or NCGS disclosure.

So, how do CD and NCGS individuals confront their new identities, while navigating powerful ideologies reinforced by family, culture, and society? More specifically, the following questions guide the project:

RQ: How do dominant food ideologies inform narratives about family interactions?

RQ: How do gluten-avoidant adults narrate the impact of food sensitivities on commensality experiences and social interactions with other adults?

This dissertation offers a qualitative study, derived from interviews with 20 participants. It follows a thematic arc marked by three concepts: *revised truth*, by which the person with CD redefines ideologies that aren't necessarily shared by family members and close friends; *familial adaptation or non-adaptive response*, which includes social stigmatization when a person no longer conforms to the beliefs of a family or social group, or, conversely, familial compassion when family and friends do conform; and *identity transformation*, which occurs when a person's identity evolves to take ownership of the disease. Further, I have added an element I call the *homeostatic shift*, or the process wherein a person realizes that every future event will be impacted by the new knowledge of the disease (or event) that altered the earlier perception of homeostasis. As we have seen, gluten-avoidant adults encounter many challenges in assuming a GF lifestyle. They have to come to terms with a new identity and redefine ingrained ideologies for themselves, all while facing the challenges of living with a diet-restricting disease and navigating interactions with family and friends who are influenced by those same ingrained ideologies. To analyze these transitions, I employed conceptual tools to associate dominant belief systems perpetuated by ableism, sexism,

religiosity, patriarchal, and etiquette ideologies that challenge “truths” at the macro level. Components of the CNSM theory are applied to the mezzo and micro level analyses, where sense-making narratives through collaborative storytelling and memorable messages provide a lens for familial responses (mezzo); and stories of redemption guiding the individual transformation (micro), after participants experienced the homeostatic shift. The rest of this chapter reviews the literature, the CNSM theory, and summarizes with a description of the remainder of the dissertation.

Literature Overview

In this review, I begin with literature relating to elements of macro-level rhetorical and cultural ideologies. I start by defining ideology and illustrate how it influences behavior. The review centers on ideologies formed from religion, media, and corporate influencers because these entities affect beliefs that translate into “truths” on sexism, etiquette, religious practices, patriarchy, and ableism, all crucial parts of my data analysis. Next, I discuss food sensitivities, and then delve into mezzo-level studies on family communication when an individual is faced with an illness or other life disruption. I consider analogous studies on micro-level identity transformations with chronic illness. I research gendered issues around diet culture, medical biases, and disordered eating to illustrate that women are often misdiagnosed and unheard when they present to the medical community with food-related illnesses. I examine qualitative studies focusing on narratives of people with disabilities that may be concealed to illustrate how individuals navigate social situations. I assess studies that use narrative theory, specifically those that pertain to diet-related illness. Finally, I review how narrative and the CNSM are a logical compliment for a study of this nature. Given the

significance of ideology to this study, I build a foundation on rhetorical approaches to those macro-level messages shaping narrative sense-making interactions.

There is a small portion of the literature that relates to food sensitivities and almost all of it is conducted from the perspective of health effects rather than communication. Relatively few studies address adults living with other adults or the social aspects of people diagnosed with CD. The corpus of literature points to the importance of narrative as a powerful sense-making device. It also leads us to consider ideology as a central component driving beliefs and behaviors. Though the literature touches on aspects of behavior, none associated it with overarching ideologies. Therefore, in order to answer my research questions, using thematic analysis supported by qualitative research, I discuss what we learn from combining ideology and sense-making through narrative and storytelling. I differentiate from other research by exploring what ideologies are, and how they relate to gender, commensality practices, and social interactions as conveyed by participants in the study. This leads to my embrace of the CNSM theory. Using CNSM, there are studies that only hint at the power of ideology; however, I believe they deserve more focus. One predominant theme emerging from the interviews in this dissertation is the role of ideology in diminishing the gravity of food sensitivities in myriad social settings.

Rhetorical and Cultural Ideologies

Scholars working with narrative across sub-fields of communication have hinted at the relationship between ideology and relational interactions. Connection between these two have not been explored deeply, and as we will see in this dissertation, dogma related to gluten or gluten-containing foods are deeply coded in ideology. When

considering mother-daughter ideologies, Koenig Kellas (2010) said, “ideologies may be socialized through communication in the family” (p. 464). Koenig Kellas (2010) associated memorable messages to predict how daughters viewed their adult intimate relationships and how ideologies learned in childhood affected adulthood relationships. Daughters reported they would likely pass messages heard from their mothers to their children, illustrating how memorable messages reinforce ideologies inter-generationally. Further, these messages perpetuated ideologies that the daughters then expected of their romantic partners. Medved, Brogan, McClanahan, Morris, and Shepherd (2009) found family and work ideologies such as *your work defines you, family is unconditional and means more than anything else* (p. 162) learned in childhood transferred to behaviors in adulthood. Similarly, food-related ideologies abound. They include *if it is made with loving hands, it is nourishing for your body, clean your plate, you are what you eat, and GF is a fad*. These ideologies put individuals on the defense when communicating the severity of their food allergies or autoimmune reactions. Popular ideologies “have the corresponding attitudes, inscribed in ritual practices” (Althusser, 1971, p. 167). This means they are a system of ideas and principles that are taken as natural and normal, implemented without thought. More simply, ideology is a *taken-for-granted reality* often learned in childhood and enacted throughout life such as those surrounding religious beliefs.

Bread is a sacred food (de Certeau, et al., 1998), and those who cannot consume it to sanctify the scriptures in the Bible feel less pious at best, and excluded from the communal practices of the church at worst. For example, in the Catholic Church, the Pope recently issued an edict that all hosts must contain gluten (Vatican, 2017). If the

Pope implies through his gluten-containing host that *a little won't hurt you*, then it must be true for Sunday dinner, too. This patriarchal ideology presents a dilemma for someone with CD who must decide whether to risk illness from gluten consumption or renounce sacred rituals by non-participation. Additionally, usurping the word of the Pope may cause pious family members to question the individual with CD's resolve to eliminate gluten from his or her diet. Fallacious statements about food sensitivities also extend to the media and serve as influencers for responding to FS individuals.

Popular culture and media further purvey ableist ideologies concerning food and behavior, with particular effects for FS and GF individuals with its trivialization of allergens in food. For instance, in the 2013 family film *Smurfs 2*, the "Corndog King" is warned by the parents of a child with peanut allergies to ensure that the corndog he's handed the child is peanut free. Just as the child bites into the corndog, the King remembers it was fried in peanut oil. This is meant to be a humorous moment in the film, but parents raising children with peanut allergies attest that it is quite far from funny (Duane, 2018). Those with allergies or gluten intolerance are regularly targeted for ridicule. CD is frequently treated with skepticism, with the server perhaps believing the customer is participating in the "gluten fad," or with ridicule influenced by celebrity chefs and others. For example, celebrity chef Anthony Bordain said he had "a gluten-free intolerance. [He] can eat bread just fine, it's the people who insist on proselytizing about their medically dubious grain-free lifestyles that piss [him] off" (Filloon, 2018). This type of rhetoric from celebrities like Bordain may influence how seriously a server takes individuals who disclose they have CD. Ableist ideologies are centered on the notion that only weaklings have food sensitivities.

In a 2018 episode of the Netflix series *Frankie and Grace*, a group mocked Allison—a character with multiple allergies—by taking shots of whiskey every time Allison mentioned another item she’s allergic to. This scene reinforces ableist discourses that render those with disabilities as weak and worthy of ridicule. It makes light of the real threats of living with allergies, and causes one to wonder how scenes like these might influence interactions with FS friends and family (Duane, 2018). Though it was edited from final cut (due to parental complaints), a Disney episode of *Quitting Cold Koala* is probably the most disturbing example of shunning the person with FS. In the scene, children threw gluten-containing pancakes at Stuart, after his nanny informs them he cannot eat them. Huesmann and Taylor (2006) point out that behavior viewed on TV can present a “threat to public health inasmuch as it leads to an increase in real-world violence and aggression” (p. 393). Even if it does not incite violence toward FS individuals, it diminishes their credibility and undermines their need for dietary adherence, and pressures them to conform and be “normal.” DeVault (1991) argues that “an enormous body of science, literature, and even humor tells us how a middle-class man and woman might ‘do’ family life” (p. 16). Food ideologies diminish the ability of FS, CD, and NCGS individuals to live free of pain and also constrain family communication—particularly if we consider the gendered dimensions of food ideologies and practices, which deeply undergird themes from this project.

One company has defined American food practices, sexism and gender-based ideologies for the past 50 years, particularly among women. With over 25 million members, Weight Watchers International (WW) has had a pervasive influence on women attaining the “perfect” body (Lockford, 1996), which is a coveted symbol of

physical capital (Bentley, 2005) and sign of success and competence. Lockford (1996) argued that a woman “endeavoring to lose weight deliberately opens up her body to the scrutiny of self and others, effectively making herself a spectacle” (p. 293), evoking ideologies of feminine physical perfection imposed by patriarchal influencers (Dworkin, 1989). The WW program helps members attain their goals through behavior transformation techniques and weekly attendance at face-to-face or online support group meetings. The support-group-style meetings reinforce that “weight consciousness is principally a women’s condition” (Bayrd, 1978 as cited in Lockford, 1996, p. 291). Surprisingly, when compared to other popular weight loss programs, WW yields the *least* weight loss per year (Statista, 2017a) with only 2.6% more weight lost in a year when compared to a control group (Gudzune, et al., 2015). Nevertheless, WW has set the standard for weight-loss practices, dietary scrutiny, and ideological rules performed by women in America since 1963.

Cultural ideologies translate into behaviors and narratives expressed on the familial level. The next section examines the social implications of FS including how those with it delineate disclosure parameters, and explores issues such as identity transformation, hidden disabilities, gender biases, and the diet culture.

Social Implications of Food Sensitivities

I examine pertinent literature on food sensitivities as they relate to social interactions and quality of life (QOL). Since relatively few qualitative studies exist on how FS individuals navigate family communication, I turn to extant literature on disclosure, compliance and everyday living to further understand applications of identity transformation, revised truths in light of having a disease, and familial responses. I

contrast diabetes, a more socially acceptable disease requiring dietary constraints, with CD and show how gender and power factor into family dynamics, with the female typically taking the role as food monitor and caregiver. Other literature explores meal practices of partnered adults when one adult has food allergies, and disordered eating practices experienced by those on extreme diets.

Both disclosure and deception carry the risk of social stigmatization and alienation from family and friends. Further, as the diagnosed person learns more about her food triggers and adapts socially with the disease, her identity evolves and she learns to live under the veil of CD or NCGS. These evolving identity elements can be a source of exasperation to cohabitants and family members, reinforced by modern ideologies (such as those captured in Figure 1.1, above) that denigrate individuals with food sensitivities. Figure 1.1 suggests that the woman's response to gluten is emotional, not physical. It illustrates the sexist ideology that women are overly emotional, as well as the authoritative belief that "gluten" is an acceptable subject for mockery.

Food sensitivities cause unintentional social blunders that cause the body to respond in anti-social ways. Brady (2015) describes how she cannot consume any food on a restaurant menu, undergo an I/V in the hospital, or eat foods from packaging using glue because of her allergy to corn. Her allergy impacts all aspects of life, causing her to avoid social situations involving food, partially because it is too hard to navigate or to explain. Similarly, Hayden's (1991) found a dearth of language to communicate illness, remarking that the ill are considered "socially deviant" (p. 264) and isolated. This could be due to the humiliating physical disruptions some diseases impose. For example, Defenbaugh (2013), Cavet (2000), and Alley (2015) focused on the social

embarrassment aspects of having a body compromising disease, and the need to plan ahead in order to gracefully conceal a disability (e.g., knowing the location of a public bathroom or taking elaborate steps to conceal “accidents”).

Those adhering to a restrictive diet are perceived as “fussy, faddy, or finicky” (Nettleton, Woods, Burrows, & Kerr, 2010), and “fad” GF dieters erode the importance of adherence for those with CD. One coping strategy includes reviewing meal fare with cohabitants, such as when a person with CD explains that gluten-avoidance is not due to following a “fad,” endeavoring toward understanding and cooperation from those involved (Kaplan, Kiernan, & James, 2006). Similarly, Metchikoff (2014) found that age played a role in how the diet was understood and implemented and that the nuances of allergies are seldom comprehended by people who do not live with them. Both the Moore (2013) and the Metchikoff (2014) studies on those without CD illustrated how haphazard adherence to a GF diet by fad dieters eroded the importance of it for those with CD. Restrictive diets can be frustrating for all parties involved and can impact all aspects of life and family culture. Partners’ interactive styles determine levels of what Brown (2011) termed “engagement or disengagement” (p. 119), when a partner does not attempt to understand or incorporate the dietary restrictions of the other when diagnosed with diabetes. Disengagement styles ultimately result in relationship dissatisfaction. By contrast, couples that engage in a “cohesive” style of interaction have better outcomes, where both partners participate and understand the dietary requirements (Brown, 2011, p. 113). Hallert et al., (2002) found that women reported less satisfaction with social aspects of their lives after long-term adherence to the GF diet. They felt isolated from food-related events and relegated to preparing meals at home for themselves. People

with cooking skills can usually adapt to a GF diet in the home, assuming other household members cooperate. In uncooperative households, some CD sufferers succumb and eat the allergenic food, even if it means becoming ill as a consequence. Nettleton, Woods, Burrows, and Kerr (2010, p. 303) describe the identity of the food intolerant as “an uneasy one” because of both the trial and error associated with determining which foods cause problems and the social consequences of being different.

In spite of social norms, most people with CD eventually disclose (Samuels, 2003) to ensure they receive GF meals prepared by someone else. Those diagnosed with a body-compromising disease must calibrate their trust parameters to understand how to perform day-to-day activities while interacting with others. Corbin (2003) observed that people who have disabilities regulated their lives on a schedule of pre-determined regimens, planning ahead in order to stay well. This takes a lot of time and can cause conflict with non-disabled people in a social setting. People with hidden disabilities report that they “develop personal disclosure policies, with a variety of specific predetermined versions of their story” (Valeras, 2007, p. 76) depending on the audience. Similarly, the person with CD must decide to whom to “come out” (Samuels, 2003, p. 237) and how much to disclose. Disclosure can trigger responses from kindness and compassion, to ridicule and mockery (Samuels, 2003). Chronic disease ebbs and flows, often surprising sufferers with unexpected symptoms that perplex others and alter daily life (Charmaz, 2006). Kinser (2016) described this dilemma as something that may “both overcomplicate and oversimplify health and well-being outcomes” (p. 32).

Concerns are further exacerbated when the FS adult ventures out to a family dinner, restaurant, or a friend’s house and must disclose their dietary restrictions in order

to eat a safe meal. Lee and Newman (2003) found most deliberate infractions occurred when dining outside of the home because of “the restrictive nature of the [GF] diet” (p. 1533). Disclosure may cause unwanted attention, scrutiny, and skepticism from others in a social context. It requires a high level of self-esteem and courage to disclose (Peniamina, Bremer, Conner, & Miroso, 2014). Navigating social situations is problematic because “some people offer acceptance readily [while] others greet every statement of limitation with skepticism” (Wendell, 1996, as cited in Samuels, 2003, p. 239), particularly when dining out. Patriarchal and ableist ideologies prevail in the restaurant setting, where CD sufferers asking for a safe meal are subject to restaurant policies and server judgment. In contrast, people with diabetes are often treated with more compassion and understanding. Studies that illuminate camaraderie in families sharing diabetes punctuate this point.



Figure 1.2. Inquisitive Server

Similar to CD, diabetes is a genetic disability that requires constant dietary vigilance and daily management. An Internet search on “diabetes fad” versus “gluten fad” reveals that diabetes is not considered a fad and is taken significantly more

seriously than CD, as demonstrated in the comics¹ interspersed throughout this document. Perhaps diabetes is not considered a fad because doctors regularly test for it as part of a regular medical check-up, and because approximately 22 million Americans have it (Statistica 2016b), compared to only one million people diagnosed with CD (Fasano, et al., 2003). Manoogian, Harter, and Denham (2013) examined the intergenerational narratives of family members living in Appalachia, where some family members had diabetes and others did not, and where some family members controlled glucose levels with dietary changes, while others relied on insulin injections. This study showed the power of narrative analysis by employing direct quotes from family members who shared how they coped, cooperated, and adapted to the disease; and others who denied it, refused to be medically tested, and continued to consume alcohol and high carbohydrate foods, ultimately going blind, losing limbs, or dying (Manoogian, et al. 2013). For example, one participant referred to his father saying, “I don’t think he watched his diet that well, he ended up with the kidney dialysis ... lost his eyesight... [and] lost limbs” (p. 46). The study showed how intergenerational family members function when confronted with bad news, and how families “co-construct meaning from illness” using narrative (p. 42).

Food and eating practices affect all aspects of culture, especially in a family setting, making compliance challenging. For example, mothers of infants with cow’s milk allergies have higher stress, and sometimes do not comply because it is too burdensome (Merras-Salmino, 2014). Further, the mother is often the parent who would need to intervene if a child inadvertently consumed an allergen (Crowley et al., 2012).

¹ Note: A request for permission to use the comics was sent to each author/artist. A sample permission letter is included in Appendix C.

Mother's often felt responsible for monitoring a child's dietary adherence (Bacigalupe & Plocha, 2015) and shoulder most of the burden of protecting the allergic child. Similarly, Arrington (2005) found that wives were stalwart forces behind their husband's survival, providing emotional and physical support to manage his disease. Later in life, these parental duties and gendered stereotypes transfer to partners when allergic young adults begin dating.

Meals are a negotiated topic for newly formed couples and are further complicated by food allergies (Bove et al., 2003). Support entails candid conversations about the disease and its impositions on diet (Coulson & Knibb, 2007). Beasley (2011), a journalist with food allergies, described this situation by asking her partner, "Do you love me? Then rinse out that glass" (p. 36). She went on to describe her dating life with allergies—having to ask her date to wash his hands, beard, and the dinner plates before putting them into the dishwasher, to prevent an allergic reaction. This extreme lifestyle creates turbulence in relationships and compounds the uncertainty of getting to know a prospective partner (Knobloch, 2015). Having allergies and living with a partner can be a true test of relationship commitment, particularly when the allergy is to a common food like gluten. These complications extend to couples in close personal relationships.

Family cooperation and cohesion are paramount when making sense of a new development such as a health crisis of one family member. Cohesive couples that tell stories with high energy and communicative cooperation are highly functional (Koenig Kellas, Trees, Schrodt, Le-Clair-Underberg, & Willer, 2010). Everyday living can be challenging for adults who have a disease and an intimate relationship: "a major part of the social context revolves around spouses and partners" (Charmaz, 1995. p. 669).

Charmaz (1995) found that “problems generally arose later as the long-term effects of illness emerge” (p. 669). The disabilities of one partner may erode a relationship if the other partner is affected in his or her daily life. This emphasizes why people with disabilities often choose to hide them in order to assimilate and fit in, even when at home. However, QOL for the women in a relationship where one partner had CD is generally lower when compared to male participants (Smith, 2009). Reasons for this included feelings of social isolation and “not wanting to be a bother” (p. 32). The constant needs of the disabled person can cause an imbalance in the relationship. For example, when one partner has a disability, the risk of interpersonal conflict increases (Braiker & Kelley, 1979) because of the imbalance of reciprocation. In close dyadic relationships, “interdependence, especially if it is extensive...does make the occurrence of conflict likely” (p. 137). When expectations of one partner’s contributions are not being met, provisions must be made indefinitely. The dietary restrictions of one partner require sacrifices by the other; however, when both participated in eating a GF diet, they reported contentment (Alley, 2015). Couples who implement reciprocation strategies while adjusting to the disability contribute to relationship success.

One of the few qualitative studies on CD conducted by Peniamina, et al. (2014) analyzed four focus groups of adults with food allergies in New Zealand, with the goal of understanding how food sensitivities affected participants’ QOL. The study identified three themes surrounding social issues resulting from food allergies: difficulties in finding adequate food, locating knowledgeable health care providers, and dealing with other’s attitudes and awareness. Participants conveyed that suitable foods were not always accessible, substitutes did not taste as good as traditional foods, and they were

forced to take risks when eating in public or social situations. The study revealed issues surrounding the requirement of those with CD to trust others to make safe meals for them, and that well-meaning people simply did not understand the severity of their reaction to gluten. It concluded by advising those with CD to take assertiveness training in order to convey their needs effectively and ensure their safety. This landmark research shed light on social complications of adults living with CD, both in the family and in public. However, the study did not describe aspects of CD as a disability or discuss dominant ideologies that influence behavior, nor did it situate a theoretical lens. Prior to Peniamina et al. (2014), most research on food-allergic people studied children and often used the Flokstra-de Blok and Dubois (2012) QOL instrument asking closed-ended quantitative questions. Extensive research exists on children with food allergies and how they affect family life (Ben-Shoshan et al., 2013; Bollinger et al., 2005; Bove, 2003; Crowley, Williams & Brown, 2012; Cummings et al., 2010; Dioun, Harris & Hibberd, 2003; Herbert et al., 2012; Komulainen, 2010; Merras-Salmino, et al. 2014; Miles, Valovirta, & Frewer, 2006; Roy & Roberts, 2011; Valentine & Knibb, 2011; Williams & Hankey, 2015; Zijlstra, et al., 2013). Children and adolescents were often studied because of the notion that children “grow out” of their food allergies. This is not always true (Herbert, Dahlquist, & Bollinger, 2012).

Identity transformation is examined in the next section, as the person with the disease engages in self-reflexivity as new knowledge is obtained, and as he or she learns to navigate situations and transform his or her identity under the veil of disease.

Identity Transformation with Disease

When diagnosed with an illness like CD, individuals enter a transformative period in order to digest new and complex information about their physical dysfunction. They are confronted with a new “normal” (Samuels, 2003), which is complicated by the visibility of the health condition. Diseases such as diabetes, asthma, rheumatoid arthritis, epilepsy, and CD are considered “hidden disabilities” (Valeras, 2007), meaning they may be hidden or optionally disclosed. Individuals make careful decisions about how to disclose and explain this new “diseased identity,” as disclosure may disrupt existing family norms and ideologies (Somers, 1994). Assimilation is a mental process that evolves as the person with a hidden disability becomes accustomed to the diagnosis, accepts it, and discloses it. Consequently, individuals transform themselves under the new identity (Somers, 1994) seeking reassurance and resisting contradictory ideologies, such as *a little won't hurt you* or *all in moderation*. For a person with CD or NCGS, a little gluten can cause weeks of physical agony.

The newly diagnosed person goes through a process that results in a unification of disease and self by incorporating trust parameters and situational practices. As the mantle of disease permeates all aspects of identity, the person transforms herself and experiments with the result. The transformation state is the process one goes through to assimilate everything in light of newly acquired information. For example, when diagnosed with a disease, everything from the present to the future must be considered with regard to the situation and the disease. Starting with the inkling that something is wrong, to enduring the diagnostic process, and finally living with the disease, the person has to consider all future life experiences in this new light. Once diagnosed with a

chronic illness, a person must adjust to his or her impairment (Charmaz, 1995) and “surrender to the sick self” (p. 661). This includes developing strategies for fitting in, living with the unknown, and maintaining a sense of normalcy in the midst of dealing with a compromised body. Not presenting with a fit body can lead to ridicule and scrutiny by others, causing people to “both internalize society’s attitudes and fear social sanctions” (Cavet, 1998, p. 62) if their disabilities were known. Secrecy about disabilities affects people of all ages. College students hide disabilities, as discovered in a study conducted by Livneh, Martz, and Wilson (2001). They discovered that “denial of disability was associated with better psychosocial adaptation” (p. 230). Social norms mandate that disabilities be hidden whenever possible (Samuels, 2003).

Surmounting the disability and attaining a level of social acceptance is a common goal of individuals with an illness. After succumbing to a disability, disabled individuals “begin to unify [with] the altered body and self” (Corbin, 2003, p. 266), while learning “where they stand physically, waiting to see if their bodies can be trusted again” (p. 266). Reestablishing a level of physical trust entails different expectations of bodily performance. When describing the acceptance process, Charmaz (1995) noted, “part of redefining personal identity depends upon seeing one’s self as more than one’s body and the illness within” (p. 671). This change in perspective occurs with heart disease, another hidden disability. In an analysis of interviews given by people who had “cardiac events before the age of 65,” Corbin (2003, p. 325) pointed out that people often detach from their body by thinking of it as an object, as well as a “vehicle for thinking, feeling, and acting” (p. 325). This disassociation is part of the acceptance process and of “learning to trust the body again after an acute episode of illness”

(Corbin, 2003, p. 265). Charmaz (1995) described a woman who “pushed her body to be slim, strong, and taut” (p. 664) prior to a cardiac event. Afterward, she lost her fitness level and viewed her body as a “failed machine” (p. 662), and ultimately changed her definition of physical perfection, leading to developing new standards and acceptance.

The evolution to accept the new body requires an identity transformation. When a person with an illness stops fighting, hiding, and denying her disease, and takes assertive and protective steps by disclosing as necessary, she has attained identity transformation. In essence, she “owns” the disease, considers it part of her lived reality and incorporates its demands into all aspects of life. When someone with a disease attains the state of identity transformation, she accepts it and expects those around her to respect her resolve. She has altered her belief system to accommodate her new situation. Her identity is reformed as a result of changes in mental and physical awareness.

The preceding sections assessed literature as it relates to social interactions for those with food sensitivities including disclosure, compliance, and aspects of everyday living. Following, I consider gender biases and diet culture.

Women and Diet Culture

A “diet culture” has evolved in the U.S. over the past fifty years, perpetuating gender biases that pressure women to pursue health, physical, and dietary standards (Lockford, 1996). Gender inequities and cultural norms complicate social behaviors specifically by affecting women and how their bodies are viewed by society. The exemplary body in Western culture is able, fit, and healthy (Spitzack, 1993). The definition of disability accepted in the field of social work is “a structural relationship between people with an impairment and a discriminating society” (Shakespeare &

Watson 1998, as cited in Cavet, 2000, p.13). This implies that the “disabled” are dependent on, and sometimes at odds with, able-bodied populations. Thus, ableist ideologies mandate that those with disabilities appear “normal” and integrate discretely (Samuels, 2003). This obsession with attaining physical perfection is a form of oppression, as women strive to maintain their goal weight (Bedecarre, 2005) and an optimal physique in order to be accepted.

When we think of a disability, we often contemplate the ability to see, or to move, and not the inability to consume common foods. Feelings of grief and loss are associated with diminished physical abilities (Valeras, 2007), particularly when one must give up favorite foods on a restrictive diet. For example, women reported feeling guilty 11 percent of the time after eating certain “forbidden” foods in the course of one week (Steenhuis, 2009). Szalia (2016) explained this in her auto-ethnography as she weighed the benefit of eating a burger and fries rather than a salad when eating out with her boyfriend. She described her guilt, comparing the “forbidden” food to a parasite in her stomach as she sleeps. Her guilt likely stemmed from defying the prevailing ideology that women’s bodies should be thin, and that women should eat little. Britton, Martz, Bazzini, Curtin, and LeaSchomb (2006) found that women self-deprecate their bodies in public in order to be accepted by their peers, and that public claims of satisfaction with their bodies led women to be ostracized from social circles. Women regularly engaged in disparagement of their body, viewing the act of enjoying food as “disgusting and transgressive” (Bordo, 1998, as cited in Magee, 2007, p. 18). Women are defined by their physical attributes to the point that their “humanity has been dismissed”

(Bedecarre, 2005, p. 215). Being overweight instilled self-loathing and emotional strife in many women who felt substandard because of their body size (Lockford, 1996).

Whether for weight loss or health reasons, dieting is a gendered cultural practice that affects medical attitudes and diminishes the lived experience of the FS. Between the ages of 16 and 45, women report trying an average of 61 diets (Smith, 2012). The weight loss industry has flourished in popular culture due to the rising weight of many Americans. Controlling one's body by limiting caloric intake has become common practice. Physical archetypes of the female body perpetuated in the media since the 1950s (Montanari, 2006) have led to dieting as a "permanent rather than temporary condition" (Andretta, 2015, p. 470) for the past half century. A weight-conscious culture and the fanatical behavior it influences combined with regular peer-surveillance (Spitzack, 1993) make dieting a gendered issue and source of social conflict, especially when coupled with a food allergy. Furthermore, others scrutinized those who have allergies for consistencies and behavior (Samuels, 2003) providing evidence that the woman with FS of CD is closely surveilled. Bedecarre (2005) pointed out the Foucaudian notion that we are a "watched society" (p. 218) and that the "body is understood as the ultimate site of self-control" (p. 218). Women regularly scrutinized each other's weight and food-related behaviors (Bedecarre, 2005) in ritualistic surveillance practices focusing on defects (Spitzack, 1993) that bound them to hegemonic doctrines defined by advertisers and the media (Lockford, 1996, p. 292).

According to Stone (1995), women are more prone to concealing their disabilities and are "morally responsible for their own imperfections" (p. 414), blaming eating habits and lack of exercise for their maladies (Spitzak, 1993). Individuals who

fear there is something wrong with their health regularly “misidentify the factors that were responsible for the maladies” (Davis, 2005, p. 171) and are often misdiagnosed by the medical community. Since there is already a propensity for food-related disorders in this demographic, the woman may not be taken seriously when she presents with a gastric-related illness and the doctor may erroneously conclude that her symptoms are caused by a life-long-cycle of dieting practices. This is true for many women with CD, who have been told there is nothing wrong with them or misdiagnosed by physicians, and left to suffer for an average of eleven years before learning that gluten is the cause (Green & Jabri, 2003). CD is overlooked for a variety of reasons, including the inability to correlate systemic symptoms with CD, inadequate medical tests (Fine, 2003), and myths indicating that it is a “mal-absorption syndrome of childhood” (Green & Cellier, 2007, p. 1731). Misdiagnosis, coupled with accelerating symptoms causes those with CD to experiment with one diet or another in order to feel better, sometimes leading to peculiar eating practices.

First coined by Bratman (2017) in 1997 as a jest toward patients following a clean, healthy diet, orthorexia is now defined as an extreme emphasis and heightened anxiety around eating healthy foods. Patients with orthorexia strive to find “acceptable” foods, often from a narrow list of ten or so selections (Timberline Knolls, 2017). Those with food allergies are prime candidates for the development of orthorexia, as they strive to find foods that do not make them sick. This aligns with the sentiment that women have “no control of their bodies and its functions” (Bruch, 1997, p. 13), which is what FS people experience when they are inadvertently contaminated and suffer the inevitable physical reactions. Their quest for clean food reinforces the ideology *you are what you*

eat but also morphs into *you manifest what you eat* (Cooks, 2009). Extreme practices associated with orthorexia create an identity through food (Guptil, Copelton, & Lual, 2013), causing relational strife for newly diagnosed individuals, as their families adjust to new eating behaviors, which may include a only few “safe” foods.

Previous sections overviewed literature on food sensitivities, family communication studies on effects of disease in the family environment, identity transformation with disease, and gender issues. The following illustrates how humans make sense of a situation through narrative and storytelling. It identifies the CNSM as the critical theory for this analysis. I conclude with a discussion of how integrating ideological drivers into the thematic interpretation offers additional insight into behaviors and attitudes about gluten. The present research questions can be explored through CNSM and by identifying ideological influencers.

Sense-Making and Truth Through Narrative/Storytelling

Sense-making through storytelling is a method families use to develop a shared “truth.” People learn through interactions with others, forming a collaborative consensus through experiences. Narrative is not just any form of conversation. Rather, it is defined as the Western process of telling a story, which includes the structure of rising action, climax, and falling action to “give meaning to an event” (Koenig Kellas, 2008, p. 244). This is the definition I use throughout this text to differentiate narrative/storytelling from everyday conversation. When faced with a life-altering illness, family members shift the evolution of the sense-making story “out of the hands of the individual [to] become a collective effort” of collaboration between the individual with the disease and other family members (Koenig Kellas & Trees, 2006, p. 50). In essence, storytelling is a way

to “do” relationships and to make sense of disruptions such as disease (Koenig Kellas, 2008, p. 248). Burke (1945) would describe this type of storytelling using the dramatic pentad such as a setting or scene, plot, or act, characters, or agent. Just as Koenig Kellas and Manusov (2003) used narrative components, including descriptions of “cause and consequence,” episodes (p. 285), character development, and conclusions to induce sense-making after a crisis, I conceptualize similar stories from my interviews. Narrative, according to Mumby (1987) is how ideologies are perpetuated. Additionally, themes provide purpose and momentum to move the storyline forward (Foss, 2018). Stories of those interviewed follow a similar format and are used to assimilate and form new “truths,” disrupting established ideologies. Fisher (1989) includes cultural norms, religious influencers, social significance, expectations of others, and belief systems, in order to gain a multi-dimensional stance to unravel and analyze the components of the narrative puzzle.

Narrative includes a protagonist, antagonist, and a moral of the story. Foss (2018) includes voice quality and tonality as determinants of whether the speaker presents victimization or heroic themes. When diagnosed with an illness, families often use storytelling to comprehend a new reality as well as to mitigate the stress imposed by a sick family member (Charon, 2002; Frank, 1995). Koenig Kellas (2018) includes “verbal and nonverbal tone, pace, warmth, engagement, coordination, humor, tension, hesitation, silences, sarcasm, touch, other-centeredness, responses, questions, and turn-taking” as integral components of storytelling (p. 62). The notion of storytelling will be revisited throughout this text as the way a person with CD assimilates his or her “truth” with and around other family members as established ideologies are disrupted. The ill

individual may utilize storytelling as a way to make sense of his or her situation (Koenig Kellas & Trees, 2006). Setting also plays a significant role in my work when analyzing on the mezzo level.

I use narrative theory to coalesce the social, cultural, gendered, and political issues as realities, agreements on “truths,” and identities assimilated through storytelling. When first diagnosed with a disease, a person often attempts to “make sense of what has happened and is happening to them by attempting to assemble or to integrate these happenings within one or more narrative” (Somers, 1994, p. 613). This new narrative remolds a person’s identity and is co-constructed by those engaged with him or her. Knowledge or meaning “emerges through interaction between persons” (Haverkamp & Young, 2007, p. 268) and evolves dynamically over time. Newly diagnosed individuals assimilate their “new normal” (Koenig Kellas & Kranstuber Horstman, 2015, p. 86) and redefine what they tell themselves and others about their disease. They must decide how much of their disability to reveal by establishing levels of disclosure in their social circles.

Narrative inquiry has been discussed in a number of health communication studies as a way of coping and to enhance the patient/physician relationship. Sunwolf, Frey, and Keranen (2005) refer to the interchange between patient and doctor as “story sharing” (p. 240). It is a “way of connecting; knowing; creating reality, remembering and visioning the future” (p. 242). This collaborative approach of sharing stories helps shape the new reality of the newly diagnosed. For example, health workers and patients co-construct “storied meanings” (Yamaski, Sharf, & Harter, 2014, p. 103) to personalize their relationship and work together on a plan toward regaining health. The storytelling

process also humanizes the patient in the eyes of the physician. Rather than labeling her as the *insert-diagnosis-here* patient, the doctor knows her “truth” (Harter, 2009).

Arrington (2005) highlights family functionality in a study conducted to hear stories told by prostate cancer survivors. Stories are often adapted as more information is revealed.

Monk (1997) describes this as a “re-authoring” (p. 20) process, when therapists encouraged patients to examine cultural norms in social constructs. For example, Koenig Kellas (2017) and her cohorts link hope and narrative as part of the acceptance process in a study of cancer-patient caregivers.

Though scholars have not directly featured CNSM in FS family communication contexts, narrative has been used as an instrument in several family communication studies when a disruptive event requires a re-assimilation of reality in order to make sense of the new normal. To illustrate, when faced with adjusting to a newly adopted family member, the storytelling process is a “dance” where family members share in the story, taking turns to tell it and sharing different perspectives (Ballard & Ballard, 2011, p. 75). Manoogian, Harter and Denham (2013) identify narrative as a tool of family coalescence, as members discuss their experiences with diabetes and form bonds with others who share the disease. In their study, participants came to grips with diabetes and formed a unified identity through the process of sharing their narratives. Koenig Kellas and Trees (2006) conducted a study using family storytelling to sort out a stressful event experienced by combinations of family members including parents, children and stepchildren. Each of these studies shows how narrative is used to assimilate “truth” through the “sense-making storytelling” (p. 59) that takes place when families collectively assimilate experiences.

As circumstances change, narrative allows the person with CD to shift his or her personal definitions of “truth,” altering how one feels, acts, and defines oneself. Consider a newly diagnosed patient with CD. Faced with a restrictive diet, she must constantly remind herself what she can or cannot eat. As this chapter’s introduction asserted, food ideologies like *a little won’t hurt you* complicate interactions between CD or NCGS diagnosed persons and their families and friends. Such ideologies become a hurtful memorable message when the person with CD or NCGS is faced with gluten-containing foods which they believe, and have explained to others, will cause them to become ill. Sense-making through storytelling and memorable messages are key CNSM components, and the subjects of the next section.

The CNSM Theory

Overview

The communicative narrative sense making (CNSM) theory, developed by Koenig Kellas and Kranstuber Horstman (2015), addresses the storytelling process families engage in when making sense of a family member’s illness diagnosis. It includes several interchangeable components that can be used when conducting a study. I describe the components and elaborate those selected for the present study. The theory describes the process used to develop stories that influence familial behaviors, establish identities, navigate difficulties, and to construct their version of “truth” (Koenig Kellas & Kranstuber Horstman, 2015). My study expands the use of CNSM theory, and Koenig Kellas’s (2015) suggestion to apply it when “family members’ stories may be muted when they are discordant with expectations of canonical narratives” (p. 83). Just as lesbian mothers must redefine their stories of origin with their children (Suter, Koenig

Kellas, Webb, & Allen, 2016), this study illustrates the process family members use to redefine their “story,” when one family member announces a diagnosis that impacts other family members. I show how a proclamation of FS by one family member disrupts family norms and how narratives must be re-scripted by family members.

Family storytelling is a collaborative process that develops the culture, belief systems, rituals, and values of a family (Koenig Kellas & Kranstuber Horstman, 2015) about shared experiences creating ingrained and consequential memories that affect the health, behavior, and emotional state of individuals (Koenig Kellas, 2018). Koenig Kellas and Kranstuber Horstman (2015) generated the CNSM theory as a lens to view the impact of family narratives on practicable versions of “truth” through the process of cultivating and evolving storytelling. It examines how humans seek understanding of social interactions and life events, with a specific regard for effect of eudemonia, or a sense of well-being. The evolution of CNSM was influenced by narrative work where meaning is assigned through the interactive communicative process (Bochner, Ellis & Tillmann-Healy, 1997), storytelling as a cultivating factor in family rituals (Jorgenson & Bochner, 2004), narrating interaction as a way of “doing family” (Langellier & Peterson, 2006, p.1), redefining identity in the familial context after a life-altering trauma (McAdams & McLean, 2013), and reshaping a personal identity after being diagnosed with an illness (Frank, 1995).

CNSM Heuristics. CNSM’s assumptions are based on the narrative process with which families engage when confronted with a life-altering disruption, separated into three heuristics: “interactional/joint storytelling, translational storytelling (interventions), and retrospective storytelling” (Koenig Kellas & Kranstuber Horstman, 2015, p. 81).

Interactional/joint storytelling refers to the scenario where two or more participants engage in an interactive narrative to make sense of a situation or challenging familial health development. It assumes the affected parties collectively form a new narrative in order to adjust to new responsibilities and adapt to a different set of beliefs.

Interactional/joint storytelling differs from a conversation because these narratives become specific stories that are told and retold in order for the family to conform to an altered lifestyle. Conversations, on the other hand are simply an exchange of everyday communication between people that may or may not be remembered. Storytelling entails telling and retelling enduring narratives that influence “values, beliefs, and actions” of sharing adults (Flood-Grady & Koenig Kellas, 2018, p. 1). Interactional/joint storytelling implies that the family’s belief system about the disruption is molded through joint narrative over time where family members collectively work together to reform the “story” of what happened and how things need to change as a result (Koenig Kellas, 2005; McAdams, 1993). This heuristic contemplates elements of engagement, turn-taking, and perspective-taking of family members to assess “family cohesion,” as the familial identity is reformed (Trees & Koenig Kellas, 2009). Studies using concepts from the interactional heuristic of the theory include topics on final life and death narratives between family members (Keeley & Koenig Kellas, 2004), meaning-finding within families in times of crisis (Koenig Kellas & Trees, 2006), perspective-taking of married couples (Trees & Koenig Kellas, 2009), mother/daughter relationships (Kranstuber Horstman, Kaliski, Hayes, Coz, Enderle, & Nelson, 2016), and communicating family identity (Koenig Kellas, 2005). Each of these examples use the

CNSM to study how family members coped with life altering events such as illness by taking the perspective of each other through storytelling.

The translational storytelling heuristic centers on how narrative studies could be applied in the community to help others coping with difficulties to improve social circumstances (Koenig Kellas & Kranstuber Horstman, 2015). Quinlan and Harter (2010) provide an example of translational storytelling by describing performances of the Dancing Wheels Company and School as a channel for those in wheelchairs to express themselves artistically and alter audience perceptions of disabilities. The outcome of this project provides readers an example of Burke's (1945, p. 59) "representative anecdote" where performers in wheelchairs offered insight into their daily plight through the medium of dance. The Holman and Koenig Kellas (2016) study on sex talk between adolescents and parents resulted in a public service announcement encouraging parents to have "the talk" with their teens. Koenig Kellas, Castle, Johnson, and Cohen (2017) helped the cancer community by encouraging narratives of hope for caregivers of cancer patients. Another example of how the translational storytelling heuristic helped the community is found with Charon's (2006) work that encouraged doctors to listen to patient accounts of symptoms and emotions, rather than focusing on medical reports. These procedures helped doctors "humanize" patients. Translational actions elucidate how narratives can "benefit participants in the context of difficulty, trauma, illness, and/or stress," and how narratives can affect positive benefits for those enduring life's struggles (Koenig Kellas, 2018, p. 69). Similar to the interactional/joint storytelling heuristic, the translational storytelling/intervention heuristic assumes input

from multiple participants. In contrast, the retrospective storytelling heuristic focuses on the affected individual.

The retrospective storytelling heuristic focuses on the individual's personal story, including what they tell themselves and others as assimilated through the lens of past experiences. Development of this model was influenced by Bruner (1990) who asserted that humans assimilate sense-making by retrospectively contemplating events, and further by McAdams' (1993) assertion that identities evolve by intertwining meaningful narratives to cultivate the "personal myth" (p. 34). These stories evolve from collaboratively formulated stories told by family members, centered on separate interpretations (Koenig Kellas & Trees, 2006). Summarizing, Koenig Kellas (2018) said, "stories we *hear* and *tell* have significant effects on our beliefs, values, behavior, and health" (p. 64), leading to proposition one of the CNSM, which states that retrospective stories draw from familial standards of behavior and belief systems (Koenig Kellas, 2018). When retrospective storytelling is "framed positively" (p. 66), it correlates with high levels of eudemonia on the part of the individual reporting the story. Degrees of positivity would be subjectively interpreted by the researcher using Koenig Kellas's approach, based on tone quality, optimism about the future, and descriptions of familial interactions conveyed by those interviewed.

Studies applying the retrospective heuristic include Castle's (2015) work, which centered on the narratives of those with lupus. In it, she asked participants to recollect stories of familial interactions with respect to their disease, pointing out that the narrative process provides an avenue for reconstituting individual and familial identity in conjunction with the illness. In her analysis, Castle (2015) used CNSM as the

prevailing theory while overlaying Frank's (1995; 2013) classifications of narratives as a framework for analysis. The result of using the framework in conjunction with the theoretical premises yielded rich insight into those living with lupus. Holman and Koenig Kellas (2018) compared what participants recalled, versus what they would have preferred their parents had said. The retrospective samples recounted by the teens represent a compilation of rich familial beliefs and histories, intertwined with trite clichés. Memories of stories about family members with mental illness provided the topic for research in a Flood-Grady and Koenig Kellas (2018) study using retrospective storytelling. Younger family members reported older members' stories with themes of "struggle and caution" (p. 1) when advising on how to cope with psychopathy. These retrospective stories conveyed by elders represented a compilation of hard-earned lessons. Another application of retrospective storytelling applies to families with adopted children who construct an origin story to compensate for not having a traditional birth story (Kranstuber & Kellas, 2011). Researchers requesting retrospective recollections from participants give voice to life events after long-term contemplation of diverse narratives from interpersonal interactions.

CNSM Constructs. The CNSM theory was cultivated from interdisciplinary rhizomes. Key constructs of sense-making used in CNSM draw from Knapp, Stohl, and Reardon's (1981) concept of "memorable messages," Scott and Lyman's (1968) notion of "accounts," Koenig Kellas, Willer, and Trees's (2013) convictions on "communicative perspective-taking," and Manusov and Spitzberg's (2008) idea of "attributions." The fundamental goal of CNSM is to provide a framework in which to

“affect and reflect psychosocial, physical, and relational health” (Koenig Kellas, 2018, p. 63).

The term “memorable messages” was coined by Knapp, Stohl, and Reardon (1981, p. 27) to describe proverb-like, positive or negative memories typically delivered by parental or authoritative figures, that imprint on the mind, becoming edicts by which to live. Memorable messages “provide a foundation for personal standards,” such as the golden rule and other rules often heard from parents (Smith & Butler Ellis, 2004, p. 114). They can be hurtful as discovered by Dorrance-Hall, Ruth-McSwain, and Ferrara (2016) who found that participants with authoritative parents reported negative memorable messages such as, *no man is going to want to marry you* [if you are overweight] (p. 250). Participants with authoritarian parents reported hurtful messages such as, *you can't wear any of your clothes; you used to be so pretty* (p. 250). Willer (2014) asked infertile women to reflect on “memorable messages” (Koenig Kellas & Kranstuber Horstman, 2015, p. 80), specifically asking for “compassionate” messages communicated by healthcare workers (Willer, 2014, p. 1). Like dietary restrictions, infertility is a topic discouraged from social discourse. Willer (2014) showed that compassionate messages from healthcare providers positively impacted women’s experiences. Memorable messages offer “brief oral injunctions that prescribe rules of conduct for solving a personal problem” (Knapp, Stohl, & Reardon, 1981, p. 36). Knapp, Stohl, and Reardon (1981) asked participants ten interview questions centered on circumstances that resulted in memorized maxims, recalled years later. Messages were delineated by whether they were conditional, prescriptive, behavioral, or consequential (p. 31). Conditional messages were “if/then” such as, *if you have the*

power to break a man's whole career, then don't get too close to him (p. 30).

Prescriptive platitudes center on “must or should” statements such as, *always remember who you are* (p. 31). Behavioral messages refer to rules such as *don't raise your voice* (p. 31). This type of message also refers to rules of etiquette. Consequent messages refer to the outcome associated with particular behaviors such as, *if you want a relationship to work, you have to work at it*. In this example, the consequence describes required action for a successful outcome. Messages can be positive, such as, *make your avocation your vocation* (p. 33), or negative, *you've never been anything* (p. 33). They found that ninety percent of the participants reported that messages positively influence their life (p. 34). When participants encountered a problem requiring an expedient resolution, they frequently recalled memorable messages. Knapp, Stohl, and Reardon (1981) found that memorable messages about social interactions were fundamental during earlier, developmental phases, and again later in life when faced with a relationship crisis such as death or divorce. Memorable messages differentiate from other constructs in that they are usually remembered throughout a lifetime, and often become positive or negative proclamations to live by.

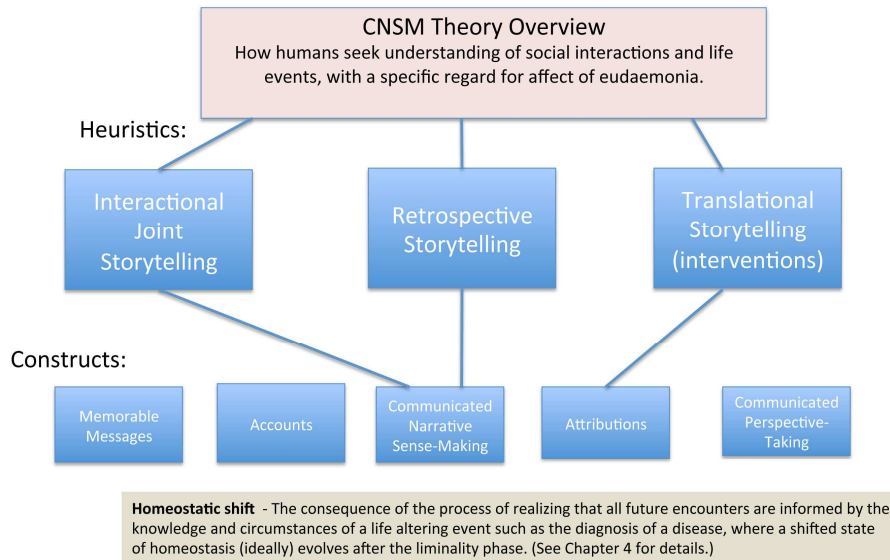
Communicative Perspective Taking (CPT) considers the perspective of two or more family members, realizing that each person's frame of reference influences their point of view (Koenig Kellas, Carr, Kranstuber Horstman, & Dilillo, 2017). The stronger ability one has to understand the perspective of another, the more collaborative the interaction (Koenig Kellas, et al., 2017). Koenig Kellas (2018) expanded the definition of CTP to consider the “ability to communicate the ability to put oneself in another's shoes” (p. 67), concluding that skill of the storyteller cultivates empathy in the

listener. CPT assumes more than one person participates in the process of perspective taking, often between family members where one has an illness and the other does not.

Separate from the CNSM theory, the communicated narrative sense-making construct pertains to the cause or reasons given to explain an individual's or other's behavior. Manusov and Spitzberg (2008) demonstrated how a person's internal thoughts transfer to the spoken word. Pointing to Heider's (1958) work on attribution modeling, Manusov and Spitzberg (2008) discussed how sense-making is a systematic process by which individuals actively engage in order to attribute a "causal locus." They identified four characteristics ascribed to justifications for sense-making including correspondence, referring to personality characteristics, and co-variation, when simultaneous events determine the causal outcome. A third attribute refers to how others make sense of someone else's plight by assigning responsibility, such as offering more sympathy to a victim than to a reckless person. Finally, bias refers to how a person's actions are viewed in light of previously formed opinions (Manusov & Spitzberg, 2008). When considering how to make sense of another's actions, all previous behavior factors into that thought process. Feelings of isolation and loneliness were found to put couples on a trajectory of demise (Doohan, Carrère, & Riggs, 2013). These characteristics were used as part of the analysis in a study attempting to attribute the precursors of marital dissolution.

Select CNSM Components. There are few studies on social aspects of adults living with CD; thus, I focus on the retrospective storytelling heuristic to give voice to a population who has seldom been asked to offer their perspectives. My study asks participants who have CD and live with other adults to tell their stories retrospectively,

offering insight into how their stories evolved over time. Elements of sense-making include asking participants to recall “memorable messages” (Koenig Kellas & Kranstuber Horstman, 2015, p. 80) about what family members said regarding their dietary requirements, as well as engaging in “retrospective storytelling” (p. 81), when asked to tell a story about their dietary issues. There is a strong relationship between memorable messages and retrospective storytelling because they both cast back on the past. For this project, I focus on these elements of the CNSM to understand how an individual disrupted with a diagnosis strives to reestablish a new level of homeostasis, although analytical themes will not be limited to this idea. CNSM is often applied in studies of families using storytelling as a sense-making instrument to sort out emotions, create a new identity, and reestablish social ties after a diagnosis or illness (Koenig Kellas, 2018). Narratives shared within families help members cope with life experiences, specifically as they apply to advancing family communication and correlating an individual’s narrative and his or her feelings of well-being (Koenig Kellas & Kranstuber Horstman, 2015). These culminate in a focus on storytelling as the basis for sense-making and communication (Koenig Kellas, 2018). The combination of the retrospective storytelling heuristic and the memorable message construct provide the structure for the present study. Further, the communicative sense making construct directly segues to interpreting behaviors of those subjugated from powerful ideologies striving to redefine “truth” and to exist in a state of eudemonia. The CNSM is summarized in the chart below:



References (Adapted from):
 Koenig Kellas, J. (2018). Communicated Narrative Sense-Making Theory: linking storytelling and well-being. In Braithwaite, D. O., Suter, E. A., Floyd, K. (Eds.) *Engaging theories in Family Communication 2nd Edition*, (pp. 62-74). New York, NY: Routledge.
 Koenig Kellas, J., & Kranstuber Horstman, H. (2015). Communicated narrative sense-making: Understanding family narratives, storytelling, and the construction of meaning through a communicative lens. In L. M. Turner & R. West (Eds.), *Sage handbook of family communication* (pp. 76–90). Thousand Oaks, CA: Sage.

Figure 1.3. CNSM Theory Overview

Analysis Overview

Koenig Kellas and Kranstuber Horstman’s (2015) CNSM provides a valuable lens to view the perspective of those interviewed. In my analysis, I use constant comparative interpretation (Lincoln & Guba, 1985) to derive themes from interviews and analyze data using an inductive scheme. Interpretive analysis is open to bias on the part of the researcher (Saldaña, 2015). As a person with CD, I have a penchant toward lifting the status of those living with this hidden disability. Denzin (2003) states, “the interview is ...a site where meaning is created and performed” (p. 81). My experience of living with the disease invited interviewees to view me as an insider (Brayboy & Deyhle, 2000) and therefore disclose more than they would to someone without the disease (Child, 2015). Inductive thematic analysis coincides with my positionality and thus provides those with FS an opportunity to tell their stories. The combination of

interview data, my field notes, and existing literature provides a “three-dimensional rendering” of the situation lived by the interviewee (Saldaña, 2015, p. 57). Data analysis details are provided in chapter two.

Summary

The purpose of the dissertation is to analyze and empower voices of people living with CD and NCGS to create an awareness of the ideologies that influence thinking about gluten sensitivities. Additional outcomes include offering best practices to enhance social interactions for this community, broadening the current definition of CD accessibility in the American Disabilities Act (ADA), and giving voice to the silent CD population. Scholars have considered the cultural aspects of food and studied the effect of hidden disabilities on QOL. However, few have synthesized the impact of living with food allergies on cultural and social aspects of everyday life. Further, CNSM discusses how family storytelling defines families, but has not contemplated how food is a part of this unification. This study explores how CNSM applies to familial traditions involving food, as well as deepens conversation of previous works.

The study is divided into five chapters. Subsequent chapters explain my methodology for analyzing the data from the study; provide detail on how the data applies to macro level ideologies, filtered down to familial interactions and identity evolution in light of having a disease. I end with suggestions, contributions, and a call to action for future research.

CHAPTER TWO – RESEARCH DESIGN AND METHODS

The previous chapter described combining ideological criticism with qualitative analysis using the CNSM as the frame for this study. Pairing these approaches seems logical when considering the nature of ideological analysis. Ideologies are a “given” truth that most are not aware of. It is only when one is on the opposing side of an ideology that she becomes vaguely aware of a social obstacle hinting at discord. As a researcher using both perspectives, I identify the affects of dominant ideologies by discussing them on the macro level in chapter three and providing examples of how they manifest in social settings on the mezzo and micro levels in chapter four. Ideological criticism, qualitative analysis, and my insider status as a person with CD afford me the unique position as a researcher who has experienced the same systems of marginalization and oppressions as the participants in the study. Because of this, I can understand and convey through this work the challenges of those living in an imperfect system.

Overview

Here, I describe the methodology used to design and implement this study. Qualitative research provides deep insight to data, foregrounding obstacles faced by those living with CD. Social aspects reviewed herein included examining adults on the gluten-free diet living with other adults, who may or may not need to eliminate gluten, extended-family meal practices, as well as complications of an identity evolving with disease. I detail methods of data coding and analysis, as well as vetting procedures. I explain the

methodology used to thematically code and analyze data from participants to accentuate how ideological influences affect behaviors on food practices. In addition to analyzing dominant influential ideologies, data are also analyzed in light of family commensality practices. Finally, the individual's evolving identity is examined in light of living with a disease. By incorporating qualitative analysis best practices gleaned from the literature, this work adds to research on CD through the communication studies lens by associating dominant ideologies with familial behaviors, giving voice to a silenced population.

Benefits of Qualitative Analysis

Brené Brown (2013) says, "Stories are data with a soul." Participants in my study shared personal stories about living with CD and FS. Inquiring about retrospective stories allows the interviewer to gather rich descriptions of participant experiences, assign meaning, and thematic developments (Creswell & Poth, 2018). Additionally, qualitative research renders the opportunity to interpret and seek links to dominant ideologies that drive intimate familial behaviors and alter individuals' thought processes, ultimately disrupting time-honored "truths." Using heuristics from the CNSM provides enriching retrospective stories and memorable messages (Koenig Kellas & Kranstuber Horstman, 2015). A nascent area of research, such as the present study on the social aspects of adults living with CD, lends itself well to the qualitative research method listening to self reflexive stories conveyed during the sense-making process, yielding insight into motivations, belief systems, and outside influences (Koenig Kellas & Horstman, 2015). Revelations from this study serve to identify underlying ideologies to help those with CD as well as their family and friends to better navigate the social nuances imposed by the disease.

In the ensuing sections, I explain the methodology used, starting with a description of Phase I, followed by details on Phase II interviews. Next, I discuss my analysis methods for theming and coding the data, elaborating the coding cycles used to organize and categorize data. Finally, I summarize and discuss how data gleaned from the analysis contribute to the subsequent ideology and family chapters of the study.

Phase I

Phase I included an online survey posted to celiac.com, a support website that sees approximately 750,000 unique visitors per month (S. Adams, personal conversation, March 29, 2017). The IRB-approved survey involved participants clicking the option to take the survey, agreeing to the consent form, and answering the survey questions (See Appendix A). I submitted a press release to PRWeb, in order to reach potential participants on multiple websites and in the press. The press release received 197,840 headline impressions. The survey asked demographic questions about participant diagnostic processes, education levels, length of time on the diet, individual and family commitment to the diet, and security and levels of trust around adherence, totaling 24 multiple choice and five open-ended questions requesting written comments. The final question asked if participants would grant permission for a follow-up interview (Phase II). Data was collected using Qualtrics, an online survey tool supported by the University of Denver. The survey took approximately ten minutes to complete. Data collection for the study began August 18, 2017, when the study was published. Within six hours of posting, the press release was picked up by 89 other websites. It was reprinted in 16,465 periodicals and run by 12,491 news aggregators. When the survey went live, 621

participants completed it, and 335 participants requested follow-up interviews in the seven days it was available. Survey questions can be found in Appendix A.

Phase II

Following IRB approval, Phase II entailed extensive phone interviews with qualified participants who granted permission in Phase I. Those who agreed to a follow-up interview were contacted via email and asked to sign up using the application Youcanbookme. The professional version of this application was purchased, shielding participants from advertising and allowing me to customize it with the University of Denver logo. The following pages will elucidate the steps taken to interview, code, theme, and derive findings from the data. The interviewing methods described below enabled me to gain deep, personal, real-life experiences from those with FS and CD. My evolving positionality is interspersed when discussing each analysis cycle, showing how my thinking progressed through the interviewing and coding process. Interview questions can be found in Appendix B. Keeping the CNSM retrospective storytelling heuristic coupled with the memorable message construct in mind, I cultivated interview inquiries to answer the research questions.

Interviewing Process

My interview method was greatly influenced by my examiner role on the interview team of Willer's study of women who had endured a miscarriage. In it, we expanded the "memorable message" construct from the CNSM (Koenig Kellas & Kranstuber Horstman, 2015, p. 80) to include a request for both a "compassionate" message (Willer, 2014, p. 407) and a "hurtful" message (Vangelisti et al., 2007, p. 357). People who have to navigate social situations experience "intense feelings of being

diverse,” particularly when discussing their restrictive diet (Hallert, et al., 2002, p. 41). These feelings are often caused from unconsciously breaching a dominant ideology. Similar to living with a hidden disease such as CD, having a miscarriage is typically shunned because of ideologies and social norms that discourage public discussion (Bute & Brann, 2015). In my work on the Willer study, one of the participant interviews started off awkwardly. However, when I asked the “compassionate memorable and hurtful message” questions, the interviewee began to tell me very personal details of her life, perhaps because I asked her about something here-to-fore suppressed that she needed to talk about. I hoped for the same level of intimacy in my study, which is why I chose this approach. Furthermore, the interview location impacts the outcome, and by choosing the site of her home for the phone interview, she could relax (Koenig Kellas, Castle, Johnson, & Cohen, 2017). The home is where people typically experience commensality. Walter (2009) says, “home is where eating connects consumers to nature most intimately.” When considering the level of intimacy conveyed during the interviews in my study, I surmised that their comfortable home environment provided participants a safe place in which to tell their food-related stories.

Gleaning useful narrative relied on my ability to put the interviewee at ease and raise questions that invited a free flow of storytelling. To facilitate this, I reviewed the Phase I surveys before lifting the receiver. I reworded questions to use the language of the respondent used in the Phase I write-ins, believing that questions written in their vernacular would be more likely to stimulate an authentic response (Kvale, 2007). I asked the same core questions in each interview to assure consistency. According to Denzin and Lincoln (2018), interview questions strive to discover how experiences are understood

and assimilated to become the participant's conscious reality. I used this notion by asking open-ended questions designed to hear frank and honest CD-related concerns of those interviewed. Kvale (2007) emphasized the importance of putting interviewees at ease by describing the purpose of the interview before asking questions. At the onset of the interview, I said, "This is Jean Duane calling to interview you about the relational aspects of food sensitivities." I also confirmed that I had their permission to record the interview. (Written permission to record was initially granted on the survey form.) To break the ice for an upcoming interview, Keeley and Koenig Kellas (2004) encouraged participants to "free-write" (p. 370) on a topic beforehand, as it encouraged narrative flow during the interview. Similarly, I developed the Phase I questionnaire as an icebreaker for the interview with the write-in questions at the end of the survey. In addition to supplying icebreaker conversation starters, these answers provided me insight into the participant's state of mind beforehand.

As an adult with FS and CD, I enjoyed immediate rapport and some level of trust with those interviewed. I was cognizant of the participant's perspective in order to formulate questions designed to encourage the interviewee to speak freely to gain a deeper level of insight and detail. Simultaneously, I heeded the nuances of how they conveyed stories and interpreted their experiences. When appropriate, I shared my personal observations on handling physical and social challenges that accompany the disease to inspire trust and rapport. Questions inquired about surprises, hurdles, early memories, harmony, disagreements, and compassionate and hurtful messages. Interview questions were designed to garner stories, opening with the question: "Tell me about your gluten-free lifestyle." I used the memorable message construct of CNSM theory in order

to understand aspects of living with the illness by asking: “Tell me a compassionate message you have heard from an adult living in your household about your diet.” Followed by: “Tell me a hurtful message you have heard from an adult living in your household.” To gather retrospective stories, I asked, “Tell me a story about a time when...” taking cues from the interviewee to fill in the subject. Other optional questions focused on the centrality of food in life; how extended family rituals have been altered as a result of dietary restrictions; and whether or not participants experience dietary interference from other adults in the household. I asked how adults in the household collaborate and negotiated ways to keep the FS person safe, how he or she views food now that the diet is restricted, and what he or she feels should be examined in more depth. Though questions were scripted, the interview style allowed for open narrative. Occasionally, I went “off script” to probe more on a tangent (Vale & Halling, 1989). Questions were designed to encourage retrospective storytelling and locate primary concerns of participants.

Though my interviews were not face-to-face, guidance gleaned from other qualitative researchers (Denzin & Lincoln, 2018; Kvale, 2007; Padgett, 2012; Smith, 2014; Vale & Halling, 1989) made me keenly aware of verbal nuances that might indicate the emotional states of those interviewed over the phone. After considering previous studies and outcomes, I decided to be an active participant in the interviews, rather than a distanced, neutral interviewer. Therefore, during the interviews, I strived to match emotions by allowing myself to cry when they cried after telling me a heartbreaking story, laughing with them after a funny story, as well as tempering my responses when appropriate. Interviewees shared stories I could empathize with and my

emotions naturally matched theirs. These responses, my willingness to share personal stories if asked, and their home-based interview location seemed to put my respondents at ease. My probing technique involved asking follow-up questions on the context, lived experience, and meaning intended by the participant. I was rewarded during the interviews when most responded to my initial question, with a lengthy narrative on what was on the forefront of their mind. This was a feature of most interviews, indicating a strong desire among participants to share their stories and further suggesting that life with CD is challenging. The interviews offered a glimmer into how others manage social situations with a disease that affects every bite of every meal consumed.

When interviewees elaborated excessively, I first assessed the situation. Willink (2010) pondered, “How does a listener translate excess into something meaningful?” (p. 207), and suggested encouraging “excess” in interviews in order to let stories flow from participants. Incorporating this concept, I encouraged stream of consciousness stories, which often yielded useful data. Further, Willink (2010) described her process as reflexive and interpretive, as she related her personal experiences to those of the interviewee. She described how she listened openly to what the interviewee said, rather than anticipating what she expected to hear. Likewise, I asked questions of my interviewees and listened without the expectation that participant experiences would mirror my own. Additionally, I often used silence to encourage more sharing. Kvale (2007) suggested silence as an interviewing technique to encourage the participant to share more information. I engaged in silence during the interviews, which often caused respondents to elaborate further. My silence seemed to allow them to relax during the interview and invited participants to say, “that reminds me of a time when,” and launch

into a retrospective story. On the few occasions when silence did not incite elaboration from a more reticent interviewee, I asked open-ended questions such as: “How did that make you feel?” “Were other people involved?” and “What were their reactions?” Follow-up questions, such as “Please give me another example,” or “Tell me more” are designed to dig deeper into the original thread. This line of questioning often resulted in memorable messages and helped me propel the questioning. It allowed the flexibility to go “off script” and for me to probe more deeply on specific topics (Smith, 2014) in order to gain rich descriptions of behavior and experience (Vale & Halling, 1989). Finally, to understand what remained on participants’ minds, at the conclusion of the interview I queried, “What should I have asked?” This question sometimes led to other retrospective stories or memorable messages; other times, participants asked personal questions about my experience with CD. A stream-of-consciousness flow of information from participants was encouraged to complement the inductive thematic interpretive method of analysis used in the study.

The thematic dimension of the interview questions corroborated the topics I wished to research. My interview design began with questions about the diagnosis process and the respondent’s life since being diagnosed with CD. Next, I ask participants to share early memories or stories about becoming gluten free and followed up with questions about how that has led to harmony or disagreements in their households. I asked what compassionate or hurtful messages they recalled. Thank-you emails were sent to participants following the interview. Additionally, I mailed a hand-written note and copy of my cookbook *Bake Deliciously! Gluten and Dairy Free* to each interview

participant. Subsequently, I received many thank you notes, and several invitations to reconnect with participants for further study.

Post Interview Process

I interviewed 66 people for an hour and randomly selected one out of three to analyze 20 for this study. Interviews were transcribed verbatim using Dragon Dictate for Mac software. After teaching the software my voice, I listened to the recorded interviews and spoke them to the software, while it typed my spoken words. Transcripts were initially prepared in a text document and later moved to a Microsoft Word document, where they were reviewed and formatted. Narrative analysis emphasizes the value of engaging in intense reflexive thought as a key element of retrospective interpretation, moving the researcher to link cultural, institutional, and interactional contexts when contemplating meaning (Gubrium & Holstein, 1998). In a similar manner, I wrote retrospective memos to capture my thought process and interpretations immediately after each interview. I devoted approximately ten minutes to thinking about voice inflection, unstated words, hidden meaning, and other clues as to how the participant conveyed his or her story with focused acumen toward associating dominant ideologies with the sense-making stories conveyed (Kvale, 2007). Additionally, I wrote auto-ethnographic reflections of personal experiences evoked from the interview differentiating mine from participants. This practice enabled me to contemplate my experiences yielding the auto-ethnographic stories presented throughout (Lincoln & Guba, 1985, p. 6). Tying stories to influential dominant ideologies is central to this work. In the next section, I explain my analysis approach with this in mind.

The Intersection of Rhetorical/Cultural Ideologies and Family Communication

Before delving into the analysis component, I'd like to elaborate the rationale for the approach taken in this work. Knowledge gleaned from my study sought to associate dominant ideologies with behaviors in the social context. Interpretive inquiry assumes that I have a personal stake in the subject matter and that situated my interpretation of the data, providing a "three-dimensional" analysis (Saldaña, 2015, p. 57). Further, this status enabled me to analyze data as an "insider" (Brayboy & Deyhle, 2000) when considering the affect of ideological influencers. Narrative emphasizes social issues to problematize the status quo (Turner, 2017) and offers insight on sense-making through storytelling.

In the following, I explicate the synthesis of the two disciplines:

rhetorical/cultural and family communication (which includes both the family's interactions and the individual's identity transformation) to highlight the distinctive characteristics of each method, and locate intersections through narrative. Incorporating the retroactive storytelling heuristic of CNSM, the macro perspective assesses the dominant dialectical discourses and ideologies affecting behavior. In rhetorical/cultural communication, scholars seek dominant discourses that convey a high degree of communal exigency, and a deep regard toward participant's attitudes to shed light on opposing sides. Burghardt (2010) states that everyday rhetorical discourses in social and public media, advertisements, editorials, news stories, religious edicts, etc., advocate hegemonic ideologies in the collective consciousness that influence family interactions and interpersonal communication. Rhetorical/cultural interpretive analysis is viewed through the context of the prevailing discourse (Leach, 2011). The dominant dialectical discourse is manifested in the object chosen for analysis such as a government

publication, television show, celebrity quote, or virtually anything that presents a critical perspective. Koenig Kellas (2018) expands this to include videos, writings, and “experimental designs” (p. 69). Throughout my analysis of both perspectives, I include cultural artifacts to illustrate rhetorical influencers with regard to those with CD and argued that attitudes are formed based on these influences affecting beliefs, values, and social behaviors. Behaviors are modeled in popular media as described in the previous chapter when food allergic characters depicted on television are rejected or shunned by their counterparts. Huesmann and Taylor (2006) emphasize the influence of public media precipitating behaviors in the family unit. They assert, “influences, such as exposure to media violence, that promote aggressive behavior in young children can contribute to increasingly aggressive and ultimately violent behavior many years later” (p. 394). Similarly bullying behaviors seen in the media were “directly associated with bullying [behaviors] at school” (Eunhee & Kim, 2004, p. 659). Congruent to how media campaigns affect smoking (Worden & Flynn, 2002), health (Roccella, 2002), seat belt usage (Williams, Wells, & Reinfurt, 2002), vaccination participation (Zimicki, et al., 2002), and sun exposure (Hill, White, Marks, & Borland, 2002), families draw on media influencers while engaging in collaborative storytelling as a model to make sense of a rupture in “normal” life due to a diagnosis or life-changing event.

Narrative analysis within the subcategory of family communication synthesizes interpersonal behaviors and as the researcher, I associate how they are influenced by ideologies and hegemonic power structures, particularly when facing life-changing episodes, such as the diagnosis of an illness (Koenig Kellas & Trees, 2006). Uniting the two disciplines provides rich insight on how CD affects social behaviors in our gluten-

centric society. Next, I discuss the macro, mezzo, and micro perspectives separately to provide further insight into how the analysis of the data was conducted.

The Macro Perspective

The macro level refers to dominant ideologies mandated by powerful societal influencers. In the analysis, I attended to the ideological dimension as a rhetorical critic, associating ideals from the church, government, corporations, and the media with behaviors described in the interviews. These translated into ableist, sexist, patriarchal, religious, and etiquette ideologies that influence food-related behaviors and practices. CNSM provides a theoretical exemplar through which to view the macro, mezzo, and micro-levels of communication, but it does not account for the force of ideologies. Rhetorical critics pay attention to the words and expressions chosen in narratives. For example, McGee (1980) “links rhetoric and ideology” (p. 1) with the concept of the ideograph, pointing out how ordinary terms such as “liberty” or “religion” (p. 7) may be pregnant with ideology because of their symbolic meaning. While this study is not an ideographic analysis, word and phrase choices of those interviewed were evaluated in light of ideologies. Ideologies mentioned in chapter one, such as, *if it is made with loving hands, it will nourish your body*, and *all in moderation* can be implicitly apparent within people’s stories and sense-making. Rhetorical critics have evaluated the ways that ideology, commonsense stories, or commonsense aphorisms affect public life. While analyzing the interview data, I assessed similar patterns and the presence of ideology within the word or phrase choices.

The interpretation of the truth (McKerrow, 1989) can be swayed by the narrator’s motivation, identity, reliability, and attitude. Nuances such as voice quality and tonality

determine whether the speaker presents victimization or heroic themes (Foss, 2018). The narrator may be laughing, crying, or angrily describing his or her interaction with other characters, offering further components for interpretation. Language and phrase choices also provide a glimpse of the state of mind, education level, and macro influencers of the narrator (Saldaña, 2013). When describing the “dramatistic point of view,” Burke (1945, p. 21) emphasizes the importance of listening both to the words stated and the words omitted to establish context and meaning. During the macro-data analysis, specific words whether used or omitted, tone of voice, and the story conveyed contributed to my hermeneutical analysis frame. Ideologies are so understood that nobody questions them. For example, taken-for-granted social behaviors in church, such as participating in communion, or around the dinner table, such as sharing the food with each other are commonplace practices. McKerrow (1989) suggests that dominance sustains itself through ideology in his *critique of domination* concept. Specifically, he states that ideologies are “rhetorical creations” (p. 92) for the ruling class to exercise control to the point that those who incorporate them do it as a taken-for-granted truth; and those who do not participate are culled from ritualistic practices. Using these concepts, the rhetorical cultural analysis looks for how dominant ideologies influence choices, actions, and behaviors. It is in the spirit of ideological criticism that I approached my analysis for this project, especially through the taken-for-granted realities that center on gluten in American life.

Global ideologies evolved into macro-themes of revised truths through deductive analysis in the present study. In the macro portion, principles such as thematic analysis, dominant ideologies, and researcher’s positionality differentiate critical narrative from

other types of examination. Analysis in rhetorical criticism required me to identify themes in the narrative and then to support them with substantiating arguments, simultaneously considering the unique position portrayed by the speaker. I challenged constructs that kept the oppressed, oppressed; and that perpetuated the dominating ideologies found in popular cultural influencers. Further, themes were derived from the literature to support the research question. Specifically, Peniama et al. (2014) provided themes for one of the analytical cycles. Other macro themes evolved through data analysis. The practice of critical analysis includes considering dominant ideologies (McKerrow, 1989) and the requirement that I engaged in *telos*, or “self-reflexive critique” (p. 91) and retrospective contemplation (Koenig Kellas, Kranstuber, 2015) in order to identify the impetus of power that may influence social constructs. Altogether, McKerrow (1989) recommends that the critical scholar consider the impact of the discourse, power structures, and knowledge of the subject group. These propositions were in the forefront of my mind, as I conducted the macro-level analysis, identifying themes of revised truths necessitated with disease.

As a critical rhetor, I associated dominant ideologies with participant’s stories.

Hariman (1991) states:

The writer of critical rhetoric appears as a thoroughly modern self: a disembodied thinker having no identifiable social location, writing in an impersonal style, and managing the disturbing powers of social life through the application of reason (p. 68).

Taking a stance using McKerrow’s (1989) concept of *critique of domination* required some degree of care on my part as the analyst when antagonizing dominant ideologies. While I did not share my assessments of associated ideologies with those I

interviewed, (because I had not yet completed the analysis, and because people do not converse on such topics in normal conversation) I show that the abundance of gluten-mockery presented in the media, a scrutinizing culture imposed by large corporations, dietary guidelines provided by the government, and religious edicts, cannot help but influence interpersonal interactions evoking ideological responses on religious, sexist, ableist, patriarchal, and etiquette levels. Likewise, while taking the stance using McKerrow's (1989) concept of the *critique of freedom*, defines "a self-reflexive critique that turns back on itself even as it promotes a realignment in the forces of power that construct social relations" (p. 1). Participants told stories questioning previous knowledge and edicts from powerful sources, and described adaptations they made that defied those decrees, exercising their freedom to do so. Transformational stories of redemption, redefining identity, and altered "truths" depicted participants' ability to surmount and redefine previously taken-for-granted ideologies. Associating gluten-related ideologies that cause the person with CD or FS to be tyrannized in social interactions provides a unique contribution to communication studies.

The Mezzo and Micro Perspectives

The mezzo perspective centered on family dynamics, including relationship adaptation strategies to accommodate traditions and rituals to assimilate, interpret, and unify. Further, it included the assessment of individual identity transformation. Social interchange refers to levels of interaction, including habitual behaviors (Vangelisti, Maguire, Alexander, & Clark, 2007), language choices (Vangelisti & Young, 2000), and the secrets disclosed that give family members "insider" status (Vangelisti, Caughlin, & Timmerman, 2001). Whereas Duck, West, and Acitelli (1997) discussed family dynamics

through shared stories in the context of interpersonal behavior, Vangelisti (2004) asserted that communication seeks to understand the social interchange used by families in order to form relationships. According to Vangelisti, et al. (1999), it can even include the thoughts family members have about each other. These levels of social interchange were an integral part of the mezzo analysis in my study, as they combined to provide depth of understanding when reflecting on a participant's interview to learn how the person with CD adjusts to it's demands.

Analysis in this section focused on how family and others mediated social exchanges as they synthesized information about the person with CD and the dietary requirements. Participants struggled with the question: "How do I come to terms with being GF with my friends and family particularly when food and gluten related ideologies are constraining us?" Setting emerged as a prominent feature in the stories of those interviewed, including various "battlegrounds" such as the immediate family dinner table, the extended family dinner table, church, school, and work. At the mezzo-level, cultural ideologies such as media references, religious, and political beliefs and practices, as well as etiquette became common sense decorum enacted through the family interactions in various battlegrounds. Family dynamics transformed in the continually evolving interplay of tension, release, affection, rejection, acceptance, and emotions present in interpersonal relationships (Koenig Kellas, 2018). These adaptations can change quickly as dyads, triads, and various family groups interact, and can be influenced by outside sources such as the daily news, a recent religious service, or a political decision. Sense-making is the process by which individuals and groups pursue a unified

understanding to gain levels of acceptance in light of a life-altering diagnosis (Koenig Kellas, 2018).

Retrospective stories and memorable messages are key elements of this analysis, offering insight to how those with CD perceive themselves and others. This level of analysis provides deep insight into the plights faced in the various battlegrounds, from worries about conforming to social norms, cross-contamination, and the humiliation of disclosing a disability all the while striving for a sense of well being. It required that participants and their family members' redefined long-held "truths" disrupted with information about the disease. This redefinition of "truth" leads to the homeostatic shift, when participants revealed they realized that life as they knew it ended with the demands of the disease, and life in the future would forever be impacted by it. This shift is discussed at length in chapter 4 as part of the process of identity transformation.

Finally, the micro-level analysis observed the individual adjusting self-narratives that contribute to redefining and transforming identity after a life-altering diagnosis, often producing stories of redemption. The question emerged: "How do I come to terms with being GF with myself particularly when food and gluten related ideologies are constraining me?" Stories conveyed by participants described how they came to terms with being GF gracefully. When analyzing data, questions such as the following were considered: *How does the participant identify with the disease? And, Is the participant the hero or victim in the way she tells the story? Does the individual speak up for himself and demand a safe meal? Or, Does he pretend to eat in social situations, going hungry and unsatisfied? Does she bring her own food everywhere she goes? Does she accept or reject the dietary restrictions? What attitude is conveyed?* These questions guided in the

understanding of how participants came to terms with navigating the nuances of the lifestyle, and steered the development of themes centering on the transforming identity with disease. Micro-level analysis included memorable messages of what participants remembered, both when they were newly diagnosed and later as they became more adapted to the lifestyle. These messages could have been hurtful or compassionate, and could have affected the way the person conducted her participation in family events and personal identity.

Data Analysis

Once interviews were conducted and transcribed, I incorporated analytical methods in order to categorize and organize data into similar groupings. Data was assessed repeatedly to isolate themes, using “open coding” methodology (Creswell & Poth, 2018, p. 87), where categories were developed and further classified incorporating “axial and selective coding” (p. 87) and where data was assembled in a “story line” (p. 88). Interpretive analysis is open to bias as I interspersed my experience and impressions throughout the study (Child, 2015), making the analysis phase a combination of analytical interpretation and art. These ideas informed my approach to identifying meaningful patterns in my data (Keeley & Koenig Kellas, 2004). Child (2015) suggested that the inclusion of an auto-ethnographic element was critical to elevate the researcher to a “participant-as-observer” (p. 60), contributing to the third-dimension of analysis. Similar to how Miller (2008) inserted excerpts from the letters and shared her insights as a family member throughout the study, I introduced my reflections as an interviewer and my experiences as a person with CD to each component by providing auto-ethnographic stories throughout.

Data is associated with dominant ideologies as the newly diagnosed individual reestablished his or her identity as a person with a disease. Protocol themes from Peniamina et al. (2014) are contemplated during the analysis process to identify similarities and differences in the data. Adjusted meta- and social narratives told specifically to family and friends elucidated the evolution the FS endured to renegotiate social norms. When applicable, results corroborating *a priori* themes in the literature are emphasized in this analysis. I used a deductive interpretive approach to assess ideological generalities and apply them to specific incidents reported by participants. Additionally, I used an inductive interpretive approach, taking specific incidents and applying them to general ideologies. The interchange of deductive and inductive analysis allows the juxtaposition of rhetorical/cultural and family communication. It entailed extracting narratives and arranging them into categories to exegete objectively (Pfeiffer, 1999, p. 23). Awareness of my biases as a person with CD enabled me to analyze data impartially (p. 24). Admittedly an analysis of this nature is speculative with its persuasiveness relying on the analyst's argumentative abilities (McGee, 1980). Thematic inductive interpretive analysis associated narratives with overarching ideologies, as well as tied responses to the research questions. Retrospective stories were reviewed to identify ideological forces that alter social behavioral patterns. Interpretations beneath the excerpts drew from literature to show parallels or differences in my work.

Coding Methodology

Data analysis using the CNSM theory is based on the interpretive approach to identify themes in social interactions using both inductive and deductive methods. Dorrance Hall, Ruth-McSwain, and Ferrara (2016) delineated steps for coordinating an

inductive and deductive analysis that necessitate carefully reading data, creating semantic domains “within the frames of analysis” (p. 249), developing and refining codes, and identifying themes and data to illustrate the themes. Inductive interpretation presupposes an *in vivo* open-coding approach (Strauss & Corbin, 1998) to viewing the data, allowing the “text to speak for itself and suspend[ing] judgment until conclusions can be based on interpretive evidence” (Pfeiffer, 1999, p. 23). Themes naturally emerged using this type of coding. In contrast, deductive analysis stems from speculation or is derived from previous understanding. “*A priori*” coding is used to match data with pre-determined “typical” characteristics (Denzin & Lincoln, 2018, p. 347). The interplay of both inductive and deductive analysis (Heath & Cowley, 2004) informed interpretations of the data in the present study.

The constant comparative method for qualitative analysis developed by Boeije (2002), allowed me to ascertain themes, categories, and codes derived from the data by continually assessing and reassessing data. This method required immersion in the data to reflect on various aspects, including tone, context, and content shared. I read the transcripts carefully and went back through them repeatedly to categorize pertinent data (Jackl, 2018). I honed my approach using methods described by Koenig Kellas and Suter (2012), who deployed constant comparison methods taking care to code noteworthy data until theoretical saturation was achieved (Aldiabat & LeNavenec, 2018). Throughout the process, I used *in vivo* coding initially coupled with cycles of constant comparative techniques to identify patterns, unify codes, and develop themes. Further, I created a codebook in analyzing data from focus group interviews to validate codes. Using the verification method of inter-rater triangulation, I shared my codebook with three peer

researchers to validate and gain feedback on my assessment (Denzin & Lincoln, 2018). Specific cyclical coding steps are now described.

Cycle One. With the research questions in mind, analysis began with cycle one, which utilized *in vivo* and open coding methods (Saldaña, 2015). Using Atlas.ti, the process entailed initially reading through the data, immersing myself without concern for coding (Birks, Chapman, & Francis, 2008), and then reading it through a second time underscoring key expressions that would serve as *in vivo* codes, and creating other pertinent words (open codes) that summed the thoughts of participants. Throughout the process, memos capture my thought processes and rationale for choosing quotes to correspond to codes to “extract meaning from the data” (Birks, Chapman, & Francis, 2008, p. 70). When finished with this step, nearly every quote from the interviews had a code associated with it.

During this phase, my positionality centered on how I related to the responses provided by participants with CD. I consider the stress/strife people described while dodging gluten in every moment of their lives, and how everyday interactions produced good and bad stories imprinted on our collective minds. That is the purpose of the study – to gather those narratives, to sort them through a meaningful lens, and to publish them in ways that enlighten those living with CD, their loved ones, friends, and associates.

Cycle Two. The next phase included a more structured approach using codes and themes from a similar study to discover how my data matches (Saldaña, 2015). For the second cycle, protocol coding enabled me to compare my study with the work conducted by Peniamina et al. (2014) in New Zealand where four focus groups reported on the QOL they experienced while living with CD. This step revealed how my study would

differentiate by providing a theoretical lens with which to analyze data, focus on deep narratives from participants, and interpret dominant ideologies that drive behavior in social situations experienced by this population through inductive analysis. Analytical findings from this step yielded consistency between my data and the Peniamina et al. (2014) data. Outcomes of Peniamina et al. (2014) yielded predictable responses regarding the QOL while living with CD. Just as in my data, people reported frustration with others' reactions to their dietary requirements, and said they felt isolated.

I took the elements of the Peniamina et al. (2014) study to a deeper level by applying a social-science analytical approach through the lens of dominant ideologies that influence behavior and other's responses to dietary restrictions. Whereas Peniamina et al. (2014) discussed "factual" responses; I sought to identify ideological influencers underlying the responses. My questions asked how people felt about what they disclosed in the interview, and I asked about coping strategies. The in-depth, one-on-one interviewing process I used, compared to the focus groups in the Peniamina et al. (2014) study, yielded rich descriptions from individuals on social situations they experience as a result of having CD. Additionally, applying the constructs of the CNSM theory distinguishes the two studies.

Cycle Three. Cycle three entailed comparing the codes developed in the two previous steps. To accomplish this, codes were grouped from both steps and synthesized, explaining why they complimented each other. The synthesized codes—ingestion risks/GF home; dining location; other's attitudes/awareness; homeostasis; attitudes of FS—are defined and rationalized. The new codes were defined, and all quotes fell into these categories. It is in this cycle that the "battlegrounds" emerged as a prominent

feature of the study. However, some code revision was required to accommodate quotes coded to multiple categories because of their rich textual data. After finishing this synthesis, I felt it still needed revising, so the next round entailed refining themes and culling the codes. Before discussing the next round of coding, I explain the approach I used for thematic analysis.

Thematic Analysis

Timmermans and Tavory (2012) noted that “salient themes in the data” (p. 180) emerged with inductive analysis. When describing themes, Saldaña (2015) asserted, “unlike a code, a theme is an extended phrase or sentence that identifies what a unit of data is about and/or what it means” (p. 297). The two disciplines of rhetorical/cultural and family communication intersect with interpretive analysis using qualitative research. Possible analytical methods to use when applying the retrospective heuristic of CNSM included conducting interviews (see Flood-Grady & Koenig Kellas, 2018) and then using thematic analysis to identify patterns in the data (Miller, 2000). Qualitative analysis of the stories focused on “content, structure, or process of narratives and storytelling” (Koenig Kellas, 2018, p. 70). Further, narrative texts are used as the centerpiece for research. Finally, both included the point of view of the researcher for authenticity. The present study uses elements of the above-described process to derive themes from the data in the next cycle of coding.

Cycle Four. As I refined the cycles described above, themes emerged. Houghton, Casey, Shaw, and Murphy (2013) explained, “the thoughts and ideas documented during data collection helped in the development of the final themes and sub-themes” (p. 16). Similarly, themes for both the rhetorical and family perspectives were derived from the

coded data. Throughout the process, they were consolidated into three primary themes. The fourth cycle step entailed corroborating my cycle-three synthesized codes into thematic phrases. I did not truncate words to describe the initial emerging themes. Five initial themes materialized from the cycle three codes:

1. Risking cross-contamination or gluten ingestion as a result of social pressure defying common etiquette practices.
2. How the dining setting affects the commensality experience (battlegrounds: family dinner table, extended family dinners, restaurants, school, work, and church).
3. How attitudes/awareness of other adults in the household affect QOL (sexist, ableist, and patriarchal ideologies).
4. Where participants feel safe and unsafe from gluten contamination and why.
5. Attitudes, strategies, knowledge, and general acceptance of the GF lifestyle, which led to identity transformation.

Boeiji (2002) contemplated themes that appear in one data group, but not in another. For this reason, I separated #2 and #3 into two categories: family adaptation or non-adaptive response and “new truths.” These initial themes seemed too broad and led me to conduct a final cycle to synthesize the themes into macro, mezzo, and micro categories.

Cycle Five. The fifth cycle of coding centered on culling themes and developing sub-themes, yielding: 1) ideological revised “truths,” 2) family adaptation or non-adaptive responses, and 3) identity transformation. Each of these is described below.

Revised Truths. This theme has two sub-categories: one for family and one for the individual. As the individual diagnosed with CD learns more about his/her disease,

notions once considered “common sense” change as new information is revealed. For example, if a person diagnosed with CD finds his/her co-habitants are uncooperative, constantly challenging his/her need for a clean, gluten-free environment, this could be because of a belief of *all things in moderation*, or *a little won't hurt you*. The person with CD and his/her co-habitants need to form a “new truth” as they begin to understand how sensitive some with CD are. This “new truth” may cause conflict for the individual with CD and in his/her relationship. It also illustrates ableist, sexism, and patriarchal ideologies if certain assumptions are made. For example, the ableist ideology is applicable if there is an assumption that everyone can eat any food, discounting an allergy or autoimmune response. Sexism or gender roles may be pertinent if one is expected to perform duties because of his/her gender. Similarly, patriarchal ideologies may be applicable if male-dominant expectations are present. Several ideologies may be applicable to a given scenario. This category includes different ways of thinking on the part of the individual with CD, and his or her family and friends. It does not include “actions” of family/friends, but rather focuses on verbalizations.

Family Adaptation or Non-adaptive Responses. Adaptation strategies may include alternative activities or adjusted behaviors to accommodate, or non-adaptive responses not to accommodate the person with CD. This theme has two categories: compassionate and hurtful. A hurtful comment in this theme is one that imprints negatively in the mind of the respondent. By contrast, a compassionate message resonates positively. This theme encompasses cooperative and uncooperative comments and behaviors of family and friends, as well as feelings described by the individuals interviewed. It can include ideologies about etiquette, religion, sexism, patriarchal, and

ableism, where ableism refers to instances of disability discrimination. It includes data that conveys feelings of isolation or stigmatization, but excludes identity proclamations or self-reflexive resolutions.

Identity Transformation. This theme includes the two subcategories: strategies to survive, specifically when eating away from a safe environment (e.g., in someone else's home); and the constant battle to survive. It includes proclamations about acceptance or positive remarks about having the disease, possibly pertaining to overall health, feeling better, or thinner. This category includes the individual's feelings, positive or negative. It differentiates hurtful from compassionate comments because it pertains to the feelings after such a message is received. This category includes self-reflexive proclamations that indicate state-of-mind living with the disease. It did not include how other people view the respondent, but rather focuses on the individual's identity and transformation with the disease.

Inter-rater Validation

In cycle five, three well-trained inter-rater research assistants review the data. Boundaries for categories and definitions were established for each, in detailed instructions to be used by a separate coder. My positionality in this phase centered on my interlocutors' reactions to my study data and how they interpreted my instructions. Neither of them had "insider status," meaning they do not have FS, NGFS, or CD. They were initially instructed to read through the data while performing *in vivo* open coding (Strauss & Corbin, 1998). The team met to compare notes on the first round of coding, rereading the data and discussing themes. Then they went back through the data and thematically coded it using the definitions provided. Inter-rater reliability corroborated

agreement 81% initially, and after collaborative discussion, the agreement rate increased to 88%. Codes and themes developed by the outside research team served as a starting place for my thematic analysis. We collaborated agreement about codes and themes when disagreement occurred through extensive discussion during the inter-rater reliability process. The inter-rater reliability process substantiated congruity with my codes and themes. Figure 2 depicts the three themes with examples from the data supporting the subcategories, showing the dynamic nature of transformation. Ideologies constantly affect familial behaviors and elements of identity transformation.

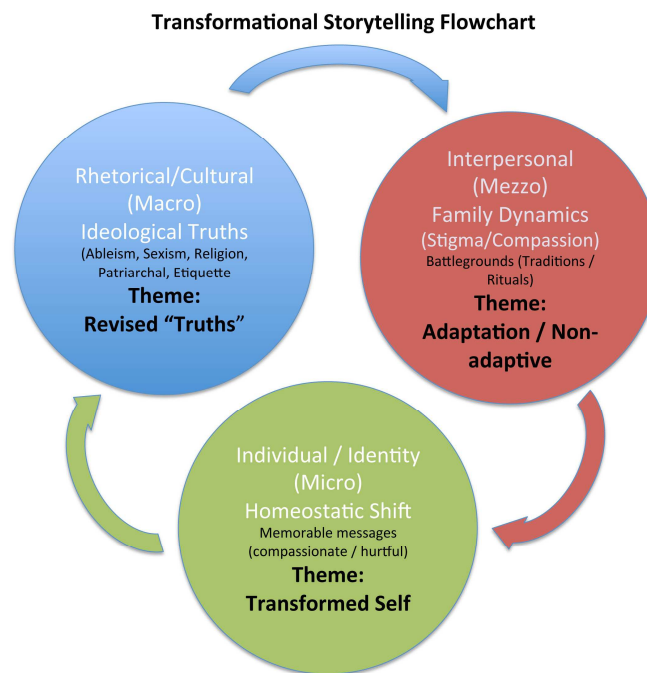


Figure 2.1. Transformative Storytelling Flowchart

Summary

After the analysis, three prevailing themes emerged: revised truths; familial adaptation or non-adaptive response; and identity transformation. Food-centered practices at the macro level such as etiquette and religious expectations, or ableist, sexism, and

patriarchal beliefs illustrated incidents when participants found themselves in opposition from deeply held ideologies. In the mezzo level, battlegrounds emerged as the scene of subjugation where memorable messages and retrospective stories took place. Finally, as individuals grew accustomed to life with CD, identities transformed to adapt. Figure 2 elucidates the unique qualities and intersections of the two communication sub-disciplines: rhetorical/cultural criticism and family communication, and the transformative effects of storytelling through the macro to micro-levels. The macro storytelling column depicts accepted ideological truths derived from religious, media, and pop culture influences. The arrows show that these truths are fundamental and affect family dynamics, as well as the homeostatic shift on the individual level. The double-sided arrows show that as contradictory information is assimilated, traditions and rituals are altered in the mezzo-level and retained as compassionate or hurtful memorable messages as these new “truths” are incorporated. The down arrows on each of the three columns indicate the dynamic characteristic of the evolution of “truth.” As facts were learned and the individual experimented with new aspects of his or her disease, truths were revised, families adapted rituals and traditions, and the individual transformed into the new self.

The next chapter identifies dominant ideologies that affect social behaviors centered on commensality.

CHAPTER THREE: IDEOLOGIES AND COMMENSALITY

Jean's Story – Momma, Weight Watchers, And The Dairy “Decision”

Momma joined Weight Watchers when I was seven years old. She was short, 5'2" inches tall, with intense blue eyes and brown hair. In middle age, she wore size 14 clothes, which saddened her. When she discovered Weight Watchers, she hoped it would be her redemption. She counted calories, weighed everything she ate, and studied the program cookbook. In those days, a hotdog with cabbage in tomato sauce passed for a WW's "skinny" meal. One dessert recipe from the cookbook instructed dieters to whip powdered milk, water, and a packet of artificial sweetener into a light cream. It tasted like sweet air. I left those meals feeling hungry and dissatisfied.

My mother stayed with the program through the years, becoming a WW lifetime member as she battled to stay thin. Foods were marked "good" or "bad," depending on how fattening they were. Cookies and cakes were "bad" and fruits and vegetables were "good." Year after year, she cycled through the loss and gain of the same 10 pounds, bouncing between making "skinny" dinners, or rich "Sunday" dinners worthy of a magazine cover. As a dutiful daughter, I celebrated and commiserated on cue. But since I was thin, I didn't need Weight Watchers. By her account, I was lucky. However, I had problems of my own.

I spent my whole childhood and much of my adulthood suffering chronic stomach pains and vomiting regularly. I was nauseated and often had a runny nose. My father had stomachaches, too, so I thought it was normal to feel sick after eating. As an adult, I came across an article on stomach issues and dairy allergies in Shape magazine, while on a flight to Hawaii with my husband. Until that moment, it had never occurred to me

that food could be causing my stomach problems. On the trip, I decided to experiment with limiting my dairy intake. I avoided dairy for a few days and felt immediately better. Not yet entirely convinced, I ate cereal and milk before an all-day excursion later in the vacation. While hiking the stunning Haleakala Crater, my stomachache returned. I was nauseated, cramped, and uncomfortable—unable to enjoy one of the most beautiful landscapes I'd ever encountered. In that moment, it clicked: a lifetime of stomachaches and vomiting was caused—I was now certain—by dairy products. When we returned from Hawaii, I excitedly called my mother to tell her what I'd learned. She cupped the phone and whispered to Daddy, "She's decided she has a dairy allergy."

In the 1980s, I worked for IBM. Their wellness program included a free Weight Watchers membership, offering lunchtime support-group meetings in the office. I arrived at the meeting wearing a dark green suit with a lizard pattern shirt and shoes. Immediately, I was ushered to the corner for the weigh-in. Stepping my 5'5" body on the scale, shoes and all, I weighed 124 lbs. The group leader looked at me, annoyed, and said, "Why are you here?" "I think I'm allergic to dairy products and need help with my diet," I responded. "We don't deal with food allergies here. And you don't weigh enough to join our program." Her comments were loud enough for my overweight coworkers to hear. A few clicked their tongues and many rolled their eyes. I was humiliated and left to figure out a healthy diet plan for myself.

Momma believed that the WW's program would allow her to control her body, to fit in, to be thin; and from time to time, it did. She believed that if you told yourself you were well and happy, you were. Sickness, health, happiness or sadness, each was a conscious decision—a choice. She believed Matthew 9:29: "as you believe, so it shall be." One afternoon, when Momma was well into her 80s, she rocked in my backyard porch swing. "One of you girls used to throw up a lot," she mused. "Yes, one of you was allergic to dairy when you were born, but the doctor said you'd 'grow out' of it."

I believe that people make the best decision possible with the information they have at the time. In my more generous moments, I imagine her choice not to acknowledge my allergy as a protective measure. Maybe she worried about the impact of a disability, trying to protect me from being different, to keep me safe from ridicule. I puzzle about

how she could have witnessed my pain, vomiting, and sinus issues, and not conclude I was still allergic? She had sinus issues, and my father always had a stomachache; neither associated their symptoms with dietary choices. Maybe it just never occurred to them. Maybe in Momma's mind, it was that simple: just as easily as she thought I had decided that I had a dairy allergy in Hawaii, she had decided that I did not have one as a newborn, and thought that if she 'believed' it, it would be true. Whatever her reasoning—ignorance or "believing it away"—consuming dairy products had a tremendously negative impact on my life.

Introduction

Ideology is a system of ideas that support hegemonic practices widely understood as natural or normal. Members of the dominant group reinforce these values and tend not to question their ideological beliefs. When individuals outside of the dominant group question the ideology, they are often subject to scrutiny, judgment, and disciplining tactics, as the dominant group seeks to protect existing ideology. Major life changes, like illness, can displace one's location from the dominant group to an outsider group. For example, when given news of a life-altering illness requiring drastic dietary alterations, one may reexamine firmly held truths around food and health. Ideological truths that once represented simple proclamations to live by suddenly contradict reality. The ill person reexamines her ideologies around social and familial situations involving food.

The dissertation reveals three themes: ideological drivers related to food and gluten; familial adaptations or non-adaptive responses, and identity transformation with disease. Each of these themes has the sub-heading of "revised truths," as people subjugated by a dominant ideology adapt to a new set of circumstances brought on by the diagnosis of disease. This chapter defines and discusses ideological influencers as they

relate to food and gluten at the deductive or macro level. “Macro” refers to dominant, taken-for-granted ideologies assumed in daily life when interacting in rituals with others. I provide examples of ideologies on etiquette, religion, sexism, patriarchy, and ableism derived from powerful entities such as government, corporations, and religion starting with a working definition of ideology used throughout. The next chapter provides inductive illustrations from the data of how these ideological disruptions manifest the familial (mezzo) and individual (micro) levels using elements of the CNSM as the frame to understand how those living with food sensitivities (FS) and celiac disease (CD) make sense of their experiences.

The Power of Ideology

To address how dominant food ideologies inform narratives about family interactions, the following provides an overview of ideology from different rhetorical perspectives to frame the forthcoming arguments. Burke (1966) describes ideology as “a spirit taking up its abode in a body: it makes that body hop around in certain ways; and that same body would have hopped around in different ways had a different ideology happened to inhabit it” (p. 6). This analogy describes precisely what transpires with the newly diagnosed person. The previous “hopping” represented the embodied truths prior to diagnosis; after diagnosis, a new type of “hopping” occurs, as these long-held beliefs are challenged by the health condition and those around the ill person. This interconnection of beliefs, “shapes... identity by determining how [one] views the world” (Black, 1970, p. 70). As the nascent diagnosed person assimilates the disease, this new identity permeates all other facets of self.

Ideologies can be further delineated into “lived ideologies” which refer to commonsense practices or ‘society’s way of life’ and ‘intellectual ideology,’ which is a system of religious or political thinking” (Billing, et al., 1988, p. 27). Ideologies are complex, with many activated at the same time around behavior, rules of etiquette, and acceptable religious practices. When on the powerful side of the ideology, life is natural and normal and social interactions are smooth. However, when on the oppressive end, one is often subject to scrutiny or even punishment until they conform to expectations. This is particularly true of practices and beliefs surrounding food. Traditional foods and preparation practices are disrupted when dietary restrictions are enforced, deviating from expectations and requiring adjustments in beliefs as new narratives emerge (Bochner, et al., 1997).

Ideology concerns the interplay between “discourse, power, and truth” (Lee, 2009, p. 288) and is seldom an individual’s original thought, but rather a thought driven by outside influencers (McLellan, 1986). These influencers propagate ideologies that can be understood as commonsense-like “truths” (McKerrow, 1989), and may be rooted in personal, self-serving interests (Eagleton, 1991). For example, a spouse who feels put out by his/her partner’s gluten-free (GF) needs may repeat the ideological “truth,” *a little won’t hurt you*, in order to avoid the burden of extreme safety practices in the home kitchen. This behavior perpetuates two attributes of ideology: a “false consciousness” and “scapegoating” (Cloud, 1998, p. 387). The false consciousness illustrates the convenient “truth” that *a little won’t hurt you*, excusing the cook from reading every label to identify gluten-containing ingredients. The partner eating the food becomes a scapegoat, or victim of this ideology when suffering the consequential reaction.

Marx associates ideologies with the power of the elite class, including political, economic, and even military entities (McGee, 1980). The government perpetuates ideologies with dietary standards and corporations create physical ideals that sway the public through advertisements. Media influencers such as television shows scapegoating FS people, quotes from celebrities about the GF diet, and mocking messages such as those the in comics gathered in this text collectively influence the behaviors and ways of popular thinking. Utilizing Van Dijk's (2006) definition of ideology as a "shared representation of social groups, and more specifically the axiomatic principles of such representations" (p. 115), this section emphasizes the macro-level (cultural) societal foundations such as the church, media outlets, weight-loss enterprises, and comics. Stated differently, ideologies are mandates prescribed by a higher power such as religion, from an authority such as science, or from a powerful government or corporate entity. Ideology can comprise a constellation of beliefs that shape identities and realities (Mumby, 2015). Those whose actions repudiate established norms are punished, often with public ridicule.

Comics mocking gluten are interspersed throughout this document. Humor can be a harmful vehicle, providing "individuals a greater license to express dangerous, irreverent, or even mean-spirited sentiments that would be considered inappropriate or forbidden in most 'serious' forms of discourse" (Case & Lippard, 2009, p. 241). The comics presented herein illustrate an ideological hostility to FS and CD, by way of denigrating barbs that make light of the GF diet, undermining the importance of it, and reinforcing negative and unkind behaviors toward those with CD. Laughing at a gluten-mocking comic implies agreement with the underpinning ideology. Freud (1905/2009) states:

If we keep in mind that tendency-wit is so well adapted as the weapon of attack upon what is great, dignified, and mighty, that which is shielded by internal hindrances or external circumstance against direct disparagement, we are forced to a special conception of certain groups of witticisms which seem to occupy themselves with inferior and powerless persons (p. 60).



Figure 3.1. Killed with Chicken Pesto Sandwich

Figure 3.1 emphasizes how grain consumption, deadly for some, is ridiculed by the dominant notion that being killed by something as common as gluten is laughable. This dovetails with McKerrow's (1989) concept of the *critique of dominance*, where those in power disparage the oppressed through humor. The comics illustrate this point. Those in the "powerful" (non-CD) group see the comics and laugh; whereas those in the "oppressed" group (CD or FS sufferers) often see the comics as a mean-spirited jab. These sentiments infiltrate the collective narrative.

Through acts of reflexive storytelling and assimilation, ideologies also influence thought processes, offering a socio-historical element guided by cultural contexts such as religion, ethnic group, and pop culture (Koenig Kellas & Kranstuber Horstman, 2015). Ideologies are assimilated through narrative, and narrative consists of a participant conveying a story. In the context of research, narrative refers to a substantial response (Polkinghorne, 1995) that intertwines cultural influences or ideological views (Fisher, 1989). The narrator must balance truth with motivations in a cohesive story with

significant meaning (White, 1980). Narratives create or reinforce the identity of the narrator (Bochner, et al., 1997), taking into consideration outside forces of culture, religion, and political influencers that culminate in a master narrative (McAdams, Reynolds, Lewis, Patten, & Bowman, 2011). Collectively, these stories form global and personal ideologies that influence dietary practices (Babrow, Kline, & Rawlins, 2005). Stories are integral to perpetuating family traditions, making meaning of shared life, “doing family” (Langellier, & Peterson, 2018, p. 1), and teaching family values (Koenig Kellas & Kranstuber Horstman, 2015). It is in our initial home where we learn fundamentals for what and how to eat, how to cook, how to participate in food-related rituals (de Certeau, et al., 1998; Pecchoni, Overton, & Thompson, 2008), as well as gender roles and power structures around food.

While ideologies can guide many facets of everyday life, people do not often consider their powerful influence. Countering a long-held belief in a social setting can cause discomfort and require re-assimilation, usually through storytelling, to reconcile new information with pervasive ideologies. People do not say, “Oh, that’s me just bumping up against an ideology,” when transgressing deep-seated rules of etiquette, for example. We do not have vernacular to discuss this phenomenon, but we are all well aware of it when someone contradicts expected behavior, prompting expressions or actions of disapproval, encouraging the resistor to fall back in line and conform.

Next, I explore how dominant beliefs, such as patriarchal, religiosity, sexist, and ableist convictions drive behavior patterns of commensality, particularly in opposition to the established system of ideas. Food is often the focal point for ritual, ceremony, and everyday life. Ideologies appear in my data and included systems of ideas we take as

natural and normal, such as patriarchy and ableism (disability discrimination), intersecting with food. So for those with CD living the GF lifestyle, these long-held ideologies intersect with their experiences of being in non-dominant groups. Here, I describe macro level ideologies giving examples from the participants when subjugated from commonly held beliefs.

Has a quarter of the U.S. population been fooled by a \$15 billion push to endure the stressful task of avoiding gluten?
—Bethany Econopouly & Stephen Jones, 2017

USDA as a Cultural Influencer

The United States Department of Agriculture (USDA) was created to regulate and manage the farming industry in 1862. In 1968, Senator George McGovern contracted reporter Nick Mottern to write *Dietary Goals for the United States*, using Harvard School of Public Health nutritionist Mark Hegsted as his primary resource (Taubes, 2001). Hegsted was highly influenced by the research and dietary recommendations of Ancel Keys and modeled *Dietary Goals* after them. Keys' work advocated that Americans consume only 30% of their diet from fat calories and of that, 10% from saturated fat (Taubes, 2001). These dietary recommendations relied on evidence provided by Keys' controversial *Seven Country Study*, launched in 1958. The study argued the merits of a dietary approach now known as the Mediterranean Diet. In this case, science and government comingled to create these still powerful and taken-for-granted ideologies on dietary recommendations.

Dominant ideologies can limit objective thought and may be “influenced by their own rhetoric of justification and by the ideological consolidation that prevails” (Mills, 1962, p. 27), as when Hegsted's USDA guidelines recommendations permeated the

public narrative. The Food Pyramid became the pervasive model for health and endorsements by the American Heart Association (AHA), American Medical Association (AMA), National Heart, Lung, and Blood Institutes, the National Cancer Institute, the Center for Disease Control (CDC), and the American Dietetic Associations (ADA) solidifying this dietary ideology in American consciousness (Levenstein, 2012). This confirms McKerrow's (1989) *critique of domination*, where taken for granted ideologies advocated by those in power, filter to the un-empowered in everyday talk and life. Further, as the USDA dietary recommendations were adopted, ideological slogans promoting this way of eating included:

- Watch your cholesterol intake
- Limit saturated fats
- Ask your doctor for lipid tests
- Food is fuel
- Eat to live rather than living to eat

These slogans became “symbolic systems” providing easy edicts to reinforce the recommendations (Charland, 1987, p. 148). In a more recent example, the *USDA 2015–2020 Dietary Guidelines* is a 144-page book that delineates what Americans should eat. It provides five suggestions for sustaining health, advocating shifts to eating healthy, nutrient-dense foods such as fruits, vegetables, protein, dairy, grains, and oils. It states that 177 out of a total of 328 million (U.S. Census, 2019) Americans have diseases that could be prevented by dietary adjustments and physical activity (*USDA Guidelines*, 2015, p. vii). However, the *Guidelines* do not mention CD or food allergies. This omission implies that *everyone* should eat grains and dairy, two highly allergenic foods,

constituting both patriarchal and ableist ideologies. Data from the present study indicates that 22% of respondents avoided both dairy and gluten. The expectation that Americans should “follow” guidelines the Government sets by the USDA evokes the Marxist notion that those in power determine behavior, such as what we should eat.

Millions of Americans engage in dieting with the goal of weight loss or improving overall health. Allergies and food sensitivities are growing evermore visible, and it is normal for individuals to avoid entire food groups as part of a diet or health regimen. Consider that since 1997, food allergies have increased by 50% in U.S. America (FARE, 2018). Speculation on the cause of this increase ranges from pesticide use and genetic alterations (IRT, 2018) to over consumption (Food-Allergy, 2018). The increase in food-related illness is further problematized by those who profess *food is food, eat what is put in front of you, be grateful for something to fill your belly*, and other ideologies that ignore food intolerances and allergies. In particular, these edicts alienate and stigmatize CD sufferers who must avoid every molecule of gluten as conveyed by Respondent #22:

I think the hardest part that I have with it is, like ‘dairy free,’ people don’t even question that. But if you say, ‘I’m gluten-free,’ there is a lot of ugly stigma about it. I just wonder why it is so hard for people to accept it? I used to be very offended by all of the videos on the Internet making fun of people who are gluten free. And, now, I’m like, ‘Well, that does apply to some people because there are a lot of people who do it for non-medical reasons. But they’ve kind of ruined it for those of us who don’t have a choice.’

Respondent #22 expresses frustration that her disease was misunderstood, while other food-related issues such as lactose or casein intolerance are taken seriously. She further explained that she feels stigmatized asking for GF foods in restaurants and suggests that “fad dieters” have diminished her credibility as a person with CD.

Consequent to the *Guidelines*’ recommendation of lower fat and lower sugar choices, the food industry developed many low-fat, high-carb, grain-based, gluten-containing processed foods. Americans began eating processed foods, starting with the Industrial Revolution in the 1920s (Hunt, 2013) representing a major dietary shift. For the previous two and a half million years, humans ate animal-based foods, vegetables, fruits, and nuts. Cordain remarks, “Is it any wonder we are having trouble with our diet? We are so far off base from what we are genetically programmed to eat” (Hunt, 2013).

Braly and Hoggan (2002) further suggest a bias in the USDA’s recommendation to consume six to eight servings of grains a day: “Because the USDA’s function is largely the promotion of agriculture and agricultural products, there is a clear conflict of interest inherent in any USDA claim of healthful benefits arising from any agricultural product” (p. 6). The U.S. government subsidizes highly allergenic foods such as wheat, soy, corn, dairy, and peanuts (Mercola, 2018), totaling \$13.2 billion in fiscal year 2017 (Forbes, 2018). The Big Food industry uses these ingredients to make pre-packaged foods widely served in restaurants, institutions, and available to purchase on the interior shelves in grocery stores. Consider that in 2013, baking mix and prepared food production generated \$21 billion in the U.S. alone (Statista, 2016c); sugar, \$10 billion (Statista, 2016d); frozen food, \$96 billion (Statista, 2016e); ice cream, \$8 billion (Statista, 2016f), juice, \$23 billion (Statista, 2016g); snack food, \$33 billion (Statista, 2016h); cookies and

pasta, \$24 billion (Statista, 2016i); candy, \$77.5 billion (Statista, 2016j); chocolate, \$16 billion (Statista, 2016K); margarine and oils, \$69 billion (Statista, 2016l); bread, \$39 billion (Statista, 2016m); and dairy products \$98 billion (Statista, 2016n). Collectively, the Big Food industry represents “\$2.1 trillion in annual sales, 14 million jobs and \$1 trillion in value to the U.S. economy” (Moss, 2014, Loc. 3901). These subsidized foods are the primary ingredients in processed foods (Franck, Grandi, & Eisenberg (2013), and Americans purchase processed foods 75% of the time (Poti, Mendez, Ng, & Popkin, 2014). Braly and Hoggan continue, “Popular beliefs and politically motivated promotion, not science, continue to dictate dietary recommendations, leading to debilitating and deadly diseases that are wholly or partly preventable” (p. 6). The economy’s reliance on these ubiquitous, subsidized foods may be one reason why those with allergies to them are often maligned. Respondent #26 conveys how this manifests for her. She notes, “Food issues can bring out the worst in people. They are very, very, very emotionally sensitive about food.”

The *Guidelines* assert: “Everyone has a role in supporting healthy eating patterns” (2015, p. 63), but the omission of allergies from such a central document discounts the prevalence of food allergies among 60 million Americans (Hyman, 2013). This omission could be one reason that the idea of the gluten-free diet triggers resistance, such as from Levinovitz (2015) who published a book entitled *The Gluten Lie*, saying gluten intolerance is probably not real. This sentiment starts with the *USDA Guidelines* (by omission) and is magnified through many forms of media, food service providers, and the medical community.

Patriarchal Ideologies

Patriarchal ideologies center on male superiority, men knowing best, and secret bonds between men such as keeping transgressive behavior from women. This transfers to attitudes about food. For example, Respondent #54's chef friend told her that the workers in the kitchen say, "What they don't know, won't hurt them" implying that if there is a little gluten in the food, it is OK. This reflects a patriarchal ideology where the male chef has superior intelligence and that anyone asking for a GF meal is inferior and lacks agency to assert the need for a GF meal. This attitude extends from the kitchen to the restaurant's manager when informed of the chef's comments told Respondent #54, "Don't rock the boat." Attitudes like these make dining out a game of Russian roulette for the person with CD. They must trust that their requests for a "clean" GF meal is taken seriously by the server, chef, and even the restaurant manager.

While most look forward to eating out, pairing flavors with wine, and the excitement of what a chef prepares that day, those with CD must assess every ingredient before consuming a single bite. Many restaurants do not offer GF dishes, or if they do, they often disclaim that foods served may be cross-contaminated, forcing the CD patron to decide whether or not to eat. Titchkosky (2009) discusses how not providing "access" exemplifies an attitude of ableists who view the disabled as an inconvenient exception. This "I know best" attitude is illustrated in Moore's (2013) report of a chef saying, "People who claim to be gluten intolerant don't realize that it's all ... in their heads. ... I serve 'em our pasta, which I make from scratch with high gluten flour" (p. 36). Similarly, Respondent #45 describes a NYC restaurant manager's reaction to her request for gluten-free food, saying he "went off about food allergies, and how it's a conspiracy, and how

nobody really has it.” This illustrates how the burden of proof rests on the CD sufferer, who may react to as little as “100 mg of gluten” (Green & Jabri, 2003, p. 386). Both of these examples illustrate ideologies of patriarchy where the chef and manager imply they know more than anyone else about gluten intolerance, discounting the need for a strict gluten-free diet, and objecting to patrons asking for it. This attitude depicts the “punishment” that one endures when defying existing ideologies.

This is further illustrated by Respondent #20’s report that a waiter said, “Oh, you’re one of *those* people,” when she asked for a gluten-free meal. Respondent #64 describes a waiter at a fast food sandwich shop who asked her if her GF request was a “preference or an allergy,” presumably to discern the severity of her dietary needs. Respondent #25 says, “I’m a little on the shy side, so usually at the dinner table when we are out to eat with friends, everybody quiets down when I talk to the chef.” She conveyed her embarrassment as her table companions listened carefully to her order, as she broke the existing ideology of not asking for special treatment and ultimately not fitting in. Instead of dealing with it, she said, “I usually go in or call beforehand, rather than having everyone sit and listen to my conversation.” Most feel vulnerable when hungry, and nothing to eat can cause more extreme responses as shown by Respondent #41: “When I ordered at a restaurant specifying my needs, and the waiter got to someone else, my dining companion said, ‘I want EXTRA gluten,’” thus undermining Respondent #41’s request. Mockery such as this is perpetuated in the following comic:



Figure 3.2. High-Maintenance Wants Latte

Figure 3.2 depicts a middle-class white woman with CD ordering a latte to suit her dietary needs. The barista insults the woman’s character, implying “she is self-absorbed and high-maintenance” discounting the woman’s intellectualism and possibly the years of suffering with CD before understanding that a complete elimination of gluten is her only relief. She dismisses the woman’s request and mocks her as one who pretentiously dares to step out of line when asking for requesting accommodation for her special needs. This comic perpetuates the ideology that the “server knows best” or is the “ultimate judge” of whether or not the patron needs GF food, discounting her intelligence, and putting her health at the mercy of the server.

Dieting is a woman’s project.
—Corrinne Bedecarre, 1971

Sexist Ideologies

Sexist ideologies surrounding expectations of the female body and eating habits abound in this study. Ideal women are thin, beautiful, submissive nurturers. Women transform themselves with food choices, often building identities around the type of diet

they follow by announcing: “I’m vegan,” or “I’m a vegetarian.” Food-identities can lead to “alternative, healthy ways of understanding personhood from food-related experiences...to construct personhood” (Curtin & Heldke, 1992, p. 4).

At some point in their lives, most Americans have tried a weight-loss or other diet to promote health. The effect of dieting is failure for 95% of the population (Statistics on Weight, 2011), and most dieters gain *additional* weight within a few years (Statistics on Weight, 2011). Websites targeted at weight loss generate \$842 million, according to a six-year trend analysis conducted by Market Data Enterprises (2016) pointing to why dieting ideologies for women permeate cultural practices. In the past sixty years, diet fads have swept the nation with promises of weight loss and health, with catchy brand names such as: “Skinny Bitch” and “The Zone,” or medical sounding names such as “Blood Type,” “Glycemic Index,” and “Macrobiotic.” Some are named after people, such as “Jenny Craig” and “Atkins,” or places like “South Beach.” Thornton (2011) discusses the “entrepreneurialization” of women and how “networks of authority, expertise, and government” (p. 399) contribute to the way ideologies are enacted. Similarly, dieting women are “governed through their own freedom and subjectivity” (p. 401), as they flip through a magazine full of food ads and diet plans with thoughts of experiencing a fulfilling life with a slimmer, healthier body, thus upholding the ideology that a “fit, healthy body ... is the best fashion statement” (Scott, 2017). Michel Foucault would likely equate regimented diet plans with the neoliberal view of government, as a way to exercise control over others using surveillance (Foucault, 1977), where individuals willingly engage in self-improvement, “optimizing productivity and fitness” (Thornton, 2011, p. 420). Dieters ultimately succumb to temptations such as a holiday, birthday

celebration, or any number of other culturally-driven events that require participation by eating foods that are not on the diet plan (Thornton, 2011). Ideologies about diet adherence equate to a “perfect” woman with a “perfect” body. Constant dieting situates women under particular scrutiny by peers for both diet-plan adherence and visible results. When not compliant, women often have feelings of insecurity, shame, guilt, and negative self-image (*Science Daily*, 2011).

The Weight Watchers (WW) Corporation cultivates a powerful diet consciousness, as the largest weight loss company in America with 3.2 million subscribers (SEC, 2017) and Oprah Winfrey on the board. Weekly meetings attract approximately 1.3 million subscribers who learn accountability, and earn rewards for compliance and goal attainment (SEC, 2017). Celebrities such as Charles Barkley, Tina Fey, Jessica Simpson, Jennifer Hudson, Jenny McCarthy, and Sarah Ferguson have endorsed WW, providing ideal standards with which to compare behaviors (Schultz, Nolan, Cialdini, Goldstein & Griskevicius, 2007). Publicly awarded trinkets and charms, group meetings, and semi-public weigh-ins create a culture of constant surveillance (Lockford, 1996) and reinforce mastery over one’s body as the symbol of success (Bordo, 1993). The popularity of WW has created ideologies on how women “perform” womanhood, perpetuating these ideals where “culture’s grip on the body is a constant, intimate fact of everyday life” (Bordo, 2003, p. 17), and self-esteem is linked to body image (Harter, 1999). Excessive dieting foments frustration and is further magnified by additional restrictions after a CD diagnosis.

In a culture of dietary surveillance, women with CD are subject to a host of assumptions around their requirement to maintain a GF diet. Some women experience

suggestions their GF adherence is actually a form of self-punishment. Others are accused of trying to evoke sympathy, as exemplified by Respondent #41's mother. She dismissed her daughter's illness, noting, "You are just trying to get attention." Some even face outright denials such as when Respondent #4 reports that her daughter "didn't believe in" the need for a GF diet. In each of these cases, the CD sufferer is called upon to defend, reiterate, and justify her medical condition to others who are influenced by forces beyond her control.

Medical Professional Ideologies

Though CD "is humankind's most prevalent genetically linked disease... [occurring] more frequently than type 1 diabetes, cystic fibrosis, or Crohn's disease" (Fasano & Flaherty, 2014, Loc. 556), doctors are often untrained in testing for CD and influenced by many of the same dominant ideologies described above. For example, Shanahan (2017) states that doctors rely on sound bites such as *everything in moderation*, when discussing diet choices in appointments lasting an average of seven-minutes. This over-simplified ideology does not serve those with FS or CD, yet it is common practice due to insufficient nutritional education in U.S. medical schools (Adams, Kohlmeier, Powell, & Zeisel, 2010; Vetter, Herring, Sood, Shah, & Kalet, 2008). Lack of training and reliance on taken-for-granted ideologies on the part of physicians exacerbates the desperation felt by those who remain ill and un- or misdiagnosed.

Many participants in this study report they were originally misdiagnosed with ailments including brain tumors, cancer, or IBS before discovering they had CD. For example, Respondent #45 reports that she was originally diagnosed with stomach cancer and then pancreatitis, enduring two separate endoscopies because the doctor neglected to

test for CD, likely because he thought it was rare, though in fact it affects “2.5 to 3 million” Americans, but only 2% are currently diagnosed” (Fasano & Flaherty, 2014, Loc. 551). Respondent #45 lived with this misdiagnosis for months until learning she had CD. Once diagnosed, her doctor offered no dietary guidance, so she relied on Internet research for information. Several respondents report having to discover foods they could eat on their own. Respondent #5 describes a lifetime of illness starting when she was young and was told she would “outgrow” it. She had stomachaches as a child, thyroid issues, and a miscarriage in her 20s. Finally, in middle age she flew to a specialized clinic in New York, where she was diagnosed with CD. There, they told her that people do not grow out of it, and that it was likely the cause of her miscarriage and thyroid problems. She lived with it until middle-aged without even knowing she had it, and likely would not have been diagnosed if she had not been a woman of means, education, and determination.

Medical tests for CD are largely inadequate, often accurate only when the patient is in the later stages of the disease (Fine, 2013). At present, the best diagnostic tool is to eliminate foods for a period of time, then reintegrate them while monitoring physical responses to the food (Cohen, personal conversation, June 1, 2005). Thus, in many cases a medical professional never sanctifies a CD diagnosis. Seventy-three percent of participants reported a CD diagnosis by doctor, often describing years of suffering and misdiagnosis before learning they had CD. A medical professional did not diagnose the other 27% of the study participants, which may cause doubt about their resolve to adopt the GF lifestyle. For example, a person may associate symptoms of brain fog or arthritis with gluten consumption and notice that symptoms subside on a GF diet. However,

without a medical test to “confirm” the diagnosis, the person never feels certain about her condition. This was true for Respondent #22. When family members judged her diet to be too extreme, Respondent #22 felt pressured to get a medical diagnosis to put their skepticism to rest. She endured the “gluten challenge,” which requires a person to consume from 0.2 to 30 grams of gluten-containing foods daily for three months, a daunting and potentially dangerous proposition for a person with symptomatic CD (Bruins, 2013, p. 4617). She reports:

I had done the gluten challenge for a month, and I went to have the test done, and on the day of the test, I was pretty miserable by then, and I got to the doctor’s office that was going to do it. He said, ‘Oh, I don’t know exactly how to do that, and I didn’t realize that’s what they were asking me to do,’ which kind of shocked me that he was not aware of it.

Respondent #22 was plagued with symptoms during the month before the test, only to learn the doctor was not educated on how to do it. Complicating things further, doctors do not agree on the duration of the gluten challenge before testing, which may alter the results (Bruins, 2013). Several ideologies are at play in this scenario, including the lack of education and cavalier attitude of the doctor, the self-doubt and feelings of having to prove her disease to her family, and her family’s ableist, doubting attitudes toward her resolve that she was ill.

Ableist Ideologies

The “ideal body” is a mark of success in life because it implies that one has the “ability to work” (Corbin, 2003, p. 264) and make a contribution to society. Ableist ideologies surround the expectation that bodies are reliable and fit, discriminating against

the disabled, pressuring them to be able-bodied. As defined by Kumari-Campbell (2009), “disablism” is “a set of assumptions (conscious or unconscious) and practices that promote the differential or unequal treatment of people because of actual or presumed disabilities” (p. 4). Being sick occasionally is excused (Stone, 1995), but being disabled is a burden to hide in order to be accepted. Davis (2005) concludes, “because we assign so much importance to meeting able-bodied standards, we sometimes compromise, or even sacrifice, other things we prize even to attain the mere appearance of being able-bodied” (p. 159). Foucault’s notion that “mastery and awareness of one’s own body can only be acquired through the effect of an investment of power in the body: gymnastics, exercises, muscle-building, ...[and that the] glorification of the body is beautiful” perpetuates high expectations that permeate Western culture (Joranger, 2018, p. 57). These practices lead to obsession with food, weight, and the development of disordered eating behaviors. People, and women, in particular, attempt to exert control over their bodies, striving to be the best (Bordo, 1988).

When it comes to CD, many people who live with the disease state that other family members have a “for *them*, not *us*” (Jones, 2013, p. 70) mentality, insisting “it’s your disease, not mine,” and ignoring genetic markers or symptoms that indicate they may have it, too. This ableist ideology causes people with CD to feel alienated from their families. Whether accidentally cross-contaminated, intentionally sabotaged, or incessantly urged to consume gluten-containing foods, those with CD live in a day-to-day state of vulnerability. Respondent #12 reflects on a family gathering where he asked his aunt about the cheesecake ingredients. She swore it was her recipe and that there was no gluten in it. The next day, he was sick. He called his aunt who then admitted she

purchased the cheesecake and had not checked the ingredients. She either did not fully understand his condition or did not take it seriously. Worse, Respondent #1 reports a situation where he was deliberately sabotaged by an ableist coworker:

I have my own area and my own desk where I cook and fix my food. Well, one of the guys over there doesn't really get my allergies. He thinks it's funny. One day, he thought it was funny to go and eat a burrito and then go by my desk and literally take his hands and wipe them all over my desk, my plate, my chair, and all over my little area. He thought this was, you know, funny. Well, I ended up getting sick later. And we found out he did this on video camera, so we actually have it on camera.

Another ableist scenario that haunts those with CD is the event of a national disaster where the Red Cross provides foods. Respondent #5 describes her concern: "They talk about when there is disasters and the Red Cross will come in and bring food to people. What do they bring them? They bring them [gluten containing] sandwiches. I wouldn't be able to eat that." Further, elderly people with CD wishing to live in a retirement home may be turned away because the kitchen cannot comply with their restrictions. Currently, there are only three gluten-free elderly homes in the United States. These ableist ideologies mandate that everybody can eat gluten. This likely stems from the position of the *USDA Dietary Guidelines*.



Figure 3.3. Hipsters with Red Cross

Food Ideologies

When considering ideologies concerning food practices, Pratto et al. (1999) argues that they are dogmatic edicts on preferred conduct. For example, popular health food adages include *you are what you eat*, whereas etiquette-driven edicts mandate *ladies don't chew with their mouths open* (Cooks, 2009, p. 101). These maxims drive behavior patterns and set social standards. Burke (1969) indicates that ideologies evolve from moral decrees. Laws can be defined in a variety of ways, including rules of etiquette that govern acceptable social behavior, rituals for traditional ceremonies, and practices to assure health and welfare. Conquergood (1991) positions this notion differently when considering communicative performance by stating that it “embodies experience grounded in historical process, contingency, and ideology” (p. 187). This rich definition illustrates the inveterate nature of ideologies and how they evolve unconsciously, manifesting into actions, speech, and thoughts, specifically when engaging in commensality.

Further, food is powerfully symbolic at celebrations and holidays (de Certeau, et al., 1998). Familiar food rituals are disrupted when a family member learns they have food sensitivities, especially if the FS person suffers dire physical consequences. The health of the FS person is usually a concern for the entire family and requires both redefinition of family practices and development of new stories to adjust for the changes imposed by a diagnosis. Families may exert significant effort to create mealtimes that occasion sharing, conversation, and commensality—key features of familial socialization (Ochs & Shohet, 2006). Successful meal planning considers the flavor pairings, food

temperature, seating, table scape, and a host of other details. Goldstein (2010) describes the relationship between eating, sharing, and joy: “If we did not enjoy our own bread—passionately, intensely, even sophisticatedly—then the giving of that bread to the other would constitute nothing more than altruism” (p. 41).

Americans take a great interest in the foods they share during mealtime, especially during holidays with extended family. Attempting to make traditional foods with alternative ingredients often requires advanced culinary skills that the average cook does not possess. To put it lightly, “cooking is fraught”, with many things to consider to accomplish a successful meal, especially when trying to accommodate someone with CD (Bowen, Elliott, & Brenton, 2014, p. 21). Etiquette rules ordain that guests should consume the foods offered by the host or hostess, as Respondent #48 notes, “It is insulting to the host for the guest not to eat. It looks bad and makes people feel uncomfortable.” This punctuates a long-held ideology that cooking is a labor of love, and consuming the food means sharing the love. Consider the effort of bread making, a staple at most meals: making the dough, kneading, rising, kneading again, shaping, rising, baking, and cooling. It takes several hours from start to finish. To reject the bread and, thus, the hours of labor can be a personal affront. Food preparation often symbolizes the mother’s love for her family (DeVault, 1991). “Doing cooking” is rich in tradition and ritual, bringing to mind the women spending the holiday carefully preparing food for the festive dinner (de Certeau, et al., 1998, p. 153). The expression of love transfers from the food made by the women, to the food consumed by the loved ones. This sentiment is echoed by Respondent #65:

My mother-in-law made a bunch of different food for Thanksgiving, and I couldn't eat it, and she was offended that I wouldn't eat anything but the ham ... that was pretty much it. She didn't understand that I wouldn't eat the other foods [to preserve] my safety and my health.

In this example, long-established traditions override objective thought on the part of the mother-in-law, possibly “influenced by [her] own rhetoric of justification and by the ideological consolidation that prevailed” (Mills, 1962, p. 27). The mother-in-law's plans and expectations for the Thanksgiving meal were disrupted by the daughter-in-law's special needs. From the mother-in-law's perspective, she labored over the preparation of the meal, likely using recipes that were passed down in her family for generations. Her food preparation practice constituted an act of love that was rebuffed by her daughter-in-law. De Certeau, et al. (1998) state, “We eat what our mother taught us to eat—or what our wife's mother taught her to eat” (Loc. 3969); thus, rejecting the traditional foods implied rejection of the mother-in-law's family, and a breach of accepted etiquette rules. When a guest in someone's home, one is expected to willingly eat the foods offered by the hostess, complimenting her on the foods. Refusing what is offered whether cake or tea, is considered an insult.

Rules of etiquette provide guidelines on how we ought to live. Edicts include: *if it is made with loving hands, it will nourish your body, clean your plate, etc.* These edicts become ideological expectations at the dinner table, indicators of tact and class. Not following them leads to punishment as Respondent #46 states, “if you don't eat the food provided by the hostess, you won't be invited back.” For this reason, CD can lead to a diminished social network. Respondent #46 continues to explain that her in-laws no

longer include she and her husband in dinner invitations. They told her, “Well, we won’t eat what you can’t eat in front of you.” This sentiment ignores the fact that there are many GF alternatives they could serve instead. The in-laws seem to emphasize what they want to eat over the social elements of a shared meal.

Similarly, Respondent #22 shares a story about how her mother could not understand why traditional holiday foods were no longer permissible with the GF diet.

She reports:

We do family reunions, and I have always been in charge of the food. And getting [mom] to understand that there were things that I couldn’t do anymore, like family favorite dishes, that I couldn’t participate in, or even make. It was really hard. She thought that I was mad that I was in charge of the food. But it wasn’t that. It was just that I couldn’t [eat it]. That’s probably one of the hardest things.

Further, Respondent #22 says that both she and her daughter have CD, and they believe their father does, too. Her father spent a great deal of time being very sick after eating wheat and gluten-containing foods. Her mother refused to believe it, operating under the ideology, *all food should be gratefully consumed* and suggested that his malady was *in his head*. Gradually, though, the mother realized gluten was making all of them sick. She now feels bad for being so harsh and insensitive to her family.

The lack of understanding of CD and the need for a strict GF diet permeates American society and culture. Social norms do not instruct us on how to deal with situations like the ones described above; thus, ideologies dictate behaviors, but do not provide a language to discuss it. Food ideologies are further perpetuated by celebrities’ quips in the popular press.

Chef Anthony Bordain said, “Your body is not a temple, it’s an amusement park. Enjoy the ride,” and Julia Child said, “The only time to eat diet food is while you’re waiting for the steak to cook.” These quotes endorse dietary indulgence, positioning the restrictive diet as a form of repression. James Beard emphasizes this by saying, “Food is our common ground, a universal experience.” In fact, food cannot be “universally experienced” by individuals with food allergies. Respondent #32 expresses feelings of exclusion when describing a hurtful memorable message from her sister. Respondent #32’s sister invited her to share a delicious gluten-containing food, before remembering that she had CD. Upon remembering, she noted, “It sucks to be you.” The context of the sister’s comment implies resistance to Respondent #32’s defiance of social norms, punctuating gluten ideologies that prevail in the U.S. culture.

Gluten-Centric Culture

Cultural influences targeting gluten as the punch line influence the development of ideologies. America’s fascination with gluten-free jabs extends to news headlines, television shows, and even to T-shirts and greeting cards. Etsy.com sells T-shirts with slogans that say: “Extra gluten,” and “this shirt is gluten free.” Doormats are available too that say, “No gluten or BS allowed beyond this point.” There is a greeting card that says, “Every moment is a gift until someone puts flour in the gravy.” Media, in their various forms, influence the emergence of ideologies. Media depictions of GF dieters and CD sufferers are overwhelmingly negative. Consider the *New York Times* headline, “The Myth of Big, Bad Gluten” (Myth, 2015), which aligns gluten with the fairytale “big, bad wolf.” *Business Insider* published a YouTube video on, “Why Gluten Sensitivity (a \$15 billion dollar industry) is fake,” which casts doubt on non-celiac gluten sensitivities

(NCGS). Further, *Business Insider* calls Tom Brady's GF, dairy-free diet "insane" (Brady, 2017). Even politicians malign gluten. President Trump weighed in on the GF bandwagon, saying he will be, "the gluten-freest presidency in history" and Tweeted a slogan "Dam tootin, no gluten" (Ishac, 2018), though it was clear he did not advocate a GF diet. This inauthenticity makes his Tweet appear as a feeble attempt to attract liberal, educated voters who pay attention to their diets. In his political campaign, Senator Ted Cruz stated that if elected President, he would not provide gluten-free meals to the military, in order to direct spending toward combat fortification (Wellness, 2016), discounting those with CD, implying that GF meals are a waste of money. Gluten intolerance is thought to affect primarily affluent white women. Though it has been previously pointed out this is untrue, the reason for this may be because women in this socio-economic group have the means to seek specialists and persist until diagnosed. Trump, Cruz, and others subtly malign the privileged, targeting the working class.

Celebrities also quip gluten vituperations. Etiquette writer Celia Rivenbark says, "As far as I can tell, the biggest side effect of a gluten sensitivity is that you actually become the number one symptom: a huge pain in the ass." As Gellner (1991) points out, ideologies are "the touchstone of both truth and falsehood" (p. 123–124) and as most people with CD will admit, their restrictions do indeed make them a "pain in the ass," defying the ideology *keep your nose clean and head down*. Talk show host Jimmy Kimmel has expressed the common position of reluctant tolerance: "Some people can't eat gluten for medical reasons... that I get. It annoys me, but that I get" (ABC News, 2018). Respondent #63 (Celiac.com) reacts to the Kimmel comment as follows:

I found the Jimmy Kimmel video very telling. It exemplifies what happens to society's point of view when something becomes 'trendy' whether there is a genuine problem some people face or not. It can be bad enough when popularity of a diet/fad/idea/opinion causes harm to businesses and industry, but it's even worse when it gets down to an individual's health and what amounts to casual poisoning. ... What a shame we have to deal with that sort of jaded disbelief.

Per Hilton's (2016) study, self-harming behavior could translate into a person with CD taking a risk of consuming the slightest amount of gluten due to peer pressure by celebrities. Both Rivenbark and Kimmel cue audiences that anyone who asks for dietary accommodations is annoying.

There is no shortage of research associating the effects of sociocultural media influences on behavior. Noteworthy examples include Ata, Ludden, and Lally (2007) who report that females are pressured by the media to lose weight. Further, media exposure, along with feedback from family and friends affected "eating attitudes and behaviors" (p. 1033). Similarly, males exposed to advertisements with muscular definition compared with males exposed to neutral ads reported high levels of physical dissatisfaction afterward (Agliata & Tantleff-Dunn, 2004). Likewise, females who viewed advertisements depicting the ideal feminine body were more likely to convey dissatisfaction with their bodies afterward (Levine & Smolak, 2002; Yamamiya, Cash, Melnyk, Posavac & Posavac, 2004). Dunkley, Wertheim, and Paxton (2001) asserted that, "media messages form a general background" and that "sociocultural agents reinforce those messages" (p. 266).

Messages similar to those expressed in the comics are replicated on late-night television, in situation comedies, in memes, YouTube videos, and other forms of media. These messages, further perpetuated by family and friends, become accepted commonsense truths affecting thoughts and actions. For example, Anderson, Carnagey, and Eubanks (2003) report that those who hear violent lyrics tend to display more hostility and aggressive thoughts than participants who were exposed to neutral songs. Eunhee and Kim (2004) found that exposure to media violence were highly correlated with bullying behavior. Humans mimic what they are exposed to. Villanti, Boulay, and Juon (2010) found that media exposure to cigarette smoking influenced viewers to smoke. Huesmann and Miller (1994) pointed out that the homicide rate has increased dramatically in the U.S. since World War II and speculate that it may be due the increase in violent behavior depicted in mass media since the 1950s. In the same way, incessant exposure to negative media on the GF lifestyle is likely to influence interpersonal interactions.

Gluten bashing is a common theme in American media, as depicted in an episode of *South Park*. In this case, however, it favors those who are following the diet. In it, town council members dread encountering Mr. Mackey because he only talks about how well he feels on the GF diet. Later in the episode, a USDA representative speaks on the recommended diet for Americans, stating that gluten won't cause catastrophic illness and is safe to eat. From the audience, Mr. Mackey yells, "if it is safe, then eat it." With some reservation, the USDA representative drinks the distilled gluten from his presentation table. Seconds pass, and the USDA representative seizes in pain. A moment later, a key body part detaches from his body and flies around the filled auditorium. Mayhem results.

The citizens of South Park hurriedly rush home to throw away all of the foods in their kitchens containing gluten. The “gluten police” go to homes with Geiger-counter-like devices and discover a beer can (beer contains gluten) in a citizen’s home, escorting the homeowner to “gluten prison” a closed-down Papa John’s pizzeria (*South Park*, Season 18, Ep. 2). The episode concludes with the USDA turning the food pyramid upside down, making grains the food to eat the least of, and meats the food to consume predominantly. In the typical irreverent *South Park* way, the episode perpetuates the ideology that gluten is the target for derision.

Consider an episode of the comedy series *Modern Family*, when a young guest of the family asks for a gluten-free breakfast. The mother in the family greets his request with disgust. The show ends with the GF guest abandoned on a deserted island, forgotten by the entire family. Sentiments like this one may transfer to restaurant or home behaviors where someone with CD may experience similar “violence and aggression” as seen on television (Huesmann & Taylor, 2006, p. 393).

Gluten ridicule seems to be a uniquely American phenomenon. Many respondents in this study report that their illness was taken very seriously in other Western countries, and they received safe meals. Realizing that “ninety-nine percent of people who have a problem with eating gluten don’t even know it” (Hyman, 2018), Americans may soon understand the importance of taking GF requests seriously, though scientific headlines confuse the public. Misleading “scientific” headlines giving only limited sound bites contribute to negative gluten ideologies. Society relies on scientists, the medical community, and the press to synthesize and share new health discoveries and findings, so they may benefit the population at large. Scientific discoveries are largely understood to

be credible and reliable sources of information, which then crystalize into ideologies and guide meaning. Contemplate how an authoritative voice reporting the news headline such as, “Gluten-free diet not healthy for everyone” (CNN, 2018) may affect a person who then adjusts her diet based on this “distorted knowledge” (Therborn, 1980, p. 8). Another headline asserts, “Health issues ... are sometimes mistaken for gluten sensitivity” (U.S. News, 2018); therein, the article describes ailments that imitate symptoms of gluten sensitivity, casting doubt on those who eliminate gluten from their diet.

Scientific ideologies presented in the media often omit valuable information and introduce inaccuracies into public consciousness. Scientific fact is a powerful “mystic” source of firmly held ideologies. When considering ideologies derived from “scientific fact,” Habermas (1970) asserted that perspectives “emerge from the critique of dogmatism of traditional interpretations of the world and claim a scientific character...keeping power relations inaccessible to analysis and to public consciousness” (p. 99). This notion suggests that the public follows surface-level scientific evidence without questioning it. These “facts” may have unintended consequences in relation to food and food sensitivities. For example, the nightly news lead may assert, “More people go gluten free than need to, study finds” (NBC News, 2016), which may cause suspicion or doubt among those living with someone following a GF diet. Such news reports rarely explore the research in detail, but the headline has nonetheless influenced thinking.

Ideologies of Bread

Extreme dietary applications disrupt traditional practices and challenge firmly held “truths.” For example, those who shun “white bread,” are considered elitist or health-obsessed. The ideology of white bread questions, *if you have the gall not to eat*

white bread, what kind of American are you? Burke (1969) would term white bread as metonymy, meaning it is a poetic device, symbolizing normalcy, imbued in many common phrases. For example, *putting bread on the table* refers to bread as sustenance. *Someone's bread and butter* define a person's trade. The word "*companion*" is derived from the Latin root "panis" (bread), referring to sharing a meal with someone. *Breaking bread with another* signifies human bonding rituals. *The greatest thing since sliced bread* refers to an innovative invention. *Knowing which side your bread is buttered on* implies knowing who is paying your way, *bread* is a synonym for money, and *man doesn't live by bread alone* means there is more to life than foraging a living.

In addition to phrases, rules of etiquette specifically dictate behaviors when handling bread at the table. When no bread plate is present, one is expected to place the piece of bread on the left side of the table (Baldrige, 1990). Crumbs on the left side of the table could cross-contaminate the neighboring diner who may have CD. Bread is to be used as a tool to sop gravy or to move peas on a fork (Baldrige, 1990). If the breadbasket is sitting to your right, it is your duty to cut it (holding it in the bread cloth) and pass it to the person sitting on your right (Baldrige, 1990). These rules could pose a dilemma for the person with CD. First of all, it is considered impolite to discuss health problems at the table, so an explanation is impossible. Handling the bread, and having the crumbs from the basket fall onto the plate when passed would potentially contaminate the polite diner's plate. Finally, the person with CD would have no way to sop gravy or to put peas on the fork, but after being contaminated with crumbs would likely elect not to eat the food on the plate at all. This poses another problem. Waiters do not typically take full plates back, even if the silverware is displayed in the "I'm finished" configuration. They

may exclaim, “Is there something wrong?” Which, of course there is, but it would be rude to elaborate.

Bread ideologies are influenced by pop culture. The Oprah effect influences behavior (Kinsella, 1997). Oprah’s casual endorsement of virtually anything can influence America’s consumption of it. For example, Oprah recently declared publicly, “I love bread.” If Oprah loves bread, then everyone else should too, and those who do not love it, find themselves contradicting Oprah. The expression “living under an ideology” means incorporating these beliefs and practices as a set of vetted, safe edicts that reduce the need for deeper thought, transforming into mindless narratives. Furthermore, bread is so integral to Western culture that entire industries are devoted to making substitute flours, so those who cannot consume gluten can participate in bread rituals. We live in a gluten-centric culture. Those who adopt a GF diet find ways to mimic wheat bread using alternative GF ingredients, illustrating how McKerrow (1989) describes the impact of the *critique of domination*, conforming to “taken-for-granted” norms (p. 91) to “sustain social practices which control the dominated” (p. 92). Those determined to find GF lookalikes for bread consider a meal without it to be incomplete (de Certeau, et al., 1998). Alternatively, McKerrow’s (1989) *critique of freedom* could be implemented where the person reconsiders her options and mindfully decides to consume naturally non-gluten containing foods such as rice or corn. In this case, the person elects to renounce firmly held beliefs, rising above the dominant norms, to consciously change her behavior and regain health. Food practices consist of rules that Counihan (1992) says are ways people “construct reality” (p. 55). To wit, food-related social interactions rely on everyday ideologies to maintain the status quo.



Figure 3.4. Let's Put an End to the Gluten Free Trend

Though ideologies stemming from religion, government publications, media, and pop culture often guide behavior, we are not always aware they are driving our actions. These associations are deduced anecdotally. Ideologies are the impetus for how people explain their behaviors and decisions, which creates a consciousness that impacts social practices (Rohan, 2000). Comic Artifact #3.4 illustrates an ideology that “gluten free” is a fad, perpetuating the notion that those who request GF meals are trend followers. It is an example of how these comics negatively influence the collective consciousness about “gluten free.” It states, “Let’s put an end to the gluten free trend,” perpetuating the ideology that CD is not a real or serious illness. It creates an environment of suspicion for those requesting GF foods and instills doubt among others. For example, a person might see this comic as she prepares food for her extended family, which includes a request for a GF option. While she may already feel inconvenienced by the request to alter her menu, the comic may increase her resentment over having to make special dispensations, or may cause her to question the relative’s true need for a GF diet. Whether conscious of it or not, the comic casts a shadow of doubt on the validity of those requesting GF foods. Those who consume gluten are often polarized by those who do not. For example, the Carrollton Market Restaurant in New Orleans held a celebration of gluten calling the

eight-course dinner “(It’s) A Celebration of Gluten (Bitches)” as a way to refute gluten-free meal requests (Carreltonmarket, 2018).

Religion and Gluten

When families of Judeo-Christian faith gather in the act of commensality, they reenact the Lord’s Supper, where Jesus ate the last meal with his disciples, breaking bread and drinking wine. The Lord’s Prayer states, “Give us this day our daily bread.” The word “bread” could be taken literally to refer to a wheat-based baked good, rather than metaphorically meaning “food.” Bread, for some in Western civilization is a sacred food that must be consumed every day in order to be a “good Christian.” Mealtime is sacred in the family unit, no matter the socio-economic status of the family (Montanari, 2006). As Burke (1969) asserts, “in the *meaning* of food there is much rhetoric, the meaning being persuasive enough for the idea of food to be used, like the ideas of religion, as a rhetorical device of statesmen” (p. 173). The rhetorical sanctity of food-related rituals translates into dominant ideologies that govern behavior. These rituals dictate behaviors passed on as traditions for generations.

Althusser (1971) points to the church as the source of widely-held ideologies. Gramsci takes this notion of ideology a step further in relation to religious practices when he associates people’s perceptions of the world to their conduct (Forgacs, 2000). The practice of communion in the Catholic Church emphasizes how the Pope’s perception about gluten permeates other levels of social interaction. As mentioned in chapter one, the Pope issued an edict that all hosts served in the Catholic Church should contain gluten. Specifically, he said:

Low gluten hosts (partially gluten-free) are valid matter, provided they *contain a sufficient amount of gluten* [emphasis added] to obtain the confection of bread without the addition of foreign materials and without the use of procedures that would alter the nature of bread” (Vatican, 2017).

The prescribed amount of gluten exceeds the 20 parts per million U.S. standard defining GF, and means that Catholic individuals with CD must consume gluten, if they wish to partake of the Holy Sacrament. Reading further in the letter, those with CD are not considered or exempted in this edict. This exclusion has an “othering” effect on the roughly twelve million Roman Catholics who have CD worldwide (BBC.com). The Pope’s edict has other implications as well. The implication that *a little gluten won’t hurt you* becomes a dominant ideology that transfers from church to other social interactions. Many view the Pope as a person with exceptional powers, and even as the human closest to God. If the Pope says it is acceptable for those with CD to consume a little gluten, it must be acceptable at the dinner table, too.



Figure 3.5. Is That Gluten-Free?

In Protestant religions, bread represents the pure flesh of Christ. The Pope’s decree corroborates the requirement to keep the recipe for bread pure by saying, “It is a grave abuse to introduce other substances, such as fruit or sugar or honey, into the bread for confecting the Eucharist” (Vatican, 2017). GF bread recipes require substitutions such

as guar gum and/or xanthan gum to replicate gluten's elastic texture. The Pope would likely consider xanthan or guar gum "foreign material." He notes, "Hosts should obviously be made by those who are not only distinguished by their integrity, but also skilled in making them and furnished with suitable tools" (Vatican, 2017). This poses a problem for those with CD. Respondent #51 describes how she was able to procure bread from the Sisters in a specific convent, and the process she endured to ensure a GF host:

When first diagnosed, I got low-gluten host from the Sisters. It was rigmarole because the Priest has to remember. I can't go to Holy Communion anywhere else, like at a wedding or a funeral. It is the most isolating thing about having CD.

Cultural Practices with Bread

Chapter one described the use of bread as an integral part of weddings. It is also a mainstay in the family dinner. Bread is such an important aspect of the Western meal that "...one does not joke around with bread... [bread] is perceived as the necessary foundation for all food..." (de Certeau, et al., 1998, p. 87). Christians refer to bread as the "staff of life." Behaviors influenced by ideologies impact rituals and customary practices such as ceremonies or traditional menus, which provide comfort and stability for participants (Boyer & Lienard, 2006). Further, sharing indigenous food with other community members can perpetuate valued customs and rituals. Bread has been an integral part of the meal for all classes of society as noted by Montanari (2006) who said, "To live on one bread and one wine that is, to share food, is in medieval language an almost technical way of signifying that one belongs to the same family" (p. 11).

Respondent #17 describes a time she felt alienated by the family during a holiday ritual. Her husband's large Italian family has a gift exchange every year, where names

were drawn prior to Christmas. She explained how participants could make requests for what they would like, and she always specified, “no food items.” One year, an older aunt drew her name. She describes the situation as follows:

So, I obviously [requested] gift cards because the easiest thing to get me is a gift card, and she got me an [gluten containing] Italian pastry! That was my gift. Of all people! And, I had to act graciously. And, this is what pissed me off...my husband did not have my back. That is what made me most angry. ... I would've loved for him to say something. And, I sat there and had to be thankful about it.

Respondent #17 felt alienated that she could not participate in the customary ritual of breaking the bread and sharing it with the other family members on Christmas morning. Alternatively, if Respondent #17 were able to consume the food item given by the aunt, she may have responded with gratitude coupled with feelings of belonging by consuming their Italian traditional foods. Food, in this case, became a symbol of alienation from the family. In contrast, food can be a bridge used to break down cultural barriers.

Respondent #10 narrates a situation she heard about in an airport where food was used to mitigate tension. She considers how, as a person with CD, she would not have been able to participate:

There was a flight that was delayed, and it was right after 9/11, and somebody announced that there was a need for an Arabic translator at gate whatever and everybody got a little scared. And then the woman who stepped forward to be the Arabic translator discovered that it was an old grandmother who was visiting her grandchildren in this country, and she just needed help understanding what was going on. And not only that, but she had cookies. And before they knew it, instead

of being afraid of this old Muslim lady, everybody was sharing her cookies. And I thought, ‘How wonderful it is that we can share the gluten-containing food to make it clear that we are all one people.’ And I just thought, ‘if I had been there, I would’ve been hiding in a corner somewhere, and they would’ve thought that I was scared, or unfriendly.’

Respondent #10’s story illustrates a social dilemma when one cannot explain a dietary issue because of a language barrier, and how the lasting impression of refusing the food would be negative. As mentioned above, etiquette ideologies mandate that one take what one is offered, a cultural practice that implies goodwill and acceptance. By not taking the cookie, she would risk offending the elderly woman. Taking a cookie would require that Respondent #10 handle gluten, and depending on her level of sensitivity, this gesture could cause devastating results. Alternatively, accepting a cookie and tucking it in a napkin to be discarded later would also present a risk of contamination, or potentially being observed discarding it, another alienating move. Rather than risking a social infraction, Respondent #10 may have felt it would be better just to take the cookie and suffer the consequences.

Extended family holiday meals pose a serious social dilemma for those with restrictive diets. Social norms dictate that food is shared around the table, but the food is often contaminated with gluten. Montanari (2006) summarizes the complications of commensality, saying, “Eating together does not necessarily mean all is love and harmony. If the table is the metaphor for life, it represents in a direct and exacting way both membership in a group and the relationships defined within that group” (p. 3). The awkwardness of non-compliance to social norms and family expectations is spotlighted

with specific examples from interview respondents. Respondent #45 comments on being mocked for her illness:

I think that people should realize that it is an incurable autoimmune disease disorder. You don't make fun of somebody who has cerebral palsy, or something like cystic fibrosis, and say: 'Oh, that cystic fibrosis person causes so much trouble.' We just never say that. But the celiac people, they're totally free to be mocked.

Respondent #45 expresses the common double standard expressed throughout this chapter, applied to CD but not to other illnesses.



Figure 3.6. Crippling Gluten Allergy

Summary

This chapter presents situations endured by those with CD who find themselves subjugated from dominant ideologies. I begin by discussing institutions that originate hegemonic belief systems, such as the government's *Dietary Guidelines*, which permeate all aspects of American culture. I then offer illustrations of how these macro level influencers affect patriarchal, sexism, ableism, and etiquette food-related ideologies. Allowing participants to speak, I present the narratives of those with CD who find

themselves in opposition to dominant ideologies to illustrate the awkwardness that results with non-conformance.

Whether kind-hearted, or mean spirited, dominant ideologies manifest in cultural practices and evolve to accommodate new truths affecting social relations (McKerrow, 1989). This section highlighted macro-level ideologies and provided examples of how deeply-seated truths affect expectations in social settings, and how they are adapted with illness. The next section focuses on mezzo-level of family and the micro-level of identity transformation to understand how gluten-avoidant adults narrate and navigate the impact of food sensitivities on commensality experiences and social interactions using the CNSM as the lens. Chapter four calls upon participants to convey retrospective stories and memorable messages describing interpersonal behaviors cultivated through the family storytelling process in order to make sense of how to incorporate the disease into daily life. On the micro-level, I explore how participants with CD adapt and transform their lives after undergoing the homeostatic shift of acceptance.

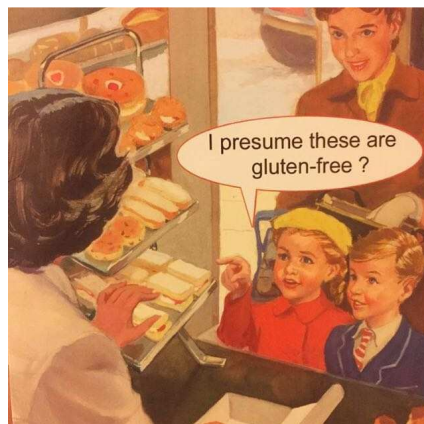


Figure 3.7. I Presume These Are Gluten-Free?

CHAPTER FOUR: FAMILY AND IDENTITY INTERSECTIONS

Jean's Story - A Thanksgiving to Remember

It was Thanksgiving Day, 2017, and we traveled to Chicago to be with my husband's loving sister, her children, and their children. My dietary needs had been discretely addressed by my niece, the hostess of the dinner, in a series of thoughtful emails inquiring what would be safe for me to eat. I was reassured with her concern and did not bring my normal array of foods. I was further encouraged when I arrived for Thanksgiving dinner to see that my niece had set aside a plate of greens with sliced apple and raw walnuts on top for me. It was a compassionate gesture, and I felt included and loved.

What would have been an unremarkable Thanksgiving memory abruptly changed. The husbands of the younger set decided to forge a new Thanksgiving tradition using the turkey fryer in the backyard. They removed every food they could scavenge from the refrigerator and prepared it to fry. A bag of Gold Medal flour was plunked on the counter, as guests eagerly dipped Oreos, macaroni and cheese, ice cream, pickles, baby food—anything they could find—in the flour. A white dust covered the counter where the Thanksgiving foods were sitting, and flour particles were visible in the air. My salad sat uncovered a few feet away. I had recently learned that I react to airborne flour from sitting in a pizzeria for two hours. In that moment, all of the preparations made to provide a “safe” meal for me were erased. My salad was tainted with flour dust, as was

the air I was breathing in that warm, cozy kitchen. What had moments before felt like a loving, compassionate environment suddenly changed to a battleground with me fighting to avoid cross-contamination. I also had that sinking feeling of realizing I was quite hungry – the bacon wrapped dates that I risked eating (a risk because they were baked in an oven that was also used for baking gluten-containing foods) had long worn off, and there was literally nothing safe for me to eat at dinner. Everything was contaminated with flour dust. I didn't even have the usual peanut butter Lara bar in my purse to sneak-eat in the bathroom.

The event was held in my niece's home, where I felt welcomed, but with whom I really hadn't spent much time. Though she had good intentions, my plight was the least of her concerns. Nearly nine months pregnant, she was trying to entertain a group of 26 people—a group who was developing fun new traditions. The last thing she needed was a needy aunt asking for special dispensation.

The majority of the guests were enthusiastically rolling everything in flour and plopping the blobs into the fryer. My feelings shifted from inclusion and love to isolation and fear. Worse yet, even remaining in the general area where the party was taking place posed danger for me, as I risked breathing airborne flour. Leaving the scene would be further isolating, making me feel like an outsider in the family. And wearing a mask (I had one in my purse) would be humiliating. So, I moved to the adjoining den where the football game was on TV, pulled my turtleneck over my nose and discretely breathed through it. During dinner, I pretended to eat, switching plates with my husband when nobody was looking, so it appeared that I ate the food reserved for me. I starved until we got back to the hotel late that evening and ate from my "safe" foods before retiring.

Coming to grips with the gravity of my disease is what imprinted this story in my memory. The shift from mundane ritual behaviors, to survival mode, trying to avoid inhaling or ingesting gluten was when I entered into the liminality phase as I redefined “truths,” juggling participating in rituals and realizing that engaging in activities that are normal for most, are health-threatening to me. This ultimately resulted in my homeostatic shift.

Introduction

This chapter begins by showing how macro-level ideologies discussed in chapter three intersect with the theme of family adaptation. Data analysis revealed that participants struggled with the question: “How do I come to terms with being gluten free (GF) with my friends and family, particularly when food and gluten related ideologies are constraining us?” Using the CNSM theoretical framework of retrospective storytelling, the communicated narrative sense-making, and memorable messages components, I present narratives to illustrate how participants answer this question, delineated by “battlegrounds” or places for potential conflict, such as the immediate family table, the extended family table, restaurants, school, work, and church. Each of these battlegrounds presents a different set of ideologies to be navigated with sense-making narratives in order to regain eudemonia in the mezzo-level. It is at this level where retrospective storytelling and memorable messages interplay to transform the identity at the micro-level. A question emerged from the data analysis on the micro-level: “How do I come to terms with being GF, particularly when food and gluten related ideologies are constraining me?” Through participant retrospective stories, I elucidate how the micro-level individual transformational theme intersects with ideological themes, as the

individual with celiac disease (CD) redefines identity when experiencing the homeostatic shift after which all is veiled with the knowledge of the disease. Transformations of identity convey best practices and adaptive lifestyles enacted by participants who have achieved a sense of wellbeing living with CD.

This chapter examines ideological postulates applied to interpersonal communication between family members to illustrate how “truth” evolves for the individual with CD and his or her cohabitants as established ideologies are redefined. I begin by discussing why the CNSM offers the optimal theoretical framework for this analysis and explain why the homeostatic shift is a salient addition. Next, I describe the mezzo-level battlegrounds to explain how participants navigate disrupted ideologies in the familial, day-to-day setting, and the micro-level battleground to illustrate how medical ideologies thwarted accurate diagnoses. I then discuss the micro-level identity transformation that occurs when a person lives with a chronic disease that affects all aspects of life.

CNSM and Narrative

The CNSM theory is designed to research how those disrupted with illness or other life-altering situations use narrative to assimilate meaning in family interactions (Koenig Kellas & Kranstuber Horstman, 2015). Significant components of the theory used in the present study are highlighted in chapter one. Here, I provide further insight into two components of communicative sense-making selected for this study: retrospective storytelling and memorable messages. The nucleus of the CNSM theory rests in familial story-sharing and interactional sense-making using narrative or storytelling (Koenig Kellas & Kranstuber Horstman, 2015). Fiese and Sameroff (1999)

describe how the narrative framework in familial interactions serves to unify a collaborative sense-making perspective, starting with the affected individual.

Comparably, the retrospective storytelling component of the CNSM enables me to extricate deeply personal stories and memorable messages from participants; describing ways that “normal” behavior was disrupted by the disease. Narratives reinforce the assimilation of new information in a continuous negotiation to seek reassurance, shun contradictory rhetoric, and develop adaptive strategies (Festinger, 1957).

Narratives are defined in this text as “storytelling,” specifically, the assimilation process as it relates to a person who has been diagnosed with a life-altering disease. The CNSM retrospective storytelling heuristic differs from conversation in that it unfolds with the telling of a sequence of events, develops into an apex, and culminates with a character metamorphosis (Creswell & Poth, 2018). Further, components of the self-reflexive narrative consist of an interviewee conveying a story with a plotline, scene, characters, conflict, and resolution (Burke, 1945; Foss, 2018; Hinyard & Kreuter, 2007; Polkinghorne, 1995). Koenig Kellas and Manusov (2003) discovered that the more coherently individuals conveyed episodic, consequential stories, the better they assimilated and comprehended events. Similarly, participants in my study who were able to convey their stories described situations fraught with feelings from everyone involved, ranging from compassion to denial, as they learned to view foods differently, and as other family members’ opinions evolved. Some participants share compassionate stories where family members assisted in cross-contamination prevention. Contrastingly, other respondents told narratives of uncooperative, non-compliant family members.

Familial stories evolve in the telling and retelling as more facts are assimilated, and as other family members join in. Throughout this (sometimes emancipatory) process, narrative is the coping mechanism, geared toward sense-making (Koenig Kellas, 2018). Characters include other family members, and their reaction to the individual's need for different or restricted foods. These "characters" may respond with resistance, moving toward the resolution to adhere—or not. Those in the individual's social circle may operate under old "commonsense" understandings from rhetorical and cultural ideologies, causing conflict until everyone adopts new "truths" derived from re-assimilating ontological meaning (Bochner, et al., 1997). Data in my study reveals that physical setting also plays a significant role in navigating food and gluten ideologies. Behavioral expectations and narratives differ from one setting to another, posing unique constraints on those with CD. Therefore, I separate the mezzo analysis into "battlegrounds" including the home, the table, extended family meals, restaurants, work, and church; and the micro-level medical examination room. These evolving narratives contribute to redefining the ill person's identity.

Stories of those with CD can evolve to advance a united perspective, shared by family members, who collectively assimilate the "new normal" to reform old beliefs and values (Koenig Kellas, 2013). Individual narratives develop as the person adjusts to the diagnosis and as the body manifests the disease. What may have "worked" as routine in the early stages may need to be completely altered in later stages (Charmaz, 2006). These adjustments require family members to adapt as the person navigates ever-changing physical and possibly mental manifestations and may cause strife and bewilderment in

familial interactions. Further, family members may discount a hereditary disease as an act of denial, fearing they too, may develop it (Manoogian, et al., 2010).

In this chapter, these dynamic narratives are interpretively analyzed on the mezzo and micro levels. My interpretation considers not just surface stories in the data, but also the broader paradigms that form meaning, associating macro-level ideologies with mezzo-level behaviors displayed by friends and family (Deetz, 1982). In time, “CD stories” for families who adapted become integrated in the family’s collective lore, and participants describe new traditions developing to replace food-centered rituals. In contrast, non-adaptive families cause strife and risked the health of the person with CD. Charland (1987) argued that individuals transform themselves under their evolved identity. In spite of social contradictions, individuals with CD revise their personal “truths” and convince others of the same. Identity transformation requires an acceptance of restrictions imposed by the disease, both physically and socially, and often problematizes the interplay between the individual and friends or family. Familial compassion or lack thereof affects day-to-day social interactions. Both individual and family member opinions form through storytelling and retaining memorable messages.

The CNSM memorable-message construct is an important component of interviews in this study. As a reminder from the discussion in chapter one, memorable messages are defined as “interpersonal messages... remembered for a long time [that] have a profound influence on a person’s life” (Knapp, et al., 1981, p. 27). They “prescribe rules of conduct for solving a personal problem” (p. 36), such as the golden rule and other edicts espoused by family members (Smith & Butler Ellis, 2004). Messages and rules expressed by parents and other loved ones impact lifelong thoughts

and behaviors (Dorrance-Hall, et al., 2016). Memorable messages often imprint on the mind during a time of significant change, such as being diagnosed with disease, when feeling vulnerable and keenly aware of loved ones' reactions. These stories and memorable messages influence behavior patterns and self-reflective acceptance or rejection of newly formed truths (Knapp, et al., 1981). Both hurtful and compassionate messages resonated with my study participants, who described the ways the illness altered their thinking after comments by others.

Redefined Truths

The present chapter centers on sense-making through the storytelling process to examine the ways in which people confront this new identity through a revelatory erosion of what they once thought to be truth. This evolving process revealed three themes in my analysis: revised ideological truths, familial adaptation, and identity transformation. Redefined truths shattered previously taken-for-granted beliefs, requiring individuals to defy gluten-free (GF) diet denials and oppressive etiquette, religiosity, sexism, patriarchal, and ableist ideologies. A taken-for-granted truth such as the dietary ideology, *all in moderation* may be a “truth” for most people, even in the medical field (Shanahan, 2017); but for a person with food sensitivities (FS) or CD, moderate amounts of an allergen or gluten could make them very ill—even kill them. Therefore “truth” for those with FS is drastically different than “truth” for the able-bodied general population. This disconnect explains the unease that results when a person with CD, non-celiac gluten-sensitivity (NCGS), or FS attends a dinner party and finds foods containing “moderate” amounts of allergens. What the host considers safe may poison a person with CD. The person with CD may then share her “truth” to explain why she is not eating. The

exchange may entail doubt or arguments from the host, and rebuttals from the person with CD. Ultimately, it may require the person with CD to support her arguments with evidence from credible sources to convince the host. In time, (hopefully) the host, family members, and those preparing foods for those with FS, NCGS, and CD can agree on the revised truth that “moderate” amounts of allergens are not acceptable. Negotiating and agreeing on revised ideologies are derived through narrative and storytelling practices.

Often the “new truths” evolve as new information is discovered. For example, a newly diagnosed person may not believe she is that sensitive, clinging to the ideology, *a little won't hurt you*. When faced with a tempting baked treat, she may indulge in just one bite; if symptomatic, she may be surprised to experience an array of symptoms that force her to rethink that “truth.” These revised (post-diagnosis) truths are formed and reformed through development of new stories over time, and are conveyed to friends and family as they evolve. Such continuous “revisions” can be a source of frustration for family members who understand one set of rules, only to have them revised as the individual with CD learns more. The discomfort experienced during the time of redefining “truths” is one phase of the homeostatic shift.

Homeostatic Shift

Coined by Cannon (1932), the word “homeostasis” refers to a constant state of equilibrium experienced by the body when all systems function properly. When this steady-state is disrupted, the body strives to re-achieve it. For example, the body maintains a steady temperature of 98.6 degrees. When this is threatened, the body adjusts to preserve its desired steady state. Cannon cites nutrition, psychological, and physical elements as potential homeostatic disruptors of the nervous, cardiovascular, muscular,

skeletal, lymphatic, respiratory, and digestive systems. Similarly, after a person is diagnosed with a disease such as CD, “truths” are altered to the point where participants in the study declared that their “steady state” of existence would forever be changed. Once diagnosed, his/her current homeostasis is disrupted with the realization that old “truths” no longer work. They experience subjugation from ideologies. Rituals are disrupted. The newly diagnosed enters into an uncomfortable period of doubt and unrest. In order to maintain a new state of equilibrium, they report the need for drastic adjustments in their ongoing lifestyle. The person enters into a state of liminality. Liminality, derived from the Latin word “limen” describes a transitional time when one reaches a threshold, where old beliefs no longer serve (Andrews & Roberts, 2015). The liminality phase is the in-between status (Nicholson, Babin, & Briggs, 2017), a restless and unsettling state, where old “truths” are challenged and new “truths” have not yet formed. In this state, a person may have contradictory responses to situations as they resolve and assimilate (Hout, 2017). It is in this state where new trust parameters, personal level disclosure policies and adaptive behaviors depending on venue are re-defined, and tested. Though most pass through the liminality phase, some stay in it indefinitely such as in the circumstance of non-familial adaptation or lack of assertion on the part of the person with CD (Simpson, Oster, & Muir-Cohrane, 2018). My research reveals the need to identify the time when mundane life events are altered, forcing the person into the liminality phase. For those that exit this phase with newly defined “truths” and resolutions, everything thereafter is veiled in the new revelation and a new level of homeostasis is established. I term this process the “homeostatic shift,” or the realization that all future events are informed by the knowledge and circumstances of having the

disease. I describe the moment I entered into the liminality phase in my Thanksgiving story—the moment when I realized that social and familial life, as I had known it previously would be forever altered by my gluten-avoidance needs. It was unsettling because I knew I would have to redefine how I attended and participated in all future social events. It was a phase of experimenting with bringing my own food to social events, politely, but unapologetically, and deciding what details about my disease I would reveal depending on the occasion and to whom. Bruner (2002) describes the cognitive process as one where the ill person identifies notable issues through conveying a story where something unexpected occurs, presenting a “plight ... and resolution” (p. 15). Plight and resolution are illustrated with the realization that change must happen. The liminality phase is the transitional phase where new “truths” are defined and the homeostatic shift is where the new state of equilibrium is enacted in *everlasting* encounters. Since it has lifelong implications that change the norm for the affected person, the “homeostatic shift” process disrupts the individual’s equilibrium to a different (permanent) constant. For a person with CD, homeostasis is disrupted with the realization that the disease must be recalled with every bite of food consumed. Gluten cross-contamination threatens CD sufferers virtually everywhere they go, as it exists in consumable products; in cosmetics; on surfaces of desks, tables, chairs, trains; and even in the air at bakeries, home kitchens, and restaurants. The liminality phase occurs when the person who experiences a life-altering event such as the diagnosis of a disease, experiments with personal guidelines to protect him or herself for all situations, redefining virtually every situation and venue encountered before with new procedures. Once solidified, the homeostatic shift is when these practices become the new steady

family meals as complicated events to derive revised truths both for CD individuals and family members. Finally, I conclude with a discussion of how identity transformation results in adapted lifestyles for some participants.

Data Analysis of Survey

Key participant demographics indicate that 91% have a diagnosis that led to adopting a GF diet, 51% have been diagnosed for eight or more years, and 49% have been eating the GF diet between four to seven years. Fifty-two percent (52%) feel that the way they were diagnosed, whether by a medical professional, or self-diagnosed affects how seriously other adult(s) living in the household take their dietary requirements, while 23% report that the way they were diagnosed, doesn't affect the behavior of co-habitant adults at all. Seventy-three percent (73%) were diagnosed by an MD, and 46% report that they check-in annually with a medical or health professional to monitor their health/diet, while 39% get medical, health, and dietary information from online sources. Eighty-seven percent (87%) report that they are not confused about which foods are GF, and 62% report that other adults in the household are not confused about which foods are GF. Further, ninety-two percent (92%) report that they are not confused about what constitutes a "healthy diet." Fifty-nine percent (59%) did not feel that other adults in the household resented their dietary restrictions, and 55% almost always eat meals with adults in the household who follow the same dietary guidelines.

When it comes to preparing meals, 36% never eat GF meals prepared by other adult(s) in the household, 46% sometimes do, and 18% always do. Sixty-six percent (66%) trust that meals prepared by other adults in the household are safe. Fifty percent (50%) report that they are very satisfied with the relationship(s) they have with other

adult(s) in the household, and 86% of the respondents report that other adult(s) in the home never interfere with their ability to follow a GF diet. Data for this study show that 85% of the respondents were female and 92% were white. Thirty-four percent (34%) have a Bachelor's degree, and 23% have a Master's degree. Thirty-three percent (33%) have a household income between \$75–149K, and 36% earn less than \$74K. The remainder preferred not to indicate their income. Details of the survey questions and complete percentage breakdown can be found in Appendix C.

Mezzo

Celiac is a social disease.

—Gonzalo Bacigalupee & Alaksandra Plocha

The Family Meal is a Complex Event

Challenging episodes can disrupt family norms, causing those involved to pause to make sense of the situation. In order to exist peacefully, the person with FS must have cooperation from other family members around dietary constraints (Beasley, 2011). Every food must be assessed for gluten-containing ingredients prior to consumption. Others in the family need to learn to identify safe foods and practice cooking techniques to avoid cross contamination, which can occur as simply as when a serving spoon is taken from a gluten-containing macaroni salad and inserted into a non-gluten containing coleslaw. The learning process involves a revision of narratives around which foods are suitable and which are not. Navigating new “truths” with evolving ideologies, combined with the realization that gluten cross-contamination is ubiquitous, emphasizes the routine dilemmas faced by those with CD.

When considering the tasks involved in creating a pleasant Thanksgiving, such as “planning, shopping, scheduling, preparing, serving, navigating table interaction,

cleaning, packing away, ... stocking supplemental ingredients, as well as knowing and accommodating family member diets, preferences, and allergies” (DeVault, 1991, p. 28), the family meal is a “complex social event” (p. 3). Traditional American meals like Thanksgiving dinner regularly include multiple gluten-containing dishes like stuffing, dinner rolls, green bean casserole, and pies. Altering the menu can cause familial rebellion as depicted in Comic Figure 4.2.

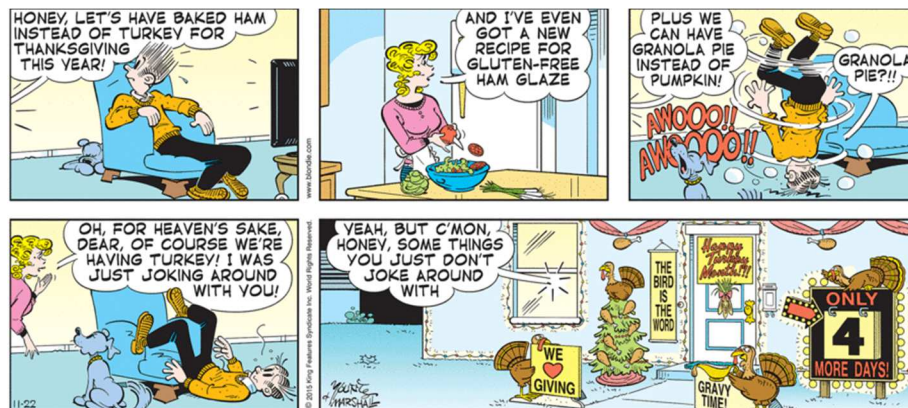


Figure 4.2. Some Things You Just Don't Joke Around With

The next section discusses how those with CD come to terms with being GF with friends and family, when facing food and gluten ideologies in battleground settings. I'll start with the family home and the dinner table, a place where many participants reported challenges in familial adaptation through retrospective stories, memorable messages, and subjugation by firmly held ideologies.

Home and the Table Battleground

High-functioning families work together to assimilate the new information and adjust accordingly (Koenig Kellas & Trees, 2006), whereas dysfunctional families are likely to create a hurtful, vulnerable domain for the ill person (Vangelesti, Maguire, Alexander, & Clark, 2007). A premise of this thesis holds that familial dysfunction

occurs when members remain intransigent to altering firmly held ideologies. They resist changing opinions and cause grief to anyone who attempts disruption. Whether harmonious or disharmonious, people living together typically need to cope with the needs of the disabled person or face relationship changes (Frank, 1995). Revised stories help redefine the experience, creating the prospect of being “successfully ill” (Frank, 1997, p. 131).

Lack of cooperation and compassion around CD dietary needs can end relationships, which some respondents report. Goffman (1971) emphasized the impact of social negativity, specifically when one feels they have been treated unjustly. Rooted in sociological research, Orbuch (1997) similarly described how people interpret unsettling events by embodying what other people say to come to closure. Respondent #10 describes how she attained closure in a dysfunctional relationship with this episode that ultimately broke up her marriage:

Probably the most hurtful thing for me was for years of our marriage, every Saturday morning my husband made waffles. That was the one meal of the week that he made. And then when I needed gluten-free waffles he said, ‘I would never make those.’ In all those years, I thought he was making them for me, and he was really making them for his own idea of what a good waffle was.

Respondent #10’s spouse communicated food ideologies about breakfast waffles and altering ingredients to make them GF did not meet his expectations. His hurtful memorable message “I would never make those,” still resonates with Respondent #10, years after their divorce. She describes this incident as the straw that broke the camel’s

back on her marriage, when she realized that her GF needs were not a priority for her (now) ex-husband.

To complicate matters, nuances of allergies are seldom understood by those who do not live with them, and medical tests for CD are not provided on a routine basis (Metchikoff, 2014). The medical community seems to resist CD testing and diagnosis, often causing those with the disease to live with no diagnosis for long periods. During this time, they may lose credibility with family members, as they struggle to understand the cause of their symptoms. For example, Respondent #17 describes how her husband repeatedly challenged her to eat gluten, asking, “How much can you have? Can’t you just have a crumb?” Her husband did Internet research, to prove her wrong when she resisted. Respondent #17 says, “That was very, very stressful.” This exchange illustrates the non-adaptive response where she could have continued in the liminality phase of unrest and no resolution, but she ultimately moved to their vacation home in California, leaving her husband in Florida to consume what she termed as his “beige” (gluten-containing) food. By moving, she shifted her homeostasis to a new state of equilibrium describing how she cooks beautiful, colorful meals for herself and makes it a daily practice to go to the farmers market to purchase interesting vegetables to accompany her dishes.

Faced with the challenges of a GF lifestyle, some couples forego eating together. Respondent #60 describes his sadness that he and his wife no longer share meals. He reported, “She goes out to eat most of the time, and I make safe food for myself at home.” His wife refuses to cook or consume GF meals, preferring to eat at restaurants with her friends. Respondent #60 feels isolated and distanced from his wife because of his extreme sensitivity to gluten, unable to participate in her social events, but remains

content with his resolve to avoid cross-contamination. This type of non-adaption can disrupt relationships.

Food preparation is often considered a woman's role in traditional marriages (DeVault, 1991). Non-compliance to the husband's pressure for gluten-containing foods may cause strife in the marital relationship. In Jackson's (1985) study, 40% of people with CD did not comply with the diet because it was too difficult. Noncompliance can lead to a host of health issues, including lymphoma (Green & Jabri, 2003). While 95% of the participants in my survey reported they never cheat on the GF diet, 38% were worried they may be cross-contaminated by others in the household, and 35% felt others in the home resented their diet. Further, since GF foods are expensive, the family may not be able to afford separate meals. Or, perhaps the meal-preparer may not have time. A woman CD sufferer might decide, for example, that it is easier to comply with her husband's desires than fight for a change. Many respondents report similar observations, indicating that family members preferred to ignore CD rather than adopt the restrictive GF lifestyle. Respondent #62 articulates a memorable message around GF restrictions, when sharing her sister's observation on her diet: "I wouldn't want to be like you." Though harsh, it is understandable why someone not suffering with a multitude of CD symptoms would say this when observing the limitations of a GF lifestyle and home.

A non-gluten free home for those with CD is similar to an alcoholic working in a bar, or living in a home full of liquor. The threat is constant, causing high levels of anxiety (Groh, Jason, Davis, Olson, & Ferrari, 2007). When describing food allergies, Mandell, Curtis, Gold, and Hardie (2005) found that events triggering anxiety include, "1) any new incident of accidental exposure; and 2) the discovery of new information

regarding potential risk.” This is pertinent to family members dealing with food sensitivities or a hidden disability because of its twofold implications. First, the family environment, if hostile, may cause more intensity and difficulty for the affected member. Second, the manner in which the person with CD processes conflict is significant.

Respondent #50 describes a hostile scenario in her non-gluten-free home:

Oh, I get gluten contamination all the time, especially from my husband. And he doesn't realize it. He'll be making a sandwich, and he will grab whatever jelly he wants. He shoves the knife in, spreads it back and forth on the toast and shoves it back in the jelly. So, it is cross-contaminated. That little teeny-tiny bit will bother me. It will make me sick.

Because her husband refuses to have a gluten-free household, Respondent #50 lives in a threatening environment and a permanent state of liminality. The husband feels he “knows best,” a patriarchal response to the wife's needs, causing her to be poisoned on a regular basis. Respondent #50 says his lack of cooperation causes her daily strife. To avoid conflict, she avoids the foods that could possibly be contaminated such as the open jelly in the refrigerator. Consequently, she has not reached the homeostatic shift because she and her husband have not come to a mutually agreeable resolution.

Similarly, Respondent #7 describes the situation she endured with her adult cohabitating daughter before coming to terms with the seriousness of her diagnosis:

She gets ‘pissy’ and she says things like, ‘God this has nothing to do with me, I can't bring anything into the house.’ She wants to bring gluten-containing foods into the house to eat with her friends in her room. I had to put my foot down. I said, ‘you guys can't eat gluten in the house. If you and your friends want to eat

gluten, you have to do it at a restaurant, or you have to stay outside. You need to rinse your hands off. Don't even come in here and touch my doorknob. You just need to leave that crap outside. If you've had a cookie that you had in your room, and I come in there and love on you, or if you come out and kiss me, then I'll get sick.'

Regarding attitudes toward eating, Arroyo and Segrin (2013) point out that when a family member, such as Respondent #7 in the above transcript, "experience[s] constant criticism, conflict, and control, [it] would not allow family members to express their thoughts and feelings, nor allow them to develop the proper skills necessary to build and maintain significant and meaningful relationships" (p. 403). This negativity can disrupt familial relationships. Respondent #7 reached the breaking point, causing discord with her daughter. She described getting continually cross-contaminated from her daughter's negligence. The daughter was not taking the mother's needs seriously. By saying, "God, this has nothing to do with me," the daughter demonstrated a non-adaptive ableist response, making the disease "her mother's" and not acknowledging possible heredity. Interestingly, the respondent also describes her daughter's small stature, halitosis, and migraines, which are all symptoms of CD (Wangon, 2009). Her daughter maintains (erroneously) that CD skips a generation and refuses to be tested. Meanwhile, Respondent #7 describes her homeostatic shift, now requiring that her "house be the place that [she is] safest," taking ownership of safety and her disease. Respondent #17 describes a more cooperative kitchen scene:

When I was first diagnosed, my husband obviously didn't have to deal with it, so he would still eat his gluten, and it was just too stressful because of the cross-

contamination. We had two different toasters, two different jars of peanut butter, two different everything. And then there were crumbs everywhere, and finally we went to a gluten-free household.

Respondent #17 describes how she and her husband changed their habits to avoid cross-contamination. After struggles and reaction episodes in the liminality phase, they ultimately decided to implement a gluten-free home. This couple quelled Respondent #17's anxiety by coming to terms with her dietary restrictions through cooperation, together shifting their home-based homeostasis.

The home is a prime battleground for those with CD. However, the challenges of adaptation carry over to the extended family holiday meals and at friend's tables.

Holiday, Extended Family, and Friend's Tables Battleground

One discerning decision for the person with CD is disclosure, determining if and how to convey the new circumstances to friends and family. This is done through narrative and storytelling. Often, the story must be told and retold in order to garner understanding and cooperation from friends and family; past behaviors no longer instruct future ones. For example, if a person eagerly consumed everything at the Thanksgiving table last year, but foregoes stuffing, pumpkin pie, dinner rolls, and even gravy because of a new diagnosis in a subsequent year, the person with CD may be challenged. He or she may be called upon to explain these new behaviors. The person with CD may appear inconsistent and fickle to family members. Foods once thought of as "good" are now considered "bad." This can cause conflict and feelings of alienation on both sides. Hosts may be insulted, and the person with CD may be stigmatized by other family members, and perhaps even excluded from future invitations to extended family meals. Narratives

and family-meal folklore have suddenly been altered, which causes all involved to readjust their perspectives in order to understand the new physical needs of the family member. Additionally, family members need to be resilient to change. Struggling between the unpleasant choices of not eating, risking cross-contamination, or bringing separate foods, Respondent #31 describes an extended family that has not adapted to her needs:

All my family lives out of state in Texas. We see them over the holidays. For Thanksgiving, I bring my own gluten-free turkey, potatoes, and bread. We've tried to educate the extended family members, but I think because we see them so rarely it is easily forgotten. And, I really don't like making people accommodate for me, especially large groups of people. I would rather just provide my own food rather than make people worry.

She describes a situation where she prefers not to impose her needs on her family's meal, saying that it is too much trouble to educate them. Her adaptation strategy is to arrive a day ahead to shop for "safe" foods for the holiday meal. In this case, Respondent #31 has given up trying to educate her extended family because of personal reluctance and their lack of interest in accommodating her needs. Other respondents, however, described harmonious adaptations to familial rituals.

Bruner (2002) focuses on knowledge paradigms, and how they shift when faced with health disruptions. Bruner (1985) describes how stories connote nuanced associations through a "paradigmatic cognition" (p.11), as a way of categorizing key elements for quick reference. Paradigmatic cognition serves as a kind of shorthand for comprehension, where an individual avoids the need to relearn the same things by

drawing on past experiences. When a paradigm shifts because of illness or dietary restrictions, all of that perfunctory knowledge must be reassessed. For example, to most, a birthday cake signifies warmth, happiness, and a symbol of love. Consider a newly diagnosed diabetic attempting to control glucose levels with dietary restrictions. That birthday cake now signifies soaring glucose, sickness, and potential coma, blindness, or even death. People who have diabetes have to “think differently” (Frank, 1997, p. 6). The paradigmatic meaning of the birthday cake has been altered from the diabetic’s perspective. Bruner (1985) contrasts “paradigmatic cognition” with “narrative cognition” (p. 11), where stories are instruments to understand social interactions and behavior. The shift in the diabetic’s perspective of the birthday cake illustrates the paradigmatic condition, or what the cake used to signify; narrative cognition reflects how it must be viewed differently because of the physical responses that require this reassessment. Other family members are forced to contrast their earlier concept of a birthday cake in light of the constraints implied by diabetes.

Changes to archetypal foods like birthday cake deviate from expectations and force a new narrative to emerge (Bochner, et al., 1997). Respondent #60 describes how her family embraced a paradigmatic shift (Bruner, 2004), when they altered their tradition from birthday cake to climbing a mountain to celebrate her 50th birthday. The family worked together to attain a successful climb. This type of retrospective storytelling is an example of how interactively told stories form to alter family customs as they come to terms with the illness of one member. Stories evolve through narrative as “narrative writes us; narrative writes family” (Ballard & Ballard, 2011, p. 80). Revising narratives is a major part of the acceptance process for the disabled. Or, in a cohesive, cooperative

situation, new foods and recipes become the status quo and the family willingly adjusts to it. One way this could occur is for the family to view the dietary changes as “ours” (versus “yours”), indicating they are approaching it with team spirit (Rohrbaugh, 2012). For example, Koenig Kellas (2005) examined family triads, asked them to decide on a family story to tell together, and revealed themes of cooperative accomplishment, overcoming adversity, and achieving shared objectives. Respondent #56 conveys her family’s cooperative attitude about CD, which they had not heard of before her diagnosis. They said: “We’re all in this together.” Respondent #56 says this compassionate memorable message helped her come to terms with her disease because she felt she had her family’s full cooperation.

A changing story of one family member also redefines the stories of other family members (McAdams, 1993). As pointed out by Charmaz (1983) in studies on the ill and the ensuing “loss of identity,” narrative cognition considers elements of bodily limitations and emotional mindset (Polkinghorne, 1995) in order to shape the narrative. Further, cognition must take into consideration the abilities of family members to understand. Returning to the birthday cake example, others in the family would need to agree that a cake made with traditional ingredients would be harmful to the person with CD. If cooperative, they may substitute a traditional cake with one that is made with gluten-free ingredients, or make other concessions to adapt the menu and still celebrate the occasion. This requires a willingness to alter inveterate beliefs and ideologies, as the diagnosed person assimilates a new identity. Harter (2009) extends this notion, asserting that narrative affords the listener to stretch his or her equilibrium to understand another’s perception of reality.

Respondent #14 conveys an example of positively coming to terms with GF constraints in describing her first post-diagnosis Thanksgiving. She reports she was initially stumped as to what to serve, so she made cheeseburgers without buns. To this day, her family jokes about that first Thanksgiving, making it an integral part of their family lore. Family adaptation is further illustrated in Respondent #41's retrospective story: "We made [GF food] a fun thing, to find places to go such as GF bakeries and places when we travel, or places we wouldn't have otherwise gone to when at home." She describes GF chocolate doughnuts her husband found at a bakery 40 miles away, and how he would occasionally get them for her as a treat. These best-practice adaptation stories illustrate positive ways families make sense and accommodate the needs of the person with CD.

Close and extended family members often share CD. However, even as CD is hereditary, many participants report they were the only person in the family with the disease. This could be because CD is under-diagnosed in America (Fasano et al, 2003; Green & Jabri, 2003); or, it could be because of social resistance to CD. Respondent #45 provides an experience of feeling like the only family member who admitted to having CD, in spite of others in the family presenting CD symptoms. She says, "One has gout and others have all sorts of autoimmune inflammatory issues, and I'm like, well now I know why" (Respondent #45). Respondent #7 observes, "Mom is sick all the time, and she has been hospitalized twice. She needs to be GF, and because my dad doesn't want to, my mom hasn't gone totally GF. She eats half-and-half [half gluten and half non-gluten containing diet]." This participant is certain her mother has CD. Since her father refuses to

eat a GF diet, her mother continues to cook and eat gluten-containing foods, thus suffering CD-related symptoms.

Misdiagnosis and the general lack of CD knowledge in the medical community contribute to familial judgment. After being diagnosed, discovering that it is a hereditary disease, and observing symptoms in her uncle and nephews at an extended family meal, Respondent #45 suggested to her uncle that his family should be tested. He responded saying, “What? Are you sure you aren’t just being dramatic? Are you maybe doing it for attention?” These hurtful memorable messages caused Respondent #45 to defend her disease in ways that other diseases would not have to be defended. Similarly, Respondent #53 reports a hurtful memorable message conveyed when a family member said, “You really don’t have to be *that* GF.” Another hurtful message delivered at an extended family meal came from Respondent #63, whose sister said, “I’m sure it’s not that bad.” Others come to see gluten-containing foods as poison and wish that their family members would not consume it. For example, when watching other family members eating gluten, Respondent #26 says, “I feel sad when I see them eating it,” knowing what it does to her and fearing what it may do to them.

Dietary requirements broke up Respondent #14’s 30-year friendship with a hurtful memorable message delivered by her best friend. After enduring many medical tests and years of suffering, she shared her CD diagnosis and GF solution with her friend, who replied, “Oh, well. See if it works.” The friend’s lack of compassion caused Respondent #14 to discontinue the relationship. Respondent #14 feels her longtime friend did not try to understand the implications of CD, treating her resolve to follow a GF lifestyle as a casual fad.

Respondent #65 describes her experience of living with risk of accidental exposure, when her mother-in-law refused to cooperate while she and her husband cohabitated with her. To avoid the kitchen battleground, her adaptive strategy was to keep their food in the bedroom. She reports, “[My mother-in-law] wanted to have gluten-containing flour in the kitchen. It really concerned us with having open flour on all of our foods; so, for at least a year, there were problems with how she handled her kitchen.”

The holiday, extended family and friend table “battlegrounds” offer ways for those with CD to navigate constraining food and gluten-related ideologies through retrospective stories and memorable messages. Another critical battleground that presents challenging situations is church.

Church Battleground

Chapter three described the Pope’s edict that communion bread must contain some amount of gluten. Effects of this decision were discussed on the macro-level in the previous chapter. Here, I examine how it affects participants on the mezzo-level, illustrating adaptive strategies for coming to terms with constraining religious ideologies. The gluten-containing Eucharist has caused problems for those interviewed, as told by Respondent #39:

Communion in my church has to be leavened bread (challis bread). It is hard for me to take communion. It gets into my stomach, and I feel sick from the bread after the service. But it is the body and blood of Christ. It is a two-inch by two-inch square, washed down with the wine, becoming part of you. I can’t have that because the bread and wine body and blood of Christ from the chalice is hard to

have, but I need to have it because you have to have communion. This is the biggest challenge for me.

Respondent #39 is a long-time parishioner at a church that follows the Pope's edict to the letter; thus, a GF host is not allowed. She felt pressured by her fellow churchgoers to participate in the sacrament with them, overwhelming her desire for health. She complies every Sunday morning, only to feel ill every Sunday afternoon. The tone of her conversation around this subject is both emotional and desperate. Respondent #39 understands that continuous gluten consumption may cause other autoimmune disorders. She indicates that she worries about it, but also feels the need to nurture her soul by taking communion. Respondent #39 lives with a spiritual dilemma, balancing her religious beliefs with her physical disorder, feeling too uncomfortable to reject the "body of Christ."

Risking ingestion and feeling pressured to participate in communion, Respondent #51 mail-orders a special "low-gluten host" that was sanctified by the church until the most recent edict. However, her church serves it to her. She arrives at church an hour early every Sunday to have it blessed and situated on the altar, so the Priest can reach it when she comes up in line. She said he sometimes forgets, causing her to hold up the line to redirect him when others behind her were ready to take communion. She expressed feelings of embarrassment for disrupting the regular process. Both Respondent #39 and #51 have come to terms with these subjugating religious ideologies by potentially sacrificing their long-term health.

Another respondent deploys a different tactic, saying what matters is what she feels in her heart. Respondent #36 reports:

Rather than taking communion, I just receive the wine at the church because the host has gluten in it. Now the Catholic Church is not going to offer a GF host. It is very isolating. The Lord knows what is in my heart, so I just take the wine in my small parish church.

Potlucks are common community-sharing events in church, a battleground that presents problems for those with CD. Individuals with severe dietary restrictions may opt to stay silent and hungry in certain social situations, in order to avoid drawing attention to them. For example, Respondent #10 stopped attending church potlucks noting, “I am absolutely terrified of going out to a potluck. There is no way to eat safely.” Respondent #11 reports a hurtful memorable message from a parishioner when she opted not to take from a dish. The churchgoer said, “A little won’t hurt you,” to which she responded, “It is rat poison to me, and I don’t want labor pains.” Respondent #10 said, “it took me two or three years to realize that cheating on the diet was just not worth it. It doesn’t matter how tasty it is.” To stay safe, both Respondents #10 and #11 quit attending social events centered on food, choosing social isolation rather than risking cross-contamination.

Another common battleground that torments those with CD is restaurants. Meals with family and friends require attendance, often in non-compliant public settings. The next section discusses what we learn about communication through retrospective stories and memorable messages as participants describe their struggles while dining out.

Restaurant Battleground

Being subjugated by established ideologies in the restaurant battleground causes awkwardness for those with FS or CD. Restaurant etiquette includes expectations of eating the chef’s special, not asking for changes, and praising the chef. When sitting at

the restaurant table, one is expected to order, but not to be obtrusive about it. Other rules include, *don't be demanding, don't embarrass others around the table, don't annoy the server, be open to eating in places where others want to eat, share food, and talk about the flavor combinations*. Those with CD break every one of these rules. Interviews reveal dissatisfaction and lack of family compassion stemming from eating outside of the home. Rather than dealing with awkward social situations, many with CD felt homebound in order to remain safe from cross-contamination and reported feelings of grief around lost social interactions. Some expressed a reduction in QOL. In addition to ensuring safety, eating at home reduces the need for disclosure and negotiating menus with others. However, many CD sufferers still endeavor to eat in restaurants. In this section, we see how participants navigate the restaurant battleground, starting with a menu that has no GF selections. Respondent #41 reports:

Early on in diagnosis, I visited my older son. He wanted to try a restaurant, and I wanted to go to a gluten-free restaurant. He insisted on the restaurant he wanted saying, 'I'm sure they'll have something.' The waiter said, 'There isn't anything in the whole restaurant that is gluten free.' I couldn't order anything. I cried and felt isolated and victimized but more than that, there wasn't anything I could eat.

Prior to going to the restaurant, Participant #41 asked her son to help her review the menu online, or to call first to see if there were accommodations made by the chef. He refused, and she went along, going hungry and remembering her son's hurtful comment, "I'm sure they'll have something" indicating his lack of understanding or compassion about navigating cross-contamination.



Figure 4.3. Couscous Without Gluten?

Respondent #22 describes an exchange involving a server and her whole family:

The waitress said, 'So, are you on some kind of freakish diet?' And my daughter said, 'I am on a restrictive diet.' The waitress said, 'Well, it's not like you need to lose weight.' My daughter is very, very thin. My daughter said, 'I'm not trying to lose weight, it just hurts me.' And the gal just kept arguing, and arguing, and my son-in-law at that point said, 'Hey, look, here's what happens if she eats that. She might sit here and poop her pants. So, go fix her a salad.' My husband was just in shock. I just started laughing. My husband said, 'I'm so sick of this.'

This episode illustrates the array of familial reactions to a typical restaurant scenario, as subjugation by several ideologies played out. The server would not relent, pushing back and judging the daughter's request, indicating an ableist ideology. The son-in-law graphically detailed her personal symptoms to the ignorant server, which cause the father to grouse and the mother to laugh. The family showed compassion and understanding, trying to defend the daughter's situation. Finally, the father expressed exasperation at this scenario, likely making the daughter feel the cause of all the unnecessary strife. Other participants echoed this struggle. In some cases, family members express chagrin when the person with CD orders in a restaurant. Respondent #40 describes a time when she was

out to eat with her daughter and son-in-law, who both think she is “high maintenance.” While ordering, the son-in-law interfered saying, “You are going to make the waitress mad.” Her daughter replied calling people with CD, “Glutards.” These hurtful memorable messages continued to resonate with this respondent. These familial scenes illustrate the process of how family members come to terms (or not) with food and gluten related ideologies in the mezzo-level. However, some report positive experiences in restaurants.

Burke (1969) terms the degree to which the listener relates to the story as “consubstantiality” (p. 21). This refers to the amount of sympathy and compassion, where the storyteller and the audience are conjoined entities relating deeply with one another (Burke, 1969). The more consubstantial the message-receiver feels to the storyteller, the more engaging the story. If the server also has CD, he would likely take care to provide a safe meal to another with CD. In a highly consubstantial situation, the narrator was likely to remove barriers (Rowland, 2009) and persuade the receiver (Foss, 2018). The following interview from Respondent #35 indicates a consubstantial situation:

I can honestly say that there was one person, and it was at a restaurant, shockingly, it was a manager who said, ‘There are people who come in here who have gluten sensitivity, but with you having an actual gluten disease, it is much more serious.’ He said, ‘here are the items that you can have, and I will make sure that they are prepared in an area where there won’t be any cross-contamination.’ He told me where the food was prepared, and he was willing to take me through the kitchen. He went above and beyond what he should have done, and I was so grateful for that. Not many restaurants are like that though.

Until the American Disabilities Act (ADA) includes restaurant meals, this will continue to be a battleground for those with CD. Public schools, however, are covered under the ADA, deeming those with CD disabled and requiring institutions to comply with dietary requirements. The next section describes one such institution, a university.

School Battleground

Perhaps the most socially isolating experience is a person living with CD at an institution such as a college campus. Large public institutions must accommodate the needs of those with CD according to the 2012 ADA Amendment, but how those needs are accommodated varies widely. Respondent #31 describes her experience as a first-year student at college. The college did not have certified gluten-free dining facilities and offered this respondent a separate dorm room with a full kitchen. The dining services director told her it was up to her to “navigate it.” She was banned from on-campus dining facilities and reported feeling isolated and “singled out.” She said, “I couldn’t participate in a lot of on-campus traditions because I was the only one that I knew who was gluten-free.” She continued:

I would always plan my classes around when I would have time to go back and eat in my dorm, and then go back out to class. So, I would have to navigate trying to find on-campus food, and plan it out that way. I guess a lot of my meals were spent alone. It was pretty disappointing my first year in college.

This experience limited her exposure to peers during times they would have formed bonds, such as meals and other college-related activities. This is an example of a person inadvertently being punished because of her physical needs in defiance of established college commensality norms. She was forbidden to attend pizza parties or to enter dining

halls where her fellow-students ate because gluten was present. Luckily, as she continued in her college career, she met others with CD and made friends with whom she would share an apartment in subsequent years.

The above mezzo section above describes ways those with CD navigate it with friends and family. These strategies ultimately re-define the ill person's identity. Bruner (2002) summed the components of remaking identity as making sense, being taken seriously, being believed, and fitting in, culminating in a "balancing act" (p. 78) for those with a disease. Identity transformation is the subject of the next section.

Micro

Redefining Identity

Doctor said, "I don't think you have it." She said, "I do too."
Respondent #43

A CD diagnosis requires extraordinary adjustments to diet and lifestyle. The news of a diagnosis of this type can cause a person to go through a period of re-perturbation, as they become accustomed to the nuances of the disease. Charon (2006) described the ill person as having "two bodies" (p.88) causing disruption in self-identity: the ill body inside and the normal body outside. Boecher and Ellis (1995) described the diagnosis, or health epiphany, as a period of time when the person is so absorbed in the news that they are unable to make sense of it and sometimes become socially immobilized. It is a period of denial and avoidance, combined with adjustment (Sunwolf, et al., 2005). This mixture of emotions often impacts interpersonal relationships (Pecchioni, Overton, & Thompson, 2008). Support from family and friends are integral to the ill person's success (Rosland, Heisler, & Piette, 2012; Brown, 2011), as "meaning is constructed socially" (Drewery &

Winslade, 1997, p 34). After being diagnosed with CD, participants reported going through phases of acceptance. They described the initial period as challenging and difficult as their homeostasis was disrupted, and those who had been diagnosed for a while described how they came to terms with it undergoing the homeostatic shift. They discussed the interplay of their evolving identity with their family's acceptance, as definitions of "truth" morphed.

Physical acceptance of a disability includes thinking of the body as part of the self. When dealing with a disability, a person often initially detaches from the body, thinking of it as an object (Corbin, 2003). This disassociation is part of the acceptance process to reestablish trust in the diseased body, create a new definition of normal, and redefine identity with the disease. Reestablishing a level of physical trust entails different expectations for performance and reintegrating the self with the body, thus de-objectifying it as part of the healing process (Corbin, 2003). This manifested for Respondent #22, who's mother's skepticism about associating physical ailments with diet drove her to a series of miserable medical tests to prove that food was the culprit. She says, "There've been times when she [her mother] said it was all in my head. And that's definitely pretty hurtful when you know what you are experiencing." For Respondent #22, getting a medical diagnosis was an adaption strategy to convince her mother of her illness. Respondent #22 now lives with the confidence of a proper diagnosis. But when the diagnosis is not correct, it can complicate the acceptance process.

Widely used medical evaluations, such as intestinal scoping and serological tests for CD diagnosis are only positive when a patient is in advanced stages of the disease (Fine, 2003). Nonetheless, those suffering with painful symptoms are desperate for a

diagnosis. The doctor-patient relationship influences how the patient copes with the illness (Charmaz, 1983). Bruner (2002) reported that patients often experience indifferent doctors who do not take their reports of symptoms seriously, leaving them with feelings of isolation. Frank (1995) termed the point at which an ill person seeks medical care as “medical surrender” (p. 6) when the prognosis of the physician becomes the centerpiece for all subsequent narratives that comprise the new identity and “truth” for the ill person, as well as direction for others. But sometimes these “truths” conveyed by doctors are untrue. CD presents with varied symptoms and is often misdiagnosed (Green & Jabri, 2003). Many respondents report being diagnosed initially with irritable bowel syndrome (IBS), stomach cancer, pancreatitis, and brain tumors making the final battleground the examination room.

Examination Room Battleground

Participants who were initially misdiagnosed lived for a period of time under one set of assumptions, reestablishing identity and dealing with the emotions of one diagnosis, while family members also adapted to the news, only to discover that the diagnosis was incorrect. For example, Respondent #3 was initially diagnosed with a brain tumor. She and her family lived with that assumption for six months. The doctor erroneously correlated her neurological response to gluten (brain fog) to symptoms consistent with a brain tumor. She describes the diagnostic meeting with the physician’s assistant as difficult because her memory was so bad at the time, she could not remember anything. Her husband was there too, and went into shock when the diagnosis was given. Monk (1997) describes the “re-authoring process” (p. 20) as a period where the newly diagnosed assimilates the new truth into her identity. During those six months, she and

her husband “went through hell” as they entered the re-authoring process as a person with a brain tumor, the ill person’s spouse, and collectively as a couple. They adjusted their narrative to accommodate the brain tumor only to discover after six months that she did not have a brain tumor and that a GF diet alleviated her symptoms.

A misdiagnosis only adds to confusion and self-doubt, and causes others to over-scrutinize those with CD. Similarly, Respondent #7, desperate for answers, lived with the same misdiagnosis of a brain tumor for *years* before being diagnosed with CD. She describes how years of suffering with mysterious maladies culminated in this retrospective story:

I could feel myself not remembering things. I was crying at work and crying on the way home, and I just had a mental breakdown. I went to the doctor and told him what was going on. He said, ‘Well, that’s a mental thing, and if you feel like you are losing your faculties, you have to go to a psychologist or psychiatrist.’ I said, ‘Well, then send me to one please.’ At that point, I was ready to go to the ER and tell them that I am suicidal. I said, ‘I can’t do this anymore. Something is physically wrong with me and you guys need to fix that.’ The doctor said, ‘Go to this clinic.’ The doctor there at the clinic said, ‘You are almost the worst case I have ever seen.’ Three days later, I had the endoscopy and was confirmed to be celiac.

Respondent #7 reveals how her self-identity has shifted with the various diagnosis she has received, from one with a brain tumor, mistrusting everything she did at work, to finally quitting her job and checking into the clinic where she was accurately diagnosed with CD. She describes how her brain-related problems diminished on the GF diet.

Another doctor misinformed Respondent #35 about her fertility prospects once diagnosed with CD. She reports, “We grieved not being able to have a bigger family and wanted at least one more child. We were okay with the miracle that we had with my son, and with just being a family of three.” She lived with this knowledge, weighing alternatives such as adoption with her husband. She continues with this retrospective story:

Then I got that positive on the pregnancy test, and I was ticked off. Let me be honest, I was not over the moon. I was pissed off. I was madder than a hornet that I was pregnant. At five months, I was put on a Zofran pump because I was so violently sick. I just could not keep anything down, and I was losing weight rapidly. I was in and out of the hospital to get fluids through IVs. It was really, really tough. And then close to the beginning of the third trimester, I started to feel better, and I felt like I had been selfish. God gave me another chance of having another precious life, and to have another child. And ever since then, I’m just thankful. I’m thankful that God gave me a boy and girl, and my family is complete.

Respondent #35 describes her mindset when she thought she could no longer reproduce, and then her surprise and anger when she discovered she was pregnant. Her gradual acceptance transformed her identity into being the happy mother of two children, drawing on her religious beliefs for strength and acceptance.

Shifting Homeostasis

Respondent #56 reports: “When I was first diagnosed, I spent a month crying... How could this happen? Where did this come from?” This sentiment describes how most

felt when initially diagnosed, though some expressed relief to finally know the cause of their maladies. The micro-level analysis observed the individual adjusting self-narratives that contribute to redefining and transforming identity after a life-altering diagnosis. After diagnosis, old “truths” of homeostasis are disrupted. The person is forced to redefine ideologies to accommodate the nascent “truths” causing her to enter into the liminality phase or a transitional state where new decisions need to be made. The individual’s status in the family, agency, and power contribute to the struggle of how this new revelation is incorporated into everyday life. The individual’s behavior is influenced by memorable messages that may be compassionate or hurtful, and by attitudes of family members and those in the medical community, for example. These factors affect the individual’s formation of a new post-diagnosis identity that permeates all elements in life. When resolved, the person exists in a shifted state of homeostasis where everything moving forward is filtered through the life-altering news.

Plight and resolution are illustrated with the liminality phase described in the following retrospective story recalled by Respondent #46 about the moment he realized that all unexamined food was unsafe to consume:

If someone had told me before how [this diet was], I would have thrown up my hands ... I wouldn’t have believed it. My wife and I went to a pool party four hours away with food to last for a couple of days. She made a bunch of food and brought it in a cooler. I ate it and became sicker than a dog the whole time. My sensitivities went nuclear. I was so tired, I couldn’t move. I kept having to visit the bathroom. I had pain and was nauseated. This isn’t working! We had an argument on the way home. ‘What is the issue?’ she asked. She’s mad, I’m mad,

and I don't feel well. I am questioning the ingredients in everything, on the grill, something was in the grilled chicken. Or maybe the garlic powder ... this was the day I realized that everything may be cross-contaminated.

His retrospective story illustrates how the event unfolded differently than what he expected, and he describes his ultimate homeostatic shift: the permeating resolve that all future behavior is altered. When defining retrospective storytelling, Koenig Kellas (2018) asserts that the stories we “hear and tell can have lasting effects on our beliefs, values, behavior, and health” (p. 64). The pre-liminality phase begins with disruptions to the initial homeostatic state, such as when one realizes they are being subjugated by dominant ideologies, and that their survival depends on re-defining long-held “truths.” The liminality phase begins when these “truths” are one-by-one redefined. For example, in the case of those with CD, the realization that all food-related situations must be reexamined. What one reflects on about a previous event influences one's attitudes as he or she contemplates all future events, as demonstrated by Respondent #46's ultimate homeostatic shift when he describes how his food-related practices have been completely altered. For example, he said he frequently eats before going to events or brings food he has prepared to protect against cross-contamination. The examples above illustrate participants who reported undergoing life-altering transformations, taking their lifestyle to extremes striving to achieve optimal health entering a state of shifted homeostasis.



Figure 4.4. Personal Muse: Bring on the Gluten

*Some people who are obsessed with food become gourmet chefs.
Others become eating disorders.*
—Marya Hornbacher, *Wasted: A memoir of anorexia and bulimia*)

Stigmatized Eating Habits

Those living in an affluent situation in Western society have the choice to eat whatever foods they wish, and to enjoy the benefits of sanitation, imported produce, refrigeration, and a bountiful variety of choices (Fuhrman, 2012). However, those with CD may be stigmatized for their eating habits. After the homeostatic shift, people with CD often see food as a functional tool for survival rather than something for entertainment and pleasure. This realization indicates a high degree of acceptance and a determination to steer clear of gluten. Overly conscious eating habits can develop with awareness of the ubiquity of gluten and the ease with which cross-contamination occurs; however, omitting traditional foods from one's diet can also cause a person with CD to alter what was once considered ordinary. Curtin (1992) points out, "ontologically....we are constituted as persons by the food we eat, and by what we will count as food" (p. 12). Even though these limitations separate the person with CD from long established food-

ideologies and rituals, respondents report feeling clear-headed and experiencing a renaissance of health, even in their later years. Some still enjoy eating, but only foods they know will not cause hours of pain, weeks of itching, and lengthy recovery.

People with CD sometimes develop extreme eating practices in order to maintain health that may replicate what Bratman (1997) terms *orthorexia*, where the patient exhibits an intense interest in foods consumed (NEDA, 2018). As described in chapter 1, those with orthorexia typically only eat a few foods they consider healthful, carefully scrutinizing labels before consuming, and exhibiting high levels of anxiety about eating in general. If someone suffers extreme physical and mental discomfort from eating certain foods such as gluten, it seems entirely rational to take steps to consume only foods that are inert. And due to a lack of cultural awareness, those with CD have to be vigilant about foods in order to stay healthy. Respondent #1 shares some of his practices:

I also have ulcerative colitis, so my triggers are sugars and carbs. I don't eat grains or fruit. I'm dairy intolerant, and I lost the enzyme to digest animal fats and meats years ago. I have a corn allergy, so I basically live on nuts, seeds, egg whites, vegan protein powders, and leafy green low-carb vegetables. So, it's basically stir-fries, omelets, and scrambled eggs. I make muffins using a coconut almond flour base, and I can make a sugar-base using erythritol or xylitol, which is a nonnutritive sugar and doesn't cause flare-ups. I stack on some kale chips to get my vitamins A, K, and C.

He describes extreme safety practices and adaptation strategies that indicate he has experienced the homeostatic shift. Other participants report undertaking similar steps to protect themselves from gluten exposure. Some describe practices that would classify

them as orthorexic; yet, they maintain these habits to stay healthy. Attaining a healthy body can drive a person to practice extreme eating habits as a form of self-preservation. Excessively reading labels is another manifestation of orthorexia, and those with CD engage in this practice because gluten is in so many products under a variety of names.

Respondent #17 conveys her homeostatic shift in her retrospective story when she realized she could not eat at her family's pizzeria, or participate in food-related holiday celebrations with her family:

I miss looking forward to eating. Sometimes I view food more as an enemy. I used to love it. I think back to the days when I would get excited about knowing we would go to a certain restaurant to eat. Or, when my mom was making lasagna for a special occasion. My family celebrated around food. When you look at photo albums of my family, there are more pictures of food than there are pictures of people. Because that's what an Italian family does. And the holidays, the special things that were baked for a specific holiday, whether it was special Easter bread at Easter time or a certain Italian cookie for Christmas, or whatever the tradition was. I miss that. And I don't feel that anymore because I can't eat lasagna. Christmas comes and goes, and my mom makes at least 10 different kinds of cookies, and multiple dozens of each one. She starts on Thanksgiving, and she would put them in the freezer. She would put them in shoeboxes. And she would freeze them. And then at Christmas, we would have them. It's been four years. And I haven't had any. And she still does it. So I'm like, don't even show me mom. She's another one, that doesn't get it. She'll call me and tell me, 'Oh, yes, this morning I tried a new recipe for this homemade muffin'... And I'm like,

“Oh, mom, really? Do I need to hear this? Do I need to hear about your homemade muffins?” So, now I look at food more like an enemy. I get angry at it. I miss that excitement.

Respondent #17’s vocal tone emanates remorse, and a longing to enjoy her mother’s food with other family members. She also expresses anger at her mother’s lack of understanding of her dietary restrictions, and at her own inability to eat foods the way she used to. Food, which once represented practices of love, is now a functional means to exist. Her homeostatic shift encompasses her grief, losing the ability to eat the foods of her heritage, as well as the acceptance that this is how it is from now on. She concludes the story by saying, “this is my reality.”

Rewarding Transformations

For some participants, the GF diet required by CD provided a rewarding transformation. McAdams and McLean (2013) concluded that those who are able to find “redemptive meaning” through a transformation story tended to be happier (p. 233). They divided the process of sense-making into two parts: first, the narrator assesses “episodic” information. Second, the narrator develops a self-descriptive “semantic conclusion” (p. 236). Koneig Kellas and Trees (2006) expand this notion by suggesting that stories solidify understanding of impactful episodes. Respondent #35 describes her redemptive retrospective story as follows:

When I was first diagnosed, I was well over 230 pounds. I gained 60 or 75 pounds in a year. Because I was so sick, and then once I was put on the gluten-free diet, I immediately felt a change in my body. I lost weight. I was feeling great, and I had a lot of energy. I have lost well over 50 pounds and 21 inches. And I am still

losing. I am pretty thankful I've gone from a size 20 to a size 12. I'm happy with the results. I am definitely an advocate for getting diagnosed with CD because I can understand the frustrations and the feelings and emotions and the cycles that you go through. Because when you stop eating gluten, you are grieving, and it's like you've lost a loved one. So it's a whole new lifestyle.

In this retrospective story, Respondent #35 describes personal satisfaction from being on the diet and advocated diagnosis. Her transformation was rewarded with a healthier body and lifestyle. Similarly, Respondent #3 describes a positive physical transformation as a result of accepting the diet and constraints of the disease:

You know it's something I had to go through to become who I am today, and, in a lot of ways, I'm a much better person than I ever have been. I mean, I eat better, I may still be overweight, but I'm getting my leaky gut syndrome taking care of, and that's going to eliminate a lot of my issues. I appreciate the things a lot more in my life now than I ever have. And I suspect that I had CD for about 10 years before I was even diagnosed. But something changed about four or five years ago, and it went from small issues to major issues.

The positive metamorphosis described by Respondent #3 illustrates a common sentiment expressed by participants. Her sickly pre-diagnosis self-narrative evolves into redemptive meaning and a positive outlook. Her weight and physical health improved after eliminating gluten, enhancing the quality of all aspects of life. Forty-five-year-old Respondent #22 reports she first attributed her physical ailments to aging, saying, "I decided that was part of getting old...like I felt like I was about 70 years old."

Correspondingly, Respondent #25 notes, "I am thrilled. I am eating healthier, and I also

noticed I was more relaxed now that I got off the gluten.” And further, Respondent #26 describes her transformation after gluten as follows, “I have increased energy and symptoms I had my whole life such as abdominal pain, fatigue, and constipation are gone. I slowly felt better and now have a lot more energy and a lot less illness in general.” Respondent #22 describes how her life changed after being diagnosed with CD. She reports, “I used to be a chef. And I have a really, really strong intolerance to gluten. I actually react tactile; if I touch it, then my hands peel and stuff. So it changed my whole life. It changed everything about my life.” Respondent #22’s family is slowly adapting to her diet. Her positive transformation was reinforced when her son said: “Mom, you make [GF] food taste good.” Her ultimate homeostatic shift included learning to cook without gluten, while still utilizing her culinary skills. These individual redemption stories illustrate how the sense-making narratives resulted in rewarding transformations after the homeostatic shift.

Though many participant stories and memorable messages depicted hurtful, uncompassionate experiences, some participants talked of how they adapted. For example, Respondent #22 reports she makes GF bread for her Mormon sacred communion and shares with others in the congregation who are GF. Respondent #4 describes how her once rebellious family now enjoys eating the same GF foods she prepares for herself, especially her desserts. And Respondent #39 reflects on a kind gesture from her brother. He had the bakery put several frosting roses into a separate bowl for her to eat, so they wouldn’t be contaminated by the cake. Participants report how they reconstructed their identities as their illness evolved. The ill person may experiment with mantles of identity, including undergoing the homeostatic shift where

they may learn to take precautions with food consumption, while reestablishing a new sense of normalcy.

Summary

This chapter explored how mezzo-level ideological constraints caused participants to establish best practices for navigating various battlegrounds. I use components of the CNSM to describe retrospective stories and memorable messages to illustrate the themes of familial adaptation and identity transformation. Mezzo analysis for the present study includes examining the levels of acceptance of other family members, as perceived by the individual with CD in the various battlegrounds. For example, stories may have centered on early experiences of familial resistance when traditional gluten-containing foods are replaced with GF foods, or family members cooperating with maintaining a GF home (or not). Other examples spotlight cooperative family members who amended traditions and rituals to accommodate those with allergies (or did not). Cooperation often depended on the ill person's position in the family as well as her personal guidelines for disclosure and her confidence with having the disease. As the person with CD navigates the GF lifestyle, develops an understanding of new physical abilities or disabilities, and as the body morphs with the disease, micro-level transformations occur. Micro-level elements include individual receptivity (positive or negative), agency, and embracing the homeostatic shift of acceptance. Many participants report contentedness with their GF lifestyle and the pleasure of regained health.

In the final chapter, I summarize the intersection of the data analysis and the three themes of ideological truths, familial adaptation, and identity transformation from the macro, mezzo, and micro perspectives. I explain how this study answers the research

questions. Finally, I conclude with limitations of the present study and suggestions for further study.

CHAPTER FIVE: CONCLUSIONS

Jean's Story – Daddy, Heart, and Home

Daddy had his first heart attack at age 55. He endured three bypass surgeries over 20 years, his first one in 1975. He had stents inserted in the arteries around his heart in between bypass surgeries. On three separate occasions, doctors split open his sternum. Long arteries were extracted from his legs and sewn around his heart, resulting in three-foot-long incision scars, ankle to thigh. Recovery from each bypass surgery took six months of rest and physical therapy to regain muscle strength. Over time, plaque would build up in his arteries, and he would start the process all over again. He took all kinds of drugs including beta-blockers and statins, and he regularly put nitroglycerin under his tongue to thwart imminent attacks. Nothing worked. Daddy's doctor told us that dietary choices were the cause of his heart disease.

After his first heart attack, our family became vegetarian overnight. We suffered through Momma's experiments with soy protein (which came in a milk carton and tasted like cardboard), beans (which she'd never cooked before and we promptly rejected), and egg dishes made only with whites. Despite our grumbling, it worked. Daddy lost weight, began running, and enjoyed good health. But compared to a rich American diet, the vegetarian menu left us feeling deprived and unsatisfied. Gradually, we added back foods allowed by the American Heart Association (AHA). To protect Daddy, we declared war on foods the doctors told us caused his heart to clog. We identified the enemies—egg

yokes, saturated fat, cocoa butter, coconut oil, Crisco, butter, whole dairy products, and red meats—and eliminated them from our diet. At the time, the AHA recommended eating more polyunsaturated oils like canola and safflower to lower cholesterol. Moving away from the Weight Watchers diet, my mother took classes at the AHA, and our family meals consisted of what we considered a low-fat, restrictive diet for years.

My father's diet was an obsession for us, becoming an emotional jumble of love, frustration, and sometimes anger for my mother whose job it was to fulfill his dietary requirements. Everything we ate was a surrogate for something else: meatloaf made with turkey burger and oats, rather than hamburger; vegetables cooked in broth rather than sautéed in oil; cookies baked with oil rather than butter.

Daddy grew up poor during the Depression years, when his family had only sweet potatoes and pink grapefruit to eat. For him, steak meant wealth. Momma's family had only popcorn during the worst of the Depression. She too associated prosperity with a rich diet. My parents had worked hard to enjoy the pleasure and status rich foods conferred, and the new diet robbed them of those experiences. Both of them missed steak, hamburgers, cheese, butter, cakes, and other foods they were accustomed to eating. Ultimately, the temptation was too strong. Over the decades, they drifted back to the forbidden foods they craved. My father's desire for those beloved foods ultimately surpassed his resolve to comply with the restrictive diet. It was a life or death situation. He chose flavor over deprivation, friends, and community over alienation, food over health. He ultimately lost the battle at age 76, believing his dietary choices caused him to succumb to heart disease.

Study Summary

Food plays an integral role in daily culture, norms, and rituals. Thus, severe dietary constraints are associated with diminished family social activities and can be a source of frustration for those who find themselves subjugated by dominant ideologies. Though the average person might not be able to accurately define the word “ideology,” ideologies profoundly influence behaviors and beliefs, specifically food practices. Observing that gluten was a punch line in nearly every form of media encountered, I was driven to research associations between dominant ideologies and behaviors in the social context. As a person living with celiac disease (CD), I was interested in gaining insight into the lived experiences and social aspects of those with CD and/or food sensitivities (FS). I felt there was a lot more to the lifestyle than just knowing how to avoid gluten. Living the gluten-free (GF) lifestyle seemed to negatively affect nearly every social engagement I attended. I felt isolated when not able to participate in acts of commensality with family and friends, and determined that I was not the only one feeling this way, considering current numbers of Americans with dietary restrictions. It prompted me to learn more about food allergies and about what studies had been conducted on this population.

Fine (2018) reports that nearly 95 million Americans are sensitive to gluten and Megiorni et al. (2008) found that 90% of white European patients carry the genetic markers for CD meaning they may develop it at some point in their lifetime. The disease spans all races (Fasano & Catassi, 2012), making it unclear why American doctors do not lead with CD tests, and why it takes patients an average of eleven years to get a diagnosis

(Green & Jabri, 2003). Perhaps it is because CD did not appear 1994 reports from both the U.S. Department of Health and Human Services and the National Institutes of Health's National Institute of Diabetes or Digestive and Kidney Diseases (Fasano & Flaherty, 2014). Though it was known about in Europe since the 1941 publication of Willem-Karel Dicke's research on the GF diet (van Berge-Henegouwen & Mulder, 1993), until the early 2000s, U.S. doctors seemed to think that CD bypassed North America (Fasano & Flaherty, 2014). Commenting on its growing ubiquity, *Grain Brain* authors, Perlmutter and Loberg (2013) declare, "Gluten is this generation's tobacco" (p. 64) and one of the "greatest and most under-recognized health threats to humanity" (p. 32). Awareness by medical professionals provides hope to all people whose immune systems treat gluten as a "component of a dangerous bacterium or bacteria...toxic to humankind" (Fasano & Flaherty, 2014, Loc. 638). Certainly, the statistics are compelling; however, it is imperative to understand the current literature.

Prior to study design, I reviewed an extensive range of literature on CD and FS in the Western world. Discovering there was a dearth of research in this area of communication studies on ideologies and food related practices, I broadened my searches to include work leading to the development of the CNSM theory, which provided insights into social implications of disruptions to family life caused by disease, infertility, and other issues. I also focused on literature pertaining to food and culture. Not finding much in either corpus related to CD or FS specifically, I expanded my review to include social-science research emphasizing hidden disabilities and medical research on food allergies.

These studies were often quantitative and few considered participant narratives. To date, sparse studies have examined the social aspects of dietary restrictions.

This work thoroughly examines the lifestyle of participants, shedding light on how social influences of how dietary adherence creates empathy (or antipathy) for people who live with this condition. At the outset of this project, I posed the following research questions: and in the remaining chapter, I address them and the implications of the study:

RQ: How do dominant food ideologies inform narratives about family interactions?

RQ: How do gluten-avoidant adults narrate the impact of food sensitivities on commensality experiences and social interactions with other adults?

Chapter Overview

The five chapters of this dissertation (introduction, methodology, ideologies, family, identity intersections, and conclusions) engage with themes of truth, social stigma, and evolution of identity throughout. Pertinent quotations from respondents are presented to indicate best practices of navigating social situations while defying established ideologies. The present study consists of two parts: an online survey posted on celiac.com, and a series of hour-long telephone interviews with celiac sufferers living with adults who may or may not have CD. A summary of the research design and methods used to conduct the study and analyze the data, including my approach to utilizing inductive thematic analysis is presented in chapter two. In the analysis phase, I group data into three prevailing themes: revised truths, familial adaptation or non-adaptive response, and identity transformation.

Next in chapter three, I elucidate how cultural and dominant ideologies elicit challenges faced by those with CD and families as they find themselves subjugated from dominant ideologies. Influencers such as the Bible, corporations, pop culture, and the media dictate commensality behaviors that manifest as ableist, patriarchal, religiosity, and etiquette ideologies showing how the U.S. is a food and gluten-centric culture. Chapter four includes an analysis of data within the Koenig Kellas (2015) CNSM theory as the family communication lens, illustrating the day-to-day elements of living with CD or NCGS. Themes on family and individual food practices, narrative, storytelling, levels of disclosure, and identity/acceptance are illuminated in venues of commensality. The CNSM “offers a way to see how narrative operates in the family in patterned ways associated with family health and well-being...[and] how people communicate to make sense of their identities, relationships, and difficulties” (Koenig Kellas & Kranstuber Horstman, 2015, p. 80). This final chapter offers conclusions on contributions of the study, constraints, as well as suggestions for future research. This study contributes to the body of existing in communication studies work because food allergies present social issues for those affected. Next, I explain how the RQs are answered by the study through the analysis.

Macro Analysis

To answer the first research question, the analysis in chapter three began with identifying macro-level ideologies such as ableism, sexism, religiosity, and etiquette derived from governmental, corporate, and media influences. Dominant ideologies influence interactions by challenging deep-seated beliefs that inform narratives about

family interactions. McKerrow's (1989) *critique of domination* argues that those in positions to influence the general population such as media outlets and the Pope, establish prevailing societal "truths." This concept provides the lens for my ideological analysis. Further, McKerrow's (1989) *critique of freedom* stance informs how taken-for-granted "truths" cause rebellion against contradictory information, when an individual attempts to liberate him or herself from an inveterate societal belief. I maintain that food is integral to human interaction; and when one member of the family has food allergies, cultural traditions are disrupted.

In chapter three, I open with the argument that the USDA's *Dietary Guidelines* set the tone for dominant ideologies present in food-related culture in the U.S. Ignoring FS in the *Guidelines*, makes those who have them invisible. Patriarchal ideologies are illuminated by participants who convey feeling dominated by male family members, chefs, or when enduring scrutiny for dietary needs by restaurant servers. Participants report being repressed by ableist ideologies when pressured to appear normal with no special needs, or when feeling alienated by family members who reject the person with CD's diagnosis. When faced with religious ideologies, participants report feelings of betrayal, as by the Pope who requires some amount of gluten in the Eucharist. Sexist ideologies pressure participants to maintain society's definition of an ideal feminine body, and endure misdiagnosis by the medical profession. These ideologies are punctuated by macro-level examples in the media, celebrity quips, and religious edicts. Cumulative artifacts herein associate ingrained ideologies with the demand for study participants to battle with friends, family, and strangers to "prove" the severity of their

disease. This macro analysis leads to the revelation of many food ideologies that drive rules of etiquette and a gluten-centric culture.

Rules of etiquette form many food ideologies, which often put someone with FS or CD in an awkward position when politely navigating inadvertent contamination. Examples provided in chapter three discuss various scenarios where these ideologies cause issues for those with CD. Taken-for-granted food-ideologies co-locate with experiences that renounce norms such as *a little won't hurt you*, and the guilt-laden *if it is made with loving hands, it will nurture the body*. The most interesting revelation of the macro-level analysis is that the U.S. is a “gluten-centric” culture. Bread is integral to life, and is the metaphoric meaning for making a living, money, and acts of commensality. Pop culture has morphed the GF craze into the punch line for jokes, T-shirts, greeting cards, and more, making gluten mockery commonplace. Respondent #40 says, “Comedians make fun of gluten. For example, Joy Behar from the View says, ‘celiac is a bunch of baloney.’ They wouldn’t be saying that about diabetes.” Respondent #44 reiterates this saying, “the media mocks people following the GF diet.” These “bread” ideologies permeate all aspects of culture that affect behaviors in the interpersonal setting.

Mezzo and Micro Analyses

To answer the second research question on how gluten-avoidant adults narrate the impact of food sensitivities on commensality experiences and social interactions with other adults, chapter four locates “battlegrounds” of commensality and how those with CD navigate social interactions constrained by ideologies, as they collaborate to make

sense of their diagnosis. A subordinate question contemplated by participants emerged: “How do I come to terms with being GF with my friends and family when food and gluten related ideologies are constraining us?” Starting with the family table as the first “battleground,” participants suggest that the impact of food sensitivities on commensality experiences with other adults is the most difficult for those with CD when non-adaptive family members do not comply with a gluten-free household. Lack of cooperation was the breaking point for several participant relationships. Contrastingly, highly adaptive families comply with safe practices, protecting the person with CD from cross-contamination.

The next battleground for social confrontation is at the extended family dinner table. Participants narrate being challenged about their dietary restrictions by extended family members, describing best practices to hide their disease, and to protect themselves from being cross-contaminated at the family dinner table. They describe how they feel their restrictions hurt or offend non-understanding relatives. Churchgoers describe this battleground as a place where they felt singled out and scrutinized by officials and other parishioners. Some dealt with it by “knowing what was in her heart,” such as Respondent #36 who decided not to participate in sacraments, while others partook in consuming gluten-containing hosts, suffering the consequences, and feeling conflicted about personal religious beliefs. Restaurant dining presents another battleground for participants who told stories about being cross-contaminated by the food and tormented by the servers. The school battleground offers new insight into how compliance with the American Disabilities Act (ADA) varies for those with CD. Each of these “battlegrounds

illustrates how the person with CD and her family make sense of newly formed “truths” and best practices. Mezzo-level commensality experiences in participant narratives in chapter four portray a range of positive and negative social interactions in the battlegrounds. Sometimes participants report negative situations such as Respondent #23 whose boss told her she was not a team player because she did not attend team lunches where gluten containing foods were featured; or a positive experience reported by Respondent #38 who says “friends go above and beyond to make sure I have something to eat.” Further, she reports the compassionate memorable message her friends conveyed: “we love you and care about you.”

A second subordinate question emerged from the analysis: “How do I come to terms with being GF myself particularly when food and gluten related ideologies are constraining me?” The second question pertains to the individual transformation as the identity evolves to accommodate new “truths” on the micro level. Forty-nine percent of the participants who lived the GF lifestyle between four and seven years report best practices and strategies for navigating the various venues of food related activities. The micro-level analysis illuminated stories of redemption and adjustment as the people with CD experience the homeostatic shift, forever redefining a new level of homeostasis. For example, Respondent #53 reports that she and her immediate family no longer are invited to extended family meals. Extended family members said, “You really don’t have to be *that* GF.” Eventually she realized that her life would be forever different on the GF diet, and that time spent with her extended family would center on non-food related activities. These participants surrendered to the disease and developed new narratives to enjoy life

in a different way than before diagnosis. Eating habits of those with CD resemble orthorexia, or an obsession with reading labels, consuming only a few foods, and living an overtly healthful lifestyle. This is one manifestation of the homeostatic shift, when those with CD accept the facts and act accordingly, thus disregarding ideologies that would have otherwise constrained them. Many participants report rewarding transformations where attitudes of acceptance altered careers and family practices. For example, Respondent #22 describes how she used to be a bakery chef, enjoying the foods she prepared with gluten. She revised her cooking methods to GF, still enjoying baking, but using alternative ingredients.

CNSM Lens

Storytelling and memorable messages, two salient components of the CNSM, combine to help those diagnosed and their family members deal with the rupture of beliefs, senses of well-being, and daily routines. Thus, the CNSM provided the optimal theory with which to conduct the analysis on the mezzo and micro levels. CNSM is a flexible theory that allows the user to interchange components as necessary. Pairing the retrospective story heuristic with the memorable message construct provided keen insight into the way those diagnosed with CD altered their self-perception, adjusted their behaviors, and assimilated new “truths” in social situations. For example, Respondent #62 tells her retrospective story about going to a swim meet for her son, and forgetting her lunch. She went to the snack bar and asked if there was anything there that was GF. The only food without gluten was a hotdog with no bun, so she reluctantly ordered it. The attendant replied with this hurtful memorable message, “Good grief. You’re worried

about gluten, but you are going to eat a hotdog?” This illustrates how Respondent #62’s “truth” was altered. Before being diagnosed, she considered a hotdog “junk food.” But after being diagnosed, the hotdog was the only food at the snack bar that did not contain gluten. It represented immediate nourishment, in spite of the attendant’s comment.

While listening to retrospective stories revealed during the interview process, I unearthed what may be a meaningful addition to the CNSM. What I’ve termed, the “homeostatic shift” theorizes the transition when individuals realize that the disease will permeate all future consciousness on food-centered activities. This shift requires a re-perturbation of what was once considered truth in the liminality phase. From going to the family dinner table, or participating in religious ceremonies, the person with CD must interrogate every future bite for gluten. Consequently, a strict lifelong adherence to the GF diet can become an obsession or a mantle of identity. Reported by several study participants, the homeostatic shift creates acceptance that life in the future is not the same as the past as new practices and “truths” are incorporated.

Respondent #46 best articulates entering into the liminality phase leading to his homeostatic shift when he said, “If someone had told me before how [this diet was], I would have thrown up my hands.” He describes the discomfort of his post-diagnosis as he engaged with his friends during the weekend, experiencing illness as a result. Frustrated, and realizing it was not working, he entered into the liminality phase where new decisions about all food-related activities would need to be redefined and that forever after his equilibrium would occupy an alternative steady state. He punctuates the liminality phase by saying, “this was the day I realized that *everything* may be cross-

contaminated,” comprehending that he would now have to think differently about his conduct at food-centered events. He described new “truths” and edicts that he incorporates now, indicating he has progressed through the homeostatic shift. This shift is applicable to anyone with a disease or life-altering disruption. It is a transition that could enhance the CNSM model because it impacts the way a person views himself or herself forever after.

Limitations of the Study

Limitations in the present study include the narrow demographics of participants, the interpretive approach to the analysis, my positionality as a person with CD, and the unconventional nature of associating dominant ideologies with familial behavior. Further, the study was limited to participants who visited the Celiac.com website. The population of the study was predominantly white women and though CD presents among all races, it is under-diagnosed, particularly among people of color (Fasano & Catassi, 2012). Today, diagnosis takes persistence, time, and money that most socio-economic groups cannot afford, leaving many undiagnosed. When medical tests for CD are more common, a repeat of the same study aimed at including a more diverse population would be in order.

The study relied on qualitative analysis using inferential generalizations and descriptive statistics of participant demographics. Lewis and Ritchie (2003) defined inferential generalization in terms of whether the findings can be applied to other “settings or contexts beyond the sampled one” (p. 264). Using comic artifacts, television show scripts, celebrity comments, and religious edicts about gluten, I attempt to associate ideological influences with familial behaviors. These associations are anecdotal, relying

on my analysis and arguments. Necessarily, the nature of a qualitative study involves the art of interpretation, as opposed to a statistical study that offers quantified correlations. I believe the richness of the qualified study illuminates insight that a quantified study omits, and that the inferences made in the analysis can be applied to other contexts beyond those provided from participant interviews.

Because I live with CD and have experienced many of the scenarios described by participants, I may not have been able to look at the data as objectively as a researcher who does not have food-related issues. However, my “insider” status may have afforded me richer results (Brayboy & Deyhle, 2000). When I disclosed my CD status, participants’ tones of voice changed, and they told me deeply personal stories about life with the disease. I do not believe an outsider would have gleaned the same level of detail, nor experienced the lengthy interview durations as I did.

The unconventional juxtaposition of rhetorical ideologies with family communication scenarios offers a higher degree of understanding than examining either in isolation. As a critic and qualitative researcher, I use narrative analysis and the critical rhetorical method to focus on global ideologies that influenced behavior. It emphasizes social issues to problematize the status quo (Turner, 2017). Narrative analysis within the subcategory of family communication allowed for analysis of how families use it to make sense of situations; understand behaviors influenced by ideologies and power structures; and reassess meaning when facing life-changing episodes (Koenig Kellas & Trees, 2006). It offers insight into how families engaged in sense-making through storytelling.

Study Applications and Suggested Future Research

As a qualitative researcher who has experienced the same marginalization and oppression as the participants in the study, I am in a unique position to shed light on an imperfect system and to offer best practices as a result of the study. The study points out ideologies that most are unaware of, but that put non-conformers in a position of subjugating norms. Those with CD are required to advocate for themselves in order to avoid cross-contamination in virtually every venue of life. Often, they are mocked or maligned for it. By pointing out the dominant ideologies that influence behaviors, perhaps those with CD will understand that living with the “new truths” imposed by the disease that cause them to be in opposition with those ideologies is not their fault.

A New Catch Phrase

Significant elements of the dissertation reveal that the CD and FS population are subjugated from dominant ideological norms experienced in a variety of battlegrounds. This is partially due to the fact that there is no language to describe this phenomenon. We see a population that endures ridicule such as in the media, and exclusion such as from meals and religious rituals, because ridicule (Freud, 1905/2009) and isolation (Smith, 2009) are two of the consequences when operating outside of established norms. Recently, I explained the concept of this dissertation to someone who does not have food sensitivities. Alluded she said, “I don’t see that people with CD are ridiculed or isolated socially.” This is a perfect example of the response of those operating on the inside of an ideology. They don’t see what those who are subjugated see. They laugh along with the jokes in the media, but because they do not live with the repercussions of ridicule, they

do not notice. It is only when on the outside of a norm that one experiences the discomfort of ridicule and social isolation. It prompts the question, “how do we communicate with family members and friends who are not GF?” Currently, when subjugated from an ideology, one experiences discomfort, but there is no language to describe it. We are aware of the discomfort, but usually not able to communicate the reasons, or to associate macro influencers with mezzo interactions and micro thought processes. To change this, one must first be aware of it. Awareness stimulates compassion (Yamamiya, Cash, Melnyk, Posavac, and Posavac, 2004). Next, one needs language to describe it. Currently, we have no language to point out when we are outside of a dominant ideology.

Thus a two-fold follow-on study would begin by asking participants to associate macro influencers with mezzo behaviors. Similar to how Mace (1998) coined the term “universal design” to initially referred to housing, it now has expanded to signify products that are accessible and usable by the general population. The phrase is widely accepted when referring to accessibility. Or how Tarana Burke coined the hashtag #metoo to signify sexual harassment, and starting a movement of no-tolerance. Perhaps using a focus group format, comics, and media examples (such as what has been presented throughout this dissertation) could be shown to those living with CD. They would be asked how they thought these comics and media snippets impacted their daily life. Similarly, another focus group of those without CD or FS would be shown the same media and asked the same questions. Once made aware of ideologies that influence behaviors, participants would be asked to try out different phrases to describe “bumping

up against an ideology” with the goal of developing a catch phrase. Many words or phrases of this nature have entered mainstream language such as: *catch-22* coined by Heller (1961) meaning a no-win dilemma, *groupthink* coined by Janis (1982) meaning blind conformity, *litterbug* coined by McKeon referring to those who litter (“Alice McKeon, Coined,” 1979), and *meme* coined by Dawkins (1976) referring to encapsulated concepts conveyed in social media. The dissertation reveals that Western culture and language is gluten-centric, causing many who shun bread to be shunned. Awareness and language to describe the situation may enable conversations by those subjugated in order to experience more compassion and understanding from family and friends, possibly leading to altering bread-related rituals. Once developed, the phrase would need to be published and promoted in popular media in order to become part of the normal lexicon used to describe when someone feels the affect of being subjugated from established ideologies. Further because of the awareness created, the catch phrase may be instrumental in altering the bread-centered rules of etiquette.

Re-choreographing Scenarios

Assuming that those in relationships want to continue to be involved with family and friends striving for a state of continued eudemonia (Koenig Kellas, 2015), a second study could entail examining adult partners where one has CD and the other does not using the CNSM interactional joint storytelling heuristic. Partners would provide a scenario and then would be asked to create a re-choreographed scenario. Though participants would be asked to convey their own stories, to illustrate the study format, I’ll describe Respondent #10’s waffle story in the Table battleground. Recall how her

husband wouldn't consider making her GF waffles. A first step would be to deconstruct the scenario from the husband's current perspective of feeling that compromised ingredients would not fit his ideal of a waffle. Questions designed to understand his perspective would offer him airtime to explain his traditional position. Other questions would be geared toward understanding the person with CD's perspective. The next question would ask each of them how the scenario could be reconstructed so that each of them is fulfilled. Their reconstructed scenario would serve as a model for others in a similar situation, to help them broach a conversation with their partners and loved ones, offering alternative strategies.

This format of deconstruction could be applied to scenarios to assist in re-choreographing strategies to help participants go from the state of liminality to the homeostatic shift. Using another example from the present study, consider that Respondent #17 and her husband participated in this follow-on study. Respondent #17 conveyed her inability to get past the state of liminality because her husband constantly pressured her to consume a little gluten. Again, the format would be to ask each partner for their perspective, and then to ask them to work together to form a solution that satisfies both partners.

Alternatively, scenarios such as those described by respondents in this study could be presented to focus groups, perhaps one with participants who have CD, another with participants living with an adult with CD, and a third of mixed participants, tasked with re-choreographing scenarios with alternative best practices. Outcomes could help others in similar situations handle them more effectively with the goal of offering alternative

strategies to cope with situations in various battlegrounds. The study could offer tools for both the person with CD, and for those they interact with.

Best Practices / Rewriting the Etiquette Book

Becoming aware of and identifying the driving ideologies that make those with CD feel subjugated is the first step toward change. For example, the discussion in chapter three revealed that we live in a gluten-centric society, which shed light on how awkward it is for someone who cannot participate in bread-related customs in religious ceremonies, around the family dinner table, at work, and in the other battlegrounds described in chapter four. The heightened awareness brought forth by this study offers a new empowerment for those with CD to re-define gluten as detrimental to health. Whereas before, the person with CD may have felt awkwardness, now they can point out that their new “truth” defies old ideologies, especially if they are equipped with a descriptive catch phrase. When describing an etiquette ideology, Respondent #48 states, “It is insulting to the host for a guest not to eat. It looks bad and makes people feel uncomfortable.” That statement represents the old ideology, but because of the awareness from this study, she could now say, “Though it used to be insulting for a guest not to eat what the host prepares, I need to protect myself from gluten cross-contamination and have brought my own food prepared in a safe environment.” Or as Respondent #14 reports, “I have several different pretty lunchboxes that I take with me depending on the event. I have one for weddings, another for work, and another for family dinners.” She makes it fun, accepting her situation, and expects that others accept that she would bring her own food to all social events.

Another example pertains to the church setting as reported by Respondent #51. She expresses feeling uncomfortable asking the priest to accommodate her GF needs, saying she has to get to church an hour before so that the GF host she brings with her will be properly blessed. When she gets to the alter she has to remind the priest of her needs, causing a delay in the line and disrupting the flow. Rather, she states, “I wrote to the Pope asking if we (with CD) could have a universal symbol, such as children do when they cross their arms that says, ‘Give me a blessing.’ I’d like a sign to let them know that I cannot receive the host. I’m hoping someday they will adopt that.” This idea represents an adaptation that would allow her to participate in the sacrament without being sickened, holding up the communion line, or making a spectacle of her special needs.

Acts of self-preservation such as bringing a pretty lunchbox to a meal, or a GF host to church, served those using them, but are they really the best practices? A study that troubles and confirms best practices to protect those with FS and CD at food-related activities, could provide tips and strategies for others struggling with the same issues. The study could entail presenting current etiquette rules and gluten-centric conundrums to a focus group of adults living with FS and CD. Ideally, participants would have been diagnosed from four to seven years, because that is the group from the present study that seemed to have adapted strategies, and the time when many experienced the homeostatic shift. The outcome of a study of this nature would serve the FS and CD community with information from those who live with it everyday. A deliverable from this study could be a best practices etiquette book for families and other social commensality situations that identifies the ideologies described in chapter three, scenarios described in chapter four,

and suggestions on how those with CD and their family members could gracefully navigate social situations.

Homeostatic Shift Research

Cannon (1932) initially defined homeostasis with regard to the steady state of physical functions. My definition extends it to include the shift that occurs in thinking after the realization that every situation thereafter must be mentally assimilated differently. Individual transformations described by participants who experienced the homeostatic shift point to another application of the study. When first diagnosed, a person goes through various stages of adjustment described throughout this text as long-held truths are challenged. Dietary adjustments are difficult enough, but as this work points out, so are the social aspects. Once progressing through the homeostatic shift, individuals no longer fight the disease. They live in a new steady state of acceptance taking pro-active measures to protect themselves. Several participants report homeostatic shifts where lifestyles or ritual practices were forever altered, such as Respondent #41 who takes her family on the weekends to find GF bakeries and restaurants; or Respondent #17 who initially mourned her inability to eat at her family's pizzerias, and who now sees foods like pizza and pasta as her enemy. Her shift enables her to interact with family members who still partake of the family's traditional foods, knowing that her "truth" is forever altered.

The homeostatic shift is the state where everything finally seems in balance. New truths have been adopted, and those living nearby seem to be on board. New rituals have been established such as bringing a pretty lunchbox for various occasions, having

ordering strategies at a restaurant such as sitting on the end of a table where the waiter can be nearest when ordering, and my personal favorite—ordering a club soda with lemon (rather than the usual lime) to test whether the waiter listens. These resolves are dynamic and rely on the cooperation of others. Things go along smoothly when family and friends comply, however a non-believing, non-cooperative person may influence these resolves not to work, causing the individual to have to re-assess new resolves when engaging in commensality with that person. Or, something like the Pope's edict requiring a compromising amount of gluten to be in the host can trigger the need for new resolves. For example, Respondent #63 surrendered to partaking the gluten-containing host at a family member's funeral, causing her to experience subsequent physical consequences. Respondent #36 found a different church, leaving Catholicism. Both of these respondents reported that their previous resolves enabled them to confidently make these decisions. The homeostatic shift indicates a mindset that the person with CD will figure out a solution that works for them when faced with new challenges. Rather than re-enter the state of liminality when challenged, once in the homeostatic shift, challenges are met with a determination to find a workable solution, approached with a sense of confidence because other resolves have "worked."

Redemptive and transformational stories provided by participants could empower others who are struggling with establishing new levels of equanimity. The dissertation offers the idea of the homeostatic shift as a part of the individual's transformation while living with disease. Two follow-on studies could examine the homeostatic shift more thoroughly. Whereas the present dissertation examines the individual's homeostatic shift,

a future work could complicate the *communal* transformation experienced by cooperative family members as they adapt rituals and practices to accommodate the needs of the person with CD. Using the CNSM interactional joint storytelling heuristic, the study could ask adult partners where one has FS or CD and the other does not how they unified in the homeostatic shift (Koenig Kellas, 2018). Examples provided could again serve to help others dealing with similar situations. A second study could examine the homeostatic shift from the individual transformation perspective using the CNSM retrospective storytelling heuristic (Koenig Kellas, 2018). Examples have been provided throughout this study of people who completely adjusted their lifestyles as a result of having CD. These stories are empowering. A study designed to learn more about adaptation strategies and alternative lifestyles would be fascinating, especially if it focused on how the individual dealt with challenges that tested his or her resolves. The concept of the homeostatic shift could be the centerpiece to trace stories of redemption as individuals transform their identity through acceptance of disease.

Jean's Story - A Reprise of A Thanksgiving to Remember

The next year, we were invited back to Chicago for Thanksgiving. Empowered by the stories I heard from Respondents who had experienced the homeostatic shift, though admittedly, I was still in the liminality stage of experimentation, I tried a new approach. I told my hostess that I would be providing my own food this year. (She seemed relieved that she did not have to accommodate my needs.) My husband ensured we had a hotel with a kitchen, and after we landed, we headed to Whole Foods so I could purchase GF foods I would eat for the duration of our stay. While my extended family members and

husband dined on the beautiful buffet of turkey, dressing, rolls, gravy, and many lovely desserts, I ate my salad in a bowl that I brought with me. Nobody batted an eye, and nobody probed about the idiosyncrasies of my diet. I ate alongside everybody else, participated in the lively conversation and enjoyed a pleasant experience with my extended family. That experience empowered me to bring my bowl to all food-related social events that take place in homes thereafter. In the past year since, I have experienced the homeostatic shift. I accept my dietary requirements with no apology. It is just a fact of life I live with. Occasionally, I am met with resistance, but my resolve prevails.

Associating Media with Behavior

There have been a few studies that correlate what children saw on television with aggression (Huesmann & Taylor, 2006), and other studies proving that humans imitate behaviors of others (McCall, Parke, & Kavanaugh, 1977), but none that examine FS, CD, and non-celiac gluten sensitivity (NCGS) behaviors with media influencers. A quantitative study to correlate snippets in the media with behaviors could perhaps present a clearer argument. Further work could also include a mixed method study using qualitative and quantitative analysis with another set of questions to ask more specifically about ideologies that drive behaviors. Even though people do not generally acknowledge they are in opposition to an ideology, carefully crafted questions could locate occurrences, providing a more in-depth understanding. A study of this nature could be pivotal in creating awareness of the behavioral affects of “gluten-negative” comments in the media.

Universal Design and the ADA

Though this study does not dwell on the legal aspects of CD, it is paramount for those with the disease to understand their rights, force compliance, and unite to expand the law's definition to include restaurants. By far, the biggest challenge facing those with CD is the inability to order a "safe" meal in a restaurant. Ninety-five percent of all study participants interviewed reported alienation at restaurants because of fear of cross-contamination. Nearly every participant had a "restaurant cross-contamination story" where a meal was provided that was not actually GF in spite of being assured that it was by the server. In a few terrible cases, participants reported being deliberately sabotaged by kitchen staff and servers, only to suffer with a reaction or hospital visit. There are simply no present regulations that make it safe for those with CD or NCGS to eat out. Until the American Disabilities Act (ADA) is amended to include restaurants, this will continue to be the biggest hurdle for those with CD. It leads me to the following discussion on the ADA, and how this study could affect a positive change.

Consider that visible disabilities impairing mobility are acceptable and covered under the ADA requiring accessibility in public pathways. In addition, hidden disabilities such as diabetes, multiple sclerosis, lupus, and cystic fibrosis carry the expectation that they will be accommodated. On December 20, 2012, in a case between Lesley University and the Justice Department, CD was deemed a disability under the ADA (DOJ, 2017). The 2012 inclusion of CD in the ADA is an important step toward easing day-to-day living for those affected by CD. The *Leslie Agreement* (justice.gov) ruled that Lesley must provide GF foods in its dining halls for students who have CD or food allergies. The

settlement also required Lesley to develop individualized meal plans, provide safe zones to prevent cross-contamination, disclose ingredients of foods, and pay \$50,000 compensatory damages “to previously identified students who have CD or other food allergies” (DOJ, 2017). This revolutionary case was expected to have a ripple effect on awareness. The CD community speculated the change in the ADA would require restaurants to disclose ingredients of foods they serve in order to protect those with CD and food allergies. However, relatively little has changed in the years since this court case. A loophole excusing compliance if it “fundamentally alters the nature of the goods, services, facilities, privileges, advantages, or accommodations” has greatly dampened the impact of the Lesley Agreement (DOJ, 2017). Consequently, restaurants are still not required to offer safe GF meals. Some restaurants have conscientious staff, but others do not. Furthermore, restaurants that are compliant one day may not be the next. Standards vary by state, by restaurant, and by servers and chefs on any given day. Though there are guidelines provided by the Gluten Intolerance Group of North America, there are currently no ramifications if restaurants fail to comply. The wording in the ADA is such that a lawsuit against a restaurant for non-compliance is necessary to force execution; however, none have been brought forth to date (ebglaw.com). Further, if the Gluten Intolerance Group of North America guidelines are mandated in the future, the change will require extensive training and safe practices. But, until the issue is forced, change in restaurants will be incremental at best.

Quiet compliance never affects change. Misgeld (1985, as cited in McKerrow) discussed the need for a critical practice to have consequences saying, “Whether the

critique establishes a social judgment about ‘what to do’ as a result of the analysis, it must nonetheless serve to identify the possibilities of future action available to the participants” (p. 55). One future action yielded from this study could be organized protests directed at restaurants that cross-contaminated a CD patron, or perhaps orchestrate a “gofundme” drive to bring a court case to require broad compliance. GF followers have a vast online social network, which could facilitate organization.

The present study adds to the conversation, empowering others to identify and possibly discuss subjugating ideologies in a gluten-centric culture. This awareness may help the GF community to unify to make positive lifestyle changes and implementing best practices described herein. Further, it may help others to become more compassionate toward the needs of those with CD and NCGS. A study emphasizing the CNSM translational storytelling heuristic could evolve into political activism to affect changes in the ADA and public awareness (Koenig Kellas, 2018).

Referring again to the term “universal design,” when considering the restaurant battleground, respondents almost universally report they do not enjoy accessibility because of fear of cross-contamination, or sabotage. Most resort to ordering salad with only a few vegetables, no croutons, and no dressing, thinking this is the safest thing to order, and still trusting that the kitchen complies with safe practices. The ADA is carefully worded to exclude recipes fundamentally altered with alternative ingredients, thus excusing most from compliance. Even those claiming to offer GF meals often present me with a written disclaimer relinquishing them of liability after I disclose I have CD. Contrarily, some restaurants conscientiously comply including sending a chef out to

ensure the food is safe. However, a visit to the same restaurant a week later may yield a completely different response, depending on the staff working that day. Those with CD can carry kits to test the meal before eating, but who wants to conduct a chemistry experiment in front of eating companions?

Using the principles of universal design, a simple compromise would be for restaurants to be required to offer one balanced meal that is suitable for most with food allergies. This could be a frozen meal prepared in an offsite GF kitchen that contains foods that are generally considered to be allergen-free. However, unless the chef and server handle the safe meal correctly, the restaurant patron could still be contaminated. Educating workers by requiring food handler certification such as SafeServ would be one step toward ensuring those with FS and CD are protected.

A work of this type serves to open opportunities for follow-on studies as described above, juxtaposing dominant ideologies with familial behaviors and identity transformations. The concept of the homeostatic shift transfers to many other chronic, or on-going challenges faced in life. I've chosen food as my lens, but "othering" of any type causes those outside of a dominant ideology to incur resistance, whether due to disease, race, sexual preference, economic status, or a host of other reasons. Ideological subjugation awareness provides endless possibilities for further study.

Jean's Story – Motherhood

When we were newlyweds, my husband teased me that if I were to become pregnant, I would have to see the dreaded "needle doctor." He knew I hated needles, so he would bring it up, jokingly, as a way to discourage the "baby" conversation. Mark

and I built a life around careers, adventure, and freedom. Thus, when I discovered I was pregnant ten years into our marriage, I was not overwhelmed with joy. Rather, I was overwhelmed with fear: fear that the life I knew with Mark was completely over.

But the source of my greatest fear was my health. My stomach hurt daily, 4:00 PM until bedtime. I was extremely constipated and bloated for years before I became pregnant. I tried a host of remedies to heal my intestines. I ate whole grains, juiced, ate vegan, practiced food combining, and read books on dieting. It was a constant preoccupation. I went to specialists who gave me strong pharmaceuticals to soothe the pain in my intestines and the gnawing ache on my left side. How could I endure that pain every day for nearly a year without pharmaceuticals? But I pressed on with the pregnancy.

The hormonal changes were overwhelming. About four weeks into the pregnancy, I felt lines of hormones from my lower to upper back, as if secreted by my kidneys and pumped up my spine. It was unpleasant to say the least, and sent my emotions into overdrive. It was like PMS on steroids. One morning during week seven, I woke up to blood on the sheets. My trusted female doctor was out, so her backup doctor did an ultrasound at the office. Coldly, he noted, "This will not become a child." He ordered a blood test and reported that my beta HcG levels—the so-called "pregnancy hormone"—were extremely high for a woman only seven weeks pregnant.

It was a molar pregnancy. The baby had turned into a tumor that could become malignant. I had to have outpatient dilation and curettage (D&C) to remove the pregnancy. I scheduled the procedure for the following week. A D&C for molar

pregnancy carries the risk of bleeding to death; and the molar pregnancy itself, even after the tumor was removed, could turn into cancer. Meanwhile, my beta HcGs doubled every day between diagnosis and the D&C. By week eight, my hormones spiked to levels consistent with a patient at the end of her final trimester. I had weekly beta HcG blood tests. Mark was right: pregnancy really did lead to the “needle doctor.” It took a year for me to get back to normal, but I was never the same. The trauma was enough to make certain I did not attempt pregnancy again until years later to no avail.

While I was writing this, my husband of thirty years, walked into my office. I shared this story with him. We both cried. We never cried together when we lost the baby. I don't think we ever fully processed our grief together as a couple; the shock of the whole incident was too much. The molar pregnancy and my celiac diagnosis changed the course of our lives. We would never have what others consider the most important experience of life. As we've gotten older and our friends are now grandparents, we now see a gap in our lives. But we understand it not as a loss, but as an opportunity. We fill the gap with people, experiences, love, and other things meaningful to us.

After I was diagnosed and began to research CD, I realized that the constant stomachache that made me fear pregnancy and the molar pregnancy were likely caused from the undiagnosed disease. Just as inappropriate food choices cost my father his life, consuming gluten all those years before being diagnosed cost us a family. If I had been diagnosed when I was younger, I would have been rid of the symptoms, free of pain, and had a body that could have endured a pregnancy. Life may have turned out completely different for us.

But my story is one of redemption. By eliminating the foods that are poison to my body, I thrive and remain grateful for what I have, living an alternative path. It led me to start a company called Alternative Cook, LLC, to produce instructional DVDs, video streams, and cookbooks. I've appeared on television and spoken at several national and international conferences. Through all this, I realized that CD is a social issue. My passion for this cause led me to pursue a PhD and carry out this study. I hope to raise awareness in my regular column "Surmounting Social Situations" in the Journal of Gluten Sensitivities on Celiac.com, and perhaps develop a following large enough to affect positive change in the ADA. It is my sincere hope that I can make a positive difference in others who live with this disease.



Figure 5.1. Jean, What the Hell?

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Appendix A – Survey Questions

Do you have a diagnosis that has led you to be gluten free?

Yes No

If you have a diagnosis that has led you to be gluten free, how long have you been diagnosed?

0-6 months 6 months-1 year 1-3 years 4-7 years 8+ years

How were you diagnosed? (Please circle all that apply)

MD Practitioner Naturopath Nutritionist Self Other

How long have you been eating the gluten-free diet?

0-6 months 6 months-1 year 1-3 years 4-7 years 8+ years

Referring to the above questions, do you feel the way that you were diagnosed affects how seriously the other adult(s) living in your household take your dietary needs?

Not at all To some degree Neutral A high degree

How often do you check in with a medical or health professional to monitor your health/diet?

Never Every 10 years Every 5 years Every year Several times a year

Where do you get most of the medical, health, and dietary information that you implement into your lifestyle? (Please circle all that apply)

MD Practitioner Naturopath Nutritionist Books/Magazines Friends Online Sources TV/Media

Are you confused as to which foods are considered to be gluten free?

Definitely confused A little confused and sometimes I accidentally ingest it Definitely not confused

Do you feel the other adults in the household are confused as to which foods are considered to be gluten free?

Definitely confused A little confused and sometimes they contaminate the food I eat Definitely not confused

Please briefly describe what it is like for you to be gluten free while living in your household.

Are you confused about what constitutes a “healthy diet?”

Yes No

Do you feel that in general you eat a “healthy diet?”

Yes Most of the time Sometimes No

Please briefly describe how you define a “healthy diet.”

Do you feel the other adult(s) in your household resent(s) your dietary restrictions?

Yes Sometimes No

When you eat meals with the other adult(s) in the household, do they follow your dietary requirements?

Rarely Sometimes Almost always

Do you eat different foods than the other adult(s) in the household?

Rarely Sometimes Almost always

Are your gluten free meals prepared for you by other adult(s) in the household?

Yes No

If your meals are ever prepared for you by another adult in the household, do you trust them to make safe meals for you?

Not at all Sometimes, but I ask a lot of questions Always

Please briefly describe how you feel about having dietary restrictions?

How often does someone else in the household prepare gluten-free meals for you?

Never 1-5 times/week 6-10 times/week Always

How often do you prepare gluten free meals for yourself?

Never 1-5 times/week 6-10 times/week Always

How do you feel, in general about your relationship with the other adult(s) in your household?

Dysfunctional Somewhat Satisfied Satisfied Very Satisfied
Ecstatic

Please briefly describe the kind of relationship(s) you have with the other adults living in your household.

How often, if ever, do you “cheat” on the gluten-free diet?

Everyday Once/week 2-5 times/week 10 times/week Never

To what degree do you feel the other adult(s) in your household interfere with your ability to follow a gluten free diet?

They always interfere

They sometimes interfere

They never interfere

Please tell a story of how the other adult(s) have either complied or interfered with your gluten free dietary requirements.

Is your diet grain-free?

Yes

No

Would you be willing to participate in an interview that should last around 30 minutes and scheduled at a later date when it is convenient for you?

Yes

No

May I contact you?

Yes

No

[Note: if the participant answers “Yes,” they will be taken to a screen that asks for their contact information. This is detailed in Appendix G entitled Demographics. If the participant answers “No,” they will be taken to a screen that thanks them for participating in the survey.]

Appendix B – Telephone Interview Questions

Hello, this is Jean Duane calling about the Relational Aspects of CD. Thank you for taking 30-45 minutes today to talk to me about the relational aspects of food sensitivities. Let me turn on my recorder. There... ready?

General Questions

1. Please tell me about your gluten-free lifestyle. What **challenges** has it caused? What changes for the better have resulted from being gluten free?
 2. Can you share an **early memory** or story about becoming gluten free?
 3. What process did you go through to be **diagnosed**?
 4. Does your diet lead to **harmony, disagreements, or arguments** with other adults living in your household? Please provide an example or story.
 5. Can you think of a **compassionate message** from another adult living in your household about your dietary needs?
 6. Can you think of a **hurtful message**?
 7. Describe to me the dietary **cooperation/respect** from other adults living in your household? Please provide details.
 8. How do you individualize your meals to suit your taste? Please give examples.
 9. How do you feel your food allergies/sensitivities affect your **social position (the power you have to influence dietary choices)** within your family?
 10. Do you **live in fear of being “glutened” or eating foods that are cross-contaminated**? Share with me how you and the other adult(s) you live with deal with your fears.
 11. Has having food allergies/sensitivities affected your **quality of life**? If so, how?
 12. To what degree do you feel your partner (or other adults living in your home) **interfere** (for example, not adhering to your requests, or not telling you ingredients of foods you may react to, etc.) with your gluten-free diet? **LOOK AT SURVEY FIRST [Q19 (resent), Q27 (satisfaction), Q28 (relationship)]**
 13. To what degree do you feel your partner (or other adults living in your home) **resent** your gluten-free diet?
 14. How does it make you **feel when you see** your family members eating gluten?
 15. How do you **collaborate** with other family members about what to eat for meals?
 16. How do you **view food**? What causes you to say that?
 17. Have your **gluten-free meals affected the culture of meals** in your home?
 18. **How do you eat your meals?** E.g., as a group around the table, while watching TV, on the go?
 19. Do you find **adherence to be expensive**? Is the expense of the diet an issue for you and/or other adults living in the household?
 20. What **do you feel needs to be examined/studied** about the gluten-free lifestyle?
- Verify mailing address**
Do you have any questions for me?
Is there a question you wish I had asked that I didn't?

Appendix C - Data Analysis of Survey

- 96% are living the gluten-free lifestyle and cohabitating with another adult.
- 87% are U.S. residents and over 18
- 91% have a diagnosis that led to being gluten free
- 51% have been diagnosed for 8+ years
- 49% have been eating the GF diet between 4-7 years
- 28% have been diagnosed between 4-7 years, 13% between 1-3 years, 5% between 7 months and 1 year, and 3% between 0-6 months.
- 52% feel that the way they were diagnosed affects how seriously the other adult(s) living in the household take their dietary requirements; 23% report that the way they were diagnosed doesn't affect the behavior of the other residential adults at all.
- 73% were diagnosed by an MD; 12% by themselves; 5% by a Practitioner, 5% by "Other;" 3% by a Naturopath and 2% by a Nutritionist.
- 46% report that they check in with a medical or health professional to monitor their health/diet once a year and 21% get checkups several times a year.
- 39% get medical, health and dietary information from online sources (39%); 21% from books/magazines; 17% from the MD
- 23% get information from TV/Media, friends, and other sources.
- 87% are not confused as to which foods are considered to be GF
- 62% of the respondents' report that other adults in the household not confused as to which foods are considered to be gluten free.
- 92% are not confused about what constitutes a "healthy diet"
- 38% feel they eat a healthy diet all the time; 48% eat a healthy diet most of the time; 11% eat a healthy diet sometimes; and 3% never eat a healthy diet.
- 59% did not feel that other adults in the household resented their dietary restrictions; 35% felt others resented their diet sometimes; 6% felt other adults in the household resented their diet all the time.
- 55% almost always eat meals with other adults in the household that follow their dietary guidelines; 32% sometimes; 13% rarely.
- 21% almost always eat different foods than other adult(s) in the household; 56% sometimes; 23% rarely.
- 36% never eat GF meals prepared for them by other adult(s) in the household; 46% sometimes do; 18% always do.
- 66% trust that meals prepared for them by another adult in the household are safe; 25% sometimes; 9% not at all.
- 5% report that someone else in the meal always prepares GF meals for them; 35% never; 52% 1-5 times a week; 8% 6-10 times a week.
- 46% always prepare GF meals for themselves; 1% never; 17% 1-5 times a week; 36% 6-10 times a week.
- 23% in general are ecstatic about their relationship with other adult(s) in their household; 3% report dysfunctional; 8% are somewhat satisfied; 16% are satisfied; 50% are very satisfied.

- 95% never “cheat” on the GF diet; 1% 2-5 times a week; 4% once a week
- 86% report that other adult(s) in their household never interfere with their ability to follow a GF diet; 13% report they sometimes interfere; 1% reports they always interfere
- 17% are following a grain free diet; 83% are not
- 85% respondents are female; 15% male
- 92% respondents are white
- 66% live with one other adult; 25% live with two other adults; 8% live with three adults; 1% live with 4+ adults
- 34% have a Bachelor’s degree; 23% have a Masters degree
- 33% have a household income between \$75-149K; 36% earn less than 74K; 31% preferred not to answer

Appendix D - Sample Letter Requesting Reprint Rights for a Cartoon

(Adapted from page 211 from: Biech, E. Swindling, L. B., (2000). *The Consultant's Legal Guide*. San Francisco CA: Jossey-Bass Peiffer.)

Date

Name
Reprints Rights Manager
Company Name
Street Address
City, State ZIP

RE: Reprint Permission for (*cartoon Identifier*)

Dear Name,

It is my understanding that (*company name*) controls reprint rights for (*name of artist's*) cartoon (*cartoon identifier*). I am an author writing a book about the social aspects of celiac disease and food sensitivities. (*Name of artist*) captures the essence of humor about gluten avoidance, and I would like your permission to reprint it in my book and use it in presentations (slides/transparencies) about the book. Of course, proper citations acknowledging (name of artist) and (reprints right company name) at the bottom of the page it appears on.

The book will be published in hard copy and electronic formats. A portion of the profits from the book will be donated to non-profit organizations whose mission is to help those with celiac disease and/or food sensitivities.

Please let me know what fees/terms are associated with this use and advise whether the artwork can be sent to me electronically. Feel free to contact me via email or phone if any further action should be taken on my part. Thank you for considering this request.

Sincerely,

Jean Duane
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Centennial, CO 80112
303-475-0818
jeanelizabethduane@gmail.com