

Trend or Treatment? Stigma, Social Challenges, and the Burdens of Managing Celiac Disease

by

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Abstract

Celiac disease is an autoimmune disease estimated to affect about 1% of the global population (Biesiekierski et al., 2014). It is managed only through strict lifelong adherence to a gluten free diet. However, this diet also commonly exists as a trend, making the existence and management of celiac disease perceptible to low social legitimacy (Moore 2014). Broadly, research on celiac disease often takes a biomedical approach or fails to acknowledge the role of the social context and its influence on lived experiences of managing celiac disease. Through a qualitative analysis, using semi-structured interviews and observation within a gluten free support group, this research seeks to understand how the broader popularity of the gluten free diet influences the lived experiences, social challenges, and burdens of illness experienced by people with celiac disease in their everyday lives. It finds that irrespective of individual trend dieters, low social legitimacy more broadly magnifies the social challenges faced by people with celiac disease in four key areas: biographical disruption, and the management of cognitive, economic, and relational burdens.

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Trend or Treatment?

Stigma, Social Challenges, and the Burdens of Managing Celiac Disease

In recent years, the words ‘gluten free’ have become trendy. From menus, grocery store shelves and cosmetic packaging, removing gluten from the diet is becoming a seemingly common practice, but why? The gluten free diet has two primary functions. The first is among dieters as a means of achieving weight loss or “health” goals. The second is the management of serious chronic illnesses. For people with celiac disease and gluten-related disorders, like me, adhering to a gluten free diet is the difference between health and illness. The contrast between these functions, along with an increasing popularity, leaves much room for misinterpretation within popular belief. Inspired by my own experiences with the restrictions of the gluten free diet and more broadly interested in the social impacts of celiac disease, I ask the following research question: *in a context where the demedicalization of gluten free diets makes them a diet of choice for some people, how do individuals with celiac disease manage the social challenges that arise because of the medically necessary restrictions that their condition imposes?*

This study uses theoretical concepts from Erving Goffman, Michael Bury, Kathy Charmaz, and is situated more broadly within medical sociology and the sociology of chronic illness, to understand the impact chronic illness has on the self and within relationships. Using this framework, this study uses semi-structured interviews to understand the lived experiences of managing celiac disease. My aim is to understand the specific social challenges that arise due to the restrictions of adhering to the gluten free diet and how these are managed among participants.

Although gluten free diets may appear to be inconsequential, the difference of one crumb can cause significant pain and suffering for an individual with celiac disease. The unique

management of a chronic illness through food leaves this group perceptible to misrepresentation and misconceptions. Contributing to the understanding of how this illness is managed can only work to enrich popular knowledge on the topic, improve the quality of life for the chronically ill, and contribute to knowledge within the sociology of chronic illness and of the sociological understanding of celiac disease.

Literature Review

I draw on theoretical concepts from the sociology of chronic illness, medical sociology, and deviance. These concepts include looping and self-ascriptive types, biographical disruption, the burden of illness, demedicalization and social legitimacy, and stigma. Together, this framework will inform my study of people with celiac disease when analyzing the function and impact of chronic illness on self-identity and within relationships.

A Unique Illness: Making Sense of Celiac Disease

Celiac disease is an autoimmune disease in which the body attacks the finger like projections, called villi, of the small intestine following exposure to gluten. Gluten is a protein mainly found in wheat, barley, and rye. It can be found in food, in cosmetics, or through cross-contamination. Celiac disease affects about 1% of the global population (Biesiekierski et al., 2014). Celiac disease can manifest in a variety of symptoms, such as abdominal pain, depression, diarrhea, and a unique rash called dermatitis herpetiformis. The result of unmanaged celiac disease is a plethora of health complications. These complications can include infertility, higher instances of certain cancers, and the potential development of other autoimmune diseases (Bandini, 2015; Copelton & Valle, 2009; Veen et al., 2010). Uniquely, there is currently no

treatment for celiac disease, and it is only managed through a strict, lifelong adherence to a completely gluten free diet.

It would be misleading to claim a significant gap in the knowledge of celiac disease. Outside of the social sciences, celiac disease research has focused on the biomedical impacts of this chronic illness, the legal implications of awarding disability status, and health-related quality of life (Bandini, 2015; Germone et al., 2022; Skjerning et al., 2014). Health-related quality of life research touches on the social impact of chronic illness, but fails to truly investigate the dynamic, lived experiences of celiac disease. For example, Germone et al. (2022) surveyed 246 children with celiac disease and their caregivers and found that both the children and their caregivers had lower health-related quality of life compared to historical controls (p. 2116). While this research demonstrates the statistically significant burden of celiac disease on individuals and their families, without exploring the specific practices or social interactions that cause this burden, we are left with an incomplete understanding of how celiac disease can impact life. By studying the subjective lived experiences of people who have strictly gluten free diets, such as the ways in which individuals are forced to change their lives in order to cope with their illness, it should be possible to provide better support for this community as well as the newly diagnosed.

As celiac disease does not have defining outward characteristics, it is considered an invisible illness (Olsson et al., 2009). Individuals with celiac disease, therefore, most often have their illness exposed through social situations (Boon & Holmgren, 2019; Copelton & Valle, 2009; Schroeder & Mowen, 2014). The resulting stigma exposes individuals with celiac disease to both physical and mental harm. For instance, Sverker et al. (2005) interviewed 43 individuals with celiac disease, finding that participants reported the emotions related to their condition as shame, isolation, and feeling bothersome (p. 175). To live 'normally,' so to speak, and to manage

their illness, participants are faced with the dilemma of weighing their health against their social lives. For instance, consider that when toasting drinks, a seemingly simple action, the gluten free individual must consider multiple risks, including, the contents of other drinks in the group and the chances of the gluten free drink being contaminated, and subsequently how to hold their glass to prevent it. Therefore, they may choose not to participate, standing out from the group and from the experience.

The Burden of Illness: Biographical Disruption and Ramifications of Chronic Illness

Celiac disease is a continuous problem needing lifelong management. It is not only an autoimmune disease, but also a chronic illness. Unlike acute diseases which can be treated, chronic illnesses are persistent and at times, life changing. To understand the role of the gluten free diet on people with celiac disease, it is essential to explore the impact of chronic illness on the self.

Drawing on data from semi-structured interviews, Bury (1982) argues that the impact of chronic illness on the self is ignited through a process called biographical disruption. That is, following the emergence of a chronic illness, when the assumptions of daily life and even life expectations are interrupted by illness, the self is subsequently changed (Bury, 1982, p. 169). For those with celiac disease, the assumption of being able to find safe food conveniently, spontaneously, or socially is broken. These changes impact the individual and their expected biography, resulting in grief toward what they anticipate in life. To illustrate, consider spontaneously going out for a meal with friends or colleagues. If no gluten free options exist, the gluten free individual will have to choose one of the following: risk being contaminated by gluten, choosing not to eat, or being left out of the experience. Expected life events or opportunities such as travelling, visiting a summer camp, eating a specific food, or even just the

desire to be spontaneous and adventurous, are all impacted by the demand to adhere completely to the gluten free diet.

Charmaz (1983) explains that chronic illnesses can also contribute to a loss of self, which is realized through a loss of self-esteem and self-identity (p. 169). Charmaz (1983) also notes that “direct restrictions become daily reminders of the lessened freedom and, often, diminished self” (p.173). As I have noted, celiac disease is managed through diet alone. Food becomes this restriction, serving as a reminder through its role as both health management and the underlying source of health risk. Similarly, Gregory (2005) found that people with celiac disease also lose the opportunity to experience and redefine their identities through food, reinforcing the notion of the loss of self within this context.

The impact of chronic illnesses does not only relate to the self, but also the relationships of the individual. For example, consider a birthday party. While everyone enjoys cake, the gluten free individual must either bring their own or sit out. This may seem trivial, but due to the importance of food in our social lives, this can happen regularly – holidays, meals at a restaurant, family dinners. Adhering to the gluten free diet may even hinder relationships. With each aspect of life needing to be planned with gluten in mind, spontaneity and flexibility become difficult. This may mean having to decline dining out with friends, refusing to kiss on a date, and being excluded from experiences for fear of contamination.

As the examples I have provided thus far demonstrate, food is not just about nutrition, it is very much social. Bury (1982) notes that chronic illness “[disrupts] taken-for-granted assumptions and behaviours; the breaching of common-sense boundaries” (p. 169). For people with celiac disease, the necessary adherence to a gluten free diet needed to manage their illness also restricts them from the ‘common-sense’ expectations of many social events involving food.

While this may seem insignificant, Nettleton et al. (2010) found that due to the important role of food in forming identity, intolerances are commonly understood, from lay perspectives, as pickiness or a product of “unconventional lifestyles” (p. 296-7).

As both a dietary restriction and an invisible illness, celiac disease has the potential to be contested by the public. Contested illnesses occupy spaces in both medical and popular knowledge as diseases without defined symptoms, treatment, and even debates on their existence (Moore, 2014). The difficulties of these conditions are not only in the burden of illness, but the need to prove or defend their existence and severity (Groenevelt & de Boer, 2023). While a dieter can remove erroneously served croutons, buy lipstick without a second thought, or order from a gluten ‘friendly’ menu, an individual with celiac disease can be harmed by a mere 200 parts per million, or about a crumb, of gluten. I argue that it is the breadth of difference between these two opposites that may lead to confusion or disbelief surrounding celiac disease. Due to the role of food in the management of celiac disease, it is also important to consider the popularization and demedicalization of the gluten free diet.

Medicalization is the process by which something is defined as requiring medical intervention. When a behavior undergoes medicalization, it is no longer deviant, but something to be treated or cured (Conrad, 2007). Demedicalization, therefore, is the process by which a deviant behaviour or problem no longer needs to be defined through medical terms (Conrad, 2007, p. 7). This concept is particularly relevant to illnesses requiring a gluten free diet as unlike most illnesses, the treatment can be managed without medical intervention or official diagnosis. As the gluten free diet grows in popularity, it is demedicalized and becomes less likely to be understood as a tool for managing illness. The status of celiac disease, both an invisible and contested illness, leaves individuals who are dependent on strict gluten free diets susceptible to

being stigmatized or facing popular misconceptions about their conditions. As the gluten free diet becomes more popular, it may be more difficult for a gluten free individual to have their condition legitimized by the public. Without visible signs of illness, how can anyone differentiate between trend or treatment?

Trend versus Treatment: Self-Ascription and Stigma

With an understanding of the function of chronic and invisible illness on the self, we must now account for the influence of the dieters, on both those with celiac disease as well as public perceptions. There are contrasting models between how the diagnosed and trend dieters, or self-diagnosed, are conceptualized and understood.

Trend dieters and the self-diagnosed can be most easily understood through looping theory. Hacking (1995) describes looping as the process by which categories of peoples are constantly redefined by experts. Within this arises self-ascription, wherein new categories of 'human kinds' are made by groups taking control of themselves (Hacking, 1995, p. 381-2). By categorizing themselves, individuals who do not medically require a gluten free diet nevertheless form a new category within the gluten free community. The gluten free community of course includes people with celiac disease, but extends to people with non-celiac gluten sensitivity, eosinophilic esophagitis among other medical conditions. While the majority of this group may be understood to be dieters looking to reach their 'health' goals, it would be wrong not to acknowledge the potential for this population to have self-diagnosed individuals, such as those without access to the healthcare needed to diagnose celiac disease. The self-ascriptive form of looping can be beneficial for this group to create an identity for themselves. Yet, as decreased social legitimacy can be harmful for individuals with medically necessary gluten free diets, the

focus of gluten free research should be returned to people with celiac disease, their lived experiences, and the stigma they experience.

Stigma is practically unavoidable with chronic illnesses. Described by Goffman (1963) as, “refer[ing] to an attribute that is deeply discrediting” (p. 3), stigma is the possession of a trait or condition which is undesirable in relation to the majority, or the ‘normals.’ In this context, the normals are those who do not deviate from the expected or the norm (Goffman, 1963, p. 5), those who eat gluten without harm. There are two broad categories for stigmatized individuals, the discredited and the discreditable (Goffman, 1963, p. 41-2). Those with discredited identities have evident, visible characteristics which mark them as different from the normals (Goffman, 1963, p. 16). While those with discreditable identities can conceal their stigmatizing traits, they may still be revealed through specific circumstances. As an invisible illness, celiac disease occupies the discreditable category as it can be revealed through social situations. When the dilemma between social expectations and physical health arises, the restrictions of the gluten free diet become apparent and spoil the identity of the individual with celiac disease (Sverker et al., 2005).

These two categories conflict. While the self-ascriptive choose to eat gluten free and do not need to adhere to the gluten free diet, people with celiac disease do. However, because neither group can be outwardly defined, broader social perceptions of celiac disease and the gluten free diet can be influenced by the self-ascriptive. Although the increased popularity of the gluten free diet, for any purpose, should logically result in higher social legitimacy, food avoidances of any type can mark a person as “picky, self-absorbed, or on the political fringe” (Moore, 2014, p. 82). These popular misconceptions contribute to the decreased social legitimacy of both celiac disease and the gluten free diet as a legitimate method of illness management

(Moore, 2014). It is necessary to consider how low levels of social legitimacy interact with the burdens of chronic illness and stigma.

Stigma is relational. It is not necessarily the gluten free diet that is stigmatizing, but the restriction that adherence demands. Stigma stems from the social consequences of difference, not the disease itself. Due to this relationship between the stigmatized and the normals, stigma has a significant impact on the self as well. Shame, as Goffman (1963) describes, can become a central piece of self-identity, as stigma is identified as an undesirable trait (p. 7). Stigma can impact various opportunities for the stigmatized individual, but in this context, I argue the greatest influence is on self-esteem. The negative perceptions of those who perhaps do not understand celiac disease, grief due to biographical disruption, and the shame of stigma can all contribute to a lowered self-esteem (Millen & Walker, 2001, p. 91). With the hypothetical burden of illness, I have previously proposed, decreased self-esteem can easily fit into changing life expectations and the need to defend the existence of the illness against the experiences of self-ascriptive individuals.

Given the conflict between the stigmatized and the self-ascriptive, individuals with stigma likewise develop specific practices or mechanisms for discrediting situations, in the hopes of maintaining their unspoiled identities (Schroeder & Mowen, 2014). In a study based on structured interviews, Schroeder & Mowen (2014) report a variety of coping mechanisms employed by individuals with celiac disease such as entrusting the stigma to close relationships and having help in accommodating their restrictions, complete transparency, or even rejecting the gluten free diet for the sake of normalcy (p. 467-9). So, as the gluten free diet becomes demedicalized as a diet of choice for the self-ascriptive, how do people with celiac disease

navigate the restrictions of their illness, and manage the stigma and decreased social legitimacy their chronic illness faces?

Methods

Semi-Structured Interviews

The foremost goal of this research is to understand the lived experiences of individuals with celiac disease. I focus on the subjective perspectives of the participants, rather than the objective or biomedical reality of celiac disease to answer my research question. To accomplish this, I used semi-structured interviews as my main method of data collection. Interviews are instrumental in recognizing how participants understand and describe the meanings and experiences of their own lives (Kvale & Brinkmann, 2009, p.116). Specifically, the semi-structured interview is flexible enough to allow for the themes and topics I drew from the previous literature to be discussed, while simultaneously allowing the participant room to express their experiences and perspectives through their own views (Marshall & Rossman, 2011, p. 144).

The interview guide for this research (appendix D) is mainly focused around forming an understanding of restrictions and management, the disruptions to everyday life caused by chronic illness, and how identity is affected throughout these changes. Notably, question 10 of the interview guide is adapted from Sverker et al. (2005); These authors use the critical incident technique to focus the illness experience down to one story the participant feels is particularly important in exemplifying their experiences (p. 172). The critical incident technique proves particularly useful for this project as it is “sensitive to minor problems of importance for the individual person” (Sverker et al., 2005, p. 172). The use of stories and narratives, as targeted by

my use of the broad questions, such as question 10, allow the participant, as an expert of their experiences, to provide a “deep detailed view of their illness experience” (Haydon & van der Riet, 2017, p. 88). Employing this technique allows me to target the small interactions that arise in social activities, which I hypothesized to be influenced by trend dieters and public misconceptions caused by decreased social legitimacy.

A Haligonian support group was used for recruitment, with additional physical posters being distributed to two restaurants, in Halifax and Dartmouth, Nova Scotia. These restaurants were chosen as they offer multiple gluten free and suitable for celiac disease menu items. While I did not ask for any proof of diagnosis, all participants were screened prior to scheduling interviews to ensure they had at least one year of experience adhering to a gluten free diet for medical reasons. All interviews were conducted and recorded virtually, although each participant was given the option of an online or in-person interview.

Following each interview, I deidentified the data and assigned pseudonyms to each participant to protect their anonymity. I analyzed each transcript by the a priori codes I had developed from my initial themes, literature review, and support group findings (Tilley, 2016, p. 155; Marshall & Rossman, 2011, p. 213). Similarly, I searched for repetition or contrasting information across the transcripts to account for unanticipated findings. All transcripts were coded using NVivo 14. Codes were grouped into themes and through connecting back to the literature, used to construct a narrative for understanding how celiac disease is managed. These findings will be discussed in the next section.

The population for this study, as presented in table 1 (see appendix E), is comprised of eight individuals covering an age range from 20s to 60s. All eight participants have been adhering to a medically necessary gluten free diet for at least one year prior to our interview.

Although the recruitment materials were catered toward any experience with a gluten-related medical condition, all eight participants reported receiving a celiac disease diagnosis. The range of illness experience, at the time of the interview for this study population is two to thirteen years, with the average being about six years. To further define my sample, seven participants identify as female, and one as male. All eight participants live with at least one other person, but only one household explicitly chooses to have an entirely gluten free home. The other entirely gluten free house is due solely to all family members having dietary restrictions. Five of the participants have at least one family member, immediate or distant, also diagnosed with a gluten-related disorder.

Analyzing Online Support Groups

To further contextualize my research and analytic themes, I used online gluten free support groups to better inform my knowledge on the lived experiences of people with celiac disease. Observing the use of online support groups can generate a better understanding of performed practices of online communities (Josefsson, 2005). Over a two-week period, from 1 to 14 January 2024, I collected and coded all 119 posts made to the same support group that was used for recruitment. It is important to note that this group has minimal barriers to entry and no identifiable or personal data was recorded. I coded and interpreted the themes of these posts. These codes were applied to interpreting interview data, specifically regarding support group use. Notably, the major themes I coded in my secondary data collection are the concept of recommendation, and the practice of sharing experience to be cautious with money and safety as to prevent risk. This process was informed both by my lived experiences with a gluten-related disorder, and previous literature on chronic illness support groups (Josefsson, 2005). This data serves to reinforce the themes of this research. While this is not necessarily a limitation, it is

important to note that an analysis of gluten free support groups may differ by city, month, or population and my findings are specific to Halifax, Nova Scotia.

Potential Risks and Limitations

The risks of this study are minimal as celiac disease is a chronic illness; the topic is one that was especially familiar to participants, placing them at no greater risk than that of their everyday life. To mitigate any possible risk, participants were informed that they could pause or end the interview at any point. To ensure continued consent, participants were reminded of this in both the consent form and prior to the interview. No questions proved particularly difficult or stressful for participants.

This study did not explicitly ask participants to self-identify race, ethnicity, or socioeconomic status. There is a possibility that these characteristics may influence how celiac disease is managed and this could direct future research. Similarly, no gendered analysis was possible due to only recruiting and interviewing one male participant. Finally, with a relatively small sample size of eight participants and the use of semi-structured interviews, the findings of this research are not representative, but instead provide a brief insight to the lived experiences of people with celiac disease.

Analysis

As I initially contextualized this project in relation to the existing trend surrounding gluten free diets, I anticipated more strife between the medically necessary and choice diets. Trend dieters themselves were, surprisingly, of little relevance to the individuals I interviewed; rather, the role of trend dieters as consumers increases the demand for gluten free products. This was explicitly acknowledged and appreciated by six participants.

Instead, I found that the major barriers facing people with celiac disease to be the challenge of navigating the demands of their relationships as they contrast with the demands of the gluten free diet and ultimately, their long-term health. Very broadly these findings reveal the impact of celiac disease on relationships as well as the self. The major topics discussed by my participants were the process of diagnosis, the function of support groups, the need for increased cognitive labour, and the relational nature of an illness managed by diet. Conceptually, these topics can be organized into the effects of biographical disruption and of the broader burden of illness. The former, which stems from diagnosis, reveals gaps in current formal medical supports in the Canadian context and reveal the development and usage of peer support communities. The latter weighs on the self and directly influences relationships through cognitive, economic, and relational burdens.

Rethinking Life After Diagnosis: Managing Biographical Disruption

Specific to the Canadian context, beginning with the diagnostic process, there are very few supports in place for those recently diagnosed with celiac disease. From a survey as recent as February 2024, a survey from Celiac Canada finds that only about 30% of respondents report their doctors being a quality source of information (Celiac Canada, 2024, p. 19). With private insurance, dieticians and nutritionists may be helpful, but broadly, there are no formal processes for support during the transition period needed to support a gluten free diet and lifestyle. To illustrate, consider the experience of Greg, a man in his thirties, who was diagnosed with celiac disease three years prior to our interview. When discussing supports after his diagnosis he shares:

It was like the middle of a workday, I was about to eat lunch, which was a sandwich, and I got a call from my doctor who says, we did some tests and found out you have celiac

disease, so, don't eat any gluten. I said, all right, and he said, all right, have a good day. [He] just kind of left it at that, so didn't really go into detail about what it was, what it means. He didn't say, you know, maybe look into this, or follow up with this, it was really just all self-discovery for me, for finding out like what exactly [gluten] is, what kind of food it's in, things to avoid and learning about cross contamination.

Because of these inadequate formal supports, the individual, like Greg, is forced to navigate the diet and lifestyle changes needed to manage their health through 'self-discovery.' Beginning in diagnosis, celiac disease ignites biographical disruption for the individual. There is no simple cure but instead life shifts to managing the risk of being glutened and preventing short-term pain and the long-term health consequences. Food becomes redefined as both illness management and a health risk. While the gluten free diet is the only management for celiac disease, contamination of one crumb of gluten can lead to short term symptoms and pain. However, where other chronic illnesses are accompanied by medical intervention, the management of celiac disease is entirely up to the individual. The experience of Greg, as well as six other participants, demonstrates how poor supports in diagnosis can augment the effect of biographical disruption on the self. The life that was once anticipated or expected has been torn away, newly diagnosed individuals must learn how to navigate the constraints of their newly limited diet and reconcile with a new life.

As noted by Bury (1982), biographical disruption extends beyond diagnosis with the condition becoming inseparable from the self. Bethany, a woman in her twenties, was diagnosed with celiac disease for eight years prior to our interview. While discussing the impacts the condition has made in her life, she shares:

I had always intended to work for [a non-government organization]. That had been my life goal, and then I found out I had celiac, and I thought, no way can I go [there] and

have a dietary restriction when there are already food limitations available to the folks who are living there and working there, I can't show up and add that level of burden. Beyond redefining food as medical treatment, celiac disease has ramifications for social life as well as self-identity, which can be understood as a loss of self (Charmaz, 1983). Without a definitive cure, the daily restrictions created by celiac disease prevent the individual from living freely and following their expected biography. This is demonstrated by Bethany's experience having to change her intended career path. The result is an experience of isolation, disappointment, having to realign possible opportunities with their personal expectations, and experiencing changes to their communities and relationships.

As a result of biographical disruption, there are many support groups for celiac disease - both in-person or, more commonly, online groups and forums. The support group, therefore, serves a significant role in the management of celiac disease. As support groups were used for recruitment, it is not surprising that every participant had at least some experience with them. For many chronic illnesses, online support groups and peer communities have emerged as a practice used by individuals in managing their illness (Copelton & Valle, 2009). As Goffman (1963) argues, "among his own, the stigmatized individual can use his disadvantage as a basis for organizing life" (p. 21). Within support groups, members bond and form community around their shared experiences and restrictions; they are not stigmatized but can refer to peers for support in navigating the challenges of everyday life. By removing stigmatization and popular conceptions of the gluten free diet, gluten free support groups can fill the gaps left by diagnosis.

Support groups act as resources for education; in matters of navigating grocery stores and learning to read food labels, socially: as spaces for ranting and sharing experiences, and as a hub for referencing and exchanging knowledge of quality, cost effective foods and the coveted

‘recommendation.’ The following three examples from Erin, Ivy, and Greg, demonstrate how celiac peer recommendations are used to navigate social situations. Erin, a woman in her forties, was diagnosed with celiac disease nine years prior to our interview. She comments on her use of peer recommendations sharing, “just knowing that this [other] person has to take the exact same precautions as I do, and this is what's working for them - I'm traveling to London later this month and I do have a friend who lived there who's also celiac. So, I sent her a message and I said, I'm going here, can you recommend restaurants?” By using the recommendation of her celiac peers, Erin, who values the shared experience, can navigate her restrictions much more easily while travelling. This also alleviates the potential health risks Erin might face while eating out at restaurants.

Ivy, a woman in her twenties, was diagnosed with celiac disease two years before our interview. As a relatively recently diagnosed individual, she comments on the importance of the peer recommendation, “at this point in my diagnosis, I've only gone to [restaurants] that I know other celiacs have gone to safely.” Comparably, Greg discusses how he uses peer recommendations for breaking his habits and trying new restaurants, “generally, I'm going off the back of seeing a few recommendations for a place and that'll get me there.” As can be expected, eating in spaces that are shared with gluten carries risk for people with celiac disease. However, eating at restaurants cannot be realistically or entirely avoided. Both Ivy and Greg use the recommendations of peers, and their experiences of safety, to navigate the risk of eating at restaurants. This enables them to continue engaging in activities that were not necessarily considered risky before their diagnoses.

It is important to draw a distinction between the idea of the recommendation and the average product suggestion. The recommendation can exist separately from product suggestions

as recommendations may aid in navigating social situations. Specifically, the recommendation indicates safety, especially for situations where the individual has little control over their food options, like visiting restaurants or while travelling. The recommendation has the potential to alleviate the fear of eating out and breaking routine, engaging with the risk of trusting others with their health. Product suggestions are related more to cost risk, insomuch as not buying a poor-quality product when a similarly priced alternative has better taste or texture. Although this is just one function of the support groups, it is essential for understanding the restrictions imposed by celiac disease and how they can be managed.

The negative aspects of online groups cannot be overlooked. Within these groups, it is easy for misinformation and myths to be spread and interpreted as fact by an already overwhelmed and perhaps vulnerable population. Bethany explicitly noted the existence of misinformation in support groups, as she shares, “it's better to have something, I think, than absolutely nothing. Just having an educated set of glasses to put on when you're reading support group information is more valuable than having nothing, and just going through it alone.” As previously noted, poor requirements for post diagnosis supports lead individuals with celiac disease to take their education upon themselves, and in some cases, to rely on online support groups. Examples of gluten related misinformation include sourdough bread being safe as gluten doesn't ‘survive’ the fermentation process and, as Lisa suggested in our interview, the existence of an alleged European wheat species, which is believed to be safe for individuals with celiac disease to consume as it will not harm the villi of the intestine.

Another common facet of misinformation within celiac disease support groups is the propagation of American information in Canadian groups. Canada and the United States have similar, yet differing labelling laws. Gluten free resources or information from one country

cannot therefore be applied to the other. This contrast was noted in an interview by Ivy.

Frequently travelling between the United States and Canada, she shares:

You have to be really aware when you're in the groups that aren't just solely for Canada. It's like, okay, I'm asking this about Canada, or I need to know about the [United] States, and making sure people are going to answer the right way. The other problem is, in the US, they put wheat in a lot of their medications versus here in Canada, we have like four medications that contain wheat.

Ivy's experience reiterates both the importance and dangers of online support groups. Although they can be instrumental and full of knowledgeable answers, there is a significant risk for misinformation that can potentially harm the long-term health of the celiac individual. The results may lead to consuming the wrong products, such as the sourdough I mentioned earlier, or hypervigilance toward certain ingredients in Canadian products, as is the case of yeast extract (Health Canada, 2020). Myths and misinformation should not be discounted within the support group as their role within the sphere of celiac disease management, particularly in the context of poor post-diagnosis supports, could prove harmful. Furthermore, the popularity of support groups exposes gaps in current diagnostic processes, and more broadly of the isolating and lived experiences of managing celiac disease. Navigating the line between information and misinformation requires effort, contributing to the significant cognitive labour needed to manage and adhere to the necessary gluten free diet.

“Never Letting Your Guard Down”: Managing Cognitive Burdens

Throughout all eight interviews, participants frequently referred to the difficulties they face in managing their celiac disease. These extended beyond the diet to influence cognitive, economic, and relational spheres of everyday life. The concept of cognitive labour has long

existed within sociology and can be briefly understood as the work of, “(1) anticipating needs; (2) identifying options for meeting those needs; (3) deciding among the options; and (4) monitoring the results” (Daminger, 2019, p. 609). Although this concept is typically applied in relation to issues of inequality in gendered work within the home, I propose to extend this concept to analyze how chronic illnesses are experienced and managed. In the case of this research, cognitive labour can apply to an array of situations faced daily by individuals with celiac disease. Cora, a woman in her forties, was diagnosed with celiac disease thirteen years before our interview. She describes how the risk of gluten contamination weighs on her mind, sharing:

You're scared to eat anything. Like someone could say, ‘oh, I made you some gluten free muffins -I hope you like them.’ But then you don't know if it's really gluten free. What if they used the spatula that wasn't washed properly, or they used a baking tray that had wheat muffins in it or something before? It's always being so scared that sometimes you're left out.

People with celiac disease are required to constantly anticipate and mitigate the risk of gluten in their everyday lives. Cora's experience emphasizes the cognitive burdens and relational nature of celiac disease. Although gluten free muffins should be safe, people with celiac disease have to consider every possible source of contamination. The dilemma between relationship and health serves as a reminder of stigma and reinforces the difference between people with celiac disease and the majority.

While the cognitive burdens of celiac disease function within social dynamics, this concept is also relevant when considering the labour it takes to find and prepare safe gluten free food. Anna, a woman in her forties who received her celiac disease diagnosis three years prior to

our interview. Reflecting on the experience of managing gluten free adherence when shopping, Anna comments:

You have to be cautious and aware - always checking ingredients because even things that you have eaten one hundred times, the packaging could change or the processing manufacturer could change and so, it's kind of like, never really letting your guard down. If you do, you end up becoming sick. It's a lot of work. It's a lot of mental work, it's a lot of actual physical work too.

Beyond simply finding a gluten free product, the management of celiac disease requires hyper vigilant cognitive labour. That is, constantly and consistently anticipating gluten, finding replacement products or opportunities, deciding options and monitoring results (or lack of contamination) to maintain good health. Anna is no exception as all eight participants discussed the 'mental work' it takes to protect themselves, and in some cases, their families, from the physical contamination of gluten.

Again, as celiac disease is an autoimmune disease, it is necessary for individuals to constantly search for possible sources of gluten in their diets and environment. This is particularly noteworthy as the majority of my participants do not have entirely gluten free households. The exception to a gluten eating household within my data is Greg, in reference to managing food with non-gluten free family members, he says:

We don't bring it in the house. I've seen that some people will be like, oh, I'm doing gluten free, but my husband or my wife isn't so they do this - and it's like, no, there's none of that. We don't mess around; it's just completely gone. If we go out to eat at a restaurant, she'll also get gluten free option [...] but it's just like it just doesn't come in the house. It's crazy to me because like what I know is that people - like you can try your

hardest, I think, to make sure stuff is separate and fully cleaned, but we all have moments where we just get lazy and it's just kind of like I'll just kind of half do this and then it's oh, now I'm feeling sick.

Although Greg's case acts as an outlier compared to the other non-gluten free households, it notes how easily contamination can occur for an individual with celiac disease. However, this example also demonstrates that the burden of celiac disease is often individual, but uniquely, Greg has a family who shares the burden of celiac disease and lessens potential risks he faces.

Health at WHAT Price? Managing Economic Burdens

It would be remiss not to discuss the burdensome effect the high cost of gluten free products has on people with celiac disease. All food prices have climbed in recent years, but as is expected with any niche market, gluten free products are expensive. Other chronic illnesses may have treatments covered by insurance, but the cost burden of celiac disease is placed almost entirely on the individual. Celiac Canada (2024) estimates the cost of gluten free food products to range from 150% to 500% more expensive than 'regular' foods (p. 12). Similarly, Celiac Canada (2024) notes that as of February 2024, only one in five Canadians with celiac disease report taking advantage of the current incremental tax benefits made available by the federal government (p. 12). To better understand how these cost differences can have an impact on the individual, consider the experiences of Ivy and Bethany. While discussing the cost of gluten free foods in our interview Ivy shares:

Pasta is triple the price if you want to have good gluten free pasta at home, even on sale. I just popped up [to the store] this morning because it was \$0.50 off the box versus like sales for regular pasta, it's like \$2 off the box. It's a big difference, but at the same time, the way the government has it set up for us, yes, we can claim the incremental cost

difference on our taxes, but it doesn't equate to us actually saving anything. I saved like \$17.00, so that didn't help me with the extra cost of food at all.

Although there is policy in place to attempt to offset the monumental costs for Canadians with celiac disease, as Ivy shares, it is not effective. High costs, limited variety, and mediocre food quality can contribute to the burden of celiac disease.

However, the burden of cost may extend beyond the wallet to impact the health of the individual. Bethany shared her experience of navigating balancing the high cost of gluten free foods early in her diagnosis, saying:

I did a lot of cost evaluations...What can I substitute with that will cost a lot less? I think my health deteriorated a little bit after being diagnosed because I wound up being maybe a little too frugal in my spending, thinking, ok, what's really affordable? Eggs are really affordable. I think I probably let go of some of the healthier, meatier things like that because I was trying to cut costs somewhere, but it was a lot of kind of negotiating with myself... And then, early in my marriage, it was a lot of like if we're buying groceries, often feeling like if I could just eat normally, it would be so much easier for us to afford other things, or travel, or do all that because the cost is so much higher now.

Bethany's experience encapsulates the myriad of ways celiac disease can impact both the individual and their relationships; the cost of maintaining a gluten free diet impacted her overall personal health in other ways, but it also highlights the intrinsic relational nature of celiac disease. As Bethany notes, the burden of illness extends beyond her and has the ability to impact her marriage, insomuch as limiting potential opportunities for her and her spouse. Celiac disease can be isolating and burdensome. It is necessary to consider how non-gluten free individuals, especially those with no knowledge of gluten, can impact the lives of those with celiac disease.

Self-Advocacy or Selfishness? Managing Relational Burdens

As I have established, once the labour, whether mental or otherwise, of accommodating the biographical disruption of illness is undertaken, the true challenge of managing celiac disease lies in managing the expectations, or actions, of others and the stigmatizing nature of celiac disease as a chronic illness. Deviation from the strict gluten free diet cannot happen without risking the short-term and long-term health of people with celiac disease. Due to this, refusing non-gluten free foods or avoiding situations where food is a focus, reinforces the stigma experienced by people with celiac disease. To explore how this concept is realized in experience, the following four examples demonstrate just a few possibilities of how celiac disease impacts the way individuals report their social interactions.

It is first important to note that the concept of burden is frequently intertwined in social situations in which celiac disease is relevant; a combination of low social legitimacy, stigma and the burden of illness can impact self-esteem. Throughout my data, participants used the word burden, primarily either in reference to how their illness made them feel, or as a descriptor for how they feel when their illness inconveniences other people. This concept was primarily manifested, in my data, almost as a conflation of self-advocacy and selfishness. To illustrate, consider the experience of Erin. When discussing necessary accommodations she received on a cruise from dining staff, she reflects:

I can eat at the salad bar, but people are throwing croutons everywhere, there's just too high of a risk, so [the dining staff] go down to their dedicated kitchen and by the end of my cruise they saw me coming and they just said, 'what can we go get you?' It was amazing, but then I get the comments, 'Oh, look, she's so high maintenance,' and 'she's a queen, everybody's like catering to her' and it's like, I'm not meaning to be like that.

It is interesting to note how the low social legitimacy of celiac disease can redefine the accommodation of an illness as a shameful or selfish action. In isolation, gluten free eating is the management of an illness, but in relation to others, it can become stigmatizing. A closer analysis of this quote also highlights Erin's phrasing of 'the comments' suggesting that this is not an uncommon experience for her. The contrast between the personal and the relational can be considered the underlying cause for many of the social challenges people with celiac disease face. The concept is emphasized by Lisa's experience. Lisa, a woman in her sixties, has been diagnosed with celiac disease for three years prior to our interview. When discussing the social challenges she faces, she shares:

I'm a leader of an organization and community. We have times of the year where we have potluck. So, I go in, I set up and I help them with whatever, but I can't touch any of it. So, some of my dear friends have said to me, "what's wrong? You never tried my [dish]," you know, and it seems like you're constantly saying celiac disease this and celiac disease that. They'll look at you funny because they don't even understand what it is. You can't say you're gluten free because if you say you're gluten free, they think it's a choice. It's difficult to explain to people when they don't understand, I guess, the anatomy of it.

Decreased social legitimacy, like what Lisa experiences, strengthens the challenges of stigma. Lisa navigates between offending her friends so as not to risk her health. However, because celiac disease has low social legitimacy and is misunderstood in public perceptions, Lisa faces the stigma of her illness as well as the negative traits associated with trend diets (Moore 2014).

The previous two examples focus on everyday struggles for people with celiac disease navigating relationships and situations with non-gluten free people. Bethany discussed one such

area of her life that she feels was especially influenced by her restrictions. Having to negotiate her restrictions as they contrast with her spouse's culture, she shares:

I'm married to someone of a different culture, and I think early on, when I was introduced to my in-laws, I think they were a bit offended by my reluctance to eat their food, even if they felt like they'd been as careful as possible. If I'm uncomfortable eating food that someone's prepared when they feel confident, they've done everything within their power [to prepare it gluten free] and I believe that they've done everything within their power, but there's something I would check for that they still probably might not think of. So, there's that relationship strain.

Bethany's experience, in the context of a relationship with especially 'high stakes,' demonstrates the impact the restrictions of celiac disease have on the self and also on relationships. The interaction between the stigma of celiac disease and low social legitimacy, in this case poor awareness of the condition's existence, act as relations burdens for Bethany through having offended her in-laws despite her best intentions. This example also demonstrates how food, as a source of identity, is restricted by the barriers caused by celiac disease (Gregory, 2005).

The final finding of relational burdens I wish to highlight is the unique dynamic of the parent and child. The majority of my participants are mothers, but only one has young children who have also been diagnosed with celiac disease. However, worrying about the future or current experiences of the child, in relation to living gluten free, arose in four of the eight interviews. To illustrate, consider the experience of Hannah, a woman in her forties, who was diagnosed with celiac disease twelve years prior to our interview. While discussing how she manages her diet in the home she reflects:

I worry that because I expose my children to so many gluten free products, whether they will have issues later in life because it would be the opposite for me, right? I was growing up on bread and things like that, and then later in life...then I became celiac, and I always think with my children they have so many gluten free products in the home. I don't know if when they move out and stop worrying about that stuff, whether it will have an impact on their health.

Other examples of this dynamic in relation to gluten, concern non-gluten free children missing out on normal experiences, such as enjoying a delicious birthday cake, the joyous experience of fast food, or in dialogue about the risk the children face of inheriting the genes of celiac disease. The anxiety around children missing out due to their parent's restriction or being at risk for the same diagnosis reminds us that celiac disease is still a chronic illness. Despite being managed through diet; it is still stigmatizing and socially undesirable.

All the examples I have provided in this section function from the difference between 'normal' people and people with celiac disease. In the current social context, these problems are worsened by the decreased social legitimacy celiac disease faces. Moving the focus beyond the gluten free diet and onto the social challenges that arise due to celiac disease helps to explain the burden of illness and struggles caused by stigma; all of which result in an increase in the cognitive labour needed to manage this chronic illness. These examples only serve to reiterate the difficulty of managing celiac disease is not the gluten free diet itself, but in how the diet impacts the way individuals interact, relate, or experience their relationships and their identity. It is a balancing act between the risk of contaminating themselves or harming their health and being able to engage completely in relationships and social lives.

Conclusion: Confronting the Trend of Treatment

The lived experience of celiac disease is in no way universal, but there are similarities throughout this data that speak to the impact of stigma, biographical disruption, and the burden of illness in the management of celiac disease. My aim with this research project was to understand the lived experiences of celiac disease within the broader social context of trend dieting. Through the eight semi-structured interviews I conducted, I was able to understand and analyze the specific social challenges that arise in the management of celiac disease: the cognitive, economic, and relational burdens, as well as the impact of biographical disruption.

The findings of this research illuminate the specific barriers faced by people living with celiac disease and the challenges they navigate in managing their condition. These findings may be extended to aid in elucidating the function of chronic illness more broadly. Beyond the biomedical implications of this chronic illness, celiac disease has a clear and significant impact on the social lives of my participants; restricting or preventing them from engaging in activities and communities as they had before diagnosis.

Though the burdens of managing celiac disease may be offset by the exchange of knowledge or experience within peer support in online groups, the stigmatizing nature of this chronic illness remains impactful. The current social context of gluten free trend diets lowers the social legitimacy of the condition, magnifying the social barriers people with celiac disease face. Although there is no clear solution to the stress, biographical disruption, or stigma and specific relational struggles created by this chronic illness, there are certainly many opportunities for changes regarding the societal narrative of celiac disease.

More broadly, the most obvious and practical change is the implementation of post-diagnosis supports; beyond meeting with a private dietician, this research acknowledges the very

few supports which are currently offered to people with celiac disease and their families.

Eliminating some degree of stress and uncertainty at the most vulnerable stage of biographical disruption and chronic illness management could improve the experiences of people managing celiac disease.

Sociologically, this research contributes to both the study of celiac disease as well as the broader understanding of chronic illnesses and their social impact. Considering the relational burden of chronic illnesses can aid future research in truly understanding the complete impact illness management has on the self and the identity.

There are many avenues left to explore within the research on the lived experiences of celiac disease. Further research in this context could seek to understand the limitations and shortcomings of current institutional supports for celiac disease, such as the current Canadian incremental tax credit. However, more specific to my findings, I would encourage future research to approach the lived experiences of celiac disease from a gendered analysis. The differences in responses from the seven women and one man I interviewed lead me to hypothesize the influence of gender and gender roles have significant impact in the experience of managing celiac disease.

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Appendix A Recruitment Poster



Trend or Treatment: exploring experiences of managing gluten-related disorders

If you;

- Are 18 years of age or older
 - Follow a medically necessary gluten free diet
 - Want to discuss your experiences of managing a gluten free diet
 - Want to share your thoughts on the gluten free lifestyle
-

I invite you to participate in my Sociology Honours research project. I am looking for participants to discuss medically necessary gluten free diets, food restrictions, and the challenges of living gluten free. Participants will be asked to complete a one-hour interview at a location convenient to them, including the option of completing an interview virtually. If you choose to participate, all information you provide will be kept confidential.

If you are interested, or have any questions or concerns, please contact Rachel MacLeod (Rachel.MacLeod@dal.ca)

Appendix B

Consent Form

Trend or Treatment: exploring experiences of managing gluten-related disorders.
REB # -2023-6949

You are invited to take part in research being conducted by me, Rachel MacLeod, an undergraduate student in Sociology, as part of my Honours degree at Dalhousie University. The purpose of this research is to interview individuals with medically necessary gluten free diets to understand their experiences. I will write up the results of this research in a paper for my class, called the Honours Thesis.

As a participant in the research, you will be asked to answer a number of interview questions about your experiences on a gluten free diet. The interview should take about an hour and will be conducted in a quiet location of your choice. Videochat interviews will take place via Teams or Zoom, so you can choose to do them from a private place where no one will overhear you. If you do an interview by videochat, there is a risk of loss of personal privacy from the use of internet-based communications. The risk is no greater or lesser than when using applications such as Teams or Zoom for other purposes. With your permission, the interview will be audio-recorded. If I quote any part of it in my Honours thesis, I will use a pseudonym, not your real name, and I will remove any other details that could identify you.

Your participation in this research is entirely voluntary. You do not have to answer questions that you do not want to answer, and you are welcome to stop the interview at any time. If you decide to withdraw from the study after the interview is over, you can do so for up to two weeks after the interview. I will not be able to remove the information you provided after that date, because I will have completed my analysis, but I will not use it in any other research.

The information that you provide will be kept private and will be anonymized, which means any identifying details such as your name will be removed. Only the honours class supervisor and I will have access to the unprocessed information you offer. The interview will be audio-recorded, and the recording will be stored on a password-protected, encrypted laptop, with a backup saved on OneDrive, a Canadian encrypted cloud storage service, as well as on an encrypted external hard drive. I will transcribe the interview, and the transcription will be stored on the password-protected, encrypted laptop. Once the interview is transcribed, I will delete the audio. A back-up of the transcription will be saved in OneDrive, as well as on the external hard drive. The transcription and any associated notes will be kept indefinitely in the above-named locations and may be referenced in future research. I will describe and share general findings in a presentation to the Sociology and Social Anthropology Department and in my Honours thesis. Nothing that could identify you will be included in the presentation or the thesis. I will keep anonymized information so that I can learn more from it as I continue with my studies.

The risks associated with this study are no greater than those you encounter in your everyday life. There will be no direct benefit to you in participating in this research and you will not receive compensation, but the research will contribute to new knowledge on how dietary restrictions impact the lives of individuals with gluten-related disorders.

If you would like to see how your information is used, please feel free to contact me and I will send you a copy of my Honours thesis after April 30.

If you have questions or concerns about the research, please feel free to contact me or the honours class supervisor. My contact information is Rachel.MacLeod@dal.ca. You can contact the honours class supervisor, Dr Martha Radice, at the Department of Sociology and Social Anthropology, Dalhousie University on (902) 494-6747, or email martha.radice@dal.ca.

If you have any ethical concerns about your participation in this research, you may contact Catherine Connors, Director, Research Ethics, Dalhousie University at (902) 494-1462, or email ethics@dal.ca.

Participant's consent:

I agree that the researcher may audio record and take notes during the interview Yes No

I would like to receive a copy of the finished thesis by email Yes No

I understand that I may withdraw at any point during the interview as well as during the two weeks following the interview Yes No

I have read the information above, and I agree to participate in this study.

Name:

Email:

Signature:

Date:

Researcher's signature:

Date:

Appendix C
Screening Questions

1. Do you follow a gluten free diet?
2. Is this diet followed for medical reasons?
3. How long have you been following a gluten free diet?

Appendix D

Interview Guide

1. How did you come to start eating gluten-free?
 - a. Give me an overview of your gf journey (how it started, why you sought advice).
 - i. If you don't mind sharing, why do you follow a gluten free diet?
 1. What was the diagnostic journey?
 - b. Do you adhere completely to the gluten free diet?
 - i. If not, what are the circumstances in which you would consume gluten?
 - ii. If yes, how would you describe the risks of gluten? How do you conceptualize glutening (short-term vs long-term)
 1. If you don't mind sharing what does the average glutening look like to you?
2. Which aspects of your life are you most conscious of when managing your illness?
3. How do you decide whether a product is worth the risk?
 - a. Either financially or related to cross-contamination/gluten
4. Do you think the gluten free diet can become an identity?
 - a. if so, how do you define a gluten free lifestyle?
 - b. Do you think there's a difference between 'being' vs 'having' celiac disease?
5. How would you describe celiac disease to a stranger?
 - a. To a friend?
6. Do you feel you miss out on anything due to the gluten free diet?
 - a. Can you share an example of how your life has been impacted by the gluten free diet?
 - b. If you had a pass, what one thing would you do?
7. What is the hardest thing about being gluten free?
 - a. And the easiest?
 - b. Has the cost of gf products/options/charges had an impact on your life?
8. How do you feel about the rising popularity of gluten free diets?
 - a. Does this impact how you describe or identify?
 - i. Do you feel you need to justify yourself?
 - b. Describe your thoughts on gluten free fad dieters.
 - i. Do you think they influence how medical GF requirements are perceived.
 - c. What are your thoughts on 'gluten friendly' or 'low gluten' markings/labels?
9. Explain the changes the gluten free diet has made in your life?
 - a. Social
 - b. Cultural
 - i. Nostalgia?
 - c. Medical
 - d. Financial
10. What is something you would recommend to someone just starting their gluten free diet?
 - a. Would your advice be different to yourself?

11. [Critical incident technique (adapted from Sverker et al., 2005);] “Can you describe the last occasion in your everyday life when you were reminded, inconvenienced, or hindered by your celiac disease [or NCGS]?”
 - a. How do you think your experience could be improved or avoided?
 - i. Who do you think should take action to make these changes?
12. What is the hardest social situation to plan for?
 - a. The easiest?
13. How do you plan for events or occasions with food?
 - a. Does this differ with social setting (i.e friends, family, work)
14. Do you participate in support groups? (online or in-person)
 - a. What is your primary focus when using them?
15. Who do you live with if anyone?
 - a. Are the other people in your home gluten free?
 - i. Do their actions impact how you manage your food at home?
 - b. Is there extra mental labour with the gf diet?
16. What is one thing you wish everyone knew about being gluten free?
17. Finally, if you don't mind my asking...
 - a. How old are you?
 - b. What is your gender?

Appendix E

Table 1: Describing the Characteristics of the Study Participants

Pseudonym	Gender	Age	Years since celiac disease diagnosis	Family member with GRD?	Lives with others?	completely gluten free household?
Anna	F	40s	3 years	yes	yes	yes
Bethany	F	20s	8 years	yes	yes	no
Cora	F	40s	13 years	no	yes	no
Erin	F	40s	9 years	no	yes	no
Greg	M	30s	3 years	yes	yes	yes
Hannah	F	40s	12 years	yes	yes	no
Ivy	F	20s	2 years	no	yes	no
Lisa	F	60s	3 years	yes	yes	no

Appendix F
REB Final Report



ANNUAL/FINAL REPORT

Annual report to the Research Ethics Board for the continuing ethical review of
research involving humans / Final report to conclude REB oversight

A. ADMINISTRATIVE INFORMATION

This report is (<i>select one</i>):				
		<input type="checkbox"/> An annual report	<input checked="" type="checkbox"/> A final report	
REB file number:	2023-6949			
Study title:	Trend or Treatment: exploring experiences of managing gluten-related disorders			
Lead researcher (named on REB submission)	Name	Rachel MacLeod		
	Email	rc422347@dal.ca	Phone	-
Current status of lead researcher (at Dalhousie University):				
		<input type="checkbox"/> Employee/Academic Appointment	<input type="checkbox"/> Former student	
		<input checked="" type="checkbox"/> Current student	<input type="checkbox"/> Other (please explain):	
Supervisor (if lead researcher is/was a student/resident/postdoc)	Name	Dr. Martha Radice and Dr. Karen Foster		
	Email	martha.radice@dal.ca and karen.foster@dal.ca		

Contact person for this report (if not lead researcher)	Name			
	Email		Phone	

B. RECRUITMENT & DATA COLLECTION STATUS

Instructions: Complete **ALL** sections relevant to this study

Study involves/involved recruiting participants: Yes No
If yes, complete section B1.

Study involves/involved secondary use of data: Yes No
If yes, complete section B2.

Study involves/involved use of human biological materials: Yes No
If yes, complete section B2.

B1. Recruitment of participants		<input type="checkbox"/> Not Applicable
B1.1 How many participants did the researcher intend to recruit? <i>(provide number approved in the most recent REB application/amendment)</i>		8-10
B1.2 How many participants have been recruited? <i>(if applicable, identify by participant group/method e.g. interviews: 10, focus groups: 25)</i>		
a) In total, since the beginning of the study: 8		

b) Since the last annual report: 8
<p>B1.3 Recruitment for this study is:</p> <p><input checked="" type="checkbox"/> complete; or</p> <p><input type="checkbox"/> on-going</p>
<p>B1.4 Data collection from participants for this study is:</p> <p><input checked="" type="checkbox"/> complete; or</p> <p><input type="checkbox"/> on-going</p>
<p>B1.5 Communication with participants related to this study is:</p> <p><input checked="" type="checkbox"/> complete; or</p> <p><input type="checkbox"/> on-going</p>

<p>B2. Use of secondary data and/or biological materials</p> <p style="text-align: right;"><input checked="" type="checkbox"/> Not Applicable</p>	
<p>B2.1 How many individual records/biological materials did the researcher intend to access?</p> <p><i>(provide number approved in the most recent REB application/amendment)</i></p>	
<p>B2.2 How many individual participant records/biological materials have been accessed?</p> <p>a) In total, since the beginning of the study:</p> <p>b) Since the last annual report:</p>	

C. PROJECT HISTORY

<p><i>Since your last annual report (or since initial submission if this is your first annual report):</i></p>
--

C1. Have there been any variations to the original research project that have NOT been approved with an amendment request? This includes changes to the research methods, recruitment material, consent documents, study instruments or research team.

Yes No

If yes, please explain:

C2. Have you experienced any challenges or delays recruiting or retaining participants or accessing records or biological materials?

Yes No

If yes, please explain:

C3. Have you experienced any problems in carrying out this project?

Yes No

If yes, please explain:

C4. Have any participants experienced any harm as a result of their participation in this study?

Yes No

If yes, please explain:

C5. Has any study participant expressed complaints, or experienced any difficulties in relation to their participation in the study?

Yes No

If yes, please explain:

C6. Since the original approval, have there been any new reports in the literature that would suggest a change in the nature or likelihood of risks or benefits resulting from participation in this study?

Yes No

If yes, please explain:

D. APPLYING FOR STUDY CLOSURE

Complete this section only if this is a FINAL report as indicated in section A

D1. For studies involving recruitment of participants, a closure may be submitted when:

all research-related interventions or interactions with participants have been completed

N/A (this study did not involve recruitment of participants)

D2. For studies involving secondary use of data and/or human biological materials, a closure may be submitted when:

all data acquisition is complete, there will be no further access to participant records or collection of biological materials

N/A (this study did not involve secondary use of data and/or human biological materials)

D3. Closure Request

I am applying for study closure

E. ATTESTATION (both boxes *must* be checked for the report to be accepted by the REB)

I agree that the information provided in this report accurately portrays the status of this project and describes to the Research Ethics Board any new developments related to the study since initial approval or the latest report.

I attest this project was, or will continue to be, completed in accordance with the approved REB application (or most recent approved amendment) and in compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2).
