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Celiac Disease: The Challenges of Affording a Gluten-Free Diet

by
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ABSTRACT

Treatment of celiac disease is a strict gluten-free diet for life. The gluten-free diet is a complex, socially restrictive and significantly more expensive diet than a regular wheat-based diet. There are both social and physical consequences to celiac disease. Social consequences include difficulty dining out and traveling as well as the negative impact on family life created by adherence to a gluten-free diet. Physical consequences related to non-adherence to the dietary treatment of celiac disease include malabsorption and malnutrition. Barriers to adhering to a gluten-free diet include limited availability of gluten-free food and the increased cost associated with purchasing gluten-free food. Food security encompasses physical and economic access to food for the dietary needs and requirements for the individual; therefore, it is important to determine how individuals with celiac disease experience and manage the dietary requirements of the disease and the costs associated with its treatment.

The objectives of this thesis are to examine how families experience and manage the and nutritional and financial requirements of celiac disease, to discover enablers and barriers to celiac disease, to explore strategies that would aid in the nutritional and financial management of the disease, and to determine whether families experience food insecurity. Understanding family experiences with celiac disease and a gluten-free diet will help in developing strategies to improve affordability and hence adherence to the gluten-free diet.

Participants in this study were primary food providers of children 16-years-of-age and younger with biopsy-confirmed celiac disease who were on a gluten-free diet for at least six months. A phenomenological approach was used to examine how families experienced and managed the nutritional and financial requirements of celiac disease. Bronfenbrenner's social-ecological systems theory provided a model to examine participants' barriers and enablers to managing celiac disease in reference to the five layers of their environment (micro-, meso-, exo-, macro-, and chronosystems) that mediated their behaviours and experiences. Data were collected through semi-structured interviews with participants and through the administration of the Household Food Security Survey Module to determine food insecurity.

Ten primary food providers (mothers) participated. How participants experienced celiac disease was greatly dependent on how knowledgeable they perceived the general population to be about the disorder. Positive experiences occurred when the participants met someone who knew about celiac disease or was interested in knowing about it. Negative experiences occurred when participants felt frustrated due to poor understanding of celiac disease in the general population and a perceived lack of seriousness of the disorder. Frustration was also observed through participants' struggles with gluten-free food, specifically the cost. Though the participants were not found to experience food insecurity using the Household Food Security Survey Module, it was clear that many struggled with the cost of gluten-free foods and displayed characteristics of food insecurity. Most participants felt a lack of food choices, anxiety over eating away from the home due to fear of gluten contamination, and worry over the financial responsibility of a gluten-free diet.

Families with celiac disease are struggling with both lack of availability and high cost of gluten-free diet. Knowledge of celiac disease is felt to be poor amongst the general public. Improving awareness of celiac disease and making gluten-free foods affordable through income supports should be high priorities for the public policy makers and health care professionals.

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1. INTRODUCTION

The nutritional management of celiac disease (CD) consists of a strict adherence to a gluten-free diet for life. Gluten-free food items have been shown to be two to three times more expensive than their gluten-containing counterparts (1,2) thus raising the question: How do families experience and manage the nutritional and financial requirements of the disease?

Celiac disease is an inherited autoimmune disease in which the body's immune system responds negatively to gluten, a protein found in wheat, barley, rye and triticale. Celiac disease is recognized as one of the most common chronic gastrointestinal diseases in the world, affecting one in 100-200 people in North America, and as many as 300,000 Canadians (3). The disease is often under-diagnosed (4) and, therefore, the actual prevalence may be even higher. Currently, the only treatment for CD is to exclude foods that contain gluten. Since gluten is found in many food items such as all wheat-based breads, a common North American dietary staple, food options are significantly limited. When members of a household have CD and are experiencing food insecurity, they may be forced to purchase cheaper food items such as highly processed foods, which are often gluten-containing. Evidence shows that the cost of GF items is a strong indicator of a person's ability to adhere to a GF diet (5). The impact of not being able to afford the necessary foods may result in food insecurity and negative health consequences due to poor management of CD.

Food security occurs when *"all people, at all times, have both physical and economic access to sufficient, safe and nutritious food to meet their dietary needs and food preferences for an active and healthy life"* (pg. 9) (6). Food insecurity can be described as the inability to obtain sufficient and nutritious food through socially acceptable means (7). Currently, it is unknown if individuals with CD are experiencing food insecurity. According to the most recent Canadian

Community Health Survey (CCHS), an estimated 10% of households in Nova Scotia have experienced either moderate or severe income-related food insecurity (8), which is higher than the previously recorded 9.3% of Nova Scotia households in the 2007/2008 CCHS (cycle 3.1).

Tarasuk et al. (9) describe the experience of food insecurity as being dynamic since, along with environmental factors, it can be influenced by an individual's needs, priorities, education, and financial well-being. There are various ways in which food insecurity can occur; however, for the purpose of this research only individual and household food insecurity will be examined. Household food insecurity occurs when the whole household experiences some level of decreased quantity of food, unsuitable food options, unacceptable means of acquiring food, and anxiety over the foods chosen and methods used to obtain food (10). Individual food insecurity occurs on a more personal level with the individual experiencing insufficient intake, an inadequate diet with lack of food choice, and a disrupted eating pattern (10). In food-insecure households, there is little money to spend on required foods; some families may be forced to choose between food or fixed costs, such as heat and rent (11). Sacrifices made to the food budget may force food-insecure households to purchase cheaper, energy dense and highly processed foods, which can compromise both the quantity and quality of the diet (9).

Although the negative impact of food insecurity on a person's ability to consume a healthy diet has been well documented (9,12,13), little information is available that specifically looks at how families experience and manage the special diet requirements of CD and whether or not these families are experiencing food insecurity. Of the research that has been published, the main focus has been on the cost of foods, specifically GF foods compared with gluten-containing foods (1,2). Therefore, research is needed to understand how households with family members with CD experience and manage the nutritional requirements of the disease. Moreover, there is a

need to examine the experience of food insecurity among children with CD, as the 2007/2008 CCHS Cycle 3.1 revealed a high prevalence of food insecurity among Canadian households with children (8). Children of food-insecure households are at greater risk for growth and developmental delays (14). In addition, children with CD are at an increased risk of nutritional inadequacy (15-17) due to following a GF diet. Therefore, children with CD who experience food insecurity are an exceptionally vulnerable population.

This research will help to inform the public, policy makers, celiac support organizations and those directly affected by CD about what actions need to be taken in order increase access to a GF diet in families who have children with CD.

1.1. Research Focus

Using a phenomenological approach the researcher examined, through the primary food provider in the family, how celiac disease was experienced and managed in the household. The focus of this research was also to investigate enablers and barriers in obtaining gluten-free foods and to determine if families with one or more children with celiac disease were experiencing food insecurity.

1.1.1. Research Question

How do families experience and manage the nutritional and financial requirements of celiac disease?

1.1.2. Research Objectives

1. To explore via semi-structured in-depth interviews, with the primary food provider, how Nova Scotian households who have one or more children with celiac disease experience and manage the nutritional and financial requirements of celiac disease and its impact on their individual and household food security.
2. To discover enablers and barriers to managing the nutritional and financial requirements of the child with celiac disease and to explore the implications for the family.
3. To explore strategies that would aid in the nutritional and financial management of celiac disease.
4. To determine if families who have a child with celiac disease experience food insecurity.

1.2. Rationale for Research

Although research has shown that GF products are significantly more expensive than their gluten-containing counterparts (2), little research has been done with respect to how the cost of a GF diet affects the lives of people with CD (1,2). Moreover, there are no published studies that have examined food insecurity as it relates to CD. The goal of this research was to investigate how families experience and manage the nutrition and financial requirements of CD. How do individuals with CD adhere to a GF diet given that the cost of GF foods is two to three times more expensive? What support systems do households utilize and do they find them effective? What are the enablers and barriers to following a GF diet? Do families with CD experience food insecurity and how so? Exploring these questions will provide valuable information on not only the economic cost of following a GF diet, but also on the social and lifestyle implications. In order for policies and programs to be designed to address the social and

economic burden of CD in the community, decision makers must understand if and how food insecurity is experienced in the household and what barriers and enablers families face in managing the disease.

2. LITERATURE REVIEW

2.1. Introduction

The purpose of the literature review is to provide the reader with information pertaining to the topics of food security and CD. Sections 2.1-2.4 provide an overview of CD, its diagnosis and dietary management highlighting the nutritional and social consequences, and the importance of and difficulty in following a GF diet. Section 2.5 addresses the financial implications of a GF diet and programs and policies available to Nova Scotian residents to aid with the financial cost of CD will be examined. In Section 2.6 the concept of food security is discussed in terms of health and nutrition with a specific focus on the apparent lack of research on the topic of food security and CD. Section 2.7 concludes with a discussion of what is known about how food insecurity is experienced and managed and the importance of examining food security in a population with CD where the health of the individual is dependent on the foods consumed.

This information aims to help the reader interpret the findings of this research and to understand how and why this research was conducted, specifically to better understand how families with CD are coping with the cost of a GF diet.

2.2. Celiac Disease

Celiac disease, also known as gluten-sensitive enteropathy, celiac sprue, or non-tropical sprue, is a gastrointestinal disorder in which genetically susceptible individuals have a permanent intolerance to specific peptides of gluten protein in cereals, such as wheat, rye, barley and triticale (3,18). Ingestion of these products causes progressive atrophy of the villi of the small

intestine, which results in malabsorption of important nutrients such as iron, calcium, fat-soluble vitamins, and folate (3).

Celiac disease is recognized as one of the most common chronic gastrointestinal diseases with as many as one in every 100-200 people in North America being affected (3). In Europe and the United States, epidemiological studies have shown that CD occurs in 0.5% to 1% of the general population (19-22). First-degree relatives of an individual with CD have a 10-15% chance of also having the disease (3,4) indicating a genetic predisposition for developing the disease. Not only is CD one of the most common chronic gastrointestinal diseases, it also is one of the most under diagnosed (4). The Canadian Celiac Health Survey conducted in 2002 included information pertaining to demographics, clinical features, and diagnosis of CD from 2681 participants with biopsy-proven CD across Canada revealed that the mean time to diagnosis after the onset of symptoms was 11.7 years (4). This finding indicates that the prevalence of CD may be significantly greater than currently reported due to under diagnosis of the disease.

The clinical presentation of CD is highly variable (23). Celiac disease can present with symptoms such as diarrhea, abdominal distention, edema, and lethargy, or no symptoms at all (23). The severity of CD varies depending on how long the individual has been exposed to gluten. As gluten damages the gastrointestinal tract affecting absorption of nutrients, there is an array of presentations, ranging from mild abdominal symptoms to severe, generalized malabsorption (23). Untreated CD is associated with higher morbidity and increased mortality due to the increased risk of developing enteropathy-associated intestinal lymphoma (23). Prolonged exposure to gluten can also result in iron-deficiency anemia, folate, calcium, and zinc deficiency. Longer-term effects include reduced bone mineral density (24), which may lead to osteopenia and osteoporosis (25). As the pathology of the gastrointestinal tract of patients with

CD changes over the course of exposure to gluten, adherence to a strict GF diet is of utmost importance.

2.2.1. Diagnosis of Celiac Disease

Currently, small intestinal biopsy is the most definitive way to confirm the diagnosis of CD; however, non-invasive serological tests are normally the first step in pursuing a diagnosis. The two most sensitive tests are IgA anti-tissue transglutaminase antibody (TTG) and the IgA anti-endomysial antibody (EMA) (3). The sensitivity and specificity of these tests is greater than 95% and 90%, respectively (18). In patients with less extensive damage to the small intestine the sensitivity and specificity of the tests may not be as high. For these reasons, negative serology results should not preclude a small intestinal biopsy, as a biopsy is the only way the diagnosis of CD can be confirmed. Serum IgA should also be measured in case the patient is deficient in IgA in which case the TTG and EMA results might be falsely negative (26). As false positive blood tests may also rarely occur, the best way to confirm the diagnosis of CD is with a small intestinal biopsy. In healthy individuals, a biopsy of the small intestinal mucosa will reveal tall and abundant villi, few intraepithelial lymphocytes, and normal numbers of lymphocytes and plasma cells in the lamina propria. In contrast, a biopsy of patients with CD will show atrophy of villi, increased intraepithelial lymphocytes, lymphocyte and plasma cell infiltration of the lamina propria, as well as marked crypt hyperplasia. These changes will lead to poor absorption of essential nutrients (18).

A study by Mubarak et al. (2011) questioned if a small intestinal biopsy was needed in the pediatric population when the TTG test shows levels greater than 100 U/ml (27). Their

investigation showed that 124 of 128 children with TTG levels over 100 U/ml all had marked villous atrophy on their small intestinal biopsy, while three of the remaining four children displayed crypt hyperplasia or increased intraepithelial lymphocytes; one patient had no histological abnormalities and did not respond to a GF diet (27). The authors' conclusions were that in pediatric patients with a TTG level greater than 100 U/ml, whose symptoms improve with a GF diet, a small intestinal biopsy may not be needed to confirm a CD diagnosis. These results indicate that less invasive methods of diagnosing CD may be used in the pediatric population thereby eliminating unnecessary risks involved with the procedure.

Once diagnosis of CD is confirmed, patients are referred to a registered dietitian with expertise in GF diet for nutritional counseling. At the IWK Health Centre in Halifax, Nova Scotia, Canada all patients under 18-years-of-age diagnosed with CD are advised to attend clinic at least once a year with a pediatric gastroenterologist and a registered dietitian (28).

2.3 Dietary Management of Celiac Disease

Dietary management of CD can be complicated and challenging. Currently, the only treatment is a lifelong adherence to a GF diet (29), meaning that all foods and beverages containing gluten from wheat, rye, barley, triticale and their derivatives must be eliminated from the diet (24). Upon elimination of gluten from the diet, symptomatic, serologic, and histologic remission will occur (24).

In order to adhere to a life-long GF diet, one must know what constitutes a GF product and understand the nutritional adequacy of the foods consumed. There are many hidden sources of gluten in the North American diet, such as hydrolyzed vegetable and plant protein, in which

wheat may be a hidden ingredient (29) that might not be easily identifiable as gluten-containing. Hidden sources of gluten can be found in products such as food additives, soup bases, flavored coffee and teas, and some medications (18) making avoiding gluten very difficult.

Education is of utmost importance in managing CD. Dietitians specializing in gastrointestinal diseases provide patients with the education and tools to recognize which foods are allowed in a GF diet, and how to identify these foods by label reading. In 2004, the National Institutes of Health (NIH) issued a consensus statement on CD where six elements were identified by a panel of health professionals regarding the role of the dietetic professional in the management of CD (30). These six elements are: 1) consultation with a dietetic professional; 2) education about the disease; 3) lifelong adherence to the GF diet; 4) identification and treatment of nutritional deficiencies; 5) access to an advocacy group; and 6) continuous long-term follow-up via a multidisciplinary team (30). Because these six elements are important to effectively manage CD, the role of the dietitian in CD management is essential.

2.3.1. Adhering to a Gluten-Free Diet

Since adherence to the GF diet is the single most important factor in the management of CD, it is important to understand more clearly why adherence may be problematic for some and what role the availability and affordability of GF foods may play in this regard. It has been reported that between 45% (31) and 80% (32) of individuals with CD strictly adhere to a GF diet. To understand variation in adherence, a study conducted by Butterworth et al. (2004) investigated factors that may influence patient compliance with a GF diet. These factors included if the individual: 1) was a member of a celiac support group, 2) was obtaining GF products on

prescription or through Government assistance, 3) understood food labels, 4) had sufficient access and availability to GF products, and 5) participated in follow-up appointments with both a physician and a dietitian (33). Further factors influencing patient adherence to a GF diet were described by Lee and colleagues (2003) and included increased age of the patient, age at diagnosis, and the overall education level of the patient including their knowledge of CD (34). While two of the factors suggested by Butterworth and colleagues (2004) were external support systems, such as a celiac support group and health care professionals, the remaining predictors of adherence to a GF diet were directly related to the GF food items, specifically if they are easily identifiable, available, and affordable.

Two determinants of adherence of a GF diet, i.e., affordability and availability, relate directly to accessibility of GF foods. A 2007 study investigated the economic burden of a GF diet in New York, Oregon, South Dakota, Georgia, and Chicago using a "market basket", which represented regular wheat-based products that consumers purchase for day-to-day living. The cost of these typical food items compared to their GF counterparts were examined. Results showed that GF foods have limited availability in grocery stores and upscale markets with GF products being available in only 36% and 41%, of the stores and markets, respectively (1). The study also determined that lower priced venues such as grocery stores in these U.S. cities were found to have the least amount of GF foods available, while the most expensive venues such as health food stores had the greatest availability of GF foods (36% and 94% of foods sold, respectively) (1). Although the availability of GF food items varied based on venue, overall, every GF product was more expensive than its wheat-based counterparts. Gluten-free staples such as bread and pasta were twice as expensive than their wheat-based counterparts (1). These results highlight how adherence to a GF diet may be impacted by affordability and availability of

the foods required. Although availability of GF foods is frequently discussed in the literature (1,2,4,32,35,36), there are limitations in the available data specifically measuring GF food available within the retail market. The main source of information pertaining to the increased availability of GF food comes from individuals with CD who are following a GF diet (36).

Adequate food labeling, or being able to easily identify GF foods, is an important determinant of adherence to a GF diet. The 2003 Canadian Celiac Health Survey of 2618 adults and 168 children with biopsy-proven CD revealed that determining whether foods were GF (85%), finding GF foods (85%) and whether these GF foods were good quality (83%) were major issues when following a GF diet (32,35). Being able to identify GF ingredients helps to avoid accidental consumption since many foods contain hidden gluten, which can often be missed while learning to follow the GF diet. In July 2008, Health Canada, acknowledging that food labels are the first step in determining the ingredients of a food product, took action to improve labeling requirements making it easier for individuals with CD to determine if gluten sources are present in food items (37). The Government of Canada announced in 2011 that in accordance with the new Consumer Product Safety Act, food labels would be required to include clearer language and a declaration of hidden allergens, such as gluten sources. These changes were to be fully implemented by August 2012 (38). While positive steps are being made in the area of food labeling, without the proper education and supports to enable consumers to understand and apply food labels to their food choices, adherence to a GF diet still poses a challenge (39).

Compliance with a GF diet in adolescence has been shown to be significantly dependent on social setting (40). Focus group interviews with 47 adolescents between 15 and 18-years-of-age with CD living in Sweden revealed that dietary treatment for CD often left them embarrassed

in social situations. The participants felt markedly different from their peers, commonly resulting in their consuming regular foods to "fit in" (40). A potential contributor to decreased adherence in social situations for adolescence is the limited knowledge peers may have of CD resulting in a lack of social support (40). In children less than 16-years-of-age, however, adherence is reported to be high (41), perhaps related to children still relying on adults for meal provision, preparation, and supervision.

2.3.2. Nutritional Consequences of Celiac Disease

Research shows that the nutritional status of newly diagnosed patients with CD is often compromised (18). This may occur in two ways. First, this occurs through malabsorption of nutrients due to damaged small intestine and second, through nutritional inadequacy of GF food items.

The impact on nutritional status is dependent on the extent of damage caused to the intestines and the resulting degree of malabsorption (18). As the proximal portion of the small intestine is where the absorption of nutrients takes place and is the most affected in CD, decreased absorption of iron, folate and calcium has been shown to occur (24). The longer CD remains undiagnosed the greater the likelihood of damage to the intestinal tract and the higher the degree of malabsorption of carbohydrates, fats, proteins, fat-soluble vitamins (A, D, E, and K) and other micronutrients (42).

Individuals with CD may also be at risk for malnutrition because many gluten-containing nutritious foods must be eliminated from the diet (15). Eliminated foods such as wheat, rye, barley, and oat products are often fortified with vitamins and minerals including thiamin,

riboflavin, niacin, folate, and iron, which help prevent deficiencies in the general population. In a study of GF foods from manufacturers, distributors, and retailers in the United States, it was revealed that only 35 of 368 products made from non-gluten sources, such as starch or refined grain, were enriched suggesting that GF foods do not provide the same amount of vitamins and minerals that enriched wheat products do (16). Other research has shown that GF cereal products provide lower amounts of folate and iron than their enriched or fortified gluten-containing equivalents (17). Patients with CD may, therefore, have to supplement their diet with the appropriate vitamins and minerals to prevent micronutrient deficiencies.

Patient and family education about managing the nutritional requirements of CD is a critical component of identifying and treating nutritional deficiencies (30). Education about the management of CD should also include the health consequences of not following a GF diet such as osteopenia, osteoporosis, and iron-deficiency anemia (25). It is important for a dietitian to provide patient education, not only on foods to avoid, but also on how to enhance the nutritional quality of GF foods.

As the incidence of CD increases, so does the need for nutritionally adequate GF alternatives. In 2006, it was reported that the market for GF products in the United States was valued at 696.4 million dollars (American) and was expected to continue to grow at 25% per year (43). In 2008 the retail sales of GF food was $1.56 billion dollars (American) according to the 2009 Gluten-Free Food and Beverage Report (44). The food industry has increased their share in the market and CD is listed as one of the most common conditions currently impacting markets (43). While it is evident that GF alternatives are increasingly available in the market, individuals with CD must have access to these items in order to effectively adhere to a GF diet.

2.4. Social Consequences of Celiac Disease

Individuals with CD are faced with significant dietary restrictions that can result in a host of social, lifestyle, health, and financial burdens. There have been numerous studies exploring the impact of a GF diet on patients' health-related quality of life (1,4,5,34,41,45,46). Using a cross sectional survey design, Lee and colleagues investigated the effects of a GF diet on food consumption and quality of life for members of the Westchester Celiac Sprue Support Group in New York State (34). Of the 253 usable survey responses, 86% of the respondents reported they had difficulty dining out, 82% reported difficulty traveling due to a GF diet, and 67% indicated that adhering to a GF diet negatively affected their family life (34). This study highlighted some of the social consequences of following a GF diet. Many gluten-containing foods may be linked to key social situations. For example, in a North American context, birthday parties are associated with birthday cake, baseball games with hot dogs, and so on. Therefore, not only do individuals with CD have to restrict food choices, but also they have to deal with the emotional consequences of social situations in which they may be the only ones unable to consume the foods available (46).

The ways in which CD affects lifestyle also play an important role in a person's social, physical and mental health. A general population based cohort study conducted in Sweden by Ludvigsson and colleagues (2007) involving 13,776 individuals with CD and 66,815 individuals matched for age, sex, calendar year, and country of residence investigated the association between CD, depression and bipolar disorder (47). Individuals with CD were recruited for the study based on a hospital discharge diagnosis of CD between 1973 and 2003 using the Swedish National Inpatient Register. Results of this study indicated that individuals with CD had an increased risk of subsequent depression (47) but no evidence of the development of bipolar

disorder. These findings suggest that the link between CD and bipolar disorder is due to detection bias where increased hospital admittance resulted in the probability of undetected CD being diagnosed. Furthermore, the association of CD with depression and not bipolar disorder indicates that detection bias is limited in its involvement with depression and that there may be a disease process specific to the development of depression (47). The authors highlighted a number of potential mechanisms for the observed association between CD and depression including a decreased quality of life after diagnosis, hyperhomocystenemia, folate deficiency, and difficulty adapting to the chronic nature of the disease (47). In a review of published research examining the relationship between folate deficiency and depression, Bottigliere (2005) concluded that a low folate status is associated with reduced neurotransmitter function and impaired methylation of the amino acid homocysteine, resulting in increased amounts in homocysteine in the body (48). Low folate and high homocysteine can lead to the metabolic consequences associated with mood disorders such as depression (48). Folate deficiency in individuals with untreated CD is a result of ongoing low-grade inflammation of the small intestine thus inhibiting its absorption (47). Furthermore, findings from the Canadian Celiac Health Survey indicate that depression may be linked to the process of diagnosis of CD, which is often a long and difficult road (4). Long delays in diagnosis are generally accompanied with feelings of frustration and anxiety, which further highlights the multi-faceted way in which CD affects the patient's life.

Celiac disease affects not only diagnosed individuals, but also their close relatives. For example, consequences of the restrictive nature of a GF diet for an individual family member with CD have been shown to impact the entire family's way of life, their ability to dine out at a restaurant or travel (34,46). Several studies have examined the social consequences of CD through the eyes of the person living with the disorder (1,5,34,46,49-51). However, the only

published study that has specifically examined this from the perspective of family members is by Sverker et al. (2007). This study examined the dilemmas experienced by close relatives such as spouses and parents living with a person with CD. Through in-depth interviews with 23 informants, including both partners and parents, the researchers found that family members reported feeling guilty or having a "bad conscience" for not having CD while their loved one did. Moreover, the authors found that family members faced increased domestic work and restricted freedom of action in the management of their daily lives. Family members of participants with CD faced social dilemmas, related primarily to concern over lack of information, knowledge, and understanding (51). These findings suggest that the role of family in managing CD in the diagnosed individual might be underestimated and that there is a need to provide relatives with better knowledge of the disease in hope of improving the situation for both relatives and the patient.

2.5. Financial Management of Celiac Disease

Since following a strict GF diet is the only treatment for CD, those affected ought to be able to afford the foods required for good health and well-being. A study conducted in two major retail chain grocery stores in Halifax, Nova Scotia compared the cost of available packaged GF items to their gluten-containing counterparts (2). All of the 56 GF products identified were more expensive, with their average cost being 242% more than their gluten-containing counterparts. The average price of GF foods per unit weight was $1.71, compared with $0.61 for regular products. These significant price differences make it easy to understand why adhering to a strict GF diet can be difficult and why financial management must be a priority for these individuals.

A study conducted in Scotland in 2011 by Abernethy and Bannerman also investigated the cost of a healthy balanced GF diet compared to a standard diet. The average cost of a preapproved, nutritionally balanced, GF basket was significantly more expensive than the standard and comparable regular, gluten-containing food basket (52). Of particular interest in this study was the examination of "own brand" versus "branded" GF products, meaning products that were naturally GF versus products that were labeled GF. This study concluded that the cost of a GF basket made up of "own brand" products was less expensive than a GF basket made up of "branded" products, which suggests that consumers may be paying more for the GF label than needed.

There are currently two programs available to residents of Nova Scotia designed to assist individuals with CD in purchasing special food items for dietary management of their disorder. The first option is a tax credit. According to the Canada Revenue Agency, individuals with CD are entitled to claim the incremental cost of GF products as a medical expense (53). The incremental cost means the increased cost of purchasing GF products compared to the cost of a similar gluten-containing product. Items that are eligible include most GF food products and alternatives; however, the amount that can be claimed is only for the person medically required to consume the product. When an entire family is consuming GF foods but only one member is required to do so, only the products required for that one individual can be claimed (53). In order to be able to claim GF products as a medical expense tax credit, documentation is required from a medical practitioner verifying a diagnosis of CD. Receipts for each GF item being claimed for a 12-month period must be kept and documentation to show the incremental cost of a GF product versus a gluten-containing product needs to be provided (53). Furthermore, the total medical expense claimed, must exceed 3% of the net income of the individual making the claim (53). In

the case of minors, the claimant would be a parent, and it would be advantageous if the parent with the lowest income made the claim.

The second option to aid in the financial management of CD is through the Employment Support and Income Assistance (ESIA) Program. For individuals and families receiving income assistance in Nova Scotia, this special diet allowance is available for individuals required to consume a GF diet (54). In order to receive this special diet allowance the applicant must be a resident of Nova Scotia and "in financial need", meaning that the monthly household income is less than the ESIA Program allows for eligible basic expenses, such as food and housing (54). To receive the $30 monthly income supplement for CD, a caseworker must have authorization from a medical professional indicating the presence of CD and need for a GF diet (54). Those with CD may receive the monthly income supplement for a wheat allergy, which is less restrictive than CD, at a maximum of $150 per month, but not a combination of both the CD and wheat allergy allowance (54). In that CD includes the elimination of wheat and other grains (rye and barley), the ESIA allowance provided for this special diet should be greater than the amount allocated for solely a wheat allergy. Currently, this is not the case; therefore, it is important to understand how the monetary values of these special diets were determined, and whether the current supplements are making a difference to those who receive them. Furthermore, it is important to acknowledge that the ESIA program's special diet allowance is only available to individuals who are on income assistance. Individuals who are living on low-income but are not on income assistance are not eligible to receive this special diet allowance.

Although in Nova Scotia there are two avenues available to get financial support for purchasing GF foods, the degree to which these programs are helpful has not been examined. Since GF foods are more expensive and this may impact adherence, it is important to determine

whether or not households have the financial means to access these foods and how this impact household food security. To date, there has been no research investigating the issue of food insecurity within this population.

2.6. Food Security and Food Insecurity

Food security is when *"all people, at all times, have physical and economic access to sufficient, safe and nutritious food to meet their dietary needs and food preferences for an active and healthy life"* (pg. 9) (6). Food security, by definition, encompasses a broad range of issues ranging from the availability of healthy foods to the means by which these foods are obtained. For the purposes of this research, the FAO definition of food security, as it relates to the financial and physical access to basic foods, will be utilized.

Food insecurity has been described as *"the inability to obtain sufficient and nutritious food through socially acceptable means"* (pg. 51) (7). There are multiple negative impacts related to food insecurity, especially in women, including poor health and nutritional outcomes. These health consequences, such as increased levels of stress, poor social supports, and increased incidence of chronic disease (9) add an element of worry to those who experience food insecurity. The idea of food insecurity was first described in Canada in the 1980s as food banks emerged and the need for emergency feeding programs was acknowledged (56). Prior to this time the concept of food security took root in the 1948 Universal Declaration of Human Rights whereby the United Nations stated that food was a right and was considered a component of ones standard of living, health and well-being.

Food insecurity is a multi-faceted issue to which there is no single solution. Dietitians of Canada, the professional organization of dietitians, emphasizes that a population health approach is needed to ensure food security for all. This statement acknowledges that the way to decrease health inequities, mainly food insecurity, is through the pursuit of social justice (11). Social justice for all means creating an equality of opportunity through means, such as proper income distribution and adequate economic supports (55).

2.6.1. Rates of Food Insecurity in Canada

Food insecurity was monitored initially in Canada through the National Population Health Survey (NPHS) and, more recently, through the Canadian Community Health Survey (CCHS). These are surveys used to gather health-related data at national and provincial levels. The Food Insecurity Supplement, a survey included in the 1998/1999 NPHS, found that 10.2% of Canadian households were food-insecure, which represented approximately 2.7 million people including 678,000 children (56). The strength of this tool was that it acknowledged the influence of severity and time on how food insecurity may be experienced by an individual or household (57). The main focus of the Food Insecurity Supplement was on the child's individual food security which has the potential to lead to underreporting of individual adult and household food insecurity since the nature and severity of food insecurity experienced by individual household members is likely to differ (58), as children often experience less severe food insecurity than their mothers (58,59-61). As a result, the Supplement may not reflect accurate prevalence of food insecurity at the individual level.

The 2004 CCHS (Cycle 2.2) Nutrition Module indicated that 14.6% of households in Nova Scotia experienced either moderate or severe income-related food insecurity, the only Canadian province to report a statistically significant higher difference from the national average of 9.2% (62). Included in this cycle of the CCHS was a 18-question Household Food Security Survey Module (HFSSM), which focused on the anxiety, quality, and quantity aspects of accessing food (62). This module was used again in the CCHS conducted in 2005, 2007/2008, and 2009/2010 but administered only in selected provinces (8,58,63). The 2007/2008 CCHS Cycle 3.1 concluded that nearly 7.7%, or 956,000 households in Canada reported experiencing moderate or severe income-related food insecurity, with the highest rate reported among households with children (9.7%), of which 25% of these households were led by female lone-parents. The 2009/2010 CCHS conducted in eight provinces and three territories, concluded that 10% of Nova Scotian households reported moderate or severe household food insecurity, a significant increase from the previous 2007/2008 CCHS cycle report of 9.3% among households in Nova Scotia (8).

Although food insecurity was reported higher in the 2004 CCHS than in the 2007/2008 and 2009/2010 CCHS, it is important to acknowledge that methodological differences limit the ability to compare the prevalence of food insecurity reported between the 2004 and more recent CCHS Cycles. Therefore, it is unknown if findings reported in 2004 and those reported more recently, reflect fluctuations in actual estimates, or variations in responses due to inconsistent monitoring (58,63).

2.6.2. Understanding Levels and Dimensions of Food Security

Food security can be examined or addressed at global, national, community, household and individual levels (12). For the purpose of this thesis the main focus will be at the individual and household levels.

Radimer et al. in the US conducted research pivotal to the measurement of household food insecurity in the early 1990s. This research, based on in-depth interviews with 32 women who said they experienced or nearly experienced hunger described as the feeling of going without food or having to eat less food than usual, provided a basis for conceptualizing the term (10). Based on the women's stories, the experience of hunger was described as having two dimensions: household and individual (10). Household hunger manifested in three different ways: 1) food depletion, or running out of food; 2) food unsuitability, or not being able to purchase the appropriate foods; and 3) food anxiety, or fear of how long the food supply will last. Whether participants perceived these topics as a problem depended on whether the household food was acquired in socially acceptable ways. Participant-identified components of individual hunger were: 1) intake insufficiency, or low consumption of the quantity of foods, 2) intake inadequacy, low intake of quality foods, and 3) disrupted eating patterns, not consuming regular breakfast, lunch, and supper. Similarly, these components were deemed a problem by participants based on whether a person felt deprived and/or without a choice with respect to food. Each identified characteristic of hunger was classified into four components; quantity, quality, psychological, and social (10) (Table 1).

Table 1: Components of conceptual definition of hunger as classified by household or individual dimension. *Adapted from Radimer et al*. (10)

	Dimension	
Component	**Household**	**Individual**
Quantity	Food depletion	Insufficient intake
Quality	Unsuitable food	Inadequate diet
Psychological	Food anxiety	Feeling deprived; lack of choice
Social	Unacceptable means of acquiring food	Disrupted eating pattern

Hamelin et al. (1999) further explicated the psychological and social components of food security described by Radimer et al. (1990) by studying food insecurity from the perspective of households who experienced it. The researchers collected data via focus groups and individual semi-structured interviews from 93 lone and two-parent households. Of these households, 77 were identified by the researchers to be food-insecure. Social consequences of chronic food insecurity included impaired learning for children and adults, increased need for health care, increased feelings of exclusion and feelings of powerlessness, and decreased constructive participation in social life (64). This study emphasizes that key aspects of human development depend on food security (64). The participant-identified consequences of chronic food insecurity resulted from not having adequate funds to purchase healthy foods, which can lead to decreased health as a result of an inadequate diet, and from the feelings associated with not being able to purchase healthy foods, which can lead to social exclusion. Work from both Radimer and Hamelin and their colleagues clearly depict food security not only as an issue of food quality and quantity, but a complex concept that has multiple social ramifications deeply rooted in psychological well-being.

2.6.2.1. Household and Individual Food Insecurity

Household and individual food insecurity, although similar in consequence, differ in terms of experience and severity. For instance, while a household may be food-insecure as a whole, the severity of individual food insecurity may vary dependent on individual needs and role within the family or household (58).

Household food insecurity occurs when food supply management and acquisition are compromised, such as when funds for purchasing foods are limited (11). As suggested by Tarasuk (2001), a household may experience ongoing food insecurity when it is faced with circumstances that continually limit financial resources needed to provide the household's basic needs. In addition, the severity of household food insecurity may vary depending on when resources are challenged, e.g., increased severity at times of high cost or when finances are limited (11).

Individual food insecurity occurs when individuals within the household feel the physiological sense of hunger (11). Household food insecurity does not always indicate that all members of the household are experiencing food insecurity. This has been shown by research conducted in Atlantic Canada addressing whether or not low-income mothers compromised their own nutrition to feed their children. Household food insecurity was reported by 78% of the mothers during the study month, with mothers' quantity and quality of intake being consistently below that of their children (65). McIntyre and colleagues provided evidence that lone mothers often sacrifice their own nutrition to ensure their children receive enough food; a phenomenon termed "maternal buffering" (66). Examples of women depriving themselves of food to ensure adequacy of their children's diets have been reported in the literature (65,66) including the early

work of Radimer et al. (10). The women in Radimer's study would employ various tactics to delay or avoid hunger in their children. Other coping strategies to deal with food insecurity employed by mothers included seeking help from friends and family, delaying utility bill payments, canceling services such as telephone and television, and selling personal items to increase the food budget allowance (67,68).

Food security has been identified by the World Health Organization as one of the ten key social determinants of health (69) and is, therefore, a key element in determining an individual's ability to maintain health and well-being. The social determinants of health, which include education, employment, and income as well as food security, are believed to have a direct impact on the health of both the individual and the population (69). Not only do these determinants impact the health of the population, but also they are strong predictors of health and well-being. A growing body of evidence suggests that the socioeconomic status of an individual is equally, if not more important, to overall health status than medical care and personal health behaviours (70,71). These findings highlight the social determinants of health, such as adequate income and food security, as important predictors in the overall health of an individual.

Determining how the four components of Radimer's conceptual definition of hunger are experienced is critical in understanding how individuals and households manage hunger and food insecurity. Literature examining the impact of a GF diet on individuals with CD has indicated the presence of a psychological component of hunger at both the household and individual levels (46) in that individuals often feel food anxiety and lack of choice. However, the experience of food insecurity in the celiac population has yet to be examined. Further research needs to be conducted in order to understand how individuals with CD experience the quantity, quality, and social components of food insecurity.

2.6.3. Income-Related Food Insecurity and its Implications

Inadequate income is considered to be the main determinant of food insecurity at both household and individual levels (11). The cost of a basic nutritious diet was monitored in Nova Scotia in 2002, 2004/2005, 2007, 2008 and 2010 using the National Nutritious Food Basket (NNFB). The NNFB consists of approximately 60 foods selected by Health Canada as being representative of a healthy Canadian diet and in accordance with dietary requirements (72). The most recent report from the Participatory Food Costing Project (73) released in 2011 showed that the cost of a basic nutritious food basket in Nova Scotia had increased by approximately 35% since food costing began in 2002 to the time of data collection in 2010 (67). As the cost of food increases without corresponding increases in income or income supports, the ability of individuals living on low-income to purchase healthy foods decreases (74).

2.6.3.1. Chronic Disease and Food Insecurity

A myriad of factors influence the development of chronic diseases ranging from genetic predisposition to the social determinants of health. As social determinants of health, education, employment, income and food security are all recognized to significantly influence health and well-being (69). Diet-sensitive chronic conditions, such as cardiovascular disease, diabetes, and cancer all require and are influenced by a healthy diet. It is worrisome that lower cost foods, which are predominantly energy-dense and less nutritious, are more affordable to consumers than nutritious foods. The Participatory Food Costing Project (73) conducted in Nova Scotia highlighted that in June 2010 a female-led lone-parent household with three children under the age of 12-years who worked for full time minimum wage would have a negative net income of

$448.40 per month if she were to purchase a basic nutritious diet. Similarly, the same family on income assistance would face a deficit of $372.27 per month if they were to purchase the nutritious food basket. Furthermore, research examining the affordability of a nutritious diet for three different household types on income assistance, revealed that between 2002 and 2010, household expenses increased without corresponding increases in household income (74). Therefore, all three households examined were faced with increasing monthly deficits if they were to purchase a basic nutritious diet (74). These findings are alarming in that many low-income families are left without adequate funds to purchase healthy food in order to manage diet-sensitive chronic diseases.

2.6.3.2. Food Insecurity: Health and Nutrition

Household food insufficiency has been linked with poor physical and mental health (13). Population based data have shown that household food insufficiency is significantly correlated with adequacy of income, therefore, as income insufficiency increases so does food insufficiency (57). Results also indicate that individuals from food insufficient households are more likely than those from food sufficient households to list their health as poor or fair, have restricted activity and multiple chronic conditions, and are more likely to suffer from major depression and distress (57). These results indicate that lack of food adversely affects both physical and mental health.

Poor health among individuals who experience food insecurity may also be attributed to the types of foods purchased and consumed. In a review of the relationship between obesity and diet quality, energy density and cost, Drewnowski and Specter (2004) found that households reporting food insecurity have lower food expenditures, lower fruit and vegetable consumption,

and lower quality diets compared with food sufficient households (75). They are often at risk for malnutrition. In food-insecure households, a higher percentage of funds are needed to purchase healthy foods. Cassady et al. (2007), who investigated the barriers to fruit and vegetable consumption in low-income families in California, indicated that in order for a low-income family to purchase a 2005 Dietary Guidelines market basket it would require between 43%-70% of their allotted food budget to purchase these items (76). This study emphasizes that fruits and vegetables are often not affordable to low-income families. As a greater percentage of a low-income is required to purchase healthy foods, families will often purchase cheaper, energy dense and highly processed foods. As the cheapest foods in the North American diet tend to be highly processed foods and staples such as wheat bread (1), securing adequate food to meet dietary recommendations of CD can pose a significant problem.

It is well established that there is a strong relationship between food insecurity, poor nutrition, and poor health. However, it is difficult to distinguish the effects of food insecurity from the effects of poverty (59,61,65,77). In order to eat a healthy diet, an individual must first be able to afford the appropriate foods. As proper nutrition is an influential determinant of a person's overall health, individuals not receiving adequate nutritious foods are at a greater likelihood of developing disease. A study examining the diet quality of Atlantic Canadian families, headed by low-income lone mothers with at least two children aged 14-years and younger found that almost 95% of the mothers did not meet the recommended number of servings of grains or vegetables and fruits, as indicated by Canada's Food Guide to Healthy Eating (61). This percentage is higher than the general population in which 70% of adult females consume the recommended number of servings of grains and 40% meet the recommended number of servings of vegetables and fruits (78). These mothers, who are at greater risk of being

food-insecure because they often sacrifice their own nutritional well-being to satisfy the needs of their children, and have been shown to have an inadequate intake of nutrients including folate, iron, zinc and vitamin A (59,65). This indicates that being food-insecure increases the risk for malnourishment. Food insecurity presents a significant barrier to the consumption of a healthy diet. In households considered to be food-insecure, the main goal is to prevent hunger with nutritional adequacy of food being a secondary concern. Not being able to purchase the foods needed to maintain health can contribute to health disparities, increased health care costs, and social injustice (13,60).

2.6.3.3. Children and Food Insecurity

It is clear that food security status is a factor affecting mothers' ability to consume a nutritionally adequate diet including the ability to purchase healthy foods and whether maternal buffering occurs (66). However, the presence of maternal buffering does not negate children's food security as in some situations increased severity of household food insecurity may result in individual child food insecurity (66). A study investigating food insecurity of low-income mothers and their children in Atlantic Canada revealed that although child hunger was lower than maternal hunger over a 12-month period, during the one-month study period, child hunger and maternal hunger were similar (23%), with child hunger being reported in almost one-quarter of the households during that study period (65). These results highlight that children are at risk for food insecurity in low-income households and, therefore, examining food security of children in special diet populations such as CD is important.

A longitudinal study conducted by Jyoti et al. (79) investigated how food insecurity over time relates to changes in reading and mathematics tests, weight and body mass index (BMI), and social skills in children. A prospective sample of approximately 21,000 children entering kindergarten in 1998 was followed until they reached grade three. Food security was addressed by means of parent interviews whereby households were grouped into four categories based on temporal occurrence of food insecurity at the beginning and end of the study period. Results of this study showed that the majority of children's households remained food-secure (77.9%). Of the remaining households 6% remained food-insecure, 9.7% became food-secure and 6.5% became food-insecure. In addition, 22.2% experienced food insecurity at one or both test periods (79). The authors concluded that food insecurity predicted impaired academic performance in both reading and mathematics, a decline in social skills for boys and greater weight and BMI gains for girls indicating that food security status has an impact on growth and developmental markers in children. Further research of children in food insufficient and low-income families by Casey et al. (2001) revealed that when compared to higher-income food sufficient households, children of low-income food insufficient households consumed fewer calories and total carbohydrates, and had a higher cholesterol intake (14). In addition, low-income food-insufficient children had higher weights, consumed less fruits and spent a greater amount of time watching television (14). Results from these studies (20,65,66,72) highlight the consequences of childhood hunger and food insecurity.

Food insecurity was first described in Canada in the 1980s as food banks emerged and the need for emergency feeding programs and children's feeding programs in schools were acknowledged (56). As a result, the House of Commons created a resolution to commit the Canadian government to eliminate child poverty by the year 2000 (56). However, the child and

family poverty rate in Canada has only decreased slightly from 11.9% in 1989 to 9.5% in 2009 (80) indicating a lack of improvement in the situation. As food security is a key determinant of health and closely influenced by income, reducing poverty is essential to ensure the health and well-being of the entire population (81).

2.7. Celiac Disease and Food Insecurity

Currently there is no published research that has investigated food insecurity in the CD population. Although research has been published in relation to the cost of GF foods (2,52) and the economic burden of CD, household and individual food insecurity has yet to be studied.

2.7.1. How Individuals with Celiac Disease Experience Food Insecurity

Individuals with chronic disorders such as CD may experience food insecurity differently than those without chronic disease. The experiences in a population faced with continuous nutritional management are influenced not only by normative changes and life events, but also by the stressors produced by the uncertainties related to the course of illness and the changing demands required to manage a chronic disease (82). As household income-related food insecurity in Nova Scotia is considered quite high compared to the rest of Canada (8) it would be of interest and importance to understand how CD affects the ability of individuals and households to be food-secure. In a recent study from New England an expert panel consisting of gastroenterologists, nutritionists, psychologists, and adults diagnosed with CD examined and described factors influencing adherence to a strict GF diet including the psychosocial burden of

the disease, symptoms, social and health support, perceived adherence, general health and self-efficacy (5). These identified domains were then assessed by two focus groups consisting of 8-12 adults with biopsy-proven CD. Researchers uncovered that individuals with CD were concerned over the cost of food items, as well as the difficulty experienced in finding quality GF products. As dietary adherence is influenced by the cost of GF items, it is important to examine how adherence to a GF diet is affected or related to the financial situation of the household. In food-insecure households there are limited funds available to purchase the required foods to manage CD. Because the cost of GF products is higher, families with CD who are also considered to be food-insecure may experience even more financial stress. Low-income families have been shown to experience both financial and emotional stress over food insufficiency, particularly over not being able to purchase and provide adequate nourishment for their children resulting in feelings of failure as a parent and provider (83).

2.7.2. How Individuals with Celiac Disease Manage Food Insecurity

The process of management incorporates how individuals cope with difficult situations and how they achieve something in spite of these difficulties. For instance, a study examining the social supports and coping behaviours of low-income families experiencing food insufficiency revealed that people cope by reaching out to family, friends, or co-workers (83). Focus groups consisting of 141 participants, who were either at risk for or had experienced food insufficiency, identified the following individual coping strategies: 1) extensive shopping for low cost foods, 2) purchasing store brand items, 3) shopping at many locations, 4) using coupons, 5) budgeting money or staggering bills, and 5) refraining from purchasing unnecessary items (83). Through in-

depth interviews with primary food providers and preparers, participants were asked to rank how they perceived the severity of coping strategies utilized when facing food insecurity (66). The coping strategies were ranked as follows from least to most severe; 1) eating less preferred foods, 2) limiting portion sizes, 3) borrowing food or money to buy food, 4) maternal buffering, 5) skipping meals, and 6) skipping eating for an entire day (66). These coping strategies indicate the ways in which families manage food insecurity. In individuals with CD, those who comply with a GF diet often manage their disease through the use of effective coping strategies (40). In a study exploring the everyday lives of 47 adolescents with CD who were compliant with a GF diet, there was a shared common acceptance of their chronic condition and the belief that, despite the social and practical inconveniences of CD, following a GF diet was a good investment in their long-term health (40).

2.8. Conclusions

Food security is achieved when *"all people, at all times, have both physical and economic access"* (pg. 9) (6) to the basic food they need (84). Gluten-free foods have been shown to be limited in availability in grocery stores and higher in price (1,2). However, little is known regarding the consequences of decreased availability and increased cost of GF foods. The ways in which families, particularly those experiencing food insecurity as described in the literature, manage this has yet to be investigated. Understanding how households with one or more children with CD experience and manage the disease will aid in the development of key policies and programs aimed at ensuring that all people at all times have both physical and economic access to healthy foods. This thesis seeks to explore these issues in detail. Investigating

the degree to which families struggle with the economic burden of the disorder is vital in ensuring food security in a special diet population, in this case CD.

3. THEORETICAL FRAMEWORK & METHODOLOGY

3.1. Introduction

The methodological approach that guided this study was phenomenology, with the phenomenon of interest being ***how families experience and manage the nutritional and financial requirements of celiac disease.*** Phenomenology aims to depict and uncover the description of experience and to expose the underlying and contributory factors that explain what is being experienced.

Bronfenbrenner's ecological framework was used to understand participants' perceived realities with regard to their experiences in managing the nutritional and financial requirements of CD, to investigate enablers and barriers to the management of the disease, and to determine implications for the family. The framework was also utilized in the examination of food security, a multi-faced concept, as it provided a systematic approach to analyzing the various layers of participants' environments which helped uncover how their behaviours and lives were mediated by their surroundings and experiences (85).

In qualitative research the researcher acts as the tool by which data are collected and analyzed. There are philosophical assumptions researchers have about the world, the nature of knowledge and knowing, the role of values, and methods of studying various phenomena of interest. These assumptions can be classified as ontological, epistemological, axiological, and methodological (86,87). These assumptions are important to acknowledge when conducting qualitative research as they shape the nature of the problems perceived, the questions that arise, and the decisions made by the researcher throughout the course of the investigation.

3.2. Ontological

The ontological assumption is based on the nature of reality (86,87). Multiple realities exist as individuals construct the environments in which they are engaged. It is important to acknowledge that the definitions or views that one individual may possess might not necessarily translate to another individual. Therefore, the role of the qualitative researcher is to acknowledge this assumption and try to view participants' experiences based on the personal realities of each individual participant (86,87).

3.3. Epistemological

The epistemological assumption deals with the theory of knowledge and how we know what we know (86,87). Knowledge is gained through understanding the meaning of processes and experience. It is through these channels that individuals determine their beliefs and what is true to them. As individuals have their own experiences, the knowledge they gain and transform into realities is personal to them. Qualitative researchers, having their own knowledge, must recognize that the knowledge of participants may be different from their own. There is a complex relationship between the researcher, who knows of the research only through an academic perspective, and the participant whose knowledge on the research topic is gained through living. The researcher, not being part of the participants' world, must recognize that as an outsider his/her presence may affect the information gathered from the participant (87). It is important for the researcher to remain reflexive during data collection by acknowledging personal biases so that the knowledge of the participant is revealed, unbiased by the researcher.

3.4. Axiological

The axiological assumption deals with the values and principles of the researcher (87). The researcher's values, intuition, and biases are important to the research as they explain the focus the research will take. As the researcher, my values include the pursuit of social justice and advocating for families with CD. Through these values the research question was formed as was the subsequent methodology. It is important to acknowledge my biases as a researcher. As a dietetic student studying Applied Human Nutrition, I view this research through a nutritional perspective. I am biased in that I have an understanding of the importance of nutrition for health and well-being. Within this research it is important to understand this bias and that participants may have different views and biases as to what they believe to be the most important contributors to health.

3.5. Methodological

Phenomenology was the chosen methodology for this study as its approach relates to the meaningful history of the individual's world (88). A phenomenological approach to answering the research question of how people experience and manage a situation given obstacles was the best fit since the major concepts of phenomenology are meaning, motive, intention, relevance and action (88). This approach, therefore, goes beyond simply answering a question or describing an experience; it aims to uncover the content of meaning of an experience as practiced and intended by the individual (88).

A social constructivist approach is similar to phenomenology in that the main goal is to develop an understanding and expansion of knowledge of the social world and experiences of individuals whose world is being explored by examining the subjective meanings, beliefs and

values that individuals attribute to their experiences (89). The social constructivist approach relies on the interdependence of social and individual processes in the co-construction of knowledge. Social constructivism, as well as phenomenology, allows the researcher to provide meaning to participants' experiences. For the purposes of this research, a phenomenological perspective was used as it complements a key concept of Bronfenbrenner's framework in that it is concerned with exploring the environment as perceived and defined by the individual. Using a phenomenological perspective, this study aimed to understand how families experience the financial aspect of CD as it relates to nutritional management. This can be achieved by examining the everyday life experiences of the participants and how various interactions within their environment influence and give meaning to their lives. Bronfenbrenner's framework provides a model through which to examine a multitude of factors that may influence participants' lives and their ability to manage the nutritional and financial aspects of CD.

3.6. Theoretical Framework

An ecological model was utilized to describe what physical, social, structural or symbolic boundaries influence, or are influenced by, the phenomenon of interest (87). The ecological model used to frame participants' perceived realities regarding their experiences in managing the nutritional requirements of CD was Bronfenbrenner's ecological systems model. This model was chosen as it focuses on forms of meaning resulting from participants' perceived experiences (88). Using the methodological approach of phenomenology, the researcher must understand that participants' perceived experiences form the basis of their reality. It is the concept of perceived reality versus actual reality that supports phenomenology as a guiding approach to this research

as the model of analysis is interested in the participants' perceived environment versus their objective environment (90,91).

3.6.1. Bronfenbrenner's Social-Ecological Framework

The social-ecological framework developed by Urie Bronfenbrenner focuses attention on developing individuals, their behaviours and their environments through a series of nested, concentric circles which represent various levels of influence from an individual's environment (85). These circles, as depicted in Figure 1, each represent a layer of environment which together influences an individual's life. A change in one layer of a person's environment is influential on the other layers; therefore, it is important to note that one's behaviours and surrounding environments are reciprocal systems as behaviours can be affecting and be affected by various levels of influence. The layers that make up the social-ecological model are the microsystem, mesosystem, exosystem, macrosystem, and the chronosystem. The microsystem represents the most proximal context in which a developing individual directly participates (85). The microsystem level consists of an individual's immediate situation; it is what connects people on a face-to-face level. In the case of this study, the microsystem would consist of how participants interact directly with, for example, other members of the family unit. The mesosystem layer is essentially a group of microsystems. A mesosystem can be defined as the interrelationships among two or more settings in which the individual is involved or actively participates in (85). For example, the interaction between a child with CD and a sibling would be considered a relationship in the mesosytem for the participant; however, in the context of the children it would be a microsystem interaction. The next layer in the socio-ecological model is the exosystem, which is the larger social system in which the participant does not function directly, but which

has an impact on the individual (85,88). Components in the exosystem layer include forces within the larger social system, such as the affordability and availability of GF foods. The macrosystem layer is the level that does not directly involve the individual, but does have an influence (85,88). This level is composed of cultural values, customs and laws which have a cascading influence throughout the interactions of the other layers (88). An example present in the macrosystem layer is that societal ideology dictates that a GF food is a "specialty food" versus a "regular food"; therefore the cost of a GF food may be priced higher owing to its special value. Encompassing all of these layers is the chronosystem, which is the element of time. Elements within this system are beyond the control of the participant and are either external, such as the timing of a friends or family member's death, or internal, such as the maturing of the participant (88). Included on Figure 1 are examples of the previously described levels of influence present within each layer of Bronfenbrenner's Ecological Framework.

Determining how participants' environments and relationships shape their experiences with managing the nutritional and financial requirements of CD is best explored using the social-ecological theory. Bronfenbrenner's framework will aid in determining how their experiences influence their lives by examining the phenomenon at various levels of environmental influence.

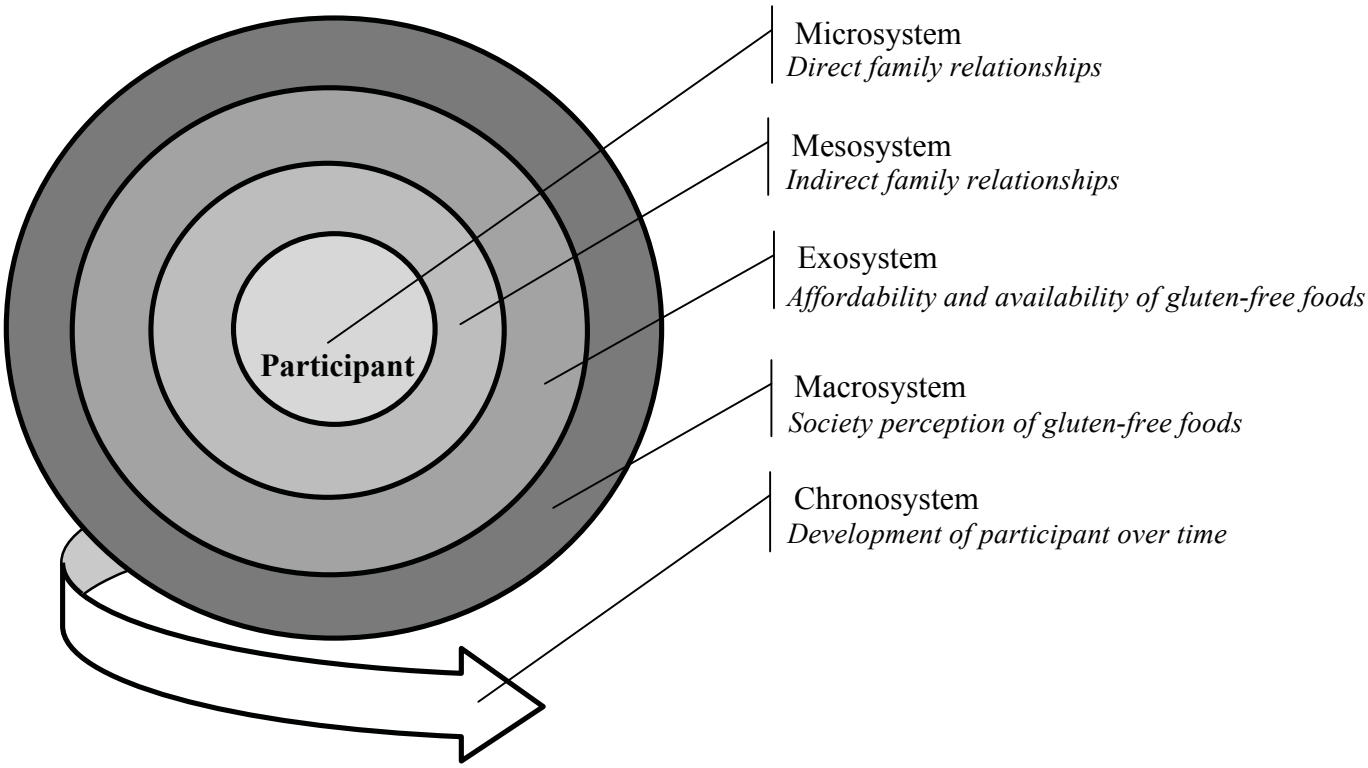


Figure 1: Bronfenbrenner's Social-Ecological Framework with Examples of Level of Influence Within the Micro-, Meso-, Exo-, Macro-, and Chronosystems. *Adapted from McLauren et al., and Rothe et al.* (85,88)

4. RESEARCH DESIGN

4.1. Introduction

Chapter 4 details how participants were recruited for this study and how data were collected, managed and analyzed. In addition, ethical issues that were taken into consideration throughout this study will be discussed.

4.2. Participant Recruitment and Selection

Participants in this study were the primary food and meal providers to children with CD attending the pediatric gastroenterology clinic at IWK Health Center between September 2010 and August 2011. The IWK Health Center is the university-affiliated tertiary-care children hospital in Halifax, Nova Scotia. Participants were recruited using purposive sampling methods in which data collection and concurrent analysis occurred. Upon receiving ethical approval from both Mount Saint Vincent University and the IWK Health Centre Research Ethics Board, a list of potential participants was generated through the IWK gastroenterology clinic. This list, provided by gastroenterologists at the IWK Health Centre, was of all children with biopsy-proven CD in Nova Scotia, 16-years-of-age and under who attended the gastroenterology clinic. It was estimated that roughly 80 children would meet the study criteria as indicated by the gastroenterology service. Recruiting through the IWK Health Centre allowed for representation of all celiac patients 16-years-of-age and under, a maximum age at which children are followed at the gastroenterology clinic. Adolescents 16-years-of-age and under were chosen for this study as they would still be living at home and, therefore, would be relying on meals provided by their parent or guardian.

A package with research information was sent to all families who met the study criteria. The package included an invitation to participate (Appendix A) and an informed consent form (Appendix B). Interested participants mailed back the completed informed consent form to the researcher using the provided return postage-paid envelope. The invitation to participate provided potential participants with a checklist to determine eligibility. Only families meeting the eligibility criteria for this study and interested in participating in the research were instructed to complete and mail the informed consent form to the researcher care of the gastroenterology clinic at the IWK Health Centre. Upon receiving potential participants' informed consent forms, participants were contacted via telephone to confirm that they met the study inclusion criteria. An interview was also scheduled once interested participants were determined eligible. Secondary recruitment was required to elicit the required number of participants for this study. Further recruitment occurred through recommendations from a member of the thesis committee who had direct contact with potential participants. Through this thesis committee member, the potential participants were engaged in conversations indicating that this research was taking place. Those interested in participating gave the member permission to pass along their names so that a recruitment package could be mailed to them directly.

Recruitment continued until theoretical saturation occurred; that is, the point at which no new concepts or dimensions emerged (88). The researcher, in consultation with the thesis advisor, determined that theoretical saturation occurred after ten in-depth interviews.

4.2.1. Eligibility Criteria

Participants in this study were the primary meal providers for households in which one or more dependents in the family had been diagnosed with CD. As CD often affects more than one

individual in a family, one participant in this study had more than one child with CD, while other primary meal providers did have additional non-celiac children. Participants were eligible to participate with more than one child with CD; however, the number of dependents with CD per family was noted, discussed and analyzed. The dependents, who were children 16-years-of-age and under, must have been diagnosed with CD by a physician and the diagnosis confirmed by a small intestinal biopsy. Children with CD were also required to have been prescribed a GF diet for longer than 6 months. This time frame assumes that families have had adequate time to become familiar with the nutritional requirements of CD and to implement a GF diet. Eligibility was initially determined by participants, and confirmed via a telephone conversation with the researcher (Appendix C).

4.2.2. Exclusion Criteria

Families who have children with CD and type 1 diabetes mellitus were excluded from this study. Children with both CD and diabetes are required to consume a diet of greater complexity, and thus the experiences and management of the nutritional and financial requirements of following a GF diet would differ greatly. Also excluded from this study were participants who were not fluent in English as the researcher can only communicate in this language.

4.3. Data Collection

Data were collected through ten semi-structured face-to-face or telephone interviews with participants fitting the study criteria. Nine telephone and one face-to-face interview were conducted from a private room at Food Action Research Centre (FoodARC), formerly the

Participatory Action Research and Training Centre on Food Security, located at Mount Saint Vincent University at times convenient for participants. All interviews were digitally-recorded with permission of the participants. In addition, notes were taken during the interview process.

An interview guide, containing mostly broad, open-ended, semi-structured questions with probes and some close-ended questions was developed by the researcher in order to stimulate discussion and address the research questions (Appendix D). The interview guide was created considering Radimer's four identified components of food insecurity and hunger: quantitative, qualitative, psychological and social (10). The guide was created to elicit information about the experiences of families with the nutritional and financial requirements of CD and how these families manage their experiences. Using the four components of food insecurity and hunger, the interview guide includes questions surrounding the relationships and experiences of participants that are formed in the micro-, meso-, exo-, macro-, and chronosystems of Bronfenbrenner's social-ecological framework.

The interview guide also gathered demographic information including number of children in the household, marital status of participant, and if the child(ren) with CD had any other chronic conditions. Furthermore, participants' location was determined to be either rural or urban based on population statistic. For the purposes of this research, rural was defined as towns and municipalities outside the community zone of an urban centre with a population of 10,000 people or less, whereas, an urban setting was defined as a community with a population greater than 10,000 (72,92).

Data on household food insecurity were collected via the Household Food Security Survey Module (HFSSM), which was administered verbally to participants at the end of the interview. This 18-item questionnaire is a validated tool (62) that measures household food

insecurity over the previous 12 months. The HFSSM includes questions that relate to food behaviours and experiences (62). In addition, the questionnaire focuses on the Radimer's four components of food insecurity: psychological, qualitative, quantitative, and social (10). Of the 18-items, 10 of the items are related to the household or to adults in the household, and eight items related to children in the household (62,101). Therefore, the HFSSM allows food security status to be determined for adults and children as separate groups.

A conversational style of interviewing was utilized in order to build a greater rapport between participant and researcher. Rapport was established in both face-to-face interviews and telephone interviews by asking questions about participants' lives, such as the names of their children, and being empathetic towards their experiences. Remaining relaxed and open throughout the interview process allowed participants to feel at ease during the interview process and aided in their comfort with sharing their experiences. As the nutritional management of CD includes lifestyle, social and financial components, it was important for the participants to be comfortable and be able to express their issues without strict boundaries. As well, a conversational style of interview fit with the phenomenological approach to conducting qualitative research as it allows the participants to express their individual opinions with greater ease.

The interview guide was reviewed prior to data collection by the researcher's thesis committee, which included experienced researchers, registered dietitians who have knowledge of CD and experience with such patients, as well as a gastroenterologist at the IWK Health Centre. Additionally, the interview guide was pilot tested to ensure it was effective at eliciting the expected responses. The pilot interview allowed the interview tool to be tested and, in addition, allowed the researcher to gather experience in data collection interviewing. The pilot interview

was transcribed, coded and analyzed prior to conducting further interviews. In discussion with the thesis supervisor, it was determined that the tool was effective and the pilot interview would become part of the data set.

4.4. Data Management

Personal interviews were digitally recorded and transcribed verbatim by the researcher and then imported into MaxQDA v 2010, a qualitative data analysis software program by VERBI Software, in which the researcher had received training. All data pertaining to the research project were stored at FoodARC. All electronic files are password protected. Electronic files are kept both on the researcher's password protected personal computer, as well as a password protected student computer drive at Mount Saint Vincent University. Copies of all electronic files are backed-up on a password protected external hard drive. All data pertaining to this study will be kept for 5-years post publication, in accordance with the University Research Ethics Board after which all records relating to study participants will be destroyed. Participant profiles were created using pseudonyms in order to characterize each participant, thus protecting their identities. During the transcription process all interviewee identifiers were removed and, therefore, participants were only known by their pseudonyms.

4.5. Data Analysis

In phenomenological research data analysis is an ongoing process beginning with the first interview until completion of the study. The purpose of data analysis in phenomenological research is to make meaning of the participants' experiences in their life-world (90), not just to

form theories and to deduce or test hypothesis. Data analysis in phenomenological research involves three steps: epoché, phenomenological reduction, and eidetic variation (90,91).

An epoché is any influences that could short-circuit or bias description (90). Epoché instructs the investigator to put aside biases and view the world in an unreflective apprehension (86). This natural attitude or naïve viewpoint is needed to abstain from incorporating "brackets" such as theories, explanations and conceptualization of the subject matter (90). While conducting interviews with participants it was important that the researcher be aware of the influences of their personal views and to be able to put these views aside and focus on the words and views of participants as they relate to their own environments. Throughout the interview process a conscious effort was made by the researcher to avoid forming conclusions based on subjective interpretation.

Phenomenological reduction, which is the conscious, effortful opening of the research to the phenomenon as a phenomenon, is the step whereby the phenomenon of interest takes textual form and is analyzed at the thematic level (91). Participants' aided in this process by reviewing a short summary of their interviews to ensure that conclusions drawn by the researcher were accurate. This form of member checking allowed for feedback from the participants and aided in the credibility of the data. If participants felt that the researcher's summary of their interviews was an inaccurate representation of their conversation, a consultation over the telephone between the participant and researcher took place. At this time participants were able to clarify points of uncertainty in order to ensure that their views and opinions were correctly conveyed.

Thematic analysis, or coding the data and organizing it into themes was undertaken. Interview material and researcher-observations were converted into text in the form of transcriptions to enable: i) lines of inquiry to be identified for emerging themes; ii) an

interpretive plan and coding protocol to be developed for further data analysis; iii) interviews to be coded; and iv) general categories to be recognized (90). A line-by-line style of coding was then utilized whereby key words were coded at a basic level. For example, each time a participant discussed the "grocery store" or said the word "cost" a code was assigned. Thematic analysis aided in the coding of data by placing data in a preparatory stage of data analysis allowing for more structured and in-depth analysis to occur (90). Once all data were coded following a line-by-line overarching style, it was coded again to provide greater depth to the data. For example, in what context or situation was the word "cost" mentioned? What coded emotions were felt in the "grocery store"? What were participants expressing when they said "cost" and "grocery store" in the same phrase?

Eidetic variation occurs when one seeks to understand the meanings of the phenomenon, to grasp "what" something is (90). It is at this step in the analysis of data that meanings and structure and precipitating factors that account for the phenomenon are uncovered. It was at this stage of phenomenological research whereby the data collected truly took form and provided meaning. Looking beyond individual participant interviews to search for the factors that contribute to their experiences provided an understanding of how their experiences were formed. Therefore, it was important that throughout the analytical process to refer to Bronfenbrenner's social-ecological framework in order to be reminded those influences affecting the participants' behaviours occur at various levels of environment and are not always apparent to the individuals themselves.

4.6. Ethical Considerations

Participants' identities were kept strictly anonymous. Confidentiality and anonymity was respected in this research project by using pseudonyms. Only the principal researcher knew the identities of participants. All participants were fully informed of the study and required to sign a consent form (Appendix B) prior to participating in this research. A $50 grocery store gift card was given to each participant as a token of appreciation and time commitment. This value was chosen because of the time commitment of 60-90 minutes in which participants would discuss personal and potentially sensitive information.

5. RESULTS

5.1. Introduction

The following chapter highlights the experiences of participants in this study in relation to their management of their children's celiac disease (CD). The chapter is organized to convey the findings of this study in a meaningful way through the use of direct quotations from participants and by highlighting thoughts and themes that emerged through interviews.

The first objective of this thesis was to explore, through semi-structured in-depth interviews with the primary food provider, how Nova Scotian households who have one or more children with CD experience and manage its nutritional and financial requirements. Two interrelated themes emerged: 1) frustrations experienced by participants in a variety of situations, such as in the community and within the school system; and 2) ways in which the level of public knowledge and understanding of CD influenced these frustrations and shaped experience.

The second objective of this thesis was to discover enablers and barriers to managing the nutritional and financial requirements of the child with CD and explore the implications for the family. The various system levels of Bronfenbrenner's Ecological Systems Theory were used to depict enablers and barriers identified at the various levels of the participants' environments. Key enablers and barriers to managing CD included the level of public knowledge about CD, the degree of support participants felt in their environments, and household income or the feeling of financial stability within their household.

The third objective of this thesis was to explore strategies that would aid in the nutritional and financial management of CD. Strategies identified by participants included improved education of the general population as well as improved quality, affordability, and accessibility of gluten-free (GF) foods.

The final objective of this thesis was to determine if families who have one or more children with CD experience food insecurity. Although the presence of food insecurity was not captured through the use of the HFSSM, participants' experiences with the financial difficulties of CD, as described in the first objective revealed that even though participants did not identify themselves as food-insecure, elements of food insecurity existed.

5.2. Recruitment Results

A total of 10 interviews were conducted, including one pilot interview. Of the initial 20 research packages that were sent inviting recipients to participate in the research study, responses were received from 11 individuals interested in participating. Of these 11 individuals two were further excluded from the study as one resided outside of Nova Scotia at the time of data collection. The second participant was excluded as it was revealed during the pre-screening interview that the child with CD also had diabetes, which meant this family did not meet eligibility criteria. Two more participants suggested by members of my thesis committee who are part of the IWK Health Centre gastroenterology team were sent recruitment packages inviting them to participate in this study in May 2011. Of these two families, one returned an informed consent form indicating interest and the other, while initially interested, decided not to participate owing to factors uncontrolled by the researcher.

5.2.1. Participant Profiles

Andrea is a married stay-at-home mother of two children. Her 8-year-old son Jacob, who has autism, was diagnosed with CD approximately a year and a half ago. Andrea stated that she was not surprised when Jacob was diagnosed with CD as she had always questioned the potential

link between CD and autism. Andrea obtains Jacob's GF foods from major grocery stores and farmers markets. Andrea and her family feel that although the GF diet is expensive, there is no alternative option and that Jacob must have the food he requires for a happy and healthy life, regardless of the cost. Andrea expressed that her main frustration with following a GF diet was feeling restricted in the quality and availability of GF foods.

Laura is a married stay-at-home mom of three young children. The eldest child Amy who is 9-years-old, was diagnosed with CD about three years ago. In addition to CD, Amy also has a peanut allergy, furthering her dietary restrictions. Amy's diagnosis with CD was an emotional "up and down" for Laura, as Amy did not display many of the classic symptoms of CD. The emotions continue for Laura as she finds shopping for GF food to be difficult and sometimes a reminder of the foods that Amy is no longer allowed to enjoy. Laura finds herself feeling empathetic towards Amy in that her daughter would never be able to consume a "regular" diet again. Laura expressed that her major frustrations with following a GF diet were trying to anticipate the unexpected, ensuring that Amy was never excluded and always had GF food available to her.

Janet is a married mother of two children. The eldest, Karen, is 7-years of age and has CD and brittle bone disease[1]. Janet and her husband both work full time and, therefore, lead very busy lives. Karen's diagnosis of CD did not come quickly. It was Janet's motherly instinct that told her to seek answers and to advocate for Karen's health, which finally led to the diagnosis. Although Janet's family is a dual income household, she says that sacrifices have been made in order to ensure that Karen has all of the foods that are required for a GF diet. Janet identified the lack of education about CD in the general population as a major frustration as decreased

[1] Brittle bone disease, or osteogenesis imperfecta, is a genetic bone disorder whereby those affected have defective connective tissue, or an inability to make connective tissue due to a deficiency of Type-1 collagen (93).

knowledge about the disease has resulted in the general population considering the disease neither immediately life threatening nor serious enough to require comprehensive treatment.

Colleen is a working married mother of two children who considers her family lucky in that her daughter, 9-year-old Katie's diagnosis of CD was a very quick one compared with other stories of diagnosis. Katie is the only family member who consumes GF foods since the cost is too prohibitive for the whole family to change their diet. In addition to cost, Colleen must drive approximately 35 minutes from her local grocery store to a larger grocery store in order to find the GF products Katie needs. Not having local access to a grocery store that carries GF products is a great barrier to managing Katie's CD. Having to travel outside of the community results in time lost from social and work related activities. Another barrier Colleen mentions is the general population's lack of knowledge as to what CD is and its impact on a family. This lack of understanding can cause Colleen to feel alone and often misunderstood as being "over protective" or "demanding" as she feels that having CD is much more than just following a GF diet.

Elizabeth is a married stay-at-home mother to two young boys. John, who has CD, is 5-years of age and Michael is 7-years old. It was Elizabeth's decision to stay home with her sons and she feels that, because of the amount of work involved in managing a GF diet, she would not be able to return to work even if she wanted to. From early on, Elizabeth felt that something was wrong with John as he was irritable and could not sit still. She was told by her physician that John's behavior was attributed to his personality; however, Elizabeth knew that it must be something different. Eventually John was diagnosed with CD and since then the entire family has adopted a GF diet. Elizabeth notes that one of the greatest barriers to following a GF diet is the cost associated with GF foods. In addition to cost, the time required to make many of the baked

goods from scratch takes time away from other daily activities. Elizabeth believed she would not be able to manage the GF diet if she worked full time.

Sarah is a married mother of two children with CD, Jessica age-16, and Ryan age-12 years. Sarah found that she has had to strongly advocate for her children not only in their diagnosis of CD but also in their ability to participate in regular social activities. Jessica was the first to be diagnosed. She displayed classical symptoms of CD. However, Sarah believes that Jessica's symptoms were not taken seriously. She requested to see a specialist, which then required multiple trips to the hospital prior to receiving a confirmed diagnosis. Sarah and her family have always tried to consume a healthy diet; therefore, following a GF diet was something to which Sarah and her family quickly adapted. Sarah said, "You learn as you go along and expand in your varieties". Although the family is not entirely GF, Sarah and her husband do make an effort to ensure that meals are similar, if not completely GF and try to purchase more GF snacks than gluten-containing ones. Sarah does find the cost of GF food to be expensive. Therefore, she has adopted the strategy to stock-pile food items when on sale, saying that "well, when the money is there, I'll do [stock piling] and when it's not there the cupboard is full to provide".

Allison is a married stay-at-home mother to two young children. The eldest Emma, age-4 years has CD. Emma's diagnosis with CD was quite a shock for Allison as she had no signs or symptoms of the disease. Allison took Emma to the doctor inquiring about her protein levels as Emma does not consume meat. The doctor decided to check celiac serology just in case, which led to Emma's quick diagnosis. Prior to Emma's diagnosis, Allison reveals that they did not really follow a strict financial budget. However, since the diagnosis, a budget has been created in order to cut back on other activities to ensure that Emma has all the GF food she requires.

Jennifer is a married mother of two children, ages 9 and 11 years. The 9-year-old Olivia has CD. Olivia's diagnosis with CD was quite a shock for Jennifer as she displayed no outward symptoms of the disease and was tested for CD secondary to treatment for a virus. A friend of Jennifer's had mentioned that she suspected her daughter to have intolerance to wheat; it was then that she discovered that the screening test for CD was a simple blood test. Since Olivia had to receive blood work due to a recent virus, Jennifer decided to ask for the celiac test to be completed as well. As Olivia's diagnosis was quite quick and unexpected, Jennifer was in a state of denial. She says that since discovering that Olivia has CD, 90% of the foods they consume as a family have become GF, with Jennifer and Olivia being 100% GF. Because Jennifer and her family view healthy eating as a priority and are able to support a GF lifestyle financially, adopting a GF diet was not a major adjustment for the family.

Nicole is a married mother of two young children; the youngest Andrew, age 4-years, has CD. Nicole is able to stay home with the children during the day and, therefore, prepares all GF food from scratch. Nicole found the process of Andrew's diagnosis with CD to be a lengthy and frustrating one. From early on, Nicole felt that there was something wrong with Andrew. After multiple trips to various health professionals he was finally diagnosed with CD. Nicole says that her intuition that there was something wrong with Andrew was correct in that his negative behaviour was a coping mechanism for his physical symptoms of CD.

Krista is a lone mother to three young children between the ages of 4 and 8-years, all of whom have CD. Moreover, Krista herself has CD and is on income assistance. Krista, along with each child, receives a $150 dollar special diet allowance through the Nova Scotia Employment Support and Income Assistance (ESIA) Program, the maximum allowance for CD and wheat allergy, to cover the cost associated with following a GF diet. Obtaining this money, however,

was not an easy process. Although the financial support received at the time of the study was acceptable to manage the family's diet, prior to receiving the ESIA special diet allowance Krista found herself consuming gluten-containing foods in order to ensure that her children received the proper foods that they needed. In addition to Krista herself having CD and working casual shift-work, she is also the only lone parent who participated in this study. Furthermore, Krista described that through her entire life she has had limited family involvement and, therefore, manages CD on her own.

Table 2. Participant Profiles

Name	Marital Status	Employment✣	Rural/ Urban*	# of Children in Household	Age of child with CD (years)	Income Assistance
Andrea	Married	Unemployed	Rural	2	10	No
Laura	Married	Unemployed	Urban	3	9	No
Janet	Married	Employed	Rural	2	7	No
Colleen	Married	Employed	Urban	2	9	No
Elizabeth	Married	Unemployed	Rural	2	5	No
Sarah	Married	Unemployed	Urban	2	12 and 16	No
Allison	Married	Unemployed	Urban	2	4	No
Jennifer	Married	Unemployed	Urban	2	9	No
Nicole	Married	Part-time	Urban	2	4	No
Krista	Lone	Casual/IA^+	Urban	3	4, 7 and 8	Yes

✣Not all participants described why they were unemployed. The researcher did not directly ask participants why they were unemployed; therefore, information gathered regarding unemployment status was voluntary information provided by participants. Unemployment status could be by choice, or not by choice
*Rural, communities with less than 10,000 people; urban, communities with greater than 10,000 people
^IA, Income assistance
+Mother also had CD
CD, Celiac Disease; #, number

5.3. Research Objective #1

To explore via semi-structured in-depth interviews, with the primary food provider, how Nova Scotian households who have a child with celiac disease experience and manage the nutritional and financial requirements of celiac disease and its impact on their individual and household food security.

All of the primary food providers in this study were mothers of at least one child with CD. Through my discussions with these mothers it was evident that although they all lead different lives, similarities existed in how they experienced and managed CD. Commonalities existed between participants in that all felt that, financially, CD did have an impact on their experiences, as well as on their ability to manage the disease. In addition, they all felt frustration when managing a GF diet and, above all, every mother in this study felt that their child's health was the most important outcome when managing CD.

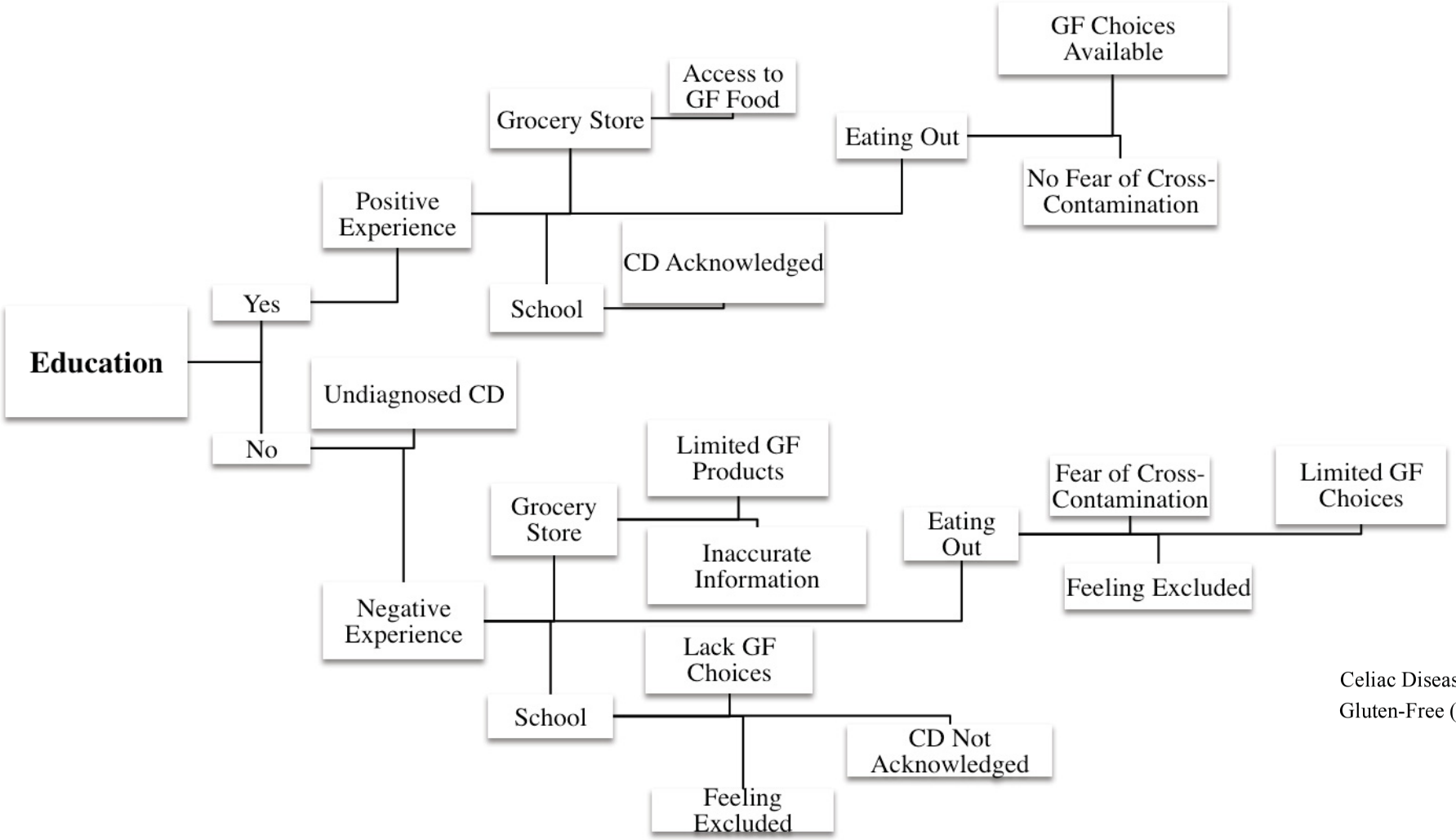
The main determinant of how families experienced and managed CD was rooted in the level or degree of education participants had about the disorder and their perceptions and experiences of this among the general population, herein referred to as "level of education". In other words, level of education, specifically how knowledgeable the general public was about CD, was the most significant factor described by participants in how their family experienced and managed CD. All women felt that the current level of knowledge about CD was very limited among the general public and that they were constantly acting as educators. Although the women were happy to share their knowledge with those who were interested, they felt that the awareness of CD should be higher in the general population, and that the system of education should come from larger, more universal sources of information, such as television awareness campaigns, or governmental agencies. Positive experiences occurred when the participants met someone who knew about CD, or was keen to know more about the disease. Negative experiences occurred

when a lack of knowledge was evident which led to participants becoming frustrated with this lack of understanding which, in turn, would lead to a perceived lack of the seriousness of the disease.

While others' education, or level of understanding, influenced participants' experiences, their own level of understanding of CD also determined their individual management of CD. For example, those who were proficient in the kitchen and were determined to research CD independently were better able to prepare GF foods in the home, and manage the GF diet when away from the home. Moreover, management of the disease outside of the home was dependent on the level of education of the general population.

Education, as the main overarching theme for how the participants experienced and managed CD, will be discussed throughout multiple sections within this chapter as it pertains to various aspects of participants' stories about their families and children with CD. Figure 2 depicts the complex role education played in participants' lives, and how the level of education present about CD influenced their experiences and management of the disease. In situations where participants encountered an individual who knew about CD the outcome would be a positive experience. For example, within the grocery store, employees would be able to accurately point out GF products to customers, within the school system participants were met with understanding and accommodation, and when eating out the fear of gluten cross-contamination was not present. When education about CD was not present, participants had negative experiences within the grocery store, at school, and while eating out. Frustration was not the only emotional outcome of lack of education. Feelings of exclusion due to limited GF food choices were also a result of the lack of education about CD as the *need* for GF alternatives was not recognized.

FIGURE 2: Summary of the Impact of Level of Education on Participant Experience and Management of Celiac Disease



Celiac Disease (CD)
Gluten-Free (GF)

5.3.1. Diagnosis of Celiac Disease

Each participant's first experience with CD, their child's diagnosis, represents their introduction to the world of CD and GF living. While the journey to discovering their child had CD varied amongst participants, their child's diagnosis with this chronic disease had a lasting impact on participants' beliefs, attitudes, and how they managed their child's disorder.

Prior to diagnosis, the majority of mothers were unfamiliar with CD, and what it would mean for their child or their family. Many of the women interviewed were shocked when they learned that their child had CD. As CD can present with or without symptoms, participants were shocked either because their child had no symptoms or because they had never heard of CD before. Allison met with her doctor for a different dietary concern as her daughter Emma did not eat meat with the result that the doctor ordered blood work to add the test for CD as a "just in case" measure.

> *It was a shock; yeah it was certainly a shock because I didn't think it was that at all. I thought maybe that it was just one of the false positive things... my husband and I discussed it and we went through with [the biopsy] and then when it came back positive we were quite shocked.* [Allison]

Although Allison did not notice any symptoms in Emma prior to diagnosis, after learning about the disease Allison was able to see that symptoms of CD were present. Once Emma began following a GF diet, Allison noticed that her health and personality improved considerably.

Jennifer was another mother who found her daughter Olivia's diagnosis with CD to be a shock. Jennifer was unaware of what CD was until a family friend who was a nurse thought that her own daughter might have the disease. At that time, Olivia was recovering from a virus and

required blood work so Jennifer asked that she also be tested for CD, more out of curiosity than possibility.

> *And I said well hey if I'm getting her blood test done and she's not feeling the best because of this virus, I want a good blood work done. So I did ask for all of it... check it off and that was it. Then within a couple of days after that I received a phone call... they said her TTG test was positive and that she should be seen by a doctor right away... We just kind of stumbled up on... it's only a blood test.* [Jennifer]

Jennifer's feeling of shock that her daughter tested positive for CD was a result of her daughter displaying no significant symptoms of the disease and, therefore, she felt that the diagnosis could not be true.

> *Well first of all wow, she can't be number one... cause the blood test, when you got to talk to people, it's not a true blood test and all this stuff right... we got two more blood tests before I was convinced enough that we had to get the biopsy done. I said oh well, they made a mistake or whatever.* [Jennifer]

> *She had the scattered sore belly but that's because... that's like any other kid you know... but nothing really. I mean she was always thriving, she always ate well, she was healthy.* [Jennifer]

In addition to the shock of their children being diagnosed with CD, some mothers felt relief in receiving a diagnosis, as it finally provided an answer as to why their children were feeling the way they were. Elizabeth and Sarah both experienced great frustration in trying to determine a diagnosis for their children, having to act as strong advocates for their children's health.

> *[John] was a month old and I remember he didn't stop crying until he was gluten-free. So at a month old he started holding his breath turning purple and we kept, my husband and*

> *I kept taking him to the doctor. There's something wrong, there's something wrong and they told us he had colic and you know... oh this was my favorite... it was his personality. But my husband and I knew that this wasn't him, that there's something wrong.* [Elizabeth]

When introducing solids to her son's diet, Elizabeth recalls that the difference in reaction between rice cereal and barley cereal was so drastic that Elizabeth and her husband had to demand that her son to be tested for something, anything. Elizabeth was quite frustrated when she was told that her son's temperament was "just his personality", and she wishes that her doctor had taken John's symptoms more seriously. When John was finally diagnosed with CD Elizabeth was relieved to have an answer, but had no idea what the disease entailed. In this case, not only did Elizabeth have no knowledge regarding CD, but also her physician did not link John's symptoms to CD suggesting a lack of awareness of the disorder.

> *I had no idea. I heard somebody say once before... "I thought gluten was a kind of pudding". I didn't think that, but I really did not know what it was. It was kind of the same thing, like what is gluten? I remember seeing things in the grocery store saying gluten-free, and what the heck is that gluten? And then he told me... a little bit about that, and that we'd set up another appointment to talk about it more. I remember him saying too that it's not the end of the world, and I remember thinking it's not, hopefully we can fix this... but it kind of is.* [Elizabeth]

In hindsight, Elizabeth realized that John's symptoms were actually very classical of CD. He had a "huge distended belly", dark circles under his eyes, foul bowel movements and constant irritability. John, not knowing what was making him feel sick, unknowingly refused to consume gluten-containing foods. When John started a GF diet he immediately began to feel better.

So I started feeding him gluten-free and two days [later] we were at the table and he looked at me, and I will never forget it, and he said "mamma, I'm your new boy. [Elizabeth]

Sarah had such a difficult experience in finding answers as to why her child was sick that her frustration with the diagnostic process led to anger.

She went 7 days straight we were going over to the IWK and we finally had this one doctor and he was fantastic, and he looked up and was like oh, this is too much, you've been over here this amount of time? And I'm like yeah, the pain is just horracious [sic], he said no I'm admitting her.... we were there 2 days... she got discharged and it was about a week or so after that this one doctor, and she was not a nice doctor, she was very cold... and she called me very cool and nonchalant and said to me, yeah, she showed positive for celiac disease. They couldn't get me in until December... it's gone on long enough and I'm not waiting till December... I want action now. [Sarah]

Nicole also had a difficult experience in that Andrew's diagnosis was delayed and with serious health consequences.

He had vomiting and diarrhea for... at one point it was up to two months... and they're going oh no you're doing a good job, just keep hydrating him, he still has tears. I was thinking easy for you to say he's doing good, what kid vomits for two months! Finally we got into see my doctor and she looked at him and went there's something wrong, and then weighed him and said there's something really wrong. [Nicole]

Nicole was very relieved with her son Andrew's diagnosis of CD as his symptoms and "his road" to diagnosis was unbearably painful not only for him but also for the entire family.

I'm sad to admit that I thought often about what life would have been like if we had not had the second child. I mean because life was exceptionally difficult. I say to people all the time that I don't know how marriages last with chronic illness that last a life time that require constant medication and attention... because two months was... and I mean we were in some serious issues already. [Nicole]

Laura also experienced shock and disbelief when her daughter Amy was diagnosed with CD. Laura was in disbelief that Amy had a disorder, as she did not appear to be physically ill. She attributed Amy's symptom of a sore belly at night to child-like behaviour in seeking attention and delaying going to bed. In addition, Amy's diagnosis was an emotional up and down for Laura as she felt guilt in that she did not recognize that Amy was sick, and worried about what it meant to be diagnosed with CD.

> *I made an appointment for the results and kind of thought that she's got something terminal... no she's okay, it's nothing. So I was kind of emotionally up and down just in my head. And then when she said she had celiac disease, I didn't actually know what it was. And then she explained what it was and I felt really upset and I was kind of annoyed because I felt this is ridiculous, it's not something fatal, it's something... even though she didn't need medication. I was kind of giving myself a hard time, but I was actually very upset, very emotional.* [Laura]

Like several other participants, Laura felt foolish in that she was upset over her daughter's having a disease in which the treatment is a change in diet. Many explained that, because CD is not considered to be immediately life threatening and can be controlled without medication, it does not justify a strong emotional reaction.

> *I was upset, especially your first child. I was quite upset, did some crying and then thought, it's not the worst thing in the world. It's not a terminal disease or anything... it's just something that for me to be positive, I had to be positive of course if she was going to be positive about it.* [Allison]

Colleen added that when Katie was first diagnosed with CD that it was all encompassing. She went on to say, however, that having to change Katie's diet was an easy thing to do in comparison to the treatment of other diseases. Those who are unaware of consequences of gluten

consumption for a person with CD may see diet modification compared to medication use as less serious.

> *But then I thought about it I said okay, she doesn't need medicine, chemotherapy... she doesn't have to go into hospital, all we have to do is change her food. So in one way I kind of thought we got off, of all the things that could have been wrong internally made it a little bit easy... because a change in diet is an easier thing.* [Colleen]

5.3.2. Perceived Seriousness of Celiac Disease

The participants in this study were all thankful that their child did not have a "serious illness" and that CD was a disorder that could be managed by diet alone. Interestingly, although all mothers viewed CD as "not as serious as other diseases", they all wished that others would take the disease more seriously. Many mothers compared CD to peanut allergy saying that they wished that people were as diligent with gluten consumption as they were with peanut ingestion.

> *One thing that bothers me is that a lot of people don't think it's serious, like it's not the same as a peanut allergy when the child has a chance of dropping, and not to belittle that because that's scary... so I find it hard to not be too dramatic when I'm explaining it, but to let people know that it is serious.* [Colleen]

> *People don't seem to get it because it's not life threatening like a peanut allergy, they don't seem to take it seriously.* [Nicole]

The attitude that CD is less serious than other diseases affected the everyday experiences of these children and caused participants to feel disappointed and frustrated with the lack of understanding about what it means to live with CD. Janet described a situation in which her daughter's ability to participate in a religious ceremony was questioned.

As far as I know the host [bread offering associated with communion] is made of bread and I don't know what I'm going to do about... the church is supposed to get back to me and tell me what my options are... I've read online that certain churches won't accept gluten-free hosts even though they are available... because technically the host is supposed to be bread. And that just really bothers me. And even the religion teacher said well, the religion teacher has gluten intolerance, and she said "well the host has never bothered me" and I just kind of feel like, would I give a little bit of peanuts to a kid with a peanut allergy... probably not! It just seems like it's not taken as seriously as it should be. [Janet]

Nicole understood why others did not view CD as a serious disease as she had previously felt the same way.

To give people a little bit of merit it isn't life threatening unless there's long term exposure. Somebody gets fed a cookie or something that has gluten-containing on it are they going to feel [bad] after absolutely, will they die the next day probably not. So I guess I can kind of understand somewhat... of people not taking it seriously, but it would be really cool if people could just get it. I don't really feel like there's nearly enough awareness of what celiac disease is. [Nicole]

5.3.3. Celiac Disease within the School System

The school system is another domain in which participants felt that CD was not taken seriously. Again, many mothers cited that teachers and parents of other students were extremely strict about peanut allergies; however, when it came to CD it was often not thought of as a disease requiring special consideration. This lack of accommodation and understanding was quite frustrating for the mothers.

We made a big deal about it at the beginning of the year... they have a bulletin board with every kid who has special needs... and they didn't consider her [daughter, Karen] to be, to need to be on that board. And I had to basically fight to get her on the board so that people would know. [Janet]

Although Karen's teachers were made aware of her CD, Janet felt that the school gave in to her wishes as a way to "appease" her. She felt that teachers were not aware of the children in the school who have special needs such as a GF diet, adding that often on special school days the school administrators provide students with cake as part of the celebration. As another example, Janet described a school-sponsored event about peanut allergies in which the school had two grocery carts, one with acceptable peanut-free snacks and a second that was not acceptable. Janet explained that out of both grocery carts there were only two items that Karen could eat. In addition, Janet felt that when purchasing GF foods it was harder to determine if these foods were also peanut-free.

> *Just the whole school side of things not understanding what we go through and not that I would ever want to endanger any other kids, but I also find that the gluten-free [food] is not labeled well for peanut allergies.* [Janet]

Colleen also found that the school system was not very accommodating to students with CD saying that the school would have special treat days where cupcakes or hot dogs were served.

> *They can accommodate... peanuts and all that stuff, but... she has to sit and watch.* [Colleen]

Not only did participants feel that the school system did not accommodate or understand their child's dietary restrictions, some mothers also felt that they were met with resistance when CD was explained.

We went through a lot of trouble at first, because our school, the school that they go to doesn't provide a lot of options for kids with celiac disease. So what has happened is we had to get lots of letters written by dietitians and doctors for them to have access to a microwave. And it took a long time, it took me basically the whole school year. [Krista]

One comment the cafeteria lady did make, she wasn't all that receptive when I did call her... I was so annoyed, she was probably the only person who made me upset, I don't think I ever really cried other than after talking to her in the beginning... one comment was 'it sounds like I don't wanna make lunches'... oh I could have went through the phone. It sounded like I would really put her out, you know there's so many allergies and... it's so difficult. And I know we have a small school and she really likes my daughter... but she didn't want to be put out anymore... and I guess that's why I didn't really push it. [Colleen]

It was very frustrating because my eight year old loves home cooked meals, and the thing was she couldn't have that, and she couldn't have the food they offered at school because a lot of the times there was hidden stuff in it that she couldn't have. And it was very frustrating because their word was... basically they said that if they let them use the microwave they would have to let everyone in the school. But I mean I found that it didn't make sense because if a child was diabetic they would have some kind of, you know what I mean, if they need a snack, or if they need certain stuff they would automatically get it... It makes me mad because they're quite aware of it, she wears a medical alert bracelet. So it's not, it's not that it's not public knowledge, it can be frustrating, it makes me a little mad. [Krista]

Although several participants noted difficulties with CD being taken seriously within the school system, this was not the case for all. Allison had a very positive experience in that her daughter's preschool provided her with up-to-date lists of all the snacks supplied each month so that she could prepare similar GF alternatives for Emma. Interestingly, participants with children who had just started school had mainly positive experiences within the school system, suggesting that greater care is taken in the protection of younger children.

A lot of people want to know, especially her preschool teachers... they didn't know what celiac disease was so I had to explain it to them. And of course because they work in a preschool they're more apt to adjust and want to learn about it. [Allison]

5.3.3.1. Feeling Excluded at School

The relationship between parents of children with CD and those working in the school system was often a struggle, fueled by a lack of understanding that stemmed from limited knowledge about CD. Not only did parents face difficulty in providing GF and peanut-free lunches and snacks, but they were also faced with the social consequences of their child being excluded from group activities.

> *The first week of school she came home crying because they had an unplanned event at school and the teacher knew she was diagnosed with celiac, but didn't really know what that meant.... so she sent home cake with her... she was bawling because like 'why does the teacher send me home cake and I can't eat it'... to have the school send that home when they should be educated on that, that really pissed me off.* [Janet]

Krista described a time when her daughter felt excluded at school because of her dietary restriction and her inability to share foods with other children.

> *People are sharing all these foods and one time my daughter for instance wasn't offered anything... the reward... everyone in the class had a treat from the teacher, but not her because she couldn't eat it. So you know, it kind of alienates the kids.* [Krista]

Elizabeth expressed that it is not just food served at school, but it is also school activities that can pose a danger.

> *They had play dough at school and I said that is the same as playing with peanuts at school. Lining peanuts, making letters out of peanuts, making them out of play dough for him, it won't kill him, but it will make him sick and it could have short term, long term effects, but no, it's not understood.* [Elizabeth]

5.3.4. Celiac Disease within the Community

The level of education and, therefore, knowledge about CD within participants' communities had an impact on their experiences. Janet described a situation where she was anxiously attempting to buy a late, out-of-town GF meal for her daughter and was relieved when the staff at the restaurant knew about CD and how to ensure that her meal was GF.

> *It was at 9:00 at night, we were starving and I was like okay I have to talk to the manager to place the order, and well he comes out and I ask him is the chicken gluten-free? And he said oh yes, does your child have celiac? And I was like oh my god thank you... I was on the phone but I would have hugged him if I was in person. If someone actually knows what we're talking about it's such a relief.* [Janet]

Many negative experiences occurred at the grocery store where participants encountered employees who were unaware of CD/GF diet, or who were uncooperative in discussion about ordering more GF products. Janet described an event where a friend attempted to accommodate her daughter's CD by asking a grocery store employee for assistance. Misinformation provided by the employee resulted in Janet's child accidentally consuming gluten-containing food.

> *There was one birthday party she went to and my friend knew she had celiac and she said we really want to get her cookies that are safe for her. And they went to the natural aisle of our store and they asked the person who works there in the store which ones were safe, and they gave them ones that were organic wheat.* [Janet]

Although Janet appreciated her friend's attempt to ensure that her daughter felt included at a birthday party, this incident shows that the grocery store employees lacked education about a GF diet. Multiple participants noted that food industry workers should be taught about various food allergy diseases and requirements. Allison described that grocery store employees often do

not understand the requirements of CD and a GF diet, which is very frustrating for her as these individuals are both resources and facilitators in obtaining GF foods.

> *The one that orders the product on the shelves [at the grocery store] is just kind of looking at you like you're, like you have ten heads because you want her to order a case of something and you want to buy, like six of something because you try to explain to them like look, you bring this product in and it's a good product that sells quickly - you have to order more of it! Because people know, and you're ordering stuff and you're having it on your shelves so long and it's terrible, so you're trying to educate someone on it who doesn't want to be educated. So yeah, very frustrating.* [Allison]

In social situations such as eating outside the home, participants felt that the lack of knowledge about CD, more specifically the risk of gluten-contamination, resulted in negative or fearful situations. The fear of gluten-contamination outside the home caused many mothers not to "take a chance" on food prepared by others, often worrying whether or not the food was prepared with the proper care to ensure it was GF. Although participants acknowledged this worry, they felt that the lack of education and perceived seriousness of the disease was a result of the way information about the GF diet was shared among the general population. Participant's felt that information was not presented through accredited health care professionals or organizations, but rather through word of mouth by individuals who had various levels of knowledge about CD. Through these channels important information about CD and the GF diet would be diluted. Furthermore, with the increased popularity and celebrity endorsement of a GF diet for weight loss versus medical necessity, members of the general population are exposed to second-hand information that may or may not be accurate.

> *People don't understand if you have a fruit tray and they cut it up at home, they don't understand that he can't have it. They'll say that it's just fruit, but I need to see where it was cut. And you know, did they just wipe up with a cloth that they just wiped the toast up*

with? It's stuff like that that people don't understand, and you wouldn't unless you were living with it. [Elizabeth]

I just don't think if they really understand what it is really. Because some people don't think it's that serious, it's just you fix it with a diet and that's it. And then some people, a lot of people just don't know about it. [Krista]

It's frustrating... I don't always know if somebody is going to try to prepare something for him, if they're going to be anal enough about cross contamination that I know his food is going to be safe... sometimes I feel like you're beating your head against a wall trying to go, like seriously if there was any chance that he would 'grow out of this' then obviously I would be jumping all over it. [Nicole]

Many participants noted that there was limited public knowledge about CD, saying that most people are being educated about CD by those who have the disorder. One participant said that you never see CD information commercials on television and wondered why that was the case.

I don't understand why... they have all these commercials... about people suffering from depression and this is the drug or whatever, and people having even ALS in the last year... or Huntington's disease, or any of these cancers... but you never see one about celiac, at least I've never seen one on the TV about celiac. I've never seen a billboard, I've never seen a pamphlet, I've never seen anything on the TV. I've never seen anything in my doctors office, until you've gone and you've asked for it. [Allison]

If on Dr. Oz two years ago had been listing off celiac and symptoms in children we would have been right to the doctor. [Colleen]

Participants acknowledged that lack of knowledge about CD among the general public was understandable. However, participants felt that those in the food industry, or those who have direct care for children such as school educators should know what CD is all about since these individuals have an impact on the lives of those with this disorder and their families.

The knowledge, it has to come from... the managers, the principles, all these people who are at the top of all her, of everything we depend on, like we depend on her school, we depend on the grocery stores we depend on the restaurants in this area... we depend on all these people. They need to be educated about this, and even the kids who are in high school working in McDonalds, they should have an idea of what celiac is. [Janet]

It's the level of people they hire... when it comes down to a student who's just there for the pay and it's a job... but it's a hang up the apron and go on... okay whatever. [Sarah]

I arrived one time, just in time to see this kid about to cut her gluten-free pizza with the same pizza cutter he had just used to cut everybody else's right. I don't know, I mean obviously he didn't know and I explained it to him, and he went oh, I wish somebody would have told me that, all these times I've been cutting the gluten-free pizzas. [Nicole]

It seems like there is more knowledge of it, it's just in pockets... it's even just knowing the word gluten-free or celiac, they don't. There are certain people who recognize that are like 'oh remind me again what does that mean she can't eat', and at least you know, that it means something. [Janet]

5.3.4.1. Feeling Excluded within the Community

A common sentiment among all participants was the feeling of exclusion, whether it was in a social situation, due to the lack of GF options available, fear of cross-contamination or worry about not being able to find GF foods.

Owing to multiple factors such as fear of gluten-contamination and limited restaurants serving GF meals, some families avoided eating away from the home thereby excluding themselves from social activities. Andrea felt that going to a restaurant was too complicated so the family avoided going out. As well, Elizabeth felt too fearful to eat outside the home worrying that her son would become ill.

> *If we took him to a restaurant just because we wanted to go to a restaurant to eat together, which that is nice... but if we did that and he got sick I would just feel so bad. And I'm kind of putting his health in someone else's hands that I don't know, and I just... I can't do that right now.* [Elizabeth]

When Jennifer and her family ate out at a restaurant that served GF menu options, she said the experience was horrible as the GF food was not comparable to regular food, making her daughter extremely upset.

> *She has this awful experience of brining her food so she's singled out already, and then for it to taste awful... she can't even take a mouthful of it. Her cousins were there and they're to going to order gluten-free food... and here she is just about... crying to break her heart.* [Jennifer]

Participants were very cognizant of how their children might feel excluded because of their dietary restriction and did their best to ensure that their children felt included in all aspects of life.

All participants felt that consuming GF food along with their child was important in ensuring that they felt included. Some participants were completely GF, while others were only partially. Elizabeth felt it was important for her entire family to adopt a GF lifestyle and felt empathetic for children with CD where their family does not also follow a GF diet.

> *We have a little guy who lives next to us, well he's 10 I think, and his family they don't eat anything gluten-free, just him... I asked him one day how do you feel about being gluten-free and everything, and he said well I fell really left out.* [Elizabeth]

Jennifer also chose to follow a completely GF diet saying that she did not want her daughter to feel alone. As a result of this dietary change, Jennifer stated that she also felt physically and mentally healthier. Whether the child with CD felt excluded or included depended

on whether GF foods were available to them. Colleen described a situation where her family had an impact on whether Katie was excluded or included in a family meal.

> *Sometimes my brother... they'll come with their apple pie sometimes for supper... that kind of bugs me because I always think to myself, well you know if their little guy had something I would never show up at their house with something that he couldn't eat. But I think that they're just not thinking, like they're not doing it on purpose.* [Colleen]

Continuing, Colleen says that her mother always makes the effort to include Katie by having fresh or frozen GF deserts available, which Colleen explained are often more delicious than the regular gluten-containing desert.

> *My mom is really really good. I'm very lucky and I mean she shed a lot of tears trying to make stuff and she... if we go there, we go there Christmas Eve she can have, she can eat everything.* [Colleen]

It was important to mothers to give their children a feeling of normalcy. This was achieved by providing their children with similar GF food so that a drastic difference between food choices was not evident.

> *I just make John his own little tray so he could have cupcakes and so could everybody else, so that he kind of feels included. And then the drinks and stuff like that he can have those, so he's not totally... I just don't want him to think that he's... well he is different, but he's not. It's just a different kind of food. So I want him to be included, but be safe at the same time.* [Elizabeth]

> *If I know a birthday is coming or whatever then I know to bake something for her, or make sure I have something here for her to have.* [Allison]

> *I try to make her feel normal. With the school I give them the muffins in advance. Like last year I had four cupcakes in the school in the freezer if something ever came up and I*

just haven't gotten able to do that yet. But I'm trying to be one step ahead all the time trying to make sure that she doesn't get in that situation where she's sitting there with all the kids around her are eating cake and she's just looking at everybody. [Janet]

Positive experiences occurred when the child with CD was made to feel included. In Colleen's example, another mother made the effort to ensure that Katie could safely consume all foods at her daughter's birthday party. Colleen and the other mother could relate to one another as both of their children had dietary restrictions and the mothers understood how important it was for the children to feel the same as their peers.

There was one little girl, she's allergic to a lot of things and her mom had a relative who worked at [a catering company] and had prearranged to have all these sweet delicacies, different cakes and all this stuff made to have for Katie at the birthday party. It was actually unbelievable, and we hadn't had desert so good! She was actually unbelievable. And I just know it was, I know every mom is good, there was a different, I guess because we could relate. It's different when you can relate a little better. [Colleen]

Jennifer and Nicole also described times when a positive experience occurred due to another parent's effort to ensure that their children felt included.

One party they adjusted and they ordered from [this restaurant] solely so they could have a gluten-free pizza... it was super... they did their research and looked online and had gluten-free tootsie rolls in their little party bags, and put all gluten-free things. That was.. very, very special... but then there's some who are oh, I never even thought of it right. [Jennifer]

When he gets to eat the same cake as everybody else I mean he talks about it for weeks, like that's the highlight for him, I got to eat the same cake as everybody else, it's such a big deal for him. [Nicole]

Although Nicole was happy to see Andrew so excited about being the same as other children, she said she also felt sad thinking about the times when Andrew was not or will not be included.

> *I get really excited because I know how excited Andrew is going to be, but it makes me sad because I think... because it makes me think of all the times that he's not totally included.* [Nicole]

5.3.5. Worrying about Child with Celiac Disease

Although all parents worry about their children, a common theme among all participants was that they worried far more about their children than they would if their children did not have CD. Participants felt that their child's health and fear of gluten-consumption was always on their minds.

> *It's made me a worrier. You know what I mean, to constantly worry about it, of what could happen if, or what's going to happen if they do this? Or if I skimp on this, because I need to do this, and it's made life a bit more stressful to say the least. Before it wasn't as bad, because I wouldn't have to worry about the kids health as much, and I wouldn't have to worry about consumption you know, about what they're eating and what they're not eating, when they're out of the house. Now that's, now that's basically what you think about. If they go to a friend's house you're not worrying about if they're having fun, you're worrying about whether they're eating something they're not supposed to.* [Krista]

> *I worry about her a lot. She's just kind of always on the back of my mind... and I kind of feel bad because I don't feel the same way about [other child]... I don't feel like I have to think about her, like every five minutes. And with Karen [child with celiac disease] its like, I wonder if she's alright... even if she's a little bit tired or not feeling great and she still wants to go to school I'll be basically waiting for a phone call all day.* [Janet]

> *The whole, well any kid can be sick at any time, it's not the same. I don't know really, it's a different feeling. Even now if she got sick my first would be what did she eat the last couple of days and is this the flu or is she sick because of something she ate and it's like,*

it's just I go back in my mind 'what did she eat, where was she at, who did she, who could she have been with. [Janet]

Participants also worried about whether GF foods were actually completely GF. As mentioned in Section 5.3.4 with respect to how CD is experienced in the community, this worry was fuelled by the increasing trend for people without CD choosing to follow a GF diet. Therefore, participants worried about their child consuming contaminated GF foods or GF foods prepared by "non-celiacs" consuming a GF diet, as these "gluten-free" foods may lack the strictness required in the diet of those with CD.

I think a lot of people... there's a demand for it because of... people saying it's a weight loss, and they're gluten-free not for the reason you should be gluten-free... because you need to be. And I'm worried about that, that people will start saying something's gluten-free when it's really not, it's contaminated or whatever, but it's okay for someone who doesn't have celiac. Okay, is this gluten-free for a celiac or is this gluten-free for somebody who's just on a gluten-free diet? [Elizabeth]

I have to worry... for John, or for me or the rest of us if there's something contaminated... but if my sister for example, makes a salad I'm kind of wondering about the sauce and that kind of stuff... I'm kind of over her shoulder. [Elizabeth]

Many participants also worried that, as their children grew and experienced increased peer pressure to be like everyone else, they would become less compliant with a GF diet.

How do you have a discussion with someone, oh yeah… you're not allowed to drink at all, but you're <u>really</u> not allowed to drink beer. [Janet]

I kind of worry… Amy's always been really…. good accepting her limitations about diet. But sometimes lately she's been getting kind of fed up and just wants to just eat what we eat, you know… what the others can have and um… just sometimes. And I've always from the beginning I've always worried about her rebelling as a teenager and just not wanting to do it anymore. You know just wanting to eat with her friends and just… regardless of

the pain, just eating what she wants to eat. Or then when she goes to university just wanting to drink, I dunno… beer or eat what she likes you know eat pizza from the take away place or…. Yeah, I do worry about her just getting fed up. [Laura]

She's not at the age yet where I let her go off to friends homes and plan or whatever. But it's something that I worry about, that I know I'm going to have to worry about in the future, especially when she goes to school. And next year I feel it's going to be a challenge because she goes to school on the bus out here, and she's supposed to stay for lunch. Well there's only so much you can send a gluten-free child that doesn't like to eat meat for lunch. I have no idea how we're going to get over that one, but we'll learn. [Allison]

I worry that when he get's older he's not having the same thing as everyone else. Right now he doesn't seem to mind or care because he knows that food doesn't make him feel good. [Andrea]

5.3.6. Availability of Gluten-Free Food

The availability of GF food varied for each participant based on geographical location, knowledge of CD/GF diet, methods of preparing GF foods, and preferences of the child. Those in an area identified as rural found that they had to travel great distances to urban areas with larger grocery stores in order to find all of the GF foods required. Participants noted that traveling to obtain certain GF foods was difficult, as it required preparation and took time away from other responsibilities or from time spent with their children. Participants in urban centres also found themselves spending a great deal of time obtaining GF foods since not all grocery stores would carry the same GF foods. Therefore, participants would have to visit multiple grocery stores in order to provide all the GF foods required and food brands preferred. Although all participants expressed that they found obtaining GF food difficult due to limited availability or limited variety, they all found that there has been an increase in GF products available since

their child was diagnosed. However, all participants wished that there were still more options and more products available to them in the grocery store.

> *I'm finding it more and more easier. When Jessica first was celiac I found the information not as available, but I'm finding it now more so.* [Sarah]
> *The availability is much better now even though we've only been doing it for a year and a half.* [Andrea]

> *There seems to be more out there, but I don't know if it's my imagination or that we've become familiar with more things.* [Laura]

Colleen explained that, although the availability is becoming better, it is still important to continually read the labels. Janet also discussed how those who follow a GF lifestyle have to constantly be reading labels as the ingredients in products can change without warning.

> *Well it seems like there's more products now... or maybe I've just discovered them, it could be that too... I also find that it seems like some of the labels are getting better. Like there was one spaghetti sauce we always bought... which goes to show you you always have to read the labels, because one of the last times I bought it I picked it up and quickly skimmed and low and behold in brackets, with barley gluten, which had never been listed.* [Colleen]

> *Certain things like hot dogs, [she] used to be able to have Top Dogs, like...two years ago we were allowed to buy... then July 1st they changed their labels and there's wheat starch in them. So now there's no hot dogs that I know of that we can get just off the shelf here for her.* [Janet]

Although participants believe that GF products are becoming more available, many felt the GF products available were not created equally resulting in a waste of money and food and difficulty obtaining the products considered "popular" and preferred.

> *I just hope that there will be more products and options for her. I don't want her to feel like, oh I've got the same old thing. You know, we have a whole grocery store to choose from and we get tired of eating the same old thing... well she's got half a shelf!* [Janet]
> *I mean they [grocery store] have sections, but they're small... there's not a whole lot of variety.* [Krista]

In discussing the availability of GF foods, Janet made an interesting point regarding the lack of "kid-friendly" products when she commented:

> *I find the diet itself is geared towards the adult palate that there's nothing out there to get little kids excited about trying new things, because there's no little animal shaped noodles that they could easily do, or you know, it's all just straight spaghetti or macaroni noodles. You think they would make like little animal character gluten-free pasta. You know there's so many little things that even I think of that they can do and it's just not out there, or it's not in Canada or around here anyway.* [Janet]

In addition, many participants wished that it were easier to identify GF foods. Interestingly, although participants hoped for more precise labeling of GF foods, they were frustrated that products with clearly identifiable GF labels were often more expensive than products without labels that were also naturally GF.

> *It would be easier if you could just walk along like with the peanuts and just know you could grab this or that or another thing. Then mind you I do find that products in the year and a half since we've been doing this it's gotten better.* [Colleen]

5.3.7. Feeling Frustrated

Participants were frustrated in many facets of life including obtaining GF food, the time commitments of CD, and the lack of understanding experienced outside the family unit. In addition, participants noted that education was a key determinant influencing how they

experienced and managed CD and, therefore, frustration level was increased by the perception and experience of limited education among the general population. All participants expressed that frustration was the most strongly felt emotion when managing CD. They felt that most of their frustration outside of their families and circle of family friends stemmed from limited knowledge about CD. Janet described that, during her daughter's diagnosis, she felt frustrated, as it was necessary for her to strongly advocate for Karen's symptoms to be taken seriously.

> *It was really frustrating, and I kind of feel like it came down to me, me pushing that there was something wrong... I was on one sense really happy that I had a doctor that actually listened to me enough to let us have the blood work... but also frustrated because if I was a more complaisant person she would still be suffering.* [Janet]

Janet's frustration did not go away. When determining whether or not a food contained gluten, many participants would call the manufacturing company. Janet felt quite frustrated when calling those in the food industry as she would not find the answers she was looking for, suggesting that those who should know whether or not a product is GF, in fact, do not.

> *We don't call because we don't get an answer. Like if it doesn't... they're not going to say that it's gluten-free if it's not on the label. I've called a couple... in the beginning I was calling the 1-800 numbers and they just couldn't tell me an answer. So I said nope, that's fine. I'm not going to waste my time calling when they're going to tell me they don't know either.* [Janet]

All participants described feeling frustrated with one or more aspects of CD. Consistent throughout participants' feelings of frustrations was the thought that the disease was beyond their control and that they were defeated or punished by unknown external factors. Specifically, participants felt frustrated and did not understand why the price of GF food was so high compared to regular food, especially as GF food was perceived to be of lower quality.

Participants also felt frustrated with the food industry in that manufactures did not clearly label their products and were not able to tell customers whether or not a product was GF.

> *Overwhelmed, and you're kind of angry at the manufacturer because they're not... Canada Government of whatever hasn't put... enough regulation on it that they should be marketing their food properly. And you know, us as a consumer and we're the ones who are spending the money for their product and they're the ones that can't label it properly... it's extremely frustrating.* [Sarah]

> *You know there's so many little things that even I think of that they can do, and it's just not out there, or it's not in Canada or around here anyway. I'm just frustrated more with it on a manufacturer level. I just don't understand why the manufacturers don't... want to get some new products out there or something. I don't know. Maybe there's not a huge market for it around here, I don't know.* [Allison]

> *I often feel like it's not fair... it just doesn't seem fair that everything Amy gets is much more expensive and then when she's older and she's in university or whatever, she's going to have to pay a lot more money.* [Laura]
> *Frustrating because a lot of it will just be thrown in the garbage because nobody want's to eat it.* [Allison]

All parents felt frustrated with the cost of GF food. Allison and Laura felt that the cost of GF food was outrageous, especially given that GF food is essential for the treatment of CD.

> *And the price! You know because somebody has to have this food, instead of a loaf of bread being $2 dollars you have to pay $9! They're ripping people off because somebody has an illness that they can't eat anything, and that's just awful. It's frustrating... it makes you feel angry that they charge you for something that is needed. You know you can't go out and give her food that has gluten in it because it will make her sick so, you know they're gouging your wallet because they know that you have to buy this... it's frustrating and cheeses you off!* [Allison]

> *It seems unfair. I guess I read recently that it costs more for the other flours and grains and things like that so it wouldn't be financially viable for people to make products that were gluten-free and charged the same price I guess. But then it seems that we and Amy are being penalized because she's sick it seems. And I kind of thought, oh is it more*

expensive because we need that and we're going to, you know supply and demand, we're going to buy it regardless of the cost because we need it? [Laura]

Allison and Nicole both felt frustrated when it came to preparing GF food from scratch as GF products available were of poor quality. Many participants felt that to be unacceptable.

I don't mind baking and I don't mind cooking and stuff... but it's more so trying something new to get her to try something new... and then it's a crap product it's no good. And then you've gone to the expensive stuff because it's cost so much, the gluten-free stuff, so yeah to have it flop it's very frustrating. It tends to lead you to go and buy something that's already prepared. [Allison]

I've never tasted any gluten-free bread other than the stuff that's like $12 a loaf, that I've found tastes and feels good in my mouth... So I prefer to bake everything myself because then it has proper texture and plus I can add more fibre and things into my own bread because like, it's not in the gluten-free breads really, not unless you go to the really high end ones and that's not something I can really afford to put in my budget. [Nicole]

Participants also believed that their children were experiencing frustration.

She's occasionally getting a bit fed up that everybody else can eat what they want and she can't. [Laura]

It does frustrate her that she can't have all the same things as everybody else. [Janet]

However, the frustration felt was less to do with diagnosis of CD and more to do with taste preference associated with GF foods. Mothers noted that refusal of food was often simply their child being a picky eater.

What's holding me back, and I think they're finally seeing it, is them being so fussy... in making that selection so limited, and I really find that hard. [Sarah]

There's sometimes they won't eat it because it just doesn't taste good. [Krista]

In addition, participants felt concerned over their child's inclusion in regular activities. Sarah revealed a situation in which her child was excluded from attending summer camp as a result of having CD.

It was very upsetting for her, and it was upsetting to see her so upset that she got rejected from going to [camp]... because they cannot guarantee to provide them a gluten-free diet and not have any concerns for contamination, the cross-contamination. [Sarah]

Parents felt frustrated for their child being wrongfully penalized because of having CD. This was most likely a consequence of a lack of understanding about CD among the general public.

We went to this one [restaurant] three times and they were totally ignorant... waiting for one of the kids meals they brought the hamburger... on the menu it said hamburger, no bun. Well it came with the bun and we said, umm... well they took it around the corner and took it off the bun and put it back on the plate and you could still see the bread crumbs on it. They tried to say they did, but no you didn't. I was to the point, manager please. [Sarah]

5.3.8. Financial Impacts of Celiac Disease

Participants felt that the cost of GF foods was "shockingly" higher than that of regular foods and had difficulty understanding why.

I can't believe the prices they charge, you know I realize in the process of making the food it probably does cost more... to the point where you're paying $5 dollars more for an item? It's unbelievable, very frustrating. And for me I always made the choice that if we could afford it I would be a stay-at-home mother, so I'm a stay-at-home mother and my husband works, so we only have one income now, and to go out and have to you know, pay these prices for the food is tough. [Allison]

Many participants felt that in the early stages of CD they were spending much more money than they do now for multiple reasons. Parents felt that they bought special food in order to compensate for their child's inability to take regular food. They were unsure about reading labels and would, therefore, purchase items that specifically said GF on the label, which would often be more expensive than naturally occurring GF foods.

It was kind of tricky in the beginning so I did buy the sweet stuff and we do have it much more than we used to, not all time the time, but much more than we used to because I felt bad that she was not getting everything else she used to love. [Laura]

I found at first, the first time it put me back quite a bit because it was new, and like I said before, I was buying all the gluten-free food that says it on the label, and you're basically paying for that label when you could go and get something that's gluten-free as well, but it'd be cheaper because it doesn't actually say gluten-free... but you read the label and it is! [Krista]

Participants felt that they were spending more money during the early stages of CD because of the quality of GF products. All participants expressed that they experienced a great deal of food wastage in trying to determine which GF products their child would eat.

I mean we're still learning, but it took a long... probably close to six months before we really got a good grasp on what she could eat and what she couldn't eat and what she liked, and what you're paying $8 or $9 dollars for that's garbage... the first year, especially the first six moths was very expensive. [Allison]

All participants expressed that as there was no alternative to treating CD other than a GF diet for life, the cost of GF food did not matter to them and that they would do anything to ensure that their child was happy and healthy including rearranging priorities so that the food budget was always adequate.

> *I can't sense a chance, and it's just the time of doing it. I mean we kind of slacked back on some other things, and our budget because of it, but we just believe in buying good healthy foods. We're active and we you know, just kind of try to do what you can to stay healthy. And if it costs a bit more to buy organic, or to buy gluten-free then it's a priority.* [Jennifer]

> *You just have to cut back on other things. She's more important, she's the most important thing so you know, you cut back on your cable or you cut back on your internet or you don't go out as much or whatever.* [Allison]

> *I don't feel like there's any negotiation type of thing on the whole [cost]. Groceries is kind of a thing you got to spend... I feel like it's not very variable.* [Janet]

Families managed with the cost of GF food by making adjustments elsewhere in their lives including being more conscious of the cost of everyday items, planning ahead to ensure that the food budget is adequate and eliminating costly activities such as eating out at restaurants.

> *Where our money is not, we don't have money to blow to be going out anyways. So, when we... we don't go out a whole lot anyways because, not just because of the gluten-free part of it, it's just that it's something we find better off to stay home and have a good meal at home and have family time rather than worrying about going out and spending more unnecessary money.* [Sarah]

Prior to Allison's daughter being diagnosed with CD, she said that budgeting was something that was never necessary. However, as she found GF foods to be quite expensive, she

began to budget appropriately to ensure that there was always enough money to be able to purchase the GF food required.

> *Before it wasn't so much a worry on saying you know... okay this is for gas, this is for the cable bill, this is for the grocery bill, and just most people have to do it, but we were lucky enough before that we didn't have to do it so much... where as now we have to spend so much more on groceries compared to most households, we spend quite a bit more I would imagine.* [Allison]

Krista was also required to rearrange her financial budget, albeit more drastically, because she was on a fixed low-income and covering the costs of GF foods meant she sometimes had to sacrifice other essential needs such as utility costs.

> *Say if I had so much money set aside for the power bill, for instance let's say, and I ran out of something I needed for CD for the school, I would take from the power bill money to make sure that the kids, to make sure the day care has food for the children.* [Krista]

Some participants stock-piled food items as a strategy to manage the cost and availability of GF products. Both Sarah and Allison spoke of stock-piling items for these reasons.

> *Well when the money's there I'll do [stock piling], and when it's not there the cupboards full to provide. You know, like I mean, going and buying yourself, like its there and you know when corn's on sale for $0.99 cents a can, well you stock pile, cause normally it's over a dollar right.* [Sarah]

> *Sometimes you just have to... on occasion you have to deal with it, not having it for a couple of weeks until they bring it in. But now we've gotten to the point where we're kind of smart that I buy, instead of going out and buying one bag of pasta we'll buy six at a time.* [Allison]

Elizabeth and her family handled difficult situations with the costs of CD by relying on a line of credit to supplement their household income. Elizabeth and her husband decided when they had children that she would become a stay-at-home mom so that she could take care of their children. The loss of Elizabeth's income coupled with the cost of GF foods added stress to the family's financial situation. Despite this Elizabeth felt that she could not and did not want to return to work since being a mother and ensuring that her son's diet is strictly GF is a full-time job.

> *You have to choose what is more important… so the line of credit came in handy there for a while which is awful, but you know what, I'd rather owe for that than to not have spent time with the kids.* [Elizabeth]

> *It's definitely me not working too, but the gluten-free… you see how expensive everything is. And just say you buy a mix of bread, it might be marked down for $4.99, usually it's $5.99, or whatever, and then you don't think about the olive oil, your egg, your milk, your other stuff that goes into it, you're baking… and then the time! This loaf of bread is worth a lot of money by the time it's done!* [Elizabeth]

While all families commented on the costs associated with CD noting that they financially felt challenged when adopting a GF diet, Krista who was on income assistance found that covering the cost of GF food was difficult for her. Krista and her family did not receive the government supplement to cover the cost of GF foods immediately; therefore, during the beginning stage of managing CD, Krista struggled to provide GF foods to herself and her children. Before Krista and her family were able to receive a special dietary allowance[2] for both wheat allergy and CD for each person, an official letter confirming diagnosis and the need for a special diet had to be written by a dietitian and sent to Krista's caseworker within the Nova Scotia Department of Community Services. As a result of the lengthy paperwork, there was an

[2] Eligible to receive a special diet allowance for celiac disease ($30) and wheat allergy ($120) through Employment Support and Income Assistance (ESIA) Program (54).

extended period of time where Krista and her family were required to consume a GF diet, but yet to receive the special diet allowance. During this period, Krista was frustrated and worried about how her family would cope with the extra financial burden they now faced because of the GF diet requirements for herself and her three children. To help with the extra cost, Krista sometimes relied on her limited family support, food charity programs such as a church food drive, and sometimes by purchasing cheaper gluten-containing foods instead.

> *I would get help from family, or I would just have to shop very wisely. I mean sometimes we would have to skimp on one thing in order to get the cost covered.* [Krista]

> *I found at first what was happening was that in order to try to pay for all this food and change I was getting really behind in other parts of my life, like the bills and the rent and stuff like that. So I found at first, the first time it put me back quite a bit because it was new and like I said before, I was buying all the gluten-free food that says it on the label, and you're basically paying for the label when you could go and get something that's gluten-free as well, but it'd be cheaper because it doesn't actually say gluten-free, but you read the label and it is! I found that it took a big impact just like I said, we couldn't grab meals. We can't grab quick meals out, if you're running in a hurry you just can't grab that quick bite you have to plan it and determine where you can go and what you can have and whether it's acceptable or not acceptable, so basically most of the time you're just buying groceries, bringing it home, which I mean for a quick meal that's pretty costly.* [Krista]

In order to ensure the safety of her children, Krista who also has CD, found that when struggling financially she would consume cheaper gluten products herself so that her children would be protected and not required to consume foods that would be harmful to them. In other words, Krista would sacrifice her own nutrition for the sake of her children, a phenomenon referred to as "maternal buffering" (66). This concept is well documented and is common among food-insecure families where mothers are the first to carry the burden and consequence of food insecurity so that their children do not suffer negative effects (58,59,61).

> *I found myself still eating the gluten food because it was cheaper…. And I find sometimes that when we get financially strapped, and it gets rough, then I find that I'm the one that would consume gluten, not the kids. Cause I mean you always want for your kids to be take care of first.* [Krista]

Most participants were able to manage the financial costs of CD effectively. However, all mothers noted personal sacrifices to varying degrees in order to be able to do so, such as eating not out at restaurants and not taking part in various other extra-curricular activities. Although all participants shared the same determination that purchasing their child's GF food was of utmost importance and would sacrifice other cost-consuming activities to do so, not all had to cut costs. Some felt no change in their overall finances, some felt more aware of their finances, and some felt that purchasing GF food was financially worrisome.

5.3.9. Management of Celiac Disease

How participants managed CD depended on two important factors: 1) time management, and 2) support systems.

5.3.9.1. Time Management

Time management can affect participants' ability to prepare GF food, as well as their ability to plan ahead for situations in which GF food is needed. Effective management of CD varied depending on the amount of time participants were able to direct towards activities in the home and their time management abilities. Of the women who were stay-at-home mothers, most were able to prepare GF foods from scratch and would take time to read labels in the grocery store. However, in addition to time, the ability to prepare GF foods from scratch was largely dependent on whether or not the participant was proficient in the kitchen and had access to the

GF ingredients necessary. Mothers who were working away from the home felt that preparing GF snacks and meals was a time consuming process that was at times difficult to manage due to the spontaneity of life. However, although these women had less time for work within the household, they all had effective time management skills and were able to cope with work inside and outside of the home the majority of the time.

In addition to preparing GF food, all participants commented on how time consuming it was to manage CD effectively, from time spent learning about CD and GF products to label reading in the grocery store. All participants felt that "being GF" was a huge time commitment equivalent to a full time job.

> *It can be [a full time job], especially because they [the kids] need to be active and you're kind of thinking ahead like this is going on this day.* [Sarah]
> *I'm thankful that I am a stay-at-home mom and I'm able to do that. If I would be working full time 9-5 it would be very difficult.* [Jennifer]

> *In general it's a lot more time consuming, because even the shopping you have to read every label every time because they may change the ingredients, it may have it this time, but not last time... like it's a lot, a lot of work. That's another reason that I'm really lucky that I'm at home, because I don't know how someone would do it and keep up with it and you know, have their child safe if they're working. And you know it's like a job really.* [Elizabeth]

5.3.9.2 Support Systems

Another strong contributor to effective management of CD was the support systems available to participants, including support from community organizations and family. Participants who felt supported through family, friends and their communities were better able to manage the requirements of the disease. All participants received support in one form or another; however, not all families received the same level of support.

Family support from not only the adults in the child's life but also from siblings, both younger and older, ensured that the child with CD was included in the family unit and in everyday life by never allowing them to feel that their disorder was a burden.

> *My son has always been, he's two years younger, he's always been pretty, he's kind of an empathetic boy, and he's always been understanding and sort of considerate. Most of the time he's really considerate of Amy not being able to get things... he understands mostly that he's not getting [a treat] you know until we get something for Amy to substitute.* [Laura]

> *I think he's really lucky that we care, and by saying that I don't mean that other people don't care, but they just sometimes just brush it off, that it's his problem.* [Elizabeth]

Friends were also important forms of support. Laura described how Amy's friends looked out for her and were excited to see her receiving GF foods that were similar to their own.

> *Her friends... the children are really kind of aware and look out for her. For example... they get pizzas brought in from Boston Pizza at school and Amy could never get the hot lunch because… except now the fact they're doing gluten free pizza. So one of her friends was telling the lunch monitor last week when it started 'Amy gets gluten free', I think she told her the day before 'Amy's getting a gluten free pizza tomorrow'. I mean you know it's quite a big... it's, everybody knows and they're all sort of aware.* [Laura]

Another important form of support came from members of the community. Krista, as a lone mother, was one participant who did not have support from a spouse and felt limited support

from family members. She, therefore, relied more heavily upon supports available within the community.

> *I don't really have one [support system] to be honest. I do it basically completely on my own. It's tiring, but it's just, it's been like that for awhile, so it's kind of something I've learned to adapt.* [Krista]

Although she felt she lacked family support, Krista did receive support from her community, which included church and various health care professionals. Receiving food from a charitable food program such as a church suggests that Krista experienced some degree of food insecurity and coped with the situation by receiving supplemental foods that she could not afford otherwise.

> *There's this church that would help me out if I get into a real pinch, and then there's also at Christmas time, when it came to making the Christmas dinner and all that stuff, they helped out with giving us a Christmas box, but with our family instead of buying all the snacks and stuff like that that they would normally buy, they went out... and bought us gluten-free and stuck it in a box instead.* [Krista]

Health care professionals such as dietitians also provided support to participants in helping to answer questions about what is and is not GF; however, not all participants found dietitians to be supportive.

> *The dietitians there that we met have been very good. And I'm sure they've said we could call if we needed anything, had any questions. I haven't been in touch with them lately but, in the beginning they were great.* [Laura]

> *When he was diagnosed we went in to speak with the dietitian about... learning about celiac... it was so totally useless. Like there was no valuable, what she did was pretty much... you have to kind of find out for yourself, you have to call the company and all that. Then she showed us a few package... this is good pasta, these are good cookies, oh these aren't good, and then kind of sent you on your way. So there's not really any support that I've found.* [Elizabeth]

Participants also had conflicting views on the support offered through the Canadian Celiac Association (CCA). Although some participants found the CCA to be an excellent source of information, many found that they were not able to engage the Association in conversation or participate in planned activities due to geographical location or time required.

> *I've been trying to call and everything, and email and I have not had a response. I don't know if I should try again, and I heard that from other people too that they don't get back to you. So there's really no, I haven't had any support from them.* [Elizabeth]

> *I'm sort of out of the loop because I'm gone during the day and then I'm home 6 until bedtime and I don't get out that much. But a friend of mine told me that there is a celiac support group starting up, but I don't know.* [Janet]

As the majority of participants were unaware of CD prior to their child being diagnosed, they understood and could tell newly diagnosed families about the difficulties in the beginning stages of starting a GF diet. It was for this reason that many participants felt they could offer the support and guidance to others that they wished they had received in the beginning of their own journey.

I would definitely suggest the better brands, and not to waste. I mean we did waste a lot of money to find out what he likes. So definitely share that information, and recipes that we've come up with ourselves. [Andrea]

5.3.10. Strategies Utilized for the Effective Management of Celiac Disease

Three important concepts that participants expressed as facilitators in the management of their child's CD were: 1) their ability to learn about the disease, 2) their personal attitude when it came to CD, and 3) their ability to plan and be prepared for all situations.

5.3.10.1. Self Education

One of the most important factors that determined participant's success in managing a GF diet was being responsible for their own education. As previously mentioned, education is a key component not only in how one experiences CD, but also in determining how to effectively manage the disease. Many participants found themselves responsible for their own education since those in the general population and those who ought to have known about CD were not always knowledgeable.

The most important thing to do is just to educate yourself when you get diagnosed, or if you have something wrong don't always wait for the doctor to diagnose you... the best thing to do is to educate yourself about it. [Allison]

5.3.10.2. Personal Attitude

All participants had positive personal attitudes when it came to facing their child's diagnosis of CD and living with the disorder, even when they felt that the disease was out of their control. They felt that there was nothing that could be done to change their circumstances

and acknowledged that the diagnosis could have been worse. The development of a positive attitude over time was a great enabler to participants as their own attitudes influenced their ability to effectively manage their child's CD. Overall, participants tried to live within their means and to manage the disease with a positive outlook rather than questioning their child's diagnosis.

> *It is what it is and we just take it at that.* [Andrea]

> *She's been off gluten, it was two years in July, so you know over time... I don't feel the guilt anymore. I don't think about that too much, I just deal with the day to day.* [Laura]

> *It's just a thing that she has, it's just a role that she's taken and I just turn something that most people would think was a negative into a positive thing... it's just... that's all you can do.* [Allison]

> *I just kind of take it day by day and plan for that day. I try not to go too many steps ahead.* [Krista]

5.3.10.3. Planning Ahead

Finally, participants identified "planning ahead" to be of utmost importance to effectively manage a GF diet. The ability to plan ahead indicates proper time management skills and, therefore, was considered by participants to be an important contributor or enabler in their day-to-day management of CD.

Janet found that being a working mom was difficult since adequate time was needed to plan ahead. To cope with her busy schedule, Janet felt she needed to be extremely organized.

> *It's kind of tough [being a working mom], like if I want to make a cake... if I'm going to have to make a cake in the middle of the week, or cupcakes or whatever, I have to make*

sure I'm at the store kind of the week before because if they run out they might not get an order in until... and if I don't get the cake mix or whatever [here], then I have to drive 45 minutes... to see if they have it. And same thing with birthday parties. [Janet]

Other participants planned ahead in order to be prepared for the unexpected. Participants described the GF diet as being a time consuming and difficult diet to follow when in unfamiliar environments. Therefore, participants felt it was essential to be in a state of readiness in order to quickly prepare and provide GF food alternatives to their child when necessary.

When Halloween comes I know I have to ready for whatever... I get the parents who are the stay-at-home moms who call me the night before Halloween and say 'oh by the way' you know. But for the most part I'm always ready with something now... there's usually stuff in the freezer. [Janet]

I try to always have a couple bags of bagels, or hamburger buns, or the pizza, I try to keep ahead of that. But if you get busy and things dwindle... now my mother just lives down the road and she usually has a stock pile as well so I can kind of get a few things from her if I run out. But there's the odd time when Katie says 'there's nothing for me here, I want a sandwich' you know, which was this morning, so I'm heading to [the grocery store] which is 45 minutes away. [Colleen]

Planning was also an effective tool to ensure that the child with CD was never excluded when left with no GF alternative. By planning ahead and providing what they described as equally tasty GF alternatives, each of the mothers ensured that their child was included in both school and household activities.

And I always carry something better. I've learnt that if you're out somewhere and some child is getting something like a chocolate bar or some chips or crackers or something that I know Emma will be upset that she can't have it... and mommy always has something in her purse that's a little bit better than what the other child has (laughing)... Yeah, so it's preparing everything, and packaging it all up, or putting in the thermos or whatever you have to do. [Allison]

If we go away, say for instance Cape Breton, I have a grandfather down there and we take like the toaster oven with us, and trying to think ahead because I'm thinking what does he have down there. Because we usually stay in a hotel for accommodations, but we eat our meals at my grandfathers place. So like things like that you have to think more ahead of the game. [Sarah]

5.4. Research Objective #2

To discover enablers and barriers to managing the nutritional and financial requirements of the child with celiac disease and explore the implications for the family.

Throughout the data collection process, participants identified enablers and barriers that provide insight into how families with CD experience and manage the disease. In developing this research project from a nutrition point of view, my thought going into interviews with the participants was that the main barriers and enablers would be related to the availability and cost of GF foods. Although participants identified these as important issues, level of education emerged as a more predominant theme in having an impact on participants' experiences and management of CD, which in turn affected many other aspects of participants' lives. Many of the enablers and barriers identified by participants were a result of the level of education, or lack of public knowledge of CD. Therefore, participants were thankful and eager to talk about their experiences and to help increase the public knowledge about the disease.

The strongest enablers identified in this study were related to participants themselves, such as their own positive personal attitude and knowledge, versus enablers encountered within a societal level, such as the public perception of CD.

While barriers related to the diet itself were identified including poor quality, and the high cost and limited availability of GF foods, most participants felt that the greater barriers to effectively managing CD were not related to the diet itself but to the public perception of the

disease. Therefore, barriers were often out of participants' control, whereas enablers identified were directly related to participants' abilities.

Bronfenbrenner's Ecological Systems Theory provides a model by which to explore psychological, societal, cultural, environmental, and political enablers and barriers affecting participants' lives, more specifically how participants experience and manage CD. A summary of the barriers and enablers, categorized through the various layers described in Bronfenbrenner's model, identified through this research are described in Table 3. Significant barriers and enablers identified in Table 3 are also depicted through the use of participant quotations throughout Section 5.4. Due to the complex and often overlapping nature of the data presented, quotations that identify barriers and enablers in Table 3, can also be found in Sections 5.3, 5.5, and 5.6. For example, the mesosystem barrier "limited accommodation at school" is present within Section 5.3.3, as it pertains to how CD was experienced within the school system, therefore, although it is a barrier to management of CD, it will not be repeated within the enabler and barrier section of this thesis.

Table 3. List of Enablers and Barriers to Management of Celiac Disease Identified at the Micro-, Meso-, Exo-, Macro- and Chronosystems Among Primary Food Providers of Gluten-Free Food for a Child with Celiac Disease in Nova Scotia

Enablers	Barriers
Microsystem	
1. Support from Family/Friends a. Inclusion of child with celiac disease b. Awareness of cross-contamination c. Providing gluten-free alternatives **2. Support from Others** a. Canadian Celiac Association b. Health care professionals **3. Personal Abilities** a. Proficient cooking/baking skills b. High level of organization c. Increased knowledge of celiac disease a. Label reading b. Budgeting d. Effective time management e. Positive attitude **4. Physical Environment** a. Access to multiple grocery stores b. High education level c. Effective time management d. Positive attitude **5. Adequate household income**	**1. No Support from Family** a. Limited family involvement b. Exclusion of child with celiac disease c. Limited knowledge about celiac disease **2. No Support from Others** a. Canadian Celiac Association b. Health care professionals **3. Personal Abilities** a. Poor cooking/baking skills b. Low level of organization c. Difficulty reading labels d. Ineffective time management **4. Physical Environment** a. Limited number of grocery stores i. Reduced availability of gluten-free food ii. Poor quality of gluten-free food **5. Inadequate household income**

Enabler	Barrier
Mesosystem	
1. Support from Family/Friends a. Inclusion of child with celiac disease b. Awareness of cross-contamination c. Purchasing gluten-free foods d. Protection from friends/ siblings **2. Support from Others** a. Canadian Celiac Association b. Health care professionals c. School administration and teachers **2. Grocery Store Environment** a. Knowledgeable/helpful employees b. Availability of gluten-free foods c. Location of grocery store	**1. No Support from Others** a. Canadian Celiac Association b. Health care professionals **2. Limited Accommodation at School** a. Lack of education about celiac disease b. Exclusion of child at school activities **3. Food Providers Limited Knowledge** a. At restaurants b. At grocery store **4. Grocery Store Location** a. Having to travel to access gluten-free foods

Enabler	Barrier
Exosystem	
1. Canadian Revenue Agency Tax Credit **2. Special Diet Allowance for Celiac Disease**	**1. Availability of Gluten-Free Foods** a. At grocery store b. At restaurants c. At school d. At food banks **2. Cost of Gluten-Free Foods** **3. Limited Public Knowledge of Celiac Disease** **4. Inadequate Special Diet Allowance** **5. Lack of Control over Food Choices/Supply**

Enabler	Barrier
Macrosystem	
1. Gluten-Free Diet as a Healthy Choice	**1. Public Perception of Celiac Disease** a. Gluten-free food as treatment b. Not a serious disease **2. Gluten-Free Diet as a Trend** a. Decreased seriousness b. Risk of cross-contamination

Enabler	Barrier
Chronosystem	
1. Age of Child at Diagnosis **2. Personal Attitude**	**1. Worrying About Child**

5.4.1. Within the Microsystem

The most predominant enabler within the participants' microsystem, the layer which represents the participants' own environment, was the level of support available to them through family, friends, health professionals, and community organizations. Higher levels of support overall resulted in participants being more able to cope with the demands of CD. Participants discussed supports in the form of words of encouragement and acts of inclusion from other mothers, family members and friends making the extra effort to ensure that the child with CD was included. Furthermore, support took the form of knowledge sharing among participants' networks of friends and family.

> *I'm driving along and my phone beeps I have a message voice mail on my phone... 'I don't know if you realize this or not but I was down to the store and… they sell gluten-free stuff...' and people [friends] are looking out more.* [Sarah]

> *There's this church that would help me out if I get into a real pinch, and then there's also at Christmas time, when it came to making the Christmas dinner and all that stuff, they helped out with giving us a Christmas box, but with our family instead of buying all the snacks and stuff like that that they would normally buy, they went out... and bought us gluten-free and stuck it in a box instead.* [Krista]

At the same time, participants identified limited support from family or friends in the form of exclusion from social activities, or lack of understanding about CD as a strong barrier. Participants who received positive encouragement felt supported and better able to manage CD and a GF diet, while those who felt little support expressed feelings of struggle or combativeness within the family when their child was excluded.

Another central enabler and barrier found in participants' microsystems was the availability of time and, more specifically, how this time was utilized. Time was considered an enabler when it was available and a barrier when it was not present. Time was an essential element in the participants' abilities to plan and prepare GF meals and snacks. Many participants felt that managing a GF lifestyle was a full-time job, stating that if they were to work a full-time job that their ability to manage the diet would greatly be affected. The negative stressor associated with not working and having limited time to manage CD was the lack of extra income resulting in the financial burden associated with a GF diet. Mothers who worked all seemed to have exceptional time management skills, were able to prioritize the needs of their child with CD, and had strong support systems in place. A strong cohesive family support system was essential for working mothers.

[others] doing a lot of the research, which saves me a lot of time and effort. [Andrea]

The greatest barrier, for us it's just the distance. It would be so easy if we could just run... 5 minutes away. I mean if we were in the city it would be a lot different... we really have to plan ahead, when it was a busy couple of weeks and the kids were sick all of a sudden you're down to the last piece of gluten-free toast. [Colleen]

Finding the food I would say. Going to five different grocery stores to get the food that you like that would be the biggest thing. To take your time to drive all over the city and even to different cities... and to see on the computer or to hear about... this manufacturer has a new product out but they haven't brought the product into the grocery store yet, or it's been out for a whole year and they still haven't brought it into your grocery store. Availability and the time it takes... taking away from other things. [Allison]

As Allison conveys in the above statement, time is essential to managing a GF diet, especially when faced with the limited GF foods available in her environment. In Allison's case, extra time was required in order to purchase food from multiple grocery stores, sometimes in different cities, in order to obtain the GF foods her family preferred and required. Similarly, participants identified the availability of GF foods within grocery stores and restaurants as a strong barrier to managing CD.

Availability and the time that it takes... taking away from other things. I would find that the greatest barrier for sure [Allison]

Sometimes there's not enough selection available when we're out and about in restaurants and things like that. [Laura]

Personal attitude was a strong enabler within participants' microsystem environments. All participants talked about how they wanted their children to be healthy and how they would do anything to accomplish this regardless of any personal consequences. In Krista's case, the

sacrifices she made to maintain the health of her children sometimes meant she was unable to adhere to a GF herself.

> *I find sometimes that when we get financially strapped, and it gets rough, then I find that I'm the one that would consume gluten, not the kids. You know what I mean? Cause I mean you always want for your kids to be taken care of first.* [Krista]

> *I want to try to make sure that just because we're gluten-free and we, he has to eat gluten-free, I want to make sure that... he gets something healthy. It doesn't have to be from a package because we can get a package.* [Elizabeth]

> *She's actually healthier than most kids... in terms of what they're eating.* [Janet]

For example, when asking one participant what was the driving force behind ensuring her daughter was included during meal times and had access to nutritious and delicious GF food, she simply said:

> *I just want Katie to be healthy and happy.* [Colleen]

In addition to support and personal abilities, physical environment and household income were also important enablers identified in participants' microsystems. Participants who lived in more urban centres and had access to multiple grocery stores were better able to purchase GF foods, specifically the brands preferred and in the quantities desired. Being able to have quick access to a grocery store instead of planning a long trip to one was a great enabler to managing a

GF diet. In addition, families who were perceived as financially secure had greater ease when purchasing GF foods.

5.4.2. Within the Mesosystem

The mesosystem portrays the relationship between multiple settings or environments wherein the mothers in this study were active participants, or the central focus of surrounding environments. An example of a mesosystem interaction within the context of this study would be the relationship between the participant's child with CD and a sibling, parent or other family member. For example, Laura's son, who does not have CD, will not have a gluten-containing treat in front of his sister, not wanting her to feel left out. This relationship between siblings has an impact both on the child with CD and on the mother who participated in this study in that she felt that her son was empathetic and understanding towards the difficulty that Anna faces in her management of CD. Many mothers noted siblings and close friends supported one another so that the child with CD would be "looked after" by their peers.

> *My son has always been, he's two years younger, he's always been pretty, he's kind of an empathetic boy, and he's always been understanding and sort of considerate. Most of the time he's really considerate of Amy not being able to get things and you know he may want something, you know like a timbit or something, and we don't have an alternative for Amy... he understands mostly that he's not getting it you know until we get something for Amy to substitute.* [Laura]

> *My mom is really really good. I'm very lucky and I mean she shed a lot of tears trying to make stuff and she you know, if we go um if we go there, well we go there Christmas Eve she can have, Katie can eat everything. The apple pie is gluten-free um you know the stuffing is gluten-free, the gravy, everything, there's nothing that she can't have.* [Colleen]

The involvement of Colleen's mother in supporting Katie to ensure that all the food at family events were GF has strengthened their relationship. In addition Colleen felt that the entire family should "come together" to support and include Katie in her treatment for CD.

The support from others, including those in the school system, was greatly appreciated by all participants. Allison noted that her daughter's preschool went the extra mile to ensure that she was included.

> *The preschool even goes out and buys gluten-free ice cream, so the whole class has gluten-free ice cream. Yeah, they're great. She goes to a wonderful preschool.* [Allison]

Having the support of family and external organizations enabled participants to actively participate in life, without fear of exclusion or worry about gluten-contamination. Support was also experienced at some grocery stores, whereby helpful employees who were knowledgeable about CD and the GF diet would provide assurance to participants when they were buying GF foods. In addition to support being an enabler, participants identified lack of support as a barrier. The lack of support within the mesosystem was mainly due to lack of education about CD.

A significant barrier in the mesosystem layer of Bronfenbrenner's ecological systems model evident throughout all of the interviews was the lack of education about CD among the general public, which had an impact on participants' ability to manage the requirements of this disease and, more importantly, how the disease was experienced. In addition, lack of education resulted in frustrating and potentially harmful situations where cross-contamination put the child at risk for accidental ingestion of gluten.

The interaction and dependence between foodservice employees or well-meaning family friends and the participant's child with CD caused great stress and worry to the mothers in this study because there is limited control over the supply of GF food when the child is outside of the family home.

> *I arrived one time, just in time to see this kid about to cut her gluten-free pizza with the same pizza cutter he had just used to cut everybody else's right. I don't know, I mean obviously he didn't know and I explained it to him, and he went oh, I wish somebody would have told me that, all these times I've been cutting the gluten-free pizzas.* [Nicole]

> *There was one birthday party she went to and my friend knew she had celiac and she said we really want to get her cookies that are safe for her. And they went to the natural aisle of our store and they asked the person who works there in the store which ones were safe, and they gave them ones that were organic wheat.* [Janet]

> *The hardest part is restaurants... going out, because you never know.* [Andrea]

5.4.3. Within the Exosystem

The exosystem consists of one or more environments whereby the mothers involved in this study are not active participants, but are influenced by what happens in these environments. For example, although the Canadian Revenue Agency's tax credit available for those on a GF diet was time-consuming, difficult to complete, and often a barrier to effective management for participants, the money refunded, large or small, was an enabler in that it added to household income.

Another example of an external structure influencing Krista's micro- and meso- system was the special diet allowance for CD. Through the ESIA Program, available to residents of

Nova Scotia who are on income assistance, Krista was able to receive funds through a special diet allowance in order manage the requirements CD. Without these funds Krista, and her children, would be unable to purchase a GF diet required for their management of CD due to the increased cost of GF foods compared to gluten-containing foods.

Participants in this study were greatly affected by factors beyond their control such as others' knowledge about CD, or level of education as depicted in Figure 2. For example, restaurant workers' lack of education about CD may be attributed to poor employee training by management within the restaurant resulting in customers with CD having potentially negative experiences dining out. Another barrier identified by participants within the exosystem layer was the influence of food manufacturers and government in determining labeling and cost of GF foods. As it was necessary to purchase these expensive GF foods, participants felt that they lacked control over their purchasing choices. Participants hypothesized that the cost of GF food was so expensive because those who needed it would be willing to pay the higher price since it was essential for them.

> *They're ripping people off because somebody has an illness that they can't eat anything, and that's just awful. It's frustrating... it makes you feel angry that they charge you for something that is needed. You know you can't go out and give her food that has gluten in it because it will make her sick so, you know they're gouging your wallet because they know that you have to buy this... it's frustrating and cheeses you off!* [Allison]

> *It was pricey... that was the biggest thing holding us back I guess.* [Andrea]

> *The hardest thing is just the money really.* [Elizabeth]

Frustration with manufacturers was also evident through discussion about the marketing and development of new GF foods as participants could not understand why GF products were not of higher quality and lower cost.

> *Overwhelmed, and you're kind of angry at the manufacturer because they're not... Canada Government of whatever hasn't put... enough regulation on it that they should be marketing their food properly. And you know, us as a consumer and we're the ones who are spending the money for their product and they're the ones that can't label it properly... it's extremely frustrating.* [Sarah]

> *You know there's so many little things that even I think of that they can do, and it's just not out there, or it's not in Canada or around here anyway. I'm just frustrated more with it on a manufacturer level. I just don't understand why the manufacturers don't... want to get some new products out there or something. I don't know. Maybe there's not a huge market for it around here, I don't know.* [Allison]

5.4.4. Within the Macrosystem

The outermost concentric circle of Bronfenbrenner's Ecological Systems model, the macrosystem, is comprised of cultural values, customs and laws. In identifying enablers within the macrosystem it was evident that all participants viewed a GF diet as a healthy one, free of processed and unnecessary additives. The value of healthy food and proper management of GF diet was in the forefront of participants' minds in preparing meals. Participants believed that as long as their child was happy and healthy, they were able to deal with the negative aspects of CD and remain positive.

The lack of perceived seriousness of CD was identified as a strong societal issue that acted as a barrier to how participants experienced and managed CD. In addition, participants felt

that since the GF diet has become a popular diet among others who do not have the disorder, it has created difficulty for those with CD who require a GF diet for medical reasons.

> *I think personally the hardest thing is... like store management doesn't understanding why we need these foods... so knowledge.* [Janet]

> *One thing that bothers me is that a lot of people don't think it's serious, like it's not the same as a peanut allergy when the child has a chance of dropping, and not to belittle that because that's scary... so I find it hard to not be too dramatic when I'm explaining it, but to let people know that it is serious.* [Colleen]

5.4.5. Within the Chronosystem

The chronosystem layer encompasses the dimension of time as it pertains to the individual's life. All participants in this study were initially shocked at their child's diagnosis of CD. It was participants' positive personal attitudes developing over time, which enabled them to successfully navigate through the ups and downs of their child's CD.

> *I just deal with the day to day.* [Laura]

Participants were thankful that their child was diagnosed early and thus avoiding the negative health consequences of undiagnosed CD as well as the belief that a child growing up with the disease will be less likely to deviate from a GF diet later in life if this is the only diet they have known. Mothers worried that, had their child known the taste difference between regular gluten-containing and GF food, they would have developed a preference for regular food.

Additionally, many participants expressed worry about their child's health as they grow and become more responsible for their own food purchasing and preparation.

> *I kind of worry… Amy's always been really…. good accepting her limitations about diet. But sometimes lately she's been getting kind of fed up and just wants to just eat what we eat, you know… what the others can have and um… just sometimes. And I've always from the beginning I've always worried about her rebelling as a teenager and just not wanting to do it anymore. You know just wanting to eat with her friends and just… regardless of the pain, just eating what she wants to eat. Or then when she goes to university just wanting to drink, I dunno… beer or eat what she likes you know eat pizza from the take away place or…. Yeah, I do worry about her just getting fed up.* [Laura]

5.5. Research Objective #3

To explore strategies that would aid in the nutritional and financial management of celiac disease.

All participants were eager to share their stories and offer suggestions that would help other people who were in similar situations. There were three domains in which participants expressed a need for change that would have made their experiences easier and more manageable: 1) improved education of the general public, and thus a better understanding of the struggles faced by individuals with CD and their families, 2) improved quality of GF food products along with improved food labeling, and 3) better affordability and accessibility of GF foods.

5.5.1. Improved Education of the Public Population

It was noted by participants that education campaigns about CD should be more visible. Allison expressed that you are always seeing information in the doctor's office and public

television about other chronic diseases but she has yet to see any information readily available about CD.

> *I would like to see more education from a top down and I don't know how that would happen exactly unless there was sort of mass advertising paraphernalia... pamphlets and things like that going to school boards and I really think it has to start in the grocery store.* [Janet]

5.5.2. Improved Gluten-Free Foods: Quality and Visibility

Although all participants purchased GF food for their child, and many mothers and families also ate a GF diet to support the child, many "non-celiacs" discussed the poor quality of GF foods. In starting a GF diet from scratch, many mothers did not know which foods or brands were "tastier" or similar to gluten-containing foods. For this reason, mothers had to learn from trial and error when it came to purchasing GF food for their child resulting in unwanted food wastage. Participants wished that the quality of GF food was better and that GF products were easily identifiable at the grocery store.

> *I would definitely suggest the better brands, and not to waste. I mean we did waste a lot of money to find out what he likes.* [Andrea]

> *I would like them to have to put... they should make them say gluten-free on a lot more stuff that is gluten-free. They should make it more kid friendly. You would think the manufacturers would start, you know doing a kids line almost of stuff that is gluten-free.* [Allison]

5.5.3. Increased Affordability of Gluten-Free Food

Ideally, all participants wished that GF foods were more affordable. When asking Andrea what she would like to see different in the management of CD she remarked:

If you could change the financials! [Andrea]

In other words, Andrea wished that GF food could be made less expensive. Laura suggested that monetary support for those requiring GF food be improved. However, she understood the difficulty in doing so as not all those who purchase GF food do so as a medical requirement, but more so as a personal health choice or preference.

> *It would really be ideal if... maybe if the government subsidized it... but then lots of people maybe eat gluten for... there are lots of people who don't eat gluten for other reasons, they don't actually have celiac disease. I think it would be really hard to organize it you know. Unless some kind of local government... federal government subsidized people who are eating gluten-free products.* [Laura]

5.5.4. Supporting those Affected by Celiac Disease

The level of support participants received throughout their child's life with CD had a pivotal impact of the lives of all those in the family unit. Support was received through words of encouragement, understanding, and acknowledging CD as serious disease. It was for this reason that participants wished for continued support as a strategy to aid in the nutritional and financial management of CD, and in addition offered their support to others in the same situations.

> *I think it'd be really nice if she had friends roughly the same age with celiac disease. It'd be nice... if there was some sort of mentoring program or something... in the Celiac Association... sort of like a Big Brother/Big Sister thing, a child who could understand what Amy's going through and just say yeah you'll be okay, that sort of thing.* [Laura]

> *Even just to talk to the parents who are just trying to figure out what's wrong with their kids or they think they have celiac and they're going for a biopsy in 3 weeks and what does that mean, you know... that was a scary process itself just going to the biopsy. Or even I know they have child services and stuff like that, but somebody who can help you to explain at their level what's going on.* [Janet]

Colleen and other participants also noted that participating in this research study was "therapeutic" in that they were able to express their wishes, frustrations, and advice to others. As well, participants felt valued as I, the researcher, was interested in exploring the topic despite the fact that I do not have CD. This indicated to participants that there is interest in the general population about CD and that their voices might be heard.

I think it was kind of good to get it all out. [Colleen]

5.6. Research Objective #4

To determine if families who have a child with celiac disease experience food insecurity.

Nine of the women who participated in this study were either financially stable or had made adjustments or sacrifices in their lives so that GF foods could be purchased without worry. Krista was the only participant relying on income assistance and a special diet allowance to supplement her limited income and, therefore, cannot be classified as financially stable.

To determine if participants were experiencing food insecurity the researcher at the end of the interview process administered the HFSSM. This questionnaire is organized into three stages. All respondents complete the first stage, however, the remaining stages are only completed if necessary. Participants in this research study only completed the first stage of the survey as negative response indicating that participants were food-secure. Although participants were determined to be food-secure via the HFSSM, analysis of participants' interviews, suggests that elements of food insecurity were present. Elements of food insecurity, such as maternal buffering and stock piling were highlighted in Section 5.3.8, and will be further discussed in

Section 6.4. It is important to note that the HFSSM questions did not capture if GF foods needed for the treatment for CD were available, rather only if food was available. Most notably, in Krista's case, she was always able to provide food for her family; however, on occasion she was not able to provide herself with the GF foods required.

Throughout the interviews with participants, the financial aspect of CD was discussed. While participants were able to adjust their lives so that their child with CD was able to consume a GF diet, they did acknowledge difficulties in purchasing the more costly GF foods and, in particular, noted how difficult it would be for families who were less fortunate.

> *I can't imagine low-income or on social assistance and having a child... people who only make minimum wage with family, and then having a child or getting diagnosed yourself with celiac. I can't imagine. I don't understand, I can't see how they would be able to do that. They would have to give up so much and have to cut back on... not even cut back. Yeah... I don't understand how they would be able to do that.* [Allison]

> *I've actually had to get supplements from the government for the food, due to the cost. I wasn't able to afford it, so therefore at first I was very, I was slacking on it because of the cost. Because you go from being able to pay like $1.97 for a loaf of bread to going to pay $9.* [Krista]

> *At first I couldn't afford it, and then now it's just that I, the money that I get for the food, I basically only use it on the food.* [Krista]

Krista, being the only mother on income assistance and receiving a special diet allowance, was also the only participant who was the sole guardian and provider to her children. As a lone mother living in low-income circumstances, she was the main source of support for her family, both socially and financially. As previously discussed, social and financial support are

both critical to successful management of CD, as well as a determinant in how the disease affects experience, whether positive or negative.

Compounding factors such as limited support, diagnosis of CD in multiple family members affected by CD, and low-income highlight the importance of adequate supports, both social and financial. If not for the special diet allowance of $150 per month Krista and her three children received to support a GF diet, it would be impossible for her family to remain adherent to a GF diet.

6. DISCUSSION

6.1. Introduction

The purpose of this study was to explore how families with one or more children with celiac disease (CD) experience and manage the nutritional and financial requirements of the disease. The objectives were to explore participants' experiences from the perspective of the primary food provider, to uncover barriers and enablers to managing the nutritional and financial requirements of the disease, to explore implications for the family, to identify strategies to address these barriers, and to determine if families experience food insecurity as a result of the high cost of gluten-free (GF) foods. This thesis highlights the experiences and stories of ten mothers who have at least one child with CD. These women came from different regions of Nova Scotia; all had different backgrounds and experiences, but all were familiar with the impact of the disease on their lives and that of their children. Participants with children who have CD were chosen for this study as it has yet to be determined if food insecurity exists within this population, and this is the first published study to examine the experiences of those managing CD through a household food security lens. This study helps to put the limited research that has been done showing the high cost of GF foods (1,2) into context by providing valuable information not only on the how the economic cost of following a GF diet is experienced, but also on the social and lifestyle costs and their implications.

This discussion explores the significant findings highlighted in the previous chapter. These include the loss of normalcy and the redefinition of normal among those with CD; the role of education and its influence on the experiences of primary food providers, specifically the lack of understanding among the general public; the effects of socioeconomic factors, such as social

support and the cost of GF foods, on the management of CD; the adequacy of social and economic supports for low-income individuals; the measurement of food insecurity in a CD population; and the role dietitians play in supporting individuals with CD. A personal critical reflection on the research process and the completion of this thesis, as well as a discussion of the limitations of this study will conclude this section.

6.2. Redefining Normal

Participants' emotional responses to their child being diagnosed with CD, a disease they felt was not perceived to be serious by others, are the same emotions felt by all patients diagnosed with a serious chronic disease (95). Although CD is not a potentially fatal disease, the transitional process of receiving a diagnosis, to living with the disease, among patients diagnosed with motor neurone disease (MND), a rapidly progressing neurodegenerative condition (95), are similar to the experiences of primary food providers in managing their child's CD diagnosis and treatment reported in the current study. Both patients with MND and mothers to a child with CD felt the "bombshell" of diagnosis. For primary food providers, the "bombshell" CD diagnosis was a result of no previous knowledge about CD, and thus shock at diagnosis. For patients with MND, the "getting on with it" phase meant that they had accepted their quick progressing, life reducing disease and believed that there was no way of changing the eventual outcome. Similarly, as there is no cure for CD, participants quickly adopted a positive attitude, which helped them effectively manage the disease and accept the loss of normal life. Within participants' chronosystem the diagnosis of their child with a serious chronic disorder can be described as a significant non-normative event (86). Participants' experience with their child's

CD diagnosis is an imprinted memory that will be remembered as the point in time when "life changed" or when life took new meaning. Also evident within participants' chronosystem is the development of their personal attitudes over time and how developing a positive personal attitude acted as an enabler to effectively managing CD.

Participants in this study all discussed feeling loss and empathy for their child with CD, as their lives would forever be changed by the diagnosis. The process of grieving for a "normal life" was confusing to participants; they felt that they were not deserving of grief or justified in their bereavement because CD treatment is a dietary change and not immediately life-threatening. See and Murray (2006) describe CD diagnosis as a positive diagnosis, emphasizing that the disease is treatable and not a terminal illness, and that focusing on the positive aspects of life will help with the management of the medical and nutritional aspects of the disease (15). Based on my conversations with the mothers who participated in this study and hearing about their struggles with their child's diagnosis, it would appear that telling them to "think of the positive" might undermine and belittle their initial feelings of loss.

In addition to focusing on the positives, the authors state that newly diagnosed patients should not isolate themselves from family, friends and social situations, as this will only exacerbate self-generated feelings of grief (15). The degree of support present within participants' micro- and mesosystems in the form of family and friend involvement was essential in effective management of CD. Krista was the only participant to note lower levels of support compared to other participants. Research suggests that women living in poverty often isolate themselves as a coping strategy to protect themselves from the implications of poverty and the associated negative stigmas (103). Therefore, Krista's perceived low level of support may be a

result of both limited family involvement, as well as self strategies to protect against stigmas associated with poverty.

It is important to acknowledge that grieving the loss of a normal diet should be allowed and supported. Participants in this study all experienced various stages of grief including denial, anger, bargaining, sadness, and acceptance (94). Participants experienced anger while searching for a diagnosis, relief and denial when their child was diagnosed, and bargaining while waiting for the results of their child's small bowel biopsy to confirm what was already suspected to be true. The feeling of sadness was common for participants. However, because participants were responsible for their child's health and wanted to do whatever possible to prevent their child from feeling ill, acceptance quickly replaced sadness. Although the stage of sadness was short lived, these findings suggest that it did occur throughout the management of CD. In instances such as birthday parties and holidays such as Halloween and Christmas, participants felt sadness when their child was unable to consume the foods that are commonplace at these events.

A recent large Canada-wide study by Zarkadas et al. (36) investigating the difficulties experienced when following a GF diet and the associated emotional impacts, revealed that of the 5,912 adults with CD surveyed, the majority of participants felt relieved when diagnosed with CD, and accepted the GF diet within the first few months of following it. Moreover, the initial relief of diagnosis decreased as time progressed, while acceptance of a GF food increased, suggesting that although thankful for a diagnosis, participants were unaware of the complexities associated with lifelong management of CD, and required time to adjust to a GF diet for life. These findings from Zarkadas et al. (2012) are consistent with how participants in this study described their emotional reactions to their child's diagnosis with CD. The acceptance of CD and the GF over time represents a chronosystem event marked by growth and development.

Acceptance was an emotion shared by all participants; however, the means by which each participant came to accept their child's CD diagnosis over time was experienced differently.

Similarities were also present between participants in this study and Zarkadas et al. (2012) in that survey respondents reported negative emotions such as frustration, anger, sadness, and isolation (36), which were also emotions predominant within participants' experiences in the current study. While anger and sadness lessened among participants in both studies, frustration and isolation remained five years after diagnosis (36), indicating that not only did all the participants in this study feel frustration and isolation long after their child's diagnosis, but so did others, therefore, these emotions are common amongst all those who have CD. As participants felt that their frustration and isolation was as a result of the general public's lack of understanding of the seriousness about CD, the finding that individuals with CD experience somewhat similar emotions is important information to help improve the public's understanding of the disorder.

As previously mentioned, learning to accept a diagnosis of CD and its dietary treatment was a quick process for participants because they wanted to ensure their child was healthy and felt that acceptance was the only option. Participants' personal beliefs and attitudes towards their child's health and disorder are elements found within the microsystems which acted as strong enablers to managing CD. Moving on from disease diagnosis to accepting the disease does not negate the feelings of loss associated with being diagnosed with a chronic disease. The loss of normal life for patients with MND were described as changes to their social interactions and their ability to participate in life in ways they were used to previously (95). The loss of normal life as a result of dietary restrictions due to CD also had an impact on participants' social and usual way of life. The loss of social activities, as reported by Zarkadas et al. (2012), was a result

of individuals with CD not wanting others to feel sorry for them because of their dietary restrictions, embarrassment about special dietary needs, and fear of the disease becoming the centre of attention (36). Participants in this study described situations in which they perceived their child with CD to be embarrassed or isolated due to their dietary restrictions and felt empathetic towards them. To the best of their abilities, participants took preventive measures to safeguard their child from inability to participate in social activities. Nonetheless, the implications of the stigma of disease affecting children highlights the important of public education to address barriers in the participants macrosystem's that compromise their ability to live as normally as possible with the disease.

Although CD is not seen as a life threatening disease, it is important to acknowledge the significant losses associated with diagnosis. Accepting GF foods and redefining what was normal was an important step for participants in effectively managing CD. Participants grieved the loss of their child's former diet and accepted a more complicated one, all the while feeling that grieving was too strong an emotion in that it implies a more "significant" loss.

6.3. Education: The Need for Increased Understanding and Awareness Among the General Public

Throughout all interviews, it was found that participants' experiences were influenced by a perceived lack of education among the general public. Throughout the interview process, it was apparent that, although the availability and affordability of GF food was an important factor in the nutritional and financial management of CD, it was not the main determinant that influenced

experience. Instead, a perceived lack of knowledge and awareness of CD among the general public had the most significant influence on participant experiences.

Some of the women participating in this study had very negative experiences with their child's diagnosis, leaving them feeling that their concerns about their child's health were not being taken seriously by their physicians. The experience of these mothers not only indicates a greater need for physician awareness of the symptoms of CD, but also the need for increased rate of screening for CD even when a child does not present with the classical symptoms. Catassi et al. (2007) findings that testing all patients showing symptoms associated with CD for TTG antibodies results in more patients being diagnosed with CD, therefore, actively seeking to diagnose CD, and being educated on the known symptoms of the disease, will help to uncover undiagnosed patients early (96). The findings of the current study suggest that actively testing for CD may not only result in increased diagnosis of CD, but should also help minimize the negative experiences associated with diagnosis as experienced by the mothers who participated in this research. The significance of these findings is important considering the severe health and nutritional consequences of living with undiagnosed CD and the need to prevent deficiencies of important nutrients during crucial stages of development in children.

The perceived levels of education about CD among those in the participants' various environments not only had an impact on their experiences with their child's diagnosis, but also on how they experienced managing the disease within their community. In the home, the sense from participants was that they were able to have full control over their child's dietary needs. Mothers acted as a protector, ensuring that their child(ren)'s diet was free from gluten-contamination and that they were receiving adequate nutrition. This finding is not surprising given the well-documented phenomenon that mothers are often the first to carry the burdens and

consequences of food insecurity and to protect their children from the negative effects of this (60,65). Within the home, mothers could ensure that their child felt included in mealtime by preparing foods that were similar to what the rest of the family was eating. When outside the home, experiences in obtaining GF food were, however, often negative and fueled by the perceived level of education about CD among the general public.

The experiences of women in this study are consistent with a recent study by Jacobsson et al. that described what life is like for women living with CD. Jacobsson's findings revealed that women strive for three conditions to normalize their world, including: 1) being secure, 2) being in control, and 3) being seen and included (97). Feeling secure within participants' own homes was evident throughout all interviews. Feelings of security were demonstrated when participants encountered someone who knew about CD or who demonstrated knowledge and understanding of the disease. Within participants' exosystem were the general public's beliefs and perceptions about CD. The beliefs or perspectives of others and how they view CD and the GF diet were strong societal issues that affected participants' experiences. Participants' experiences, both positive and negative, were dependent upon whether they, or their child, encountered individuals who knew the importance of a GF diet for a person with CD. For example, in social settings mothers were faced with situations where the seriousness of gluten-contamination was downplayed, i.e., the belief that children "grow out" of CD, or that it is possible to build a tolerance. These comments are examples of how the lack of education about CD can lead participants to feel unsecure or have a lack of control in social situations.

Jacobsson et al. (2012) also noted that when participants felt insecure it had a profound negative influence on their identity and ability to make choices in life (97). In this study feelings of security were felt when participants were able to control their own food supply. For example,

a participant's choice to consume GF food at home versus at a restaurant can be attributed to the financial cost of eating out as well as to feelings of insecurity when not in control of their child's food supply. The third condition that women strive for when seeking normalcy is being seen and included (97). The previously quoted study (97) also revealed that participants felt ignored and excluded in situations where others did not acknowledge their disease, a finding similar to the experiences of primary food providers in this study. The findings presented in that study regarding how women with CD experience life with the disease (97) are confirmed in the current research in how the mothers experienced life managing their child's CD, suggesting that women's experiences with CD may be universal. Furthermore, acknowledging the three conditions women strive for to normalize their world (97) are important considerations in effectively managing CD and a GF diet and in increasing awareness about CD. Only when the seriousness of CD is acknowledged can those with the disease feel more secure in their dietary management.

Participants felt that within the school system there was a large discrepancy in knowledge about dietary restrictions, specifically between a peanut allergy and gluten sensitivity. All participants commented about how they wished that more people in the school system were aware of CD and took the disease as seriously as a peanut allergy. For example, there are multiple levels of reaction to a peanuts, from minor reactions to life threatening ones; however, all peanut allergies within the school system are treated as though the most severe reaction will occur, thus protecting all children with peanut allergies from coming in contact with the allergen. However, because CD has no immediately life threatening consequences, it is not taken as seriously as a peanut allergy. Although the reactions to these two dietary restrictions are vastly different, they both warrant equal attention. The discrepancy in knowledge about CD and the

perceived lack of seriousness of the disease in the general public stems from the overarching ideology that as CD is a disorder characterized by a dietary treatment versus medical treatment, therefore, public perception denotes the disorder to not be serious. Furthermore, the exosystem barriers of limited education and public knowledge about CD, as well as lack of control over which foods are available within the school system exacerbate this belief.

A "minimization effect" that has been described in Olsson et al. (2009) is echoed in experiences of participants in this research study, most notably, in their experiences within the school system and when dining away from the home. Olsson et al. (2009) investigated the stigma experienced by adolescents with CD and determined that when participants were in public situations they felt discriminated against when asking "others" for a GF meal, as the reaction to the request would either amplify or minimize the importance of their dietary needs (98). The amplification warranted unwanted attention, while the minimization resulted in the diminished importance of CD and a GF diet thereby risking gluten-contamination. The adolescents in Olsson's study expressed feelings of anger, alienation, and inequality in comparison to their peers at being identified as "different" because of their consumption of a GF diet. This suggests that inclusion of those with "differences" is critical in order for children to feel normal when dining away from home. Therefore, increasing education about the dietary treatment for CD in the school system and increasing access and availability to GF foods in schools is essential. Moreover, increasing education about CD will help ensure that children with the disease feel included by combatting the alienation, stigma and negative feelings associated with being "different" as a result of requiring GF food and the amplification of attention associated with "special food" (98).

Participants who struggled with finding GF alternatives felt that, if grocery store personnel understood their *need* for GF food, more products would be available. Although research (43,44) suggests that the GF industry has acknowledged the rising demand for GF products, participants highlighted a perceived lack of communication between the manufacturers of GF foods, and those who provide it directly to the consumer. The lack of communication was evident in that GF foods were not always available to purchase. It is important for suppliers of GF products, such as grocery stores and restaurants, to be aware of the increasing demand for GF alternatives, and to be able to respond to it.

Moreover, the finding that participants did not understand how the cost of GF food could be so much more expensive compared to regular gluten-containing foods suggests a further lack of communication between the food industry and consumers. Participants felt that if the food industry knew how much those with CD needed GF foods that the cost would be lower. It is important for producers of a product to recognize their consumers' needs, therefore, increasing communication between what consumers with CD want and what producers can give is an important means by which to ensure that consumers of GF products feel valued.

The finding that there was a perceived lack of education and understanding of CD within the food service industry, specifically with respect to low-cost chain restaurants, among participants is interesting in light of recent findings in the United States. Using a survey, Simpson et al. (2011) determined that trained chefs were more knowledgeable about CD than untrained chefs, and that their awareness of gluten-related dietary issues was positively correlated with the cost of a restaurant meal (99). Simpson's findings corroborate the experiences of the participants in this study as they felt that dining out at low-cost chain restaurants, which are often considered kid-friendly and do not necessarily employ highly trained chefs, was

difficult due to employees' lack of education putting their children with CD at risk of gluten consumption.

Increasing awareness of CD should be a top priority for patients, health care professionals, and policy makers within the health care system. While some evidence suggests that increasing awareness about a disease can be effectively achieved through increased media awareness (100), participants noted that media coverage has increased about CD but primarily due to celebrity endorsements of the GF diet for health and weight-loss and not CD. The finding that participants and the general public are receiving important information about CD and the GF diet via unqualified sources in the media suggest that it is important to combat misinformation through accredited and reliable sources, such as the Canadian Celiac Association and accredited health care professionals, to ensure that the public perceives the GF diet not as a weight loss diet, but as a necessary and serious treatment for CD.

6.4. Socioeconomic Factors Affecting the Dietary Management of Celiac Disease

Consistent with findings from research that examined the cost of GF food (1-5,52), all participants noted that GF foods were strikingly more expensive than their gluten-containing counterparts. The extra cost required to purchase GF foods resulted in participants revising their current spending patterns or developing a household budget to ensure that enough money was available to purchase all the GF food required. The degree to which it was necessary to adjust the household budget varied for each participant; however, common among all was the acknowledgement that the household financial situation changed when their child was diagnosed with CD. The high cost of GF food not only affected participants' grocery budgets, but also took

away from other aspects of social life involving food, such as dining out. The high cost of GF food was identified as a barrier within participants' exosystem as it was an external force that affected how CD was experienced and managed. This exosystem barrier resulted in participants feeling a loss of spontaneity in purchasing and eating while away from the home. Although having to prepare GF food alternatives in anticipation of time spent away from the home was time-consuming and often difficult to plan, participants felt that in order to lead a normal life that they had to prepare for the unexpected.

Prioritizing and budgeting finances is not a new concept. In food-insecure households, where there is often little money to spend, families are forced to choose between flexible food budgets and fixed budgets, such as utilities and rent. Often, the food budget is the first to be sacrificed (11). The majority of families who participated in this study noted that they had to reprioritize their finances to ensure they had enough money to cover the cost of a GF diet. These findings suggest that families with CD living in circumstances where they are vulnerable to food insecurity may have to choose between following a strict GF dietary treatment for CD and sacrificing fixed costs, such as shelter, or allocating the food budget to fixed costs and consuming cheaper gluten-containing foods which are detrimental to their health. Participants in this study did not sacrifice fixed costs, but did sacrifice social activities in order to prevent financial insecurity and to, therefore, remain food secure. During my interview with Krista she mentioned she was behind on bill payments, such as rent, in the early stages CD due to purchasing a GF diet. Although Krista did not describe sacrificing fixed costs, she did describe sacrificing her own nutritional well-being by consuming gluten-containing foods instead of GF foods so that her children had the GF foods they require.

Of the women who participated in this study, only Krista, who was dependent on income assistance, was considered to be financially insecure and, therefore, struggling with the financial management of CD. Recent research investigating the affordability of a nutritious diet for a lone-mother with three children on income assistance in Nova Scotia revealed that this family of four would not have adequate income to purchase a basic nutritious diet (74). Williams et al. (74) determined that in 2010 a lone-mother with three children would face a deficit of $391.93 per month when purchasing a basic nutritious food basket (74), significantly higher than the monthly $112.01 deficit reported in 2002 for the same family. This study highlights that despite increases in the personal allowance for those on income assistance, the cost of basic needs, such as shelter and electricity, have also substantially increased, and at a much faster rate (74). In other words, as fixed costs for basic needs have risen far beyond the flexible costs of a nutritionally adequate diet, despite increases in income assistance, individuals and families on income assistance are at significant risk of compromising their nutritional status (74).

Williams et al. (74) reported that the cost of NNFB in 2010 was $660.84 per month for a lone mother with three children. However, the cost of a GF diet, specifically packaged GF products, has been shown to be two to three times more expensive than a regular diet (1,2). Therefore, we can estimate that Krista would be required to spend significantly more per month on food as a result of having to purchase expensive GF foods. It needs to be stressed that the cost of a GF diet in the Canadian study (2) pertained only to packaged foods and may not necessarily apply to a "food basket" which would contain fresh, naturally GF food products as well. Therefore, it is difficult to calculate precisely the cost differences. However, an increased food budget also suggests that Krista and her family would face a significant deficit, exceeding the estimated 2010 amount for her family scenario. It is important to note that Williams et al. (2012)

reported increasing deficits between 2002 and 2010 for all household scenarios (74), suggesting that in 2013, further deficits may exist.

In my interview with Krista, it was evident that she was struggling with other aspects of life as well, most notably an absent support system, limited employment, low-income, social isolation, and elements of food insecurity, all of which are described as social determinants of health, or factors affecting the ability to maintain health and well-being (69). As a lone parent with three children with CD, and a patient herself, Krista was left alone to manage CD. The lack of enablers in Krista's micro- and mesosystems, such as support and availability of GF food, coupled with her limited income to purchase GF foods, resulted in her greater struggle with the management of the disease. Her attitude differed from the other participants in that she felt down about her social circumstance and financial situation. Lone-mothers living in poverty often feel worry and anxiety in relation to their perceived inability to provide their children with "normal" lives (103). The fear of not providing for their children and being portrayed as a "bad mother" represents a social expectation placed on mothers within the macrosystem, or overarching embedded system of beliefs and perspectives (86).

Although Krista was the only participant to have financial insecurity leading to occasional food insecurity, she was not the only participant to experience various elements of food insecurity. Several other participants expressed elements of food insecurity as described by Radimer, et al. (10), including the quality and quantity of food as well as the psychological and social dimensions of food insecurity. Consistent with Tarasuk's discussion on the concept of food insecurity, these findings highlight the dynamic nature of food insecurity (58). Participants within this study expressed that they felt the strongest financial worry during the initial stages, or crossover, from a gluten-consuming household to a GF household. As participants stated, it was

during the initial stages of a GF diet that the portion of the household budget allocated to food was at its highest, not only because of the increased cost of GF versus gluten-containing food but also because of the varying taste and texture qualities of different GF foods which could lead to unwanted food wastage. Participants expressed that GF food products were not rich in quality citing incidences of spoiled food, expired "best by" dates, damage from freezer burn, and lack of variety.

Psychological dimensions of food insecurity experienced by participants included, for example, worrying about access to GF food when away from the home. Although food anxiety was not observed among participants in relation to whether adequate funds were available to purchase the necessary foods, anxiety was felt over whether or not GF foods were available to purchase.

The social dimension of food insecurity, as described by Radimer (10), manifests in behaviours that deviate from social norms, such as accepting foods from charitable organizations. Krista described deviating from the social norm by accepting GF foods from her local church in times of need; however, this was not a manifestation of the social dimension of food insecurity for other participants. While Krista was dependent on income assistance, which has been shown by Williams et al. (74) to be inadequate, other participants described how adequacy of their household income allowed them to always purchase food through socially acceptable means. The main social element of food insecurity experienced by all participants was social exclusion, which occurs in food-insecure households when families deviate from social activities of life in an effort to hide or conceal their financial struggles (58). Deviation from the social norm, as practiced by participants in this study, included reducing social activities such as

eating out, due to the need to reduce their budgets in order to purchase GF foods and worry that foods considered GF would be contaminated with gluten.

6.5. Measuring Food Insecurity in the Celiac Disease Population

In this study the Household Food Security Survey Module (HSSFM) was administered to participants in order to determine whether food insecurity was experienced within their household. Unfortunately, in this small sample this tool was ineffective at accurately determining if participants experienced food insecurity. As the HFSSM was a researcher administered questionnaire aimed at determining food insecurity within the household based on the availability of regular foods, participants answered that although they were able to afford all of the foods they needed, they did not always have access to the GF foods required. This reduced access was mainly due to limited availability as opposed to the foods being unobtainable due to cost. The finding that the tool did not identify Krista, who did experience elements of food insecurity, and the uncertainty of how the general questions about food did not differentiate between "the *kinds* of food", GF versus regular, raises questions about the validity of the HFSSM for identifying food insecurity in the CD population.

All participants including Krista indicated that they were able to purchase the foods necessary for a GF diet; however, some participants described that they did not always have the types of foods they wanted as GF foods lacked quality compared to regular foods. Although Krista was not found to be food-insecure according to the HFSSM, through my conversation with her and further analysis of her interview, my impression was that Krista had experienced elements of food insecurity such as maternal buffering (66) and obtaining GF food through

charity programs (7). While Krista reported never to be without food with her special diet allowance through the income assistance program, she described how, in times of greater financial strain, she would consume cheaper gluten-containing foods so that her children could consume GF foods. This finding of Krista's sacrificing her own nutrition for the sake of her children and being without the food required for her CD management was not captured using the HFSSM, as this tool does not take into consideration the difference between acceptable and unacceptable food for a GF diet in a CD population. Moreover, as food security is not a static phenomenon, but rather dynamic in nature (9), the HFSSM does not consider the element of time and how an individual's needs or financial situation may change. Participants in this study all experienced CD and the GF diet differently over time. For example, in the early stages of purchasing GF foods participants were more aware of the economic burden of CD due to the drastic price difference between GF foods and gluten-containing foods. In addition, participants felt greater financial strain during the early stages of CD due to purchasing multiple GF food products to determine which products their children preferred, purchasing GF foods that were labeled GF and, therefore, often more expensive, as well as feeling the need to compensate for their child's loss of a normal diet by supplementing their GF diet with "special foods". Participants in this study completed the HFSSM after following the GF diet for greater than six months. Given that participants felt financial worry was at its highest in the first few months of following a GF diet, had the HFSSM been administered during the initial stages of CD results may have differed.

The inefficacy of the HFSSM to measure and therefore capture food insecurity in the CD population may suggest that food insecurity in this population does exist, but remains uncovered. Limitations of the HFSSM to measure food security in the CD population suggest that in the

overall assessment of food insecurity in Canada, those with CD experiencing food insecurity might be under reported and, therefore, an at-risk population where the prevalence of food insecurity should be examined. Estimations from the IWK Health Centre suggest that approximately one in every 10 families with CD may be suffering financially due to the increased cost of GF foods (28), statistics consistent with the prevalence of moderate or severe income-related food insecurity (10%) in Nova Scotia from the 2009/2010 CCHS (8).

Although these findings suggest that HFSSM was ineffective in identifying food insecurity in households where children have CD, it has been successfully used within a population with type-2 diabetes (101). A study examining the prevalence of household food insecurity among adults receiving diabetes care at a clinic in Calgary, Alberta utilized the HFSSM and determined that the food insecurity rate amongst the 314 participants was 15%, more than double that reported for Alberta in 2007 using the same survey (101). This study highlights the apparent links between diabetes, low-income, and food insecurity, suggesting individuals who develop type-2 diabetes, are also those more likely to be living at low-income and, therefore, at risk for food insecurity (101). This link may suggest why the HFSSM was effectively utilized within the diabetes population, but not the CD population, as low-income level does not contributed to an increased risk of developing CD. Another possible explanation why the HFSSM was effective within the diabetes population is that the diet for diabetes essentially does not differ from a normal healthy diet, therefore, individuals with diabetes have do not face the same dietary restrictions based on food type.

To ensure that the CD population is accurately captured in prevalence estimates of food insecurity, it may be necessary to tailor and modify the current HFSSM to incorporate the need for special GF foods. For example, the statement asking respondents if they worried about food

running out could be reworded to include “food for your dietary requirements”. Adding this statement to the existing HFSSM would allow incorporation of special diets, such as CD, diabetes, high calorie, and other food allergies. Specifically, it is important to capture that, although food may be available to combat hunger, the food consumed may not be adequate for the dietary requirements of CD.

The development of a standardized assessment tool to be used within the health care system to identify clients who may be struggling with the financial aspect of CD would provide health care professionals with valuable information to better provide tailored nutrition information and to advocate for financial supports in purchasing a GF diet. Questions pertaining to the barriers and enablers identified at multiple levels of the participants’ environments in this research including where food is being purchased or obtained, whether all members of the household will be following a GF diet, and if support systems are available or not, may be important to identify patients are at risk for food insecurity.

6.6. The Role of Dietitians in Celiac Disease Management

The role of the dietitian in management of CD is to provide the client with the tools to be able to effectively manage a GF diet. Tailoring nutritional information to the patient’s needs and capacity is the most important way to ensure that the patient is comfortable with the nutrition prescribed. Therefore, the more a dietitian can tailor the nutritional information provided, the greater the chance that the patient will adopt the recommendations. Findings from this research revealed that the majority of participants valued the support they received from dietitians. In Krista’s case, without the dietitians advocating for her to receive financial support, she would not

have been able to cope with the dietary requirements. Therefore, in the case of patients who have a limited income, it is important for dietitians to acknowledge the complexity and cost of the diet. Providing dietitians with an effective screening tool to determine if patients are experiencing food insecurity or are at risk of developing it would be beneficial both in tailoring nutrition counseling and in collecting data regarding the prevalence of food insecurity in this population.

Currently in Nova Scotia, patients who require extra financial support through a special diet allowance provided by the Department of Community Services must provide written documentation to their caseworker from a medical professional, such as a dietitian, indicating that there is a need for such a support (50). The development of a standardized tool to adequately identify risk of food insecurity for a household in which a member has CD would help to improve the process by which special diet allowance funds are allocated.

Dietitians are the health care professionals who provide patients with the tools and skills they need to live a GF life. They also advocate for better financial support. Therefore, dietitians have first- hand knowledge as to what patients with CD require in the form of financial assistance, making them the strongest advocate for overall patient health.

The findings of this study raise questions about the adequacy of the current special diet allowance for a GF diet. The current Nova Scotia ESIA program special diet allowance is a maximum of $150/ month. Patients with CD may receive special diet allowances for both CD ($30/ month), and wheat allergy ($120/ month) as the GF diet for CD requires the elimination of gluten found in wheat products (50). While Krista described the current value of this allowance as being necessary for her and her children to adhere to a GF diet, there is little published

research related to how special diet allowances within the income assistance program are calculated, and if the amounts are adequate for all age and gender categories. Krista and her children all receive the same allotted funds. Her children were in a period of growth and development, therefore, it is not clear if their special diet allowance for CD reflected the costs associated with purchasing GF foods at the caloric level required for their different ages, genders and activity levels. Dietitians, as important advocates for financial supports for those in need, should also advocate to the Department of Community Services for the development of special diet allowances which not only reflect adequate funds to purchase a GF diet for the management of CD, but also the specific dietary needs of the individual.

Recommendations for increasing income assistance rates to account for actual cost of a healthy diet and essential living expenses have been published based on research that raises questions about the ability of those with low-income to purchase a basic nutritious diet (74,102). Considering the challenges related to obtaining GF food, such as availability and affordability, the difficulty in preparing the Canada Revenue Agency tax credit, and the management of CD being considered "a full-time job" that have implications for income adequacy, low-income households where a member is required to follow a GF diet may be at increased risk for food insecurity. Although previous research has examined the cost of GF foods (1,2), additional research is needed to examine the actual cost, both financially and socially, of a special diet for the individual with special dietary considerations such as CD.

6.7. Limitations

It is important to acknowledge the concept of social desirability as a potential limitation in this research. Since this study was a discussion of food insecurity as it relates to the economic burden of CD and more specifically to the health of participants' children, it is possible that mothers may have portrayed themselves as being more financially secure or better equipped to manage CD than was actually the case in order to appear more favorable. Moreover, in order for participants to portray themselves as more socially desirable, they may have projected personal difficulties in managing CD on external factors in order to place ownership of responsibility elsewhere. In addition, participants may have overemphasized or underemphasized their experiences in managing CD and a GF diet. It is not clear if social desirability bias occurred in this study.

Another potential limitation to this study relates to the hereditary nature of CD resulting in some of the participants caring for multiple dependents with CD. This variable may affect the experiences of the participant in that each participant's experiences will be shaped by a varying degree of responsibility caused by the number of dependents requiring specialized needs. Participants with more than one child may have been able to better manage the GF diet, as multiple members of the house were required to consume it. Participants with more than one child with CD may have experienced a great deal of stress and frustration as they had increased responsibility in caring for multiple dependents with CD. Participants with more than one child with CD were not excluded from this study as CD affects first-degree relatives and, therefore, most families will have one or more children or family members with CD.

Another potential limitation of this research was my inexperience as a researcher. This thesis project was my first major research endeavor, and my skills as a researcher were continually developing throughout the study process. Although participant interviews did elicit valuable information, a more experienced researcher may have been able to probe participants to reflect more on their experiences with CD. Furthermore, 9/10 interviews were conducted via phone, the preferred method for those participants because of its convenience. Telephone interviews may have resulted in misinterpreted or lost data due to not being able to interpret non-verbal communication. Furthermore, face-to-face interviews, instead of telephone interviews, may have yielded different data due to the discussion of sensitive topics, such as adequacy of household income, as participants may have felt more comfortable to reveal information in person. However, this is not believed to be a major issue as a strong rapport was built between the researcher and the interviewee over the telephone and during face-to-face interviews, and in addition, participants discussed financial aspects of managing CD freely in all interviews.

6.8. Critical Reflection

There were many times while conducting this research that I felt both overwhelmed and lost. The development of this project stemmed from my involvement in the Nova Scotia Participatory Food Costing Project and an interest in special diets, specifically a GF diet for CD. At first, I wished to examine the cost of GF diet compared to a regular (gluten-containing) diet. However, through preliminary research and discussions with peers and mentors, I realized that what was needed was to investigate how the cost of GF foods affected those who are required to purchase them.

Determining how the cost of GF food affects those on a low-income was challenging. I was limited in my ability to recruit participants on low-income with CD as this population had previously not been researched and it was unknown if food insecurity even existed in those with CD. Through the guidance of my thesis committee, we determined that the participant demographics of this study were an accurate representation of those struggling with the economic burden of CD. Looking back on participant recruitment and data collection process, interviewing more participants who are low-income and have CD would have been preferable. However, as the sample population was determined to be an accurate representation, I am satisfied with the information uncovered from the participants in this study. I do believe that further research focusing on the low-income CD population would be beneficial and provide greater depth to the findings of this study.

My desire to produce meaningful research was both exciting and intimidating. Being new to research and specifically qualitative research, for me this was a leap in a new direction. Participant recruitment, data collection and knowing where to begin were all daunting tasks. Now, almost three years from starting this project, I still feel somewhat overwhelmed, but no longer lost. The women who took time out of their lives to talk with me about their experiences with CD taught me that when faced with limitations one must persevere.

7. CONCLUSIONS AND IMPLICATIONS

7.1. Introduction

This is the first study to explore how families with one or more children with CD experience and manage the nutritional and financial aspects of the disorder and its impact on their food security. Ten women with one or more children diagnosed with CD participated in this study. The majority of these women were married, stay-at-home mothers. Of the mothers who worked, two worked full time, one worked part-time, and the other was a casual employee supplemented by income assistance. The latter participant was the only household to receive a special diet allowance for the management of CD.

Findings from this study highlight the importance of further investigation into how families, specifically low-income families, are coping with the cost of a GF diet. Although the high cost of a GF diet has been well documented (1,2), no research has been published on the impacts of the cost of the diet on families with CD and whether families experience food insecurity. In this study all ten participants noted some elements of food insecurity, such as decreased quality and quantity of the foods required to manage CD. Despite observations consistent with well-documented characteristics of household food insecurity (7-10) that emerged from the data, no participants identified themselves as food-insecure in their responses to the HFSSM. Moreover, the HFSSM does not account for the requirement of special foods including GF food; therefore although food may be available, it may not be the food required to ensure good health.

In the experience of my thesis committee, particularly those who work directly with families living with CD on a day-to-day basis, it was determined that the mothers who

participated in this study were an accurate representation of the CD population they have encountered, with roughly 1/10 individuals experiencing financial difficulty in purchasing GF food. Therefore, notwithstanding the limitations inherent in the study design, this thesis portrays an accurate picture of how families in Nova Scotia with one or more children diagnosed with CD experience and manage the nutritional and financial requirements of the disorder. This, coupled with the finding that all participants noted some degree of food insecurity according to Radimer's conceptualization of the phenomenon (10), also brings forth the following question: Is the prevalence of food insecurity in the CD population represented within national and provincial findings on the prevalence of food insecurity? Given that this research raises questions about the ability of the HFSSM that is used in national surveys to measure food security to identifying food insecurity risk in a special diet population such as CD, it is possible that current national data do not account for food insecurity in those with special diet requirements, such as CD.

Examining the findings of this study through Bronfenbrenner's Ecological Systems Model allowed the complexity surrounding how families experience CD and a GF diet to be revealed. For example, as previously discussed perceived level of education among the general public played a key role in determining participants' experiences. However, the level of education about CD present in the population is influenced by multiple factors that are outside of participants' control. Factors include the willingness of the general population to learn about CD, effective means of disseminating information about CD, and methods of combating misinformation present in the public. Although perceived knowledge and awareness about CD was shown to positively influence participants' experiences, simply increasing education among the general public will not necessarily result in eliminating negative experiences brought on by a perceived lack of education. To mitigate negative experiences and to promote positive

experiences, multiple areas of concern must be addressed, including increasing the support systems available to those with CD, examining the availability and cost of GF foods, changing how the disease is perceived by the general public, and increasing awareness of CD such that the disease is widely accepted and acknowledged.

The complexity of how CD is experienced means that complexity exists in how to improve the experiences of those who live with CD. For example, participants in this study felt a lack of control or ownership over their food supply, as it was not prescribed specifically for the dietary treatment of CD and, therefore, food considered vital to the treatment of CD is available to the general public to purchase and consume. Moreover, the perceived lack of seriousness of CD, which was a great frustration to participants, was a byproduct of not being able to distinguish between GF for personal choices and GF for medical necessity. As the "prescription" for CD is widely available to all at a high price, participants felt it to be unfair that they pay "over-the-counter" prices for GF items that are required for the dietary treatment of CD.

7.2. Conclusions and Implications for Policy, Practice, and Measurement

7.2.1. Conclusion #1.

The quantity and quality of gluten-free food plays an important role in the health and happiness of primary food providers who have one or more children with celiac disease. Increasing the availability and quality of gluten-free products will aid in the overall well-being of those required to consume gluten-free food as well as those who are responsible for providing and preparing the diet.

All participants noted that obtaining GF food is time-consuming, difficult, and frustrating because of the limited number of GF products available in grocery stores, the need to search multiple grocery stores in order to obtain higher quality and preferred products, the need to read

confusing nutrition labels in order to ensure products purchased were GF, and the time it takes away from their children. While participants acknowledged that the availability of GF food had increased since their child was first diagnosed with CD, it is not clear from this study whether or not the increase in participants perceived availability of GF food was an actual increase in the quantity of GF food items during the study period or an increased awareness of GF foods by the purchaser. Increasing access and availability to GF food is of utmost importance as these two factors are shown to influence adherence (28-30). Moreover, increasing the quality and quantity of GF foods available to the consumer would aid in increasing adherence to a GF diet, as well as ease the difficulty in obtaining GF food.

7.2.1.1. Implications for Policy

- As the only treatment for CD is the strict adherence to a GF diet, it is crucial that GF foods be available to all those who require them. The GF food industry is growing, with more products becoming available for purchase (92). Ensuring that these products are available to the consumer, and properly labeled and identified as GF are important contributors to consumption and safety (30-33).

7.2.1.2. Implications for Practice

- The dietitian plays an important role not only in the dietary management of CD, but also in facilitating and providing support systems for those with CD. Participants were clear in this assessment that not all GF foods were of equal quality. In addition to providing patients with lists of "safe", high quality foods, connections with other families with CD would also be beneficial. Participants in this research who were nervous about preparing GF meals from

scratch wished they had someone to show them how to prepare GF recipes. Participants who were proficient in the kitchen, and were easily able to prepare GF food from scratch, were keen to help others and offer guidance. Linking these types of patients together to form a mentoring relationship would be mutually beneficial.

7.2.1.3. Implications for Measurement

- Gluten-free foods are not only available for purchase by those with CD, but also by the general public. Participants noted that they would purchase large quantities of certain GF food in order to ensure it was always available for family consumption as products deemed superior in taste and texture are quickly sold and, therefore, available for a limited duration. Therefore, it is important for the GF food industry and retail sector to monitor the purchasing patterns and demographics of those consuming GF products in order to gain a better understanding of who is purchasing GF food and for what reasons. Understanding the consumer market will help ensure that GF products are available in the quantity needed.

7.2.2. Conclusion #2

Increasing awareness of celiac disease is necessary to address the experiences of participants that celiac disease was not perceived to be a serious disease by the general population. Acknowledging the psychological and social dimensions of celiac disease will provide greater understanding and acceptance of the disorder, and ease the psychological and social burdens of the disease for those affected.

The social effects of CD were evident throughout all participant interviews; from the grief related to the loss of a normal diet, feelings of exclusion, worrying about GF food and social situations, to the feeling that CD was not taken seriously by others. This research suggests

that improving education to the general public through awareness campaigns is an important step in highlighting that CD is a serious disorder that should be taken seriously.

7.2.2.1. Policy and Practice Implications

- Education is a key component of combating the psychological and social consequences of CD. Producing mainstream public awareness campaigns will not only educate the general public about CD so that they have a greater appreciation of what the disease entails (100), but also will help those with undiagnosed CD understand the signs and symptoms and, therefore, seek help in a timely fashion.

- Restaurant owners and grocery store management must provide employees with education on CD and the GF diet as these are the employees who have direct contact with consumers. Restaurant employees who serve GF menus must strictly ensure that contamination does not occur, while grocery store employees must be able to identify GF products in order to help the customer. Furthermore, caretakers of children such as teachers and daycare employees must also be knowledgeable about CD as these employees are responsible for the health of the children in their care. Emphasizing the need for a strict GF diet and its practices will help lessen the worry felt by participants in this study when their children were not under their direct supervision. When outside the home, it is important for parents to feel that they can trust that their child's disease will be taken seriously and that they are not at risk of gluten exposure.

- The Nova Scotia Department of Education must provide employees of the school system with information as it pertains to CD and the GF diet. Providing information to those in the school system will help increase the awareness of the seriousness of CD and potentially improve how CD is treated within the school system. Participants expressed concern that their child's CD was not taken as seriously as other dietary requirements. In-school activities need to be safe for all students. In addition, students need to feel similar to their peers and not singled out for their differences. This can be achieved by ensuring that school activities are not always food-based, and also by offering GF alternatives in the school cafeteria.

7.2.3. Conclusion #3

Celiac disease is a costly disease requiring a myriad of changes in order to improve access to the gluten-free food required for treatment. As the cost of gluten-free food is a main determinant of whether celiac disease patients adhere to the dietary treatment of the disorder, it is important that gluten-free food be affordable to all those who require it.

Participants in this study expressed frustration with the cost of GF foods. The finding that participants experienced the cost GF foods to be significantly more expensive than gluten-containing food is consistent with previous research on the actual cost of GF food (2-3). While it is critical that GF foods be affordable to ensure dietary adherence among all those required to purchase it for medical reasons, GF food is not purchased on a prescription. Therefore, it is hard to determine who is purchasing GF foods out of necessity and who is choosing GF foods for other perceived health reasons. Currently, those with CD in Canada are eligible for an income tax benefit for purchasing GF foods. However, because the application process, as described by participants in this study, is both lengthy and complicated, participants admitted to sometimes not completing and submitting the application. A revised system is needed whereby GF foods are

comparable in price to gluten-containing foods, or where those medically required to purchase receive a greater financial incentive to do so.

Furthermore, the current Nova Scotia special diet allowance for those on income assistance (50) who have been diagnosed with CD ($30) and a wheat allergy ($120) requires reexamination. As CD requires a more restrictive and specialized diet than a wheat allergy, it is unclear why the special diet allowance for a wheat allergy is higher than that of CD. Revision of these special diet allowances is necessary.

7.2.3.1. Implications for Policy

- The Canadian Revenue Agency income tax credit process for CD needs to be simplified so those who would benefit from completing it would have greater ease. Currently, in order to apply for this tax credit, applicants must provide documentation of all GF foods purchased for a 12-month period. In addition, only GF food purchased for the individual with CD may be claimed. This documentation can be difficult for applicants since participants noted that many members within the household consume GF meals for convenience as well as support. Replacing the need for strict documentation of receipts with standardized monetary values based on a number of dietary contributing factors, such as age and recommended caloric intake, may provide a simpler means of determining tax credit allowance.

- The Nova Scotia special diet allowance for those on income assistance must be updated to allow funds to be allocated based on the individual needs of the recipient. Providing a standard monetary figure to aid in the purchasing of GF food will not meet the needs of all individuals as each individual requires varying caloric intake based on age, and activity.

Moreover, individuals may be faced with different household circumstances, such as housing costs and number of dependents, which will affect their financial contribution to their grocery bill. Further research is required to determine the monetary value required to purchase a GF diet while on a reduced income. This can be achieved through food costing research in which data are gathered through use of NNFB which is adapted to include a GF component, and affordability scenarios representing those living on income assistance with CD.

7.2.3.2. Implications for Practice

- Dietitians play a vital role in advocating for greater financial relief for those with CD. Dietitians can contribute by engaging in research as well as through advocating to the Nova Scotia Department of Community Services for example for improved financial supports for CD.

- Understanding the cost of a GF diet is essential for dietitians in order to tailor nutrition information to meet individual needs. Being aware of the financial constraints of the client will help determine the course of nutrition education as well as which financial supports should be utilized.

7.2.4. Conclusion #4

Determining the prevalence of household and individual food insecurity in a celiac disease population is of utmost importance.

This is the first study examining food insecurity in a CD population. Characteristics of food insecurity such as inadequate food choices, disrupted eating patterns, and anxiety over food

(8) were identified among all participants. Krista, as the only participant who was determined to be on a low-income also obtained food at times through charitable food systems (7). However, the interviewer administered HFSSM did not identify participants as food-insecure. The findings from this qualitative study suggest that current food security monitoring surveys, such as the HFSSM and the National Nutritious Food Basket (NNFB), should be revised in order to accurately capture the dietary needs of a special diet population in which GF foods are represented as prescribed foods. It is important to acknowledge that revision to the HFSSM to capture "food for dietary requirements" versus "food" would be much more extensive than simply adding words to the questionnaire. All questions in the HFSSM would have to be revised in order to accurately reflect any special dietary needs of members within the household. Furthermore, questions would have to be revised to ensure they are delivered in a way that is easy to understand and administer. Altering the current NNFB would require revision to reflect GF choices. Although many of the NNFB food items are naturally GF, in-depth revision would be required to accurately capture the change from gluten-containing to GF products. From a nutrient perspective, the NNFB is reflective of the recommended dietary intakes of a healthy Canadian diet (72). As not all GF products are nutritionally comparable to their gluten-containing counterparts (16,17), ensuring that the NNFB accurately reflects the Canadian diet, based on dietary recommendations, would require substantial review.

7.2.4.1. Implications for Policy and Practice

- Providing information on food insecurity in the CD population holds great significance to policy and practice. Within the macrosystem, policy influences all aspects of participants' lives. Providing policy makers with an accurate picture of the prevalence of food insecurity

in the CD population and the various consequences of food insecurity will help to create better access to and affordability of GF foods especially for those living at a low-income level.

7.2.4.2. Implications for Measurement

- Tools to determine the prevalence of food insecurity must include a diet-specific component in order to capture the difference between having enough food versus having the types of foods required. Persons with CD may be able to purchase food; however, they may not be able to purchase GF food because of the increased expense.

- A revised NNFB tailored to the population with CD would provide important information regarding the cost of a GF diet. This information would help to inform policy makers of the financial supports those on income assistance require in order to purchase a GF diet. Through food costing research using a CD-specific NNFB, affordability scenarios can be created to provide real-life examples of families living on low-income or minimum wage with CD. These affordability scenarios will help determine if the GF diet is obtainable based on the available income supports for different household scenarios.

7.3. Future Directions

Qualitative research has the ability to provide meaning to participants' experiences. Contributing more in-depth, qualitative research on the topic of food security and CD will add to the existing literature and strengthen the depth of research on this topic. Specifically, further qualitative research is needed to investigate how low-income individuals, particularly those with

CD who are living on minimum wage and income assistance, experience the disease and cope with its management.

This research study was therapeutic for participants in that it gave them the opportunity to express their feelings and discuss their experiences with CD. Actively involving those with CD in CD based research would be beneficial. Research, particularly participatory action research, is needed so that participants are active in the research and able to contribute to the research that has a direct impact on their lives. Common among all participants was their desire to connect with other families diagnosed with CD and to share both their failures and successes in managing their child's disease, specifically in the initial stages of diagnosis. Participatory action research examining how families and individuals with CD cope with the management of CD, including the social and psychological aspects of disorder, would fulfill participants' desire to connect and contribute.

Finally, research examining the prevalence of food insecurity in the CD population is required. Although current methods of measuring food security proved to be ineffective at accurately capturing food insecurity in the celiac population, the analysis of participants' interviews determined that families diagnosed with CD are at risk of becoming food-insecure. In order to address the issue of food insecurity in a special diet population such as CD, it must first be concluded who experiences food insecurity within the family, demographically where food insecurity occurs, and why food insecurity is occurring within the CD population. By tailoring current measurement and monitoring food security tools to provide a valid assessment of food insecurity among special diet populations, researchers will be able to determine further steps and actions in order to eliminate food insecurity in the CD population.

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APPENDIX A. Invitation to Participate

[IWK Letterhead]

You have been invited to participate!

You're invited to participate in a research study looking at how families experience and manage the nutritional and financial requirements of celiac disease. The aim of this study is to investigate how the challenges of following a gluten-free diet affect families.

1. Is your child with celiac disease 16 years of age or under?
2. Has your child been prescribed a gluten-free diet for longer than 6 months?

If you answered **YES** to these questions I would like to hear from you! With your involvement you can help shed some light on this important issue. The more information available to the public, and to policy makers, the greater the opportunity for increased supports for families affected by celiac disease.

What is required?

Your participation and interview will last about 60-90 minutes, can take place in person or over the phone. As thanks for your participation you will receive a $50 grocery store gift card as a token of appreciation! If you are interested in participating and fit the selection criteria please review the informed consent form enclosed in this package and mail back in the postage-paid envelope provided.

For more information please feel free to contact me, Lesley Neil, or Dr. Rashid.

Thanks kindly,
(signature)

Lesley E. Neil
Graduate Student Researcher
Department of Applied Human Nutrition
Mount Saint Vincent University
lesley.neil@msvu.ca

Dr. Mohsin Rashid
Thesis Committee Member
Associate Professor of Paediatrics
Division of Gastroenterology & Nutrition, IWK
Department of Paediatrics, Faculty of Medicine
Dalhousie University
Member, Professional Advisory Board, Canadian Celiac Association
mohsin.rashid@iwk.nshealth.ca

APPENDIX B. Informed Consent Form

[MSVU Letterhead]

STUDY TITLE: *How families experience and manage the nutritional and financial requirements of celiac disease.*

RESEARCHER: My name is Lesley Neil. I am a Master student in the Department of Applied Human Nutrition at Mount Saint Vincent University in Halifax, Nova Scotia. As part of my master thesis, I am doing research under the guidance of Dr. Patty Williams.

INVITATION: I invite you to participate in the study, *How families experience and manage the nutritional and financial requirements of celiac disease.* The purpose of this study is to explore how families with children diagnosed with celiac disease manage the nutritional and financial requirements of following a gluten-free diet. Although research has shown the increased cost of gluten-free products, there is little research available regarding the implications this has for families.

I would like to interview you to talk about your experience as the primary meal provider for a family in which one or more of the children have celiac disease. The interview will take between 60-90 minutes and can be held in the location of your preference, either in your home, or in a public space. Interviews can also take place via telephone if this option best suits you. With your permission, interviews will be audio taped. In agreeing to participate you will be compensated for your time.

YOU CAN TAKE PART IN THIS STUDY IF:

- You are the primary meal provider for your household
- Have a dependent under the age of 16 years who has been diagnosed with biopsy-proven celiac disease

POTENTIAL BENEFITS AND RISKS: Sharing your experiences will help us understand how families experience and manage the nutritional requirements of celiac disease. This information will help inform public and policy makers what barriers families face in consuming a gluten-free diet.

Some issues that may arise during the interview process could be sensitive and personal. It is your choice whether or not to discuss an issue that may make you uncomfortable. Your participation is completely voluntary and you may withdraw from the study at any point.

COMPENSATION: As a small token of appreciation for your time, you will receive a grocery store gift card valued at $50 dollars, and paid parking at the IWK Health Centre for the date of your child's appointment if your interview takes place at the time of his/her appointment.

CONFIDENTIALITY: All information collected, including informed consent forms, audiotapes, interview transcripts and notes will be kept in a locked room, accessible only to the

student researcher and her supervisor. No actual names will be used in any public documents. All electronic files will be password protected.

If during the course of the interview it becomes apparent to the researcher that a violation of the Criminal Code has occurred, she will be obligated to report the violation to the appropriate authorities.

According to the Mount Saint Vincent University Research Office requirements, all documentation will be securely kept for five years, in the event that an audit of the thesis research is conducted, or that the information is required for further analyses. After the five year period, all material will be destroyed by the supervisor.

CONTACT INFORMATION OF RESEARCHERS:
If you have any questions about this study, please talk to the student researcher, her supervisor, or a University representative.

Lesley E. Neil
Graduate Student Researcher
Department of Applied Human Nutrition
Mount Saint Vincent University
lesley.neil@msvu.ca

Dr. Patty Williams
Thesis Supervisor
Associate Professor and Canada Research Chair in Food Security and Policy Change
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Dr. Mohsin Rashid
Thesis Committee Member
Associate Professor of Paediatrics
Division of Gastroenterology & Nutrition, IWK
Department of Paediatrics, Faculty of Medicine
Dalhousie University
Member, Professional Advisory Board, Canadian Celiac Association
mohsin.rashid@iwk.nshealth.ca

University Representative
This research activity has met the ethical standards of the University Research Ethics Board at Mount Saint Vincent University. If you have any questions or concerns about this study and wish to speak with someone who is not directly involved with this study, you may contact the University Research Ethics Board, by phone at (902) 457-6350 or by e-mail at research@msvu.ca.

[MSVU Letterhead]

Informed Consent Form

If you have read the 2-page information sheet that explains the research study and are willing to take part, please read the following and sign below.

I understand that:

- I will take part in a 60-90 minute interview with Lesley Neil where I will be asked questions about my experience with managing the nutrition and financial requirements associated with celiac disease;
- Participation is completely voluntary, I may choose not to answer any question and I may withdraw from the interview at any point;
- All information I provide is confidential, only Lesley Neil and her thesis supervisor (Dr. P. Williams) will have access to the original data;
- I am free to discuss any questions or concerns about taking part in this study with, Lesley, her supervisor or a Mount Saint Vincent University Representative, whose contact information has been provided;
- I should keep a copy of the information sheet and informed consent form for my records.

I have read the information sheet on the research study titled: *How families experience and manage the nutritional and financial requirements of celiac disease*, and I am willing to be interviewed. I have been provided with enough information to make a decision as to whether or not I would like to participate in this research.

Participant's Name (print) _____

Signature _____ Date _____

I agree to be audio taped. YES _____ NO _____ Signature _____

I would like to receive a copy of the summary report when the study is finished, (approximately one year's time from now). YES _____ NO _____

If yes, please provide your name and mailing address:

Name: _____

Street Address: _____

City & Province: _____

Postal Code _____

APPENDIX C: Telephone Recruitment Guide

To determine eligibility study potential participants must meet the following criteria:

Script: Hello. May I speak with [Participants Name]? My name is Lesley Neil. I am a graduate student at Mount Saint Vincent University conducting research on the nutritional and financial management of celiac disease.

Option A: Received consent form.
Script: I received your signed consent form, thank-you for indicating you would like to participate… I appreciate it! I have a few questions to ask to ensure you meet all the study criteria. Do you have a few moments to answer these questions? *Go to questions.*

Option B: No consent form.
Script: A few weeks ago I mailed a package to you inviting you to participate in my research study on how families manage the nutritional and financial requirements of celiac disease. Did you receive this package?

1. Yes, not interested. Thank-you for your time.
2. No. Yes, unsure. Explain research.

Explanation of research:
Script: The research study is on how families experience and manage the financial and nutrition requirements of celiac disease. The aim of this study is to investigate the challenges of following a gluten-free diet. Participation would involve an interview with the primary food purchaser that would last between 60-90 minutes for which you would be compensated for your time. All information provided would be strictly confidential. Is this study something you would be interested in? I am really excited about this research and it is my hope that it will help shed some light on the way celiac disease impacts families. *Either thank for time or go to questions.*

Questions:

1. Are you the primary meal provider for your household?
2. Do you have a child under the age of 16 years who has been diagnosed with biopsy-proven celiac disease?

Is participant eligible?

Yes. Continue
No. Thank them for their time.

Script: Thank-you for agreeing to participate. If it is okay with you I would like to set up a date and time for your interview.
List dates and times. In-person interview or telephone-interview?

Date: _____
Time: _____
Location: _____

APPENDIX D: Interview Guide

Participant Interview Guide
Interview date and time: _____
Length of Interview: _____
Signed consent form received: _____

Title of Study
How families experience and manage the nutritional and financial requirements of celiac disease

Introduction
Introduction of researcher/interviewer (MScAHN thesis project)
Purpose of the interview:

- To explore how you and your family experience the financial and nutrition aspects of celiac disease
- To discover what can be done to increase adherence of a gluten-free diet
- Informed Consent; Procedures; Taping: Test audiotape/recorder

START OF INTERVIEW

A. <u>Demographics</u>

1. Male ☐ Female ☐
2. Age: _____
3. Number of children with celiac disease:
4. Affiliation with celiac disease patient
   - Mother, father, grandparent, legal guardian, other?
5. Household consists of (number of dependents):
   _____
   _____
6. Are there any other chronic diseases in your family? (any other special diet needs in the family)_____
   _____

B. <u>Celiac Disease</u>

Can you tell me a bit about your experience with celiac disease (CD)?

- How long has your child had CD? Tell me a bit about the diagnosis. *Age, time period.*
- What was your experience/ reaction to the diagnosis? Fear, anxiety, relief?

C. Food Insecurity

Tell me about your experience with obtaining gluten-free foods.

- Cost, availability, preparation?
- How do you usually obtain gluten-free foods? Where do you shop? Food banks? Family practice/involvement?
- What happens when you cannot obtain all the gluten-free foods your child needs?

D. Social/ Lifestyle

How has having to follow a gluten-free diet affected your child?

- How have your relationships been affected? *Between yourself and your child, relationship with other family members.* How has celiac disease affected you, your child, and the rest of your family?
- How has your child's life changed due to their food restrictions? *What about your child's relationships with their peers, siblings, parents?*

What social support networks to you rely on? *Friends? Spouse? Co-workers?*

E. Economic Burden

Can you share how the diagnosis of celiac disease has impacted you financially? *What is the financial situation in your household? Both parents working?*

- How has your financial situation changed since your child has to follow a gluten-free diet?

How does a typical visit to the grocery store look like for you?

- What do you look for? What do you end up purchasing? Can you describe a situation where you've been unable to purchase gluten-free food? How did this affect your child and family? *If purchasing of gluten-free foods does not occur, what channels are used to obtain food?*

Are you aware of any financial supports available to individuals with celiac disease? Tell me about them. *Celiac disease special diet allowance and tax credits*

- Do you feel that these supports are beneficial to you? How long have you been using these supports, and why? Are these supports adequate?
- How have these supports impacted how you manage the financial requirements of celiac disease?

F. Enablers and Barriers

What do you feel are the greatest barriers to obtaining gluten-free foods? What is most important? What has the biggest impact?

- Cost, availability, knowledge of what to purchase? *Education?*

What do you feel are the greatest enablers to obtaining gluten-free foods?

- Knowledge of the disease, health, support systems? Can you tell me about any programs or organizations that enable you?

What would you suggest be done in order to reduce and eliminate the barriers you have identified?

G. Open Discussion

Looking back on when your child was first diagnosed with celiac disease, how do you feel your nutritional and financial management of the disease has changed?

- What was the most important thing you've learned? What would you share with others?

Do you have any other comments or suggestions you would like to make regarding this study?

- Future recommendations for further research?

H. Household Food Security Survey Module (HFSSM) adapted from Health Canada Canadian Community Health Survey Cycle 2.2 Food Insecurity Supplement*

Explain Canadian Community Health Survey (used to gather health-related data). Are participants willing to complete the survey? The following questions are about the food situation for your household in the past 12 months.

Which of the following statements best describes the food eaten in your household in the past 12 months, that is since [current month] of last year?

1. You and other household members always had enough of the kinds of food you wanted to eat.
2. You and other household members had enough to eat, but not always the kinds of food you wanted.
3. Sometimes you and other household members did not have enough to eat.
4. Often you and other household member members didn't have enough to eat.
5. Don't know, Refuse to respond [END]

Now I'm going to read you several statements that may be used to describe the food situation for a household. Please tell me if the statement was often true, sometimes true, or never true for you and other household members in the past 12 months.

The first statement is: … You and other household members worried that food would run out before you got money to buy more. Was that often true, sometimes true, or never true in the past 12 months?

1. Often true
2. Sometimes true
3. Never true
4. Don't know, Refuse to respond

The food that you and other household members bought just didn't last and there wasn't any money to get more. Was that often true, sometimes true, or never true in the past 12 months?

1. Often true
2. Sometimes true
3. Never true
4. Don't know, Refuse to respond

You and other household members couldn't afford to eat balanced meals. In the past 12 months was that often true, sometimes true, or never true?

1. Often true
2. Sometimes true
3. Never true
4. Don't know, Refuse to respond

Now I'm going to read a few statements that may describe the food situation for households with children.

You and other household members relied on only a few kinds of low-cost food to feed your child because you were running out of money to buy food. Was that often true, sometime true, or never true in the past 12 months?

1. Often true
2. Sometimes true
3. Never true
4. Don't know, Refuse to respond

You and other household members couldn't feed your child a balanced meal, because you couldn't afford it. Was that often true, sometime true, or never true in the past 12 months?

1. Often true
2. Sometimes true
3. Never true
4. Don't know, Refuse to respond

Your child was not eating enough because you and other household members just couldn't affod enough food. Was that often true, sometime true, or never true in the past 12 months?

1. Often true
2. Sometimes true
3. Never true
4. Don't know, Refuse to respond

The following few questions are about the food situation in the past 12 months for you or any other adults in your household

In the past 12 months, since last [current month] did you and other household members ever cut the size of your meals or skip meals because there wasn't enough money for food?

1. Yes
2. No
3. Don't know, Refuse to respond

How often did this happen?

1. Almost every month
2. Some months but not every month
3. Only 1 or 2 months
4. Don't know, Refuse to respond

In the past 12 months, did you (personally) ever eat less than you felt you should because there wasn't enough money to buy food?

1. Yes
2. No
3. Don't know, Refuse to respond

In the past 12 months, were you (personally) ever hungry but didn't eat because you couldn't afford enough food?

1. Yes
2. No
3. Don't know, Refuse to respond

In the past 12 months, did you (personally) lose weight because you didn't have enough money for food?

1. Yes
2. No
3. Don't know, Refuse to respond

In the past 12 months, did you and other household members ever not eat for a whole day because there wasn't enough money for food?

1. Yes
2. No
3. Don't know, Refuse to respond

How often did this happen?

1. Almost every month
2. Some months but not every month
3. Only 1 or 2 months
4. Don't know, Refuse to respond

Now, a few questions on the food experiences for children in your household.
In the past 12 months, did you and other household members ever cut the size of your [child/children's] meals because there wasn't enough money for food?

1. Yes
2. No
3. Don't know, Refuse to respond

In the past 12 months, did your [child/children] ever skip meals because there wasn't enough money for food?

1. Yes
2. No
3. Don't know, Refuse to respond

How often did this happen?

1. Almost every month
2. Some months but not every month

3. Only 1 or 2 months
4. Don't know, Refuse to respond

In the past 12 months, was your [child/children] ever hungry but you just couldn't afford more food?

1. Yes
2. No
3. Don't know, Refuse to respond

In the past 12 months, did your [child/children] ever not eat for a whole day because there wasn't enough money for food?

1. Yes
2. No
3. Don't know, Refuse to respond

I. Conclusion

Thank you for your thoughtful responses and your contribution to this study. To help ensure that I have correctly interpreted what you have told me today I would appreciate it if you could review either a full transcript of this interview, or a summary which I will make based on your transcript.

- Which form of review? Member checking.
- Remind that everything is confidential
- Summary of thesis results?
- End positively! Thank you for participation!

*Health Canada. Canadian Community Health Survey, Cycle 2.2, Nutrition (2004). Income-related household food security in Canada. Ottawa, ON: Office of Nutrition Policy and Promotion; 2007. Report No.: 4696.

APPENDIX E. Certificate of Research Ethics Clearance from Mount Saint Vincent University

MOUNT SAINT VINCENT UNIVERSITY

Excellence • Innovation • Discovery

University Research Ethics Board

UNIVERSITY RESEARCH ETHICS BOARD

Certificate of Research Ethics Clearance

[Renewal]

Title of project: ***How Families Experience and Manage the Nutritional and Financial Requirements of Celiac Disease***

Researcher(s): **Lesley Neil**
Supervisor (if applicable): **Patricia Williams**
Co-Investigators: **n/a**

File #: 2009-075

The University Research Ethics Board (UREB) has reviewed the above named proposal and confirms that it respects the *Tri-Council Policy Statement* and the *MSVU Policies and Procedures: Ethics Review of Research Involving Humans* regarding the ethics of research involving human participants.

This certificate of approval is valid one year from the date of issue Renewals are available for up to four years in addition to the initial year and are contingent upon an annual submission to the UREB of a written request for renewal accompanied by a satisfactory annual ethics report thirty days prior to the expiry date as listed below. A final report is required within 30 days of expiry. Researchers are reminded that any changes to approved protocol must be reviewed and approved by the UREB prior to their implementation.

[redacted]

Dr. Michelle Eskritt, Chair
University Research Ethics Board (UREB)

May 7, 2012
Effective Date

[Expires: May 21, 2013]

Renewal is contingent upon submission to the UREB of a written request for renewal accompanied by a satisfactory annual ethics report thirty days prior to expiry.

166 Bedford Hwy Halifax Nova Scotia B3M 2J6 Canada
Tel 902 457 6350 • Fax 902 457 2174
www.msvu.ca

APPENDIX F. Continuing Review Ethics Certificate from the IWK Health Centre

IWK Health Centre
Research

5850/5980 University Avenue
PO Box 9700, Halifax
Nova Scotia B3K 6R8
Canada
tel: 902.470.8888
www.iwk.nshealth.ca

Approval - Continuing Review
July 15, 2012

Principal Investigator: Lesley Neil
Co-Principal Investigator: Dr. Mohsin Rashid
Title: How Families Experience and Manage the Nutritional and Financial Requirements of Celiac Disease
Project #: 1000540

On behalf of the IWK Research Ethics Board (IWK-REB) I have examined the application for continuing review. I am pleased to confirm the Board's approval to continue the study.

The IWK-REB approval will expire on July 15, 2013.

[redacted]
Adam Huber
Co-Chair, Research Ethics Board

This statement is in lieu of Health Canada's Research Ethics Board Attestation: *the Research Ethics Board for the IWK Health Centre operates in accordance with:*
- *Food and Drug Regulations, Division 5 "Drugs for Clinical Trials involving Human Subjects"*
- *The Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans - TCPS (2)*
- *International Conference on Harmonization - Good Clinical Practice Guidelines - ICH-GCP*