

Experiences of those with celiac disease in rural versus urban areas of western North
Carolina

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Table of Contents:

Section One: Literature Review

Celiac Disease.....	3
Health Disparities	13
Rural Populations.....	18

Section Two: Experiences of those with celiac disease in rural versus urban areas of western North Carolina

Abstract.....	25
Introduction.....	26
Methods.....	28
Results.....	32
Discussion.....	63
Conclusion.....	67
Acknowledgements.....	68
Reference Page.....	69

Part One: Literature Review

Celiac Disease

Introduction

Celiac disease (CD) is a genetic autoimmune disease that requires life-long strict adherence to a gluten-free diet. Gluten is a protein found in wheat and has equivalent proteins in rye and barley. Those with CD may also have to eliminate oats from their diets due to concerns of cross contamination between the oats and gluten containing grains caused by crop sharing of fields or other contamination during processing. For someone with CD, ingesting gluten causes an inflammatory reaction in the mucosal villi of the intestine causing progressive damage and atrophy to the intestinal villi¹. This leads to the malabsorption of carbohydrates, fat, the fat-soluble vitamins A, D, E, and K as well as other micronutrients as the disease progresses². Intestinal damage and malabsorption can occur whether symptoms are present or not in the patient or if only a small amount of gluten is being consumed. Celiac disease can have a vast array of symptoms including the most common gastrointestinal related symptoms such as stomach pain, bloating, abdominal distention, diarrhea, constipation, and flatulence. Other non-gastrointestinal symptoms may include anemia, osteoporosis and osteopenia, weight loss, fatigue, depression, infertility, dental problems, arthritis, epilepsy and ataxia, and reduced growth in children¹. If not properly managed CD is also linked to increased risk of developing other autoimmune diseases, neurological problems, and cancer².

Celiac disease affects a higher prevalence of people than once thought; according to a large epidemiological study approximately one in every 133 people in the United States has the disease. It is estimated that roughly 3 million Americans have CD, which is slightly

lower than 1% of the population and is similar in prevalence to European population estimates². Currently, the only treatment for CD is a strict gluten-free diet which can be complex and confusing to begin and requires a substantial amount of dedication in the form of dietary and lifestyle changes³.

Removal of gluten from the diet can be difficult, expensive, and result in nutritional and taste deficiencies. Wheat is the second most highly cultivated grain worldwide and provides essential sensory characteristics to food items, especially bakery items, where it is responsible for the elasticity, firmness, cohesion, and moisture of baked goods. The substitutes that are most commonly used in gluten-free foods such as rice, potatoes, maize, millet, buckwheat, amaranth, quinoa, soybeans, and sorghum are unable to provide the consistency to baked goods that wheat can. Additionally, to be safe for consumption by someone with CD these substitutions must have been produced in a dedicated manner that prevents cross contamination with gluten containing grains. The gluten-free diet, like every diet, can be unhealthy if not treated with consideration of nutrient value. The diet is especially at risk to be low in fiber, iron, folate, niacin, phosphorus, and zinc if the patient is consuming high amounts of refined gluten-free grains and starches. The gluten-free diet is also likely to be high in fat as adding in extra fats during processing is common to achieve a consistency more like that of gluten containing food items. Eliminating gluten from the diet is also difficult because of the vast hidden sources in foods and other items. Gluten is often used in unexpected places like soups, sauces, marinades, spices, food spreads, ice cream, and malt based beverages. Even non-food items that come in contact with the mouth like lipstick and postage stamps must be monitored for gluten in someone with CD¹.

Challenges with Celiac Disease

Those with celiac disease face numerous initial challenges while trying to adhere to a strict gluten-free diet. Economic factors such as the high cost of gluten-free products can create a barrier for those trying to follow the prescribed diet. Along with increased cost, limited availability of gluten-free products can also make the diet more difficult to manage. While a strict adherence to the diet is essential for the proper treatment of CD, adherence can vary among individuals based on their perceived barriers as well as the disease specific education and support they have access to.

Cost

A major factor in difficulty following the gluten-free diet is due to the increased cost and decreased availability of gluten-free foods. The demand for gluten-free items such as flours are typically lower than gluten containing flours and usually cost more because of this¹. In a study conducted in the Federal District of Brazil 75% of survey respondents with CD reported dissatisfaction with the price and availability of gluten-free food items⁴. In a study done in Canada it was found that gluten-free foods cost an average of 242% more than their gluten containing equivalents⁵. Paralleling these results, a study based in the United States comparing the cost of a gluten-free market basket containing basic food items such as pasta, pretzels, and bread found that generally the cost of gluten-free food items was 240% more than the gluten containing items in the regular market basket. On top of this, it was found that the same gluten-free food items purchased in a health food store were 123% more expensive than those purchased in a grocery store. This also differed between types of food with the authors noting that gluten-free snack foods like pretzels, cookies, and crackers were considerably more expensive than the gluten containing versions. Gluten-free pasta cost more

