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The differences between the quality of life and personal health profile between individuals diagnosed with celiac disease and those who follow a gluten-free diet for non-celiac reasons.

By: Ellie Fuechtmann

Abstract

Background: Celiac disease is an autoimmune disorder triggered by gluten proteins in wheat, barley, and rye, necessitating a strict gluten-free diet. However, many individuals without celiac disease are adopting gluten-free diets for various health reasons.

Purpose: This study compares the quality of life and health profile of individuals with celiac disease and those following a gluten-free diet for non-celiac reasons.

Methods: A survey was conducted and distributed via social media to people diagnosed with celiac disease and those adhering to a gluten-free diet non-celiac. The results were analyzed via Google Forms and Excel to better interpret the data for visualization.

Results: According to the survey, celiac disease patients experienced a lower quality of life, had strict dietary restrictions, and were better informed and less anxious. In contrast, non-celiac gluten/wheat-sensitive individuals reported a better quality of life, fewer diet restrictions, and improved overall health. Both groups faced micronutrient deficiencies, raising concerns about the nutritional value of gluten-free products.

Conclusion: Understanding these differences is crucial for providing better healthcare and nutritional support for individuals adhering to gluten-free diets. However, the study has limitations due to self-reporting bias and small sample size, requiring further investigation to establish causative relationships.

Introduction

Celiac disease is a complex disease that develops from an autoimmune response to gluten proteins. Gluten is a protein found in wheat, barley, and rye. The only treatment for those who have celiac disease includes a gluten-free diet that can be very tedious and difficult to manage. In a study conducted by Spector et al., it was discovered that individuals with celiac disease who consumed 50 mg of gluten per day damaged their villi within 90 days. In contrast, those who consumed 10 mg or less had no changes in their villi.¹ The burden of adhering to a lifelong gluten-free diet is high. In contrast, some people abstain from gluten for other health reasons, including non-celiac gluten/wheat sensitivity, irritable bowel syndrome, thyroid disease, weight loss, and reduced inflammation and acne. This study aims to determine if there are any differences between the quality of life and personal health profile of individuals diagnosed with celiac disease and who follow a gluten-free diet for non-celiac reasons.

Literature Review

Celiac Disease: Overview and Health Implications

Celiac disease (CD) is a severe autoimmune disorder that can significantly impact a person's life. This condition occurs when the body's immune system attacks the villi in the small intestine after consuming gluten. Gluten is a protein found in wheat, barley, and rye. These proteins contain high proportions of prolamins. Since gastric and pancreatic enzymes cannot fully break down these proteins, the immune system causes an overactive and destroys the villi.²

Celiac disease symptoms can be severe and debilitating, ranging from digestive issues to fatigue and malnutrition. It is essential to get a diagnosis and follow a strict gluten-free diet to manage the condition and prevent further damage to the intestines. The average prevalence is about 1% of the population.² According to the National Health and Nutrition Examination Survey (NHANES) conducted by the Centers for Disease Control and Prevention (CDC), 2 million Americans aged six or older were said to have been diagnosed with CD between 2009 and 2014 (the most recent data).³ There are over 250 symptoms of CD, including gastrointestinal and extraintestinal symptoms.⁴ Symptoms vary widely among people, including anemia, anxiety, brain fog, constipation, diarrhea, headaches, infertility, thin bones, and dermatitis herpetiformis (skin rash). Due to the variety of symptoms, CD can be challenging to diagnose, resulting in 83% of people with CD going undiagnosed or misdiagnosed.⁴

The gold standard for diagnosing CD is a small intestinal biopsy showing atrophy of the villi and a positive IgA anti-transglutaminase two antibody. The only treatment for CD is adherence to a gluten-free diet.² Given the psychosocial effects of adhering to a gluten-free diet,

it can be both difficult and tedious; however, new clinical and pharmacological treatments are currently being studied.

Non-Celiac Gluten/Wheat Sensitivity (NCG/WS): Overview and Health Implications

Non-celiac gluten/wheat sensitivity (NCG/WS) is characterized by intestinal and extraintestinal symptoms occurring soon after ingesting gluten. Avoiding gluten can improve these symptoms, even if you don't have celiac disease or a wheat allergy.⁵ According to a 2010 survey, NCG/WS was between .06%-6% in the Western populations. However, this number may only be partially accurate as many people begin a gluten-free diet without formal clinical testing or management by their physician.⁵ More realistic numbers have recently been reported due to introducing an accepted diagnostic test, a double-blind, placebo-controlled gluten challenge. However, this test is lengthy and can be difficult for the participants to comply with for three weeks. Therefore, a new trial, ALCAT5, was conducted to evaluate the toxic effect of gluten on neutrophils.⁶ This study compared the results of an ALCAT5 test to the double-blind, placebo-controlled gluten challenge to determine if it is accurate and could be used to diagnose NCG/WS. It was concluded that the ALCAT5 could be used as a screening tool to evaluate the presence of NCG/WS and potentially direct them to a blinded gluten challenge for better confirmation.⁶

Individuals who adopt a gluten-free diet without CD or NCG/WS are rising. It is estimated that 25% of Americans consumed gluten-free products per a 2015 study, with only 1% having CD and up to 6% having NCG/WS.⁷ The popularity of adopting a gluten-free diet raises questions about why people choose to consume gluten-free foods without a medical diagnosis.⁷

Arslain et al. found that the reasons for a gluten-free diet were weight loss, acne, and digestive health. Personal research was the most influential reason for trying a gluten-free diet, followed by “healthcare center or health professional.”⁷

Gluten-Free Diet Trends and Reasons for Adoption

There has been a rapid increase in the popularity of a gluten-free diet and ever-growing sales. “By 2032, the market is projected to be valued at 14 billion U.S. dollars, more than double the 2022 market value.”⁸ Reasons for popularity include social media coverage, traditional media coverage, aggressive consumer-directed marketing, medical literature reports, and mainstream press on the clinical benefits of a gluten-free diet. The gluten-free diet has also become popular among healthy people who believe that a gluten-free diet can have immediate health benefits or help with disease prevention in the future. “Such people may seek to cut back or eliminate gluten due to symptoms that have not been proven to arise due to gluten ingestion, or they may be asymptomatic.”⁹

According to a study conducted in 2018, 1819 young adults (25-36-year-olds, 57% women and 69% white) showed that 13% of this population valued gluten-free foods.¹⁰ Appreciating gluten-free food was related to more healthy behaviors and less unhealthy behaviors. They concluded that enjoying gluten-free foods may help make healthier food choices and a healthier lifestyle.¹⁰ Compared to those who do not, people who preferred gluten-free products consumed more fiber, fruits, and vegetables and reduced their intake of sodium, trans fats, and added sugar. A non-contributing relationship exists between consuming a gluten-free

diet and positive health outcomes in the general population.⁷ The scientific consensus remains that removing gluten from the diet for NCG/WS individuals does not improve health.¹¹

Benefits and Disadvantages of Gluten-Free Diet

According to the 2009-2014 NHANES data, it was determined that a gluten-free diet might be beneficial in weight management for those without CD. However, there is no significant difference in the prevalence of metabolic syndrome and cardiovascular risk scores in 155 individuals who follow a gluten-free diet and do not have CD.³ The gluten-free diet, however unclear, did show improvements in HDL levels, although glycemic levels were conflicting.¹² Although there were no statistical differences, people who follow a gluten-free diet without a CD diagnosis do so for different reasons and goals. Eliminating highly processed foods can lead to potential weight loss and an improved sense of well-being.³

According to authors Niland et al., gluten-free diets for those with irritable bowel syndrome (IBS), where CD was definitively excluded, can be beneficial. The low FODMAP diet has improved overall IBS symptoms such as abdominal pain, fatigue, bloating, and poor bowel habits.⁹ A research study examined the effects of a gluten-free diet on individuals with IBS who have a non-celiac gluten sensitivity or wheat sensitivity. The study found that these individuals could maintain a gluten-free diet over a long period, which resulted in sustained improvements in their symptoms. This is another reason why some people without CD may follow a gluten-free diet.¹³

Following a gluten-free diet may have drawbacks, such as lacking essential nutrients and potentially gaining unwanted weight. Studies have shown that individuals with celiac disease and

non-celiac gluten/wheat sensitivity may experience weight gain, with approximately 20% of those with celiac condition falling into the overweight or obese category.¹⁴ This could be due to the poor nutritive properties of gluten-free products, the reduced thermic effect, and the subsequent reduction in metabolic rate, also adding to the weight gain. These trends, along with cardiovascular disease and dyslipidemia, caused an increase in mortality in these populations. Although there may be a change in the classical presentation of CD and a rise in the number of obese patients, this does not exclude the possibility that these patients are also malnourished regarding micronutrient deficiencies.¹⁴ Regardless, adopting a gluten-free diet increases the risk of malnutrition and micronutrient deficiencies.¹⁴

Although gluten-free diets may seem beneficial according to the current fad diets and media, they may only sometimes be as advantageous as people think, even for those who require this diet for medical reasons. Gluten-free products contain lower levels of vitamins E, D, B12, iron, folate, magnesium, potassium, and sodium than gluten-containing foods.¹⁵ Only 5% of gluten-free breads contain all four mandatory fortification nutrients (calcium, iron, niacin, thiamine), and only 28% are fortified with calcium and iron.¹⁵ Not all countries mandate food to be enriched or fortified. This could be a reason for the increased micronutrient deficiency in people with CD.¹⁵ According to the study by Jivraj et al., nutrient deficiencies were common in patients with CD and those without who were both following a gluten-free diet.¹⁶ It was found that the most common micronutrient deficiency was zinc, ferritin, and vitamin D. Of 221 participants, 182 were diagnosed with CD, and 39 were in the control group.¹⁶ There were no differences in the micronutrient deficiency within either group or how long they followed a gluten-free diet.¹⁶ This study concluded that the nutrient deficiencies might be related more to the gluten-free diet's poor nutritional value than those with CD malabsorption. This study

highlighted the importance of monitoring nutritional status in those with restrictive diets, whether those with CD, NCG/WS, or other reasons.^{14,16} Although the nutrients that are lower in gluten-free foods, Vitamin E, D, B12, iron, folate, magnesium, potassium, and sodium, are different in comparison to the study where zinc and ferritin were the most deficient, excluding vitamin D, this study did acknowledge that some of their participants were taking supplements, including B12, which could have camouflaged the deficiencies.¹⁶ We cannot exclude the data suggesting that those who follow a gluten-free diet may also pursue a healthier lifestyle and obtain these nutrients from other food sources.¹⁶

According to the study, “Effect of Gluten free diet on gut microbiota composition in patients with celiac disease and non-celiac gluten/what sensitivity,” it was shown that in all groups analyzed, CD, NCG/WS and healthy individuals, a gluten-free diet reduced the bacterial richness of the gastrointestinal tract.¹⁶ It affected the gut microbiota composition differently depending on the disease state.¹⁶ There was a decrease in the beneficial species of bacteria in healthy subjects who followed a gluten-free diet; however, for those with CD or NCG/WS, a gluten-free diet improved the gut microbiota by lowering the pro-inflammatory species.¹⁷ Suggesting that a gluten-free diet in a healthy individual may harm the gastrointestinal microbiome.

Quality of Life in Celiac Disease

In the past, patient health related to chronic illness and celiac disease has been evaluated through the biomedical model of medicine, often disregarding the significant influence of psychological and social factors on the patient’s overall well-being.¹⁸ “Health-related quality of

life is a broad concept that can be defined as the patient's subjective perception of the disease impact and the impact of treatments on the patient's daily life, well-being, psychological health, and social functioning"¹⁸ The burden of following a gluten-free diet in celiac patients is an essential factor. It has been demonstrated to be higher than many other chronic illnesses, including end-stage renal failure patients on dialysis.¹⁹ The burden of following a gluten-free diet includes finances, lack of education regarding the dietary guidelines, lack of cooking skills, and lack of health assistance.

In a study evaluating the quality of life of adult patients with celiac disease, 171 participants completed the questionnaire in Saudi Arabia.¹⁸ There was no correlation between higher educational levels; however, a population-based study in Spain found that a higher education level was associated with good compliance with a gluten-free diet and fewer complications.^{18,20} A different study found that high school students had significantly lower quality of life scores than those with college or graduate degrees.²¹ These discrepancies could be due to cultural differences.

Marital status in Saudi Arabia also showed no impact on those with celiac disease quality of life. Marital status was divided into married, live-in partner, single, divorced, or widowed and did not influence the total health-related quality of life.¹⁸ Comparatively, in a different study, higher quality of life scores for celiacs who identified as married than those who identified as single or engaged. However, this finding was not statistically significant.²¹

Males also had better health-related quality of life and higher quality of life scores.¹⁸ This was supported by a study that examined a questionnaire designed to assess the quality of life in individuals with CD.¹⁸ The findings revealed that males obtained higher scores on the CDQ (Celiac Disease Questionnaire) than females. Specifically, females reported experiencing more

significant distress from daily life limitations and perceived a higher burden associated with CD than their male counterparts.²⁰ Another study again proved this when women had more social anxiety than men, decreasing their quality of life.²¹

This study also found that adherence to a gluten-free diet was 83.9%.¹⁸ This is likely because of the Argentinian public health department that helps regulate the information for celiac patients. Participants on a strict gluten-free diet and those not taking antidepressants showed a higher quality of life.¹⁸ Interestingly, those who do not take antidepressants showed a significantly higher quality of life. This could be because the Argentinian people emphasize psychological needs, with the most significant number of therapies per capita.¹⁸ In this study, income and gender questions were the most frequently not answered, likely because of their sensitive nature. A separate study discovered a higher prevalence of anxiety and depression among individuals without CD when compared to those diagnosed with CD.¹⁶

Another study investigated the association between individuals with celiac disease and their adherence to a gluten-free diet, food insecurity, and health-related quality of life.²² It was discovered that 73% of participants adhered to a gluten-free diet, and 62% were experiencing mild to severe food insecurity. Food insecurity was significantly associated with poor adherence and overall health-related quality of life.²² Similarly, another study found that a lower income level also showed lower quality of life scores.²¹ Commitment to a gluten-free diet was not directly associated with health-related quality of life, but food insecurity was significantly associated with health-related quality of life. It can be noted that an increased concern for the ability to obtain and maintain any food supply can lead to anxiety and depression, therefore decreasing quality of life scores as well.²²

The findings of this study demonstrated a notable difference in the quality of life among individuals who followed a gluten-free diet for less than one year compared to those who adhered to it for ten years or more.²¹ Specifically, participants with a shorter duration of dietary adherence reported significantly lower quality of life. However, for those who had been on a gluten-free diet for ten years or more, there was a noticeable improvement in their quality of life.²¹

According to a study regarding the long-term effects of the gluten-free diet in NCG/WS, it was found that the quality of life between NCG/WS and people with CD did not differ. It showed that both groups face comparable difficulties and challenges in everyday life.²³ It was reported that NCG/WS and CD patients improved their quality of life after starting a gluten-free diet. However, those with CD had decreased quality of life when asked about dining out, travel, family, and career.²³ According to a validated 80-question survey called the State-Trait Personality Inventory, it was observed that gluten consumption in NCG/WS people led to higher depression scores in comparison to a celiac group. However, the anxiety, anger, and curiosity scores were similar between both groups.²⁴

Methodology

This study aimed to compare two groups: those with celiac disease and those who follow a gluten-free diet but do not have celiac disease (NCG/WS). The survey assessed participants' experiences with a gluten-free diet, quality of life, and overall health profile. The two groups differed in demographics and geographic locations; their only similarity was their CD diagnosis and adherence to a gluten-free diet. This study was approved via the IRB application process. The study design allowed for a direct comparison of the two groups using the same set of

questions, enabling the identification of similarities and differences in their lives. The survey comprised 12 questions, including two short answer questions and ten multiple-choice scale questions. The target population for the survey included individuals diagnosed with celiac disease or non-celiac gluten/wheat sensitivity who followed a gluten-free diet. A sample size of at least 30 participants was determined to achieve a 95% confidence level, with a 5% margin of error, for the measured/surveyed values. The survey instrument was developed based on research questions and information from a literature review. It was administered online via email, text, and social media platforms. Participants were provided with an anonymous Google Forms survey link, allowing them to complete the survey at their convenience. Personal identifying information, such as names, ages, and emails, was not collected at the survey initiation. The survey remained available online for one week. The response rate was 34, with 38% of those diagnosed with CD and 59 % with NCG/WS. The survey was distributed via word of mouth and social media to maximize response rates. The data was statistically analyzed with Google Forms and Google Sheets. The survey incorporated two short answer questions that were analyzed with descriptive statistics. The survey was voluntary, and informed consent was present before the survey. Participants were able to skip questions if they felt uncomfortable answering them, as well as stopping the study at any time. The limitations of this study include potential sources of bias, including reliance on self-reported data and the use of social media platforms for recruitment.

Results

This study addresses the differences in the quality of life and the health profile of individuals with and without celiac disease. The demographics included anyone diagnosed with

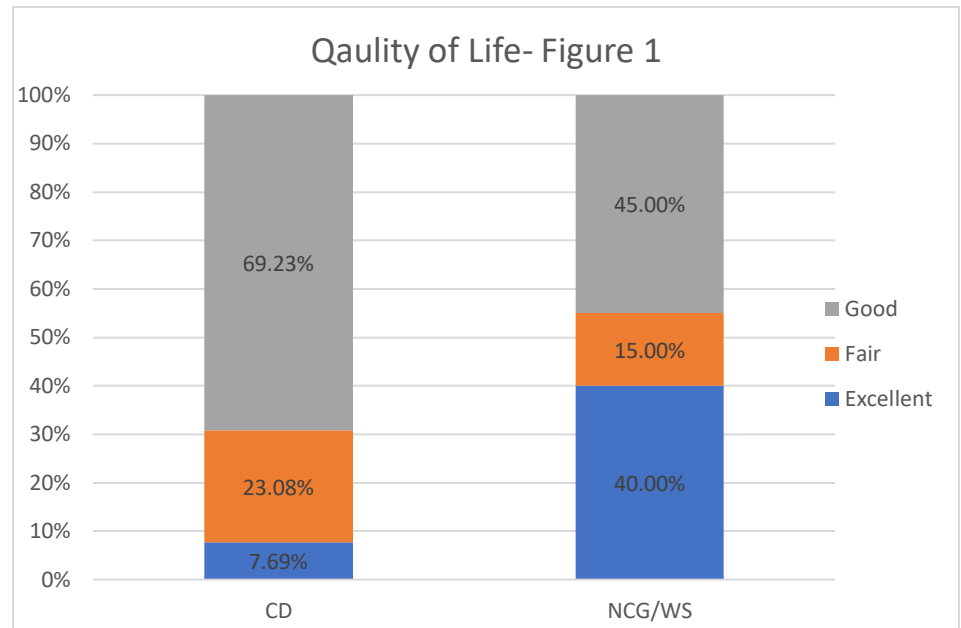
celiac disease or following a gluten-free diet for personal reasons. The overall response rate was 34 participants: 13 with diagnosed celiac disease, 20 with non-celiac gluten sensitivity, and one who answered “other.” The “other” response listed that they follow a gluten-free diet due to the diagnosis of collagenous colitis.

Apart from celiac disease, the results showed multiple reasons for following a gluten-free diet, including IBS, GI symptoms (abdominal pain, bloating, constipation, vitamin/mineral deficiencies), wheat allergy, thyroid disease (Hashimoto’s), dermatologic (rosacea, acne), refractory celiac disease type 1, headaches, brain fog, and anxiety. The most common physical symptoms included diarrhea (mentioned 12 times), bloating (10), constipation (10), headache (9), fatigue (6), abdominal pain (5), brain fog (5), and rash (4).



Regarding the participant’s quality of life, the following data was collected. The data provided insight into adherence to a gluten-free diet, resulting in 92% of those with CD reporting a very strict diet and only 45% of those with NCG/WS reporting a very strict diet. No participant selected the options for not very strict and not at strict. When the participants were surveyed about their quality of life after following a gluten-free diet, none of them chose the options of poor or very poor. For those with CD, about 8% rated their quality of life as excellent, while 40% of NCG/WS rated their quality of life as excellent. Further data is depicted in Figure 1.

Of all the participants diagnosed with CD, 38.46% mentioned that they often feel very limited or restricted due to their diet. In contrast, none of the participants with NCG/WS reported feeling limited or restricted very often.

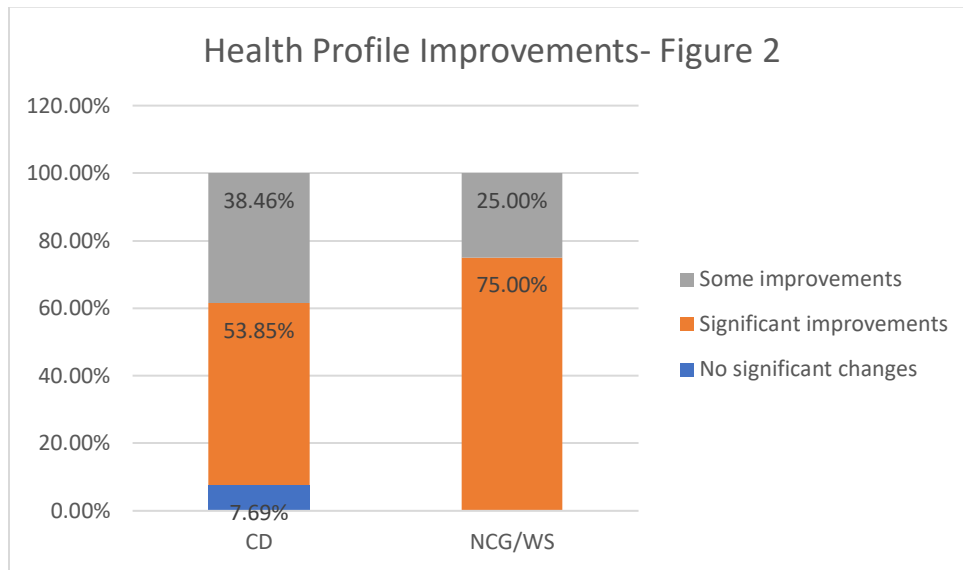


During the study, participants were questioned about their anxiety due to their dietary restrictions, with a rating system from 1 to 5, where 5 represented the highest level of anxiety. The results showed that 30% of CD participants rated their anxiety at a 4 or 5. In contrast, 60% of NCG/WS participants reported a rating of 4 or 5, indicating a higher overall level of anxiety regarding their dietary restrictions.

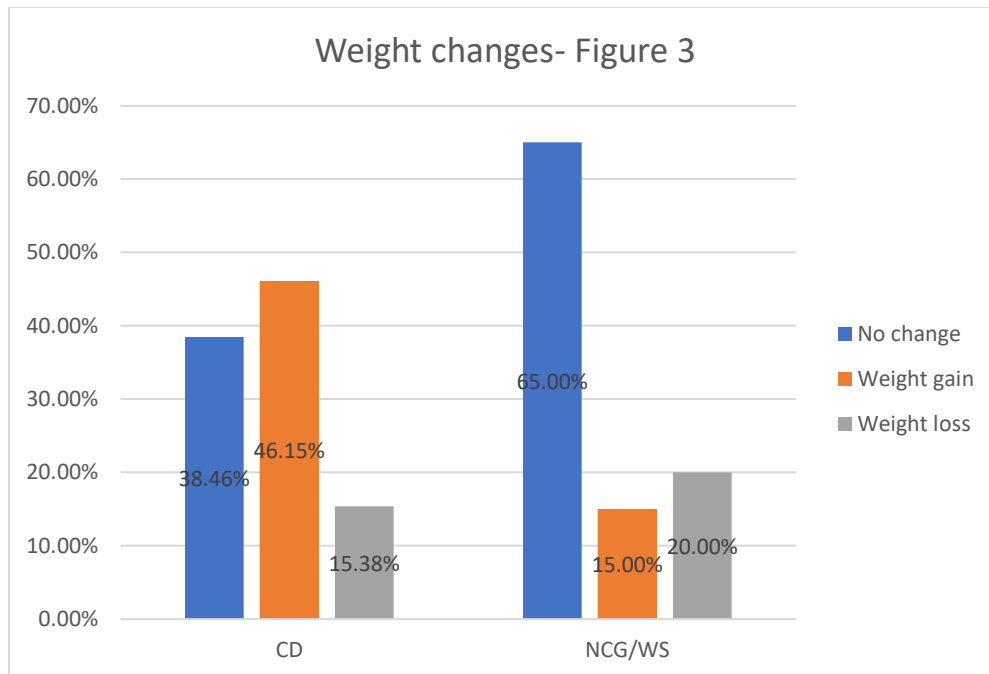
When asked about their level of knowledge in managing their diet, about 50% of CD and NCG/WS participants reported feeling very informed. None of the CD participants felt uninformed, while about 20% of NCG/WS felt somewhat or not informed. This could suggest that those with CD may have received more education about their diagnosis than those with NCG/WS.

The following questions were asked regarding the participant's health profile, and data was collected. When asked, Have you experienced any improvements in your overall health

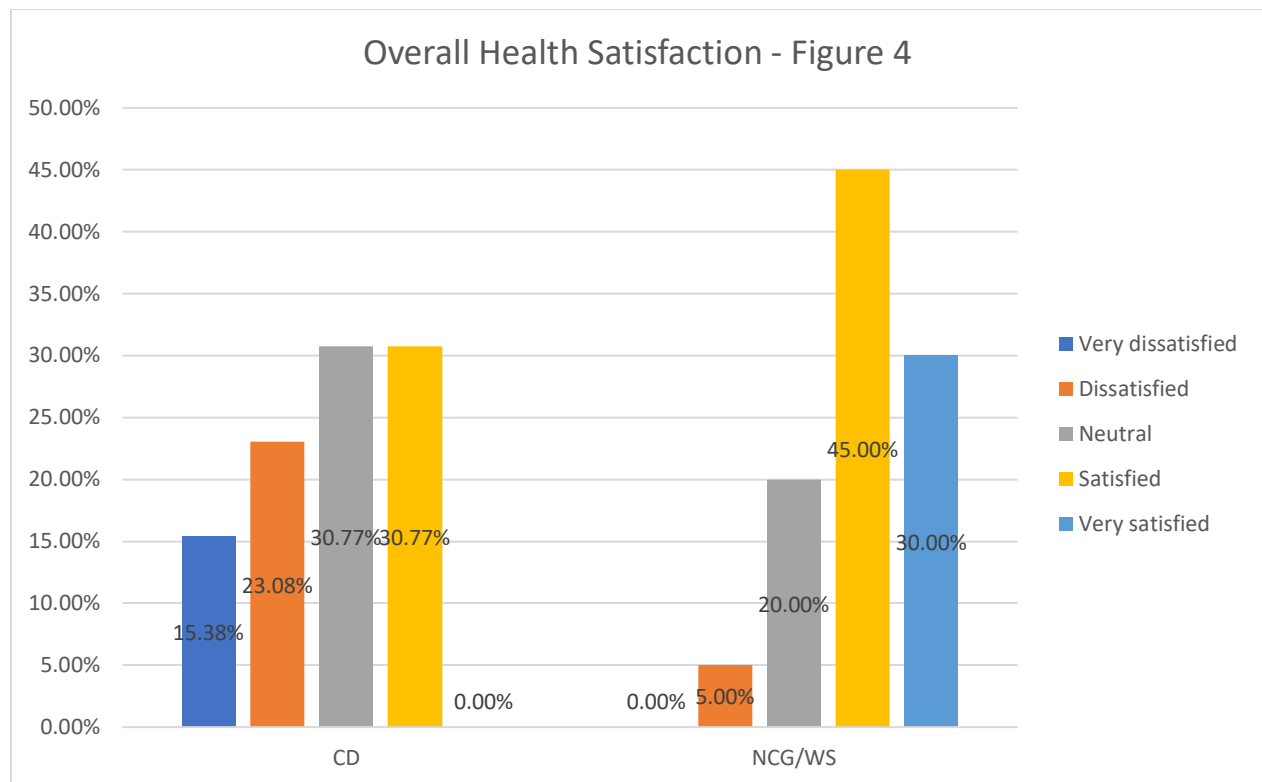
since following your dietary requirements, neither group had participants who selected “decline in health?” All NCG/WS participants reported some, if not significant, improvements in their diet, while about 8% of the CD participants did not see any changes once beginning the diet. Further data analysis can be seen in Figure 2.



As per the reports of both groups, approximately half of the individuals in each group have reported experiencing a deficiency of some kind in vitamins or minerals, while the other half have not. Participants were asked about their weight changes, and the results showed that among those with CD, 46.15% experienced weight gain, 15.38% experienced weight loss, and 38.46% reported no change. In the NCG/WS group, 15% experienced weight gain after starting a gluten-free diet, 20% experienced weight loss, and the remaining 65% did not experience any weight change.



All participants were asked, “How satisfied are you with your overall health?” No one with CD reported being very satisfied with their overall health, whereas 30% of NCG/WS reported being very satisfied. About 40% of CD participants were dissatisfied or very dissatisfied with their overall health, but only 5% of those with NCG/WS reported any dissatisfaction. This suggests that those with NCG/WS are more content with their health overall than those with CD. Study limitations included small sample sizes, self-reporting bias, and potential confounding factors that were not controlled for.



Discussion

A gluten-free diet can affect a person's quality of life and health, depending on several factors. Whether someone follows this diet for non-celiac reasons or as a necessary treatment for their disease, both patients and healthcare providers need to understand the different aspects of this diet. When surveying a group of NCGW/S participants, there were multiple reasons for adhering to a gluten-free diet. Arslain et al. also found that acne and digestive health were the top reasons reported, similar to the findings of the top 8 symptoms reported as CD and NCG/WS.⁴

Individuals with celiac disease (CD) appeared to have a stricter gluten-free diet than those with non-celiac gluten sensitivity/wheat sensitivity (NCG/WS). This aligns with the recommended treatment for CD patients. However, the quality of life of CD and NCG/WS

patients varied, contrasting with a study conducted by Tovoli et al. Their study found no significant difference in the quality of life between the two groups. According to this current study, individuals with CD have an excellent quality-of-life rating of 7.69%, while those with NCG/WS have an excellent quality-of-life rating of 40%.

Of the participants, 38.46% of those with CD frequently reported experiencing limitations or restrictions with their diet. However, none of the participants with NCG/WS said they felt restricted very often. Interestingly, the NCG/WS group experienced higher levels of anxiety despite not needing to follow a strict diet like those with celiac disease. According to the survey, the NCG/WS group had a better quality of life overall. Conversely, those with CD reported a decreased quality of life and felt more restricted in their daily diets but experienced slightly less stress overall. This could be due to the higher level of education regarding CD among this group, as they felt more informed about their diets.

Interestingly, those with NCG/WS had an overall improvement in their health when they began a gluten-free diet. When looking at the health profile and vitamin and mineral deficiencies, both groups experienced deficiencies. No other questions were asked regarding types of vitamins or minerals or if their deficiencies were found before or after beginning a gluten-free diet. Similarly, these results compare with the study by Jivraj et al., which found that nutrient deficiencies were common in people with CD and NCG/WS.¹⁶ Regarding weight changes after starting a gluten-free diet, 46.15% of participants with CD reported weight gain, and 15.38% reported weight loss. Based on previous studies, weight gain was experienced in both groups.¹⁴ Baseline BMI was not surveyed during this current study. Therefore, it is still being determined if the weight gain now puts these individuals into a healthy weight category and if they were previously malnourished before beginning a gluten-free diet.¹⁴ Per the 2009-

2014 NHANES study, it was determined that a gluten-free diet might be beneficial for weight management; however, according to this current study, 20% of those with NCG/WS reported weight loss, and 15% reported weight gain with a majority having no changes in their weight.³ There was a noticeable difference between the CD and NCG/WS groups regarding their overall health satisfaction. None of the participants in the CD group reported feeling satisfied with their overall health, while 30% of those in the NCG/WS group reported feeling very satisfied.

In the future, to improve patient care, it would be beneficial to offer additional nutrition resources and education to healthcare providers during their schooling. It's also important to monitor individuals who follow gluten-free diets for potential nutrient deficiencies, regardless of whether they have been diagnosed with celiac disease. Furthermore, offering a quality-of-life survey to all celiac patients during their yearly check-ups would be helpful. The community needs to be educated about the strict limitations individuals with CD and NCGWS face.

However, surveys that compare different things have certain limitations. They may have biases in selecting participants or response rates, rely on self-reported information, and require further proof to establish cause-and-effect relationships. Nevertheless, this survey provided valuable insights into the effects of diseases, patient preferences, treatment efficacy, and the effectiveness of various interventions. Ultimately, this information can aid in improving patient care, developing new treatments, and deepening our understanding of specific diseases.

Conclusion

In conclusion, participants with Celiac Disease reported feeling more restricted in their diets and had a lower quality of life but were more informed. Despite adhering to a gluten-free diet, their health profiles did not show notable improvements, and they even gained weight. This is likely due to their lower initial BMIs. They were also less satisfied with their overall health. On the other hand, Non-Celiac Gluten/Wheat Sensitivity participants felt less restricted by their diets. They had a higher quality of life but were more anxious and felt less informed. They did experience better outcomes regarding their symptoms after starting a gluten-free diet and reported more satisfaction with their overall health. However, many did not experience any change in their weight. Lastly, receiving comprehensive education on adhering to a gluten-free diet for those with CD, NCG/WS and even those without medical conditions seems imperative. This will enable them to gain a deeper insight into their nutritional needs and overall health and significantly improve their quality of life.

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