Developing a Local Networking Group for Adults with Celiac Disease in Southern Virginia

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Abstract

Celiac disease is an autoimmune disease affecting the microvilli of the small intestine. Celiac disease requires a strict diet free of wheat, rye, and barley. Even a minimum exposure of a few crumbs can cause microvilli damage and can cause symptoms for up to two weeks. Individuals with celiac disease often report decreased quality of life due to the social and emotional challenges of maintaining a strict gluten-free diet. Support groups have been shown to be an effective way for individuals to navigate social and emotional challenges for disease management. The purpose of this project was to develop a support group for individuals with celiac disease in southern Virginia to address emotional support, access to evidence-based research, and build empowerment to adhere to a strict gluten-free diet. Support groups

The pilot program was delivered as a virtual support group. It focused on providing emotional support and empowerment by discussing hidden sources of gluten, balancing a healthy diet, and social navigation. Additionally, it served as a safe space for participants to feel heard, share their challenges, and learn from others.

Evaluation surveys indicated that participants felt heard and their learning needs were met by the support group. Implications arose as only one individual participated. The results are limited but support the existing literature that virtual support groups can provide emotional support for adults with celiac disease.

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Introduction

Background and Setting

Celiac disease is an autoimmune disease affecting the microvilli of the small intestine. Currently, the only treatment for celiac disease is a strict gluten-free diet. Celiac disease was first described in modern medicine in 1887 by Dr. Samuel Gee, who hypothesized that celiac disease could be treated through diet.[1] In 1924, Dr. Sydney Hass hypothesized that a banana diet (high in bananas and no starch) could cure celiac disease.[1] A study in 1952 showed that celiac disease patients improved when gluten was removed from their diets.[1] Through the 1990s, specific genes (HLA-DQ2 or HLA-DQ8) and tissue transglutaminase (TtG) were found to be associated with celiac disease and accepted as an autoimmune disease.[1] Since the 1990s, no significant advancements have been made in the treatment of celiac disease.

Celiac disease requires a diet free of gluten, which includes wheat, rye, and barley as well as malt derivatives from barley. The threshold of gluten exposure for an individual with celiac disease is about 10 milligrams (mg) of gluten a day.[2] This is equivalent to a few crumbs of bread.[2] Due to the low threshold of gluten exposure an individual with celiac disease can tolerate, monitoring cross-contact is vital to avoid an immune response that attacks the small intestine.[3] Gluten exposure reactions can vary from person to person as there are over two hundred known symptoms of celiac disease, and reactions can last up to two weeks.[4] Untreated celiac disease can lead to early-onset osteoporosis or osteopenia, gallbladder infection, heart disease, infertility, iron-deficiency anemia, liver failure, malnutrition, neurological symptoms, pancreatic insufficiency, small intestine cancer, and vitamin/mineral deficiencies.[3] Eating a one-hundred-percent gluten-free diet is essential for an individual with celiac disease to avoid long-term health conditions.

It is estimated that one in one hundred individuals worldwide have celiac disease, and only thirty percent are accurately diagnosed.[3] Currently, there are forty-five celiac centers in the United States, according to the National Celiac Association (NCA).[5] The only celiac center in the state of Virginia is the Celiac Clinic at the University of Virginia (UVA) Digestive Health.[5] Patients that are seen by the Celiac Clinic at UVA Health are typically referred by another provider or seen by self-referral. If patients come to the clinic with a positive celiac disease blood serology, they are then seen by the doctor and dietitian to discuss endoscopy testing and a gluten-free diet. Alternatively, if patients come to the clinic wanting testing for celiac disease, they speak with the doctor and then get a blood test for celiac disease. Pending the result and medical appropriateness, an endoscopy is then performed. When positive results from testing come back, patients will meet with the doctor and dietitian and discuss the diagnosis. The following patients will follow up in the clinic at three months, six months, and then one-year post-diagnosis. After one year and once labs have normalized patients will then follow up in the clinic yearly.

Statement of the Problem

Patients of the Celiac Clinic at UVA Health reported they were interested in attending a virtual support group for individuals with celiac disease on navigating its challenges.

Significance of the Problem

Currently, there is no support group associated with the Celiac Clinic at UVA Health.[6] From the early 2000s to 2010, there was a celiac disease support group associated with the Celiac Clinic at UVA Health, but it dissolved due to the physician and dietitian leaving UVA Health. This project aims to provide support for individuals with celiac disease in the southern Virginia region.

There is an abundance of misinformation online regarding adherence to a gluten-free diet. The project will provide evidence-based research regarding best practices for managing celiac disease. The use of evidence-based knowledge discussed in the support group will improve patient outcomes and build credibility and trust in the field of dietetics.

Needs Assessment Data

Data were collected from seven individuals with celiac disease in Charlottesville, Virginia. Questions were asked verbally at the end of a clinic visit. The third question was open-ended. *If no was answered for #1, no further questions were asked.

Table 1. Needs Assessment Questionnaire Responses from Target Audience (n=7)

Questions		
Would you be interested in attending a support group for individuals with celiac disease?	**Yes**	**No**
	5	2
Do you have a preference for virtual or in-person?	**Virtual**	**In-person**
	4	1
Are there any topics you would like to discuss with other individuals with celiac disease?	Tips and suggestions on dining out	3
	Hidden forms of gluten	1
	Food labeling	1

National Celiac Disease Association

The National Celiac Association (NCA) is a non-profit organization dedicated to empowering individuals with celiac disease.[7] It provides evidence-based knowledge and resources on its website.[7] Resources include educational handouts, tools to find providers, restaurants, and food banks.[7] Additionally, the NCA has a section on how to stay connected, one of these being a monthly virtual support group for individuals with celiac disease.[8] The NCA hosts a monthly virtual support group for individuals with celiac disease. A virtual meeting was held with two NCA representatives who facilitate the support group. Information was given on how to start a local support group in southern Virginia.[8] Representatives discuss expected outcomes and to send invitations two weeks before the proposed data.[8] The NCA has an informal partnership with the Celiac Clinic at UVA Health.[6] The NCA recognizes the Celiac Clinic at UVA Health. This connection gives credibility to the Celiac Clinic at UVA Health as the NCA is a nationally recognized organization.

Purpose of the Project

The purpose of this project was to develop a support group for individuals with celiac disease in southern Virginia to address emotional support, access to evidence-based research, and build empowerment to adhere to a strict gluten-free diet.

The main question the research aims to address is:

- What impact does a virtual support group for individuals with celiac disease have on participants' self-efficacy to adhere to a gluten-free diet?

Project Objectives

Process Objective:

- The pilot support group "Charlottesvilla" will be piloted on April 22, 2025, at 12:00 pm Eastern time for a group of adults, with an enrollment goal of at least five participants.

Outcome Objective:

- Upon completion of the pilot support group on April 22, 2025, 75% of participants will have gained confidence and self-efficacy in adhering to a gluten-free diet.

Definition of Keywords/Terms

- Celiac Disease: an autoimmune disease that occurs in genetically predisposed people where the ingestion of gluten leads to damage to the small intestine.[3]
- Gluten: a protein found in wheat, rye, and barley.[3]
- Autoimmune Disease: a health condition that happens when one's body attacks itself instead of defending itself.[9]
- Cross-Contact: gluten-free food comes in contact with a gluten-containing food.[10]
- Tissue transglutaminase (tTg): an enzyme that modifies gluten and inaccurately tags gluten, causing the body to attack itself.[11]

Literature Review

Review of Literature

The purpose of this review of literature is to summarize the scientific evidence as it relates to celiac disease, barriers to eating a gluten-free diet, and the effect of support groups in disease management.

Celiac Disease Pathophysiology

Celiac disease is an autoimmune disease that causes damage to the mucosal lining of the small intestines.[12] Gluten is a protein found in wheat, rye, and barley.[3] Gluten is commonly found in baked goods, soups, and sauces. Gluten is ingested by mouth and then brought to the small intestine for digestion. Gluten is broken down to gliadin and glutenin and moves from the lumen to the mucosa by leaky gap junctions.[12] Next, deamination occurs as tissue transglutaminase (tTg) enzyme converts the glutamine residues on the gliadin into glutamic acid.[12] The result of deamination results in the presentation of antigen-presenting cells (APC) in the lamina propria.[12] The APC then presents the deaminated peptides to the T cells, activating the T cell and triggering an inflammatory response.[12] This inflammatory response targets the mucosa of the small intestine, causing damage to the microvilli in individuals with celiac disease.[12]

The damage to the mucosa of the small intestine due to untreated celiac disease causes malabsorption and can lead to nutritional deficiencies.[12] Deficiencies of vitamins D, E, A, K, B-12, B-6, folate, and minerals iron, calcium, zinc, and copper can be directly linked to untreated celiac disease.[12] Additionally, gluten-free grains are often low in thiamin, riboflavin, niacin, and folate as they are not enriched as many gluten-containing counterparts are.[12]

Barriers of Celiac Disease

Celiac disease requires strict adherence to a gluten-free diet, which can cause some individuals with celiac disease decreased quality of life.[12] Individuals and family members of those with celiac disease often report significant disruption in social events.[13] Individuals often share that they avoid events entirely due to accidental exposure to gluten and or having to bring their own food.[13] Individuals with celiac disease report that their social life is the most significantly disrupted due to celiac disease.[13] Additionally, individuals share that the spontaneity of their social life is restricted when choosing safe restaurant options, as well as meal planning and preparation to ensure safe options.[13]

Individuals with celiac disease often report feeling like a “nuisance” to their family in friends.[13] Individuals often report avoiding social events entirely or feel shame or guilt for attending events. [14] Individuals with celiac disease report the disturbance of “traditional gender arrangements,” especially to their spouses as they report they do not understand the severity of celiac disease.[13] Individuals share that family/friends oftentimes do not understand the severity of their disease, assist in label reading, or sympathize with the disruption of activities of daily living that celiac disease causes.[13] Low family support can hinder one's likelihood of adhering to a strict gluten-free diet.[15]

Access to gluten-free products at grocery stores and accommodating restaurants is essential to one's likelihood of adhering to a gluten-free diet.[15] Individuals report even with access to gluten-free products they often do not like the taste and or texture of the gluten-free counterpart.[15] Individuals often report the barrier of ensuring restaurants offer gluten-free products with cross-contact procedures in place.[13] Individuals with celiac disease report that most restaurants are unable to accommodate their dietary needs due to a lack of knowledge about their condition and cross-contact procedures.[15]

Virtual Support Groups

Virtual support groups can reach a large number of people, and are especially helpful to individuals living in rural areas. The Health Belief Model has six constructs to describe preventive health behavior. Individuals in geographic regions often report depression and isolation, creating a support group that meets virtually removes the perceived barrier of the stigma of being in a geographically isolated region.[16] The Celiac Clinic at UVA Health in Charlottesville, Virginia, is the only celiac center in Virginia that provides care for individuals across the state, including rural areas. Creating a virtual support group has its advantages, but it also has perceived barriers such as technological issues, reduced interpersonal connections, limited access to high-speed internet, and difficulty creating a sense of community support on a virtual platform.[16]

A key component of the success of a virtual support group is setting up guidelines about Zoom etiquette.[16] A gap in this research is what the best community guidelines for Zoom etiquette are and how the facilitator can appropriately present guidelines to the group. Studies have shown that the perceived benefit of attending virtual support groups has provided emotional support overall. [17] Virtual support groups, even with their disadvantages, provide emotional support to individuals and reach individuals in rural areas.

Gluten-Free Resources

Educational resources are often given to newly diagnosed patients with celiac disease. Resources are vital for an individual with celiac disease, as many lifestyle changes are needed to adhere to a strict gluten-free diet. Self-efficacy from the Health Belief Model plays a large role in one's adherence to a gluten-free diet. Printed handouts are an effective way to reiterate verbal teaching and serve as a resource for future review. It is important to empower the individual with knowledge about how to handle their new diet in social settings such as the workplace.[18] Additional information to educate patients about rights protected by the Americans with Disabilities Act. Disability accommodations could include absence from work/school.[18] Gluten-free software, such as food label readers, can be a great resource for individuals to increase confidence and self-efficacy; it can also take away the perceived barrier of label reading for individuals with celiac disease.[19] There is little research available about the scope of education provided by healthcare providers to newly diagnosed patients with celiac disease.

Questions Regarding Celiac Disease

Adhering to a strict gluten-free diet can be very mentally and physically challenging. There is a plethora of information available on the internet; however, it can be difficult for patients to decipher which resources provide accurate, evidence-based information. With many resources easily accessible online, it is hard to decipher which resources provide accurate, evidence-based information. Reading food labels and the fear of cross-contact for individuals with celiac disease requires additional research for individuals. According to et al., 60% of websites were missing at least 50% of the core information about celiac disease necessary to adhere to a gluten-free diet.[20] Having these large gaps in web resources can cause continued frustration as well as additional questions for individuals with celiac disease and how to manage their diet. Asking restaurants questions about cross-contact procedures is essential for individuals with celiac disease. Sainsbury et al. found that 33% of participants in the study did not ask about dining-out options regarding cross-contact procedures.[21] The perceived barrier of speaking to a restaurant associate about these procedures outweighs an individual's adherence to the diet. It is unclear what information individuals with celiac disease commonly search for on search engines, as the intent behind the search is unknown, and it is uncertain whether the individual has celiac disease.

Summary

Overall, this literature review showcases the barriers to managing celiac disease. Understanding the disease is essential to one's adherence to a gluten-free diet. Medical providers need to provide evidence-based education and counseling on the gluten-free diet. The vast amount of information online may cause confusion to individuals with celiac disease. Individuals with celiac disease often report social isolation due to the restriction of the diet itself. Emotional support and association with others with celiac disease are correlated with higher adherence.[15] Virtual support groups can reach a vast number of individuals, as the Celiac Clinic at UVA Health supports and can provide emotional support and a sense of community.

Project Methodology and Design

Theoretical Framework

The Health Belief Model is a theory that was explained by social psychologists to grasp preventative health behavior. [22] The model explains how "individuals perceive health threats and decide how to act based on the value individuals place on a particular goal and the likelihood that actions taken towards that goal will be successful in achieving the goal." [22] The Health Belief Model has six main constructs that further explain the model.

One construct is a cue to action. This construct explains whether certain surroundings can influence the action an individual takes.[22] These can include external cues such as a virtual support group. The research question is, "*What impact does a virtual support group for individuals with celiac disease have on participants' self-efficacy to adhere to a gluten-free diet?"* applies to this construct of the Health Belief Model as it evaluates if the external cue (the support group) motivates one in the decision-making process of adhering to the health intervention (a strict gluten-free diet).[22] This construct directly relates to the research question by evaluating whether the environment created by a celiac disease support group encourages individuals to adhere to a strict gluten-free diet.

Another construct of the Health Belief Model is perceived severity. This construct explains an individual's understanding of the severity of the disease and or unfavorable outcomes if no additional actions are taken.[22] After an individual is diagnosed with celiac disease, educational materials are often given to patients to help them understand the condition. These should address what celiac disease is, the associated conditions, treatment (strict gluten-free diet), and resources. outcomes. Additionally, a key part of the education that healthcare providers impart to newly diagnosed patients with celiac disease is the potential consequences of not following a gluten-free diet. This reinforces the perceived severity construct of the Health Belief Model.

As mentioned previously, self-efficacy is vital for adherence to a strict gluten-free diet and is another construct of the Health Belief Model. In the Health Belief Model, self-efficacy is explained as an individual's belief in the capacity to perform a behavior or task effectively. [22] Additionally, it explains the likelihood of an individual engaging in the desired behavior. [22] This relates to the component of information. Feeling informed is a key component of self-efficacy. The more knowledge and information a person has, the higher confidence and self-efficacy they will have to adhere to a gluten-free diet.

Research Design

This program was designed as a virtual support group for patients and caregivers for individuals with celiac disease in southern Virginia. This support group included a brief presentation about which foods contain gluten, strategies for navigating food at social gatherings, tips for understanding food labels, and recommendations for dining out with celiac disease. The presentation was followed by a guided, interactive conversations. This support group was modeled after the National Celiac Association support group.

Methodology

A mixed-methods approach was used to evaluate the piloted support group. A narrative inquiry allows observation of individuals with celiac disease who have shared their personal experiences. This approach collected in-depth qualitative data about the study population. Gaining this knowledge will allow a better understanding of support group members' beliefs and attitudes and will allow comparison to the six constructs of the Health Belief Model.

Recruitment

Two weeks before the pilot support group, an electronic medical record email notification (MyChart) message was sent to all patients who were seen by the Celiac Clinic at UVA Health in the past year (April 2024 to April 2025). A typed message and flyer were sent in the message advertising the support group. (See Appendix A, B) The initial goal was to recruit at least five participants to attend the support group and give feedback.

Program Materials

A PowerPoint presentation was developed for the first part of the program to provide structure and evidence-based knowledge on celiac disease (See Appendix C). Participants were encouraged to ask any questions or share any thoughts regarding the PowerPoint materials. The facilitator then guided the group through a conversation based on five questions.

Questions:

1. Has anyone had any recent success in eating out in the area where they reside?
2. How do you maintain a positive outlook when you face difficulties related to celiac disease?
3. What do you find is best to educate friends/family with celiac disease?
4. What piece of advice do you wish you were given when you started eating gluten-free?
5. How do you navigate social events?

Data Collection

During the event, open-ended questions were asked to guide the conversation. Individuals' stories as well as attitudes and beliefs expressed, were collected by the facilitator. Post-survey questions were given at the end of the session via a Google form. (See Appendix D) The form was anonymous and did not collect participants' names or email addresses. The last question was an option, open-ended question asking for ideas for future improvements. (See Appendix D)

Questions:

Responses to questions were requested on a scale of one to five, with one being strongly disagree and 5 being strongly agree.

1. Was the information shared in the PowerPoint relevant to your learning needs?
2. Did you feel your needs were met by the support group?
3. Was there a sense of community in the group?
4. On a scale of 1 to 5, how satisfied were you with the support group?
5. Did you feel comfortable sharing your concerns in a virtual format?
6. Any additional comments or suggestions (fill in the blank- optional)

Outcomes

A support group event was held virtually on April 22, 2025, at 12:00 pm. One participant joined the session.

Table 2. Post Survey Results from Celiac Support Group Participants (n=1)

"Questions will be rated on a scale from 1 to 5, with 1 meaning "strongly disagree" and 5 meaning "strongly agree"

Question	**Responses**
Was the information shared in the PowerPoint relevant to your learning needs?	5 - strongly agree
Did you feel your needs were met by the support group?	5 - strongly agree
Was there a sense of community in the group?	5 - strongly agree
On a scale of 1–5, how satisfied were you with the support group?	5 - strongly agree
Did you feel comfortable sharing your concerns in a virtual format?	5 - strongly agree

Any additional comments or suggestions (fill in the blank- optional)	*“This was a great support group.”*

Table 3. Qualitative Feedback

Stakeholder	**Qualitative Feedback**
UVA Registered Dietitian[6]	“Abigail did a great job showing empathy in the support group.” “Abigail did an awesome job asking follow-up questions and facilitating conversation during the support group.”
National Celiac Association Representatives[8]	“Expectations that only one individual may attend the piloted support group”
Program Participant	“It has taken me over 18 years to figure out a gluten-free diet; I had no clue about cross-contact.” “I did not know there were sources of hidden gluten, such as supplements.” “I never realized how good I would actually feel when I finally stopped getting hidden sources of gluten in my diet.” “It is hard to eat out” “Frustration regarding food labels.”

Discussion

Post-Survey Feedback Analysis

Although there was only one participant in the pilot support group, the survey results show preliminary insight into the subject. The results should be interpreted with caution due to the limited sample size. However, this response can still highlight initial trends that a virtual support group can be a good medium for providing learning, support, and a sense of community. Additionally, the participant commented, *“This was a great support group.”* This positive response can serve as a basis for the future growth of a virtual support group for individuals with celiac disease.

Registered Dietitian Feedback Analysis

A registered dietitian oversaw this project and supported the facilitation of the support group. Comments were made on the intern evaluation form: “Abigail did a great job showing empathy in the support group,” and “Abigail did an awesome job asking follow-up questions and facilitating conversation during the support group.” These comments create the theme of support that corresponds to the participant's post-survey results.

National Celiac Association Representatives' Feedback Analysis

A meeting was held with the National Celiac Association Representatives. The National Celiac Association has a monthly virtual support group and supports smaller celiac disease support groups throughout the United States. During the interview, the representatives shared “Expectations that only one individual may attend the piloted support group.” They further elaborated, mentioning that not considering it a failure if one individual shows up, as it is still providing emotional support to the participant. Additionally, the representative reported that one participant was normal for a first-time support group in the area.

Program Participation Feedback Analysis

In the pilot support group, a participant stated, “It has taken me over 18 years to figure out a gluten-free diet; I had no clue about cross-contact.” This supports the literature that most online resources are missing at least 50 percent of permanent knowledge about celiac disease and a gluten-free diet. [20] The statement made by the participant and supporting literature support the idea that there is a lack of information given to individuals with celiac disease on how to maintain a gluten-free diet. A participant stated, “I did not know there were sources of hidden gluten, such as supplements,” and further elaborated that a “provider had suggested the individual take an over-the-counter supplement that contained gluten for over sixteen years.”

This statement reinforces that providers and handouts are missing all the necessary information regarding going gluten-free.

Qualitative Summary

These outcomes further support the Health Belief Model, the construct of perceived severity, likely due to the lack of information given to individuals when they are diagnosed with celiac disease. Verbal and written information provided by healthcare providers can help guide the individual in adhering to a strict gluten-free diet, but more counseling and discussion allows participants to understand how to apply the information and recommendations to their unique circumstances. A participant from the pilot support group stated, “I never realized how good I would actually feel when I finally stopped getting hidden sources of gluten in my diet.” The participant, due to the information provided at diagnosis, did not understand the perceived severity of continuing to include gluten in the diet and the perceived benefit of better health when adhering to the diet.

Discussion Summary

This pilot support group provided valuable opportunities to evaluate the development of a virtual support group for individuals with celiac disease in southern Virginia. Through this process of developing and implementing a virtual support group, many lessons were learned for future iterations of the support group. Key insights from the literature review showcased the importance of tailoring the support group to the unique emotional and informational needs of participants, while real-world experience underscored practical recruitment and scheduling. The hands-on experience allowed the implementation of a support group at a major hospital. Future improvements will focus on participation, identifying the best meeting times, and continuous program feedback on the support group’s effectiveness.

Strengths

A major strength of this study was the target audiences reached. One hundred and one individuals were invited to participate, and all had confirmed celiac disease. Having this common ground among participants enables a level of comfort to share freely.

An additional strength of this study was the Celiac Clinic's continual informal partnership with the NCA. The relationship between the NCA and the Celiac Clinic at UVA Health builds credibility and allows for the collaboration of resources and best practices for individuals with celiac disease. It also enhances expertise as the NCA provides continual updates on research and evidence-based practice. This partnership also provides guidance and best practices that the NCA has found for their monthly support group to implement in this study.

Lastly, another strength of this study was the use of the virtual platform to provide evidence-based nutrition knowledge. A virtual support group provided accessibility to individuals in a large geographic region, similar to the Celiac Clinic at UVA Health's patient population. It was also offered at zero additional cost to UVA Health, as employees/interns have a Zoom account with their employment. Additionally, it was free for participants to join.

Limitations

The main limitation of this project is that there was only one participant attending the support group. This limits the peer support aspect of the group. Peer support can be a beneficial connection to hear stories of challenges and successes. As there were two facilitators present, the peer-to-peer support was significantly limited. As facilitators were able to provide one-on-one support, the participant did not have a sense of community or other perspectives. Due to the sample size, the facilitators had to shift more to a counseling role, which was not the original intent of the project.

Implications and Opportunities for Future Growth

Creating a celiac disease support group in southern Virginia may limit the scope and overall size, but it provides a highly personalized group meant to foster individuals in a similar setting. Implications of widening the population group to the whole state of Virginia or even across the United States may dilute the personalized effect of the selected size of southern Virginia. Having individuals across the United States may negatively impact the peer-to-peer relationship, especially for those in rural Virginia who may not have access to different restaurants or stores others may use.

In the future, hosting multiple support groups at different times could increase participation rates. Offering an evening group meeting may help to accommodate those with work schedules that prohibit them from attending during the daytime hours.

Another strategy to consider in the future implementation of this group is to adjust marketing methods to make recruitment more personable. For example, invitations could be made more personable by starting to invite people to the support group in the fall, and then have the electronic medical record email notification sent as a reminder.[23] Personal invitations could be discussed at the end of clinic appointments by the provider or registered dietitian. This personal invite and the social aspect of accountability through a verbal invitation could have produced more participants.[23] A plan for future recruitment of the support group will be essential for future research. In the future, broadening the target population to outside of southern Virginia could also increase participation.

Additionally, incentives could be provided to individuals who attend the virtual support group.[23] This could be added to the electronic medical record email notification sent to individuals to entice them to attend. An option that would not cause financial constraints for

UVA Health would be for the facilitator to reach out to local gluten-free restaurants and grocery stores who were willing to donate items for this support group. Having incentives and finding incentives that support the populations needs could increase one's motivation to attend a support group.[23]

Future directions of the support group should take into consideration that expanding the geographic area of the support group could inhibit the peer-to-peer relationship. Adding an incentive that could come across as a need to the population could additionally increase participation.

Conclusion

Celiac disease is a condition that requires a multidimensional approach for successful management of a strict gluten-free diet. Based on the review of the literature, there is a gap in resources provided to individuals newly diagnosed with celiac disease. Additionally, many web resources provide inaccurate or incomplete information. Social navigation is an unpredictable and challenging aspect of celiac disease. Even though participant results are limited, the data support the existing literature that virtual support groups can increase one's self-efficacy and adherence to a gluten-free diet. Approaches for future research and projects can include expansion of sample size and being a personable recruiter for the planned event.

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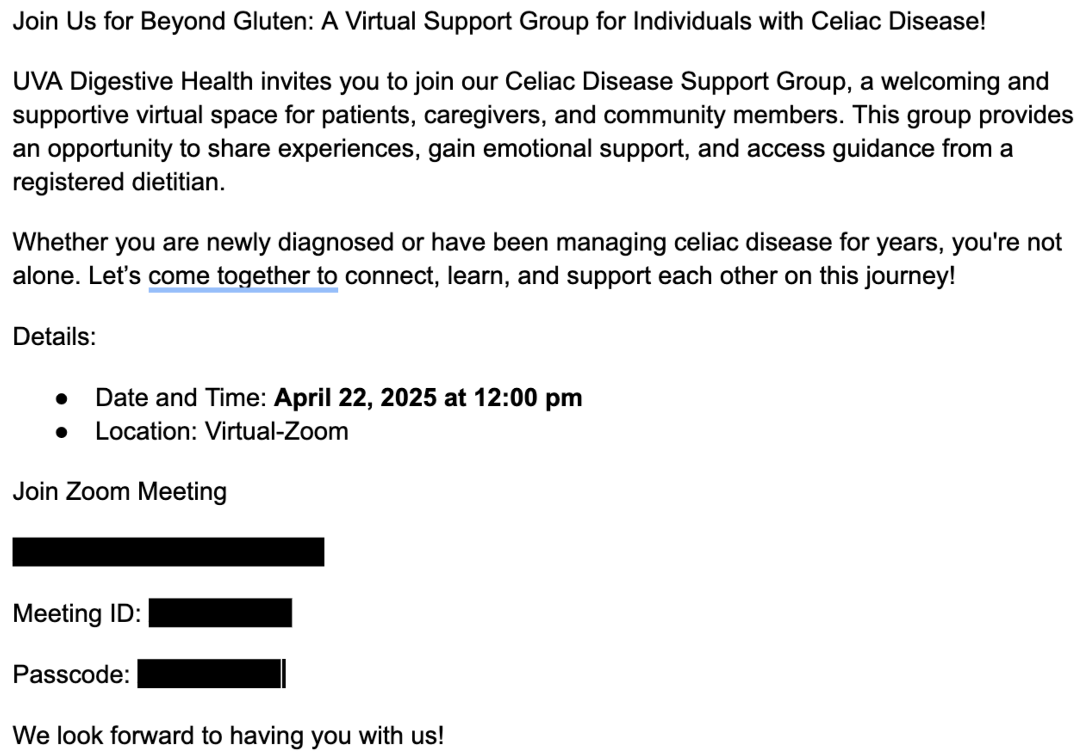
Appendices

Appendix A. Electronic Medical Record Email Notification (MyChart) Message Promoting Celiac Disease Support Group



Join Us for Beyond Gluten: A Virtual Support Group for Individuals with Celiac Disease!

UVA Digestive Health invites you to join our Celiac Disease Support Group, a welcoming and supportive virtual space for patients, caregivers, and community members. This group provides an opportunity to share experiences, gain emotional support, and access guidance from a registered dietitian.

Whether you are newly diagnosed or have been managing celiac disease for years, you're not alone. Let's come together to connect, learn, and support each other on this journey!

Details:

- Date and Time: **April 22, 2025 at 12:00 pm**
- Location: Virtual-Zoom

Join Zoom Meeting

[redacted]

Meeting ID: [redacted]

Passcode: [redacted]

We look forward to having you with us!

Appendix B. Promotional Flyer for Celiac Disease Support Group

Beyond Gluten

Navigating Celiac Disease Together

Do you or a loved one have Celiac disease! You’re not alone!

Join us

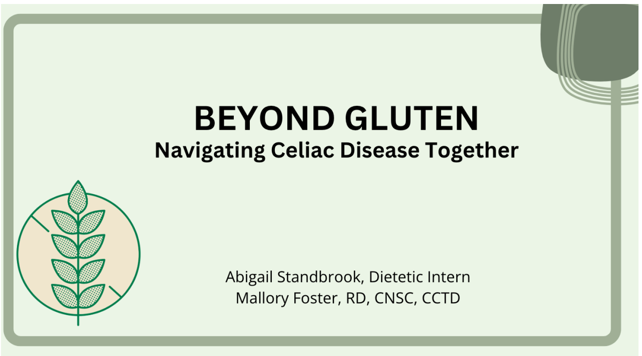
For a Celiac Disease Support Group for connections, support, and resources to help navigate a gluten-free lifestyle

Location:
Zoom
Meeting ID:
Password:

Meeting Time
April 22, 2025
at 12:00pm

Hosted by Mallory Foster, RD, CNSC, CCTD
and Abigail Standbrook, Dietetic Intern

Appendix C. PowerPoint Presentation Slides for Celiac Disease Support Group



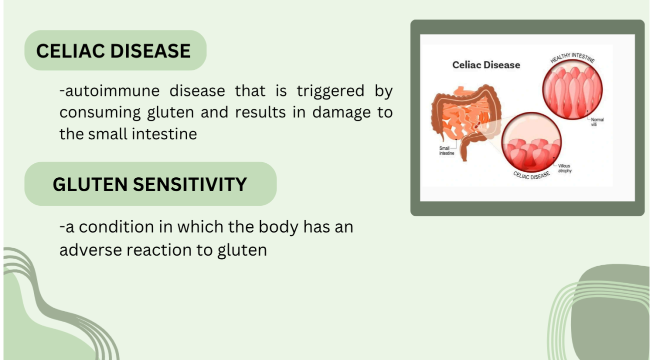
BEYOND GLUTEN

Navigating Celiac Disease Together

Abigail Standbrook, Dietetic Intern
Mallory Foster, RD, CNSC, CCTD

OBJECTIVES

- **Understand the Differences:** Define celiac disease vs. non-celiac gluten sensitivity.
- **Define Gluten:** Understand what gluten is, including its components and where it is found.
- **Balanced Gluten-Free Nutrition:** Learn how to create balanced, nutrient-rich meals without gluten.
- **Social Navigation:** Tips for managing social situations (dining out, events) with dietary restrictions.
- **Empowerment & Advocacy:** Encourage self-advocacy and educate others about your dietary needs.

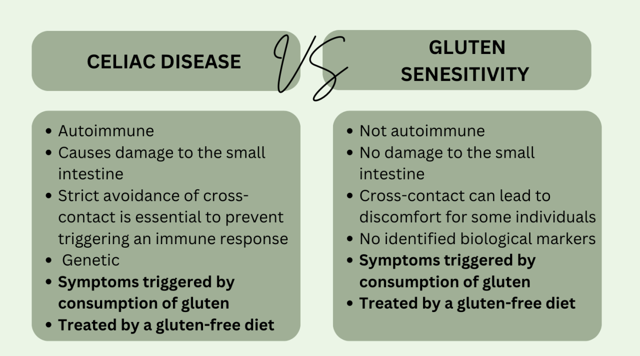


CELIAC DISEASE

-autoimmune disease that is triggered by consuming gluten and results in damage to the small intestine

GLUTEN SENSITIVITY

-a condition in which the body has an adverse reaction to gluten



CELIAC DISEASE	VS GLUTEN SENSITIVITY
Autoimmune Causes damage to the small intestine Strict avoidance of cross-contact is essential to prevent triggering an immune response Genetic **Symptoms triggered by consumption of gluten** **Treated by a gluten-free diet**	Not autoimmune No damage to the small intestine Cross-contact can lead to discomfort for some individuals No identified biological markers **Symptoms triggered by consumption of gluten** **Treated by a gluten-free diet**

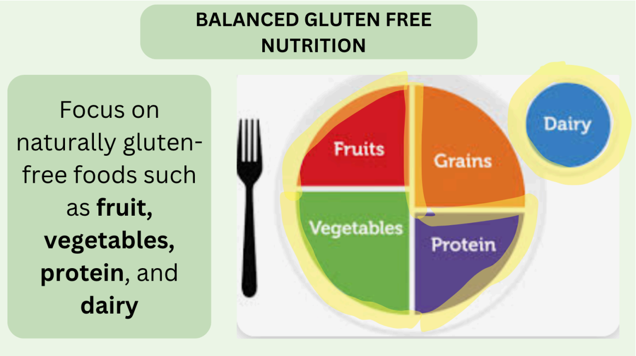
What is Gluten?

Wheat
- commonly found in baked goods, pastas and grains, cereals, and beer

Barley- (and Malt)
-commonly found in beer, whiskey, malt-based beverages, pearled barley, and barley flakes

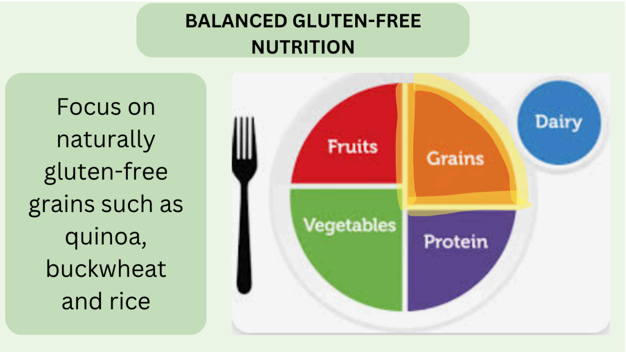
Rye
-commonly found in breads and baked goods, rye crackers, rye-based cereals, soups (as a thicker)

Oats** -Due to the manufacturing process, those with celiac disease should only eat oats if labeled "gluten-free."



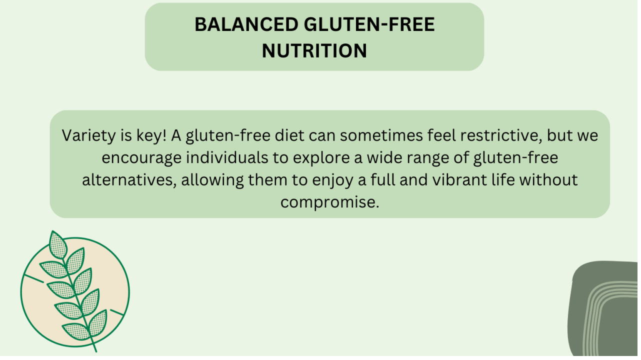
BALANCED GLUTEN FREE NUTRITION

Focus on naturally gluten-free foods such as **fruit, vegetables, protein**, and **dairy**



BALANCED GLUTEN-FREE NUTRITION

Focus on naturally gluten-free grains such as quinoa, buckwheat and rice



BALANCED GLUTEN-FREE NUTRITION

Variety is key! A gluten-free diet can sometimes feel restrictive, but we encourage individuals to explore a wide range of gluten-free alternatives, allowing them to enjoy a full and vibrant life without compromise.

SOCIAL NAVIAGTION

Dining Out

- Check the establishment's website or use resources like "Find Me Gluten-Free" to gather information on gluten-free options.
- If possible, call ahead to inquire whether they offer a gluten-free menu or have specific procedures in place to prevent cross-contact

Events

- Check with the host in advance to let them know you have celiac disease or gluten intolerance, and kindly ask if they can accommodate your dietary needs.
- At the event, inquire about their cross-contact procedures, and when in doubt, opt for packaged and naturally gluten-free foods to ensure your safety.

Packing snacks ahead of time

- If you're unsure about the food options at an event, it's always a good idea to bring your own snacks and meals to ensure you have safe options available.

Gluten-Free Labeling

-Gluten-free claims are **voluntary**, but if used, they must comply with the rule of less than 20 parts per million (ppm)

visual approximation of 10 mg of gluten from wheat toast

What labels are regulated?

In 2013, the Food Drug Administration (FDA) regulated that" gluten-free, free of gluten, no gluten, without gluten" must contain less than **20 parts per million (ppm) of gluten**

Third-Party Certification Labeling

-some manufactures choose third-party certifications for extra assurance

Gluten-Free Certification Organization (GFCO): requires less than 10 ppm

International Gluten-Free Certification (NSF): verifies compliance with FDA (less than 20 ppm)

Celiac Support Association (CSA): requires 100% free of wheat, barley, rye and oats

EMPOWERMENT & ADVOCACY

Educate Yourself and Others

- Educate friends, family, coworkers, and even restaurants or food establishments about celiac disease. Raising awareness can foster understanding and empathy, helping others better support your dietary needs.

Build a Supportive Environment

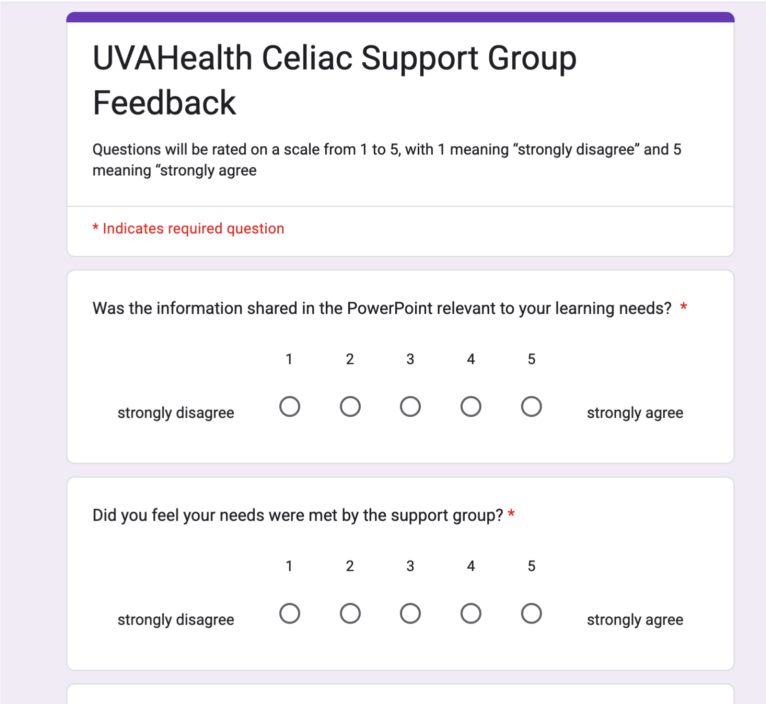
- Having a strong support system is key. Share your needs with loved ones and ask them to help you create a gluten-free-friendly environment.

Advocate for Safe Food Practices

- When dining out or attending events, advocate for your dietary needs by requesting gluten-free options or asking about cross-contact procedures

THANK YOU

Appendix D. Post Survey for Celiac Disease Support Group



UVAHealth Celiac Support Group Feedback

Questions will be rated on a scale from 1 to 5, with 1 meaning "strongly disagree" and 5 meaning "strongly agree

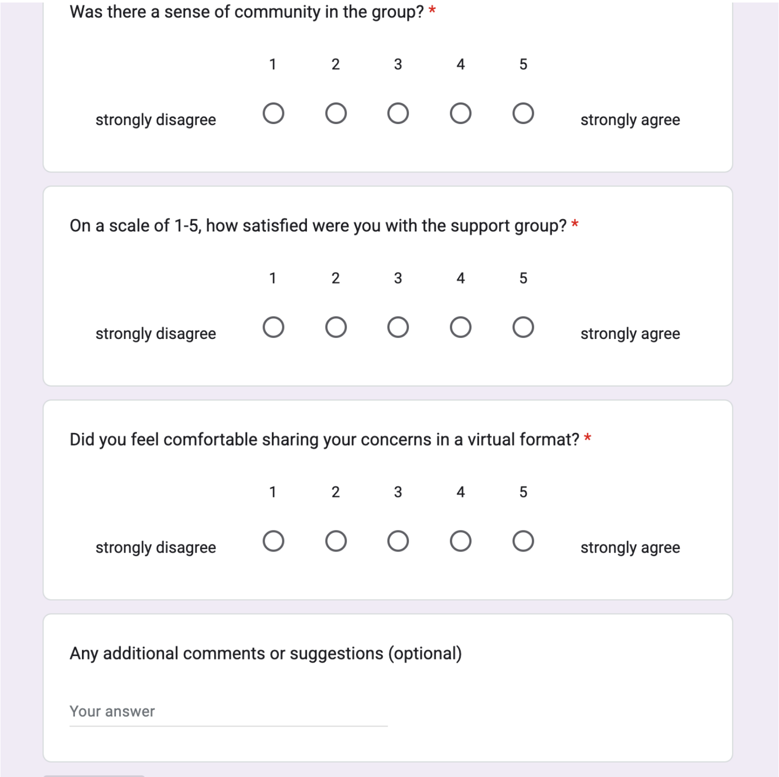
* Indicates required question

Was the information shared in the PowerPoint relevant to your learning needs? *

	1	2	3	4	5	
strongly disagree	○	○	○	○	○	strongly agree

Did you feel your needs were met by the support group? *

	1	2	3	4	5	
strongly disagree	○	○	○	○	○	strongly agree



Was there a sense of community in the group? *

	1	2	3	4	5	
strongly disagree	○	○	○	○	○	strongly agree

On a scale of 1-5, how satisfied were you with the support group? *

	1	2	3	4	5	
strongly disagree	○	○	○	○	○	strongly agree

Did you feel comfortable sharing your concerns in a virtual format? *

	1	2	3	4	5	
strongly disagree	○	○	○	○	○	strongly agree

Any additional comments or suggestions (optional)

Your answer