CeliacForum
JOURNAL FOR HEALTHCARE PROFESSIONALS ABOUT CELIAC DISEASE

COMPLIANCE AND THE GLUTEN-FREE DIET

Celiac disease was once thought to be a rare childhood disorder, but it is now recognized to affect about 1% of the population, worldwide.[4,5] The only treatment for celiac disease is lifelong adherence to a gluten-free diet.

The strict nature of the diet has implications on an individual's quality of life, especially when one considers the importance of dietary compliance and the rigidity of the dietary pattern.

As quality of life is influenced by and impacts ones physical health and perception of wellness, an individual's quality of life will be affected by their physical health, presence of symptoms, their prognosis, and ones perception of their health. Quality of life is important to study in individuals with celiac disease because the gluten-free diet will impact all aspects of ones life. One must also recognize that eating encompasses more than just meeting ones physiologic need for nutrients. It is often interwoven into the fabric of our lives, culture, social, and emotional needs. Quality of life issues are the roots of non-compliance among individuals with celiac disease.[11] Individuals are faced with many roadblocks to following a gluten-free diet. Inadequate food labeling, ubiquitous use of wheat as an additive in many foods and medications, lack of knowledge of ingredients in restaurants, and lack of public awareness and acceptance of gluten intolerance are a few of these road blocks.

The quality of life in individuals with celiac disease has been subject of numerous studies in Europe.[1,8,13,14] Generally there has been a negative impact on overall quality of life. Quality of life has been studied by Hallert, Lohiniemi, and Mustalahti and others[1,8,13,14] in Europe but as yet has

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SYSTEMATIC REVIEW: ADHERENCE TO A GLUTEN-FREE DIET IN ADULT PATIENTS WITH CELIAC DISEASE

Celiac disease is increasingly diagnosed in adult patients who present with atypical symptoms or who are asymptomatic and detected by case screening. Its treatment, a gluten-free diet, can have a considerable impact on daily living. Understanding the factors associated with non-adherence is important in terms of supporting patients with their condition. A literature search of multiple electronic databases using a pre-determined search string for literature between 1980 and November 2007 identified a possible 611 hits. After checking for relevance, 38 studies were included in this review. Rates for strict adherence range from 42% to 91% depending on definition and method of assessment and are the lowest among ethnic minorities and those diagnosed in childhood. Adherence is most strongly associated with cognitive, emotional and socio-cultural influences, membership of an advocacy group and regular dietetic follow-up. Screen and symptom-detected celiac patients do not differ in their adherence to a gluten-free diet.

N.J. Hall et al.: Systematic review: adherence to a gluten-free diet in adult patients with coeliac disease. Aliment Pharmacol Ther 30, 315-330, 2009.

not been studied in depth in the United States.[6, 12] The European and American populations had different perceptions on the impact of celiac disease and the gluten-free diet on their quality of life.[8, 11, 14] Hallert[7] showed that there was improvement on a general depression rating scale after one year on the gluten-free dietary pattern. Johnston's study[9] also showed overall improvement in quality of life after one year on the gluten-free diet, specifically the areas of social function, emotional well-being and mental health. However the study group still scored lower than the controls even after being on the gluten-free diet.[9] One area of difference between the European and Americans is response by gender. In a Swedish study, women were found to be more symptomatic and had a lower quality of life rating compared to the men[8]; while in the United States men were found to have an equally negative impact on family life as the women. American men were also found to have a more negative impact dining out.[12] Similar results were found in the Canadian study[15], which thus far has been the only study to include a paediatric subgroup in the discussion of quality of life. However the paediatric responses were reported by parent proxy and used the abbreviated SF 12 tool, not the SF 36, nor a disease or age specific instrument.

COMPLIANCE ISSUES

The overall implication of these studies is the recognition of the difficulty in dietary compliance especially in social situations in a disorder where the only treatment is strict lifelong dietary compliance. The study by Ciacci[2], which used a modified Zung depression scale, it was found that adults with celiac disease felt that dietary restrictions were very hard to accept, especially if the individual had an active social life. The individuals with celiac disease had a lower HRQOL score when compared to non celiac controls. The study describes the pattern of emotional – psychological response to the diagnosis of celiac disease. The initial reaction to the diagnosis of celiac disease is often relief with having a confirmed condition.[2] This initial relief is often followed by feelings of fear, anger, anxiety, and sadness. These feelings tend to correlate to the patients dietary compliance. Often the adults correlated these feelings to feelings of being different and isolated. Ciacci found those patients that express anger had a decreased compliance to the diet.[2] Green found that individuals would "intentionally cheat" on the diet in social situations, dining out, parties, and other functions outside of the home. Only 68% of individuals reported following the diet "all the time" and 30% reported following the diet "most of the time".[6] Although this adherence rate may be viewed as positive amongst other diet regimes the consequence of non-adherence for the individual with celiac disease are grave. There are increased risks of infertility, peripheral neuropathies, bone loss, lymphomas, and cancers of the small bowel and esophagus.[4]

In a subsequent study it was found that the degree of perceived dietary compliance was in sharp contrast to the actual compliance.[10] When individuals were queried as to how compliant they were both males and females responded with a high degree of compliance (98%). However when furthered queried as to specifically when or where they would ingest gluten both genders reported high dietary indiscretion. Males reported intentionally ingesting gluten at social activities, 81% of time, at restaurants 82% of the time, and with friends 58% of the time. Females reported higher dietary indiscretion rates than did males. At social activities and restaurants females reported dietary indiscretion 88% of the time. While with friends they reported a 67% rate of indiscretion.

When individuals were queried as to the reasons for non compliance both genders had similar responses. The restrictive nature of the diet was reported as the main reason for indiscretion by 73% of the responders. While discomfort in social settings, difficulty of the diet, and tastelessness of the diet were also noted but to a lesser extent, 69%, 68%, 45% respectively. Of interest the increased cost was noted by 33% of the study population as also being a reason for dietary noncompliance.

The economic domain of quality of life is included in studies[6, 11, 12] done in the United States but not those done in Canada or Europe. The reason for this may be the difference in the method of providing medical care. A study was conducted in the United States to evaluate the cost and availability of gluten-free foods. The study used a market basket of products identified by name brand, weight or pack-

age size for both regular wheat based products and gluten-free counterparts was developed. The differences in price between purchase venues, both type of store (general grocery store, an upscale grocery store and a health food store and four internet based grocery sites) and regions were evaluated. As can seen in Figure 1 the availability of gluten-free products varied between the different venues, regular grocery stores carried 36%, while upscale markets carried 41%, and health food stores 94%, compared to 100% availability on the Internet.[10]

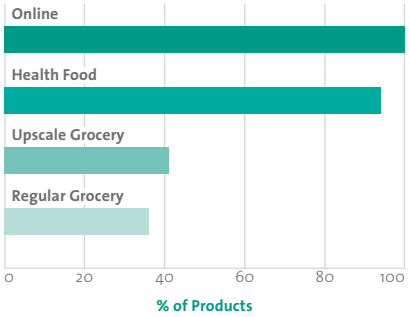

Figure 1: Availability of Gluten-Free Products According to Venue: The bars represent the mean of all products for all the regions analyzed.

The study also found that overall, every gluten-free product was more expensive than their wheat based counterpart ($p \leq 0.05$). As can be seen in Figure 2 bread and pasta was two fold as expensive as their wheat-based counterparts in most regions of the United States.[10]

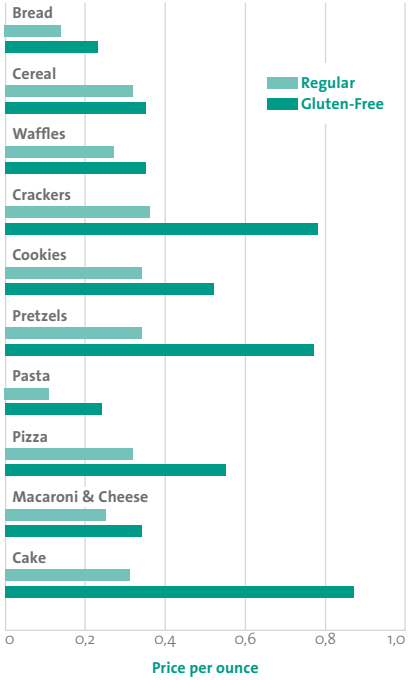

Figure 2: Comparison of Regular and Gluten-Free Products: Values are mean of price per ounce of all venues in all regions.

In the United States the financial burden of care lies with the patient whereas in other areas it is included in the government provisions of medical coverage.

CONCLUSIONS

When reviewing the impact of strict dietary compliance to the gluten-free dietary pattern it becomes apparent that the results are multifaceted. Many domains of an individuals life are negatively impacted by the gluten-free diet and this impact affects overall dietary compliance. When counselling an individual with celiac disease the various domains of quality of life must be considered to maximize dietary compliance.

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RETREATS: LEARNING THE GLUTEN-FREE DIET NATURALLY

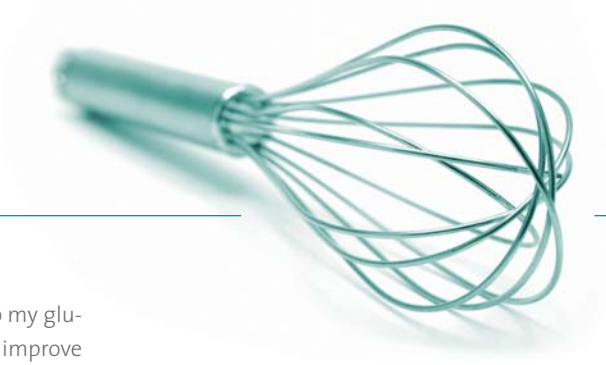
"Travelling and worrying about the food is still my biggest challenge." I hear this often from my patients with celiac disease, and not necessarily just the newly diagnosed. The diagnosis of celiac disease brings with it a rather dramatic change in eating for many people. Once the bare necessities are understood – what gluten is, where it's hidden, where to buy safe food, and how to prepare it, people with celiac disease then have to find a way to reorient themselves in a gluten filled world outside their own home.

Fortunately, dining out is becoming easier for those following the gluten-free diet as the restaurant industry recognizes this market niche. Over 1% of the American population, some 3 million people, currently might have celiac disease, although the vast majority of those have not been diagnosed. In addition, there are some with irritable bowel syndrome or an inflammatory bowel disease who find that their intestines respond well to the removal of wheat gluten. As awareness grows, the whole experience of dining out gluten-free will improve – in the meantime, it is the role of the dietitian to help patients understand how to successfully and safely eat outside the home.

It is for this reason that I designed the gluten-free health retreats. Between 10 and 14 people join me for a weekend of nutrition workshops, hiking and other relaxing activities (yoga, reiki, recipe sharing) and all gluten-free meals and snacks. Providing a gluten-free (and other allergen-free) environment in a real-world setting allows people to learn naturally together in a group and hone important skills. In the dining out workshop, we role play restaurant scenarios on the scene to practise the key questions that should be asked in ANY restaurant, as well as specific ethnic ones. Jack Foresteire, a returning participant this year, commented, "I liked the dining out tips and actually practicing in a restaurant which is a challenge for me. I liked just listening to other people and how they deal with the gluten-free lifestyle."

A common barrier to dining out which I hear in nutrition clinic is: "I just don't want to draw attention to myself." What this shyness or reservation often translates into is a plain piece of chicken, a baked potato and a dry salad. And slowly resentment builds within the person. A more effective tactic is to learn about food ingredients, food preparation and cross contamination in a restaurant setting. Confidence leads to "graceful assertiveness" which results in a night you will remember, not just for the company, but perhaps for the food, as well.

A big focus of the weekend is the concept that it is not JUST what we need to remove from the diet but what we also need to proactively add to maximize nutrition. Although still understudied, the research on the quality of the gluten-free diet shows that the typical gluten-free diet is low in calcium, iron, fibre and grains. Additionally, a compromised intestine can poorly absorb both macro and micronutrients. Healing the small intestine often requires more than simply removing gluten. So, the nutrition workshops focus on the major nutrients of interest to those with celiac disease: calcium and vitamin D, iron, B vitamins, and trace minerals, such as zinc, magne-



sium and selenium, as well as fish oils. The topic of probiotics, which are quite helpful in certain circumstances, is also addressed.

The participants practice with live food labels and learn to identify hidden gluten, a task made much simpler by the changes in food labelling laws. They also practice identifying sodium, fibre, carbohydrate and fat content – comparing one product to another to find the healthiest choice. One participant commented: "I learned how to read the labels better from a nutritional perspective and not just a gluten-free perspective. It has helped me think beyond just ‚is it gluten free?'". Some of the participants started on new supplements after learning about the various deficiencies in their diets.

The peaceful on-location experience is more conducive to natural learning than the clinical setting. We continue our workshop conversations on the trails during the day, led by certified outdoor guides, and during our free time. Questions arise and are answered through the course of the weekend. And messages, both for the newly diagnosed and for the "veterans" are reinforced by the other members' sharing. This year the group will also have the chance to experience yoga and reiki, enhancing the retreat experience.

One of the main frustrations I hear from patients about the gluten-free diet is the perception that there is no variety, nothing that tastes like it used to, and no food out there that tastes good. In fact, following a gluten-free diet opens one up to a world of new foods, in particular the whole gluten-free grains that are eaten in many other parts of the world where wheat does not have such a stronghold as in the northern hemisphere. To help dispel the scarcity myth, I bring in products that contain some of the less familiar grains: amaranth, buckwheat, millet, sorghum, teff and quinoa. Each has its own particular nutritional profile that makes it superior to the more commonly consumed rice, corn and potatoes, always bearing in mind to avoid contamination. Thanks to an impressive number of sponsors (20 for this year's retreat), participants are exposed to meals and products that are both healthy and taste good. Jack commented: "The weekend definitely encouraged me to try other products (free samples and other things in the grocery store) and helped me to build up my gluten-free choices. And I've tried to improve the quality of my food some, too. That is still a work in progress."

The intention of a retreat is to create an atmosphere conducive to sharing and learning from one another. People living with celiac disease, gluten intolerance or wheat allergies are welcome as each of them faces similar dietary changes. Their families and friends are welcome because the more support an individual has in learning and following the diet, the more quickly he/she can assimilate it into daily life. This educational forum can complement but not replace a clinical visit with a dietitian skilled in celiac disease.

If you are interested in learning more about gluten-free retreats, please feel free to visit www.DeletetheWheat.com.

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DIETETIC TREATMENT AMONGST FORBIDDEN FOODS AND DIETARY SUPPORT

It is often the case that dieticians are at the end of a long diagnostic chain the patient has to get through until finally the cause of the ailment is found.

It is these dieticians who pave the patient's way towards new eating habits. It is regrettably too often the case that diagnostic findings for dietetic treatment are not complete and must first be requested and seen by the appropriate doctors to enable efficient dietetic treatment. Tolerance towards lactose and fructose, and also to fats, can be determined by an experienced dietician from a 7-day nutrition and symptom report. However, access to previous findings also shows information which can be used to offer the patient nutritional guidance. These are all building blocks, the importance of which should not be underestimated, that encourage the patient to implement and adhere to the gluten-free diet.

REQUIREMENTS FOR EFFICIENT DIETETIC TREATMENT

Structural requirements	Purpose and opportunities for dietetic treatment
Judicial indemnity and release from confidentiality	• Allows open communication with doctors • Economical safeguarding of dietetic treatment
Access to findings • Laboratory parameters • Biopsy	• Securing of the diagnosis/mandate for dietetic treatment • Allows checking of progress
Access to files (more detailed findings, other previous medical conditions, accompanying measures)	• Ability to recognise the requirements for dietetic treatment and to offer efficient tools for the patient
7-day nutrition report	• Identify mealtimes and preferences of patient • Detect potential inappropriate eating behaviour • Ability to address nutrient imbalances

Besides being informed about a strictly gluten-free diet, patients also need support for following a completely different kind of diet, which has an impact on all areas of life and hence quality of life – not only for the patient, but also friends and the whole family.

Patients with a long history of suffering or patients with an obvious gastro-intestinal condition view the requirement for this kind of exorbitant change in behaviour as a very positive thing. It is after all the only way for them to rid themselves of the ailment. Working with up-to-date lists from country-specific celiac associations eases the change and creates a sense of security. Practical tips for making gluten-free dough should be planned in for some of the consultancy time.

↘ Dietetic treatment on initial manifestation of celiac disease

- Assistance in good illness management
- Involvement in accepting the disease
- Knowledge transfer in all things related to celiac disease
- Conveying the basics of gluten-free food
- Learning about and using what celiac associations have to offer
- Rectification of possible malassimilation disorders as a consequence of villous attrophy
- Reading food labelling
- Practical tips for preparing gluten-free dough
- Transfer/preparation of the necessary expertise for assistants (kindergarten, school)
- Balancing of nutrient deficiencies
- Shopping training
- Holiday planning, gluten-free eating in hotels, restaurants, etc.

Dietetic treatment is very different for patients who were diagnosed by mere chance. If symptom association is not detectable by the patient on eating the wrong food, the necessity of a serious life change to a gluten-free diet will require some serious explaining. But young patients also often represent a particular challenge. Specifically in this age group, there is seldom symptom association when eating the wrong food. The task of the dietetic therapist is to present contemporary alternatives and to associate a “feel-good factor” to the gluten-free lifestyle.

Overall, dietetic treatment for those with celiac disease places huge demands on dieticians. This is underestimated far too frequently. In addition to continual training in an area of knowledge that has seen many new developments in recent years, both in regard to diagnostics and treatment, a profound level of basic knowledge with regard to the physiology and pathophysiology of digestion is required. However, successful dietetic treatment is only complete when it is possible, with suitable communication tools taken from didactics and methodology, to take the patient by the hand so that he or she is able to confidently and safely venture down the route of a gluten-free lifestyle independently.

Resources

Gluten Free Restaurant Awareness Program: www.glutenfreerestaurants.org
Celiac Disease Awareness Campaign: www.celiac.nih.gov
Gluten Intolerance Group: www.gluten.net
Celiac Disease Foundation: www.celiac.org
American Celiac Disease Alliance: www.americanceliac.org
National Foundation for Celiac Awareness: www.celiaccentral.org
Celiac Sprue Association: www.csaceliacs.org
Canadian Celiac Association: www.celiac.ca
American Dietetic Association: www.eatright.org
Gluten Free Passport: www.glutenfreepassport.com
Bob and Ruth’s Dining and Travel Club: info@bobandruths.com
Gluten Free Travel Agency: www.glutenfreetravel.com
Gluten Free travel information: www.celiactravel.com

Books

Celiac Disease; A Hidden Epidemic by Dr. Peter Green and Rory Jones. 2006 by Harper Collins

Gluten Free Eating; The Complete Idiots Guide by Tricia Thompson and Eva Adamson. 2007 by Alpha Books

Cookbooks

Gluten Free Gourmet Cooks Fast and Healthy by Bette Hagman

NEWS

BODY MASS INDEX IN CELIAC DISEASE: BENEFICIAL EFFECT OF A GLUTEN-FREE DIET

BACKGROUND: There is concern about celiac disease patients being overweight and gaining more weight while on a gluten-free diet (GFD). METHODS: BMI of celiac disease patients in the United States at diagnosis and after 2.8 years (mean) on a GFD were compared with national data. RESULTS: Among our patients (n=369, 67.2% female), 17.3% were underweight, 60.7% normal, 15.2% overweight, and 6.8% obese. All patients were followed by a dietitian. Compared with national data, females had lower BMI (21.9 vs. 24.2, P<0.0001) and fewer were overweight (11% vs. 21%, P<0.0001); more males had a normal BMI (59.5% vs. 34%, P<0.0001) and fewer were underweight (9.1% vs. 26.7%, P<0.0001). Factors associated with low BMI were female sex, Marsh IIIb/c histology, and presentation with diarrhea. On GFD, 66% of those who were underweight gained weight, whereas 54% of overweight and 47% of obese patients lost weight. CONCLUSIONS: A GFD had a beneficial impact on BMI, underweight patients gained weight and overweight/obese patients lost weight. The improvement in BMI adds to the impetus to diagnose celiac disease. Expert dietary counseling may be a major factor in the beneficial effects we noted.

Chang J, Brar PS, Lee, AR, Green PH. J Clin Gastroenterol, 2009 Sep 23 (Epub ahead of print)

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CELIACCENTER.ORG THE PLACE FOR PROFESSIONALS

We introduced our professional website at the American Dietetic Association FNCE and received rave reviews. We would encourage you to log on so you can access the most up to date information. Logging on allows you access to more information for the professional. It is free and Celiaccenter.org is constantly updated so we can bring you the latest news, research, and tips on counseling your patients. All of our educational materials as well as nutrient analysis of our products are available for you to download for your convenience.

PREVIEW
The next edition will appear in April and will cover diagnose and complications of missing diagnoses.

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