

Celiac Disease:

The Role of the Gastroenterologist in a Patient Managed Disease

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Objectives

- Review the presentation and diagnosis of Celiac disease.
- Discuss the specifics of the gluten free diet.
- Examine the global effects of Celiac disease on patients.
- Reinforce the role of the gastroenterologist in the long term care of Celiac disease patients.

Celiac Disease

- Immune mediated enteropathy seen in genetically predisposed individuals.
- Manifestations occur through an inflammatory response in response to gluten exposure.
- Celiac disease is the most common autoimmune gastrointestinal disease, effecting approximately **1 in 133** Americans.

Gluten

- Gluten is a protein found in wheat, barley, rye, and triticale.
- Oats are also often an issue for a number of reasons.
 - Cross contact.
 - Immune response to oat protein.
 - Intolerance.

Presentation

- Diarrhea
- Weight loss
- Abdominal pain
- Iron deficiency anemia
- Fatigue
- Vitamin deficiencies
- Osteoporosis
- Dermatitis herpetiformis
- Anxiety
- Depression
- Poor dentition
- Infertility/miscarriage
- Migraines
- Neuropathy
- Ataxia
- Abnormal LFTs

Diagnosis

- Serology
 - Total IgA level, tissue transglutaminase (TTG) IgA.
 - HLA DQ2, DQ8 genotyping.
- EGD
 - Duodenal biopsies.

Management

Gluten Free Diet



Gluten Free Diet

- Strict gluten free diet.
- Label reading.
- Cross contact.

Products that contain Gluten

- Breads
- Baked goods
- Pasta
- Sauces
- Seasonings
- Soy sauce
- Imitation crab meat
- Beer
- Lunch meats and sausages
- Candy
- Potato chips
- Play dough
- Medications
- Lip products
- Shampoo and Conditioner
- Moisturizer
- Face wash
- Paper straws



Label Reading

- FDA requires food that is labeled as “Gluten Free” to contain less than **20 ppm** of gluten.
- Allergen statements:
 - “Contains.....” -> required to list the top 8 allergens, which includes wheat.
 - Barley, malt, rye are not listed in this space.
 - Wheat free does NOT mean gluten free.
- Be wary of “processed on shared equipment” claims.

Cross Contact

- Even a crumb of gluten containing food can be enough to make your Celiac patients sick.
 - Average Western diet: **5-15g** of gluten per day.
 - Celiac disease: as little as **50mg** of gluten per day can be harmful.
- Separate food preparation areas, utensils, sponges in the home.
- Restaurant safety.

1. Am J Clin Nutr 2018;107:201-207

PSYCHOSOCIAL IMPACTS:

FOOD CHOICES, ACCIDENTAL GLUTEN EXPOSURE and BURDEN of the GLUTEN-FREE DIET

JOY BURWELL

ANXIETY

SOCIO ISOLATION

GUILT

THE DIFFERENT BURDENS

- CHILDREN — "BEING DIFFERENT"
 - AT SCHOOL
 - AT PRIVATE PARTIES
 - IN COLLEGE TOO

FAMILY TESTING — HOW DO FAMILY DYNAMICS AFFECT IT?

IS IT ABOUT THE DISEASE ITSELF — OR — THE CONVERSATION

HOW DO THEY DEAL WITH IT?

SHARE WITH OTHERS? KEEP IT TO YOURSELF?

RELATIONSHIPS

- SPOUSES
- FRIENDS
- SIBLINGS

ASPECTS OF DENIAL

JOB — PRODUCTIVITY

- BUSINESS IMPACT
- ECONOMIC IMPACTS

CHALLENGES in EVENT PLANNING

RISK-TAKING — COMPENSATION...

- CONSEQUENCES?
- "CHEATING"

HOW DO YOU COPE?

- DECISION TO HAVE CHILDREN OR TO ADOPT

WHERE DO YOU GO FOR INFORMATION...

- DOCTOR?
- INTERNET?

HOW COMFORTABLE ARE YOU EXPRESSING YOUR NEEDS?

ATTITUDE SHAPES EXPERIENCE

TIME ASPECTS...

- DURING THE DAY
- HOW OFTEN DO YOU THINK ABOUT FOOD?



RELIGIOUS ASPECTS — IMPACT OF FAITH, CHURCHES

DEPRIVATION MENTALITY

- RATIONING FOOD
- BINGING
- EATING DISORDERS

PEOPLE'S REACTIONS



IN REALITY IT AFFECTS EVERY ASPECT OF YOUR LIFE!

THE IMPORTANCE OF HAVING OPTIONS...

...in RURAL vs. URBAN ENVIRONMENTS

FAMILY ATTITUDES, EFFECTS

- PARENTS
- CHILD

★ THE FAMSS QUALITATIVE TOOL also FAAMSS

FAMILY ASTHMA MANAGEMENT SCALE

HOW TO CAPTURE ADOLESCENTS' FEELINGS?

HOW DO YOU PHRASE THE QUESTIONS?

- SAME QUESTIONS AS ADULTS?

TWO SETS OF TOOLS

HOW DID YOU REACT WHEN YOU LEARNED OF THE DIAGNOSIS?

"THE FIRST DAY OF A HEALTHY LIFE!"

SUICIDAL THOUGHTS

ETHNICITY

- eg. CHINESE DENIAL



www.BeyondCeliac.org

—JOE AZAR crowleyandco.us

Celiac Disease Facts

- **49%** of patients have sacrificed life experiences because of the gluten free diet and Celiac disease. ^{1,2}
- **60%** of college students with Celiac disease report getting sick as a result of their campus dining. ³
- **70%** of patients remain exposed to gluten, even while attempting a strict gluten free diet. ^{4,5}
- Patients with Celiac disease report a higher negative impact on their quality of life than those with type II diabetes, congestive heart disease, or inflammatory bowel disease.

1. National Foundation for Celiac Awareness (Beyond Celiac) Survey. "Understanding the Patient's Experience with Celiac Disease". 2015.
2. National Foundation for Celiac Awareness (Beyond Celiac) Survey. "Gluten-Free College Student Survey" 2013.
3. Joseph A. Murray MD, Gastroenterologist, Mayo Clinic. "Alba Therapeutics Announces Positive Results of Phase IIb Trial in Celiac Disease". 2014.
4. J Gastrointestin Liver Dis. 2011 Sep;20(3):241-5.
5. American Journal of Gastroenterology. 2014;109(9):1304-1311.



Follow up for Celiac patients

- Repeat endoscopy to document healing 6-12 months after diagnosis
- Routine monitoring of labs:
 - IgA TTG
 - Vitamin D, A, E, B12, folate, copper, zinc
 - CBC and iron profile
 - TSH
- DEXA scan within a year of diagnosis

Follow up care

- Routine follow up with gastroenterology.
 - Yearly, once symptoms have resolved.
- Nutritionist support.
- Mental health consideration.

Summary

- Celiac disease is a common autoimmune disorder triggered by dietary exposure to gluten.
- The gluten free diet can be complicated to adopt, but is the only treatment for Celiac disease.
- Celiac disease has a global impact on patients, even when their inflammation is under good control.
- Long term follow up with gastroenterologists, and ideally a multidisciplinary team, is ideal for adequate care of Celiac patients.

Thank you!

- Questions