

McMaster  
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HEALTH SCIENCES



Department of  
**Family Medicine**

McMaster  
**Family Health Team**

# A Unique Inter-professional Approach to Delivering Ongoing Care to Patients with Celiac Disease in a Primary Care Setting : A Dietitian, Physician and Chaplain Collaboration

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# Disclosure

Presenters perceive no conflict of interest with this presentation.

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# Who are we?

## McMaster Family Health Team

- Provide primary care for nearly 30 000 patients in Hamilton and surrounding area
- 2 clinical teaching units affiliated with McMaster University and Hamilton Health Sciences



McMaster Family Practice



# Our Interprofessional Celiac Team



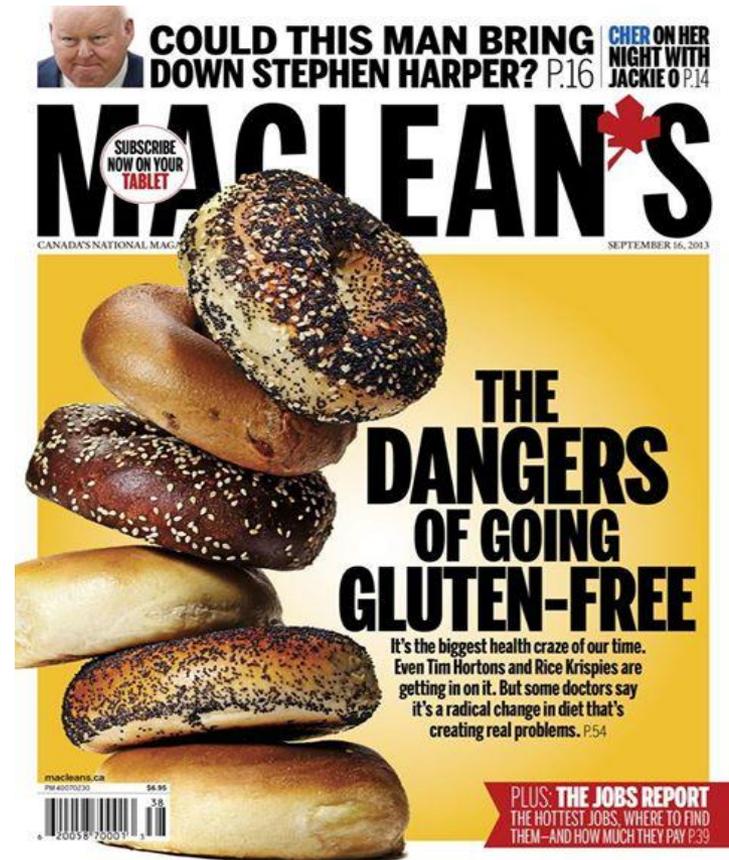
# Objectives

At the end of this sessions, you will be able to:

1. Identify the prevalence of celiac disease in the Canadian population and the need for ongoing education for this vulnerable group that is often lost to care in family practice
2. Utilize strategies to identify patients with celiac disease in your practice more easily
3. Become familiar with an unique interprofessional team approach for providing care to patients with celiac disease in a primary care setting.
4. Describe options for maximizing capacity for providing care including templates, tools, and connecting with an interprofessional team
5. Think about how you could use this approach in your practice

# Gluten-free Eating In the News

It's the biggest health craze of our time, though some doctors fear it's creating real problems. (Even the Wheat Belly guru is worried)



Prevalence of Celiac Disease in  
North America is

***1:105***

***1% of the population***



# Gluten- Free Eating



- Complex to follow
- Expensive \$\$\$\$
- May unnecessarily limit foods if not CD
- Typically low in fiber, iron, B vitamins and high in calories from refined foods
- Not an appropriate eating style for weight loss since many patients gain weight on gluten-free eating!

# Effective Management of Celiac Disease

- Requires a multidisciplinary approach
  - Patient education to support lifelong adherence to a gluten-free diet by a Registered Dietitian
  - Physician management of active medical issues and future complications
  - Emotional support
  - Support of advocacy group
  - Ongoing follow up from multi-disciplinary team

# Why Start a Celiac Group?

- A review of our clinic data identified a need to better support this vulnerable and underserved population
  - Rising in prevalence yet very few identified in patient database
  - Requiring ongoing education and treatment for celiac disease and other co-morbidities but very few referrals to RD and MD in clinic for management of CD
  - Patients reporting limited time/education from specialist
  - Very limited use of community services

# Why Start a Celiac Group?

- High risk population
- Often lost to care in family practice
- Not receiving appropriate ongoing education or multidisciplinary support
- Condition commonly under-diagnosed
- Need for education to increase clinician awareness of celiac disease for more timely diagnosis and earlier intervention

# Goals for our Celiac Group

- Things we wanted:
  - Improved access
  - Ongoing education and medical management
  - Links to community supports
  - Increase in self-management behaviors
  - Provider and learner education

# From Celiac Group to Celiac Group Medical Visit

- Based on model used for other chronic illnesses (eg: Diabetes)
- Provides patients with an opportunity to:
  - Reconnect with health care team
  - Update their knowledge of celiac disease management including resources within the clinic and the community
  - Share their concerns of living with celiac disease
- Set small goals for change to enhance self care

# From Idea to Proposal

- Submitted to our FHT Priorities & Planning Committee for approval
- Then off to REB for ethics approval
- We got the green light!



# Next Steps

- Share initiative with larger team
- Rounds on Celiac Jeopardy
  - Education signs and symptoms of CD
  - Clarifying diagnoses
  - Learning about gluten-free eating
  - Ongoing medical management for CD

Pop?  
Quiz



# Celiac Jeopardy

Where's the Gluten?	Celi-what?	Who am I?	Supermarket Sweep	Looking Forward	Celiac Potpourri
100	100	100	100	100	100
200	200	200	200	200	200
300	300	300	300	300	300
400	400	400	400	400	400
500	500	500	500	500	500



Stomach Pain  
Gas/bloating  
Diarrhea/constipation  
Lactose Intolerance  
Depression  
Unresolved anemia



# What are some symptoms of celiac disease?



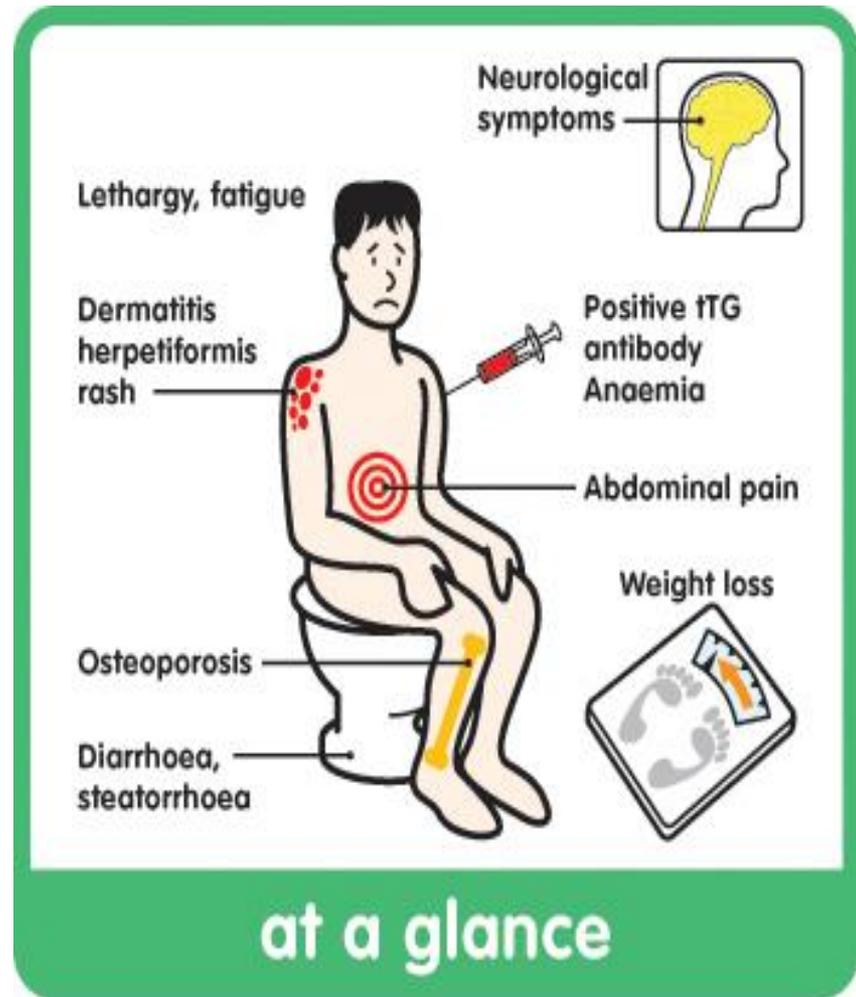
# Why should I be tested for Celiac Disease?

## Children with Celiac:

- Failure to thrive
- Short stature
- Delayed puberty
- Dental defects
- Gastrointestinal
- Irritability

## Adults with Celiac:

- Gastrointestinal
- Reproductive
- Bone and joint
- Neurological
- Metabolism
- Oral and Skin



## Celiac Disease

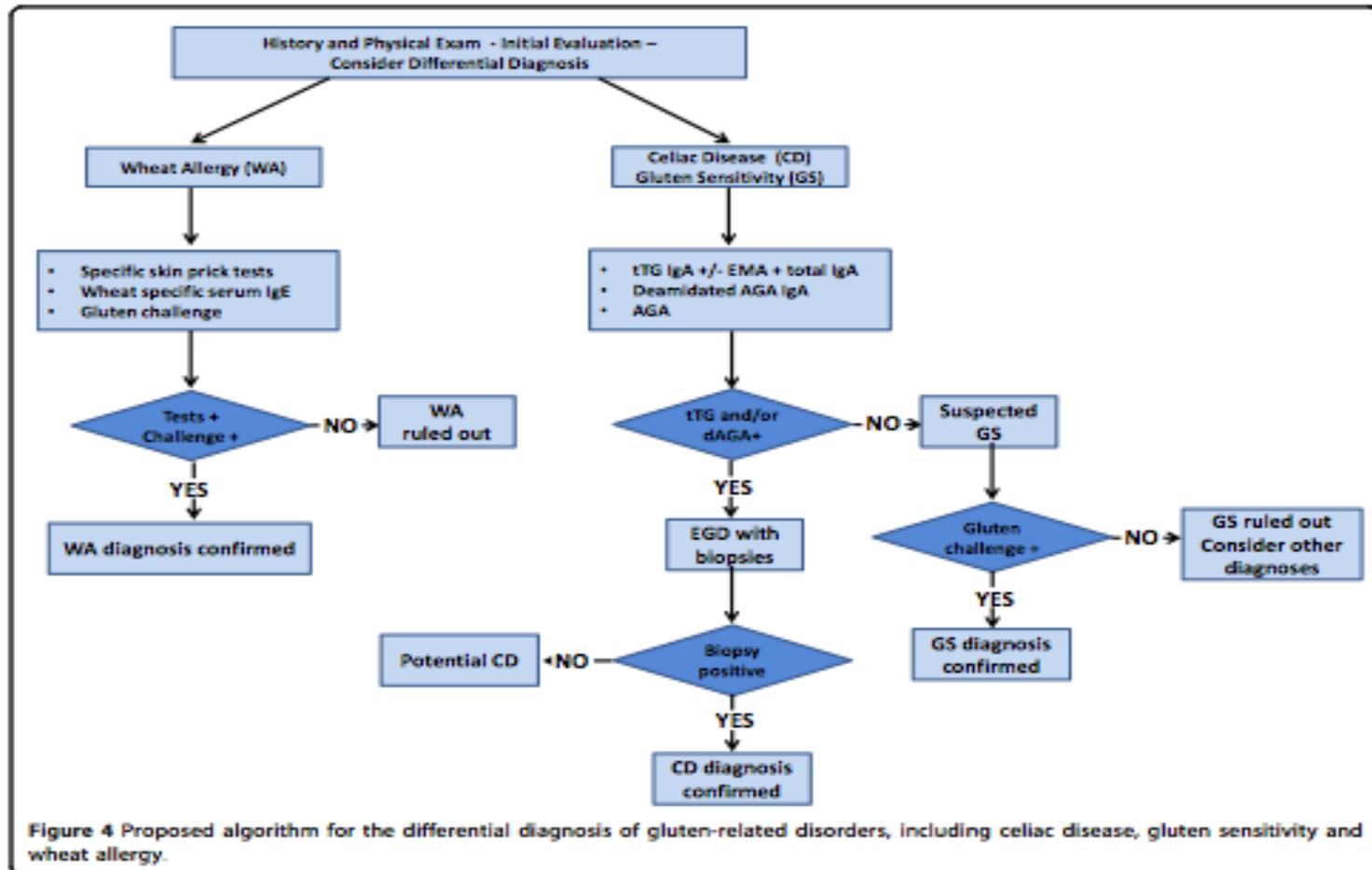
# Celiac Jeopardy

The average length of time until diagnosis for patients living with celiac disease as reported in the Canadian Celiac Health Survey in 2007.

# Answer

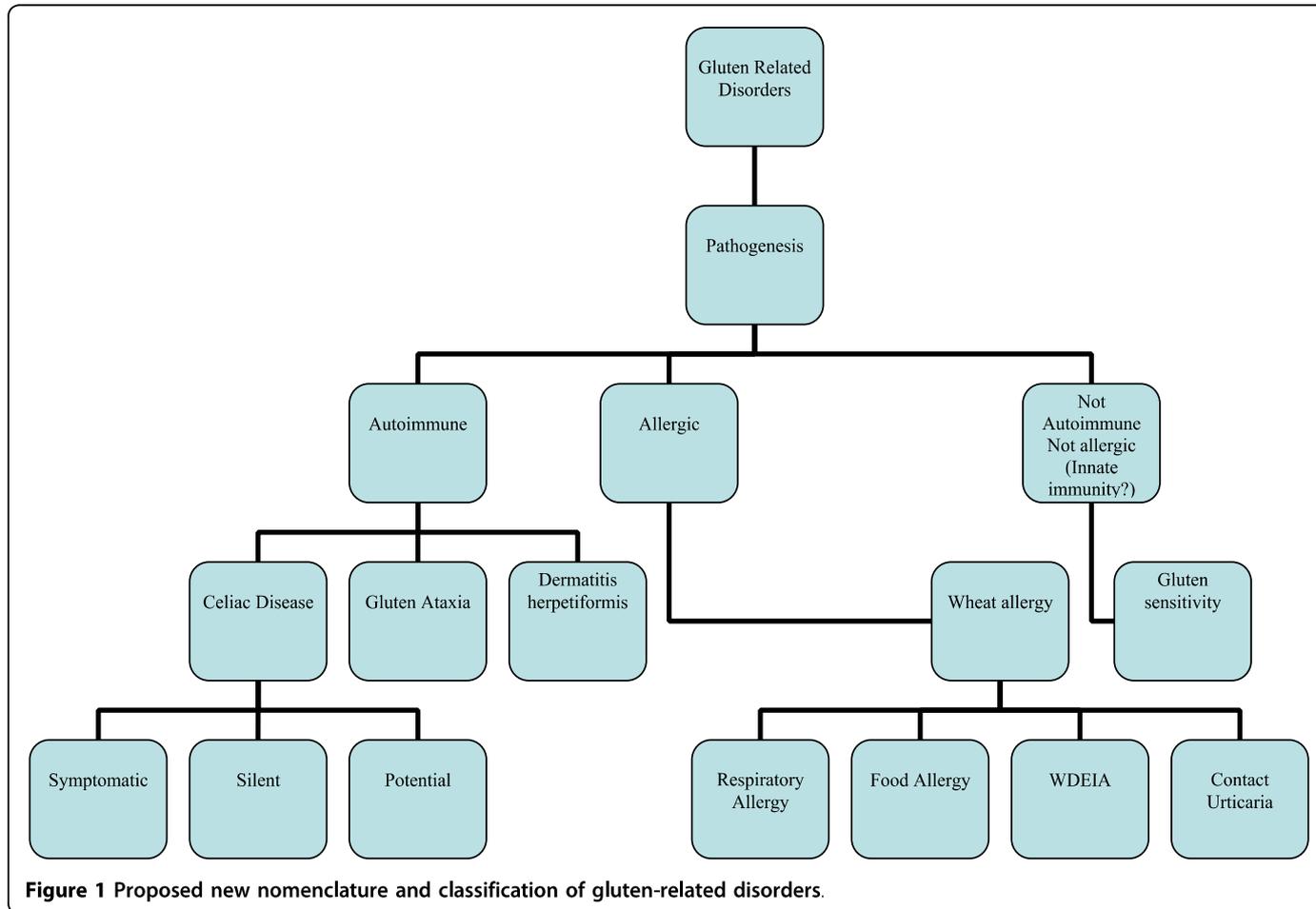
What is 11.7 years?

# Diagnostic criteria



Sapone, A., Bai, J., Ciacci, C., Dolinsek, J., Green, P., Hadjivassiliou, M., Kaukinen, K., ... Fasano, A. (February 2012). Spectrum of Gluten-Related Disorders: Consensus on new nomenclature and classification. *BMC Medicine*, 10 (13).

# Celiac Disease vs. *Gluten* Sensitivity?



Sapone, A., Bai, J., Ciacci, C., Dolinsek, J., Green, P., Hadjivassiliou, M., Kaukinen, K., ... Fasano, A. (February 2012). Spectrum of Gluten-Related Disorders: Consensus on new nomenclature and classification. *BMC Medicine*, 10 (13).

# Identifying our Patients with Celiac Disease

- EMR Search- billing code 579
- Only 15 identified
- MRP's notified and supported initiative
- Invited by phone, in person to participate in group
- 11 out of 15 patients happily agreed

# Outline of Celiac Group Visit

- Welcome/introduction to celiac group/team
- Introduction of group medical visit approach
- Consent/confidentiality
  - Nutrition management (Visit #1)
  - Emotional management (Visit #2)
  - Medical management (Visit #3)
- Group sharing
- Skill Building Activities
- Goal setting
- Follow up plans/expectations
- Evaluation measures: satisfaction/self efficacy

# Celiac Group: Nutrition Update

- Update knowledge of nutrition recommendations for celiac disease and new labeling legislation
- Emphasize key nutrition principles to:
  - Reduce risk of gluten exposure
  - Correct nutritional deficiencies
  - Promote acceptance of gluten-free eating
  - Provide symptom management
  - Reduce risk of long term complications from anemia to osteoporosis
  - Deal with Challenges: Shopping, Eating Out, Cross-Contamination
- Provide Skill building activities and games to reinforce nutrition and labeling knowledge eg. Nutrition Myths or Truths
- Discuss supports in the clinic and in the community

# Produce Department: Naturally Gluten-Free

**Enjoy!**

- Fresh fruit
- Fresh vegetables
- Fiber-rich!



**Suspicious...**

- Dried fruit



# Let's Practice: Label Reading Exercise:



# Which treat is *gluten free*?



# Are you getting 2-3 Calcium Servings Each Day?



# We're Here to Help

- Update knowledge
- Improve GI symptoms
- Correct deficiencies
  - Iron, Calcium
  - Vitamin B12, folate, A,D,E,K
- Manage Co-morbidities
  - Osteoporosis- Bone density screening
  - Cholesterols (LDL and HDL)
  - Blood Glucose ( Diabetes)



# Medical Management

- Medical education update focused on:
  - Preventing complications
  - Blood work needed
  - Supplementation needed
  - Assess need for specialty services



# What blood work and other tests are needed to monitor celiac disease and other co-conditions?

- GI profile ( IgA tTG, Total IgA)
- Anemia profile ( CBC, ferritin, folate, serum B12)
- Vitamin profile (vitamin D3)
- Lipid profile ( LDL cholesterol, HDL, Triglycerides)
- Electrolytes (Na, K, Cl)
- Urinalysis to screen for Iga nephropathy
- Bone density screening within first year then q 2 years
- Other (TSH for thyroid)

# Our Role in Providing Self Management Support

- Encourage participants to share experience of living with celiac disease
- Focus on empowerment through sharing of experiences and peer support
- Review supports in the community and available at Stonechurch

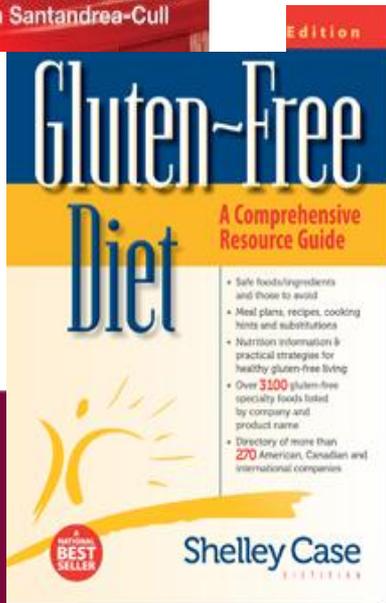
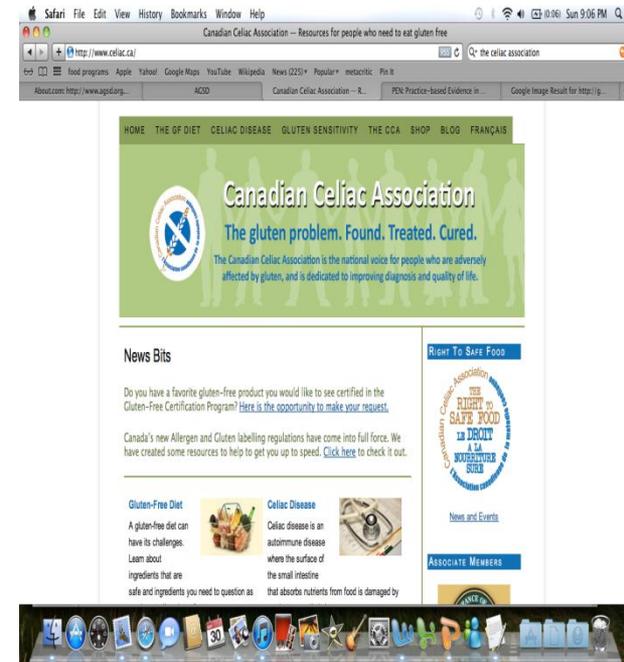
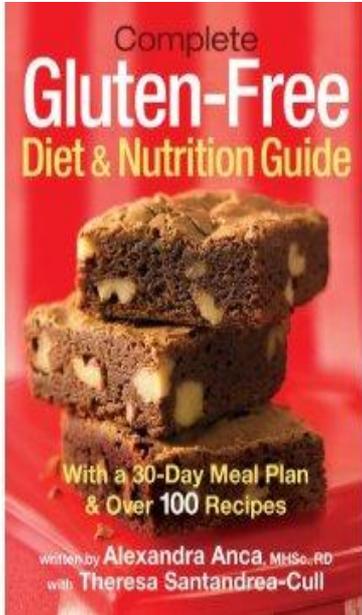
# Celiac Passport

	Visit #1	Visit #2	Visit #3	
Attended Nutrition Update				
Feel confident reading labels + eating out				
Meeting nutrient needs (Iron , Vitamin B12 and D, Calcium ,Fiber)				
Completed blood work and other tests Iron, B12, D, Cholesterols, Glucose Bone mineral density				
Getting support from Family doctor/ Celiac Team/ Specialist Community resources				
Setting a goal for change: This week I will .....				

# What do the patients leave with...

- Goal to work until we meet again
- Appointment date and time for next GMV or individual appt
- Lab requisition (as needed)
- Sense of empowerment
- Knowledge of when to access celiac team if needed

# Credible Resources



# Outcome Measures

## First steps: The Service Model

- Self-efficacy
- Patient satisfaction
- Provider Satisfaction

## Next steps: Outcomes Evaluation

- Behavioral changes
- Clinical outcomes
- Knowledge Translation

# What We Learned

## **Patients love it!**

- Increased access to physician and dietitian team
- Getting their questions answered and helping others

## **Providers too!**

- Opportunity to reach many patients with the same message at the same time
- Scheduled opportunities for collaborative care and team discussion

# Patient Statistics

Of 19 patients identified in database

- 9 patients attended celiac group visits (2 Men, 7 Women)
- All 9 patients presented with:
  - common nutritional deficiencies (vit D, vit B12, iron)
  - ongoing GI symptoms
  - unable to eat out safely
  - were not aware of new gluten free labeling
  - were not aware of need for ongoing education or medical monitoring for common co-morbidities
  - only 2/9 were accessing community supports

# Patient Experience

“I haven’t talked to anyone in years about gluten-free eating or how to better manage my celiac disease”

“ I’m so glad we have a forum to talk with a doctor and dietitian about new gluten free products, how to manage symptoms, my vitamin needs and medical testing I need. “

“It’s invaluable having multiple disciplines”

# Self Efficacy

- Pre/post self- efficacy scores
- Most challenging areas
- How confident...
  - do you feel that you can follow your diet when you have to prepare or share food with other people who do not have celiac disease?
  - are you that you can keep emotional distress caused by your disease from interfering with the things you want to do?

# Satisfaction

- Patients

- >90% of patients who attended celiac group
  - Found it was helpful to be in a group like this
  - Would recommend attending group medical appointments to others
  - Would come to another group like this

When asked how often, 9/10 reported q 3 months

# Sharing Knowledge with the Larger Team

- Team discussions
  - Rounds- Celiac Jeopardy
  - Sharing diagnostic tips and tools
  - Hallway consults, case discussions
- EMR changes
  - Added celiac disease code/celiac registry
  - Creating template for clinicians
  - Creating Celiac Passport for patients

# How long do patients need to eat gluten containing foods to confirm diagnosis?

- If eating gluten-free before diagnosis, blood tests may show normal results and proper diagnosis could be missed
- How much gluten is needed to cause villi changes?
  - Gluten challenge for 3 months eg. 3-4 slices bread/day
  - Too much gluten for too long
  - Newer research - 1 slice bread/day with 3.5 g gluten for as little as 14 days can show villi atrophy

# Our Conclusion

- Combining nutrition, medical and emotional support into a planned visit such as a group medical visit is an efficient and effective method to help patients reconnect with their health care team, update their knowledge, gain support from their peers and build self management capacity.



# In Summary...CELIAC

- C =consultation with a dietitian specializing in gluten-free eating
- E =education about the condition
- L=Lifelong adherence to a gluten-free diet
- I =Identification of nutritional deficiencies
- A=access to a support /advocacy group
- C =continuous long-term follow up with multidisciplinary team



# Thank you!

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