Challenges of a Dual Diagnosis of Celiac Disease & Type 1 Diabetes (or a Triple Diagnosis with Thyroid Disease!)

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Nothing to disclose
Outline

- Overview of the demands of dual diagnosis
- Literature review
- Psychosocial support
- Resources
- Cases
Mealtime with no dietary restrictions

- I’m hungry
- What is there to eat?
Mealtime with Diabetes and Celiac

- I’m hungry
- What is there to eat?
- What is my blood sugar?
- Is the food labeled?
- Does it have gluten?
- Has it been prepared without cross-contamination?
- How many carbs does it have?
- How much of it am I going to eat?
- Did I do any physical activity today/will I do any later?
- What is my insulin dose?
- Do I need a complex/extended bolus?

(adapted from http://www.livingwithout.com/issues/4_20/celiac_disease_diabetes_type_1-2889-1.html)
PHYSICAL AND EMOTIONAL DEMANDS
Physical Demands of T1D

• Insulin
• BG checks
• Carb counting
• BG during exercise
• Treating low BGs
• Carrying supplies
• Sick day mgmt
• Feeling sick with high/low BG

Physical Demands of CD

• Gluten=sick
• Finding hidden gluten
• Stuck without GF food

• Label reading
• Carrying food
• Special prep for events
• Special prep for events
Emotional Demands of T1D

- Fear of low/high BGs
- Family conflict
- Burden of self-management
- No break/forever
- Feeling different
- Harder to be spontaneous
- Frustrating
- Overwhelming
- Ignorant responses
- Coping with the “Diabetes/Food Police”
- Anger – “Why me?”
- Depression/anxiety

Emotional Demands of CD

- Socially limiting
- Fear of gluten contamination
- People want to share food experiences
- Health care providers treat it differently
- Ignorant responses
- Coping with the “Diabetes/Food Police”
- Anger – “Why me?”
- Depression/anxiety
What does the research say?
Diabetes + depression

- Per parent and youth report, youth with diabetes experience more clinical depression, anxiety, psychological distress and overall behavior problems than comparison groups\(^1\)

- Rates of depression are higher in adults with diabetes than in the general population\(^2\)

\(^1\)Reynolds & Helgeson, 2011; \(^2\)Anderson et al., 2001
Diabetes + quality of life (QoL)

- QoL in youth with T1D is similar to that of a sample of youth without diabetes\(^1\)

- In adults, QoL has also been shown to be similar between patients with T1D and a control group\(^2\)

\(^1\) Laffel et al., 2003; \(^2\) Tahbaz et al., 2006
Living with celiac disease

- Patient reported burdens of celiac disease (UK)\(^1\)
  - Questionnaires completed by patients (ages 18-75) on GF diet for \(\geq 1\) year with biopsy-confirmed CD
  - 67% reported dietary restrictions reduced enjoyment of food
  - 46% thought their food cost them more
  - 54% said they did things they enjoyed less often because of their diet

\(^1\)Whitaker et al., 2009
Living with celiac disease

- Influence of CD on daily life (US)\(^1\)
  - Questionnaire completed by patients >19 years old with self-reported biopsy diagnosed CD and adherence to GF diet
  - Other household members were used as control participants.
  - More controls had positive health perception (94%) compared to pts with CD (85%; p<0.0001)
  - Negatively impacted areas: dining out, travel, family/work
  - With increasing years of dx, less impact on dining out/travel
  - 98% of pts with CD reported adhering to a GF diet, but a majority reported intentionally going off diet occasionally

\(^1\)Lee et al., 2012
Living with celiac disease

Reasons for intentionally going off GF diet

- Too restrictive: 70%
- Uncomfortable in social settings: 70%
- Difficult to follow: 60%
- Tasteless: 40%
- Too expensive: 30%

1Lee et al., 2012
Living with celiac disease

- Canadian Celiac Association survey¹
  - Participants aged ≥18 years reporting biopsy-confirmed dx of CD
  - 25% said they suspected their family/friends were afraid to invite them for meals

How often did you intentionally ingest gluten in the past year?

![Bar graph showing gluten ingestion frequency]

1Zarkadas et al 2012
Celiac disease + depression

- Estimates of rates of depression in CD vary from 6-57%\(^1\)

- Some studies note depression to be more common in patients with CD than in the general population\(^2,3\)

- However, others find rates of depression to be low or similar to the general population\(^4,5\)

\(^1\)Garud, 2008; \(^2\)Ciacci, 1998; \(^3\)Carta, 2002; \(^4\)Roos, 2006; \(^5\)Ciacci, 2003
Celiac disease + quality of life

• Health Related QoL has been found to be lower in those with CD than in the general population, especially for women\textsuperscript{1}

• One study found perceived QoL to be lower for people with CD but that it improved after maintaining a GF diet\textsuperscript{2}; others have found that adherence to GF diet had negative impact on QOL\textsuperscript{3}

• Those diagnosed in childhood rate overall QoL higher than in those diagnosed later in life (84% vs. 50\%)\textsuperscript{3}

\textsuperscript{1}Hallert, 2003; \textsuperscript{2}Grech, 2000; \textsuperscript{3}Lee, 2012
Diabetes + celiac disease

As many as 10 percent of children with type 1 diabetes test positive for CD antibodies compared with 1/100 in general population

Screening for CD in T1D\textsuperscript{1,2,3}

- Pediatric guidelines
  - Shortly after T1D Dx; repeat screening \textasciitilde\text{every 2 years}
  - When symptoms suggestive of CD (erratic BGs, unexplained hypoglycemia, poor growth, etc.)

- Adult guidelines
  - Consider screening shortly after T1D diagnosis and whenever symptoms present
  - No re-screening frequency recommendation

\textsuperscript{1}Holmes, 2001; \textsuperscript{2}Rewers et al., 2004; \textsuperscript{3}Chiang et al., 2014
Diabetes + celiac disease + psychosocial factors

- Chart review study (n=600 CD; n=200 IBS; n=200 controls)\textsuperscript{1}
  - Rate of T1D was significantly higher in CD patients (5.8%), compared with IBS (1.5%) and controls (2.0%)
  - Rate of depression in all CD patients was 17.2% (18.5% in IBS; 16.0% in controls)
  - 37% of patients with T1D + CD had clinical depression

\textsuperscript{1}Garud et al., 2009
Diabetes + celiac disease + psychosocial factors

- QOL in children with CD + T1D (n=35 with T1D+CD; n=40 with T1D)\(^1\)
  - No differences in self-reported QoL between groups
  - Parents of youth with T1D+CD reported lower social functioning in youth than parents of T1D only

\(^1\)Sud et al., 2012
Diabetes + celiac disease + psychosocial factors

- Possible reasons for difference in perception?
  - Parents may perceive more difficulty
  - Parents feel angry/guilty
  - Parents aren’t used to the prevalence of food allergies that kids are
Research summary

- Depression is more common in people with diabetes than in people without diabetes
- Quality of life is not affected by diabetes
- Depression may or may not be more common in people with CD than in people without CD (measures, research methods, etc.)
- Quality of life is impacted by CD in adults, but maybe not in youth
- There is a need for further research on psychosocial issues related to a diagnosis of T1D + CD
Clinical experiences

- Which is worse, T1D or CD?

- CD feels more restrictive than T1D

- If no symptoms, very hard to adhere to GF diet

- If no diabetes complications, very hard to adhere to diabetes treatment plan
Psychosocial support

- Counseling (individual; family; support groups)
- Help identify what is hardest about and problem solve
- Multidisciplinary team that has an understanding of T1D and CD
- Have everyone in family eat the same when at home
- Give resources for support/resources for GF foods (also restaurants with GF menus)
Psychosocial support

- Consider other food restrictions (vegetarian, halal, kosher)
- Family culture of food (social events, family food traditions)
- For kids, plan for school events, playdates, birthday parties, babysitters
- Consider the siblings
- Focus on the positive (what foods CAN you eat?)
Resources for people with dual diagnosis

http://www.childrenwithdiabetes.com/clinic/celiac.htm

Children with Diabetes mailing list for parents of children with diabetes and celiac disease; celiac@childrenwithdiabetes.com

CELIAC-DIABETES LISTSERV
Support list (about 350 members) for all persons with celiac disease and diabetes. To subscribe, send in a message to: CELIAC-DIABETES@LISTSERV.ICORS.ORG

Gluten free food bank: www.piercespantry.com

Celiac Camps
- Camp Celiac in Rhode Island. www.campceliac.org
- Camp Celiac in California. www.celiaccamp.com
- Camp Nejeda in New Jersey. www.campnejeda.org - weekend family camp for families with diabetes and celiac disease
### National restaurants with gluten free options

<table>
<thead>
<tr>
<th>Restaurant Name</th>
<th>Restaurant Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 Guys Burgers and Fries</td>
<td>Olive Garden</td>
</tr>
<tr>
<td>Bertuccis</td>
<td>On the Border Mexican Grill</td>
</tr>
<tr>
<td>Bugaboo Creek Steak House</td>
<td>Outback Steak House</td>
</tr>
<tr>
<td>California Pizza Kitchen</td>
<td>P.F. Chang's China Bistro</td>
</tr>
<tr>
<td>Carrabbas Italian Grill</td>
<td>Romano’s Macaroni Grill</td>
</tr>
<tr>
<td>Chili’s</td>
<td>Ted’s Montana Grill</td>
</tr>
<tr>
<td>Legal Seafood</td>
<td>Texas Roadhouse</td>
</tr>
<tr>
<td>Naked Fish Restaurants</td>
<td>Wagamama</td>
</tr>
</tbody>
</table>
Cases
T1D and Celiac Co-occurrence

Mom

Mom diagnosed with Celiac 2008

Middle daughter diagnosed with Celiac 2008 (age 14)

Oldest son diagnosed with T1D 1996 (age 3)

Dad

Son

Daughter

Dad

Daughter

Youngest daughter diagnosed with T1D 2010 (age 12)
T1D – And more….

- T1D Dx 04/02 at age 22 months
- A1c values 7.3-8.6% (only 9 values >8% of 44 tests)
- Normal growth and development
- Routine labs 04/10 at age 8 10/12, suppressed TSH, mild symptoms of hyperthyroidism 06/10 at age 10
  - Jittery, heat intolerance, growth fine
  - Tapazole Rx (symptoms resolved)
- Labs 06/14, suppressed TSH again, unresponsive to increased Tapazole dose
- Celiac screen negative 07/13; rechecked 10/14 +++
- Gluten-free diet started immediately, TFTs improved
Summary

- Living with diabetes AND celiac disease is HARD
- Many social issues
- Depression/Anxiety
  - Increased in T1D
  - Unclear in CD (different measures, research methods, population)
- Quality of life
  - Comparable to peers in T1D
  - Decreased in CD in adults; not as much in youth
- Psychosocial support
  - Validation, problem solving
  - Peer support
  - Family/sibling issues
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