



THINKING OUTSIDE THE GUT:

PATIENT-REPORTED GLUTEN EXPOSURE SYMPTOMS IN CELIAC DISEASE & GLUTEN-RELATED DISORDERS

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OBJECTIVES

We sought to understand the distribution of gastrointestinal (GI) and non-gastrointestinal (non-GI) symptoms experienced by people diagnosed with celiac disease or other gluten-related disorders (GRD) when exposed to gluten.

METHODS

An online survey was taken by adult participants (≥ 18) registered in the Go Beyond Celiac patient registry, maintained by a patient advocacy organization. Questions were related to symptoms and their severity after gluten exposure. Registry participants self-identified as having celiac disease (93.7%) or another GRD (6.3%). Responses from the 2235 participants who completed the survey were tabulated and descriptive analyses were performed.

DISTRIBUTION OF SYMPTOMS IN THOSE SYMPTOMATIC AFTER GLUTEN EXPOSURE (N=2235)

| GI SYMPTOMS | n | % | NON-GI SYMPTOMS | n | % |
|-------------------------------------|------|------|---|------|------|
| Abdominal pain or discomfort | 1740 | 85.6 | Fatigue | 1695 | 83.4 |
| Abdominal bloating | 1667 | 82 | Brain fog | 1557 | 76.6 |
| Gas | 1506 | 74.1 | Irritability or fussiness | 1294 | 63.6 |
| Diarrhea or loose stool | 1495 | 73.5 | Headache or migraine | 1289 | 63.4 |
| Stomach rumbling (intestinal noise) | 1360 | 66.9 | Anxiety | 1213 | 59.7 |
| Nausea | 1138 | 56 | Joint pain | 1164 | 57.3 |
| Constipation or hard, bulky stool | 793 | 39 | Sadness | 947 | 46.6 |
| Incomplete bowel movements | 774 | 38.1 | Lack of interest in eating or in food | 900 | 44.3 |
| Vomiting | 651 | 32 | Numbness or tingling | 846 | 41.6 |
| Pale, foul smelling stool | 645 | 31.7 | Itchy skin rash | 789 | 38.8 |
| Black tarry stool | 317 | 15.6 | Canker sores | 551 | 27.1 |
| Blood in stool | 234 | 11.5 | Problems with muscle coordination or ataxia | 464 | 22.8 |
| | | | Difficulty or pain when swallowing | 336 | 16.5 |

RESULTS

- 2033 (91%) reported experiencing symptoms with gluten exposure.
- 2000 (98.4%) of the symptomatic participants have GI symptoms and 1956 (96.2%) have non-GI symptoms.
- Most common GI symptoms were abdominal pain or discomfort (85.6%), abdominal bloating (82.0%), gas (74.1%), and diarrhea (73.5%).
- Most common non-GI symptoms were fatigue (83.4%), brain fog (76.6%), irritability (63.6%), and headaches (63.4%).
- 67 (3.4%) symptomatic participants report only GI symptoms.
- 23 (1.1%) report only non-GI symptoms.

CONCLUSIONS

This survey contributes to the understanding of the symptom diversity with gluten exposure in people with celiac disease and GRD. Limitations include that diagnosis was self-reported. Many people with only non-GI symptoms may not be diagnosed with celiac disease, so this group is most likely underrepresented. Physicians and dietitians should be aware of common non-GI symptoms when considering diagnostic screening or celiac disease management.

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