Is the prevalence of medically unsupervised activated charcoal use a cause for concern in patients with celiac disease?

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Introduction

- At least 3 million people in the United States are living with celiac disease—97% of them are undiagnosed.[1]
- Celiac disease (CD) is a hereditary autoimmune disorder that affects the small intestine of the gastrointestinal tract. Exposure to gluten causes an immune-mediated inflammatory process.[2]
- Signs and symptoms of CD can include excruciating gastrointestinal pain, fatigue, headache, weight loss, or iron-deficiency anemia amongst others.[3]
- While medications to treat CD are currently in development, the only treatment option for CD is avoiding the consumption of gluten, a protein found in wheat, rye, and barley.
- Avoiding gluten is not straight forward and people with CD can unintentionally ingest gluten from cross contamination or hidden sources.
- To alleviate the symptoms of acute accidental gluten ingestion, the current remedy trialed by the CD community is activated charcoal (AC), which has never been tested in this patient population.

Methods

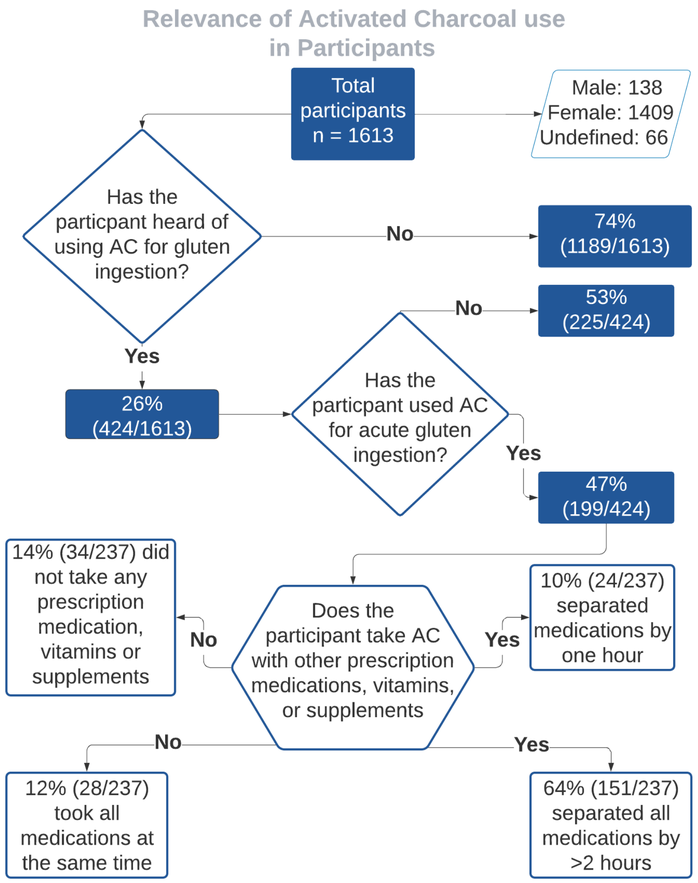
Data Collection and Process:

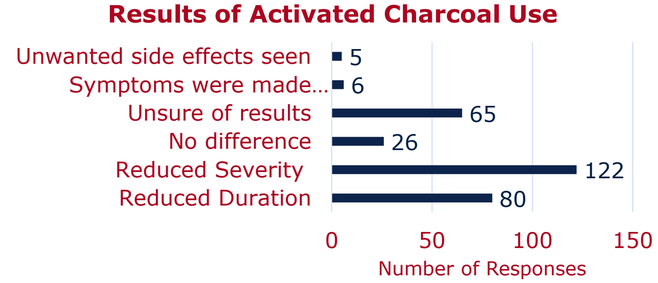
- A link to a survey containing 18 questions was posted on several celiac disease support groups across Facebook and Twitter or support group newsletters.
- Respondents to the survey were anonymized using The University of Arizona's RedCap Survey tool.
- Exclusions: Incomplete surveys or anyone not diagnosed by small bowel endoscopy or Celiac blood panel.

Data Analysis:

- Chi square was used to find correlation between sources of disease information in the following groups: "Participants who have heard of using activated charcoal and have used it" versus "Participants who have heard of using activated charcoal and have not used it."
- A Post-Hoc analysis was completed to find where the groups differed.
- A Bonferroni correction was conducted to prevent a single false positive from disrupting the findings.

Results





Discussion

- The top three sources of information between all groups regarding remedies for anything related to CD were Social Media Networks (28.6-31.1%), Gastroenterologist (19.4-23.3%), and YouTube (15.6-17.4%).
- The survey was primarily from US respondents but also included the UK, Brazil, and Australia, among others.
- Only 12% of the 1613 that responded reported they use or have used AC. Of those 61.4% reported having only used AC one or two times.
- Of those participants who have used AC 47% (199/424) reported subjectively feeling a reduced severity and/or reduced duration of symptoms.
- A limitation includes population of mostly women was analyzed, findings may not be as generalizable. However, 60% to 70% of those diagnosed with CD are female.[4]

Conclusion

- Gastrointestinal doctors should be made aware of this trend to trial AC in order to educate patients. There is concern that 81% of those using AC failed to report the use to their physicians (n=177) or continued using it despite their doctor's advice to not use it (n=14).
- While only 12% of participants with CD reported using AC, doses used varied and answers varied as to its benefit.
- Pharmacists should be aware of the off-label use of AC for accidental gluten ingestion in CD. Pharmacists should educate that there is not sufficient evidence to support its use and there are risks when not separating form other medications.

References

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