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

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ABSTRACT

Background/Objectives: Celiac disease is an autoimmune disorder which causes an intolerance to gluten. Due to hidden sources, lack of clear labeling, and cross-contamination, it is not uncommon for people with celiac disease to inadvertently ingest gluten. Currently, the only treatment is a lifelong adherence to the gluten-free diet as medications to treat celiac disease are not available. It is important for pharmacists to be aware of this use of activated charcoal to provide patients with accurate recommendations. The purpose of this study was to identify the frequency of activated charcoal use in individuals with celiac disease as a remedy despite the lack of literature on the safety and efficacy of the practice; and to describe where the recommendation for activated charcoal use as a treatment for acute gluten ingestion is originating from.

Methods: Using a descriptive study design, a web-based survey was sent to members of the celiac disease community via celiac disease center social media pages and through Facebook celiac support groups for participants who were at least 18 years of age and diagnosed with celiac disease, or the guardian of a child younger than 18 years of age with celiac disease. The survey was voluntary and anonymous. Participants were grouped based on method of diagnosis and whether they were using activated charcoal as a remedy for acute gluten intoxication. Resources participants utilized for treating acute gluten intoxication, amount of activated charcoal ingested and frequency, knowledge regarding spacing from other medications or vitamins, length of celiac disease diagnosis, and the effect activated charcoal had on the symptoms of gluten intoxication were also assessed. Chi-square was used to look for an association between activated charcoal use and non-physician references.

Results: In subjects with celiac disease, the use of activated charcoal for treatment of accidental gluten ingestion was prevalent in 12% of the documented participants. Of those, 61.4% reported having only used activated charcoal one or two times. In total 26% (424/1613) of respondents had heard of using activated charcoal for gluten ingestion. The top three sources of information

between all groups regarding remedies for anything related to celiac disease 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 United Kingdom, Brazil, and Australia, amongst others. Of those participants who had used activated charcoal, 47% (199/424) reported subjectively feeling a reduced severity and/or reduced duration of symptoms. A noted limitation includes the population, as mostly women were included in the analysis. Thus, findings may not be as generalizable. However, 60-70% of those diagnosed with celiac disease are female.

Conclusion: In order to educate patients, gastrointestinal doctors should be made aware of the trend to trial activated charcoal by those with celiac disease. There is concern that 75% of those using activated charcoal failed to report the use to their physicians or continued to use it despite their doctor's advice not to use it. Pharmacists should be aware of the off-label use of activated charcoal for accidental gluten ingestion in celiac disease. Pharmacists should educate patients with celiac disease that there is not sufficient evidence to support the use of activated charcoal and about the risks associated with concomitant prescription medication use.

Keywords: Activated charcoal, gluten, celiac disease, gluten intolerance, remedy, support groups

INTRODUCTION

Celiac disease is a hereditary autoimmune disorder that affects the gastrointestinal tract, with the small intestine being the most affected.[1] When an individual who has celiac disease consumes gluten, it causes an immune-mediated inflammatory process due to an inherent elevated sensitivity. This differs from food allergies which are immunoglobulin E or immunoglobulin G mediated and require an initial exposure to prime the immune system.[1] Gluten is a protein found in grains such as wheat, rye, and barley. Currently, celiac disease affects nearly three million Americans with approximately 97 percent of them being undiagnosed.[1]

The only effective treatment for celiac disease is a lifelong strict gluten-free diet (GFD).[2, 3, 4] Strict adherence to a GFD requires enormous personal sacrifice and has an impact on patients' psychological and social spheres, which often makes strict adherence difficult.[5, 6] As a result, patients risk accidently being exposed to gluten. Short-term consequences of being inadvertently exposed to gluten vary greatly depending on age.[3, 7] In children, the symptoms that are most likely to develop are diarrhea, malnutrition, and bloating among others. Whereas, in adults they can present with severe gastrointestinal symptoms and malabsorption, extraintestinal symptoms, or have no symptoms at all.[7, 8] Notably, malabsorption results in the long-term effects of the disease, such as growth failure in children, weight loss, severe anemia, neurologic disorders from deficiencies of B vitamins, and osteopenia from a deficiency of vitamin D and calcium.[7, 9]

Given that the immediate and long-term effects of the condition are uncomfortable and that there is no effective treatment for the condition, patients are turning to remedies with little to no clinical evidence. In the celiac disease community, this includes trialing activated charcoal for treatment of acute gluten intoxication. Historically, toxicologists have used activated charcoal to prevent gastrointestinal absorption of certain drugs and toxins that are present in the stomach at the time of charcoal administration.[10, 11, 12, 13] However, the efficacy of activated charcoal in celiac disease has never been tested. The beneficial effects of activated charcoal are believed to stem from strong binding to certain toxins while the toxin is still in the stomach that allows the gut to be decontaminated. Once the toxin leaves the stomach activated charcoal is believed to no longer work. The reaction gluten causes in celiac disease occurs in the duodenum. It should be

noted that while the mechanism of activated charcoal is not definitive, there are clear contraindications. The most notable contraindications are depressed mental status, increased risk of aspiration, and the presence of GI obstructions. Another concern is that there is data documenting that activated charcoal can reduce exposure to common prescription medications like apixaban, carbamazepine, and others up to 6 hours after ingestion.[14, 15, 16, 17] Additionally, data on the adverse effects of activated charcoal are not clear, but it has been noted that it can induce vomiting. At this time, the FDA has not evaluated the use of activated charcoal and there are no recommendations for its use.

OBJECTIVES

The primary objective was to identify how widespread the use of activated charcoal to alleviate the symptoms of acute gluten ingestion is in the celiac disease community despite the lack of literature supporting its use. The secondary objective was to describe the sources of recommendations being used by the celiac disease community to trial this remedy for the disease.

METHODS

This was a descriptive study that used data acquired from a set of online surveys. An anonymous link to a survey containing 15 questions was posted on several celiac disease support groups across Facebook, Twitter, celiac disease center social media pages and support group newsletters. Subjects were provided an explanation of the objective of the study, information stating that participation was voluntary, and that no identifying information would be obtained. Clicking to proceed with the survey was noted as providing informed consent to participate. The questionnaire consisted of 11 disease state specific questions, three questions to determine the demographics of the respondents, and a query that allowed additional comments. A trial run of the questionnaire was conducted with local pharmacists at an academic medical center in Tucson, AZ to assess the face validity of the questionnaire. These respondents were excluded from final data collection in the study. To receive a questionnaire, the participant must have been a part of one of the following groups A) a celiac disease support group on Twitter/Facebook, or B) a part of a celiac disease support listserv or social media group, and either A) have biopsy-

proven celiac disease or been diagnosed via the celiac blood panel, or B) represent a child who has celiac disease. Subjects without a history of biopsy-proven or blood test celiac panel positive for celiac disease were excluded. Participants were recruited using a snowball sampling technique through a Facebook celiac disease support group, Twitter, and national celiac disease support groups. The participant was then stratified by method of celiac disease diagnosis: biopsy proven/serology testing versus self-diagnosed. Participants were excluded from the analysis if they had an incomplete survey. Respondents were anonymized using The University of Arizona RedCap Survey tool. A sample size of 1,613 participants was obtained. Participants were stratified into three major groups: 1) Participants who had heard of using activated charcoal and had used it; 2) Participants who had heard of using activated charcoal and had not used it; and 3) Participants who had neither heard of using or used activated charcoal. All three groups were then asked to select what source they used for any medical information regarding celiac disease. The sample size of 1,613 underwent a chi square analysis to find correlation between sources of disease information. Alpha priori level was set to 0.05. A post-hoc analysis followed to find where the groups differed. Participants that had used activated charcoal were then asked to answer if they were taking activated charcoal with their current prescription medications, vitamins, or supplements. Additionally, this group was asked about changes in symptoms, duration, frequency, dose, and healthcare provider awareness related to activated charcoal use.

RESULTS

A total of 1,613 participants met the inclusion criteria. Among the surveyed population of 1,613 participants, 424 of the respondents had heard of using activated charcoal for gluten ingestion (26%) while 1,189 of the participants had never heard of using activated charcoal for acute gluten ingestion (74%). Out of the 424 participants who had been introduced to the idea of using activated charcoal for gluten ingestion, 199 participants admitted to using activated charcoal as a remedy for gluten toxicity (47%), while 225 participants had never tried it (53%) but were aware of its use being suggested. The top three sources of information between all surveyed groups related to celiac disease were social media (28.6-31.1%), gastroenterologists (19.4-23.3%), and YouTube (15.6-17.4%). Of the participants who had heard of using activated charcoal and had used it to treat gluten exposures, sources of recommendations for using the substance were analyzed as follows: 14 reported being told by their primary care physician, 9

reported being told by their gastroenterologist, 8 reported being told by their dietician, 19 reported being told by national celiac disease groups, 142 reported being told by social media outlets, 34 reported being told by YouTube/Google, and 48 reported being told by a friend. A chi square analysis was performed to identify if the sources of recommendations varied between the group that used activated charcoal versus the group that did not ($p=0.07$). No variation was found. After ingesting activated charcoal 122 participants reported reduced severity of illness, 80 participants reported reduced duration of illness, 65 participants were unsure of the results, 26 participants reported no difference, 6 participants reported worsening symptoms, and 5 participants saw unwanted side effects. Overall experience with activated charcoal was low where 61.4% of those who ingested activated charcoal reported only using 1-2 capsules once and had not repeated activated charcoal ingestion. After taking activated charcoal, 75% of those using the substance failed to report the use to their physicians ($n = 177$) or continued using it against the advice of their physician ($n = 14$).

DISCUSSION

The need for an antidote to treat acute gluten ingestion resonates with celiac disease patients around the world. Over a quarter of the participants in this study had been introduced to the idea of using activated charcoal for gluten ingestion through various sources. Of the total people who had heard of this remedy 47% ($n=199$) had used it. There is concern that a significant percentage of people with celiac disease who have used activated charcoal failed to report doing so to their healthcare provider. It is important that healthcare providers are aware of the medications being used in order to maintain patient safety. Without adequate communication between patient and provider, the patient may not receive the education necessary to be properly informed of the risks and benefits of using activated charcoal for acute gluten ingestion. Over 50% of the participants who tried activated charcoal reported only using it once, despite the reported anecdotal findings ranging from reduced severity to no change of “glutened” symptoms. This raises a question regarding the validity of activated charcoal and whether it should be recommended for use in the celiac disease community. Provided the limited literature supporting its use and the variable benefit reported in our findings we suggest that patients be advised against using activated charcoal for gluten ingestion until more data is available. Primarily, this suggestion comes from the documented changes in the pharmacokinetics of other drugs that is

seen with activated charcoal use. Another relevant finding is that the top three sources of information between all groups regarding remedies for anything related to celiac disease were social media networks, gastroenterologists, and YouTube. When comparing the impact that the sources of information made on the participants' decision making to use activated charcoal or not, it appeared to make no significant difference how reliable the source was ($p=0.07$). This outcome suggests that those with celiac disease are willing to consider treatment options for gluten reactions outside of the usual advice from a licensed medical practitioner. This can be problematic provided how easily misinformation is spread on the internet and a lack of disclosure to healthcare providers. Provided with these two factors, it is essential that healthcare providers become informed of the off-label use for activated charcoal that is trending among the celiac disease community to make informed recommendations on the subject. More importantly, physicians and pharmacists should educate patients with celiac disease that there is not sufficient evidence to support its use.

LIMITATIONS

Of the total number of participants who took part in the survey ($n=1613$), the population was mostly females ($n=1409$) suggesting the findings may not be generalizable between genders. Despite the differences in our surveyed population there is evidence to suggest that 60 to 70 percent of individuals diagnosed with celiac disease are female. Another issue is that there was no effective way to prevent a participant from submitting the questionnaire under multiple email addresses. While we suspect there would be little to no incentive to do this, it remains a possibility.

CONCLUSION

In celiac disease, the use of activated charcoal for treatment of accidental gluten ingestion is prevalent in 26% of the documented participants. The present study suggests that recommendations for anything related to celiac disease are social media (28.6-31.1%), gastroenterologist (19.4-23.3%), and YouTube (15.6-17.4%). Gastrointestinal doctors should be made aware of the trend to trial activated charcoal in order to educate patients. There is concern that 75% of those using activated charcoal failed to report the use to their physicians or

continued to use it despite their doctor's advice not to use it. Pharmacists should be aware of the off-label use of activated charcoal for accidental gluten ingestion in celiac disease. Pharmacists should educate patients with celiac disease that there is not sufficient evidence to support the use of activated charcoal and the risks associated with concomitant prescription medication use.

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