EDITORIAL

Current Diagnostic Algorithms May Fail to Identify Black Americans With Celiac Disease

Celiac disease remains vastly underdiagnosed, and the work presented in this issue of *Gastro Hep Advances* by Dr Cartee et al suggests that Black Americans with celiac disease may be at particular risk for lack of detection.[1,2] There is a commonly held viewpoint in the medical community that celiac disease is rare in Black Americans. Much of the data behind this belief stems from studies estimating celiac disease prevalence using serology.[3] Although more recent studies have called this viewpoint into question, there is a dearth of data evaluating and characterizing the Black community with celiac disease.[4]

In the study published by Dr Cartee et al, the authors created a registry of patients with both potential and confirmed celiac disease seen in their health system and used this registry to compare those with celiac disease who self-identify as Black and non-Hispanic Whites. Cases of celiac disease were first identified through International Classification of Diseases coding but then confirmed through chart review. Those with celiac disease were divided into possible celiac disease, probable celiac disease, and biopsy-proven celiac disease. Of 852 individuals with celiac disease, 42 self-identified as Black (4.9%). Given that these individuals were identified through routine clinical care, the authors estimate that the prevalence of celiac disease in the Black community may be even higher.

One of the more striking findings of this paper was that Black individuals with biopsies consistent with celiac disease were more likely to have negative but detectable tissue transglutaminase antibodies than non-Hispanic Whites. Differences in celiac serology between races have been identified previously. One study noted a higher concordance of tissue transglutaminase and endomysial antibodies in Whites than in non-Whites, with the latter being more likely to have a positive endomysial antibody in the setting of a weakly positive tissue transglutaminase.[5,6] Additionally, a systematic review and meta-analysis found that although Africa had the lowest seroprevalence of included continents, the prevalence of biopsy-proven celiac disease in Africa was similar to that in North America.[4]

The reason that there may be serologic differences between non-Hispanic Whites and Black individuals is not clear, and these potential differences certainly need further confirmation and investigation with larger population-based studies. It is noteworthy that prior studies have identified the Black American community as having increased rates of adopting a gluten-free diet without a prior diagnosis of celiac disease.[3] This raises the possibility that Black Americans with celiac disease are unintentionally self-treating.

If the Black American celiac disease community is more likely to have lower or normal tissue transglutaminase levels at diagnosis, this puts them at increased risk for going undetected. The recent 2023 American College of Gastroenterology guidelines on celiac disease continue to endorse a diagnostic approach of screening for celiac disease with tissue transglutaminase serology and only obtaining confirmatory duodenal biopsies in cases where serology is positive or where serology is negative or normal but suspicion for celiac disease is high.[7] Therefore, for a Black American with celiac disease and a normal tissue transglutaminase to trigger a diagnostic upper endoscopy, they would need significant symptoms, a notable family history, or conditions associated with celiac disease. This conditional requirement for proceeding with diagnostic biopsy has significant associated concern. The study by Dr Cartee et al found that Black individuals with celiac disease were more likely to have a higher body mass index (which is not classically associated with celiac disease), and prior studies have found that Black individuals with concerning symptoms (diarrhea, anemia, and weight loss) were significantly less likely to undergo duodenal biopsies.[8]

The Black celiac disease community may be caught in a vicious cycle. Relying on data from seroprevalence studies may underestimate prevalence in the Black community if they indeed are more likely to have normal serology. This potentially faulty belief of low prevalence in Black Americans will in turn demotivate proceeding with upper endoscopy in cases of Black Americans with suspected celiac disease but normal serologies. We need a better understanding of serologic status in Black individuals with celiac disease, and these studies need to be designed to avoid potential bias.

The diagnostic accuracy of tissue transglutaminase in the general population has already been called into question, with one study suggesting sensitivity may be as low as 57.1%.[9] The work by Dr Cartee et al suggests that tissue transglutaminase may be a particularly poor screening tool in the Black American population. We need to take a closer look at our current diagnostic algorithms, and in particular, the practice of relying on tissue transglutaminase to identify cases.

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