

# Celiac Disease in African-Americans

Pardeep Brar · Ann R. Lee · Suzanne K. Lewis ·  
Govind Bhagat · Peter H. R. Green

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**Abstract** Celiac disease is generally under diagnosed in the United States and it is unclear whether the disease is encountered in ethnic minorities. Our purpose is to describe a case series of African-American patients with celiac disease. Nine (1.3%) African-American patients with celiac disease were identified from a prospectively generated database of 700 patients with biopsy proven celiac disease and seen between 1981 and 2004. Females predominated, with seven, compared to two males. Diarrhea was the presentation in only two patients, while three presented with iron deficiency anemia. One third had at least one autoimmune disease. Compliance with a gluten-free diet, the only medical therapy of this disease, was poor. Only four patients adhered strictly to the diet. Celiac disease occurs in African-Americans and may well be underdiagnosed. Special attention needs to be given to methods that encourage adherence to the diet in minority groups.

**Keywords:** African-American · Celiac disease · Compliance · Gluten-free diet · HLA DQ typing

## Introduction

Celiac disease is an autoimmune enteropathy that occurs in genetically predisposed individuals and is precipitated by the ingestion of gluten containing grains [1]. The disease is

multigenetic, however, there is a requirement that an individual must possess the HLA alleles that encode for DQ2 and/or DQ8 [2]. These molecules are involved in the presentation of pathogenic deamidated gliadins to antigen presenting cells [3].

Formerly, celiac disease was considered rare in the United States; however, it is now estimated to occur in about 1% of the population [4, 5]. The prevalence of this disease in minority populations within the United States is not known. It is, however, considered rare in African-Americans, partly because HLA DQ2 and DQ8 are regarded as primarily Caucasian genetic traits. We have, however, detected celiac disease in African-Americans at our institution and present these findings in the current report. This is especially important because celiac disease, an eminently treatable condition, is considered to be underrecognized in the United States.

## Methods

African-American patients who were treated for celiac disease at the Celiac Disease Center of Columbia University were identified from an anonymized database of 700 celiac disease patients (65% females and 35% males). We defined African-American patients as those Black patients who reported their ethnicity as African-American. Only biopsy-proven celiac disease patients were included in this study. Data regarding age, sex, age at diagnosis, mode of presentation, serologic profiles, and response to a gluten-free diet were prospectively recorded.

Small bowel histology was reviewed for all patients. The study was approved by our institutional review board. All patients had intraepithelial lymphocytosis and villous atrophy corresponding to Marsh stage III [6]. We classified the degree of villous atrophy as partial villous atrophy (PVA), subtotal villous atrophy (STVA), or total villous atrophy (TVA).

P. Brar · A. Lee · S. Lewis · G. Bhagat · P. H. R. Green  
Department of Medicine, Columbia University  
College of Physicians and Surgeons,  
New York, New York, USA

P. H. R. Green (✉)  
Herbert Irving Pavilion, Room 645, 161 Fort Washington Avenue,  
New York, New York 10032  
e-mail: pg11@columbia.edu

**Table 1.** Demographics, presentation mode, serology, and histopathology.

No	Sex	Age at diagnosis (yr)	Mode of presentation	Associated conditions	IgA/G	EMA or tTG	Villous atrophy	HLA DQ2/8
1	M	64	Anemia		+	+	Subtotal	DQ2
2	F	37	Edema		+	NA	Subtotal	DQ2
3	F	54	Incidental at EGD	Rheumatoid arthritis, SLE	+	–	Partial	NA
4	F	30	Anemia	Myasthenia gravis, DH	+	NA	Partial	NA
5	F	59	Anemia	IDDM	+	NA	Subtotal	NA
6	F	83	Diarrhea	MC, osteo-porosis	+	+	Partial	NA
7	F	28	Diarrhea	DH	+	NA	Partial	DQ2
8	F	15	Abdominal pain		–	–	Partial	DQ2/8
9	M	15	Growth failure		–	+	Partial	NA

*Note.* EGD, esophagogastroduodenoscopy; +, present; –, absent; NA, not assessed; EMA, endomysial antibody; tTG, transglutaminase antibody; M, male; F, female; SLE, systemic lupus erythematosus; DH, dermatitis herpetiformis; IDDM, insulin-dependent diabetes mellitus; MC, microscopic colitis.

## Results

A total of nine African-American patients, two males and seven females (Table 1), were identified from the database of 700 patients, representing 1.3% of all patients. Their mean age at time of diagnosis was 42 years. Two were children, aged 15 years.

Only two (22%) patients presented with the classical presentation of diarrhea. The other seven patients had “silent” celiac disease, presenting with iron deficiency anemia ( $n = 3$ ), abdominal pain ( $n = 1$ ), growth failure ( $n = 1$ ), edema because of hypoalbuminemia ( $n = 1$ ), and one as an incidental finding during endoscopy for gastrointestinal bleeding. Two had already been diagnosed with biopsy-proven dermatitis herpetiformis, though they had not been advised about a gluten-free diet. Two had osteoporosis and three patients had autoimmune diseases, including myasthenia gravis, systemic lupus erythematosus, rheumatoid arthritis, and insulin-dependant diabetes mellitus. One patient had concomitant microscopic (lymphocytic) colitis.

### Serology, HLA, and pathology (Table 1)

All patients had at least one serologic test performed at the time of diagnosis and all except one had at least one positive serologic result. Three of five patients had either a positive endomysial (EMA) or a positive tissue transglutaminase (tTG) antibody present. Four patients were assessed for the presence of HLA DQ2 or DQ8 and had positive results. One patient (No. 8) had a negative serologic profile but was both DQ2 and DQ8 positive. All patients had villous atrophy (subtotal  $n = 3$ , PVA  $n = 6$ ), at presentation.

### Follow-up on gluten-free diet (Table 2)

All patients were advised a gluten-free diet. They were seen by a dietician experienced in the gluten-free diet and were

referred to a celiac support group. The mean duration of follow-up was 39 months. Four patients adhered to the diet strictly; two did not attempt the diet, despite counseling from the physician, the dietician, and a local support group, while three had poor compliance, admitting to only intermittent adherence to the diet. Despite poor compliance in three patients, all those on the diet showed an improvement in symptoms. Antibodies persisted in three of five patients with available follow-up antibodies, as did villous atrophy, though it was less marked in three patients.

## Discussion

We identified nine African-American patients with celiac disease, representing 1.3% of all patients seen at our specialist referral center. The demographic profile of the African-American patients was similar to that of the other patients seen at our center, in that females predominated, and at least one associated autoimmune disease was present in a third of the patients [7]. The majority of the patients presented with “silent” celiac disease, a trend noted by us and others [8, 9], and iron deficiency anemia was the most frequent presentation [10].

Celiac disease is being increasingly diagnosed throughout the world. While it is recognized throughout Europe and in countries populated by those of European origin such as South Africa, Australia, New Zealand, and South America, it is now being diagnosed in populations where celiac disease was traditionally not thought to occur. The disease appears to be common in North Africa [11, 12], as well as in the Middle East [13, 14] and northern India [15, 16]. Celiac disease has also been documented in Cuba [17] and in West Indian children living in England [18].

Celiac disease is considered rare in individuals of central African descent [19], however, the blood donor screening study by Not *et al.*, in Baltimore, Maryland, in the United

States, revealed that 1 of 250 African-Americans had positive endomysial antibodies, a frequency similar to that of entire group [20]. There have been no systematic screening studies of celiac disease among African-Americans, so we are not aware of just how common this disease may be. African-Americans make up 12% of the U.S. population, yet only 1% of the patients with celiac disease that we have seen were African-Americans. The low prevalence of disease may be due to a lower frequency of the DQ2 or DQ8 alleles in the African-American population or it may be the consequence of other factors such as referral bias or socioeconomic factors affecting access to health care. We are not aware of studies of the frequency of DQ2 or DQ8 among African-Americans. Future research should include studies of HLA DQ2/8 frequency among African-American patients from different geographic locations in the United States.

One striking feature observed in our series of patients is the poor dietary compliance among five patients, with two not attempting the diet at all. Compliance with a gluten-free diet is often a problem. In France and Belgium, less than half of all adult patients studied adhered strictly to the diet for more than 1 year postdiagnosis [21]. In the United Kingdom a low compliance has been reported for both teenagers and adults [22]. Reasons for poor dietary compliance include expense, availability, and palatability of gluten-free food. Other factors associated with poor compliance with the diet include lack of symptoms at diagnosis [23], inadequate initial dietary counseling [24], inadequate medical or nutritional follow-up [25], and inaccurate dietary information provided by resources such as the Internet [26]. Minority populations have been noted to have compliance difficulties. One study from the United Kingdom, comparing dietary compliance between members of a minority population (South Asians) and Caucasians, all with celiac disease, reported a higher compliance rate among the Caucasians [27]. South Asians were less likely to attend dietetic clinics, join a support group, and be satisfied with information provided by doctors and dietitians. Compliance with diet in those with celiac disease should be encouraged because it is associated with a good quality of life [28].

In conclusion, we have identified celiac disease in only nine African-Americans. The true prevalence of celiac disease among this population in the United States needs to be determined. In addition, when celiac disease is identified in minority groups, special attention needs to be placed on factors that increase dietary compliance.

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