Inflammatory Bowel Disease in African American Children Compared With Other Racial/Ethnic Groups in a Multicenter Registry

JOLANDA M. WHITE,* SIOBHÁN O'CONNOR,‡ HARLAND S. WINTER,§ MELVIN B. HEYMAN,‖ BARBARA S. KIRSCHNER,¶ GEORGE D. FERRY,# STANLEY A. COHEN,** ROBERT N. BALDASSANO,‡‡ TERRY SMITH,§§ TRACI CLEMONS,‖‖ and BENJAMIN D. GOLD*

*Department of Pediatrics, ‡Department of Medicine, Emory University School of Medicine, Atlanta, Georgia; §Department of Pediatrics, MassGeneral Hospital for Children, Boston, Massachusetts; ‖Department of Pediatrics, University of California, San Francisco, San Francisco, California; ¶Department of Pediatrics, The University of Chicago, Comer Children's Hospital, Chicago, Illinois; #Department of Pediatrics, Baylor College of Medicine, Houston, Texas; **Children's Center for Digestive Healthcare, Atlanta, Georgia; ‡‡Children's Hospital of Philadelphia, Philadelphia, Pennsylvania; §§Texas Children's Hospital, Houston, Texas; and ‖‖EMMES Corporation, Rockville, Maryland

See Kappelman MD et al on page 1907 for companion article in the December 2008 issue of *Gastroenterology*.

Background & Aims: **Few epidemiologic investigations characterize inflammatory bowel disease (IBD) in non-Caucasian children. Our study compared IBD characteristics between African Americans and non–African Americans enrolled in a multicenter pediatric IBD registry with endoscopic- and pathology-based diagnosis.** ***Methods:*** **The study retrieved data entered from January 2000 to October 2003 on children 1 to 17 years old, inclusive, followed by a consortium of academic and community US pediatric gastroenterology practices. Analyses examined racial/ethnic differences by comparing the proportions of African Americans and non–African Americans in the following categories: each diagnostic disease classification (any IBD, Crohn's disease, ulcerative colitis, indeterminate colitis); age group (<6 y, 6–12 y, or >12 y) at diagnosis or symptom onset; presence of extraintestinal manifestations, Z-scores for height and weight, immunomodulatory therapy, anatomic disease location, and abnormal hemoglobin, albumin, or sedimentation rate at diagnosis.** ***Results:*** **A total of 1406 patients had complete data, 138 (10%) of whom were African American. African Americans more often were older than 12 years of age at diagnosis (52% vs 37%; odds ratio [OR], 1.82; 95% confidence interval [95% CI], 1.28–2.59) and symptom onset (46% vs 30%; OR, 1.99; 95% CI, 1.40–2.84); had Crohn's disease (78% vs 59%; OR, 2.36; 95% CI, 1.56–3.58); and had a low hemoglobin level at diagnosis (39% vs 17%; OR, 3.15; 95% CI, 1.92–5.17).** ***Conclusions:*** **IBD in African American children and adolescents presents more commonly with Crohn's disease and at older ages compared with non–African Americans. Racial/ethnic differences in the epidemiology of IBD, particularly Crohn's disease, among American youths require further investigation.**

Inflammatory bowel disease (IBD) encompasses the distinct disease classifications of Crohn's disease (CD), ulcerative colitis (UC), and indeterminate colitis (IC).[1,2] IBD can cause substantial morbidity among children in the United States and throughout the world.[3,4] Recent epidemiologic studies have described incidence rates of IBD among African American (AA) adults[5–7] and African Caribbean children[8] approaching those in Caucasians. Few investigations have described the clinical characteristics of IBD in diverse pediatric populations.[9–11] A recent adult study reported significant differences of IBD among different racial/ethnic groups,[12] whereas a recent pediatric investigation found similar phenotypic features among AA, Hispanic American, and white children.[13] One single-center study reported an equal distribution of IBD disease classifications among AA and non-AA pediatric patients. However, when compared with non-AA children, AA children had longer symptom duration, and were older at IBD diagnosis than non-AA children.[11] In a preliminary investigation of IBD in adults, Straus et al[14] reported lower hemoglobin (Hgb) levels and more frequent prednisone use among AAs compared with Caucasians. These observations suggest that disease phenotype might differ between racial/ethnic groups.

To fill gaps in understanding the epidemiology of pediatric IBD in the United States, a national network of clinicians and researchers developed a large registry of pediatric IBD patients. Six large tertiary and community-based US pediatric gastroenterology practices comprise the Pediatric IBD Consortium (subsequently referred to as *Consortium*). The sites are geographically diverse, representing Western (San Francisco, CA), Midwestern (Chicago, IL), Northeastern (Boston, MA), Eastern (Philadelphia, PA), Southwestern (Houston, TX), and Southeastern (Atlanta, GA) regions of the continental United States. Each practice follows up pediatric patients from urban, suburban, and rural areas, collecting clinical, laboratory, and demographic data on every enrolled subject, and entering it into the database.

By using the Consortium patient registry, the present study examined the epidemiologic and clinical manifestations of IBD in AA children. We hypothesized that AA children with IBD have distinctly different clinical characteristics and disease patterns when compared with non-AA children diagnosed with

Abbreviations used in this paper: AA, African American; Alb, albumin; CD, Crohn's disease; 95% CI, 95% confidence interval; EIMCs, extraintestinal manifestations and complications; ESR, erythrocyte sedimentation rate; Hgb, hemoglobin; IBD, inflammatory bowel disease; IC, indeterminate colitis; OR, odds ratio; UC, ulcerative colitis.

1542-3565/08/$34.00
doi:10.1016/j.cgh.2008.07.032

IBD. To test this hypothesis, we compared age distributions, disease classifications, and the clinical presentation of AA and non-AA IBD patients enrolled in the multicenter Consortium registry from 2000 to 2003.

Methods

Data Extraction From the Consortium Registry

This study retrospectively retrieved and analyzed data recorded from January 2000 to July 2003 on children with IBD followed up by the 6 academic referral- and community-based pediatric gastroenterology practices of the Consortium: Emory University—Children's Healthcare of Atlanta and Children's Center for Digestive Healthcare (Atlanta, GA); Baylor College of Medicine—Texas Children's Hospital (Houston, TX); University of California, San Francisco—Children's Hospital (San Francisco, CA); University of Pennsylvania—Children's Hospital of Philadelphia (Philadelphia, PA); University of Chicago—The University of Chicago, Comer Children's Hospital (Chicago, IL); and Harvard University—MassGeneral Hospital for Children (Boston, MA). AA comprised varied proportions of the catchment populations of each consortium site: 28% in Atlanta, 17% in Houston, 6.5% in Boston, 19% in Chicago, 17% in Philadelphia, and 8% in San Francisco.[15] The registry contains cross-sectional and longitudinal data on IBD patients aged 1 to 17 years, inclusive, abstracted from medical records and uniformly entered by each of the sites' investigators and study coordinators. Data on patients newly diagnosed or currently followed up by a Consortium gastroenterologist include the following: medical, surgical, and procedural histories; endoscopic and histologic evaluations of mucosal biopsy specimens; patient clinical status (eg, presence of extraintestinal manifestations [EIMCs], perianal disease, skin tags, fissures and abscesses, abdominal pain/tenderness, stool pattern); laboratory results; radiographic studies; medication history; and use of nutritional supplements. At each site, the investigating physician or nurse researcher recorded data from the inpatient and outpatient clinic medical record. More than 80% of the patients in the data registry were enrolled prospectively, the remaining patients being enrolled retrospectively. All sites had approval from their respective Institutional Review Boards before data collection and entry. Informed consent and assent (when appropriate) was obtained from all participating parents and subjects before enrollment.

Case Definitions

The diagnosis of IBD is standardized across the Consortium based on a combination of clinical, laboratory, radiologic, endoscopic, and histologic findings. CD was defined by the following: (1) presence of granuloma in any one biopsy specimen from upper and/or lower endoscopy; (2) in the absence of granuloma, evidence of skip lesions on colonoscopy and/or microscopic focal chronic inflammatory changes in upper endoscopy; (3) segmental small intestinal radiologic findings consistent with CD; (4) presence of perianal disease (ie, abscesses, fistulae, large skin tags); and/or (5) evidence of transmural inflammation (ie, strictures, fistulae). UC was defined as contiguous disease confined to the colon without evidence of small intestinal involvement (other than backwash ileitis) on biopsy or radiology. IC was defined as colitis that could not be definitely classified as either CD or UC, based on the earlier-described criteria. Patients with infectious, eosinophilic, or other underlying cause for enteritis or colitis were excluded.[10]

Eligibility Requirements

All IBD patients followed up by any Consortium gastroenterologist are eligible for enrollment in the registry. To minimize selection bias, the investigators attempted to enroll all newly diagnosed patients and those newly followed up by the Consortium, regardless of race/ethnicity or IBD classification. Established patients were enrolled as time and research personnel permitted. The study cohort consisted of all patients enrolled in the registry during the study period (January 2001–July 2003) who had complete data, as of October 2003, for age at diagnosis, IBD classification, self- or parent-reported age of IBD symptom onset, and race/ethnicity.

Definition of Terms and Disease Classification

For purposes of the study, patients (or their parents) identifying themselves as black, non-Hispanic were considered AA. Non-AA encompassed all other children with a self- or parent-reported race/ethnicity of Caucasian, Asian Pacific Islander, American Indian, Hispanic and non-AA, or race not specified. In this study, the most recently recorded IBD diagnosis as of the October 2003 data retrieval date represented the disease classification. The first diagnosis (if different) was not used because clinical disease can evolve over time, thereby changing the initial diagnosis,[10] and because this information was not available for all those initially diagnosed outside the Consortium. For patients newly diagnosed by the Consortium, the date of the first definitive endoscopic and/or radiographic (small-bowel barium contrast study) diagnosis of IBD by a Consortium pediatric gastroenterologist defined the date of diagnosis. For patients diagnosed outside of the Consortium but subsequently followed up by a Consortium gastroenterologist and entered into the registry, the date of disease diagnosis recorded in the medical record and confirmed by subsequent Consortium endoscopy or radiographic evaluation denoted the date of diagnosis. Date of symptom onset was the approximate onset of symptoms consistent with IBD, as reported by the case child and/or the parent/legal guardian. *IBD disease classifications* were defined as CD, UC, IC, or any IBD; any IBD refers to the sum or combination of all cohort patients diagnosed with CD, UC, and IC. The following anatomic disease location categories were used to subanalyze CD: isolated upper (esophagus and/or stomach); isolated small bowel (proximal, middle, and/or distal small bowel); isolated colonic (any portion of the colon); isolated ileocolonic (any portion of the colon plus ileum); and all other combinations. For ease of data analysis, the following anatomic disease locations were used to categorize UC: pancolonic (cecum to left colon inclusive, with/without rectum); extensive colonic (transverse colon to left colon inclusive, with/without rectum); left colonic (left colon with/without rectum); and isolated rectum.

For this study, at or around the time of diagnosis was defined as the period extending from 90 days before until 30 days after date of diagnosis. *Perianal disease* included fissures, tags, erythema, abscesses, or fistulae in the perianal region. *Fistulae* were recorded as a separate variable in the data registry and thus could be analyzed separately when comparing ethnic/racial groups. The term *fistulae* defined one or more fistulae arising