ADVANCES IN IBD

Current Developments in the Treatment of Inflammatory Bowel Disease

Section Editor: Stephen B. Hanauer, MD

Racial and Ethnic Disparities in Inflammatory Bowel Disease

Marie L. Borum, MD, EdD, MPH
Professor of Medicine
Director, Division of Gastroenterology and Liver Disease
George Washington University
Washington, DC

G&H What are the prevalence and incidence rates of inflammatory bowel disease by race and ethnicity, and how have they changed?

MB The prevalence and incidence rates of inflammatory bowel disease (IBD) have increased significantly during recent decades among non-White individuals. Data extracted from the 1999 National Health Interview Survey, which included 30,801 adults with an 87.6% response rate, estimated an IBD prevalence rate of 1.0% among non-Hispanic White individuals and 0.32% among non-Hispanic Black individuals.[1] In the 2015 National Health Interview Survey, which included 33,673 adults with a 55.2% response rate, Dahlhamer and colleagues found that the age-adjusted prevalence rate of IBD increased to 1.4% among non-Hispanic White individuals and 0.5% among non-Hispanic Black individuals.[2] Aniwan and colleagues evaluated a population-based cohort of 814 residents of Olmsted County, Minnesota who were diagnosed with IBD between 1970 and 2010.[3] The adjusted incidence rate of IBD was 18 per 100,000 person-years in White patients and 6.4 per 100,000 person-years in non-White patients between 1970 and 1984. The incidence rates of IBD in White and non-White patients subsequently increased to 21 and 9.3 per 100,000 person-years, respectively, between 1985 and 1999, and to 25 and 15 per 100,000 person-years, respectively, between 2000 and 2010. The authors determined that the incidence rate of IBD increased by 39% in White patients and by 134% in non-White patients.

G&H Are there key differences in IBD presentations across racial and ethnic groups?

MB A number of studies have reported differences in IBD presentations in non-White patients compared with White patients. Shi and colleagues performed a systematic review and meta-analysis of population-based cohort studies and reported that Black patients with Crohn's disease had less ileal disease (P=.01), more perianal disease (P=.02), and a higher proportion of penetrating disease (P<.05) than non-Black patients.[4] Barnes and colleagues evaluated more than 5000 patients with IBD in a collaboration of 7 academic medical centers and found that Black patients were significantly more likely to present with a Crohn's disease complication at baseline than White patients.[5] Black patients also had a nonsignificant increase in perianal and other Crohn's disease–related fistulas. In subsequent evaluation, Black patients with Crohn's disease were significantly more likely to develop new abscesses or anal fissures. While there may be differences in presentation that may modify medical management, the primary concern is when Black patients have the same presentation as other patients, but are not diagnosed with IBD.

G&H How and why may the diagnosis of IBD be delayed or incorrect in Black and Hispanic patients?

MB Historically, it was taught that Black and Hispanic individuals are not at risk of developing IBD. When IBD is not considered to be a disease that can occur in these individuals, they may not receive appropriate diagnostic testing for symptoms that would prompt an evaluation for IBD in White patients, leading to a delay in diagnosis or misdiagnosis.

In addition, the age of onset and duration of IBD prior to diagnosis may differ by ethnicity. It has also been reported that the country of birth can influence the age of diagnosis, as it may impact whether IBD is considered upon initial presentation. A retrospective study of patients with IBD found that the disease is diagnosed later in non–US-born Hispanic individuals compared with Hispanic individuals born in the United States and non-Hispanic White individuals.[6] However, most studies did not identify a difference in the age of presentation of IBD in Black patients compared with non-Hispanic White patients.[7,8] Notably, a multicenter study reported that Black children were more likely to be diagnosed 12 years after the presentation of symptoms, highlighting the concern that a low index of suspicion in minority children can delay diagnosis.[9]

Access to care may also result in delayed diagnosis and progression of disease severity. Social determinants of health and the ability to access care continue to be concerns for all patients. The intersection of socioeconomic issues, access to care, and IBD awareness may affect an individual's ability to advocate for an evaluation. However, racial and ethnic minorities who have access to care may experience a delay in IBD diagnosis if there is a lack of awareness of increasing IBD prevalence.

G&H What are the consequences of delayed diagnoses or misdiagnoses of IBD?

MB A delay in diagnosis or a misdiagnosis resulting in untreated IBD can lead to persistent inflammation, development of systemic symptoms, and potential complications from aggressive disease. The presence and severity of systemic symptoms is dependent upon the clinical severity of intestinal disease. The transmural inflammation of Crohn's disease that leads to fistulization, phlegmonous changes, abscess formation, and stenosis may be more likely to occur in patients who are untreated or suboptimally treated or who have a delay in treatment. The consequences of unmanaged IBD can be profound. The severity of initial disease manifestations may affect long-term outcomes in some patients, making it imperative that diagnoses are established early in all patients.

The impact of extraintestinal manifestations should also be considered when addressing the effects of delayed diagnoses. With the exceptions of primary sclerosing cholangitis, uveitis, and ankylosing spondylitis, manifestations involving other organs can follow the clinical course of colitis. When intestinal disease is not managed, the potential for extraintestinal complications becomes an additional concern. Intestinal and extraintestinal complications are significant issues in patients with persistent IBD activity. Additionally, a systematic review and meta-analyses by Knowles and colleagues demonstrated that quality of life in adults with IBD is worse in individuals with active disease.[10]

Early diagnosis and initiation of treatment optimizes outcomes by addressing intestinal disease, extraintestinal manifestations, and complications that can result from disease activity.

G&H How may IBD therapy differ across racial and ethnic groups?

MB Nguyen and colleagues found that Black patients with IBD were less likely to receive infliximab than other racial groups.[11] However, this study did not identify differences in the use of immunomodulators. At last year's annual meeting of the American College of Gastroenterology, Alsabbagh Alchirazi and colleagues presented a study reporting that Black patients were less likely than White patients to be treated with 5-aminosalicylic acid ($P<.0001$), methotrexate ($P<.0001$), thiopurines ($P<.0001$), and biologic agents, including anti–tumor necrosis factor agents ($P<.0001$), ustekinumab (Stelara, Janssen) ($P<.0001$), vedolizumab (Entyvio, Takeda) ($P<.0001$), and tofacitinib (Xeljanz, Pfizer) ($P=.0044$).[12]

It should also be noted that data on treatment outcomes in non-White patients with IBD are limited. A review that evaluated racial and ethnic minority enrollment in IBD clinical trials reported that studies primarily enrolled White patients, with Black patients comprising less than 3% of study participants.[13] Thus, racial and ethnic minority groups are not well represented in outcome-based IBD studies, which are often the basis for guideline development. Much more needs to be done to ensure that treatment options are available to all patients and that treatment choice is appropriately individualized.

G&H What differences have been reported in terms of surgical outcomes and hospitalization across racial and ethnic groups in IBD?

MB A retrospective study using the American College of Surgeons National Surgical Quality Improvement Program database reported that Black, Hispanic, and Asian patients undergoing colorectal surgery for IBD had higher rates of postoperative complications, readmissions, and hospital length of stay than White patients.[14] Hispanic patients had the highest rate of readmission, and Black patients had the highest rate of sepsis, bleeding requiring transfusion, and renal impairment.

Additionally, Walker and colleagues found that Black patients with Crohn's disease had significantly higher hospitalization rates than White patients.[15] Another study

found that Black patients with IBD had higher unplanned readmission rates than White patients.[16] As the incidence of IBD continues to increase in racial and ethnic minorities, disparities in health care access and surgical outcomes require further evaluation.

G&H How can health care providers address these disparities?

MB All health care providers must be aware that IBD can occur in White and non-White patients. Improving education and engaging minority communities will increase awareness among patients and health care providers. Non-White patients with IBD have often expressed that their race or ethnicity likely impacted the establishment of their diagnosis because it was assumed that IBD did not occur in racial or ethnic minorities. Increasing awareness of IBD and its rising prevalence in non-White patients will reduce delayed diagnosis and prompt initiation of early treatment. Clinicians should ensure that all patients, including those of color, receive the resources that are required for their health care needs. All patients with IBD should be referred to IBD specialists for management. Lack of referral to providers who care for patients with IBD can result in suboptimal management, more frequent complications, and increased emergency room utilization and hospitalization. Patients must be empowered to navigate the health care system to ensure optimization of their care.

In addition, health care providers should become familiar with and provide information about IBD advocacy groups to their patients. Although patients benefit from medications and enhanced specialty care, advocacy groups can provide additional resources that can optimize IBD care. Advocacy groups may also offer formal and informal support groups that can improve the well-being of patients and optimize their care beyond physicians' offices.

G&H What further research is needed?

MB The incidence of IBD is increasing in minority populations. Most IBD research has been conducted in White patients, which has contributed to the disparity in care that can be received by non-White patients. In addition, there are limited data on pharmacologic, endoscopic, and surgical outcomes in Black and Hispanic patients. More minority patients must be included in future clinical trials.

Additionally, there should be focused efforts to evaluate issues related to genetic factors and potential environmental influences upon IBD expression. Continued, intentional efforts to evaluate factors that can ensure health equity among all patients with IBD are needed.

Disclosures

Dr Borum has served as a consultant and speaker for Takeda.

References

1. Longobardi T, Bernstein CN. Health care resource utilization in inflammatory bowel disease. *Clin Gastroenterol Hepatol*. 2006;4(6):731-743.

2. Dahlhamer JM, Zammitti EP, Ward BW, Wheaton AG, Croft JB. Prevalence of inflammatory bowel disease among adults aged ≥18 years – United States, 2015. *MMWR Morb Mortal Wkly Rep*. 2016;65(42):1166-1169.

3. Aniwan S, Harmsen WS, Tremaine WJ, Loftus EV Jr. Incidence of inflammatory bowel disease by race and ethnicity in a population-based inception cohort from 1970 through 2010. *Therap Adv Gastroenterol*. 2019;12:1756284819827692.

4. Shi HY, Levy AN, Trivedi HD, Chan FKL, Ng SC, Ananthakrishnan AN. Ethnicity influences phenotype and outcomes in inflammatory bowel disease: a systematic review and meta-analysis of population-based studies. *Clin Gastroenterol Hepatol*. 2018;16(2):190-197.e11.

5. Barnes EL, Kochar B, Long MD, et al. Lack of difference in treatment patterns and clinical outcomes between black and white patients with inflammatory bowel disease. *Inflamm Bowel Dis*. 2018;24(12):2634-2640.

6. Damas OM, Jahann DA, Reznik R, et al. Phenotypic manifestations of inflammatory bowel disease differ between Hispanics and non-Hispanic whites: results of a large cohort study. *Am J Gastroenterol*. 2013;108(2):231-239.

7. Jackson JF III, Dhere T, Repaka A, Shaukat A, Sitaraman S. Crohn's disease in an African-American population. *Am J Med Sci*. 2008;336(5):389-392.

8. Moore L, Gaffney K, Lopez R, Shen B. Comparison of the natural history of ulcerative colitis in African Americans and non-Hispanic Caucasians: a historical cohort study. *Inflamm Bowel Dis*. 2012;18(4):743-749.

9. White JM, O'Connor S, Winter HS, et al. Inflammatory bowel disease in African American children compared with other racial/ethnic groups in a multicenter registry. *Clin Gastroenterol Hepatol*. 2008;6(12):1361-1369.

10. Knowles SR, Keefer L, Wilding H, Hewitt C, Graff LA, Mikocka-Walus A. Quality of life in inflammatory bowel disease: a systematic review and meta-analyses–part II. *Inflamm Bowel Dis*. 2018;24(5):966-976.

11. Nguyen GC, LaVeist TA, Harris ML, Wang MH, Datta LW, Brant SR. Racial disparities in utilization of specialist care and medications in inflammatory bowel disease. *Am J Gastroenterol*. 2010;105(10):2202-2208.

12. Alsabbagh Alchirazi K, Mohammed A, Eltelbany A, et al. Racial disparities in utilization of medications in inflammatory bowel disease patients. Presented at: American College of Gastroenterology Annual Meeting; October 21-26, 2022; Charlotte, NC. Poster A0370.

13. Cohen NA, Silfen A, Rubin DT. Inclusion of under-represented racial and ethnic minorities in randomized clinical trials for inflammatory bowel disease. *Gastroenterology*. 2022;162(1):17-21.

14. Dos Santos Marques IC, Theiss LM, Wood LN, et al. Racial disparities exist in surgical outcomes for patients with inflammatory bowel disease. *Am J Surg*. 2021;221(4):668-674.

15. Walker CH, Arora SS, Colantonio LD, et al. Rates of hospitalization among African American and Caucasian American patients with Crohn's disease seen at a tertiary care center. *Gastroenterol Rep (Oxf)*. 2017;5(4):288-292.

16. Mudireddy P, Scott F, Feathers A, Lichtenstein GR. Inflammatory bowel disease: predictors and causes of early and late hospital readmissions. *Inflamm Bowel Dis*. 2017;23(10):1832-1839.