ADVANCES IN IBD

Current Developments in the Treatment of Inflammatory Bowel Disease

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Differences in Inflammatory Bowel Disease Across Ethnicities and Racial Groups

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G&H What is the prevalence of inflammatory bowel disease across ethnicities and racial groups in the United States?

OD Data from the National Health Interview Survey in the 1990s suggested that the prevalence of inflammatory bowel disease (IBD) in the United States was highest among non-Hispanic White individuals. It was traditionally taught in medical school that IBD was a disease that primarily affected White Europeans and those of Jewish ancestry. However, reflecting what clinicians are seeing with increasing frequency in their practices, more recent data suggest that the prevalence of IBD among racial and ethnic minority communities in the United States—including Hispanic Americans, Black Americans, and Asian Americans—is substantially higher than previously recognized and continues to rise.

A study published in *Gastroenterology* in 2023 analyzed 4 large administrative claims datasets from Medicare, Medicaid, and commercial insurers and estimated the prevalence of IBD among Hispanic Americans at 458/100,000 individuals—comparable to Asian Americans (403/100,000 individuals) and slightly lower than that of Black Americans (504/100,000 individuals). All 3 groups had a considerably lower prevalence than non-Hispanic White Americans (812/100,000 individuals). These figures are higher though than what was assumed historically for minority populations.

This pattern is also reflected in many international studies; Westernization has been directly associated with a rise in IBD in populations where the disease was previously rare. In my view and based on my patient population in South Florida, the true prevalence of IBD among minority populations in the United States is likely underestimated relative to non-Hispanic White Americans, including in the aforementioned 2023 study. A significant proportion of cases go undetected owing to social barriers, limited access to health care and insurance, and detection bias—stemming from low awareness of IBD occurring within minority communities and detection bias on the part of providers.

G&H Are there phenotypic differences in IBD across these groups?

OD Hispanic and Asian immigrants coming to the United States tend to have an older age of diagnosis and presentation of IBD. Studies comparing Hispanic Americans with those in their countries of origin have found that the age of diagnosis is consistently later than in non-Hispanic White Americans. Although limited access to care could contribute to delayed diagnosis, there is also the question of whether the environment itself leads to a later disease presentation in patients from developing countries. One theory is that there may be a longer period of environmental protection against IBD in these populations, although this remains unproven.

This later age of diagnosis could have phenotypic consequences. Based on standard clinical criteria, a later age at presentation is generally associated with a milder overall disease course, although that does not always guarantee a less aggressive nature, including in elderly populations.

Beyond age at diagnosis, there are data suggesting phenotypic differences by race and ethnicity in IBD. For example, Black Americans have been shown to have more perianal disease and less ileal involvement in Crohn's disease. In a study recently published in *Gastroenterology,* our team in collaboration with Cedars-Sinai and the University of Puerto Rico examined genetic ancestry in approximately 7300 Hispanic participants and found that those with a higher proportion of African ancestry were significantly more likely to have penetrating or perianal Crohn's disease and to require IBD-related surgery. This is consistent with what has been observed in Black Americans and raises the important question of whether these phenotypic differences have a genetic basis. However, they could also be confounded by social factors, such as limited access to care, that disproportionately affect patients with a higher proportion of African ancestry, potentially leading to delayed diagnosis and more advanced disease at presentation. That question has not been adequately answered.

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By contrast, the same pattern of more aggressive phenotype has not been consistently observed for Hispanic patients overall. Many studies, including work conducted at our center, continue to show that IBD phenotype among Hispanic patients is broadly similar to that of non-Hispanic White Americans. Notably, however, a study in California found that Hispanic Americans have a lower response to biologic therapies after adjusting for several clinical variables, which raises the question of whether all Hispanic patients should be grouped together or whether Hispanic Americans in California have a different disease trajectory than those in Florida. This speaks to a broader issue: historically, Hispanic patients have been treated as a single homogeneous group, but they are in fact a highly diverse population with significant variation in genetic ancestry, environmental exposures, and country of origin, all of which may influence IBD risk and phenotype. Therefore, in brief, the answer to the question of whether there are phenotypic differences in IBD is both yes and no. There are some differences in phenotype by ethnicity and race, but there is also a lot in common as described previously.

G&H Are there different IBD genetic risk factors across these populations?

OD Absolutely. This is an area that my colleagues at the University of Miami and Cedars-Sinai, in collaboration with the IBD Genetics Consortium, have been actively working on, particularly when it comes to understanding the genetics of IBD in Hispanic patients. Health disparities are often thought of in terms of access to care and social barriers, but genetics is another dimension that does not receive nearly as much attention. Most genome-wide association studies published to date have been conducted in European and White populations, with much less representation of minority groups. As a result, much of the research that feeds into drug development has been based on a population that is primarily European and White. That raises real questions about whether differences in genetic makeup among minority populations could translate into differences in drug response, and that concern is compounded by the fact that minorities are also underrepresented in clinical trials.

Our recent study examining genetic ancestry in Hispanic patients found that the interleukin-23 receptor (IL-23R) genetic variant was underrepresented in Hispanic communities with higher proportions of Amerindian ancestry. That is a clinically important finding because the IL-23R risk variant was foundational to the development of IL-23 inhibitors, which are now among the most widely used therapies for IBD. One of the important next steps is figuring out whether patients who carry this genetic variant respond differently to IL-23 inhibitors than those who do not. This issue does not apply only to Hispanic patients. There are also meaningful differences in IBD genetic risk variants among Black Americans and Asian Americans that also deserve much attention.

G&H Could you discuss different potential environmental impacts across these groups?

OD We are starting to understand that the environment plays a very important role in IBD, particularly exposures that occur during early childhood and even during the perinatal period. Those early exposures appear to matter even more than exposures that occur in adulthood. My colleagues and I, along with other teams in the United States and Europe, have looked at the timing of environmental exposures and their impact on IBD onset. The broad finding is that a more Westernized environment primes the immune system to be more reactive. Growing up in a rural environment with farm animals, less sanitation, and exposure to a wide variety of people and microorganisms trains the immune system to be more tolerant and promotes a more diverse microbiome. A Western

environment, by contrast, is more hygienic and involves practices such as widespread antibiotic use, nonsteroidal anti-inflammatory drugs, Caesarean sections, and lower rates of breastfeeding, all of which can prime the gut microbiome composition early in life to be pro-inflammatory. The consistent theme that has emerged across studies is that as countries become more Westernized, rates of IBD rise. That pattern holds across very different populations and regions of the world.

Diet is another important piece of this puzzle. The Western diet, which tends to be high in added sugars, ultra-processed foods, and red meat while being low in fiber from grains, fruits, and vegetables, has been shown in epidemiologic studies to negatively affect the microbiome and contribute to the onset of IBD.

G&H Have differences also been reported regarding surgical outcomes and hospitalization across racial and ethnic groups?

OD Yes, and this is an important but complicated area to interpret. The core challenge is teasing out whether the poorer surgical outcomes and higher rates of hospitalization seen particularly in Black patients reflect truly more severe disease or whether they are primarily a consequence of delayed diagnosis, limited access to medications, and barriers to timely care. That distinction matters enormously because the implications for how the problem is addressed are very different depending on the answer.

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Most of the research on this topic has been conducted in Black American patients, although there are smaller studies looking at Hispanic and Asian American patients as well. The data consistently show higher rates of complications, more hospitalizations, and worse surgical outcomes in Black patients compared with non-Hispanic White patients. However, when looking more carefully at these studies, many of these differences attenuate or disappear after adjusting for socioeconomic factors, insurance status, and access to care. That suggests that a significant portion of what is being seen is not driven by biology but by systemic inequities in the health care system.

Social determinants of health play a major role here. Patients who lack insurance, live in areas with limited access to gastroenterology specialists, or face language and cultural barriers are less likely to receive timely diagnosis, less likely to be started on advanced therapies early in their disease course, and more likely to present to the hospital with advanced complications that require surgery. By the time some of these patients are seen, the window for medical management may have already passed. Therefore, although I think there is likely some contribution from disease biology, particularly given what was discussed regarding genetic ancestry and perianal disease, I believe the dominant driver of these disparities in outcomes is access to care and the broader social determinants of health that shape it.

G&H Are there any other differences involving IBD that you would like to discuss?

OD There are several things that are worth highlighting. Minority populations face not only underdetection of IBD, which leads to delayed diagnosis and delayed access to medications, but also a lack of access to IBD specialists and gastroenterologists more generally. On top of that, there is increased reliance on the emergency department as a point of care, which often means that patients are seen at a more advanced and complicated stage of their disease rather than being managed proactively in an outpatient setting.

Health literacy is another layer. It can vary considerably and that affects how patients understand their diagnosis, navigate the health care system, and make decisions about treatment. Closely related is cultural competency on the part of health care providers. Understanding the cultural variables that shape health-seeking behaviors, particularly among immigrant communities, does not always receive enough attention but can have a real impact on whether patients engage with care or fall through the cracks.

Finally, the underrepresentation of minorities in clinical trials is a problem that runs through all of these issues. Studies have reported that Black individuals represent as little as 3% of participants in randomized controlled trials for IBD, and the picture is similarly concerning for other minority communities. That means the evidence clinicians rely on for treatment decisions has largely been generated in populations that do not reflect the patients many of us see in practice every day. There is growing recognition of this problem, and some meaningful steps are being taken to address it, but there is still a long way to go.

G&H What are the next steps in this area?

OD In my opinion, the most important shift that needs to be made is moving away from simply describing health disparities and social barriers toward building health equity frameworks that take concrete steps to reduce them. That is admittedly more of a health systems level challenge than something an individual clinician can solve on a day-to-day basis, and I think it is important to be honest about that. It can feel overwhelming for a clinician to try to tackle what is ultimately a systemic problem. That said, clinicians are not powerless. Advocacy is something every clinician can participate in, and it matters. However, meaningful change must come from multiple levels simultaneously, from government policy all the way down to how care is structured within our own clinics.

We also know that environmental factors play a significant role in predisposing minority populations to IBD, particularly given what was discussed about Westernization and the changes that occur when immigrant communities adopt a Western lifestyle and diet. The logical next step is prevention, which will require a much deeper understanding of how and when microbiome shifts occur, how to identify patients in a predisease state before full onset of IBD, and when and how to intervene at that early stage. There are already trials underway in this space, and I think meaningful progress will be seen over the coming years.

Building on that, we need to continue understanding how genetic ancestry influences treatment response across different populations and how diet can be used as an intervention to improve outcomes, including personalizing diet by genetic makeup, microbiome composition, and cultural preferences.

Underpinning all of this is the need to improve minority representation in clinical trials. At the moment, the evidence base clinicians rely on to make treatment decisions simply does not reflect the diversity of patients seen in our clinics every day, and that has real consequences for how well we are able to care for these populations. Addressing that gap is not just a research priority but a fundamental part of making progress on everything else that has been discussed.

Disclosures

Dr Damas has no relevant conflicts of interest to disclose.

Suggested Reading

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