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Racial disparities in the care of patients with irritable bowel syndrome: The need for a unified approach

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Abstract

Irritable bowel syndrome (IBS) is a highly prevalent disorder of gut-brain interaction, which significantly erodes the quality of life of those it affects. Recent studies have confirmed that its prevalence varies quite markedly between countries, implying that it is affected by cultural and socioeconomic factors. In an important study, Silvernale et al. have recently reported racial disparities including potential referral biases, with reduced opportunities to access specialist care and differing patterns of healthcare utilization affecting ethnic minority populations with IBS. Similar disparities have also been reported for other gastrointestinal disorders. In this paper, we, therefore, discuss the potential implications of such disparities and how they can impact clinical outcomes, and discuss ways in which this problem could be addressed, and highlighting areas for future research.

Keywords

bias, DGBI, irritable bowel syndrome, racial disparity, stigma

Key Points

• Healthcare disparities are widespread and can negatively impact patient outcomes.
• Ethnic minority patients with IBS receive fewer specialist consultations than white patients.
• Ethnic minority patients with IBS in secondary care are more likely to be referred for invasive investigations than their white counterparts.
• A multipronged approach involving improved communication, awareness, recruitment and mentoring of students, and young medical professionals from diverse backgrounds may be needed to help address the problem.

1 RACIAL DISPARITIES IN THE HEALTHCARE UTILIZATION OF PATIENTS WITH IRRITABLE BOWEL SYNDROME

The study by Silvernale et al. in this issue of Neurogastroenterology & Motility has provided an important insight into racial disparities in the care of patients with irritable bowel syndrome (IBS). Following critical events over the past 12 months, this comes at a time where there is a heightened global awareness of the need to address inherent racial disparities within society brought to the forefront by the death of George Floyd in the United States (US) and the subsequent Black Lives Matter movement. The term racial disparity is used in this context, rather than the term racial difference, as the implication is that some observed differences in society as whole or in health care more specifically are caused by underlying inequity. With regards to healthcare provision and patient outcomes, these racial disparities have been
shown to have existed in the past and continue to manifest themselves in the present. An example of a historic racial disparity is the enforced sterilization of “undesirable” people in the United States in the 1940s. In the present, numerous studies have demonstrated that during the COVID-19 pandemic individuals from ethnic minorities are more likely to die after contracting the virus than Caucasian people. As with most things in health care, these observed disparities are not thought to be unifactorial but are caused by multiple, often incompletely understood and overlapping, factors including culture—as distinct from race—communication, socioeconomic status, and bias from healthcare professionals or health structures.

Within the field of gastroenterology, racial disparities have been shown to exist in numerous “organic” conditions including inflammatory bowel disease and colorectal cancer. 77.7% of Black patients were referred for investigations versus 50.5% of white controls (p = < 0.01); for Hispanic patients, the values were 71.8% compared to 49.4% (p = < 0.01), and for Asians, 62.8% versus 45.5% (p = < 0.01).

Despite the study not being designed to identify the precise underlying reasons for observed racial differences, the authors concluded that these were potentially due reasons including communication difficulties, bias and socioeconomic status.

The study, while of considerable interest, was limited by several key factors, which need to be considered when assessing its key findings. Firstly, the study did not measure or correct for socioeconomic status between ethnic minority and control groups. Socioeconomic status has been shown by numerous studies to impact on patients healthcare experiences and management. This is especially true in the United States, where this study was performed. It is possible that an underlying reason suppressing the numbers of ethnic minority patients being managed in secondary care was a discrepancy in mean comprehensiveness of insurance cover between racial groups. Further to this point, data from the United States show that the average Black or Hispanic individual is comparatively less wealthy than the average white individual. Another limitation is the fact that culture was categorized within ethnic minority and control groups. Ethnic minority and white populations are not monolithic in nature. There exist many cultural identities with the potential for different relationships toward health, disease, and healthcare professionals. These can presumably impact the study findings. An example of this can be found in the aforementioned Sperber et al. paper. In this study, the prevalence of IBS was determined to be 4.6% in Bangladesh, compared to 0.2% in India. This difference may reflect cultural differences between populations (as opposed to differences in data collection or true differences in disease occurrence), which would otherwise be both classified as “Asian”. Similar differences can be seen in black and white populations for example between Nigeria with an IBS prevalence of 2.7% and Ghana with a prevalence of 0.3%, and between Romania (3.5%) and Russia (5.9%). Lastly, no data were collected pertaining to IBS subtype. Variations in the types of IBS between ethnic minority groups and controls may be a potential reason explaining observed differences in investigations such as colonoscopy, which is more likely to be indicated in patients with the diarrhea sub-type.

2 Understanding Factors that May Contribute to Disparities in the Approach to Irritable Bowel Syndrome across Cultures

Culture can be defined as the beliefs and practices of a group of people in a society religion or an organization. It is often the case that rather like a set of nesting dolls, cultures can exist on numerous interlocking levels from the all-encompassing to the personal. A culture can be present as follows: across a multi-ethnic society; within specific ethnicities in that society or on a familial level. Although racial groups may share the same culture and by extension have specific beliefs about diseases and health professionals, cultures have the potential to transcend racial groupings.
Within health care, there is thought to be three broad bastions of culture. These are patient culture, clinician/healthcare professional culture, and the culture of health organizations within which clinicians practice. Each of these cultures can and do affect health interactions in various ways (Table 1).

Communication difficulties between patients, their clinicians, and their health providers have been shown to have the potential to negatively affect health outcomes. Communication could be impaired by differences in language which may result in patients not being as forthcoming as they would otherwise be or patients being unable to fully convey the symptoms they are experiencing. This can be a problem as a patient’s history is one of the most powerful tools available to a clinician attempting to make a diagnosis. Furthermore, in the opposite direction, if clinicians are unable to be fully understood by their patients’ compliance with proposed treatment strategies and patient satisfaction can be negatively impacted. On an organizational level, failure to ensure adequate support for patients who may have different first languages can exacerbate problems. Communication issues offer a potential explanation for the two important observations made by Silvernale et al.1

With respect to the reduced numbers of ethnic minority patients with IBS being seen in secondary care, the inability of patients to comprehensively describe their symptoms may have falsely reassured primary care clinicians leading to a reduction in referrals for subsequent assessment in secondary care. Conversely, in secondary care, impaired communication could have prompted clinicians to “play it safe” by relatively over investigating ethnic minority patients. In DGBI practice, enhanced communication is vital in optimizing the patient-provider relationship and providing an understandable explanation of the diagnosis of IBS describing the gut-brain axis. Such barriers in effective communication could, therefore, potentially reduce the chances of acceptance of the diagnosis of IBS, patient and clinician satisfaction and, therefore, negatively affect the therapeutic alliance, adherence, and outcomes. In the current climate, following the COVID-19 pandemic, clinicians will need to be even more mindful of this due to the increase in remote consultations via telemedicine, which have become a “new norm” in outpatient clinics. Remote teleconsultations are likely to continue in some form after the pandemic but may prove to be a further barrier to effective communication for some patients from different cultural and racial backgrounds who may be better served with a face-to-face consultation.

TABLE 1 Cultural factors potentially influencing racial disparities in health care

| Patient cultural factors                      |                      |
|-----------------------------------------------|----------------------|
| Communication                                 |                      |
| Well-being                                    |                      |
| Trust                                         |                      |
| Acceptance of advice given by clinicians      |                      |
| Relative wealth                                |                      |
| Stigma                                        |                      |

| Clinician cultural factors                    |                      |
|-----------------------------------------------|----------------------|
| Communication                                 |                      |
| Stigma                                        |                      |
| Bias                                          |                      |
| Approaches to consultation (Collaborative/paternalistic) |      |
| Lack of awareness of cultural differences     |                      |

| Organizational cultural factors               |                      |
|-----------------------------------------------|----------------------|
| Communication                                 |                      |
| Stigma                                        |                      |
| Bias                                          |                      |
| Lack of awareness of cultural differences     |                      |

People from different racial and cultural backgrounds often view and manage their illnesses in contrasting ways. For example, in a 2004 study by Roy et al.44 investigating the willingness of different ethnicities to use home remedies to treat their children, significant differences were observed both between minority and non-minority groups and also between different ethnic minority groups. Separate to race, studies have shown people of different genders display different health-seeking behaviors.45 Men tend to attend their primary care physicians less frequently than women.46 With regards to men, this has been shown to result in delayed presentation leading to late diagnosis. Differences in views of what constitutes ill health and what needs to be done about it between ethnic minority and white patients may explain the observation that minority patients with IBS are more likely to be managed in a primary care setting. Although the study did not measure patient satisfaction, it would have been useful to quantify this so as to assess patients feelings about the status quo.

Lack of trust in healthcare professionals or organizations has the potential to suppress healthcare utilization. In the Silvernale et al. paper, a lack of trust may provide an explanation as to why there were reduced numbers of minority patients with IBS managed in secondary care. Trust can be affected by individual bad experiences. However, historical prejudice and discrimination such as the profoundly unethical Tuskegee syphilis experiment in the United States47,48 has been shown by studies to have reduced the trust some ethnic groups feel for clinicians and health providers.49 As mentioned in the Silvernale et al. paper, this may manifest as ethnic minorities being less willing to trust a clinician’s diagnostic opinion and more likely to insist on being referred for what is perceived to be a more objective test.

With regards to the relationships between patients and their clinicians, studies have shown people from some ethnic minorities are on average less likely to trust advice given to them by their doctors.50 This may result in an increased desire to be referred for more diagnostic tests in secondary care.

As mentioned earlier, the discrepancy between primary and secondary care consultations between ethnic groups observed in the Silvernale et al. study may be a reflection of socioeconomic differences between patient groups. Access to health care in the United States largely depends on the presence and comprehensiveness of insurance cover.51 Furthermore, even though a consultation/procedure may be covered by insurance there may still be a co-payment. As a result, if certain ethnic minorities have access...
to less comprehensive insurance cover, they may be more willing to be managed in a comparatively less expensive primary rather than secondary care setting. In future studies, it would, therefore, be interesting to see whether these data are replicated in other countries, particularly in those with government-funded healthcare systems, which provide free to the point of delivery care.

Stigma, defined as a shameful or disgraceful characteristic potentially leading to discrimination,\textsuperscript{52} may also be an important factor in accounting for racial disparities in patients with IBS. Three types of stigma are recognized; perceived stigma which describes an individual’s expectation of discrimination due to stigma; enacted stigma which describes discrimination due to stigma; and internalized stigma where an individual begins to view themselves as tainted or discredited due to a stigmatized attribute or condition they possess.\textsuperscript{52-54} IBS can be stigmatizing on several levels. Firstly, it is a condition which involves the bowels, which can be a taboo subject for many cultures and societies.\textsuperscript{54} Secondly, it can be misunderstood by patients, the wider public and healthcare professionals as a condition, which is purely psychological (and, therefore, less serious with the implication that its sufferers are by extension not truly unwell).\textsuperscript{54,55} In some cultures, this may result in reduced acceptance of the diagnosis. In addition, antidepressants used to treat IBS\textsuperscript{56} may be stigmatizing in themselves. This may be because the use of antidepressant medications may conflate IBS and mental illness. Interestingly, a study in functional dyspepsia, a DBGI, by Yan et al. showed some people who received treatment with antidepressants developed stigma associated with their medications.\textsuperscript{57}

Bias is another factor which can have an impact on healthcare outcomes. Studies have shown that clinicians tend to view patients with IBS negatively.\textsuperscript{55} A potential explanation for this is reports of physicians finding managing patients with IBS more onerous.\textsuperscript{58} Furthermore, though it may be distasteful to imagine, there is a possibility that bias (conscious or unconscious) from clinicians means they treat ethnic minority patients with IBS differently to white patients. Therefore, explaining the differences with regards to specialist consultations and investigations. There is some literature in support of this, including a 2015 systematic review by Hall et al., which aimed to investigate the prevalence of bias amongst healthcare professionals.\textsuperscript{59} It showed that in 14 of the 15 studies analyzed, there existed low-to-moderate amounts of bias.\textsuperscript{59} This manifested itself as more positive attitudes toward white patients and more negative attitudes toward ethnic minority patients.\textsuperscript{59}

3 | UNDERSTANDING THE POTENTIAL IMPACT OF RACIAL DISPARITIES ON PATIENT OUTCOMES

Although IBS has traditionally been considered a diagnosis of exclusion,\textsuperscript{60} it is now recommended that a positive diagnosis of IBS should be made proactively and safely provided that patients do not display any “red flag” symptoms.\textsuperscript{16,19,61} However, it can be posited that a transition from a negative to a positive approach toward diagnosis is conditional on clinicians being able to adequately communicate with patients and obtain a comprehensive history.

With respect to the study findings in the Silvernale et al. paper, the observation that ethnic minority patients undergo more investigative procedures than white patients can be viewed as having both positive and negative connotations. In a positive light, being referred for diagnostic tests may suggest to minority patients that their symptoms are being taken “seriously” and may lead to increased patient satisfaction with healthcare professionals. Supportive evidence for such speculation comes from studies showing that patient satisfaction with health provision increases when physicians are more willing to refer patients for investigations or prescribe treatments patients express a preference for.\textsuperscript{42,62,63} Furthermore, increased satisfaction is linked to positive health outcomes including improved compliance with medications.\textsuperscript{52}

Conversely and more negatively, more referrals for often invasive diagnostic tests may indicate, as has been mentioned earlier, a relative deficit of communication between minority patients and their clinicians.\textsuperscript{65} Although no information about physicians ethnic backgrounds was collected as part of the Silvernale et al. study, other studies have shown that the majority of gastroenterologists within the United States are white,\textsuperscript{64} and it is unclear whether this could have been a contributing factor. Endoscopic investigations while useful are not risk free. Patients are at risk of, sedation related complications, perforation, hemorrhage, and increased mortality.\textsuperscript{65} Depending on the study, the risks of perforation following colonoscopies range from 0.00007% to 0.0001%.\textsuperscript{56,64} With regards to hemorrhage, colonoscopies have been reported to have risks ranging from 0.00008% to 0.0007%.\textsuperscript{56,68} Hence, ethnic minority patients could potentially be put at increased risk of harm if they are over investigated. Furthermore, repeated testing which ultimately does not find a clearly identifiable organic cause for a patients symptoms may lead to anxiety and reduce patient acceptable of the eventual diagnosis of IBS. Evidence in support of this contention comes from several studies showing that referring patients for investigations may reassure them in the short term but ultimately does not provide reassurance in the medium to long term.\textsuperscript{69}

4 | FUTURE DIRECTIONS: TOWARD A UNIFIED APPROACH TO UNDERSTANDING AND ADDRESSING RACIAL DISPARITIES

As there are multiple potential causes of racial disparities, a multifactorial approach is needed to address the problem. With the publication of an increasing number of studies, the magnitude of racial disparities in numerous diseases is starting to be better quantified. Furthermore, more information is emerging as to the contributing factors toward observed disparities.

However, despite this laudable progress, there remain gaps in our collective understanding which require filling and further research. Some specific gaps which pertain to the Silvernale et al. study include the importance of physician ethnicity in relation to patient ethnicity,
and the impact of any incongruence on IBS management. It is unknown whether physicians who share or differ with respect to ethnicity would manage patients with IBS differently. Furthermore, in some areas it is possible that ethnic minority patients managed in their local primary care setting may be more likely to be seen by clinicians from similar ethnic backgrounds to their own, and in that situation, one could speculate that personal choice, rather than bias, may be a factor that could potential account for the reduced referrals to secondary care.

As a strategy to tackle racial disparities, it has been suggested that recruiting more doctors from ethnic minorities so that the makeup of the medical profession more closely reflects the nature of the current multi-ethnic and multi-cultural societies, which they serve will go some way toward improving communication between clinicians and their patients and trust in health care. Part of this process includes speaking to children in schools to make them aware of medicine as a career option and providing mentors to individuals to help support and guide them through the process applying for and working their way through medical school and subsequent specialty training. However, it must be noted that with the long period of time needed to fully train a doctor, and this is a long-term approach.

As multiple cultures exist simultaneously within a multi-ethnic society, some authors have suggested that medical students, clinicians, and health organizations should be taught to be more aware of how interactions between cultures may lead to difficulties in communication. This process of cultural navigation is thought to be one of the hallmarks of effective modern medical practice. It is hoped that increased awareness would result in a reduction in bias, stigma, and ultimately a reduction in disparity. This could be achieved via more thoughtful communication between doctors and patients and the provision of more support for patients whose first languages are not English. Additionally, an increased awareness of stigma may improve disparities by improving psychological well-being and compliance with treatments.

If the findings from the study by Silvernale et al. are replicated by others in future studies, it may be that there is a specific need to educate primary care providers in particular as a means to raise awareness, and ensure that patients from minority backgrounds are not being denied equal opportunities to see a gastroenterologist for comparable IBS symptoms to their white counterparts.

Finally, following the recent considerable progress in understanding the epidemiology of IBS, there is now a need for further research to determine whether acceptance of the diagnosis, adherence, and outcomes to medical and non-medical interventions for this condition varies between cultures and races, and the importance of health care and cultural beliefs in driving any disparities in care provision. IBS is a multifactorial condition, and an integrated multidisciplinary approach involving medical gastroenterology, dietetics, and psychological approaches has now been shown to be superior to conventional medical-only care, and this is increasingly likely to become the standard of care for IBS. Dietary modification is often recommended as one of the first-line approaches for IBS. As diets vary significantly between different races and cultures, particularly with regards to certain types of carbohydrate intake, it is unknown whether individuals from certain cultures who may have a staple diet rich in fermentable oligosaccharides, disaccharides, monosaccharides, and polyols (FODMAPs), for example, compared with those on a Mediterranean diet, may be more likely to benefit from dietary therapies in the community, to such an extent that referral to secondary care for IBS management may not be warranted due to symptom relief. Alternatively, it may be that some patients may find such dietary exclusion advice, or referral for psychological therapies such as gut-focused hypnotherapy or other gut-brain therapies such as antidepressants unacceptable due to cultural beliefs and associated stigma, and therefore, may not be amenable to referral to secondary care services for these reasons. These factors warrant investigation in future studies.

5 CONCLUSIONS

In conclusion, the approach to diagnosing and treating patients with IBS should follow evidence-based practice, offering the same treatment options and advice to all patients irrespective of race or cultural factors. While further research is required to determine the exact reasons for apparent racial disparities in IBS care, a concerted effort is required to raise awareness of this issue, optimize patient-doctor interactions and promote diversity within gastroenterology workforces in order to minimize this problem.

DISCLOSURES

No competing interests declared.

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