



# Cultural considerations in gastroenterology: barriers to care and a call for humility and action

Anjali U. Pandit<sup>1,2^</sup>, Kathryn N. Tomasino<sup>1^</sup>, Tina Aswani Omprakash<sup>2,3^</sup>, Dawn E. Epstein<sup>1</sup>

<sup>1</sup>Division of Gastroenterology & Hepatology, Northwestern University Feinberg School of Medicine, Chicago, IL, USA; <sup>2</sup>South Asian IBD Alliance, New York, NY, USA; <sup>3</sup>Sommer Consulting, New Hope, PA, USA

**Contributions:** (I) Conception and design: All authors; (II) Administrative support: None; (III) Provision of study materials or patients: None; (IV) Collection and assembly of data: None; (V) Data analysis and interpretation: All authors; (VI) Manuscript writing: All authors; (VII) Final approval of manuscript: All authors.

**Correspondence to:** Anjali U. Pandit, PhD, MPH. Division of Gastroenterology & Hepatology, Northwestern University Feinberg School of Medicine, 676 N. St. Clair Street Suite 1400, Chicago, IL 60611, USA; South Asian IBD Alliance, New York, NY, USA. Email: a-pandit@northwestern.edu.

**Abstract:** Culture is a broadly defined term and patients' cultural identity may show up in the medical setting in visible and invisible ways. In this paper, we aim to discuss cultural considerations in gastrointestinal (GI) care. Our definition of "culture" reflects the commonly ascribed race and ethnicity and will also discuss other minority groups such as sexual and gender minorities (SGMs). We will review what is known about rates of GI conditions across various cultural groups, acknowledging that our data reflect inequity in representation. While the healthcare system has overall shown an increased awareness of the role that systemic and institutional racism plays in affecting patient care, this has not been widely studied in the context of GI though has a profound impact. Multiple factors affect the interaction between patients' cultural identities and engagement in and quality of GI care. Stigma related to cultural factors or cultural intersection has the capacity to shape if, when, and how medical care is approached, received and applied. Conditions and symptoms in GI are often complicated; health literacy (HL) is the ease with which patients can navigate getting from diagnosis to treatment and engage in self-management and also interacts with cultural context. Some aspects of a patient's experience, background and skill are imperceptible and require the healthcare provider to attend to treatment with humility, respect and self-reflection if they wish to effectively engage. We introduce the concept of cultural humility to GI and offer practical suggestions for those providing clinical care. We also call for future investment in a diverse healthcare delivery system and continued legislation to promote social equity.

**Keywords:** Cultural representation; stigma; health literacy (HL); cultural humility

Received: 16 February 2024; Accepted: 20 June 2024; Published online: 20 August 2024.

doi: 10.21037/tgh-24-17

**View this article at:** <https://dx.doi.org/10.21037/tgh-24-17>

## Introduction

Culture is defined by United Nations Educational, Scientific and Cultural Organization (UNESCO) as "*the set of distinctive spiritual, material, intellectual and emotional features of society or a social group, that encompasses, not only*

*art and literature, but lifestyles, ways of living together, value systems, traditions and beliefs*" (1). People may identify with culture as it relates to their nationality, race or ethnicity, and also through other social groups such as gender, sexual orientation, geography or any other group of belonging or

<sup>^</sup> ORCID: Anjali U. Pandit, 0000-0002-5440-5340; Kathryn N. Tomasino, 0000-0002-4905-8807; Tina Aswani Omprakash, 0000-0002-7087-6628.

interest. The intersectionality of cultural identity guides medical care fluidly in conscious and unconscious and explicit and implicit ways.

It is important to consider the patient in context, as their clinical presentation is the consequence of varied factors, including sociocultural. Applying the biopsychosocial model (2) in clinical practice is useful when considering the multifaceted experience of individuals with gastrointestinal (GI) conditions and the role of culture. A biopsychosocial model suggests that there is a dynamic and interactional relationship between biology, psychology, social, and cultural factors that influence patients' experiences, and these experiences and perceptions are modulated by their context. Together, these components have the potential to impact patients' clinical course in a variety of ways, both directly (e.g., impact of chronic stress on disease course) and indirectly (e.g., symptom reporting, healthcare utilization), and it is crucial to consider the health consequences of sociocultural and financial inequities. Allostatic load (AL)—the cumulative physical impact of repeated, chronic stress (3)—is used to predict morbidity and mortality of a number of chronic health conditions, including GI conditions (4,5). It is higher in sexual and gender minority (SGM) groups (6,7), and has been associated with lower socioeconomic status, lower educational attainment, ethnicity and racial discrimination (8). Higher AL appears to negatively impact engagement in lifestyle habits known to promote good physical and psychosocial health (e.g., physical activity, sleep, nutrition) (9). The health of individuals who immigrate to the United States (US), for instance, tends to decline after they move (10)—an outcome that may be explained by lifestyle and environmental changes and their impact (11), as well as the stress of acculturation and experience of discrimination or racism (12). AL and its wear and tear effect on the organs of the body can be accumulated longitudinally and play a role in health disparities in minority populations. At present, there is limited research considering the ways in which cultural identity can interact with stress and shapes a patient's experience with GI care. This paper aims to add to the literature on this topic by exploring the complex and nuanced relationships between culture, health behavior, patient-provider dynamics, and health outcomes in GI, and offers a pathway to improved care through use of cultural humility in practice and a call for investment in a diverse healthcare workforce and advocacy to promote social and health equity.

## Methods

We searched major databases including PubMed and Google Scholar to inform this review article. We conducted the search from November 2023 to February 2024 and used terms including but not exclusive to, “DGBI”, “disorder of gut brain interaction”, “Inflammatory Bowel Disease”, “IBD”, “esophageal disorders”, “GERD”, “pelvic floor disorders”, “dyssynergic defecation” and “prevalence”, “global”, “rates”, “racism”, “structural racism”, “stigma”, “health literacy”, “cultural competence”, and “cultural humility”. Additionally, authors did a hand search of reference lists of seminal manuscripts to find related articles for review and possible inclusion. Articles that cited the target article were also identified and reviewed. Please see *Table 1* for more details on our search strategy.

## Representation in research on global burden of digestive disease

The US is becoming increasingly diverse, with the US Census Bureau projecting that one in three people in the US will identify with a race other than non-Hispanic White by 2060. These changes are related to global migration patterns, changes in birth and death rates for certain groups, and the increased number of people identifying as Two or More Races—a group projected to grow about 200% in the coming decades (13). We are also seeing an increase in the number of people identifying as SGM groups (e.g., including but not exclusive of lesbian, gay, bisexual, transgender, queer, nonbinary, asexual and intersex) (14). At least 7% of the adult population self-reports as not cisgender and/or heterosexual, this number is likely low due to underreporting and is likely to increase as younger generations are self-identifying as SGMs more commonly than older generations (14).

These shifts in population signify a critical need to assess whether our current healthcare system is prepared to care for patients who come from diverse backgrounds. In GI care, it is relevant to be aware of the global burden of conditions and understand how the prevalence rates are determined, as methods of diagnosis vary internationally and symptom reporting and interpretation can be influenced by cultural factors. Our understanding of disease is heavily informed by research, and there is a notable lack of minority representation in GI clinical trials and research. There are

**Table 1** Search strategy summary

Items	Specification
Date of search	November 2023–February 2024
Databases/sources searched	Google Scholar, PubMed
Search terms used	<p>Global burden in gastroenterology: “prevalence”/“rates”/“global”/“representation” and “DGBI”, “disorder of gut brain interaction”, “IBS”, “functional GI”, “inflammatory bowel disease”, “IBD”, “Crohn’s Disease”, “Ulcerative Colitis”, “esophageal disorders”, “GERD”, “pelvic floor disorders”, “pelvic floor dysfunction”, “dyssynergic defecation”</p> <p>Gastroenterology and racism: “Racism”/“structural racism”/“institutional racism”/“bias” and “gastroenterology”, “GI”, “medicine”, “healthcare”, “culture”, “DGBI”, “disorder of gut brain interaction”, “IBS”, “functional GI”, “inflammatory bowel disease”, “IBD”, “Crohn’s Disease”, “Ulcerative Colitis”, “esophageal disorders”, “GERD”, “pelvic floor disorders”, “pelvic floor dysfunction”, “dyssynergic defecation”</p> <p>Gastroenterology and stigma: “Stigma” and “gastroenterology”, “GI”, “medicine”, “health”, “culture”, “DGBI”, “disorder of gut brain interaction”, “IBS”, “functional GI”, “inflammatory bowel disease”, “IBD”, “Crohn’s Disease”, “Ulcerative Colitis”, “esophageal disorders”, “GERD”, “pelvic floor disorders”, “pelvic floor dysfunction”, “dyssynergic defecation”</p> <p>Gastroenterology and health literacy: “health literacy” and “gastroenterology”, “GI”, “medicine”, “healthcare”, “culture”, “DGBI”, “disorder of gut brain interaction”, “IBS”, “functional GI”, “inflammatory bowel disease”, “IBD”, “Crohn’s Disease”, “Ulcerative Colitis”, “esophageal disorders”, “GERD”, “pelvic floor disorders”, “pelvic floor dysfunction”, “dyssynergic defecation”</p> <p>Cultural Humility in Gastroenterology: “cultural humility”/“humility in medicine”/“cultural competence” and “gastroenterology”, “GI”, “medicine”, “healthcare”, “culture”, “DGBI”, “disorder of gut brain interaction”, “IBS”, “functional GI”, “inflammatory bowel disease”, “IBD”, “Crohn’s Disease”, “Ulcerative Colitis”, “esophageal disorders”, “GERD”, “pelvic floor disorders”, “pelvic floor dysfunction”, “dyssynergic defecation”</p>
Timeframe	All years
Exclusion criteria	Studies not originally published in English, pediatric populations
Selection process	Authors independently searched databases using terms above. Sections of the manuscript were initially written independently by authors, all authors reviewed writing and provided feedback on search and synthesis of information gathered

limited studies conducted in the irritable bowel syndrome (IBS) and inflammatory bowel disease (IBD) literature (15,16) examining this underrepresentation, and even fewer in gastroesophageal reflux disease (GERD) and pelvic floor disorder (PFD). Many studies also cite methodological flaws in reporting of diversity data, which distort our current understanding (17).

The global burden of non-malignant digestive diseases is significant and represents a growing public health concern. In 2019, there were 2.3 billion prevalent cases of non-malignant digestive diseases according to data analyzed from the Global Burden of Diseases, Injuries, and Risk Factors (GBD) Study 2019, representing almost a third of the global non-communicable disease prevalence, with 89 million disability-adjusted life years (DALYs) lost and 2.56 million deaths attributable to these conditions (18). Disease

burden varies by condition, geographic location and level of social and economic development, but globally, digestive diseases continue to be a leading cause of DALYs.

### ***Disorders of gut brain interaction (DGBI)***

DGBI are a heterogeneous group of disorders with a shared underlying pathophysiology classified based on anatomic domain. The Rome Foundation has defined DGBI as “a group of disorders classified by GI symptoms related to any combination of the following: motility disturbance, visceral hypersensitivity, altered mucosal and immune function, altered gut microbiota, and altered central nervous system processing” (19).

DGBIs are highly prevalent worldwide, with more than 40% of individuals from 26 countries in six continents meeting Rome IV criteria for at least one DGBI (20), and

about a third of those individuals meeting criteria for two or more disorders (21). Female predominance is consistently observed across all anatomic regions, and prevalence rates for DGBI appear to decrease with advancing age. Of note, prevalence rates for DGBI vary widely between studies, due in part to a high degree of methodological heterogeneity (e.g., survey and sampling methods) and, notably, a lack of multicultural representation in research. In DGBI studies, fewer than half of the clinical trials reported race and only one-third reported ethnicity (15). Higher reported pooled prevalence rates tend to be seen in studies where participants self-administered questionnaires compared to those where questionnaires were administered by an interviewer in-person or over the telephone (20,22), possibly due to disease-related stigma and willingness to disclose sensitive, personal health information. Moreover, study materials are frequently designed for English speaking populations and are not translated or adapted appropriately for the population of interest (20). Other potential factors contributing to variation in prevalence rates are cross-cultural differences in symptom interpretation and reporting, patients' explanatory model of illness, physician attunement to cultural considerations, and how healthcare for these conditions is delivered (22-24).

### **IBDs**

IBDs, including ulcerative colitis (UC) and Crohn's disease (CD), are a group of incurable conditions characterized by chronic inflammation of the GI tract and a progressive or relapsing-remitting course. In 2017, IBD was considered the fourth-leading cause of years lived with disability (YLD) among digestive diseases (25), and the number of people living with IBD globally has been steadily increasing.

According to the GBD Study 2019, there were nearly 4.9 million cases of IBD worldwide in 2019 (18), representing a 47.45% increase in IBD cases between 1990 and 2019 (26). Historically, IBD has been considered a disease of the Western world (i.e., Western Europe and all countries influenced by Western European culture) (27), and while prevalence of IBD continues to be highest in countries with a higher index of development (26), overall incidence of IBD in Western countries appears to be stabilizing (27), with rates in Asia, Latin America and the Middle East climbing in the past two decades (28,29). Indeed, a recent study reporting on IBD burden in 204 countries and territories noted the largest decrease in age-standardized prevalence rate (ASPR) in North America and the highest increase in

East Asia between 1990–2019 (26), and rates are expected to continue rising in Asia in the coming years (28). A recent modeling study projected a 4-fold increase in prevalent IBD cases in India, 2.5-fold increase in Iran, 2.3-fold in North Africa and the Middle East, and a 1.7- and 1.6-fold increase in number of prevalent IBD cases in high-income Asia-Pacific and Southeast Asia, and East Asia, respectively, by 2035 (30). Adoption of a diet, higher in red meat, processed foods, and refined sugars, is considered a risk factor for IBD in higher-income countries of Asia (31). Interestingly, first- and second-generation offspring of Asian immigrants in North America and European countries appear to confer a higher risk of developing IBD, with some studies suggesting higher rates for those individuals than the general population and a more complicated disease course (32). However, there is a known global lack of representation and reporting in randomized clinical trials (RCTs) for IBD (33). A recent review identifies that there were very limited RCTs conducted in regions outside the developed world, suggesting that more efforts must be established on the ground in South America, Africa, and Asia to understand response to clinical trial medications (33). In pharmaceutical trials for IBD, variables of race/ethnicity are underreported with CD trials reporting race in only 22% (induction) and 26.7% (maintenance) (34); in UC the rates of reporting are 37.9% (induction) and 65.5% (maintenance) (35). With the data available, race was predominantly reported as White and often analyses were conducted by grouping patients into White versus non-White groups rather than a more refined categorization (34,35).

### **GERD**

GERD is an increasingly common GI disorder that typically presents as recurrent burning retrosternal pain and regurgitation of acidic gastric contents into the esophagus (36). GERD is becoming more prevalent worldwide, and is associated with reduced health-related quality of life, poorer mental health, and reduced work productivity, with the degree of impairment proportional to the frequency and severity of symptoms (37,38).

In 2019, there were 783.95 million prevalent cases of GERD globally, with 6.03 million YLD due to GERD. This represents a 77.53% increase in total number of prevalent cases and a 77.19% increase in YLDs between 1990 and 2019 (39). Due to its chronic, relapsing course, the clinical management of this condition is both burdensome and costly (40). Yet, there is a decreasing trend in GERD burden

in the US of late, and a heavier burden seen in countries with less developed economies and fewer resources (41). In 2019, the highest ASPRs were observed in Latin America, the Caribbean, South Asia, North Africa and the Middle East, with the lowest ASPR noted in China and East Asia. It was purported that these changing trends may be related to certain lifestyle factors, including smoking and alcohol use (39).

### **PFDs**

PFD involves the abnormal activity or function of the pelvic floor musculature, and is associated with a diverse array of conditions. The pelvic floor functions to support the pelvic organs and contributes to sexual function and continence of urine and feces. Pelvic floor symptoms (PFS) meaningfully impact health-related quality of life, leading to impairment in several domains of functioning (e.g., social, occupational, sexual) and increased psychological distress (42).

PFD is common in both females and males (43); however, global prevalence data for PFD is scarce, mostly restricted to females, and likely inaccurate due to underreporting, possibly due to stigma (44). In females, global prevalence rates range from 1.9% to 46.5% (45), with a considerable percentage of females endorsing concomitant PFS (46) and one in nine women requiring surgical intervention (45). Concomitant PFS commonly occur in males as well, but symptom clusters differ between the sexes and women tend to report more pelvic pain than their male counterparts (47). Representative research in PFD is stark with White women comprising 70–89% of PFD research; Black women, 6–16%; Hispanic women, 9–15%; Asians, 0.5–6%; and Native Americans, 0–2% (48). Very little is known about PFD in SGM groups (49).

Pooled global prevalence rate for fecal incontinence (FI) is 8%, with approximately 1 in 12 persons suffering from FI worldwide. Prevalence rates appear to be higher in women, individuals over the age of 60, and in countries with higher social and economic development (50). Higher rates in high-income countries (HIC) relative to low- and middle-income countries (LMIC) have been attributed to longer life expectancy and obesity in HIC and reduced reporting due to stigma in LMIC (51). Obesity is an independent and potentially modifiable risk factor for PFD; in adults with obesity, prevalence of FI ranges from 16–68% (52), compared to around 6–10% in the broader global community (50). Global burden associated with PFD is expected to rise as the population ages and the prevalence of obesity continues to climb. By 2030, almost half of the adult population is

projected to have obesity and nearly a quarter are expected to meet criteria for severe obesity (53).

Chronic constipation (CC) is one of the most common GI disorders worldwide, with global prevalence ranging from 11–18% (54), and PFD/dyssynergic defecation is detected in 27–59% of individuals with CC (44). Constipation is more common in women, individuals over the age of 65, and those of lower education level and socioeconomic status. A dyssynergic pattern of defecation is associated with higher levels of psychological distress, somatization, and a history of physical or sexual abuse (55), and risk related to these factors varies by sociocultural background.

### **Barriers to care**

It is clear that diverse populations and minority identities are not adequately examined or understood in the literature examining global burden of GI diseases. Nonetheless, from the data that do exist, it is evident that these conditions can differentially impact individuals based on cultural identity, ethnicity, country of origin, sexual and gender identity, and likely the care setting and geographic location in which their symptoms are presenting. There are many related barriers to GI care; for this review, we have selected structural and institutional racism, stigma, and variations in health literacy (HL) as areas of focus. These are factors that can profoundly impact a patient's journey and are often overlooked by medical journals (56). Topic selection was also informed by the authors' clinical and patient advocacy experiences, with direct exposure to the shortcomings of our healthcare delivery system. In efforts to personalize these concepts please see supplementary material ([Appendix 1](#)) written by co-author and patient advocate T.A.O.

### ***Structural and institutional racism***

Categorically not synonyms, culture and race are often tied and can be conflated for one another. In a discussion about culture in healthcare, we cannot overlook the power of racism and inequity in shaping the research literature from which clinical care is derived and the lived experiences of patients coming into and navigating the healthcare system. As defined by the National Institute of Health, institutional racism refers to “*policies and practices entrenched in established institutions, which result in the exclusion or promotion of designated groups... no individual intent is necessary*” (57).

Racism in GI can impact health-care-seeking behavior,

and may contribute to clinical outcomes through lifestyle behaviors (e.g., medication adherence) (58), AL (59) and changes to the gut microbiome (60). In addition to impacting health outcomes, self-reported discrimination has also been linked to lower levels of health-care related trust, communication, and satisfaction (61). Historically marginalized groups have poorer health outcomes (62) due in part to a paucity of health care providers (HCPs) trained to deliver adequate care (63), implicit bias leading to inequitable treatment (62) and decreased use of preventative care in these populations (64). In combination with other factors, an effect of systematic racism has resulted in disparities in health insurance access with Medicaid enrollment differences related to poverty level, ethnicity, employment status (65). People with Medicaid have reduced access to appointments compared to private insurance counterparts (66) and therefore are likely to wait longer to be seen and have fewer choices for their care. Similarly, SGM groups face discrimination in the healthcare setting, and for a variety of reasons have been found to be less adherent to treatment, visits with HCPs, and are less likely to receive preventive care which can increase need for emergency services (67).

Despite race being a socially defined rather than biological construct, race and ethnicity are also used in clinical decision making and included in the American Society of Gastrointestinal Endoscopy (ASGE), American Gastroenterological Association (AGA), and American College of Gastroenterology (ACG) guidelines for screening and surveillance in *H. pylori*, Barrett's esophagus and gastric intestinal metaplasia respectively. Using race and ethnicity may distract from markers which may more accurately inform clinical decision-making, inadequately capture people of two or more races or ethnicities, and further reinforce racist practices in GI (68).

Further, in their scoping review of tools to measure institutional and structural racism in GI, Liu *et al.* [2023] (69) found that studies primarily defined groups using residential racial segregation. They found that more segregation was associated with poorer health outcomes for racial and ethnic minority groups and found the most robust evidence in GI cancer incidence, screening and outcomes. The authors called for more refined and more frequent measurement of structural and institutional racism, increased efforts to engage in intervention to minimize impact of structural and institutional racism, and more attention to SGM and other marginalized groups.

### **Stigma**

Stigma also serves as a significant barrier to care in GI. Broadly, stigma has been defined as social devaluation based on a particular attribute, trait, or condition (70,71). Stigma can be enacted (or experienced), perceived (felt), and internalized. Enacted stigma has been defined as external stigma or discrimination; enacted stigma contributes to social inequality for people with stigmatized conditions (72). Perceived stigma is the experience of negative treatment based on a particular trait or condition. Internalized stigma is when an individual begins to believe or align with the negative attitudes or beliefs others hold about their condition, which is considered to be particularly damaging (71). Multiple aspects of a person's identity can be stigmatized, and lead to enacted, perceived, and internalized stigma.

Discussing digestive functions is taboo in many cultures (56), and more so for those who identify as female. Flatulence, bloating, vomiting, diarrhea, incontinence, constipation, heartburn and belching are often considered embarrassing or unacceptable social behaviors, increasing stigmatization and internalized stigma across GI conditions. Patients with DGBI may experience additional stigma based on beliefs about the legitimacy of their condition. Historically, many of these conditions have been dismissed as psychosomatic (73,74) due to a lack of structural evidence, and are still often viewed as "stress-related", as stress can trigger and exacerbate symptoms. Increased stigma may also be due to high rates of psychiatric comorbidity in patients with DGBI and the use of neuromodulators to improve these conditions (75). Indeed, the idea that the symptoms or condition could be successfully managed with changes to diet/lifestyle and stress management lends credence to the idea that a GI condition, particularly a DGBI without structural evidence, is due to ineffective behaviors or character or moral failing, thus increasing vulnerability to stigmatization.

Research on stigma in GI conditions has largely been conducted in populations with IBS (76,77) and IBD (78,79), with a few studies on stigma in gastroparesis (56), functional dyspepsia (FD) (75,80), and eosinophilic GI disorders (81). These studies demonstrate that people with GI conditions—particularly DGBI—experience enacted stigma, by the general population as well as HCPs (82,83), as well as perceived and internalized stigma. For a comprehensive review on stigma in GI conditions, please see Ruddy & Taft, 2022 (56). In a study of enacted stigma in persons with

IBS and IBD in the US, male patients with IBS appeared to experience the most enacted stigma (74). However, this study only assessed impact of disease and sex on stigma and did not include other aspects of cultural identity. In existing studies on stigmatization in GI conditions, participants have tended to be White, non-Hispanic, and English speaking, and these investigations have primarily been conducted in the US. One study of patients with FD in China found that male gender, lower educational attainment, and more symptoms were associated with greater FD stigmatization (80).

Cultural beliefs about the etiology of a condition, acceptability of symptoms, prognosis, and impact on strength and vitality vary across cultures and can thus differentially impact stigmatization. GI conditions or symptoms themselves may be stigmatized, and various aspects of a patient's cultural identity or the broader culture in which they reside may intensify this stigma. While we could not find specific studies examining this interaction in the GI literature, we can draw from prior research on cultural differences in stigma in mental illness to highlight this phenomenon. For example, a recent study compared differences in mental illness stigma in cultures labeled as "Eastern" or "Western", based on United Nations specifications (with Eastern countries in this study including China, Korea, Bangladesh, and the Philippines and Western including the US, New Zealand, West Germany, Spain, Great Britain, and Belgium). The research demonstrated higher levels of stigma seen in Eastern cultures (84), attributed to the perception of mental illness as a "moral failing" that violates the cultural norm, and therefore may impact the well-being and economic or social prospects of family and friends (84). Thus, there are differences in degree of stigmatization toward individuals with multiple stigmatized identities (i.e., minority groups with a stigmatized condition) and this can vary across cultural groups and specific conditions.

The impacts of stigmatization in GI are broad and far-reaching. Stigma can lead to alienation and social withdrawal (77,85); it can also affect patient quality of life, emotional health, and willingness to disclose their condition (56). It can impact symptoms, health care utilization, patient-provider trust, and treatment adherence (56,74,75,77). In the 2020 study by Yan and colleagues of patients with FD in China, the use of neuromodulators to treat FD was found to increase perceived and internalized stigma (80). Stigma resistance is the rejection of enacted stigma (56) and tends to protect against the damaging effects of stigma and reduce internalized stigma.

Unfortunately, stigma resistance also appears to vary across cultural identities, with underrepresented minority patients with IBD reporting less stigma resistance and high levels of perceived stigma (86).

Taken together, it is clear that GI conditions are highly stigmatized and that the stigma attached to GI conditions likely varies cross-culturally. Internalized, perceived and enacted stigma is likely to have a greater negative impact on underrepresented minority populations, who are already faced with discrimination and may have less stigma resistance.

### HL

As in many other fields, such as law and finance, the healthcare system has its own language and norms. Individual patients are often burdened to learn this new language in order to be successful navigators of the system, and the stakes are high. HL refers to the skills which enable a person to "obtain, understand, appraise and use information to make decisions and take actions that will have an impact on health status" (87). HL has been shown to vary with income and educational attainment (88,89); and lower HL is associated with more hospitalization, more medication errors, more use of emergency services and less use of preventive screenings and vaccines (88). HL also appears to explain some racial disparities in health outcomes (88).

The HL burden in GI is high and starts with the challenges of evaluating and treating a set of organs embedded within the human body, its functioning invisible to HCPs without objective testing. Patient collected and communicated data (e.g., location, type, frequency, triggers) is the starting point for HCPs decision making about testing, behavioral or dietary changes, medications and attaining a diagnosis. The patient's objective and subjective experiences have the ability to shift the treatment approach and level of HL can affect subjective experiences such as pain (90). As etiology of symptoms can vary (e.g., structural, inflammation, DGBI or combination), patients may have difficulty with uncertainty and misunderstanding. The variety of testing available for the GI tract can also be confusing. For example, when a patient is experiencing esophageal symptoms, the HCP may order testing to evaluate multiple aspects of esophageal functioning (i.e., upper endoscopy, barium swallow test, pH monitoring, BRAVO, esophageal manometry). The results of these tests provide the HPC with important data points about the functioning of the GI organs but they also come with their

own set of costs and risks and benefits to the patient which must be individually weighed.

As described above, the condition of GERD is a common yet complex condition; the challenges may start in recognizing that the words to describe the condition are numerous, including acid reflux, acid indigestion, heartburn, backflow, cardialgia, indigestion, pyrosis and water brash. If a patient is experiencing a DGBI component, that may add to more confusion with reflux hypersensitivity or functional reflux. Patients and HCPs may also have varying understanding of symptoms that may be attributable to GERD and as such, patients may not know to discuss extra-esophageal symptoms as possibly related (91); this is concerning when much of the decision-making regarding testing is based on patient self-reported subjective symptoms. In this modern world, people are reliant on the Internet and are likely obtaining much of their health information from the web. A study examining the readability of definitions of reflux coming from websites of self-proclaimed “reflux and GERD centers” found that across the 52 websites evaluated, none of them included language at or below the recommended reading level of 6<sup>th</sup> grade and the majority were written in a reading level between 10–17<sup>th</sup> grade (92). Similar findings have been found when looking at reading level of GERD-focused apps available (93). In their study investigating patient recall after a hypothetical clinician encounter in which a new diagnosis of GERD was received, the older adults included recalled only about 50% of information conveyed, with those with low HL having significantly poorer recall of information compared with those with higher levels of HL; medication instructions were most impaired in participants with low and marginal HL (94). Surprisingly, even fewer studies have looked at HL in IBS. One study of people without IBS noted misunderstandings about what the disorder is, the symptoms, the etiology and where to properly and effectively obtain treatment (95).

As IBD is a chronic condition, patients are tasked with a range of self-management skills and to navigate treatment decisions within the context of their understanding of risks and benefits, preferences, financial/insurance limitations and feasibility. Not all patients diagnosed with IBD develop IBD-specific HL at a similar pace and there are consequences of low HL. In a prospective study of IBD patients at a tertiary medical center, 40% of the patients had low HL, and this was associated with subjective health status and depression symptoms. Importantly, of these patients, those with CD and limited HL had significantly lower rates

of clinical remission (96). Presumably, patients receiving IBD care at a tertiary care center may have a higher level of disease-related knowledge and are less likely to be adjusting to a new diagnosis compared to patients receiving care in rural or local community hospitals. Poorer understanding of and less knowledge about a GI condition is also associated with greater likelihood of stigmatization while improved knowledge and education regarding conditions and treatments can decrease stigma (80).

### **Clinical care considerations and recommendations**

Given most of our understanding of digestive disease is based on data from majority groups, it is necessary for HCPs to recognize that patients’ experiences outside of and within healthcare (e.g., discrimination), illness explanation and level of support (e.g., stigma), and ability to take in and use health information (e.g., HL) all play a role in their clinical presentation and influence treatment efficacy.

Take the following vignettes: a patient who is experiencing abdominal pain and coming from a cultural background or gender identity in which enduring pain is a sign of admirable inner strength may not present to a medical provider for weeks, delaying implementation of treatment. Another patient who comes from a religious background in which pain and symptoms are considered “God’s Will” or “karma” may view symptoms as a form of existential punishment and thus may be reluctant to pursue evaluation and treatment and may inherently view themselves differently as a result of the pain experience. Finally, a patient who has experienced chronic abdominal pain but is the sole financial provider for their family and working multiple jobs with high consequence for missing shifts may delay medical attention and decline intervention which they view a burdensome from a financial or time perspective.

How can the HCP create an environment in which some of these cultural and structural factors can come to light and be considered in discussions with the patient and in decisions about the plan of care?

### ***Cultural humility in GI***

The attitude and beliefs of the HCP can make a critical difference in how that provider approaches care and the outcome of that interaction. Cultural competence was first introduced to help to bridge these gaps; this model



emphasizes the idea that competence can be taught or achieved and assumes the more cultural knowledge, the more equipped a provider is to work with a patient (97). Limitations to this approach include the inference that with enough study, a HCP can attain “competence” and highlights a lack of uniformity in a definition or approach. While certainly an unintended effect, training in cultural competence may reinforce stereotypes and inhibit clinical intuition and decision making. By focusing solely on a patient’s culture, providers may lose sight of other, possibly more relevant or influential, identities a patient may have (98). Beyond this, it is difficult to study effectiveness of cultural competence interventions due to heterogeneity and self-reported outcomes (99) and it is unclear whether they have the effect they are intended to have on patient outcomes and satisfaction (100) and in reducing disparities (99). Instead, it may be more relevant for clinicians to come into all patient interactions with a sense of curiosity and respect for their patient’s background and work to understand how or if culture or intersectionality may be influencing their medical understanding or decision making. With this in mind, the concept of cultural humility (98) has grown and has been conceptualized as an approach in which a HCP commits to continual self-reflection and self-critique as lifelong learners to redress the power imbalances in the physician-patient dynamic, and to develop mutually beneficial and non-paternalistic partnerships with communities on behalf of individuals and defined populations. It emphasizes the patient as an individual rather than assumed collectivist characteristics of their culture and assumes that understanding of someone else can never be “achieved”.

GI providers may benefit from using a lens of humility to better understand their patient’s experience of symptoms or condition and their explanatory model for illness, to find and address any gaps in knowledge or adherence, and to better establish a long-term working relationship. A lens of cultural humility ought to be applied to all patients regardless if they identify with minority or majority groups; it is the HCP’s duty to approach patients as individuals while leveraging medical knowledge to tailor guidance. We offer practical suggestions for HCPs in GI summarized in *Table 2*.

## Conclusions

The burden of digestive disease is very high across the world and within the US. Providers practicing in GI will undoubtedly continue to see a more diverse caseload of

patients as the country’s population continues to shift and visibility of historically marginalized groups, such as SGM groups, increases. The pace of these changes is occurring faster than medical and healthcare training and research has been able to adapt, leaving gaps in our understanding of major sections of the population and our ability to care for them. This understanding must start with purposeful data gathering for all groups in our research endeavors; perhaps by proactively targeting this in recruitment and allowing individuals to self-identify their cultural identities related to country(ies) of origin, gender identity, sexual orientation and other categories. With this wider understanding we may learn more about rates of various conditions, responses to treatments, and experiences within digestive disease. Understanding these aspects would allow for the development of an armamentarium of precision medicine tools that may help with swifter diagnosis and more timely prescription of therapies, reducing the burden of disease and disability in cultural communities.

Authors of this paper are practicing GI-psychologists and a patient advocate and it is with this context that this review focuses on the psychosocial factors of institutional racism and racism in medicine, stigma and HL and their consequences to health and morbidity. Only modest exploration into these areas in the GI space has been completed and our aim was to draw attention to these overlooked factors. Despite our best efforts, this review has a number of limitations: (I) there were several critical topics that we did not include in this review, such as a focus on the role of religion, health and death beliefs, the role of the family, and beliefs about medications; (II) we did not focus on cultural groups outside of race, ethnicity and SGM groups or explore further on the intersectionality and complexity of factors related to socioeconomic status and access to basic services; (III) we also did not focus our review on the benefits and protective factors which come with cultural group identification and belonging. With this in mind, it is possible that our review failed to fully capture how to best articulate how culture may affect patients within GI and we recognize that the lens of the manuscript is specific to the authors’ backgrounds and areas of expertise.

A striking finding throughout the review has been the dearth of evidence related to experiences of SGM groups within GI. Per Vélez *et al.*, the disparate experiences of SGM lends to the minority stress model; that is, the structural inequities and discrimination SGM experience can be a driving factor in developing health conditions, including digestive diseases. Life stressors can lead to psychosocial (e.g.,

**Table 2** Practical suggestions for healthcare providers in GI practice

Areas to target	Practical suggestions
Fostering a positive patient-provider relationship in the tenor of cultural humility	<p>In a healthcare system where HCPs have high patient volumes and limited time with each patient, building a trusting rapport can be difficult in the time allotted</p> <ul style="list-style-type: none"> <li>• It is recommended that HCPs introduce themselves using their pronouns, offer all patients to supply their own and actively use those pronouns in conversation and documentation (101)</li> <li>• We recommend that HCPs avoid using gendered language and avoid assuming gender of partners (101)</li> <li>• Ask open-ended, non-leading questions which are framed with curiosity and respect</li> <li>• When asking certain questions that may be sensitive (e.g., country of origin, length of time in country, sexual orientation, gender identity, experiences of discrimination within and outside of the healthcare setting), we suggest that HCPs explicitly state why they are eliciting this information and how it may be used in care</li> <li>• We recommend that HCP use visual guides and pictures to aid in providing education or treatment recommendations to reduce reliance on a verbal only delivery (102)</li> </ul>
Use a teach back method when educating patients	<p>Across healthcare settings, the use of a “teach-back” has been widely recommended to increase patient understanding of their condition and increase adherence to treatment recommendations (103)</p> <ul style="list-style-type: none"> <li>• E.g., “We went over a lot of information today; it is not just okay, but expected that the things we discussed may not be entirely clear. Can you show or tell me in your own words what we discussed or your understanding of what we just discussed? When you go home and share with a loved one what we talked about today, what will be the key points that you’ll share with them?”</li> </ul> <p>A teach-back can also be paired with additional questions aimed at assessing patients’ knowledge and preparedness</p> <ul style="list-style-type: none"> <li>• E.g., “When you have an autoimmune condition like IBD, should you choose to get your flu vaccine, covid vaccine, both or neither?”</li> <li>• E.g., “If you notice blood in your bowel movements, what will be your next steps? How could you contact me?”</li> </ul>
System-wide initiatives to decrease burden on URMs	<p>More broadly, while we develop patient-targeted interventions to improve patient health literacy within GI, the healthcare system must work to develop processes and systems to decrease burden for patients of diverse backgrounds and improve outcomes</p> <p>On a healthcare system level, GI practices must</p> <ul style="list-style-type: none"> <li>• Employ or contract with medically trained translator services (104)</li> <li>• Request or be open to family/support people attending visits with the patient</li> <li>• Recognize that some cultures make healthcare decisions as a unit (e.g., family) or with input from traditional healers</li> <li>• Be mindful when providing written information following a medical appointment to not rely on direct translation to convey patient-facing information. Input from cultural experts is advised (104) (e.g., dietary recommendations for American diet that is directly translated to another language will unlikely be helpful for patients whose diet is primarily comprised of culturally traditional foods)</li> </ul>

GI, gastrointestinal; HCP, health care provider; IBD, inflammatory bowel disease; URM, underrepresented minorities.

discrimination, stigma, depression, anxiety), behavioral (e.g., altered diet, physical activity, sleep, alcohol/tobacco use), and gut-brain axis (GBA) factors (e.g., autonomic nervous system reactivity, inflammation), which can then lead to GI conditions and an altered microbiome (105). It is clear that the GI field would benefit from more focused research to explore the experiences of SGM patients.

A workforce which is representative and therefore

diverse may be a promising strategy to narrow the health equity gap (106,107), as patient/provider racial concordance is associated with improved communication satisfaction, information-giving, partnership building, participatory decision making, visit length, supportiveness and respect in conversation (106-109). While there have been increases in providers who are underrepresented in medicine (URiM) in many areas, URiM GI physicians are few and the field

would benefit from focused recruitment to diversify the specialty (110,111). Efforts to ensure that recruitment and retention of culturally diverse trainees is a priority, as is the support of those students in social, academic and financial support domains to minimize attrition in the field (106-108).

The model of cultural humility has not been explored in GI. If opted for, cultural humility training would benefit all staff and care providers in a GI clinic, as multidisciplinary care (gastroenterologist, dietitian, health psychologist, social worker) has shown to improve health outcomes for GI patients regardless of sociodemographic status and insurance coverage (112).

Finally, GI HCPs have a duty to continually assess how their specialty and healthcare system may be explicitly or implicitly contributing to inequitable care across cultural groups and commit to a broad range of interventions to close these gaps. Further, HCPs are on task to publicly and formally advocate for legislative and societal change.

## Acknowledgments

*Funding:* None.

## Footnote

*Provenance and Peer Review:* This article was commissioned by the Guest Editors (Sara H. Marchese and Tiffany H. Taft) for the series “Social and Emotional Impacts of Chronic Digestive Diseases” published in *Translational Gastroenterology and Hepatology*. The article has undergone external peer review.

*Peer Review File:* Available at <https://tgh.amegroups.com/article/view/10.21037/tgh-24-17/prf>

*Conflicts of Interest:* All authors have completed the ICMJE uniform disclosure form (available at <https://tgh.amegroups.com/article/view/10.21037/tgh-24-17/coif>). The series “Social and Emotional Impacts of Chronic Digestive Diseases” was commissioned by the editorial office without any funding or sponsorship. T.A.O. reports consulting fees from AbbVie, Ardelyx, Johnson & Johnson, Genentech-Roche, Pfizer, Boehringer Ingelheim, Hollister, Inc., Parexel, Walgreens and Convatec; honoraria from AbbVie, Iterative Health, Johnson & Johnson, Genentech-Roche, Takeda, Pfizer, Hollister Inc., Boehringer Ingelheim and Parexel; support for attending meetings and/or travel from South Asian IBD Alliance, Crohn’s & Colitis Foundation,

AGA, Pfizer, Genentech, Johnson & Johnson, Medscape, and Helmsley Charitable Trust; participation on a Data Safety Monitoring Board or Advisory Board for Ardelyx, Johnson & Johnson, Genentech-Roche, Takeda, Pfizer, Tillotts AG, Parexel and Merck (all for patient advisory boards); leadership or fiduciary role in South Asian IBD Alliance and United Ostomy Associations of America and he is employed by Sommer Consulting (healthcare market research firm). The authors have no other conflicts of interest to declare.

*Ethical Statement:* The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

*Open Access Statement:* This is an Open Access article distributed in accordance with the Creative Commons Attribution-NonCommercial-NoDerivs 4.0 International License (CC BY-NC-ND 4.0), which permits the non-commercial replication and distribution of the article with the strict proviso that no changes or edits are made and the original work is properly cited (including links to both the formal publication through the relevant DOI and the license). See: <https://creativecommons.org/licenses/by-nc-nd/4.0/>.

## References

- 2009 UNESCO Framework for Cultural Statistics [Internet]. [cited 2024 Jan 18]. Available online: [https://uis.unesco.org/sites/default/files/documents/unesco-framework-for-cultural-statistics-2009-en\\_0.pdf](https://uis.unesco.org/sites/default/files/documents/unesco-framework-for-cultural-statistics-2009-en_0.pdf)
- Engel GL. The need for a new medical model: a challenge for biomedicine. *Science* 1977;196:129-36.
- McEwen BS, Stellar E. Stress and the individual. Mechanisms leading to disease. *Arch Intern Med* 1993;153:2093-101.
- Wallden M, Nijs J. Before & beyond the pain - Allostatic load, central sensitivity and their role in health and function. *J Bodyw Mov Ther* 2021;27:388-92.
- Chang L. The role of stress on physiologic responses and clinical symptoms in irritable bowel syndrome. *Gastroenterology* 2011;140:761-5.
- Desjardins G, Caceres BA, Juster RP. Sexual minority health and allostatic load in the National Health and Nutrition Examination Survey: A systematic scoping review with intersectional implications. *Psychoneuroendocrinology* 2022;145:105916.

7. Mays VM, Juster RP, Williamson TJ, et al. Chronic Physiologic Effects of Stress Among Lesbian, Gay, and Bisexual Adults: Results From the National Health and Nutrition Examination Survey. *Psychosom Med* 2018;80:551-63.
8. Guidi J, Lucente M, Sonino N, et al. Allostatic Load and Its Impact on Health: A Systematic Review. *Psychother Psychosom* 2021;90:11-27.
9. Suvarna B, Suvarna A, Phillips R, et al. Health risk behaviours and allostatic load: A systematic review. *Neurosci Biobehav Rev* 2020;108:694-711.
10. Argeseanu Cunningham S, Ruben JD, Narayan KM. Health of foreign-born people in the United States: a review. *Health Place* 2008;14:623-35.
11. Shad NS, Shaikh NI, Cunningham SA. Migration Spurs Changes in the Human Microbiome: a Review. *J Racial Ethn Health Disparities* 2023. doi: 10.1007/s40615-023-01813-0.
12. Scholaske L, Wadhwa PD, Entringer S. Acculturation and biological stress markers: A systematic review. *Psychoneuroendocrinology* 2021;132:105349.
13. Vespa J, Medina L, Armstrong DM. Demographic Turning Points for the United States: Population Projections for 2020 to 2060. [cited 2024 Feb 13]. Available online: <https://www.census.gov/content/dam/Census/library/publications/2020/demo/p25-1144.pdf>
14. Jones JM. LGBT Identification in U.S. Ticks Up to 7.1%. [cited 2024 Feb 13]. Available online: <https://news.gallup.com/poll/389792/lgbt-identification-ticks-up.aspx>
15. Bar N, Surjanhata B, Weeks I, et al. Analysis of Age, Race, Ethnicity, and Sex of Participants in Clinical Trials Focused on Disorders of Gut-Brain Interaction. *Gastroenterology* 2022;163:757-760.e1.
16. Wieland ML, Grover M. Inclusive Clinical Trials for Disorders of Gut-Brain Interactions. *Gastroenterology* 2022;163:583-5.
17. Craven MR, Kia L, O'Dwyer LC, et al. Systematic review: methodological flaws in racial/ethnic reporting for gastroesophageal reflux disease. *Dis Esophagus* 2018;31:dox154.
18. Global Burden of Disease (GBD) [Internet]. [cited 2024 Feb 12]. Available online: <https://www.healthdata.org/research-analysis/gbd>
19. Drossman DA. Functional Gastrointestinal Disorders: History, Pathophysiology, Clinical Features and Rome IV. *Gastroenterology*. Published online February 19, 2016. doi: 10.1053/j.gastro.2016.02.032.
20. Sperber AD, Bangdiwala SI, Drossman DA, et al. Worldwide Prevalence and Burden of Functional Gastrointestinal Disorders, Results of Rome Foundation Global Study. *Gastroenterology* 2021;160:99-114.e3.
21. Sperber AD, Freud T, Aziz I, et al. Greater Overlap of Rome IV Disorders of Gut-Brain Interactions Leads to Increased Disease Severity and Poorer Quality of Life. *Clin Gastroenterol Hepatol* 2022;20:e945-56.
22. Lovell RM, Ford AC. Global prevalence of and risk factors for irritable bowel syndrome: a meta-analysis. *Clin Gastroenterol Hepatol* 2012;10:712-721.e4.
23. Fang X, Francisconi CE, Fukudo S, et al. Multicultural Aspects in Functional Gastrointestinal Disorders (FGIDs). *Gastroenterology* 2016. doi: 10.1053/j.gastro.2016.02.013.
24. Fairlie T, Shah A, Talley NJ, et al. Overlap of disorders of gut-brain interaction: a systematic review and meta-analysis. *Lancet Gastroenterol Hepatol* 2023;8:646-59.
25. The global, regional, and national burden of inflammatory bowel disease in 195 countries and territories, 1990-2017: a systematic analysis for the Global Burden of Disease Study 2017. *Lancet Gastroenterol Hepatol* 2020;5:17-30.
26. Wang Y, Huang Y, Chase RC, et al. Global Burden of Digestive Diseases: A Systematic Analysis of the Global Burden of Diseases Study, 1990 to 2019. *Gastroenterology* 2023;165:773-783.e15.
27. Ng SC, Shi HY, Hamidi N, et al. Worldwide incidence and prevalence of inflammatory bowel disease in the 21st century: a systematic review of population-based studies. *Lancet* 2017;390:2769-78.
28. Chen X, Xiang X, Xia W, et al. Evolving Trends and Burden of Inflammatory Bowel Disease in Asia, 1990-2019: A Comprehensive Analysis Based on the Global Burden of Disease Study. *J Epidemiol Glob Health* 2023;13:725-39.
29. Jairath V, Feagan BG. Global burden of inflammatory bowel disease. *Lancet Gastroenterol Hepatol* 2020;5:2-3.
30. Olfatifar M, Zali MR, Pourhoseingholi MA, et al. The emerging epidemic of inflammatory bowel disease in Asia and Iran by 2035: A modeling study. *BMC Gastroenterol* 2021;21:204.
31. Ananthakrishnan AN, Kaplan GG, Ng SC. Changing Global Epidemiology of Inflammatory Bowel Diseases: Sustaining Health Care Delivery Into the 21st Century. *Clin Gastroenterol Hepatol* 2020;18:1252-60.
32. Aniwaniwan S, Santiago P, Loftus EV Jr, et al. The epidemiology of inflammatory bowel disease in Asia and Asian immigrants to Western countries. *United European Gastroenterol J* 2022;10:1063-76.
33. Pathiyil MM, Jena A, Venkataramana Raju AK, et al. Representation and reporting of diverse groups in

- randomised controlled trials of pharmacological agents in inflammatory bowel disease: a systematic review. *Lancet Gastroenterol Hepatol* 2023;8:1143-51.
34. Sedano R, Hogan M, McDonald C, et al. Underrepresentation of Minorities and Underreporting of Race and Ethnicity in Crohn's Disease Clinical Trials. *Gastroenterology* 2022;162:338-340.e2.
  35. Sedano R, Hogan M, McDonald C, et al. Underrepresentation of Minorities and Lack of Race Reporting in Ulcerative Colitis Drug Development Clinical Trials. *Inflamm Bowel Dis* 2022;28:1293-5.
  36. Maret-Ouda J, Markar SR, Lagergren J. Gastroesophageal Reflux Disease: A Review. *JAMA* 2020;324:2536-47.
  37. Gorczyca R, Pardak P, Pękala A, et al. Impact of gastroesophageal reflux disease on the quality of life of Polish patients. *World J Clin Cases* 2019;7:1421-9.
  38. Gong EJ, Choi KD, Jung HK, et al. Quality of life, patient satisfaction, and disease burden in patients with gastroesophageal reflux disease with or without laryngopharyngeal reflux symptoms. *J Gastroenterol Hepatol* 2017;32:1336-40.
  39. Zhang D, Liu S, Li Z, et al. Global, regional and national burden of gastroesophageal reflux disease, 1990-2019: update from the GBD 2019 study. *Ann Med* 2022;54:1372-84.
  40. Gawron AJ, French DD, Pandolfino JE, et al. Economic evaluations of gastroesophageal reflux disease medical management. *Pharmacoeconomics* 2014;32:745-58.
  41. Li N, Yang WL, Cai MH, et al. Burden of gastroesophageal reflux disease in 204 countries and territories, 1990-2019: a systematic analysis for the Global Burden of disease study 2019. *BMC Public Health* 2023;23:582.
  42. Peinado-Molina RA, Hernández-Martínez A, Martínez-Vázquez S, et al. Pelvic floor dysfunction: prevalence and associated factors. *BMC Public Health* 2023;23:2005.
  43. Notenboom-Nas FJM, Knol-de Vries GE, Beijer L, et al. Exploring pelvic floor muscle function in men with and without pelvic floor symptoms: A population-based study. *Neurourol Urodyn* 2022;41:1739-48.
  44. Rao SS, Patcharakul T. Diagnosis and Treatment of Dyssynergic Defecation. *J Neurogastroenterol Motil* 2016;22:423-35.
  45. Peinado Molina RA, Hernández Martínez A, Martínez Vázquez S, et al. Influence of pelvic floor disorders on quality of life in women. *Front Public Health* 2023;11:1180907.
  46. Knol-de Vries GE, Blanker MH. Prevalence of co-existing pelvic floor disorders: A scoping review in males and females. *Continence* 2022;2:100028.
  47. Knol-de Vries GE, Malmberg GGA, Notenboom-Nas FJM, et al. Exploring concomitant pelvic floor symptoms in community-dwelling females and males. *Neurourol Urodyn* 2022;41:1770-80.
  48. Mckay ER, Davila JL, Lee JA, et al. Representation of Minority Groups in Key Pelvic Floor Disorder Trials. *Female Pelvic Med Reconstr Surg* 2021;27:602-8.
  49. Zwickl S, Burchill L, Wong AFQ, et al. Pelvic Pain in Transgender People Using Testosterone Therapy. *LGBT Health* 2023;10:179-90.
  50. Mack I, Hahn H, Gödel C, et al. Global Prevalence of Fecal Incontinence in Community-Dwelling Adults: A Systematic Review and Meta-analysis. *Clin Gastroenterol Hepatol* 2024;22:712-731.e8.
  51. Islam RM, Oldroyd J, Rana J, et al. Prevalence of symptomatic pelvic floor disorders in community-dwelling women in low and middle-income countries: a systematic review and meta-analysis. *Int Urogynecol J* 2019;30:2001-11.
  52. Poylin V, Serrot FJ, Madoff RD, et al. Obesity and bariatric surgery: a systematic review of associations with defecatory dysfunction. *Colorectal Dis* 2011;13:e92-e103. Erratum in: *Colorectal Dis* 2012;14:531.
  53. Kenne KA, Wendt L, Brooks Jackson J. Prevalence of pelvic floor disorders in adult women being seen in a primary care setting and associated risk factors. *Sci Rep* 2022;12:9878.
  54. Soares NC, Ford AC. Prevalence of, and risk factors for, chronic idiopathic constipation in the community: systematic review and meta-analysis. *Am J Gastroenterol* 2011;106:1582-91; quiz 1581, 1592.
  55. Sadeghi A, Akbarpour E, Majidirad F, et al. Dyssynergic Defecation: A Comprehensive Review on Diagnosis and Management. *Turk J Gastroenterol* 2023;34:182-95.
  56. Ruddy J, Taft T. The Pervasive Impact of the Stigmatization of Gastrointestinal Diseases-A Patient's Perspective. *Gastroenterol Clin North Am* 2022;51:681-95.
  57. Understanding Racial Terms and Differences | Office of Equity, Diversity, and Inclusion [Internet]. [cited 2024 Feb 13]. Available online: <https://www.edi.nih.gov/blog/communities/understanding-racial-terms-and-differences>
  58. McQuaid EL, Landier W. Cultural Issues in Medication Adherence: Disparities and Directions. *J Gen Intern Med* 2018;33:200-6.
  59. Lewis TT, Cogburn CD, Williams DR. Self-reported experiences of discrimination and health: scientific advances, ongoing controversies, and emerging issues. *Annu Rev Clin Psychol* 2015;11:407-40.

60. Amato KR, Arrieta MC, Azad MB, et al. The human gut microbiome and health inequities. *Proc Natl Acad Sci U S A* 2021;118:e2017947118.
61. Ben J, Cormack D, Harris R, et al. Racism and health service utilisation: A systematic review and meta-analysis. *PLoS One* 2017;12:e0189900.
62. Williams DR, Lawrence JA, Davis BA. Racism and Health: Evidence and Needed Research. *Annu Rev Public Health* 2019;40:105-25.
63. Roberts TK, Fantz CR. Barriers to quality health care for the transgender population. *Clin Biochem* 2014;47:983-7.
64. Powell W, Richmond J, Mohottige D, et al. Medical Mistrust, Racism, and Delays in Preventive Health Screening Among African-American Men. *Behav Med* 2019;45:102-17.
65. Cohen RA, Cha AE. Health Insurance Coverage: Early Release of Estimates From the National Health Interview Survey, 2022. Available online: [https://www.cdc.gov/nchs/data/nhis/earlyrelease/insur202305\\_1.pdf](https://www.cdc.gov/nchs/data/nhis/earlyrelease/insur202305_1.pdf)
66. Hsiang WR, Lukasiewicz A, Gentry M, et al. Medicaid Patients Have Greater Difficulty Scheduling Health Care Appointments Compared With Private Insurance Patients: A Meta-Analysis. *Inquiry* 2019;56:46958019838118.
67. Hsieh N, Shuster SM. Health and Health Care of Sexual and Gender Minorities. *J Health Soc Behav* 2021;62:318-33.
68. Siddique SM, May FP. Race-Based Clinical Recommendations in Gastroenterology. *Gastroenterology* 2022;162:408-414.e2.
69. Liu JJ, DeCuir N, Kia L, et al. Tools to Measure the Impact of Structural Racism and Discrimination on Gastrointestinal and Hepatology Disease Outcomes: A Scoping Review. *Clin Gastroenterol Hepatol* 2023;21:2759-2788.e6.
70. Fleary SA, Ertienne R. Social Disparities in Health Literacy in the United States. *Health Lit Res Pract* 2019;3:e47-52.
71. Earnshaw VA, Quinn DM. The impact of stigma in healthcare on people living with chronic illnesses. *J Health Psychol* 2012;17:157-68.
72. Heijnders M, Van Der Meij S. The fight against stigma: an overview of stigma-reduction strategies and interventions. *Psychol Health Med* 2006;11:353-63.
73. Looper KJ, Kirmayer LJ. Perceived stigma in functional somatic syndromes and comparable medical conditions. *J Psychosom Res* 2004;57:373-8.
74. Taft TH, Bedell A, Naftaly J, et al. Stigmatization toward irritable bowel syndrome and inflammatory bowel disease in an online cohort. *Neurogastroenterol Motil* 2017.
75. Feingold JH, Drossman DA. Deconstructing stigma as a barrier to treating DGBI: Lessons for clinicians. *Neurogastroenterol Motil* 2021;33:e14080.
76. Hearn M, Whorwell PJ, Vasant DH. Stigma and irritable bowel syndrome: a taboo subject? *Lancet Gastroenterol Hepatol* 2020;5:607-15.
77. Taft TH, Riehl ME, Dowjotas KL, et al. Moving beyond perceptions: internalized stigma in the irritable bowel syndrome. *Neurogastroenterol Motil* 2014;26:1026-35.
78. Taft TH, Keefer L, Leonhard C, et al. Impact of perceived stigma on inflammatory bowel disease patient outcomes. *Inflamm Bowel Dis* 2009;15:1224-32.
79. Saunders B. Stigma, deviance and morality in young adults' accounts of inflammatory bowel disease. *Social Health Illn* 2014;36:1020-36.
80. Yan XJ, Qiu HY, Luo QQ, et al. Improving Clinician-Patient Communication Alleviates Stigma in Patients With Functional Dyspepsia Receiving Antidepressant Treatment. *J Neurogastroenterol Motil* 2022;28:95-103.
81. Guadagnoli L, Taft TH. Internalized Stigma in Patients with Eosinophilic Gastrointestinal Disorders. *J Clin Psychol Med Settings* 2020;27:1-10.
82. Dalton CB, Drossman DA, Hathaway JM, et al. Perceptions of physicians and patients with organic and functional gastrointestinal diagnoses. *Clin Gastroenterol Hepatol* 2004;2:121-6.
83. Taft TH, Keefer L, Artz C, et al. Perceptions of illness stigma in patients with inflammatory bowel disease and irritable bowel syndrome. *Qual Life Res* 2011;20:1391-9.
84. Krendl AC, Pescosolido BA. Countries and Cultural Differences in the Stigma of Mental Illness: The East-West Divide. *J Cross-Cult Psychol* 2020;51:149-67.
85. Taft TH, Ballou S, Keefer L. A preliminary evaluation of internalized stigma and stigma resistance in inflammatory bowel disease. *J Health Psychol* 2013;18:451-60.
86. Veracruz, Nicolette, Taft T. Stigma Internalization in non-white patients with IBD and its relationship with patient outcomes. *Inflamm Bowel Dis* 2022;28:S96-7.
87. Nutbeam D, Lloyd JE. Understanding and Responding to Health Literacy as a Social Determinant of Health. *Annu Rev Public Health* 2021;42:159-73.
88. Berkman ND, Sheridan SL, Donahue KE, et al. Low health literacy and health outcomes: an updated systematic review. *Ann Intern Med* 2011;155:97-107.
89. Dewalt DA, Berkman ND, Sheridan S, et al. Literacy and health outcomes: a systematic review of the literature. *J Gen Intern Med* 2004;19:1228-39.

90. Köppen PJ, Dorner TE, Stein KV, et al. Health literacy, pain intensity and pain perception in patients with chronic pain. *Wien Klin Wochenschr* 2018;130:23-30.
91. Fischer JL, Tolisano AM, Navarro AI, et al. Layperson Perception of Reflux-Related Symptoms. *OTO Open* 2023;7:e51.
92. Ekkel E, Seeras K. Readability of Online Patient Material Provided by Reflux Centers in the United States. *Am Surg* 2023;89:2782-4.
93. Bobian M, Kandinov A, El-Kashlan N, et al. Mobile applications and patient education: Are currently available GERD mobile apps sufficient? *Laryngoscope* 2017;127:1775-9.
94. McCarthy DM, Waite KR, Curtis LM, et al. What did the doctor say? Health literacy and recall of medical instructions. *Med Care* 2012;50:277-82.
95. Sherwin LB. Layperson's knowledge and perceptions of irritable bowel syndrome as potential barriers to care. *J Adv Nurs* 2018;74:1199-207.
96. Tormey LK, Reich J, Chen YS, et al. Limited Health Literacy Is Associated With Worse Patient-Reported Outcomes in Inflammatory Bowel Disease. *Inflamm Bowel Dis* 2019;25:204-12.
97. Seeleman C, Suurmond J, Stronks K. Cultural competence: a conceptual framework for teaching and learning. *Med Educ* 2009;43:229-37.
98. Tervalon M, Murray-García J. Cultural humility versus cultural competence: a critical distinction in defining physician training outcomes in multicultural education. *J Health Care Poor Underserved* 1998;9:117-25.
99. Truong M, Paradies Y, Priest N. Interventions to improve cultural competency in healthcare: a systematic review of reviews. *BMC Health Serv Res* 2014;14:99.
100. Shepherd SM. Cultural awareness workshops: limitations and practical consequences. *BMC Med Educ* 2019;19:14.
101. Baldwin A, Dodge B, Schick VR, et al. Transgender and Genderqueer Individuals' Experiences with Health Care Providers: What's Working, What's Not, and Where Do We Go from Here? *J Health Care Poor Underserved* 2018;29:1300-18.
102. Mbanda N, Dada S, Bastable K, et al. A scoping review of the use of visual aids in health education materials for persons with low-literacy levels. *Patient Educ Couns* 2021;104:998-1017.
103. Talevski J, Wong Shee A, Rasmussen B, et al. Teach-back: A systematic review of implementation and impacts. *PLoS One* 2020;15:e0231350.
104. Karliner LS, Jacobs EA, Chen AH, et al. Do professional interpreters improve clinical care for patients with limited English proficiency? A systematic review of the literature. *Health Serv Res* 2007;42:727-54.
105. Vélez C, Casimiro I, Pitts R, et al. Digestive Health in Sexual and Gender Minority Populations. *Am J Gastroenterol* 2022;117:865-75.
106. Rengers TA, Warner SG. Importance of Diversity, Equity, and Inclusion in the Hepatopancreatobiliary Workforce. *Cancers (Basel)* 2024;16:326.
107. Wilbur K, Snyder C, Essary AC, et al. Developing workforce diversity in the health professions: a social justice perspective. *Health Prof Educ* 2020;6:222-9.
108. Fernandez C, Bean N, Williams R. Cultivating Cultural Competency in Gastroenterology Practices. *Clin Gastroenterol Hepatol* 2023;21:1138-40.
109. Takeshita J, Wang S, Loren AW, et al. Association of Racial/Ethnic and Gender Concordance Between Patients and Physicians With Patient Experience Ratings. *JAMA Netw Open* 2020;3:e2024583.
110. Cryer B, Quezada S, Culpepper-Morgan JA, et al. Bridging the Racial, Ethnic, and Gender Gap in Gastroenterology. *Gastroenterology* 2022;163:800-5.
111. Carethers JM, Quezada SM, Carr RM, et al. Diversity Within US Gastroenterology Physician Practices: The Pipeline, Cultural Competencies, and Gastroenterology Societies Approaches. *Gastroenterology* 2019;156:829-33.
112. Wang CP, Zylberberg HM, Borman ZA, et al. Impact of Care in an Interdisciplinary Inflammatory Bowel Disease Specialty Clinic on Outcomes in Patients Insured with Medicaid. *J Clin Gastroenterol* 2023;57:908-12.

doi: 10.21037/tgh-24-17

**Cite this article as:** Pandit AU, Tomasino KN, Aswani Omprakash T, Epstein DE. Cultural considerations in gastroenterology: barriers to care and a call for humility and action. *Transl Gastroenterol Hepatol* 2024;9:74.