

**HOLDING SPACE FOR NUANCE IN IRRITABLE BOWEL SYNDROME:
THE ETHICAL DIMENSIONS OF MEDICAL AMBIGUITY**

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ABSTRACT

Irritable bowel syndrome (IBS), a disorder of gut-brain interaction, is common and yet remains perplexing for physicians and patients alike. Symptoms can be ambiguous, and understanding of this disorder has been limited, in part, by blunt diagnostic tools. Ironically, the lack of sophisticated scientific approaches itself has contributed to the perception that IBS is a less objective diagnosis. A syndrome that rests among intricate and poorly delineated relationships between biologic, psychologic, and social domains, IBS does not always lend itself well to traditional clinical discussions. Here, I offer narrative ethics as a potential tool to carry the nuances of this diagnosis. Invocations of narrative demand interrogation of stories and how they operate, and I argue stories work particularly potently for IBS patients. Finally, I consider how lay narratives about IBS may contribute to care disparities among different groups. Through these three sections, I seek to explore the ethical considerations of ambiguity within medical spaces and the traps that exist when dealing with illness that lies just beyond the margin of contemporary scientific understanding.

DEDICATION

To my brother

ACKNOWLEDGMENTS

I wish to first thank my partner, family, and friends for their unconditional love and encouragement. I am grateful that they take my thinking seriously; their engagement – whether over the phone or over dinner – pushes my inquiry further. I must also thank the patients whom I've had the privilege of working with, in whatever small capacity. These relationships are rarely explicitly framed as bidirectional, but clinical care is highly collaborative. I gain so much from the people I meet in the office.

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CHAPTER 1: INTRODUCTION

I am in my final year of gastroenterology training. Ever since medical school I was attracted to the field. I appreciated that it was procedural and that it involved multiple, big organs. I loved that you could see things on a monitor screen and that acute concerns, like gastrointestinal bleeding, could be managed definitively.

As I continued to learn, I also found myself increasingly drawn to the things that couldn't be seen in endoscopy: symptoms – pain, dyspepsia, or bloating – that couldn't be explained by endoscopic images or biopsies. Patients often had troublesome, chronic, murky concerns that brought them to the office repeatedly over months or years. I now practice with an interest in conditions like irritable bowel syndrome (IBS) and other disorders of gut-brain interaction, diagnoses that continue to carry some ambiguity and that rest at a medical frontier that has been incompletely explored.

Ethical questions come up everyday in clinical practice – even routine decisions, like whether to order a procedure for a patient, are laden with ethical weight. I find an even greater ethical potency in the care of IBS patients, a field in which the social dimensions of care factor so prominently in not only the experience of the illness but also its pathophysiology. Practice standards are continually evolving; through this three-part manuscript, I hope to introduce new ways of thinking about these disorders and, as a result, new avenues of clinical approach.

CHAPTER 2: DISEASE TAXONOMIES AND DISORDERS OF GUT-BRAIN INTERACTION

When I was a medical student, I took notes on the margins of textbooks, which were organized by organ system, each containing subsections of diseases, grouped according to their similarities with each other. I was excited to learn this specialized body of knowledge; medicine had its own internal language and what felt like an inherent ordering of information. Now, as a gastroenterology fellow, it's hard to remember that distinctions – between diseases or even between illness and health – appeared so clean as they did to me then.

The Role for – and Illusion of – Distinct Disease Categories

In thinking about disease classifications, it is worthwhile to consider the benefits of groupings. In many ways, finding patterns among observations forms the very basis of scientific investigation. In medicine specifically, classifications help group patients together and, as an extension, shared therapies can be applied in service of symptoms that emerge for shared pathophysiologic reasons. With that in mind, it is also worthwhile to interrogate the nature of our classification schemes.

Disease categories, while often taken as a given, are not as sharply delineated and straightforward as they may initially seem to an early learner. Seeing distinct disease headings in medical texts can make such categories seem as though they have always existed that way, instead of evolving through time. This in turn supports a kind of rigidity in thinking that may not fully encapsulate how and why symptoms exist. As a result, this sort of thinking may constrain therapeutic paradigms.

As an example, I often see patients with symptoms as broad as generalized abdominal pain, a change in bowel habits, or post-prandial bloating. Numerous disease states can lead to symptoms like these, and when eliciting information, determining an underlying etiology can often be surprisingly difficult to uncover. Instead, I find myself listening for alarming details, like gastrointestinal bleeding, weight loss, or a sudden onset for the symptoms. If there are none, I listen closely for certain bits of information or general patterns to help offer a diagnosis and potential treatments. Yet the more I practice, the more I find myself confined by certain clinical criteria. If a patient has had symptoms for two months instead of three months, but meets all other criteria for IBS, do they not qualify for the diagnosis? And will they not benefit from some of the associated medications? What if they have symptoms consistent with gastroparesis, but their gastric emptying time is not sufficiently delayed – are they on their way to develop gastroparesis, or am I missing another disease?

By their very nature, categories, while necessary for organization, sort and group rather than fully encapsulate ambiguity. This quality is helpful for large amounts of information, and a reliance on classification may be an extension of medicine's progressive affinity toward science and efficiency over the course of the twentieth century. The number of hospitals in America exponentially grew from the end of the nineteenth century into the 1930s¹ and as medical historian Joel Howell notes, this encouraged the development of administrative sciences, with the delineation and creation of new departments.² Social scientist Annmarie Adams has highlighted how greater attention was paid to the design and workflow of hospital spaces during this time.³ Medical documentation also necessitated changes; the physician Lawrence Weed

introduced categories for physician notes to deal with increasing informational complexity, recommending a “SOAP” format, standing for subjective, objective, assessment, and plan. In a widely publicized interview on the topic, Dr. Weed said that though creating notes with categories “cannot change the multiplicity of problems physicians face, [it] enables a highly organized approach to that complexity.”⁴

However, classifications carry certain problems and limitations. Here it may be useful to borrow from scholar Annemarie Jutel, who has closely examined the sociologic implications of classification and diagnosis in medicine. As she outlines, classifications in medicine are inherently social processes with real-life implications in the care of patients. She states, “Classification is not value-free...Each and every classification engages some social perspectives and shuts down others, but once a classification is established it reproduces itself in an intuitive way that silences debate.”⁵ Determining whether something qualifies as disorder or if it does, where it falls among a hierarchy of other disorders, is a process that rather than relying on an inherent truth, involves, at some level, a decision. She goes on to point out that medicine has at times, separate and parallel goals: “We can see one important paradox that medicine faces with regards to classification...medicine seek[s] to establish similarities via classification in order to promote population health, allocate resources, focus research, and so on. Medical practice, on the other hand, focuses on the idiosyncratic individual.”⁵ Such tension exists for all diseases to some extent, and perhaps even more for those that, by their very nature, do not lend themselves easily to classification.

An Introduction to Disorders of Gut-Brain Interaction

Neurogastroenterology is a relatively nascent name for a field with longstanding history. It involves the study of disorders of gut-brain interaction, which are broad-ranging and at times seemingly disparate diagnoses that span the entire GI system. They are grouped as a collective under a classification scheme called the Rome criteria, an outgrowth of a working group of self-appointed experts that initially convened in Rome in order to address difficult-to-treat conditions.⁶ These diseases are lumped together by the existence of symptoms on the basis of shared pathophysiologic mechanisms, specifically arising due to some combination of motility disturbance, visceral hypersensitivity, altered mucosal and immune function, altered microbiota, and altered central nervous system processing.⁷ IBS is one of the most common disorders of gut-brain interaction, with a global prevalence hovering at around 3% of the population.⁸ Numbers are higher in Western countries, including the United States, with suggestions of up to 15% of the population affected.⁹ Despite the fact that many people carry the diagnosis, IBS has historically been challenging for patients and physicians alike, with a perceived lack of clarity regarding pathogenesis and treatment among many physicians and ongoing biases regarding who develops symptoms.¹⁰ Such a context presents a number of complexities for classification schemes.

Although the gut-brain axis has perhaps been intuitively understood for some time, diagnostic criteria regarding disorders of gut-brain interaction, including IBS, have only developed in the last few decades – the first clinical criteria for IBS were published in 1989.⁷ Subsequent iterations have since developed, with a nonprofit foundation built around these working groups providing resources for further study. In the latest rendition

of the Rome Criteria, an IBS diagnosis requires that a patient has recurrent abdominal pain on average at least one day per week in the last three months of presentation associated with two or more of the following (1) a perceived relation to defecation, (2) a change in the frequency of stool, and/or (3) a change in the appearance (or form) of stool.

Several updates were made in Rome IV criteria compared to previous renditions. For one, abdominal symptoms are now described as “pain” rather than previous descriptions of “discomfort,” due to concerns that the word “discomfort” does not exist in some languages and cultures and was perhaps ambiguous.⁷ Additionally, there is a general departure from classifying disorders of gut-brain interaction as “functional” diseases. The word “functional” was frequently deployed to describe poorly understood symptoms that did not have objective or “organic” basis in the form of biochemical testing. Usage of this terminology on the part of physicians has perhaps been stigmatizing over time with the suggestion of a lack of legitimacy, given medicine’s preferential bias towards diseases with obvious histopathologic abnormalities (like inflammatory bowel disease, by contrast).

Although “functional” is still used as a qualifier in the literature when other diseases could be confused with the disorder (functional heartburn, for example, is used to establish the difference in pathophysiology with gastroesophageal reflux disease, which manifests with similar symptoms), increasing awareness that our understanding of disorders of gut-brain interaction has been incomplete and limited, in part due to the blunt diagnostic tools currently available, has shifted lay conversations. Critiques regarding medical paternalism and systemic determinations of illness validity have been growing, both within patient advocacy circles and from members of the medical establishment.

Blurred Classification Lines

Speculation still exists about the cleanliness of our categorizations. For example, chronic nausea vomiting syndrome, a disorder of gut-brain interaction that is characterized by ongoing symptoms in the absence of biochemical or endoscopic abnormality, may be on a spectrum with other disorders that have objective testing abnormalities to support their diagnosis. Gastroparesis is often characterized by similar symptoms, with the distinction that these symptoms are coupled by delayed gastric emptying on a four-hour radiolabeled food scan. Chronic nausea vomiting syndrome, could therefore, represent an early gastroparesis, or could be a result of slowed gastric emptying that doesn't meet standardized society cutoffs.¹¹

Disorders of gut-brain interaction, including IBS, rarely fit neatly into discrete categories in clinical practice. This is not just true for this group of disorders, but also for a whole host of contested diseases which do not hold wide-scale legitimacy among medical professionals. In a review and survey-based study aimed at understanding how physicians approach these diseases, Debra Swoboda notes that, "...when physicians are confronted with a set of symptoms that are unclear or mysterious, they attempt to arrive at an 'organized illness:'"¹² Despite the fact that knowledge in medicine is constantly evolving, use of reductive shorthands becomes entrenched with time:

Experienced physicians are more likely than novices to form provisional diagnostic hypotheses early in the medical encounter, relying on heuristics and tacit knowledge to do so. Despite these tenets, diagnostic reasoning usually focuses on pathophysiological mechanisms, and the primary concern is to affix disease causality. The more detectable and consistent the abnormality, the easier the disease is to diagnose. Clinical medicine is rarely an exact science, however, since many diseases lack an identified pathogenic mechanism. As a result, diagnosis of many diseases involves a substantial degree of uncertainty.¹²

Numerous cognitive biases exist in the practice of medicine. Yet one that is seldom explicitly stated is that if a disease is easily comprehensible, it is more satisfying to diagnose and treat. Another more explicitly stated bias is in favor of objective markers of disease. Such reliance on data and distaste for the abstract has likely always plagued those areas not conducive to traditional scientific study. A recent New Yorker article on the national decline of humanities majors comments on how this attitude has lately trickled down to the undergraduate level: “Today, a quantitative idea of rigor underlies even a lot of arguments about the humanities’ special value. Last school year, Spencer Glassman, a history major, argued in a column for the student paper that Harvard’s humanities ‘need to be more rigorous,’ because they set no standards comparable to the ‘tangible things that any student who completes Stat 110 or Physics 16 must know.’¹³

And while IBS has become more legible among medical professionals, there remains a paucity of data causally linking proposed pathophysiologic mechanisms with symptoms. As mentioned earlier, this is partly due to limitations in our diagnostic tools. The microbiome, in all of its complexity, is difficult to fully characterize, though we have started to try. Small-scale disruptions to the gut barrier may not be perceptible on histopathology slides. The neurohormonal connections between the brain and the gut are difficult to comprehensively chart.

Therefore, authority for the diagnosis of IBS is offered in the form of consensus criteria. And as Jutel notes, “Expert consensus panels commonly lead the discussions around disease classification, a transition to a ‘big science’ approach to classification, where experts are appointed by authoritative bodies, evaluate the evidence/condition, and make recommendations...Consensus is, of course, a social process, as is membership in

such panels. Like any other social process, it enables the promotion of some values and the extinction or backgrounding of others.”⁵ Classification involves power structures, particularly in contexts of evolving understanding.

Contemporary IBS guidelines advocate for a “positive diagnostic strategy,” one that strays from the idea that one must routinely exclude other, more life-limiting diseases in the process of identifying this syndrome.¹⁴ One argument for this approach is that patients may feel as though something is being missed if a large diagnostic workup is pursued prior to an IBS diagnosis. Another argument for this approach is that clinical consensus criteria for the diagnosis of IBS are accurate. It is likely also that this strategy rests in a rationale of healthcare cost containment. Regardless, I find that the current paradigm doesn’t always completely encapsulate the experiences of patients who seek care in the office.

When I evaluate patients in clinic with IBS, some of them come bearing a diagnosis from a prior physician, and some meet Rome IV criteria for the disease. I am nevertheless suspicious that the syndrome may be contributing to the symptoms of a large group of patients who do not meet explicit criteria. What leads me to wonder? In a disorder with no biochemical marker for disease, there is something about the way they describe their experience that catches my attention.

And while certain patterns may exist in the description of symptoms, there are also unique elements that lead me at times to consider whether a patient may have visceral hypersensitivity, a change in central nervous system processing, or some localized change in the gut that can’t be fully characterized. For example, a young patient who works in finance who started experiencing nausea only after immigrating to America

without any other symptoms. Or an older woman who describes a right-sided arm burning that only remits with bowel movements. Or, more recently, a patient with a negative endoscopic and manometric evaluation, who has simultaneous rectal urgency and vomiting when she eats fried foods, as she has learned through a detailed food diary. These are idiosyncratic details shared during visits; however, in the absence of other information, one can start to imagine proposed mechanisms that explain these symptoms that are shared with IBS. Saying that these patients have IBS, however, would also feel inaccurate and would miss something essential about each of their experiences too.

Our classification schemes therefore may not be as sophisticated as we need them to be. Carol Snyder, in an article exploring Foucault and directing graduate students to question the categories being offered to them as fact, states, “...classifications both reflect and direct our thinking. The way we order represents the way we think.”¹⁵ With this understanding in place, it is useful to question the cleanliness and accuracy of our disease categories and to contemplate other modes of understanding.

Narrative Ethics as a Tool for Capturing Nuance

One of the reasons I was drawn to gastroenterology was the fact that the patient’s history still seemed to matter. Although history factors heavily in any medical subspecialty, the stories of gastrointestinal illness are deeply personal and the symptoms deeply human. While I always gather a history, at times work in clinic can feel like a game of fitting a story’s details to a preexisting narrative scaffold rather than allowing it to take its own shape. Such a tension may reflect a distinction that Jutel makes between clinical practice, which is often about the individual, and the larger project of medicine,

which is focused on shared pathophysiology and epidemiology. However, narrative ethics may act as a bridge, pointing us to the ways that shared principles can emerge from individual stories.

Rita Charon, a pioneer in the field of narrative medicine, describes narrative ethics as a “subdiscipline of clinical bioethics that starts with the narrative accounts patients give of their lives and helps patients to envision and then choose among the alternative futures ahead.”¹⁶ She goes on to describe its emergence in the 1980s “as a means to perform a ‘ground-up’ ethics that would start with the situation of the singular patient and move toward fitting ways of thinking about a particular patient’s situation instead of trying to fit sanctioned theories or rules to the individual case.”¹⁶ Such an approach no doubt offers a paradigm shift for patients with IBS and other disorders of gut-brain interaction. Considering elements of a story that might allow a physician to identify gut-brain dysregulation even if patients do not fit clinical criteria would likely offer more flexibility in addressing and treating patient concerns. This is particularly helpful as many interventions for these disorders are relatively low-risk, such as the introduction of soluble fiber or biofeedback. While some physicians will offer these treatments off-hand, understanding that the patient’s story can itself point to potential pathophysiologic processes that cannot currently be identified via biochemical testing lends legitimacy and rigor to a field and patients that are, at times, not taken seriously.

If stories become paramount, it becomes important to examine their formulations and structures in greater detail. Charon reminds us that stories carry a vantage point: “Narrative ethics as we understand it in narrative medicine reminds writers and readers that narratives of any kind by necessity privilege certain perspectives and positions, that

marginalized voices are often silenced, and that commitments to equality require ‘equal access’ to the author/teller position.”¹⁶ In addition to thinking about who is telling the story, it is important to consider how stories themselves are limited by prior experience and how they, in turn, limit future considerations.

CHAPTER 3: INTERROGATING NARRATIVES

The very worlds of sense and experience are configured uniquely by each perceiver, for consciousness itself is shaped by narratives we have heard. Thought, fantasy, belief, emotion, attachment, and ultimately action are *in their making* shaped by the stories that have framed each person's individual consciousness. Hence, what we call experience is not a pure blank reality. It rests in some way on prior perceptions, on anecdotes and imagined subsequents. This is not to suggest that there is no innovation, for the imagination *creates* the new and the never-seen, yet always from a perceptual foundation inflected by one's individual private experience.¹⁶

As Rita Charon beautifully articulates in this quote, individual experience is indelibly colored by the stories we tell ourselves. Similarly, the illness experience is one that is very much shaped by the context from which a disease emerges. For patients, many variables including biologic, psychologic, and social affect a disease course. Context also affects physicians treating those biomedical diseases, which contributes to the way patients experience disease in a feedback loop of sorts. These interactions, while present in all medical spaces, may have an outsized role in disorders of gut-brain interaction like IBS, which evolve out of a particularly rich biopsychosocial milieu.

The Stories We Tell About Our Gut May Shape Our Symptoms

No disease is without a social element and illness, our own or others', affects the way we move through life. Both of my grandfathers are dead. My father's father died in India, when performing the last rites for his sister-in-law in the Ganges. It was cold that morning, I am told, and he had a heart attack. His South Asian genes, his presence in a river at 6 am, and his lack of access to an ambulance that could transport him – through Hardiwar traffic – to a capable hospital within a 90-minute window are inextricably

linked to his death. This experience has, for me, changed the mythology around a river that is widely-held as holy. It has also instilled a deep fear; whenever my father travels outside of America, I lay awake imagining his own coronaries covered in plaque, able to rupture at any moment.

My mother's father, prior to his own death, had most of his right lung removed due to an infiltrating infection from undiagnosed tuberculosis. Even at his old age, he was fit, with shadows of muscles from lugging fuel cannisters onto his motorcycle in Delhi, traveling throughout the country for his business. Yet, he still had significant post-operative shortness of breath, handicapped from an infection that unfortunately still plagues the subcontinent he came from.

While sickness frequently carries metaphorical weight, and while these stories leave their mark on individuals, meditating on these narratives doesn't necessarily precipitate a worsening of an underlying condition. Envisioning what plaques may already have taken hold in my father's vessels doesn't hasten their development. Likewise, though I have frequently imagined inhaling spores of mycobacterium when behind a coughing auto driver in India, such thinking has not produced an infection in me.

But for disorders of gut-brain interaction, the mind plays a role in the perception and perhaps the propagation of symptoms. It should be clear that data remain sparse in this area, and that contemporary excitement about links between the enteric nervous system, the central nervous system, and the gut microbiome outpaces conclusive evidence.^{17,18} Nevertheless, dysbiosis and alterations in central nervous system processing are thought to play a key role in the existence of disorders of gut-brain interaction. Furthermore, the paradigm by which we currently understand these disorders, including IBS, makes it

impossible to separate the disease from the social or psychological domains that all work in concert with individual gut physiology to produce symptoms.¹⁹ The coexistence of mental health disorders with IBS is well-established, though gut symptoms are not thought to be a direct consequence of comorbid anxiety or depression.²⁰ Managing stress and compounding mental health disorders, however, is an important therapeutic target for this patient population.

With the brain involved somehow in the pathophysiology of IBS and with the body placed along an axis in continuity with cognition, several new considerations emerge. Grace Lucas, a scholar with interests in embodied methodologies, points out that as our mental conception of the lines between mind and body continue to blur, our research likely requires more sophisticated approaches. She writes,

In healthcare, unreliable bodies have awaited interpretation by the superior, objective, rational mind endorsed by a positivist biomedical epistemology. Subjective and experiential evidence is usually downgraded versus the objective and empirical in terms of medicine's evidence hierarchies. Healthcare's bodies do not know, they are to be known. Objectivity is understood to relate to reason and logic, but if the gut is an organ of the mind and the body is involved in thinking, what does this mean for this hierarchy and privileging of mind over body? How might subjective and individual bodies offer insights into minds and guts...If the gut is thinking, it also demands a methodological response from humanities disciplines.²¹

Although such wording ascribes agency to the body, it is productive to consider how such explicit linkages between the brain and gut relate to symptoms. Our mental state can have a profound effect on gastrointestinal symptoms, rather than just our symptoms producing a change in our mental state. This shifts a dynamic in medicine. For example, it is well-known that certain diagnoses like cancer can lead to depression via numerous avenues. But depression itself isn't linked to the development of cancer. And while somatization has been understood for some time, the bidirectionality of the

communication between the brain and the gut in terms of *mechanistic* development of symptoms distinguishes disorders like IBS from other diseases in medicine.

With our minds factoring so heavily in IBS, the narratives that exist within them – about our symptoms or about how we understand ourselves – take on greater importance. Stories, as Arthur Frank states, give life to the bodies that tell them: “Bodies are realized – not just represented but created – in the stories they tell. This realization can and should be reflexive: by telling certain stories, ethical choices are made; the choices in turn generate stories. Common sense understands people as having some responsibility for their stories and for their bodies. Common sense is less accustomed to the possibility of exercising that responsibility for bodies *through* stories.”²² This idea, I think, carries even more weight when thinking about the brain being enfolded into symptom development. Telling certain stories may have even more tangible effects on disease progression, illness experience, and symptom severity in the context of IBS.

How a patient understands who they are in relation to the health system – everything from whether they pose a diagnostic or clinical “challenge,” to whether their symptoms are unusual or common – can, in turn, shape their illness experience. Such understanding undoubtedly affects clinical trust, and engagement with these stories affects therapeutic outcomes. Placebo effects, defined as improved well-being from “identifiable health care paraphernalia and settings, emotional and cognitive engagement with clinicians, empathetic and intimate witnessing, and the laying on of hands”²³ has been shown to play a large role in IBS patients.²⁴ The word placebo suggests inertness, yet IBS patients show symptomatic improvement even in open-labeled placebo trials,²⁵ suggesting durable potency even when patients know what version of therapy they are

receiving. It is perhaps not such a surprise when thinking about the power of stories in these patients, that efforts to bear witness offer valid therapeutic strategies.

Placebos are traditionally used as a control for “real” therapeutic trials in medicine, offered as a baseline for traditional pharmacologic or procedural therapy. Placebo response can be confusing for physicians grounded in basic understandings of disease. Social interventions may be seen as less valid, and the patients that respond to them may be seen as less sick. Lay narratives about IBS, even when well-intentioned, affect the way physicians interact with patients and limit therapeutic considerations.

The Stories Doctors Tell Shape Patient Experience

To take Rita Charon’s quote further, knowledge in medicine and science is, by nature, limited by prior understandings. The answers that research yields depends on the questions asked. The questions asked are often based on observations, and data grow slowly through this iterative process. Science does not exist in a vacuum, and social context shapes the way we frame observations. One does not need to look far back through history to know that medicine has frequently worked from false and dangerous premises.

Beyond research in clinical practice, diagnostic medicine frequently relies on heuristics. In many ways, such shorthands are unavoidable in a field that requires individual people to synthesize large amounts of data in a repetitive fashion. However, the linkage of certain types of diseases to certain types of people, without context for how identity stands as a proxy for more accurate risk markers, can create inaccurate and troubling biases.²⁶ Such biases can have far-ranging effects, altering a perceived

predictive value for disease and narrowing the scope of legitimacy within patient populations.

As Arthur Frank states, all of us have self-stories, and “the self-story is told both to others and to one’s self; each telling is enfolded within the other. The act of telling is a dual reaffirmation. Relationships with others are reaffirmed, and the self is reaffirmed. Serious illness requires both reaffirmations...”²² When physicians are unable to fully affirm a patient’s story due to their own biases, this has its own ricochet effect on that original story. Within the context of IBS, the increased prevalence of the disorder within Western communities, the frequency of comorbid mental health disorders with the diagnosis, and the nature of the symptoms being non-life-limiting, have contributed to lay understandings about who has the disease. The stereotype I learned informally through medical training about IBS patients is that they tend to be young, white, female, and anxious. Such mental images limit fuller understandings of illness and shed no further light on the true mechanistic underpinnings of the syndrome. Furthermore, research regarding minority IBS patient populations remains sparse. One wonders what patients and diagnoses may be missed due to cognitive biases and, more importantly, how these narratives ultimately shape patient experience.

While both patient and physician stories are important to IBS care, it is worth recalling the inherent narrative power in these dynamics. There is one story that permeates the medical record and ultimately dictates available treatments. While there has been a shift in the last two decades toward patient-centered models of care, disorders like IBS that are firmly based in lived experience may require even more amplification of patients’ voices.

CHAPTER 4: MEDICAL HEURISTICS AND DISPARITIES IN IBS CARE

Given active biases about who IBS patients are, and with the disease emerging within a rich biopsychosocial context, disparities may feature especially prominently in the care of IBS patients. Yet, there is scant research actually demonstrating larger structural disparities in disorders of gut-brain interaction (perhaps because of falsely held preconceptions about who develops symptoms). To clarify how perceptions of illness may shape actual outcomes, my colleagues and I performed a retrospective study among patients who received outpatient care at Temple Gastroenterology. Table 1 presents key takeaways.

Table 1. Key Takeaways.

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| <ul style="list-style-type: none">• There is a paucity of data regarding disparities in IBS care• Our data demonstrates that minority patients with IBS undergo more procedures than white patients with IBS• More procedures counterintuitively do not reflect higher quality care• Disparities in IBS is even more important to understand given that social experience is an important component of disease development and symptom severity |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

Racial disparities in healthcare are broad-ranging and well documented across fields. The precise reasons for the differences observed are often unclear, with some combination of social, economic, and systemic issues usually cited.²⁷ One recent (and singular) study showed that minority IBS patients may undergo more diagnostic procedures than their white counterparts in this disorder that is primarily symptom-based.²⁸ Such reliance on testing for a disorder whose diagnosis is made primarily by symptoms may suggest a relative lack of communication between patient and provider.

To better assess disparities in IBS care and to clarify potential reasons for differences in care, outpatient records from the Temple Gastroenterology practice were reviewed retrospectively, with IRB approval. Patients with an ICD-9 or ICD-10 code of IBS on at least two clinical encounters from January 2011 to December 2021 were included. Variables of interest, including race and primary language, were collected, and ANOVA and t-testing were performed to compare groups.

A total of 602 patients (85% female, mean age 56) were included in our study. Three hundred and fifty-five patients identified as White (59%), 128 as Black (21%), and 119 as Hispanic (20%). One third of Hispanic patients were Spanish-speaking, comprising 7% of all patients. Minority IBS patients had more office visits, colonoscopies, endoscopies (EGDs), and abdominal CTs than White IBS patients (Table 1, all $p < 0.05$). When taking into account breath testing, anal and esophageal manometry, and gastric emptying scans, there was no significant difference between groups in total number of procedures.

Race N (%)	Sex N (%)	Age Mean (SD)	IBS Subtype N (%)	Language Spoken N (%)	Number of Office Visits Mean (SD)	Number of Colonoscopies Mean (SD)	Number of Endoscopies Mean (SD)	Number of Abdominal CTs Mean (SD)	Total Number of Procedures Mean (SD)
White 355 (59%)	Female 286 (80.6%)	55.3 (17.6)	IBS-C 117 (33%) IBS-D 149 (42%) IBS-Mixed 9 (2.5%)	English 350 (98.6%)	8.30 (7.80)	.75 (0.97)	1.24 (1.85)	.55 (1.48)	3.63 (3.39)
	Male 69 (19.4%)			Spanish 4 (1.1%)					
Black 128 (21%)	Female 120 (93.8%)	58.2 (15.0)	IBS-C 57 (44.5%) IBS-D 51 (39.8%) IBS-Mixed 20 (15.6%)	English 128 (100%)	9.71 (7.17)	1.43 (1.2)	1.23 (1.27)	1.87 (2.47)	3.85 (2.83)
	Male 8 (6.3%)			Spanish 0 (0%)					
Hispanic 119 (20%)	Female 103 (86.6%)	54.9 (14.3)	IBS-C 55 (46.2%) IBS-D 41 (34.5%) IBS-Mixed 23 (19.3%)	English 79 (66.4%)	9.96 (6.86)	1.34 (0.95)	1.57 (1.44)	3.14 (5.33)	3.85 (2.78)
	Male 16 (13.4%)			Spanish 40 (33.6%)					
					p=0.029	p<0.001	p=0.002	p<0.001	p=0.252

Table 2. Demographics and Care Utilization of IBS patients. ANOVA-testing was performed to compare identity groups, yielding statistical significance for all categories except for total number of procedures (which included, in addition to colonoscopies and endoscopies, flexible sigmoidoscopies, breath testing, anal and esophageal manometry, and gastric emptying scans).

In analysis by primary language, Spanish-speaking patients had similarly increased numbers of office visits, procedures, and imaging (Figure 1, all $p < 0.05$). A majority of EGDs and colonoscopies (more than 68% of patients' first procedures and more than 95% of patients' last procedures) were performed due to reasons other than traditional IBS symptoms (e.g. abdominal pain, nausea, vomiting, and change in bowel habits).

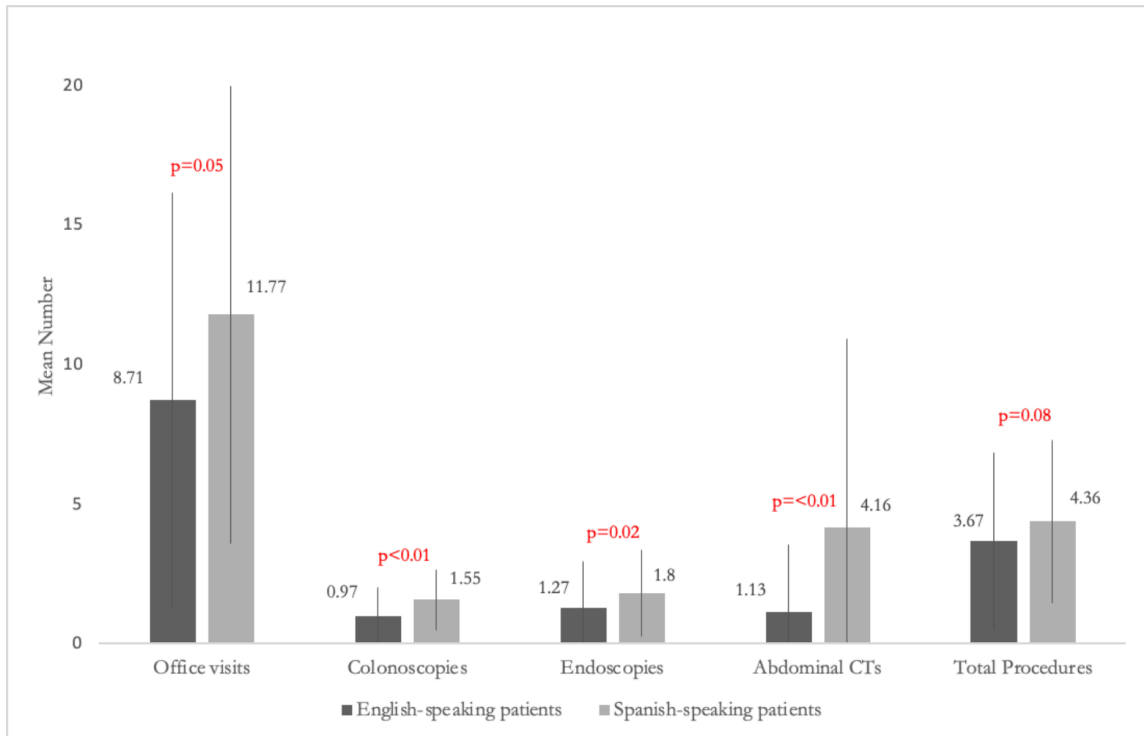


Figure 1. Care Utilization of English-Speaking IBS patients Compared to Spanish-Speaking IBS Patients. T-testing was performed between groups, yielding statistical significance for all categories except for total number of procedures (which included, in addition to colonoscopies and endoscopies, flexible sigmoidoscopies, breath testing, anal and esophageal manometry, and gastric emptying scans).

Health disparities research has vastly expanded in the last two decades, with an awareness of structural racism now factoring into national guidelines for disease treatment and prevention, and time has brought more nuanced approaches to this field of study. Recognizing that there is a lack of accompanying socioeconomic data in our study

and an inability to be more granular in our racial identification categories, highlighting the disparities data nevertheless remains important.

Although the absolute differences are modest, they are statistically significant. Somewhat counterintuitively, minority IBS patients seem to be undergoing more gastroenterology-related procedures, including colonoscopies, than white IBS patients. This is surprising when thinking broadly about intervention-based care in the US, which minority patients seem to receive less of overall, including cardiac catheterizations, surgeries, mammographies and cervical cancer screenings, as examples.^{29,30}

IBS is a clinical diagnosis that does not require the assistance of procedural evaluation. In this context, then, a colonoscopy may not reflect higher quality care. A reliance on testing may indicate uncertainty on the part of either patients or providers within the paradigm of clinical diagnosis, hinting at the possibility of impaired clinical communication. Our study seems to support this possibility given that Spanish-speaking patients received more testing than English-speaking patients. Prior literature also supports this explanation. At a very basic level, language concordance between patient and provider has demonstrated improvement in quality of care.³¹ Even with language concordance, however, studies suggest that communication between minority patients and physicians has the potential to be fraught with misunderstanding and mistrust,³² which may, in turn, lead to deviations from established clinical algorithms.

Racial categories are less likely to reflect genetic differences in diseases than they are to approximate environmental, social, and cultural contributions to disease. This is all the more important in IBS, in which the environmental, social, and cultural milieu from which the syndromes emerge are also thought to play a mechanistic role. Simultaneously,

existing cultures of care make it difficult to account for these variables, and hegemonic biomedical narratives have historically excluded minority experiences. This is most commonly understood in the context of implicit bias.

Just as studies have demonstrated that problematic beliefs about biological difference may significantly affect care as basic as opiate prescribing practices among physicians,³³ one wonders what lay cultural narratives exist about IBS patients and how those narratives might vary by race. Heuristics are often invoked in the practice of clinical medicine, and it is possible that minority patients may prompt additional diagnostic testing by virtue of deviating from preconceived patterns.

Identity-based inquiry, particularly involving culture and felt experiences, may not lend itself well to traditional quantitative approaches. Even if identity categorizations could be standardized, heterogeneity will always exist regarding the larger social context of illness. The literary critic Nina Baym, who studied the patriarchal limits to the English canon, once noted: “That a field to some degree is always constituted by the questions we ask of it, that the status of the objective is problematical, does not cancel this obligation so much as make it a more difficult and subtle one to satisfy.”³⁴

CHAPTER 5: CONCLUSION

Caring for IBS patients demands that one contend with larger questions. What constitutes illness? How do the stories patients and physicians tell change symptom and treatment experience? In what ways are we biased? And how does that change outcomes for patients? IBS is a disorder that requires more complex consideration than some other diseases. Exactly how the biologic, the psychologic, and the social shape symptoms remains somewhat ambiguous to providers and patients alike. Grappling with this ambiguity will likely require more sophistication. Multidisciplinary approaches, including invoking narrative ethics, celebrating story, recognizing bias, and continuing quantitative inquiry, can help hold nuance in service of more comprehensive and sensitive patient care.

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