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## **“The Gastrointestinal Woman,” Diagnosis, and Practices of Silencing**

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### **Abstract:**

Amy Vidali describes the figure of “the gastrointestinal woman,” characterized as “overly-anxious” and burdening others, which often frames the perception of people with IBS. I connect it to Kristie Dotson’s account of testimonial silencing and testimonial smothering in hope that recognizing the figure can help in challenging its effects.

### **Paper:**

Irritable Bowel Syndrome (IBS) is commonly understood as a condition that causes abdominal pain or discomfort, bloating, gas, cramping, and, depending on the subtype, diarrhea, constipation, or some mixture of both. It is also generally found to be more common in women than in men.<sup>1</sup> It is a functional disorder, which means that there are no definitive biomarkers that will show up on medical tests, such as colonoscopies. This particular mix – a functional disorder which is believed to be primarily experienced by women and which is associated with aspects of our embodied life that are generally taboo – is a perfect storm of possibility for stigma and stereotype.

In a 2013 article, Amy Vidali (who has IBS) coins the term “the gastrointestinal woman” to describe a figure or stereotype that emerges in both 19<sup>th</sup> century and contemporary medical writing on gut disorders who is “consistently characterized as overly-anxious, responsible for her own care (or overburdening others), and excluded from the medical conversations about what is best for

her.”<sup>2</sup> I argue that recognition of the existence of this particular stereotype or figure of the gastrointestinal woman can contribute to the growing literature on epistemic injustice in health care.<sup>3</sup> In this paper, I explore one aspect of this by drawing on Kristie Dotson’s work on epistemic violence through testimonial silencing and testimonial smothering.

The characterization of the gastrointestinal woman as “overly-anxious” is connected to an overemphasis on psychological factors in IBS, which risks glossing over the fact that IBS is not a monolith, but an umbrella concept that can include a range of different causes for similar symptoms.<sup>4</sup> Failing to notice and unpack the presence of the figure of *the gastrointestinal woman* in our thinking risks allowing us to believe that we already know what is going on with IBS, whether we are patients, health care professionals, employers, instructors, family members, or friends. By naming it, we can better raise the question of whether it is the figure of the gastrointestinal woman that is shaping our thinking and reactions in a given case such that we are not listening to what people are saying. This paper will be primarily focused on health care settings, but much of it can be extended to interactions with employers, instructors/professors, friends, and family.

### IBS, stigma, and diagnosis

IBS is described as a functional gastrointestinal disorder (FGID), meaning that while it affects normal bodily processes, there are no specific biomarkers for it and it cannot be definitively established from a diagnostic test. Diagnosis is given based on a cluster of symptoms, usually after having ruled out other conditions.<sup>5</sup> Recently the Rome Foundation, a non-profit organization which has developed several versions of the IBS diagnostic criteria, has determined that “the term functional GI disorders, although entrenched in the literature, was imprecise and to some degree stigmatizing.”<sup>6</sup> The Rome Foundation has thus shifted their language from FGIDs to Disorders of

Gut-Brain Interaction, DGBIs, to reflect concern around this stigma as well as developments in research around the brain-gut axis.

The Rome Foundation's concerns around stigma are borne out in some of the experiences of people with IBS. There has been speculation about whether there is greater stigma for functional disorders generally than for similar conditions with a clearer medical pathology. While one study found that perceived stigma was similar in both IBS and IBD (inflammatory bowel disease, a term that encompasses Crohn's disease and ulcerative colitis),<sup>7</sup> more recent studies of perceived and enacted stigma tend to show greater stigma for IBS.<sup>8</sup>

In addition to being a functional disorder, it may also likely more accurately described as an umbrella term rather than being a single thing. Benjamin Brown argues that the various symptoms associated with IBS are better and more effectively explored and targeted on their own, suggesting that IBS "could be considered a set of symptoms that require further investigation and not a disease per se."<sup>9</sup> If this is correct, then paying attention to the specific testimony and experiences of people with IBS is crucial in order to determine which of several underlying causes might warrant targeted therapy. Regardless, given that diagnosis is entirely based on symptoms, the uncertain nature of IBS points to the importance of paying careful attention to the particulars of patient testimony.

And yet, the responses from health care professionals often do not reflect this need, but rather general perceptions of what "IBS patients" are like in general may come into play. This may occur despite good intentions -- as Carel and Kidd note, the structure, routinization of tasks and time pressures involved in health care are often barriers for adequate and effective communication between patients and health care practitioners.<sup>10</sup> A study conducted by Dixon-Woods and Critchley of twelve doctors and twelve patients in the UK concerning their views on IBS found that while "it would be wrong to characterize doctors as being universally hostile toward IBS patients," that IBS was "a source of frustration for many doctors... fuelled as much by the absence of effective

treatments and poor medical understanding of the condition as by the perceived personality characteristics of IBS patients.”<sup>11</sup>

They note that given the unsettled nature of IBS research, “while most doctors were able to produce a textbook-type list of symptoms that defined IBS, they also drew on other resources, including experiential knowledge and absorbed prejudices, in their private ‘definitions’ of the condition.”<sup>12</sup> Dixon-Woods and Critchley note the importance of recognizing and acknowledging these private views, which “formed the basis for the ‘rules of engagement’ given their relationship with IBS patients” and “may be far more influential in determining doctors’ behaviour than publicly acceptable views.”<sup>13</sup> In an editorial, Lars Agréus, professor of family medicine, notes that the clinical definitions (such as the Rome definitions) are too complicated for “the busy clinical workday,” and so “clinical impression”, experience, and “‘unstructured’ knowledge” must be used.<sup>14</sup> This context means that it is important that we understand underlying and underacknowledged stereotypes that affect perceptions of people with IBS symptoms, so that we can better recognize when they are at play.

### The Gastrointestinal Woman

Amy Vidali’s 2013 article, “Hysterical Again: The Gastrointestinal Woman in Medical Discourse” tracks the assumptions made about women with chronic constipation and Irritable Bowel Syndrome (IBS) in nineteenth and twenty-first century medical texts. In close readings of these texts, she finds “a ‘gastrointestinal woman’ who inhabits medical discourses of GI disorder and distress, and she is characterized as having unjustified anxiety and is to blame for her condition.”<sup>15</sup> This figure persists across more than a century, despite changing scientific understandings. Contemporary articles “typically position women with GI disorder and distress as having real medical concerns,” and yet “the gastrointestinal woman persists in the form of an anxious, stressed, or worried patient who is

subjected to various impersonalized assessments and takes up too much of her doctors' time."<sup>16</sup>

One of her examples is a 2005 study on the role of worry for IBS. Here, while the authors' results show that "in general, our population was not a clinically anxious group," they persist in their suggestion that "worry could significantly predict GI symptoms."<sup>17</sup> As Vidali summarizes, "The symptoms of the gastrointestinal woman simply must be caused, or exacerbated by, worry or anxiety, even if study evidence says otherwise."<sup>18</sup>

Vidali's point is not to deny that there may be psychological factors. As she writes, discussing the genesis of her article:

the medical establishment is often interested in why I am in pain; however, when a clear cause cannot be found—as is the case with functional disorders like IBS—medical professionals either ignore my body or deduce a typically psychological cause which may or may not be true, and often, is left untreated anyway.<sup>19</sup>

Additional examples bearing out Vidali's observations of the presence of the gastrointestinal woman can be easily be found. For example, in an article for the *American Journal of Nursing*, Heitkemper and Jarrett write that "studies have shown that women with IBS tend to have a higher incidence of psychological distress."<sup>20</sup> The citation given for this leads to a 1990 article by Corney and Stanton. Their study had 42 participants; 11 male and 31 female. While they asserted that "More women than men were considered to be suffering from an [psychiatric] illness of moderate or marked intensity," the confidence intervals showed substantial overlap between the two.<sup>21</sup> This makes sense, given the small number of participants in the sample, but means that the conclusion reported by Heitkemper and Jarrett cannot be established – and yet, it appears as a fact in their article that can then be repeated and continue to feed into the perception of the gastrointestinal woman.

Meanwhile, there are also examples of asserting something special about women's experience of IBS which is obvious and can remain unarticulated. In describing the profile of the

patients they surveyed, Dixon-Woods and Critchley write, “Because of a strong theoretical prior belief about the significance of being female and having IBS, all patients interviewed were women.” This “strong theoretical prior belief” is not discussed, and there is no citation to further discussion.

Another example of this is found in the description of a specific therapeutic group for women at Johns Hopkins Integrative Medicine and Digestive Center. After noting that IBS is “one of the most common gastrointestinal complaints,” they note that:

Research suggests that it manifests in women 2-3 times more frequently than in men. In recognition of the unique emotional and medical challenges that women with IBS must face, JHIMDC is offering a complement to regular medical care for IBS: Cognitive Behavioral Therapy (CBT) Group for Women with IBS.<sup>22</sup>

It is unclear what is “unique” about the emotional and medical challenges that women face with IBS, other than it merely being more common. After all, men also experience stigma and anxiety related to IBS, and, in fact, the gendering of the gastrointestinal *woman* stereotype may be a barrier to them.<sup>23</sup> The “unique emotional and medical challenges” are not spelled out here, but are asserted in a way that assumes the reader already understands what they might be. While there is a significant literature on the ways in which women’s health is often overlooked in research and clinical settings, this does not seem to be what JHIMDC is pointing to; rather the wording seems to suggest something distinctive to women’s experience of the condition itself, best addressed through therapy.

These linkages serve to associate women’s experiences with IBS with anxiety (perhaps even a tinge of hysteria), as well as making it harder to get at the particularity of patients’ experiences. A Swedish qualitative study found “gender bias in healthcare encounters, where women risk being trivialized and men risk being overlooked due to the ‘woman’s health concern’ label attached to IBS.”<sup>24</sup> To further explore some of the harms that are caused by the figure of “the gastrointestinal woman,” we can draw on Kristie Dotson’s account of silencing.

### Silencing “the Gastrointestinal Woman”

The figure of the gastrointestinal woman seems to contribute to expectations of IBS. While people with IBS may not generally be seen to be an oppressed group, the stigma around the condition and the stereotype of the gastrointestinal woman lead to harmful effects. As mentioned above, treating targeted symptoms seems to be more efficacious. The gastrointestinal woman draws us away from that specificity and toward more generalized explanations of anxiety, stress, and so forth.

Kristie Dotson describes two forms of practices of silencing – testimonial quieting and testimonial smothering – that can occur when the existence of stereotypes around a given objectified social group contribute to an audience’s pernicious ignorance (ignorance which is consistent and which harms another person). Testimonial quieting occurs when someone is undervalued as a knower due to stereotypes about the group of which they are a member.<sup>25</sup> The audience fails to give to speaker uptake – in other words, fails to take them seriously.

We can see this in the case of IBS. Dixon-Woods and Critchley talked to both doctors and patients in the UK as part of a qualitative study, and comment that many patients “perceived themselves as a very stigmatized group who were discredited in the eyes of the medical profession.”<sup>26</sup> They quote one patient: “He actually said ‘there’s nothing wrong, go away, it’s all in the mind dear.’”<sup>27</sup> Meanwhile, while many doctors reported genuinely wanting to help their patients, they did report frustration, and distinguished between ‘good’ and ‘bad’ patients depending on whether they easily accepted their doctors’ explanations or continued to seek more.<sup>28</sup> Given what Brown has pointed out about the usefulness of therapies targeted to specific symptoms, what the ‘bad’ patients here are asking for is more likely to help them, and yet given doctors’ “informal private theories” about IBS, they are often not taken seriously.<sup>29</sup> As Dixon-Woods and Critchley summarize, they have “transgressed the implicit rules laid down by doctors” and “continuing to

complain of severe and troublesome symptoms meant that they unwittingly placed themselves at a disadvantage. Their behaviour resulted in them being labelled as neurotic.”<sup>30</sup>

A study in Sweden found a similar result:

A common experience is to be told that the symptoms are caused by nervousness or depression. The more symptoms the women presented to their physicians, the easier it was to be dismissed as ‘whiny’ and neurotic. The women reported painful encounters, which led them to doubt their own experiences and they began to think that they were imagining their symptoms or that they were going crazy.<sup>31</sup>

We can see the gastrointestinal woman at work. While scholarship on epistemic injustice in health care reveals that patients in general often lack epistemic credibility in the health care setting,<sup>32</sup> the prevalence of the “gastrointestinal woman” stereotype specifically means that health care practitioners might already be predisposed to conclude that their symptoms are “all in the mind”<sup>33</sup> rather than pursuing targeted investigation of specific symptoms. The lack of specific biomarkers for IBS (the fact that it is a functional disorder) can also contribute to the risk of disbelief or insufficient uptake.<sup>34</sup>

The effects of the gastrointestinal woman figure can also be seen in Dotson’s discussion of testimonial smothering. Here, the speaker discerns that, based on qualities demonstrated by the audience, that it is too risky for them to share their testimony. Dotson describes three circumstances at play here:

1) the content of the testimony must be unsafe and risky; 2) the audience must demonstrate testimonial incompetence with respect to the content of the testimony to the speaker; and 3) testimonial incompetence must follow from, or appear to follow from, pernicious ignorance.<sup>35</sup>

Because of this, the speaker “smothers” their testimony in a kind of “coerced silencing.”<sup>36</sup> In the situation of people with IBS, particularly women, the audience’s testimonial incompetence in a health care setting is not so much likely to be ignorance of official clinical characteristics of IBS, as misapprehension of IBS shaped by the psychological qualities of the gastrointestinal woman stereotype. If, as a result of this, health care practitioners, deliberately or inadvertently, signal the belief that it is “all in their head,” or even *primarily* in their head, they demonstrate an unlikeliness to take particular symptoms seriously as candidates for targeted therapeutic treatments.

The testimonial smothering may also extend not only to encounters with health care practitioners but also employers, friends, and family. The sense that someone is going to respond badly to disclosure of IBS symptoms or accommodation needs may cause people to avoid the topic. As Houghton et al observe, the social expectations on women to not express their needs can lead them to “the silencing of certain thoughts, feelings, and behaviors rather than jeopardize relationships that are in place,” which has clinical implications, particularly combined with negative attitudes to IBS patients.<sup>37</sup>

Recognizing the effects of the gastrointestinal woman stereotype can help to identify those instances where someone with IBS is unable to be taken seriously with regard to their condition; where because of long-standing associations with anxiety they are treated as someone to be placated and told to work on their feelings rather than attend to their symptoms. Pursuing this work does not mean denying the usefulness of therapy where it is appropriate, or pursuing connections to psychological symptoms where warranted; it does mean, however, listening carefully to the specific experiences of the patient and taking their testimony seriously. As Vidali writes,

Understanding how medical discourse represents us is the first step toward refashioning the gastrointestinal woman into a figure who is empowered regarding her disorder, situates the psychological dimensions of her condition in the ways

that make sense to her, and narrates her own experience of pain, treatment, and identity.<sup>38</sup>

The figure of “the gastrointestinal woman” affects the quality of the healthcare received by patients with IBS. Challenging and dislodging this figure can help us to pay more attention to the situations and needs of individuals with IBS and related conditions, without lumping them into the same set of assumptions. This task is not just a matter of improved gastroenterological or neurogastroenterological research, but of considering the kinds of work we expect diagnosis to do, and the ways in which we take people’s own testimony about their bodies seriously.

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<sup>1</sup> The usual figure given is that IBS is 2-3 times more common in women. This number will vary depending on the population surveyed, such as whether it is a survey of the general population or IBS patients specifically; see Young Sun Kim and Nayoung Kim, “Sex-Gender Differences in Irritable Bowel Syndrome,” *Journal of Neurogastroenterology and Motility*, 24 no. 4 (October 2018), 545-6. It is unclear how much of the detected gender difference represents an actual difference in incidence vs. a difference in who is more likely to seek care, or a combination of these and other factors. The claim is sometimes made that the ratio of men and women with IBS is close to equal in India and Japan. At least in the case of Nigeria, that claim seems to be based on one study, with a more recent study reflecting the more common worldwide ratio; see Nwokediuko et al, “Irritable Bowel Syndrome in Nigeria: Disparity Between the North and the South,” *Nigerian Journal of Gastroenterology and Hepatology* 11 no. 1 (June 2019), 12. There is very little research on IBS and trans people, but the research that does exist suggests that trans women likely have higher levels of IBS symptoms than trans men; see Agata Mulak, “Sex hormones in the modulation of irritable bowel syndrome,” *World Journal of Gastroenterology* 20 no. 10 (March 2014): 2437.

<sup>2</sup> Amy Vidali, “Hysterical Again: The Gastrointestinal Woman in Medical Discourse,” *Journal of Medical Humanities* vol. 34 (2013): 54.

<sup>3</sup> See Ian James Kidd, “Epistemic Injustice, Healthcare, and Illness: A Bibliography,” at <https://ianjameskidd.weebly.com/epistemic-injustice-healthcare-and-illness-a-bibliography.html>

<sup>4</sup> Benjamin I. Brown, “Does Irritable Bowel Syndrome Exist? Identifiable and Treatable Causes of Associated Symptoms Suggest It May Not,” *Gastrointestinal Disorders* 1 (2019): 314-340.

<sup>5</sup> International Foundation for Gastrointestinal Disorders (IFFGD), “Testing in IBS,” <https://aboutibs.org/testing-in-ibs.html> (last updated March 29, 2020).

<sup>6</sup> Douglas A. Drossman, “Functional Gastrointestinal Disorders: History, Pathophysiology, Clinical Features, and Rome IV,” *Gastroenterology* vol. 150 (2016): 1267.

<sup>7</sup> Karl J. Looper and Laurence J. Kirmayer, “Perceived stigma in functional somatic syndromes and comparable medical conditions,” *Journal of Psychosomatic Research* 57 (2004): 373-378.

<sup>8</sup> Mark Hearn, Peter J. Whorwell and Dipesh H. Vasant, “Stigma and Irritable Bowel Syndrome: a Taboo Subject?” *Lancet Gastroenterology and Hepatology* 5 (2020): 607-615. See especially Tiffany H. Taft et al, “Perceptions of illness stigma in patients with inflammatory bowel disease and irritable bowel syndrome,” *Quality of Life Research* 20 (2011): 1391-99 and Taft et al, “Stigmatization toward irritable bowel syndrome and inflammatory bowel disease in an online cohort,” *Neurogastroenterology and Motility* 29 (2017): e12921, <https://doi.org/10.1111/nmo.12921>

<sup>9</sup> Benjamin I. Brown, “Does Irritable Bowel Syndrome Exist? Identifiable and Treatable Causes of Associated Symptoms Suggest It May Not,” *Gastrointestinal Disorders* 1 (2019): 314-324.

<sup>10</sup> Ian James Kidd and Havi Carel, “Epistemic Injustice and Illness,” *Journal of Applied Philosophy* 34 no. 2 (2017), 178.

<sup>11</sup> Mary Dixon-Woods and Sophie Critchley, “Medical and lay views of irritable bowel syndrome,” *Family Practice* 17, no. 2 (2000): 112.

<sup>12</sup> Dixon-Woods and Critchley, “Medical and lay views,” 112.

<sup>13</sup> Dixon-Woods and Critchley, “Medical and lay views,” 112.

<sup>14</sup> Lars Agréus, “Rome? Manning? Who Cares?” *American Journal of Gastroenterology*, 95 no. 10 (2000): 2680.

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- <sup>15</sup> Vidali, “Hysterical Again,” 34.
- <sup>16</sup> Vidali, “Hysterical Again,” 34.
- <sup>17</sup> Keefer et al, “Towards a Better Understanding of Anxiety in Irritable Bowel Syndrome: A Preliminary Look at Worry and Intolerance of Uncertainty,” *Journal of Cognitive Psychotherapy* 19 no. 2 (2005), 166 and 168; cited in Vidali, “Hysterical Again,” 50.
- <sup>18</sup> Vidali, “Hysterical Again,” 50.
- <sup>19</sup> Vidali, “Hysterical Again,” 35.
- <sup>20</sup> Margaret Heitkamper and Monica Jarrett, “ ‘It’s Not All In Your Head’: Irritable Bowel Syndrome,” *American Journal of Nursing* 101 no. 1 (January 2001): 26-34.
- <sup>21</sup> Roslyn H. Corney and Ruth Stanton, “Physical Symptom Severity, Psychological and Social Dysfunction in a Series of Outpatients with Irritable Bowel Syndrome,” *Journal of Psychosomatic Research* 35 no. 5 (1990): 487 and Table IV, “Psychiatric Scores.”
- <sup>22</sup> “Cognitive Behavioral Therapy for Women with Irritable Bowel Syndrome (IBS),” *Johns Hopkins Medicine Integrative Medicine & Digestive Center*, [https://www.hopkinsmedicine.org/integrative\\_medicine\\_digestive\\_center/services/cognitive\\_behavioral\\_therapy.html](https://www.hopkinsmedicine.org/integrative_medicine_digestive_center/services/cognitive_behavioral_therapy.html) Accessed August 17, 2021
- <sup>23</sup> Dancy et al, “Perceived stigma, illness intrusiveness and quality of life in men and women with irritable bowel syndrome,” *Psychology, Health & Medicine* 7 no. 4 (2002): 381-395. In a qualitative study on men with IBS in the UK, Nigel Campbell quotes one participant, Eddie: “*I didn’t think it was IBS because the general thing about IBS is yogurt and bloating and women basically. You know that’s the general idea that you get bloating. Everyone is obsessed with going on about this bloating thing and I didn’t ever get bloating (Eddie, 799-805).*” Nigel Campbell, *An Exploration of Adult Male Experiences of Having Irritable Bowel Syndrome (IBS): A Qualitative Study*, Doctoral thesis for Professional Doctorate in Counselling Psychology, London Metropolitan University (2015), 135; for a discussion of bloating as a gendered symptom in IBS, see Björkman et al, “The gendered impact of Irritable Bowel Syndrome,” *Journal of Advanced Nursing* 70 no. 6 (2014), 1340. Similarly, in another qualitative study, researchers in Sweden found that “the men suffered ... because the disorder is seen as psychosomatic and a ‘woman’s disease’, thus labelling them as emotional and weak in contrast to traditional masculine ideals.” Björkman et al, “The gendered impact of Irritable Bowel Syndrome,” 1339.
- <sup>24</sup> Björkman et al, “The gendered impact of Irritable Bowel Syndrome,” 1341.
- <sup>25</sup> Kristie Dotson, “Tracking Epistemic Violence, Tracking Practices of Silencing,” *Hyphatia* 26 no. 2 (2011), 242.
- <sup>26</sup> Dixon-Woods and Critchley, “Medical and lay views of irritable bowel syndrome,” 111.
- <sup>27</sup> Dixon-Woods and Critchley, “Medical and lay views of irritable bowel syndrome,” 111.
- <sup>28</sup> Dixon-Woods and Critchley, “Medical and lay views of irritable bowel syndrome,” 111-2.
- <sup>29</sup> Dixon-Woods and Critchley, “Medical and lay views of irritable bowel syndrome,” 112.
- <sup>30</sup> Dixon-Woods and Critchley, “Medical and lay views of irritable bowel syndrome,” 112.
- <sup>31</sup> Björkman et al, “The gendered impact of Irritable Bowel Syndrome,” 1339.
- <sup>32</sup> See e.g. Kidd and Carel, “Epistemic Injustice and Illness.”
- <sup>33</sup> Dixon-Woods and Critchley, “Medical and lay views of irritable bowel syndrome,” 112.
- <sup>34</sup> Houghton et al, “Age, Gender, Women’s Health and the Patient,” *Gastroenterology* 150 (2016), 1333.
- <sup>35</sup> Dotson, “Tracking Epistemic Violence,” 244.
- <sup>36</sup> Dotson, “Tracking Epistemic Violence,” 244.
- <sup>37</sup> Houghton et al, “Age, Gender, Women’s Health and the Patient,” 1333
- <sup>38</sup> Vidali, “Hysterical Again,” 55.