

Bridging the gap



## Irritable Bowel Syndrome (IBS) and medical misinformation: lessons to be learned from the COVID-19 infodemic

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**ABSTRACT:** Irritable bowel syndrome (IBS) is a multifactorial condition for which there is no known aetiology. The lack of evidence base surrounding the aetiology of IBS coupled with the variety of management tools employed by affected patients has meant that the condition has been an increased topic of interest amongst “patient influencers”. While there is a notable value to such influencers on social media in terms of peer-to-peer support and fostering discussions of lived experiences with an affected community, concerns remain over the quality and accuracy of information being shared. Medical misinformation poses a new global health threat; medical professionals remain powerless to filter through what has been dubbed by some as “misinformation mayhem”. The COVID-19 pandemic exposed significant gaps in health literacy and a lack of trust in the medical and political systems that were responsible for communicating health information. This literature review outlines the missed opportunities for counteracting medical misinformation during the COVID-19 pandemic and identifies the ways in which these lessons could be applied to future communication and interaction with IBS (mis)information within the social media sphere.

**KEYWORDS:** Irritable Bowel Syndrome. Medical Misinformation. COVID-19.

Submitted Oct. 8th, 2023, Accepted Apr. 10th, 2024,

Published May 13th, 2024

J. Évid-Based Healthc., Salvador, 2024;6:e5444

<http://dx.doi.org/10.17267/2675-021Xevidence.2024.e5444> | ISSN: 2675-021X

Assigned editors: Luís Correia, João Segundo

*How to cite this article:* Lees EM. Irritable Bowel Syndrome (IBS) and medical misinformation: lessons to be learned from the COVID-19 infodemic. J Évid-Based Healthc. 2024;5:e5444. <http://dx.doi.org/10.17267/2675-021Xevidence.2024.e5444>

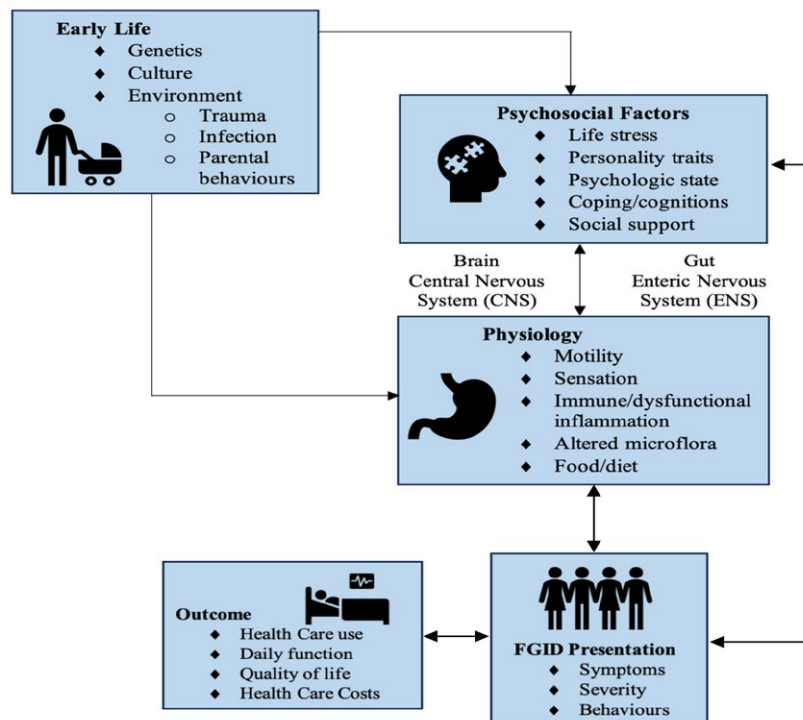


## 1. Background and context

Functional Gastrointestinal Disorders (FGIDs) encompass the most common gastroenterological diagnoses, of which irritable bowel syndrome (IBS) is the most common and well-researched. IBS is a multifactorial condition for which there is no known aetiology, though research by Drossman<sup>1</sup> on behalf of the Rome Foundation hypothesised a biopsychosocial conceptual model, as highlighted in Figure 1. The lack of evidence base surrounding the aetiology of IBS, coupled with the variety of symptom management tools employed by affected patients, has meant that the condition has been an increased topic of interest amongst “patient influencers”.<sup>2,3</sup> Willis et al.<sup>4</sup> define “patient influencers” as health education agents, who utilise their lived experience with a disease or condition to communicate complex health information to their community of followers, who may also share the same diagnoses and lived experiences.

In summary, IBS is of particular interest within the biomedical research field, much of which can be attributed to the disorder’s ambiguous nature.<sup>5</sup> Cross-functional biological and medical research (i.e., biomedical research) approaches health in a multidisciplinary fashion, whereby answers are being sought not only from a cellular level but also physiologically and on a wider population level, i.e., population genetics and public health.<sup>5</sup>

**Figure 1.** A biopsychosocial conceptual model for the pathogenesis, clinical experience, and effects of functional gastrointestinal (GI) disorders. Adapted from Drossman’s modification of Rome III<sup>1</sup>



Source: the authors (2024).

Online health information seeking behaviour (HISB) has increased in prevalence worldwide, with a comparative study of 28 European countries reporting that 72% of Europeans use the internet for searching health-related information.<sup>6</sup> It is hypothesized that HISB may have a positive influence on patient health advocacy and treatment adherence, though many have cited concerns surrounding the opportunities for medical misinformation.<sup>7-9</sup> A survey study by Neely et al.<sup>10</sup> found that 63% of social media users from a sample of 1003 United States (US) based adults were unlikely to fact-check health-related media with a medical professional, despite 76% of participants confirming “a little” reliance on social media.

Medical misinformation is defined as any claim of health-related fact that does not align with the evidence-based scientific consensus.<sup>11</sup> While this is not an entirely new concept, it poses a significant threat to global public health in the digital age, especially within the context of the COVID-19 pandemic.<sup>11,12</sup> With medical professionals powerless to filter through what has been dubbed by some as “misinformation mayhem” to consumers of such content, the call for content regulation on social media platforms continues to rise.<sup>12-14</sup> A study published by the Cambridge University Press, for example, noted a positive correlation between COVID-19 conspiracy beliefs and the use of social media as an information source relating to COVID-19 in a three-part survey of social media use.<sup>13</sup> Prominent characteristics of such online medical misinformation include media sensationalism and emotive scaremongering tactics. Often framed in a manner that provokes outrage amongst consumers, these tactics utilise the promotion of unverified evidence or even “bends” the details of true events to fit a narrative that will appeal to the masses.<sup>14,15</sup> One such example of this in action during the COVID-19 pandemic was the “exposure” of a biological warfare conspiracy to influence population control.<sup>15-17</sup>

## 2. Methods

The method utilised in this literature review is similar to that employed by Hilton in their review of COVID-19 policy and media releases in Australia.<sup>18</sup> Key terms and terminologies were identified through a contextual analysis of research literature. The literature search employed Boolean operators and was performed using PubMed, Google Scholar, Cochrane Library, and Web of Science. The results were refined to peer-reviewed studies published in academic journals, either in the English language or with an available English language translation. Literature specifically discussing the effects of post-COVID syndrome in relation to IBS or not specifically discussing IBS in reference to medical misinformation was regarded as out of scope of this literature review.

## 3. Results

Table 1 summarises an example literature search and yielded results for context-specific research within the scope of this literature review.

**Table 1.** Example literature search and yielded results for context-specific research

Search Terms	Search Engine	Results
[Irritable bowel syndrome OR IBS] AND [medical misinformation OR misinformation OR infodemic] AND [patient influencer OR social media influencer] NOT [post-COVID OR post-COVID syndrome]	PubMed	356
	Google Scholar	457
	Cochrane Library	0
	Web of Science	258

Source: the authors (2024).

## 4. Discussion

While medical professionals have a role to play in encouraging health literate practices and health-seeking behaviours of their patients, the burden does not solely rely on their stewardship.<sup>17-19</sup> Patient empowerment and health education initiatives are vital in ensuring that members of the public do not fall victim to unreliable health information sources.<sup>18-20</sup> This concept has seen health literacy dubbed as the “social vaccine” as to increase health literacy levels would, in turn, increase health protective behaviours such as the adherence to health policy guidance.<sup>19,21</sup> A prolific example of a medical misinformation crisis is the linking of vaccinations with autism in children, which resulted in a decline in child immunisation and a measles epidemic in European countries as well as being declared a state of emergency in Washington State, USA.<sup>20</sup>

Scientific communities fear the potential of medical misinformation to derail future epidemiological interventions for the prevention and management of new and emerging diseases, particularly following the global public reaction to COVID-19 lockdown measures and vaccination policies.<sup>20,21</sup> Suggestions to criminalise the act of spreading (medical) misinformation have been on the rise<sup>22</sup>; however, concerns have been noted from human rights, targeting the “free speech” narrative and expressing concerns over the possibility of further restrictive policies being implemented in the future.<sup>23</sup>

The general mismanagement of communication initiatives and a lack of evidence-based policymaking during the COVID-19 pandemic in part contributed to the facilitation of speculative theories and medical misinformation on a global scale.<sup>16,24,25</sup> Many studies have sought to establish the relationship between individual socio-political characteristics and the perception of COVID-19<sup>15</sup>, to which Franz and Dhanani<sup>26</sup> concluded that disease perception and beliefs relating to COVID-19 span beyond just political affiliation, as they are also strongly entangled in varying social and cultural factors.

In the case of IBS, the rising tide of medical misinformation has seen the spotlight turn to the current clinical applications of the gut microbiome.<sup>27-29</sup> Researchers have cited concerns that the role of the gut microbiome in clinical practice is overstated within the media, as it has yet to revolutionise clinical

diagnostic tools or provide therapeutic targets for dysbiosis-associated pathologies such as IBS.<sup>30</sup> Similarly, the role of food and diet is often seen as the primary causal factor for symptom onset.<sup>31</sup> However, Francisconi et al.<sup>32</sup> suggest individualised factors, i.e., genetics, hygiene, and the nervous system, as well as cultural differences, gender, and family systems are of equal importance. While promising developments in microbiome research have been made, such as the potential applicability of faecal microbiota transplantation (FMT), it is predominantly agreed across scientific literature that further clinical trials with larger participant cohorts are warranted before such treatments can be promoted from bench to bedside.<sup>27-29</sup> Contrastingly, a content analysis of popular press sources found that American and Canadian audiences were subject to an overhyped communication of the microbiome’s impact on health and disease, with 79% of the 830 sampled articles describing the way individuals could reap the benefits of the microbiome.<sup>33</sup> Sampled articles referenced probiotic intake (27%) and food/drug recommendations for maximised health benefits (45%), while just 22% of articles detailed specific scientific research developments within the field.<sup>33</sup>

Similarly, a content analysis of 900 Instagram posts under the “IBS” hashtag was found to be ambiguous in nature (67%) when compared to medical guidelines, with most posts (~46%) originating from non-professional individuals, i.e., bloggers and influencers.<sup>2</sup> A content analysis of YouTube videos for IBS patient education found that 60% (n=18) were produced by for-profit companies, with the top 10 sampled videos scoring an average DISCERN score of 2.38 out of a possible 5, indicating low-intermediate quality content.<sup>34</sup> Additionally, the lower-quality videos were found to have at least three times the number of “views” (3.67 million) compared to those of intermediate quality (1.25 million).<sup>34</sup>

More recently, Jafri et al.<sup>35</sup> noted similar trends in a cross-sectional study of TikTok content quality relating to IBS. They reported that most non-educational videos were posted by non-medical professionals, with social media influencers’ content receiving a higher average number of shares (16,382).<sup>35</sup> Furthermore, of the 30 videos that were rated as educational, 53% were found to be nonfactual compared to current medical guidance.<sup>35</sup>

Without the rapid advocacy and effective communication of evidence-based health promotion initiatives to IBS-affected populations, medical misinformation will continue to disrupt public health efforts, as seen with the COVID-19 infodemic.<sup>13,21,23,25</sup> The growing concerns of the scientific community regarding infodemics should be used to facilitate meaningful discussions that can be translated into evidence-based decision-making for future health policies.<sup>19,20,23</sup>

Regulatory bodies should issue clear guidance for social media influencers regarding the promotion and recommendation of products or services for the treatment and management of IBS symptoms on social media platforms, putting evidence-based practice at the forefront of IBS social media content. Furthermore, increased awareness regarding digital health literacy and engagement with health literacy-building initiatives are crucial for encouraging consumers' critical thinking towards the advertisement of products and supplements claiming to "cure" conditions such as IBS. Lastly, authors of biomedical research should consider the potential to which their work could be misinterpreted or misrepresented to audiences within a broader (social) media sphere and should aim to mitigate this impact where possible.<sup>36</sup>

### Conflicts of interest

No financial, legal, or political conflicts involving third parties (government, private companies, and foundations, etc.) were declared for any aspect of the submitted work (including but not limited to grants and funding, advisory board participation, study design, manuscript preparation, statistical analysis, etc.).

### Indexers

The Journal of Evidence-Based Healthcare is indexed by [DOAJ](#) and [EBSCO](#).



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