

# Reducing the Spread of Internet Misinformation in IBD: Ethics and Responsibility

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## EDITORS' COMMENTARY

The amount of information that the average American consumes on a daily basis is 5 times greater than it was 30 years ago.<sup>1</sup> More than 50% of all internet searches are done on a mobile phone. Information is literally “at your fingertips” in the second-by-second reality in today’s fast-moving age of technology. With the arrival of the internet and social media, a paradigm shift in the patient-physician relationship has occurred. For most of the 20th century, the physician was the main source of information for the patient. Beginning in the 1960s, this hallowed bond evolved from a paternalistic to an autonomy-oriented approach that increased the independence of patients and gave them more responsibility in their own care. Along with this development came a power shift in the dynamic of the patient-doctor relationship, a well-justified correction with a wide range of mostly positive consequences. As the 21st century began, the internet and social media arrived and made their presence felt, chipping away at the trust forged in this relationship. There is no single culpable entity, but there are a number of missteps that have been identified and need to change to salvage the patient-doctor relationship.<sup>2</sup> Technology is a welcome and necessary tool to help more people than ever by increasing the connectivity of patient and provider. At the same time, physicians have an ethical responsibility that has gone largely unrecognized. We as physicians must strive to reduce the harm that the internet and social media can and will pose through the spread of medical misinformation without proper intervention.

Complex disease processes can be challenging for both physicians and patients to understand. In the 2003 National Assessment of Adult Literacy, only 12% of adults had proficient health literacy whereas 36% had basic or below basic health literacy.<sup>3</sup> Inflammatory bowel disease (IBD) is one of the most complex diseases in modern medicine, with many identified influences from the dysregulation of the immune system to the environment to diet to genetics. Individuals with IBD may experience a range of symptoms that have a profoundly negative impact on their quality of life. This negative health-related impact places patients into a particularly vulnerable position, susceptible to misinformation in part because of the expected deficit of disease-specific knowledge in the layperson and the human instinct for self-preservation. Out of this intricate imbalance of influential factors have come a myriad of untested theories to treat or “cure” one’s IBD, resulting in a substantial obstacle to the care of both pediatric and adult patients with IBD.

When searching online, one finds plentiful patient theories when it comes to offering alternative diagnoses followed by alternative treatments, coupled with the fear of the most advanced medical therapy even with its resounding evidence and reassurance. Certainly there is a role for complementary and/or alternative medicines in IBD, but they are just that—“complementary”—and do not hold up to scientific scrutiny as the mainstay in therapy. Although we would not argue against *patients* sharing their own experience, the recommendation by a *provider* to use alternative therapy as a replacement for conventional therapy is irresponsible, particularly when the

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provider has a monetary incentive associated with these alternative therapies.

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## WHERE DO PATIENTS OBTAIN INFORMATION?

The health care space to see and treat patients with IBD has become crowded with many hospital systems launching their own websites filled with scientific information. A Google search for IBD diagnosis, treatment, or prognosis results in links to academic and private hospitals, nonprofit foundations, and medical websites that contain generally comprehensive information with the usual disclaimers surrounding the material on complementary and alternative medicines to reduce symptoms. For many users, this type of information search lacks the personal appeal of communicating with another like-minded human being who has the shared experience of stress and anxiety from battling with the disease itself and its concomitant therapies. This is the void that social media platforms such as Facebook and Twitter have filled. In a cross-sectional survey of patients with IBD, 32% used social media to discuss subject matter related to IBD.<sup>4</sup> Although IBD may encompass a broad range of topics for patients to investigate, searching online opens the door to unreliable ultracrepidarians. The snake-oil salespeople are no longer standing among passers-by in a busy market hoping to catch their attention; they now have a direct earpiece into thousands (if not millions) across the globe.

Patients may also be looking for non-health care providers to validate their concerns around the use of medications including biologics. In a study of patient perception surrounding biologic use in IBD posted to social media (using natural language processing), almost 55% of posts were related to negative experiences, 37% were related to decision-making, and 28% were looking to peers for information.<sup>5</sup> This confirmation bias then degrades the patient-provider relationship when discussing starting or escalating therapy.

## WHY DO PATIENTS TURN TO ALTERNATIVE SOURCES?

Mistrust in the health care system and physicians is relatively new to our society since the advent of modern medicine. We have an evolutionary instinct to question decisions that directly affect our health and well-being. Although instinct and thirst for knowledge are what brought us to this point in medicine, they are also what hold us back from taking the next step

and eradicating diseases such as measles and chickenpox. There is a downside to “autonomy”—when it comes to mean total self-sovereignty over anything and everything that affects one’s health or identity. And if an intervention—ie, a vaccine, medicine, diet, procedure, or mask-wearing—impedes on this autonomy, then an individual has a right to say no even if it means possible infringement on another individual. This is where the lines are blurred and possibly why our legal system is so busy today. Respect for autonomy is a principle of medical ethics taught in every medical school, sometimes at the expense of beneficent paternalism (or parentalism). The emphasis on autonomy allows patients to defer or decline evidence-based treatment and/or to seek alternative treatments even if this quest is futile.

Patients who reject conventional medicine and seek alternatives to us as the providers and what we are prescribing do so on the general belief that we do not have their best interest at hand, that our medicines may harm them, and/or that the alternatives have been ignored by science and are better. Mistrustful patients may believe that our motives are not to help them but that these decisions will directly benefit us first via monetary or academic compensation. It is not a “team” approach to their well-being but instead an us-vs-them approach. Patients also may believe, sometimes with good reason, that big pharma is pushing specific medical therapies to increase profits and that physicians are just another cog in the wheel of the medical industry. This is not a far reach when glancing at any business-news headline and reading about how one of these companies posted another “record-breaking year” in profits. It is not a far leap for the patient to then assume that what we are prescribing is not only profitable to us but is also potentially harmful to them.

This is where solicitors on social media have been able to plant their flag and find new consumers. If a snake-oil salesperson can draw in patients based on their own confirmation bias, then that person can present his or her pseudoscience and produce a new follower. Private groups on social media sites allow the unhinged dissemination of medical misinformation at a speed far greater than we have ever encountered. We have gotten to the point in society where there is an abundance of conspiracy theorists that allows for alternative theories and treatments to be presented and amplified by social media in what seems to be an ignored solution for a larger problem in society and is posed as a much safer and cheaper treatment than the expensive and toxic therapy presented by one’s physician. And who would not want to cure their Crohn disease with colloidal silver? If we do not combat this dangerous misinformation proactively, we will be derelict in our responsibility to put the interests of our patients first.

## REDUCING THE SPREAD OF MISINFORMATION

Mistrust in medicine/physicians is certainly not a new concept, but it has been taken onto a new virtual playing field

that many providers have not previously entered. And although there may be generational hesitancy to walk onto this new field, we are obligated to do so to reduce the spread of misinformation and pseudoscience just as physicians have in the past. One exemplary effort in this regard has been the Choosing Wisely (<https://www.choosingwisely.org/>) campaign by the American Board of Internal Medicine, whose goal is to redirect patients to useful sources of information and improve evidence-based communication between patients and providers. The board provides online modules for individual provider education and steps to implement the program in a practice and in the community. The board also provides patient education resources on common health issues with a focus on proper testing in an effort to reduce overtesting.

There are several steps that a clinician can take to help discuss and mitigate the spread of misinformation with patients. Patient education is an imperative part of any well-rounded visit. The existence of reliable websites is not enough. We must advocate for them as well. Although it may seem logical to providers that a patient will use a nationally recognized website, the physician endorsement goes a lot further. Moreover, patients are often looking for information on complementary and alternative medications. We must continue to advocate for reliable sources that depend on peer-reviewed evidence about these approaches. We must also prioritize safety. If a patient with IBD chooses an innocuous but ineffective alternative approach, the ethical duty to redirect the patient is less powerful than if he or she chooses an approach that may be toxic. If we do not ask, then we will not be able to engage in the conversation.

Although it is easier to hand patients an institutional packet of information, we cannot assume that this is the only piece of literature they will read. We must ask the question “Where do you find information?” relating to their disease and well-being. Many have encountered the patient/parent who replies with “Well, Facebook!”; herein lies the opportunity to have the conversation on where and how to obtain reliable information. As difficult as it may be, it is important to remain nonjudgmental to be sure of having the attention

of the listener. We must continue engaging on the pros and cons of the patient’s information, be willing to investigate the patient’s theories, and acknowledge that we may not have all the answers but that there is good evidence in our recommendations relative to their anecdotal sources. Most important, we must always be respectful and listen more than we talk.

Finally, creating a presence on social media can have a larger effect than one might think. Allergy physicians led by Dr. David Stukus (20.9K followers on Twitter as of September 1, 2020) have spent several years developing and publishing on the impact that social media can have on patient perception of vaccines.<sup>6</sup> By creating an online voice, this community can quickly respond to vaccine pseudoscience and antivaccine propaganda, reaching a large audience of caregivers and patients. They have even created a website for providers to learn the ropes in all aspects of online media forums (<https://www.pediacastcme.org/hcsm/>). In the wake of online attacks, groups such as Shots Heard Round the World (<https://www.shotsheard.org/>) formed to protect physicians from the barrage of threats by antivaccine activists to their social media accounts and practice websites. The group has published a 76-page toolkit to manage and recover from such discord.

If you can type an email on your phone, you can use social media. Our patients are listening. If we do not talk to them, someone else will.

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