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Mitigating Misinformation and Changing the Social Narrative



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The SARS-COV-2 coronavirus disease 2019 (COVID19) pandemic has exposed a defining issue of our time—incorrect/misleading information, often propagated on social media. Over a 3-week period alone, the *Washington Post* noted 2 million tweets containing conspiracy theories about coronavirus, citing “dangerous disinformation online.”¹ The director general of the World Health Organization stated: “we’re not just fighting an epidemic; we’re fighting an infodemic” citing that incorrect information “spreads faster and more easily than this virus.”² This mass amount of incorrect information makes it more difficult to address medical solutions, reduces trust, and increases confusion among people.

Misinformation has contributed to situations such as mask refusal despite public health orders to do so, or lack of physical distancing despite surging cases in areas of the United States. Although data from a University of Colorado survey suggests more concordant health beliefs (agreement with governmental measures and the importance of wearing a mask in public to protect others), this survey noted a significant relationship with daily media consumption and higher state anxiety, which denotes that information overload could have potentially detrimental effects (M. J. Greenhawt, MD, unpublished data, 2020).

In recent years, there has been increasing reliance on cable news cycles and news reporting from social media, often occurring in real time. During public health crises, such as the recent H1N1 epidemic, with heightened risk perception, the public has become more heavily reliant on social media to inform their understanding of health information. This has become particularly evident during COVID-19. This information is available for public consumption, often unvetted for accuracy, and at times politicized. However, even before the pandemic, there was a shifting to the internet and forms of social media (such as Facebook and Twitter) for basic medical information, easily accessible by patients for consumption and professionals for dissemination. With this has come the tendency for misinformation to be disseminated within many aspects of medicine. Allergy as a specialty has not been immune to this. Over 50% of all patients may search online information sources before allergy appointments. If online information is incorrect, as noted in an article about “Dr Google,” “this can not only damage the patient-provider relationship, risk polarizing health beliefs and set up discourse between clinician and patient, but also lead patients to seek non-evidence-based promises of miracle cures, costly treatments, or unnecessary testing.”³ Worse, it may deter actual medical progress being made to address treatment of their allergic disease.

Take as one example IgG4 testing as a marker of food allergy or sensitization, a test that has been uniformly denounced by multiple allergy organizations including the Canadian Society of Allergy and Clinical Immunology. However, this is heavily marketed, often directly to consumers or by nonallergists, as a valid and reliable test. IgG4 testing has potential harms including leading to unnecessary elimination diets (impacting growth/nutrition), heightened anxiety about food choices, increased health care costs/service utilization, and the potential to increase the risk of IgE-mediated food allergy in young children due to misguided advice for specific food avoidances.⁴ However, despite the consistent disapproval of using these tests by the medical community, IgG4 testing is increasing in popularity among certain segments of the population, is helping to foster labels such as “non-celiac gluten allergic” within popular culture, and may be driving consumer demand for such tests (some of which can be obtained without clinician involvement). In fact, in Canada, allergy testing was the most common test advertised by naturopathic clinic’s websites, and “allergies” were the most common treatment ailment advertised.⁵ The Centers for Disease Control found that in 2016 Americans spent \$30.2 billion out-of-pocket on complementary health approaches.⁶

Another example, consider influenza vaccination in children with asthma. Although the influenza vaccine is broadly and universally recommended in the US population, children with asthma are noted to be higher risk for influenza-related

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respiratory complications, and influenza vaccination is uniformly recommended among children 6 months and older. Asthma is the most common comorbid medical condition among children who require hospitalization due to influenza infection.⁷ However, influenza vaccine uptake among children with asthma in the United States can be as low as 48%.⁸ For years, there was a question of the safety of this vaccine in asthmatics, build largely on expert theory and thin on evidence. Ultimately, after years of equivocation, this myth has been debunked, but doubt still lingers, years later. Studies have noted significant misinformation contributing to vaccine hesitancy including concern that the vaccine might cause significant harm, low perceived safety and efficacy of vaccines, low perceived susceptibility to complications from influenza, and significant misconceptions about the influenza vaccine (such as that influenza vaccination can cause symptomatic flu).⁹

So why is such misinformation so pervasive? Misinformation dominates our social culture, and yet, “advocates and affected individuals dominate discussions,” while researchers and health professionals are busy diagnosing/researching.¹⁰ Although medical policy and research is important, it may not be reaching our patients, as the public becomes more reliant on the media and social relationships to inform their level of risk perception, and to become their more trusted source of health care information. Who society views as a trusted health care expert has shifted, in particular when there is ample access to a litany of information for patients to research and influence their health beliefs.

With increasing health social movements, there is now extended overlap between scientific knowledge, popular culture, and a more complex “public shaping of science” that physicians have to engage, and not dismiss.¹¹ The media has significant leverage on the framing of public health perception and is instrumental in changing this narrative.¹⁰ Engagement of the media through interviews, blogs, and press releases, and distilling of this message through social media sources, would be impactful and is required to reach our patients. As noted in a recent infoveillance study of tweets during the COVID19 pandemic, “there is...a need for a more proactive and agile...health presence on social media to combat the spread of fake news.”¹²

Social media could also be used to monitor and track misinformation, and therefore be an instrument to help respond to it. One such avenues is a public twitter dataset, as was recently established for COVID19.¹³ This dataset is available to the research community and has republished over 123 million tweets as well as statistics related to those tweets such as reactions to COVID-19-related events. The interesting aspect of this dataset is that it aggregates in real time and can capture trends in how misinformation may segment among viewers. This type of social media dataset is anticipated to have a role moving forward in tracking misinformation as well as contextualizing the COVID19 on-the-ground response. Physicians can sign up for alerts on major search engines, join listserves to receive updates, and use the available information to better arm ourselves to counter misinformation.

However, in shifting the narrative to target misinformation, we need to recognize that social media is only one part of the larger problem. The ecological model, often used in health promotion, provides a broader way of contextualizing misinformation in terms of individual influences, relationships, community, and society.¹⁴ As noted in a recent book, “Ecological models of health behavior emphasize the environmental and policy contexts of behavior, while incorporating social and psychological influences. Ecological models lead to the explicit consideration of multiple levels of influence, thereby guiding the development of more comprehensive interventions.”¹⁴

As one example, consider influenza vaccine hesitancy. Although social media may influence an individual’s health behavior, there is also a distinct role for interpersonal influences such as interest among social circles in alternatives to traditional medications, and both familial and peer group vaccine hesitancy. There are also broader community and societal factors contributing to vaccination rates and attitudes including access to primary care, cost, and lack of compulsory vaccination policies in the United States. To truly change the social narrative, whether it be COVID19 response, alternative health beliefs, or vaccination, we need to view an individual’s opinions, even if largely shaped by social media, within their broader social and societal context.

The COVID-19 pandemic is shifting our world in ways beyond our imagination but has also uncovered ways in which our system has to change. One of those ways is an increasing recognition and response by physicians to the pervasive and dangerous misinformation that abounds, in all areas of medicine. As physicians, we need to learn how to contribute to the discussion and better inform our patients and change our mindset to engage in less traditional avenues of knowledge dissemination.

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