

## MEDICINE AND SOCIETY

Debra Malina, Ph.D., *Editor***Escaping Catch-22 — Overcoming Covid Vaccine Hesitancy**

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On September 8, 2020, AstraZeneca announced that it was pausing its late-phase SARS-CoV-2 vaccine trial because of a serious adverse event in a U.K. participant. The next day, my hairdresser, Ms. J., asked me what I thought about the news. I said the halting of the trial to investigate the adverse event was reassuring — an example of science doing its job. “What do you think?” I asked.

“There’s no effing way I’m getting a vaccine,” she said.

Ms. J., who lives in New York City, had Covid-19 in April. Though she didn’t require hospitalization, the virus incapacitated her for weeks, leaving her weak and unable to tolerate solid foods; for months, she continued to become dyspneic with exertion. She was terrified of getting the virus again and derived little comfort from the possibility that she had enduring immunity. Yet the prospect of getting a Covid-19 vaccine was even scarier. Emphasizing the haste of vaccine development, the need for long-term safety data, and concern that side effects could “make everything worse than it already is,” Ms. J. added that most of her friends and relatives were similarly “really suspicious” of the vaccines.

And they are not alone. Though many people initially believed a vaccine was the magic bullet that would save us from a devastating pandemic and return our lives to normalcy, we now find ourselves contemplating simultaneously how to ethically allocate a limited number of vaccine doses to the many people who want them and how to increase vaccine uptake among those who don’t. Though estimates vary, public health officials suggest that about 80 to 85% of Americans would need to be vaccinated for the country to achieve herd immunity. Vaccine confidence seems to be rising, but recent polling suggests that about 31% of Americans wish to take a wait-and-see approach, and about 20% remain quite

reluctant.<sup>1</sup> The behavioral obstacles to widespread vaccination are thus as important to understand as the scientific and logistic hurdles.

Accordingly, since September, I have been talking with people about their perceptions and concerns about Covid-19 vaccination. Before the election, people often mentioned the prospect that a vaccine would be approved prematurely by a desperate Trump administration, but concerns about long-term safety are common, persistent, and not unfounded. Even though adverse events tend to occur within the first 6 to 8 weeks after vaccination, vaccines are typically not approved until 2 years of follow-up data have been gathered. In addition, some SARS-CoV-2 vaccines, such as those based on messenger RNA, use new technologies for which long-term data are lacking. We also don’t yet know the durability of immunity, the degree to which vaccines prevent asymptomatic infections, or whether boosters will be necessary, especially given the emergence of viral variants. In the midst of a pandemic that is taking thousands of lives daily and devastating society, many people will find these uncertainties acceptable. But for others, as with many trade-offs in medicine, the magnitude of benefit may have less emotional resonance than the possibility, no matter how minimal, of risk.

## MORE THAN MESSAGING

For those with intent to be vaccinated, interventions such as default appointments and onsite vaccination effectively increase uptake.<sup>2,3</sup> Less is known, however, about how to increase uptake by modifying the beliefs of the hesitant. In one randomized trial targeting parents with children eligible for the measles–mumps–rubella (MMR) vaccine, researchers tested various messaging strategies that either corrected misinformation or had emotional appeal. One strategy refuted

the claim that vaccines cause autism, while others featured pictures of children with the diseases the MMR vaccine prevents or a dramatic narrative about an infant who nearly died of measles.<sup>4</sup>

These strategies not only failed to increase intent to vaccinate, but among vaccine skeptics, they actually did the opposite. Graphic pictures of a child with measles increased fears of vaccine-related side effects rather than fear of the disease itself. And though accurate information reduced the misperception that vaccines cause autism, intent to vaccinate still decreased among the most hesitant parents. Extrapolating these findings to a paralyzing pandemic comes with countless caveats, foremost among them that vaccination will initially target adults. Nevertheless, as we embark on far-reaching messaging campaigns, some humility about our intuitions about human behavior is in order.

We do know that the confidence of physicians and public health officials can be instrumental in allaying people's fears.<sup>2</sup> One elderly couple I spoke with in October, for instance, after expressing reservations about a vaccine being approved prematurely for strictly political reasons, concluded, "If Anthony Fauci approves it, we will go for it." This sentiment is consistent with what we know about vaccine uptake in general: the seemingly most effective way to increase vaccination rates is with clinician recommendations.<sup>2,5</sup> As Robert Jacobson, a Mayo Clinic pediatrician who studies vaccine hesitancy, pointed out, since health care workers are among the first groups to be vaccinated, they will be able to speak to their patients with authority and confidence: "I got this vaccine, and I want you to have it, too."

As critical as recommendations from trusted authorities will be, in an environment rife with misinformation and distrust of expertise, disseminating evidence-based information may be insufficient to persuade some people. That's partly why Heidi Larson, an anthropologist at the London School of Hygiene and Tropical Medicine whose recent book, *Stuck*, summarizes her decades of research on vaccine hesitancy, sees Covid-19 as an opportunity to rethink our approach to vaccine uptake. Larson, who studies rumors, cautions against the impulse to merely correct misinformation and assume our work is complete. Writing before the pandemic, Larson observed that "Vaccine reluctance and refusal

are not issues that can be addressed by merely changing the message or giving 'more' or 'better' information."<sup>6</sup> Though the pandemic has cast the dangers of misinformation into stark, soul-crushing relief, the gravity of a falsehood's consequences doesn't render it more correctable with truth.

Larson's own thinking was transformed in 2003, when, while overseeing vaccine strategy and communication at UNICEF, she was called to Nigeria, where a government-led boycott of the polio vaccine was under way. There, Larson discovered that resistance reflected not specific concerns about the vaccine but rather a convergence of broader social factors, including rumors that Western vaccines were intended to sterilize children; a fear, in the aftermath of 9/11, that the United States was at war with Muslims; and ongoing conflict between the local and central governments. Quashing the rumors seemed to matter less than addressing the nexus of questions, concerns, beliefs, and historical forces that gave rise to them. Though the reasons for skepticism may vary among communities, Larson's approach to vaccine hesitancy is universally relevant: before you attempt to persuade, try to understand.

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#### THE UNDECIDEDS

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Mr. K. is a 56-year-old man who avoids vaccines and decided with his wife not to vaccinate their children. "People disregard you as a conspiracy theorist," he told me, "but we put a lot of thought into making that decision." Many of Mr. K.'s beliefs were informed by his father-in-law, a pediatrician who has concerns about the safety of vaccines. "He is not a pharma-driven doctor," Mr. K. explained. "He's not part of the medical establishment." The problem with that establishment, as Mr. K. sees it, is not just its drug pushing and profiteering, but its censoring of people who disagree. For instance, in July, when social media companies removed a viral video of physicians suggesting (misleadingly) that hydroxychloroquine was an effective treatment for Covid-19, Mr. K. saw a parallel to attempts to quash antivaccine sentiment. "What is going on with this country where people can't make their own decisions?" he asked. "I try to find the scientists out there who aren't afraid of losing a

grant — people who have nothing to lose if they speak the truth.”<sup>7,8</sup>

In both his aversion to mainstream medicine and his perception that people questioning medical dogma are censored, Mr. K. highlights a Catch-22 of vaccine hesitancy: by challenging untruths, we may inadvertently feed the perception that the “real” truth is being suppressed. Larson describes in her book the fallout after pressure from the scientific community resulted in removal of the antivaccination film “Vaxxed” from the Tribeca Film Festival in 2016. The pulling of the film confirmed the belief of vaccine doubters that physicians and scientists are unwilling to engage with any dissent. Moreover, notes Larson, these instances of so-called censorship attract people who, while not necessarily antivaccine, identify with broader rights agendas promoting “freedom” and “a fundamental democratic right to choose.”<sup>6</sup>

Indeed, while people firmly opposed to all vaccines may be relatively few in number, they wield outsized influence, particularly on social media, over the undecideds. A recent study of expressions of vaccine-related sentiments by 100 million Facebook users found that antivaccine clusters of people, though less numerous than provaccine clusters, have a more central presence in large networks and interact with more undecided clusters.<sup>9</sup> Provaccine clusters, meanwhile, engage predominantly in smaller networks, so even though they exert less influence, they often have the “wrong impression that they are winning.” Provaccine clusters are also disadvantaged by the tendency toward “monothematic” messaging, whereas antivaccine pages deploy multithemed narratives to broaden their appeal, touching on safety concerns, alternative medicine, Covid-19 (both causes and cures), and various conspiracy theories. In response to these dangerous disinformation campaigns, social media companies have intensified efforts to label falsehoods and eliminate them. But as Neil Johnson, a physicist and the study’s first author, explained to me, such efforts can backfire.

One of the most widely shared Covid conspiracy theories, for example, is that the vaccines contain microchips that will be used by elites (Bill Gates is often mentioned) or by the government to track people’s behaviors. People propagating the rumor often point to a study of a new

technology that delivers microparticles intradermally during vaccination, creating a digital vaccine record.<sup>10</sup> The research, funded by the Gates Foundation before Covid, aims to address the challenge of vaccine record keeping, particularly in low-resource countries. Although this technology is not present in any Covid vaccine, Johnson, who has been monitoring vaccine sentiment online throughout the pandemic, cautioned against dismissing the rumor as mere misinformation. “We can hope that Bill Gates won’t eventually use it to track Covid vaccine behavior, just like we hope our neighbors won’t one day wake up and plow their car into our house,” Johnson said. “They could in principle, but it’s highly unreasonable to think that they would.” If the vaccine hesitant feel that they’ve been unfairly accused of spreading misinformation, Johnson explained, they become further emboldened in their doubts. Even ideologically disparate groups unify around such shared skepticism.

Johnson’s observations remind us why teaching the public to “understand science,” the seemingly obvious way to mitigate antiscientific sentiment, may fall short. Many discussions about science denialism conclude with some version of “We just need to get the public to understand science.” But evidence suggests otherwise. Sociologist Gordon Gauchat, for instance, in describing temporal trends in distrust in science, has shown that at least among conservatives, it’s the most educated subgroup who have become increasingly skeptical.<sup>11</sup> One possible explanation is that highly educated people are more facile at finding evidence to support their views or in poking holes in evidence that doesn’t. Accordingly, in a 2019 essay on the so-called crisis in truth, in which antivaccine sentiment features prominently, history-of-science professor Steve Shapin makes the surprising argument that there isn’t “too little science in public culture,” but “too much.”<sup>12</sup> That’s partly because people who deny climate change or reject vaccines co-opt the language of science to bolster the legitimacy of their views. Their arguments, Shapin writes, are often “garnished with the supposed facts, theories, approved methods, and postures of objectivity and disinterestedness associated with genuine science.”

Where do these bleak observations leave us as we seek to raise confidence in Covid vaccines?

## FROM STIGMA TO EMPATHY

As the pandemic has sharpened the polarization over science, disdain for science denialism has made it easy to conflate true antiscientific sentiment with simple fear of the unknown. In my many conversations about vaccines, what struck me most was the shame that often preceded any expression of doubt. Some people simply refused to talk to me; others, particularly those who work in health care, were skittish about being identifiable. And those who had questions often prefaced them with “I’m not an antivaxxer but . . . .” One common question, for instance, was whether people who are young and unlikely to die of Covid should get a vaccine whose long-term side effects are unknown.

My instinctive response to this sort of question is to emphasize the population benefits of vaccination and the reality that some young people do die from Covid and that even survivors may have long-term sequelae we don’t fully understand. But why not simply acknowledge the legitimacy of the concern? For many of us in the medical community who are haunted by the consequences of science denialism, validating any aspect of vaccine skepticism may feel like ripping your mask off in a crowded elevator. But it isn’t “antiscience” to admit that we still don’t know some things. It’s just truth.

Nevertheless, among people who take no solace in rigorous science, more than transparency will be needed to build trust. Larson notes how quick the scientific community is to justify medical recommendations by saying, essentially, “Science said so.”<sup>13</sup> Referring to the pausing of the AstraZeneca trial due to an adverse event, for instance, Larson notes how much of the media coverage featured scientists noting the “normality” of pausing a trial to investigate any adverse events. To Larson, though, this response lacked expressed empathy for the person(s) who experienced an unexpected reaction. “It’s not normal for the person who was hurt,” she said. In our rush to defend the vaccine and the evaluation process, the scientific community may fail to convey how the participant’s symptoms were addressed, though it’s the latter — more than fidelity to science — that may be foremost on people’s minds. After speaking on the radio about this oversight, Larson was contacted by a trial participant who’d experienced an adverse event

and wanted Larson to know how well she’d been cared for by the trial’s clinicians. “The scientists were doing the right thing,” Larson told me, “but they weren’t communicating it.”

Of course, people who are determined to undermine confidence in vaccines will always find ways to spread misinformation. But a much larger proportion of the population may be willing to get vaccinated given the proper reassurances, and dismissing their concerns often leaves them seeking someone to validate them. I suspect that’s one reason why correcting misinformation often falls short. Some people, for instance, may truly believe that vaccines cause autism. But for others, this ostensible fear may mask less easily expressed needs such as maintaining one’s identity, belonging to a group, or simply being heard. And yet respecting these more basic instincts also raises an uncomfortable question: At what point does empathy sacrifice scientific truth?

Or perhaps this is a false dichotomy. One of my best friends practices in a region where many people, including some health care workers and patients in her practice, are hesitant to get vaccinated. Even my friend — whose brilliance and rationality I have always admired — has reservations about vaccination, though she knows that expressing them is taboo. But I think that it’s only because she understands why people are scared that she’s effective not just at allaying fears, but at convincing people who don’t know anyone who’s willing to get vaccinated that what is known about the vaccine is more important than what isn’t. Indeed, the staff members who were initially reluctant to be vaccinated, changed their minds after speaking with her.

Although the scientific community’s obligation will always begin with championing truth, the pandemic has shown that society’s health also depends on understanding why so many people reject it. While some trust scientific experts, Larson notes that others seek “truth” elsewhere — their experiences, perhaps, or “heard truths” from their social networks. The pandemic, then, has reminded Larson why getting the public to understand science may be insufficient.<sup>14</sup> Maybe, she suggests, it’s also time for science to understand the public.

**This article is Part 1 in a two-part series. Next week: “No Cure without Care — Soothing Science Skepticism.”**

Identifying details have been changed to protect people's privacy.

Disclosure forms provided by the author are available at NEJM.org.

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