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Countering Hesitancy and Misinformation on Side Effects to Complete the Course of COVID Vaccination

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Abstract

It has been well-documented that concerns about side effects prevent many from soliciting immunization. And family medicine providers play a key role in addressing concerns about COVID vaccines. However, there are few documented examples of the decision-making process regarding second shots after the emergence of a concerning and previously unknown side effect. Therefore, we present a case where a primary care provider and patient worked together to analyze real-time adverse event data on post-vaccination shingles to decide whether to receive the second dose.

Keywords

COVID-19, social media, patient safety, medications/adherence, clinician–patient relationship, misinformation, Parler app, VAERS

The patient presented to their physician with a worrisome reaction to the first COVID vaccine dose and wanted to know what to do about the second. But, there was no clinical research about this particular side effect. In the end, a controversial data source revealed the path forward.

The patient was me. I am a side effect scientist, qualified in hypothesis generation (pharmacovigilance) and etiology (pharmacoepidemiology). Two days after the first vaccination I started to manifest shingles.

Many symptoms of COVID vaccine reactogenicity and the initial stages of shingles overlap. I was initially not considering the latter, and neither was my physician. I had already been reporting lymphadenopathy to my physician and to US Centers for Disease Control and Prevention (CDC) through the vsafe app (https://www.cdc.gov/coronavirus/2019-ncov/vaccines/safety/vsafe.html) starting on March 26, 2021. After each submission, an acknowledgment appeared saying that someone from the government *may* contact me for more details. That call eventually came 80 days later (June 14, 2021) after the side effect had been resolved, but in the meanwhile, I had to make a decision on the second dose during the vaccination window in April. At the moment, I rationally knew that more severe adverse events, like atypical blood clots, should take triage precedence. Yet, during those days of indecision in April, I felt the conflicting impression that my debilitating symptoms were not worthy of medical attention. Consequently, I delayed visiting my physician's office. A keen-eyed nurse on my research team first raised the possibility after I kept excusing myself for not showing my rash-strewn face on video calls. My physician quickly confirmed shingles.

I responded well to valacyclovir and required a week of opioid pain medication to cope with skull-splitting neuralgia. Now my physician and I had to decide about the second dose, and if I should resume the antiviral preventatively. Since the annual incidence of shingles in my age and gender group is about 1 per 1000 (1), the question of causality lingered. Over the phone, the manufacturer demurred, saying shingles were not a known adverse event. Clinical colleagues and literature review provided no leads. I started to question the connection.

Luckily, I was familiar with the CDC Vaccine Adverse Event Reporting System (VAERS) public data interface, having used it in research routinely. On April 13, 2021, I conducted a search using wonder.cdc.gov, searching for

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symptom codes and free text descriptions matching "shingles" and "herpes zoster," with limits for the Pfizer/BioNTech and onset time since the vaccine was available. I found 150 cases of shingles following COVID vaccination. Reading the narratives afforded me a sense of validation and communion. Other patients posed the same question: Should I get the second dose? Using standard quantification methods, I excluded duplicate, incomplete, and low-quality reports (2,3). There was a 10:1 ratio of shingles occurrence comparing the first versus the second dose. Even considering time lags and underreporting, this ratio was reassuring: The worst was past. I sent the analysis to my physician, and we decided to proceed with immunization without antiviral. I returned for the second dose and tolerated it uneventfully.

An alternative etiology cannot be ruled out since zoster reactivation is documented in COVID patients without vaccination (4). But, the timing and similarity to VAERS reports, other vaccines associated with varicella reactivation (5), and a lack of alternative explanations align with the criteria (6) for "probable/likely." Since my episode, the same association has been posited by physicians in Turkey (7), Italy (8), and the United States (9). Physicians at a dermatology practice in Nevada, United States of America, also reported a spate of shingles cases reported to them on their social media accounts, following a television news report (10). What is now a scientifically documented hypothesis was unknown at the moment of care when I most needed advice.

For completing my immunization course, the public adverse event data were decisive. However, open access to adverse reaction data is controversial because the reports can be misconstrued. VAERS has limitations that have been well characterized (11,12). In my lab, we monitor social media for health misinformation. The social media Parler app yields justifications for concern (13). A widely circulated graph was masterfully distended. A timeline originating in 1990 seemed to display a baseline of hundreds of deaths per year, skyrocketing to thousands as COVID vaccines became available. But raw reports are not assessed for causality: Many deaths were coincidental among frail seniors targeted by early vaccination campaigns (14). There will always be those who twist these data with nefarious intent (15). However, when properly presented and contextualized, adverse event data offer emotional validation and commiseration enabling therapy continuation. From scientist to patient, a new benefit embodied in these data has come to my appreciation.

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Ethics Review

All analyses were conducted with anonymized publicly available data for the intent of individual patient care. As such it does not constitute human subjects research as defined in federal regulations, and no institutional review board approval was required.

Contributorship

The author is solely responsible for this manuscript.

Data Sharing

All data described in this analysis are publicly available in the Parler App or via wonder.cdc.gov.

Declaration of Conflicting Interests

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Author Biography

Nabarun Dasgupta has a passion for telling true stories about health, with numbers. By profession he is an epidemiologist studying the safety of pharmaceuticals, including drugs and vaccines. However, in this essay he writes as a patient struggling with side effects and misinformation.