8-24-2023

"We Just Have to Trust the People in White Lab Coats": Analyzing Distrust in Vaccine Hesitant Comments on the HHS Nondiscrimination in Health Programs and Activities Proposed Rule

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by

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A thesis submitted in partial fulfillment of the
requirements for the degree of

Master of Science
in
Sociology

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Portland State University
2023

Abstract

Vaccine attitudes provide a valuable site for analyzing trust relations on both interpersonal and institutional levels. This study is a content analysis of public comments submitted from August through October 2022 in response to a proposed rule issued by the U.S. Department of Health and Human Services, which sought to strengthen non-discrimination protections in healthcare programs. Specifically, it examines the role of distrust in shaping and reinforcing vaccine hesitant beliefs, experiences, and healthcare decisions. The five themes identified in the study illustrate a breakdown in trust in pharmaceutical companies, government actors, and healthcare providers, reflecting broader social patterns. In the Roots of Rejection theme, commenters describe the concerns about vaccine technology that lead them to vaccine hesitant beliefs. The theme Encounters in Medicine demonstrates how interactions with healthcare workers impact commenters' vaccine-related beliefs and medical decision-making. The Science and Truth theme illuminates a tendency among commenters to position themselves as being in search of the "real" truth and "real" science. The Freedom and Tyranny theme shows how commenters' vaccine stances are often tied up with their identity as Americans. The final theme, Social Consequences, discusses the issues vaccine-hesitant individuals interpersonally and/or encounter outside of healthcare that reinforce their beliefs about vaccines. These results reveal a need for further studies to address ways to mitigate both interpersonal and institutional-level distrust when considering interventions for vaccine hesitancy.

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Introduction

Vaccine attitudes offer a valuable site for studying trust in the health system in a way that accounts for the intricacy of trust relations, as vaccine acceptance requires trust on multiple levels: the vaccine product itself, vaccine providers, and policymakers (e.g., the government and state health authorities) who regulate and promote vaccination (Larson et al. 2018).

In early August 2022, the U.S. Department of Health and Human Services (HHS) issued a proposed rule seeking to strengthen and address critical gaps in Section 1557 of the Affordable Care Act (ACA). Section 1557 is vital to the maintenance of patients' civil rights, as it "prohibits discrimination on the basis of race, color, national origin, sex, age, or disability in a health program or activity, any part of which is receiving Federal financial assistance" (U.S. Department of Health and Human Services 2022). The 2022 proposed rule specifically seeks to reinstate and reinterpret the protections and scope of Section 1557, which were severely limited in a 2020 ruling under the Trump administration. That HHS did not implement protections for unvaccinated individuals was contested among vaccine skeptics. Prominent anti-vaccination non-profit Informed Consent Action Network, in a September 2022 press release, urged its followers to "make [their] voice heard" and protest what it called a "widespread form of discrimination."

The ensuing public comments submitted in response to the Section 1557 proposed rule provide a valuable and unique source to delve deeper into vaccine hesitant individuals' personal experiences and perceptions of the social and political dimensions of vaccination. Although the skepticism expressed in the data is not limited to COVID-19

vaccines, the comments also allow for an analysis of how pandemic conditions provoked new and specific concerns. Conducting a content analysis of these particularly unique data allows for a qualitative understanding of a phenomenon often studied quantitatively.

In this study, I examine how vaccine-hesitant individuals responded to the nondiscrimination proposed rule. In particular, I am concerned with what these responses illustrate about the role of trust—both institutional and interpersonal—in shaping and reinforcing vaccine hesitant attitudes. Trust relations are fluid and ever-changing, and they are sociologically relevant insofar as they are heavily impacted by broader patterns in society. These relationships, rather than being linear, constitute a "complex 'web of interaction'" between individuals and systems, on various interpersonal and institutional levels (Meyer et al. 2008). This study takes up the opportunity presented by Meyer et al. (2008) and aims to investigate both interpersonal and institutional trust relationships. I argue that the comments submitted in response to the proposed rule illustrate a breakdown in interpersonal and institutional trust relationships that reflects broader shifts in society, which strongly impact vaccine-hesitant individuals' beliefs about vaccines.

Background and Literature Review

Vaccine Hesitancy

Although a myriad of definitions have been developed to effectively capture the phenomenon, the term vaccine hesitancy is aptly characterized as a diverse continuum of vaccine beliefs that may range from simply delaying or deviating from recommended vaccine schedules to rejecting vaccination altogether (Dubé et al. 2021; MacDonald 2015). Anti-vaccination attitudes and their proponents may fall into this continuum, but do not represent the entirety of vaccine-hesitant experiences. Vaccine uptake—the "proportion of a population that has received a specific vaccine"—cannot necessarily be taken as an indicator or measurement of vaccine hesitancy, especially given that the ultimate decision to vaccinate does not provide any information about potential underlying doubts (Dubé et al. 2021). The present study, then, is well-positioned to assess a range of vaccine-hesitant beliefs shared in a unique political context.

Vaccine hesitancy can lead to consequences that pose a serious threat to public health. These consequences range from outbreaks of preventable diseases like measles and pertussis to outright discontinuation of vital vaccine programs (Dubé et al. 2021; Rossen et al. 2019). More dire still is the potential break in herd immunity, a term describing the phenomenon whereby immunizing most of a population prevents disease transmission to the unvaccinated few. Since the threshold for herd immunity is remarkably slim, those few vaccine refusals from anti-vaccine and vaccine-hesitant individuals may very well be the difference between a protected community and a community at high risk for contracting disease (Attwell et al. 2021).

The issue of vaccine hesitancy has proven to be a serious public health challenge since the inception of vaccination. An immensely complex problem, vaccine hesitancy is determined by numerous sociocultural, historical, economic, and other factors; thus, developing a comprehensive understanding of this phenomenon requires a holistic appraisal of all of its dimensions. The Vaccine Hesitancy Determinants Matrix, developed by the SAGE Working Group on Vaccine Hesitancy, categorizes these myriad drivers of vaccine hesitancy as *contextual* (related to structural elements, e.g., socioeconomic and historical circumstances), *individual and group* (related to personal and peer-group elements, e.g., risk/benefit assessment, previous experiences with vaccination), and *vaccination* (related to the vaccines themselves, e.g., cost, access, program design) (MacDonald 2015).

Trust and Distrust

Larson et al. (2018) define trust as "a relationship that exists between individuals, as well as between individuals and systems, in which one party accepts a vulnerable position, assuming the best interests and competence of the other, in exchange for a reduction in decision complexity." The average citizen is expected to rely upon the judgment and expertise of those involved in evaluating vaccine data, and the imbalance of power resulting from such information asymmetry makes understanding trust paramount to understanding vaccine hesitancy (Larson et al. 2018).

Groenewegen (2006) describes several societal changes that have changed the face of healthcare and, in turn, transformed trust relations: increased division of labor and specialization; bureaucratization of health organizations; globalization; the

transformation of patients into self-reliant consumers seeking to decrease information asymmetry; the movement of power into the hands of third parties like the government, private owners, and insurance companies; and market penetration into healthcare activities, which is emblematic of a larger political and economic turn towards neoliberalism. This study is particularly concerned with examining the latter three shifts.

While it is true that a considerable amount of anti-vaccination information centers upon conspiracy theorizing involving "shadowy elites" and mind control operations, even these theories at times echo real anxieties about the undue influence of the pharmaceutical industry in health policymaking, concealment and corruption in health industries and government, and state control (Davis 2019; Dubé et al. 2021). Previous studies on the role of trust in influenza vaccine decisions strongly suggest that distrust in the government and pharmaceutical companies is a recurring reason cited for lack of trust (Jamison et al. 2019; Quinn et al. 2016). Jamison et al. (2019) specifically found that the profit-motive of pharmaceutical companies are viewed as "[corrupting] the entire healthcare industry." Indeed, distrust of pharmaceutical companies and their drive for profit features prominently across all demographics: age, race, and gender alike (Quinn et al. 2016).

Distrust in the government might also lead to uncertainty in the information and resources provided by state institutions like the FDA and CDC (Lee et al. 2016). In the COVID-19 context, for example, those who believe that there is a political motivation behind scientific public health recommendations have been found through survey data to be "less likely to perceive risk and adopt preventative health measures" (McLaughlin et al. 2021). In a survey study examining MMR vaccine attitudes, Justwan et al. (2019)

concluded that individuals who demonstrate lower levels of trust in health authorities such as the CDC show increased skepticism in vaccination. Similarly, earlier survey research regarding H1N1 (swine flu) vaccine attitudes confirmed that confidence in the government's ability to address the H1N1 pandemic served as a predictor of willingness to vaccinate (Mesch and Schwirian 2015). These findings may be especially applicable given the current circumstances of the COVID-19 pandemic.

Healthcare providers also play a pivotal role in vaccine attitudes. Hornsey et al. (2020) suggest that "people seem to be "pushed" into vaccine hesitancy via *mis*trust of conventional medicine." Parents with vaccine-exempt children in school, according to Salmon et al. (2005), were "less likely than parents of vaccinated children to consider medical authorities to be good or excellent sources for vaccine information," lending more credibility instead to complementary and alternative medicine (CAM) practitioners. In an in-depth interview study conducted by Peretti-Watel et al. (2019), vaccine-hesitant participants "spontaneously displayed" distrust in allopathic medicine as a whole but expressed that they sought out a physician they felt they could trust, often because the provider shared or respected their views. Glanz et al. (2013) found that parents who refused vaccines for their children were about 36 times more likely than vaccine-accepting parents to "express a low level of trust" in the vaccine information received from their pediatrician.

Methods

Data Collection

This study employs qualitative content analysis of public comments on the HHS Section 1557 proposed rule document; these comments are made available for download by the Federal government at http://www.regulations.gov. I used a purposive sampling strategy to produce my final sample from a total of 53,520 comments, which were submitted between August 3 and October 3, 2022 (the time period during which the proposed rule was open to public comment). After uploading all comments to an Excel spreadsheet, I filtered the comments to display those containing the prefix 'vaccin-' which produced 967 total results. To ensure that these data were substantive enough to allow for a robust analysis, I calculated the word count of each comment and sorted them from highest to lowest, since comments less than 100 words were generally repetitive and did not contain information that would be notable to the analysis.

Comments that briefly mentioned vaccination but primarily discussed a different topic (such as abortion or transgender rights) were removed. The two comments expressing ostensibly pro-vaccination views were excluded under this criterion, meaning the final sample did not illuminate any counter viewpoints. Duplicate comments, such as the pre-written template provided by the Informed Consent Action Network, were also removed. However, the few comments from individuals outside of the United States were included, since I deemed geographic location less important than the fact that they were responding to this specific proposed rule. regardless of whether they were mistaken about which government is instituting it.

My final data set was comprised of the 160 comments with the highest word count, ranging from approximately 110 to 900 words. Any identifiable information was removed and/or replaced by a pseudonym.

Data Analysis

I performed my analysis in the qualitative data analysis software Atlas.ti v.22, using a general inductive approach. This approach to analysis enabled me to develop my initial research question—how did commenters respond to the proposed rule?—such that I could address distrust, which quickly emerged as a major strand in the data. A simultaneous deductive dimension to the analysis considered the consistency of the findings with previous research examining the rhetoric and narratives of anti-vaccination.

Analytic decision-making and memoing was recorded in a research journal to ensure transparency. After establishing familiarity with the dataset through an initial close reading, I performed a second close reading during which I identified concepts that were notable in my review of the literature as well as potential codes, topics, and themes that I anticipated being useful in my analysis. Based on these first impressions, the data were revisited to solidify a preliminary coding scheme and develop a foundational, broad codebook, which was then revised after reviewing and briefing with a peer. I then moved forward with an initial coding of the data, using the refined codebook as a guide. The ensuing codes were grouped into two primary categories: justification for vaccine rejection and justification for inclusion as a class protected against discrimination (specifically focusing on experiences in healthcare). Following initial coding, I performed a situational analysis loosely based on Clarke (2005) and Barcelos (2018) to map out key

actors and elements in the data (e.g., healthcare workers, the U.S. government, schools, and the various contested vaccines), while also cohering salient themes and narratives that had emerged from the coding process. The comments that accurately captured the themes included in the findings were edited and corrected to ensure clarity, but all formatting (e.g., capitalization for emphasis, use of emojis) was left intact to preserve valuable non-textual information.

Findings

Roots of Rejection

Perhaps the most immediate and obvious question at hand is precisely *what* concerns vaccine-hesitant individuals about vaccines as a technology. The most frequently cited concerns were, broadly, about four issues: safety, ingredients, efficacy, and, often with respect to COVID-19 vaccines specifically, the rigor and/or depth of research (coded in the analysis as "experimentation"). Although the basis for these concerns may have reflected a very real anxiety about political and economic interests, they were often supported with false, misinterpreted, or unproven claims, consistent with previous literature about the problem of mis/disinformation in vaccine critical spaces (Dubé et al. 2021; Kricorian et al. 2021).

The COVID-19 vaccines produced by Pfizer and Moderna—the "mRNA vaccines"—were by far the most frequently referenced in these data. However, individuals also discussed their opposition to other vaccines, including varicella (chickenpox), influenza, hepatitis, HPV, MMR (measles, mumps, rubella), and Tdap (tetanus, diphtheria, pertussis). Vaccine-hesitant parents more generally described their doubts about the child and adolescent immunization schedule provided by the CDC, which includes many of the aforementioned vaccines. "Many parents feel that the explosion of the vaccine schedule is a cash cow for pharmaceutical companies," said one commenter, echoing the popular stance that the recommendation and promotion of vaccines indicates some level of collusion between state and corporate bodies for the sake of profit—a relationship that was not to be trusted.

Whether or not vaccination is actually a safe practice constituted a significant doubt among the comments submitted. Those who argued against the safety of vaccines did not always cite any particular reason for why they are unsafe or provided reasons that did not necessarily have a scientific basis, such as one comment that asserted, "Ex-vaxers [sic] have been around since inoculations started because they were just as unsafe as the disease." Unsurprisingly, issues with safety commonly occurred alongside issues with the ingredients of vaccines, a co-occurrence that has been recorded in prior studies about perceptions of vaccine safety (Salmon et al. 2015). Some of the ingredients that commenters believed to be controversial—despite their proven safety (if they are added at all)—included "mercury, aluminum, aborted fetal tissues, and dangerous pathogens," "foreign DNA from fetuses as well as other species of animals," and "carcinogens added in to be adjuvants which break the brain barrier."

The discussion about safety was largely oriented around the potential side effects of vaccines. One person, speaking specifically about COVID-19 vaccinations, suggested that they "have now, according to official VAERS data, caused tens of millions of serious, debilitating adverse reactions and tens of thousands of deaths, and yet are still pushed by all governmental and public health sources." Others claimed that vaccines have caused "literal brain damage," "more incidence of cancers," and "can cause injury to various parts of the body—even death." These claims lent themselves to a larger trend, wherein individuals relied heavily upon highly personal, emotion-laden narratives about experiences with vaccine injury to elucidate the danger of vaccinating. It is demonstrated by one commenter, who said:

> The top reason for us to stop vaccinating is because we witnessed a loved one change or die. Those that changed didn't become superheroes. They became shells of themselves with their soul trapped inside, unknowing why they are now like this.

This person went on to describe what they thought to be the fallout of their son's first MMR vaccine:

> My son gets his first MMR shot. Within 2 days regresses in speech, eating habits change to being "picky" and doesn't make eye contact anymore. You have failed my son! Thankfully TRS helped him detox and luckily he has some form of himself again.

This tendency is emblematic of one rhetorical strategy commonly employed by anti-vaccination activists, who use dramatizations and angry emotional appeals to question the safety and emphasize the risks of vaccination (Argyris et al. 2021). Risk perception indeed played a large role in commenters' overall characterization of vaccines; for many, the safety risk outweighed the utility of vaccines, whose efficacy was deeply contested. Some people saw vaccination as being minimally effective or ineffective altogether: "[COVID-19 vaccines] were marketed and promoted by the CDC as an inoculation that defends completely against this virus but did not actually deliver anything close to that promise," one person complained.

Others, however, argued that being unvaccinated was *more* effective against disease than being vaccinated: "If you do the unvaccinated vs. vaccinated study, you'll find out that the unvaccinated are far more healthy than their vaccinated counterparts," suggested one commenter. In a similar vein, other commenters claimed,

> It has been found that those who chose not to take the [COVID-19 vaccine] have a better chance of combating the virus than those who, out of fear, succumbed to the government's edict.

> My children are not all the way vaccinated and her healthy and hardly ever miss school due to illnesses, yet my completely vaccinated niece and nephew miss

> many weeks of school each semester due to illnesses. I know for a fact they are all related to vaccines and their ineffectiveness.

The issue of efficacy has been a longstanding feature of vaccine-hesitant discourse, ironically arising alongside concerns about ingredients (which were frequently added in pursuit of improving vaccine effectiveness) (Dubé et al. 2021). These misconceptions about efficacy, which are frequently introduced by the internet and news media, have been exacerbated by COVID-19 (Biswas et al. 2021; Dubé et al. 2021). Specific to the COVID-19 vaccination campaign was a misguided concern that the vaccines given were not properly or thoroughly tested before mass administration, which one person suggested was "stage three [of the] clinical trials." Commenters frequently referred to the vaccines as "experimental drugs" that were "basically … untested." These concerns illuminated commenters' overall distrust of pharmaceutical companies and the influence of corporate power in the state, which was seen as fraudulent, deceptive, and corrupt:

> …I along with many other millions of people will not be subjecting our God-given bodies to man-made liability free, so-called medicine. And medicine that does not have a good safety profile, that is regulated by an agency that has been captured by the very pharmaceutical companies it is supposed to regulate. It's all very corrupt.
>
> Fascism defined is government agencies lining their pockets as they pave the way for corporations to become filthy rich. If the shoe fits, wear it! You are a fascist agency, whether you realize it or not you have lied, stolen and murdered the very people you claim to represent.

The relationship described in these comments between the state and corporations is a hallmark of neoliberal capitalism, which was ushered in beginning in the 1970s through deregulation, privatization, and an ideological move away from "the idea of governments as direct providers of public goods, such as … healthcare" (Green and Bell

2022). In theory, neoliberalism requires that the state must limit its interference in economic and social arenas; in practice, however, neoliberalism has transformed the state such that it now ultimately serves the market—it is intimately connected with corporate interests, mobilizing its resources to surveil and maintain market power (Lebow 2019; Holloway 2018; Navarro 2007). Attwell et al. (2017) describe from an Australian context how vaccine-rejecting parents view this connection as untrustworthy, with pharmaceutical companies working as "puppet-masters" behind the state, especially in the United States. It is clear here how these doubts are echoed by and translate to vaccine-hesitant individuals in the United States, sowing a deep distrust in both the pharmaceutical companies and the government involved in vaccination.

Encounters in Medicine

Experiences in healthcare settings such as hospitals, clinics, pharmacies, and rehabilitative centers featured prominently in vaccine-hesitant individuals' comments about supposed discrimination against the unvaccinated. Poor encounters with healthcare providers were often characterized by a strong sense of coercion or undue pressure to vaccinate. In contrast to "honest doctors," who "present multiple options with pros and cons," these providers engaged in behavior that vaccine-hesitant patients generally perceived as abusive. "Only after being bullied by the pediatrician, I finally gave the go ahead for [my daughter's] MMR," one person commented, echoing a comment from another individual who said they were "…made to feel uneducated, irrational, and [like I] didn't know my baby." Similar to the vaccine injury narratives used to justify their

vaccine rejection, in-depth, emotional stories were employed to illustrate the shame and stigma people faced from various healthcare workers.

> The way I was treated at my doctor's office when I refused to get the flu and COVID vaccines was awful. She talked down to me and acted angry at my refusal to get both the flu and COVID vaccine. She stated, "I hope you don't get COVID and bring it home to your husband and he dies." Then said, "I hope you don't die," in the most disgusting tone of voice … She acted so mad, like nothing I have witnessed before.

> I was denied the filling of my Ivermectin prescription at my local independent pharmacy. I politely engaged and challenged her as to why. After presenting data from several peer-reviewed sources to her, she became frustrated and belligerent and shouted, "just get the vaccine!" … [She] raised her voice commanding me to take the vaccine. She abruptly turned and left me standing as other people watched. So basically, she was refusing me a lifesaving treatment, and demanding I take an unproven, experimental product. All in front of other customers and employees.

These conflicts, together with various protective measures such as requiring masks, testing, or spatial separation from vaccinated individuals, served to reinforce their feelings of alienation and, subsequently, their vaccine hesitancy, especially since the right to reject medical advice is key to the beliefs about informed consent and freedom discussed later in the findings. The role of healthcare providers is crucial in developing a strong understanding of vaccine hesitant beliefs. Physicians and nurses in mainstream biomedicine are, overall, the most trusted source of vaccine information, and positive encounters with healthcare providers have been shown to improve the likelihood of vaccine uptake, including in parents who believe vaccines are unsafe (Smith et al. 2006; Dubé et al. 2021).

In many cases, the eventual outcomes these people described (for themselves and/or their children) were that (1) they were refused or offered a modified version of treatment, and/or (2) the provider severed the client relationship and barred them from

receiving further services at that practice. Unsurprisingly, these outcomes constituted a major concern:

> The unvaccinated citizen is entitled to health care, equally entitled as any other group. It has become pervasive in some medical institutions and among some doctors to discriminate against the unvaccinated by refusing treatment or enacting stringent guidelines that make receiving treatment difficult, if not impossible.

Whether and how vaccination should be considered in determining the administration of treatment and/or services has been the subject of an ongoing and heated ethical debate (Conklin 2022; Klitzman 2022). These individuals were deeply worried that their decision to reject vaccination precluded them from receiving appropriate medical care, especially because finding physicians who accepted their viewpoint presented a serious challenge. As a result, many people who were removed from allopathic medical practices decided instead to see complementary and alternative medicine (CAM) practitioners:

> In the long run, this was a blessing in disguise, because we never saw a pediatrician again for [their daughter or her younger sibling] and we did all care through chiropractic. Had that pediatrician not treated us so badly, we may have never known the health services available through chiropractic care.

> I have driven 15 hours to take my child to a naturopathic doctor who is also a state award-winning pharmacist of the year who understands medication and natural cures and treatments and how they interact. She offers full informed consent and does not threaten to kick you out of the practice if you don't do exactly as you are told by the CDC or follow some guidelines that could cause physical harm.

Attwell et al. (2018a) suggest that vaccine hesitancy and CAM have a "symbiotic relationship," in part because "both derive legitimacy from a larger expert system that elevates parents' own expertise, unlike the biomedical expert system." This validation, as expressed in the data, was not generally present in vaccine-hesitant individuals' encounters with mainstream healthcare providers.

Science and Truth

Crucially, CAM may be popular with the vaccine-hesitant in part because it enhances self-trust: the confidence in one's own competence and expectations about future actions (Attwell et al. 2018a). In these data, the idea of self-trust was particularly salient, representing a larger theme whereby vaccine-hesitant individuals, who generally did not believe in allopathic medical providers or scientists, positioned themselves as "truth-seekers."

As truth-seekers, these people made a point to "do their own homework," beyond the expertise of the health professionals who shunned them, making them knowledgeable about the real data and truth: "I have done more research apparently than this pediatric dentist or nurse ever has on this subject … why is this not talked about more? Why don't pediatricians know about this?" asked one person, who diagnosed her daughter with "methylation issues" using an at-home DNA test. According to another, the unvaccinated were "ostracized by the medical community and others" because they chose to be cautious after they "read the data and the studies, used proper treatment when we got sick, and are glad we did." That COVID-19 vaccines were promoted at all was, to another commenter, an indication that we have "well surpassed the logical and rational decisions of real, ethical scientists and doctors," who did not see the dangers of the ingredients they added to vaccines.

Although the idea of "doing your own homework" comprised a large part of the truth-seeker position, these individuals ultimately asserted that choosing to reject vaccines involved a level of enlightenment and intelligence that vaccinated people and

scientific institutions did not have, or did not care to develop: "My intuition, reality, and facts are never wrong, and [mandating vaccination in the workplace] is negligence and discrimination against a life, my life," one unvaccinated nurse claimed, comparing her intrinsic, second-nature hesitancy to the situation of a "transgendered person." Another individual cited "common sense and logic" as two of the myriad "good, legitimate reasons" one may choose not to get vaccinated. Relying on natural immunity and other forms of COVID-19 mitigation rather than vaccines was "smart." Truth-seekers saw beyond the fraud and deception to reality, and chose to operate based on "real" facts and science:

> Do NOT allow any deviation from true scientific method! Let ALL voices be heard and respected so that actual "facts" can emerge… and not just the desired/incomplete (on purpose most of us believe!) downright evil "narrative" can prevail over real science and basic common sense.
>
> What is most unbelievable and frightening to me is that many people in America don't even know they are being censored and lied to by these tyrants ["corrupt money driven billionaires, pharmaceutical companies, central banks, media companies, newspapers and insurance companies"].

Ultimately, the discrimination they experienced was perpetuated by people who were not committed to or grounded by "real data." The narrative found here confirms an interview study from Attwell et al. (2018b), who found that vaccine-rejecting Australian parents often characterized those who chose to be vaccinated as ill-informed, ignorant, and inferior in terms of health practices, in opposition to their well-reasoned, carefully researched, thoughtful awareness of the pitfalls of vaccination. In this case, the narrative extended beyond those who made the mainstream choice to vaccinate and included other actors involved in such decisions, such as the conventional medical and scientific establishment.

The overarching theme of institutional distrust is apparent, captured by one comment that said, "We just have to trust the people in white lab coats. These people have been wrong on many accounts and often have nefarious agendas afoot." Hendriks et al. (2016) argue that "trust in scientists is not only based on features that are indicative of the epistemic quality of their work … but also their moral integrity … as well as the usefulness of their work for the benefit of society." As previously discussed, the vaccine-hesitant individuals in these data routinely pointed to the poor efficacy and "experimental" nature of vaccinations as a driver of their vaccine rejection. Terms and phrases like "downright evil," and "nefarious agendas," illuminate the moral dimension to the way these individuals view scientists and scientific institutions.

Freedom and Tyranny

A primary concern of commenters was about informed consent; specifically, they argued that HHS not expressly prohibiting the various instances of discrimination described above—a non-action viewed as the equivalent of allowing and/or encouraging acts they perceived as discriminatory—negatively impacts the right to informed consent. In particular, not protecting vaccination status under Section 1557 would allow people to be coerced into agreeing to vaccines, which is antithetical to informed consent:

> All human beings must always be free to make their own informed decisions regarding their bodies and medical procedures, based on their individual risks and discernment and should never be coerced through methods of discrimination for doing so.

Another commenter shared similar concerns, but suggested instead that the discrimination experienced by individuals unvaccinated for COVID-19 was *secondary* to

the decision they had made based on informed consent; from this perspective, the right to informed consent was eroded by the response, rather than the strategy for delivery:

> These "Unvaccinated" American citizens suffered real harm in the form of lost jobs and homes, and the denial of other needed medical care for nothing more than saying, "As an adult human being, I alone have the greatest understanding of my body, health and health history, and the greatest vested interest in maintaining my health, well-being, and ability to work. Therefore, I alone am able to make the best and most fully informed choices for my health, and I have the God-given right to do so without interference from anyone whose understanding and interest is less than my own."

Furthermore, in making this argument, they frequently referred to international law; the purported claim is well-illustrated by one commenter, who said, "The mandates, restrictions, and discrimination against unvaccinated individuals is unconstitutional and actually violates the Nuremburg Code." This particular comment begins to reveal a more interesting pattern about how vaccination was viewed politically—a pattern wherein narratives about vaccination were intimately linked with vaccine-hesitant individuals' identities as *Americans*. The Nuremburg Code was certainly a key legislative element, but the Constitution and the Bill of Rights were equally as important. The possibility of violating international law was unacceptable, but the possibility of HHS supporting actions they deemed unconstitutional would shatter the foundations of what the United States stands for. This was expressed by one commenter, who asserted,

> Aside from being just sick and wrong, it is unconstitutional. The United States of America is a constitutional republic, not a totalitarian state, which is where we are headed if people are not allowed to have informed consent regarding their very personal health care. Informed Consent is the first article of the Nuremburg Code and should be protected at all costs.

This commenter's worry about a "totalitarian state" was emphasized in another comment, which reminded, "We live in the United States of America not Nazi

Germany!!" Invoking Nazism and totalitarianism in the vaccine context was in many ways a part of a larger story regarding their beliefs about what the United States represents: democracy and freedom. "How is this even happening in America?" one person asked, "Where have our rights and freedoms gone?" Another suggested that nondiscrimination signifies "fairness and equal treatment," which, to them, was a "worthy aspiration and a foundational concept of the United States of America." Lamenting the end of pure American liberty, one individual said,

> So long are the days of progress, we have regressed to a medieval mindset. Our forefathers are turning in their graves, how we allowed tyranny to come back after fighting a revolution to be independent. Independence Day is now a joke as we are now back to being ran by tyrannicals [sic] for greed.

Some people's concern about "un-American" tyranny spilled over into doubts about the potential involvement of the United States's geopolitical adversaries, particularly China: "China DOES NOT have a child vaccination requirement. They keep their citizens healthy while weakening ours. Wake up AMERICA!!!" one commenter argued. Indeed, discrimination against the unvaccinated was so authoritarian that, in another comment about China, the same person who described nondiscrimination as foundational to the U.S. considered what it might mean that the NIH was "involved in gain-of-function research at Wuhan."

The culmination of these fears about what the United States might become if left unchecked was the assertion that *real* Americans, those who supported non-vaccination, would simply not let it happen; they were "freedom-fighters," combating the encroaching authoritarianism and tyranny by fighting for the right to refuse vaccination. This was often framed in terms of revolution or war: "Think of our people before we revolt,"

warned one person. ""We, the people," are the power. You, "the Government," and the private materialistic people must listen to us. I will fight for my species' birthrights," another declared. They often referred to the impending consequences for the authoritarians and tyrants who did not heed their warnings, suggesting that those people and institutions would be punished for breaking the law:

> Maybe the most important question or statement I'd like to share with you, HHS dictators (dics for short ☺), IF you THINK we TRUE AMERICANS will allow YOU and/or your corrupt and lying agencies to force us to take your so-called "vaccines" or any other medical therapies WITHOUT OUR CONSENT, (informed or not) or TELL US how to CARE FOR OURSELVES AND OUR LOVED ONES AND COMPLY WITH YOUR UNLAWFUL MANDATES, GUIDANCE, SUGGESTIONS, etc…etc…then I suggest you … be as smart as the virus may be ☺

The "freedom-fighter" narrative overall demonstrates the close relationship between trust in the government and attitudes towards vaccination—specifically, attitudes towards modes of vaccine delivery.

Social Consequences

Although not the main focus, vaccine-hesitant individuals often used non-healthcare related social consequences to bolster their arguments about the discrimination they were experiencing. Here, the analysis was split into two categories: social restriction and social ostracization.

Social restriction described situations in which non-vaccination legally barred individuals from entering particular spaces or participating fully in social activities, generally due to mandates. One of the primary social consequences vaccine-hesitant individuals discussed in this category was employment. "We now have to decide where

we live, what jobs we have, all based on what state laws are … and what employers try to regulate for their employees," one person said, describing the outcome of their decision to no longer vaccinate. People also brought up loss of employment—or the threat of it—as a form of discrimination they experienced, largely related to COVID-19 vaccination:

> I have several family members who initially chose not to get the COVID vaccine but eventually had to comply or lose their jobs. That is not acceptable under any circumstances … I thankfully was able to retire before I had to make that unfair and unethical decision.

Issues of employment sometimes intersected with vaccine injury narratives. This was most frequently the case with individuals who had been required to be vaccinated by the military or in healthcare settings:

> I was injured by a Hepatitis B series of vaccines I had to take for a healthcare job … I will never be able to take another vaccine. Nor will I ever be compensated by the company who required I do this if I wanted to keep my job.

Vaccine-hesitant parents were particularly concerned about the restrictions on education. They often described having trouble finding schools to accept their children, or being turned away from opportunities due to their child's vaccination status:

> …my children are unable to go to certain schools because I refuse to give them vaccines after she was neurologically damaged by them. She could not go to a Headstart program because they require fully vaccinated children.

Beyond issues in employment and schooling, which comprised the most frequently mentioned sites of discrimination, vaccine-hesitant people also discussed COVID-19 pandemic-specific issues with entering coffee shops and restaurants, entering airports and other travel-related areas, being allowed to volunteer, and being allowed to participate in sports. One person recognized that vaccination was mandated both by local

government officials and individual establishments, but the concern overall was that these restrictions made it difficult, if not impossible, to live their normal lives.

On the other hand, social ostracization was defined by a more general sense of alienation in interpersonal and/or group relationships. They described a feeling of alienation from others, as well as the shame they experienced, especially when they came into contact with vaccinated people. Those who decided not to vaccinate were "demonized," "marginalized, vilified, and shamed," and "labeled" as unvaccinated or anti-vaxxers. They often told stories of how their family and/or friends treated them differently due to their vaccination status:

> [My sister's] pediatrician told my sister that if we don't get the Tdap vaccine, then we can't be around her children, or we will kill her children. This has been extremely hard on my family, as my sister took this discriminatory and false advice from her pediatrician seriously. I have never met my nieces … and I am completely estranged from my sister and her family. Our mom has since learned the dangers and risks of vaccines and won't get them either, so my sister has barred our mom from seeing her family too. This has been emotionally and mentally very difficult for me, my family, and our mom.

During the COVID-19 pandemic, this perception of stigma was reinforced by the protective measures mandated for those who were not vaccinated, such as required masking or testing. One person described their experience as an unvaccinated teacher:

> [The school nurse] was forced to test me weekly for the COVID-19 virus … I was made to stand in a hallway where other adults and children could see me. Most people figured out quickly that the line was full of unvaccinated people.

These findings confirm an interview study conducted by Wiley et al. (2021), who found that non-vaccinating parents' social experiences pointed towards a process of "systematic stigmatization" wherein they felt labeled, stereotyped, othered, and resulting a loss of status, all of which strengthened their vaccine refusal.

Discussion and Conclusion

This content analysis of public comments submitted in response to the HHS proposed rule on Section 1557 of the ACA illuminates how vaccine hesitant individuals justify and describe their vaccine hesitancy. I argue that these justifications, and the narratives constructed about vaccination, provide insight into the institutional and interpersonal distrust that ultimately underpins their vaccine hesitancy.

Justifications for vaccine rejection, which were which were highly consistent with previous literature regarding the determinants of vaccine hesitancy, were largely concerned with efficacy and safety risks. Calculations of risk are inextricable from calculations of trust (Ekberg 2007). Beck (1992) theorizes that the world has transitioned from an industrial society to a society organized around risk. The postmodern risk society is organized around uncertainty engendered by the scientific and technical progress of the industrial age—progress that has required that society grapple with new risks that are technological and manufactured, rather than natural. In such a society, the management of risk through the maintenance and trust in expert systems in turn causes an uptick in anxiety and doubt, as science no longer appears as an unerring truth (Ekberg 2007). This phenomenon is apparent here, where vaccine hesitant individuals not only call attention to the inefficacy and fallibility of science, but also to its producers, who are no longer rational actors. In the face of uncertainty, these individuals take it upon themselves to negotiate risk, positioning themselves as "truth-seekers" and researchers who "do their own homework." Further, the truth-seeking tendency demonstrates the societal shift towards patients as self-reliant consumers.

By "proving" that vaccines are unsafe and ineffective through visceral narratives about vaccine injury and harm, vaccine hesitant individuals ultimately called into question the motives of the pharmaceutical industry that manufactures them. Furthermore, it called into question the relationship between state and corporate power, reflecting an anxiety about market-first economic policies specific to neoliberalism, which has reorganized healthcare and medicine. Their distrust of the United States government specifically was reflected in the worries they expressed about tyranny and authoritarianism, which ultimately led to their positioning their fight for the rights of the unvaccinated as being a fight for freedom.

Vaccine-hesitant individuals often shared stories of experiences they felt were discriminatory in healthcare settings. Although the two main forms of discrimination they described were being refused regular treatment or being removed from the practice altogether, the way healthcare providers communicated with them about vaccination was also significant in shaping their attitudes. Vaccine-hesitant patients who had poor experiences with providers generally felt that they could not trust physicians and sought out more trustworthy providers instead. Their vaccine hesitancy was further reinforced by other stigmatizing social experiences, both in employment and school settings as well as in interpersonal settings with family and friends.

The question of sufficiently addressing vaccine hesitancy is difficult to answer and efforts thus far have had mixed results (Jarrett et al. 2015). Challenging vaccine criticism would require a "collaborative community approach" to manage and shift risk perception (Dubé et al. 2021). Chou and Budenz (2020) suggest that "positive emotional appeals" to counteract the otherwise negative emotions at the forefront of anti-

vaccination campaigns, such as promoting prosocial, community-oriented motivations for vaccinating, may be part of a viable strategy. Multi-level, dialogue-based interventions appear to be the most successful overall (Jarrett et al. 2015). Importantly, communication about vaccination should be transparent and open (Dubé et al. 2021).

This study is limited by several notable factors. Because of the variation in vaccine hesitant experiences by locale—which impacts the historical, social, cultural, and other contexts within which vaccine hesitant individuals operate—this study is not representative of all, or even most, vaccine hesitant individuals. Individuals who submitted comments are English-literate (there were no comments submitted in other languages) and have or had internet access, which excludes a considerable number of people who may also be vaccine hesitant. There are also no demographic data included, so these characteristics are precluded from the analysis, even if some commenters may have chosen to self-identify. Commenters generally did not explain the sources of their information, and thus there was no way to trace the misinformation they often based their concerns upon.

Despite these limitations, the data used in the current study remain useful to this analysis because they enable an understanding of how vaccine-hesitant individuals detail their own vaccine attitudes and beliefs; furthermore, that the comments are submitted to and aimed at one object of these individuals' distrust offers a particularly distinct perspective.

Future qualitative research on the topic should aim to include demographic variables, as this study is highly limited by the anonymous nature of the data; this is especially important considering that the vaccine question is both racialized and gendered

(Choi et al. 2022; Reich 2014). Furthermore, research should aim to generate institutional-level strategies to address the layered distrust that is at the root of vaccine hesitancy.

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