

Questioning Science with Science: The Evolution of the Vaccine Safety Movement

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ABSTRACT

This paper sets out to understand the values that motivate vaccine safety advocates who question the safety of vaccines and oppose vaccination mandates. As is generally the case for public scientific controversies, the vaccination debate is inherently asymmetrical. The vast majority of medical researchers advocate for vaccination mandates. While a (smaller) majority of the general public also support vaccination mandates, a vocal and growing minority opposes vaccination mandates. This minority is generally dismissed by most mainstream voices in the scientific literature and the mass media as uninformed and irrational. However, efforts to sway these individuals through public health campaigns have been largely ineffective to date. To understand the factors that motivate individuals within the vaccine safety movement, we conducted interviews with 10 individuals who self-identify as vaccine safety advocates, asking them about the values and information behaviors that have shaped their skepticism of vaccines. Using thematic analysis, we identified four key themes that reoccurred across these interviews: benevolence toward children, intellectual curiosity about vaccines, skepticism toward scientific elites, and respect for the scientific method. The results of this study can help us to understand how values motivate individuals to take positions outside of the mainstream in public scientific controversies, such as climate change and genetically modified foods. Further, the findings help to demonstrate that enhanced understanding of the values that motivate vaccine safety advocates can help us to create shared dialogues that unite rather than divide factions within the vaccination debate, moving from conflict to consensus.

KEYWORDS

public scientific controversies, vaccination debate, vaccine hesitant, anti-vaccine, information and human values

INTRODUCTION

A common tendency is to treat those outside of the scientific mainstream as ill-informed or irrational. In contrast, Martin (2014) argues for the need to understand and highlight the

human values that animate scientific controversies. He asserts that scientists and engineers routinely act as if debates around scientific controversies such as abortion, creation science, pesticides, fluoridation, nuclear power, smoking, climate change, nanotechnology, genetically modified organisms, and vaccination are purely factual in nature, however the judgment is in itself a value judgment, but an unstated (and often unquestioned) one.

This paper focuses on one particular public scientific controversy, the vaccination debate, focusing in particular on understanding the values that motivate the beliefs of individuals who self-identify as vaccine safety advocates. The paper begins with a brief history of the vaccination debate, culminating in posing the question of what values motivate individuals to self-identify as members of the vaccine safety movement. We then describe the interview-based approach that we took to understanding these individuals' values, and the open-coding approach that we used to analyze the interview data. We report the results of the interviews, describe how they relate to the literature to date, and discuss their implications for theory and practice.

TERMINOLOGY

Both in the literature around the vaccination debate and among people in the movement, there is inconsistency with the terminology used to describe people who are critical of vaccines. These individuals are often referred to as "anti-vaccine" or, often pejoratively, "anti-vaxxers." They may identify as "vaccine hesitant" in cases where they seek a more moderate positioning or "pro-vaccine safety" to cast their position as affirmative rather than negative (similar to the abortion debate, where the two sides label themselves as "pro-life" and "pro-choice," with few seeking to be labeled as "anti-life" or "anti-choice"). While any binary classification inherently flattens a much richer spectrum of opinion on this debate (MacDonald & SAGE Working Group on Vaccine Hesitancy, 2015), in the spirit of attempting to adhere with how our participants articulate their stance, we adopt the term *vaccine safety advocate*.

BACKGROUND

In 2000, the Centers for Disease Control and Prevention (CDC) declared measles eliminated from the United States (Papania et al., 2014). In 2014, more than 50 years after the introduction of a vaccine for measles in 1963, 667 cases of measles from 27 states were reported to the CDC, more cases in one year than the total of a 10-year period from 2002-2011. In addition, the United States has seen a rise in cases of per-

tussis, also known as whooping cough. There was a 15% increase in reported cases of pertussis just from 2013 to 2014 (28,639 to 32,971 cases respectively) (CDC, 2015). The recent spike of preventable diseases like measles and pertussis is a pertinent public health concern because both are highly contagious and have the potential for negative, lifelong effects. With the widespread availability, distribution and promotion of vaccines that prevent these communicable diseases, it is surprising to see an uptick in cases over the past few years.

This recent rise in vaccine-preventable communicable diseases in children has been attributed to the growing trend of parents deliberately choosing not to vaccinate their children. While there are a variety of reasons why a parent may choose to not vaccinate, the most common reason is because they do not believe that the benefits of the vaccines outweigh the risks (Funk, Kennedy, & Hefferon, 2017; Kennedy, Brown, & Gust, 2005; Olpiński, 2012). In the United States, it is mandatory that a child be vaccinated to attend private, public or parochial school. While legislation varies from state to state, most states offer a medical exemption and a personal belief/religious exemption to this requirement. While this has worked for many years, there are growing pockets/clusters of parents who are opting out of vaccinating their children.

This is a major public health concern because when there are large clusters of people who are not vaccinated, it is much easier for communicable diseases to spread. The choice to not vaccinate against those diseases potentially affects not only the health of their own children but also the health of immunocompromised children and adults, and those too young to be vaccinated. Their immune systems are either too weak or not adequately prepared to defend against measles, whooping cough or other like diseases. Through herd immunity, communities are able to keep those who are unable to be vaccinated and the immunocompromised safe from infection. Herd immunity is the concept that if a large portion of a community is vaccinated, then when someone who is not vaccinated catches a disease, the disease will have much greater difficulty spreading through the community and protect those are not vaccinated (Fine, 1993; Fu, Rosenbloom, Wang, & Nowak, 2011).

Vaccine dissent is not new. As long as there have been vaccines, there has been resistance against them. The modern-day movement has arisen largely as a result of a (since retracted) journal article published in 1998 by Andrew Wakefield that suggested a link between the MMR (measles, mumps, and rubella) vaccine and autism. Although the claim of a link between vaccines, particularly the MMR vaccine, and autism has been widely discredited, it is still one of the most commonly cited reasons of causing distrust in the MMR vaccine and other vaccines (Jones et al., 2012; Kata, 2012; MacDougall et al., 2015). Wakefield continues to advocate against the use of vaccines, and still holds a strong following among vaccine safety advocates.

Throughout the literature on the vaccination debate, values come up as an emergent theme. Values are commonly described as what is important and salient to a person in their life (Fleischmann, 2014; Friedman & Kahn, 2008; Rokeach, 1973; Schwartz, 2003). These can manifest through goals, preferences, attitudes and beliefs. There are a wide number of

ways that researchers operationalize or measure values. Cheng & Fleischmann (2010) developed a meta-inventory to bridge different disciplines' understanding of values. Schwartz (1994) proposes in his work that values are universal throughout cultures and people. Martin (2014) argues in his book that there is a need to understand the relationship between human values and opinions, decisions, and behavior, particularly in relation to scientific controversies. Values are cognitively related to attitudes about topics which can influence the decisions people make about topics (Hitlin & Piliavin, 2004). Previous studies have shown that there is a relationship between values and attitudes towards controversies (Cheng, Fleischmann, Wang, Ishita, & Oard, 2012; Templeton & Fleischmann, 2011) and this arguably applies to scientific controversies as well (Fleischmann, 2003). Values prove to be a consistent predictor of how a person will feel, generate an opinion or even vote on a particular issue.

Values are relevant and key to understanding the vaccine controversy. Values have influence in public policy (Fisher, 1978; Wallace, 1963). It has been found that values guide decision and opinions on health care policy issues, particularly in cases in which people have low ambivalence about the topic and low knowledge about health care reform (Blendon et al., 1994). Values are often used as a guide for voting or decision making, particularly in cases where a person lacks information or interest in a topic (Price, 1992). Values have even been found to influence attitudes and how issues are framed regarding vaccine legislation (Dekker, 2008). Values have relevance when discussing legislative matters involving the vaccination debate and public health policies. They are also seen when discussing community level influences. There seem to be unique values salient to the vaccine safety community as observed through a content analysis of vaccine safety websites and messages (Brunson & Sobo, 2017; Mitra, Counts, & Pennebaker, 2016; Moran, Lucas, Everhart, Morgan, & Prickett, 2016; Wang, Baras, & Bittenheim, 2015). A content analysis of vaccine safety websites found that values of freedom, choice and individuality were prevalent throughout their content (Moran et al., 2016). There is also evidence to support that values play a role in forming opinions and attitudes about different organizations and institutions. Vaccine safety advocates tend to hold more negative views or attitudes and less trust in pharmaceutical companies and the government. (Funk, Kennedy, & Hefferon, 2017; Goldstein, MacDonald, Guirguis, & SAGE Working Group on Vaccine Hesitancy, 2015; Gust et al., 2005; Salmon et al., 2005; Scherer, Shaffer, Patel, & Zikmund-Fisher, 2016). For both interpersonal and individual levels, values are inherent in how a person interacts with other people & health care providers, and in how they form opinions and decide what is salient. A study of vaccine safety messages and attitudes in social media found that new converts to the vaccine safety movement converted as a result of their prior values and beliefs (Mitra et al., 2016). As such, it is evident that values play a vital role in the formation of attitudes about vaccines.

What the public thinks about scientific institutions and scientists ultimately can reflect upon what they think about scientific claims. Based upon theories about how elites influence the public's opinions, the Gateway Belief Model (GBM) has emerged. The GBM states that people's beliefs on scientific issues are heavily influenced by the beliefs of the scientific

community (van der Linden, Leiserowitz, Feinberg, & Maibach, 2015b). When there is low consensus within the scientific community (or elites), there will be greater confusion or conflicting opinions about that scientific issue in the public. If there is greater consensus among the scientific community, there is less uncertainty among public opinion. This model shows some promise for application to scientific controversies such as genetically modified (GM) foods and vaccines. A study found evidence that by increasing the perception of consensus in the scientific community, it improved support of GM foods; however they found that people who had low support of GM foods prior to the start of the study were less affected by the GBM (Dixon, 2016). This model was also applied to improving opinions and support of vaccines, which did find evidence to support for the GBM, but the GBM may not work for those who already have very low vaccine support (van der Linden, Clarke, & Maibach, 2015a). While the model shows promise for the majority of the public, it may not be effective for vaccine safety advocates.

This brings up concerns about whether there should be efforts to reduce the prevalence of online information advocating for vaccine safety. As per the GBM, providing a balanced message of both positive and negative information about vaccines can increase uncertainty about the autism-vaccine link versus receiving only pro-vaccine materials (Dixon & Clarke, 2013). Following this model, the appropriate tactic would be to limit the amount of vaccine safety content available. This question brings up part of the vaccine safety community's complaints about censorship. There have been numerous incidents where vaccine safety articles are removed from sites like Huffington Post or delisted from Google's search results. This echoes Brian Martin's concerns about censorship and free speech in the vaccination debate. Martin (2015) suggests, while acknowledging the danger of giving the vaccine safety community a platform, censorship of vaccine safety material only amplifies tensions between the two sides of the debate. Besides being exposed to multiple messages causing confusion, misinformation can have long-lasting effects. Both sides in the vaccine debate hold that the main challenge is misinformation, although what they would label as misinformation varies widely. Belief echoes, which are attitudinal effects of misinformation, are incredibly difficult to change, even after the misinformation has been corrected (Thorson, 2016). Not only does misinformation have long lasting effects, trying to correct information about vaccines can have a backfiring effect and further polarize a person on this topic (Martin, 2015). A common side effect in vaccine information studies is that vaccine safety advocates, after being exposed to vaccine advocacy material, become more confident and solidified in their vaccine safety advocacy (Attwell & Freeman, 2015; Betsch & Sachse, 2013; Nyhan, Reifler, Richey, & Freed, 2014). There is some work being done on how to minimize the backfiring effect through prevention strategies, but there is still much to be done on this topic (Peter & Koch, 2016).

In addition, there is growing evidence that following a deficit model to change attitudes in scientific issues is not effective (Sturgis & Allum, 2004). The deficit model states that low knowledge on a scientific topic is what leads to low public understanding and therefore negative attitudes about scientific topics; however, this model is proving to be less and less

precise in explaining attitudes on scientific topics, particularly vaccines as a person can be highly knowledgeable on a topic and still hold negative attitudes (Faasse, Chatman, & Martin, 2016; Hart & Nisbet, 2012; Sturgis & Allum, 2004). In a study analyzing comments from both sides of the vaccination debate on Facebook, vaccine safety comments were found to have more analytical thinking and provide more scientific sources when compared to vaccine advocacy comments (Faasse et al., 2016). As it stands, the models that are currently used to understand dissenting opinions on vaccines are incomplete and do not capture the entire vaccine safety movement. There are still unknowns and misconceptions about the movement.

METHODS

This study focused on active and vocal members of the vaccine safety movement. Ten participants (eight women, two men) were recruited from an autism conference, an online forum and through snowball sampling. All participants completed an online consent form approved by the University of Texas at Austin IRB before engaging in a phone interview. Interview questions covered topics from how they came to hold their beliefs about vaccines, the sources of information they trust, their interactions with others about vaccines, and their values. Semi-structured interviews lasted on average for an hour (45 - 80 min) and were recorded to facilitate transcription. Participants were geographically distributed across the United States and had occupational roles ranging from advocating full time for vaccine safety to health care, academic research and technology. In addition, participants also had a range of higher education degrees (e.g., PhD, MA) and certifications.

We used thematic analysis (Braun & Clarke, 2006) to analyze the interview data. The first author, who conducted all 10 interviews, took detailed notes during each interview and audio recorded each interview. Based on a review of the detailed notes, the first author identified some emergent themes from the data, informed by the broader literatures on human values and the vaccination debate discussed above. The second author then independently reviewed the notes and themes, and they collaboratively developed an analytical framework for understanding and interpreting the interview data, boiled down into four key value-related themes that cut across multiple interviews and best represented the interview data.

Finally, we employed respondent validation as a means for validating our results (Torrance, 2012). Participants were given the opportunity to review a draft of this paper to provide feedback on the content of the paper and their own quotes. We used this feedback to ensure that our results accurately depicted the views of our interview participants.

RESULTS

As a result of our thematic analysis, we identified a consistent pattern in the values and evolutionary decision-making process of our participants in their journey to becoming vaccine safety advocates. Eight of the ten participants were initially in support of or ambivalent about vaccines prior to eventually evolving to become vaccine safety advocates. This pattern of conversions was made up of four values: benevolence toward children, intellectual curiosity about vaccines, skepticism toward scientific elites, and respect for the scientific method. This section will outline each of these emergent themes.

Benevolence toward Children

During the interviews, participants were asked to describe how they came to hold their attitudes and beliefs about vaccines. While not all of the participants had children of their own, several participants described incidents involving their own children, or children they were close to, having serious, negative health effects, and in the case of one participant, death, in reaction to the child receiving a vaccine. While not every parent in this study has a child (or close to a child) with a vaccine injury, the participants' concern for children (both their own and others) was consistently mentioned. To sum up the theme of what led most participants to first doubt the benevolence of vaccines, participants consistently stated a strong concern for the safety, health and wellbeing of children. This conflicts with the trope that vaccine safety advocate parents are "selfish" and "only care about their children and not others." Participants' concern for children's well-being goes beyond just their own children, but extends to all children, both in the United States and worldwide.

Participants emphasize that their viewpoints or their attitudes come from a desire to protect children. One participant stated, "So the question becomes how can we protect against diseases...the best way possible without doing collateral damage to children's bodies and children's brains." One participant stated, "I think we are screwing up a whole generation of kids and something has to change." Another participant described how she had never questioned vaccines. Her children and grandchildren were vaccinated because that is what they thought was best. Only after learning and hearing about countless stories of girls suffering from side effects from the human papillomavirus (HPV) vaccine and experiencing terrible injustices from the medical system, she shifted her opinion. When asked about her advocacy work, she said, "I know it's saving lives. I know it's saving families." In addition, many participants brought up the predictive statistic that if the autism rate keeps climbing at the same rate, by 2032, one out of two children will develop autism spectrum disorder (ASD). Another participant stated, "I want us to be having these conversations that are so vitally important to the health of our [children] and humankind." These statements reflect a deep desire for the health and the protection of children.

Often the language used by participants captures this sentiment that their concern is not out of a selfish want for their own child, but the for the protection of all children. One participant stated when asked about their values, "I very, very, very much value the Earth and the environment and I am concerned about human behavior harming our society and harming our planet. I value having a healthy future for our children." The use of "our children" in this person's interview and in others does not refer specifically to their own children, but rather to all children around the world. Another participant stated, "Our children aren't dying of vaccine preventable diseases. Healthy children aren't dying of measles." This participant and statement expressed a high level of worry and concern for the health of children everywhere. They expressed a genuine desire to help prevent children from vaccine injuries or side effects. The sentiment among all the participants emphasized that their position on vaccines was not out of an isolationist viewpoint of focusing just on their own family and needs, but on the welfare and safety of other families and children.

Intellectual Curiosity about Vaccines

The next emergent theme found was that participants had a deep intellectual curiosity about vaccines. Since it is a generally accepted norm that vaccines are safe and necessary, many people feel no need to seek out additional information. However, once a person becomes interested in the topic of vaccines, a search for more information occurs. Several participants stated that, initially, they "never questioned anything about vaccines" or "always believed what they were told." As one participant stated, "I was definitely in the camp of follow in the mainstream. You always follow what the doctors tell you. Why would you ever question it? That is what science says and they know best." There is a consistent trend among most (8/10) participants: they started out from a point of acceptance or non-questioning about vaccines. While reasons vary about what started the participants down the path of vaccine information seeking (e.g. own child's reaction, testimonies of others, news stories), they were in support of vaccines by default prior to this search. Misinformation is often discussed as a main cause for parents to begin to doubt vaccines' safety, but participants argue that misinformation stems primarily from the opposite side of the debate as they were initially in support of vaccines.

Parents describe an internal questioning and curiosity about vaccines. One participant stated, "I can't necessarily trust what a doctor tells me in his office. I need to research these things for myself as a parent. And I'm you know, I knew how to research. And so I started researching." There seems to be a moment when participants do not just trust information blindly. They often talk about conducting their own efforts of researching and exploring sources beyond their healthcare provider. One participant said, "I started realizing that I wasn't getting any of the truth from mainstream sources and that route that was the single biggest change. The single biggest change was 'you are on your own with regard to finding out information because you're not going to get the truth.'" This participant felt that their information needs were not being met by the typical sources. They had to go out and go search out for more. This does not mean that these participants were searching for non-trustworthy sources. Participants emphasized that they specifically were looking that sources they could trust and critically evaluating them.

In asking about what sources of information they trust, many participants listed PubMed and other reputable scientific journals as among their main sources. "I've done a lot of research in the last...year and a half. I've read every PubMed article I could find." Participants consistently stated that they heavily rely on peer reviewed scientific journal articles about vaccines. They often stated that in their research process, they focus on scientific sources. Another example of this is that many participants stated that they read the vaccine package inserts that are written by the pharmaceutical companies that produce the vaccines. They often rely on those package inserts as a source of information about the potential side effects of vaccines. This may go against the popular notion that vaccine safety advocates do not trust any information from the pharmaceutical companies. There is a high degree of focus on relying on scientific and reputable sources. We will discuss this finding in more detail below. Despite participants saying that they trust and rely on these scientific journals and

sources, all of the participants described evaluating information very critically.

When asked about their system of evaluating sources of information, they use a rather rigorous set of standards. They evaluate studies by their logic and reasoning. They critically evaluate elements like methods, the argument and the data analysis of a study. “You need to ask yourself if this makes sense.” Another participant reiterated this statement. “When I started, I trusted CDC (The Centers for Disease Control and Prevention), NIH (National Institutes for Health), etc., they now come second. Peer reviewed published papers are a much better source. You need to look at who funded it. How did they do it? Placebo? Control? Does it make sense?” Many participants also mentioned being aware of financial conflicts of interest, but that will be discussed in the next section. When asked about their interactions with people when discussing vaccines, participants described enjoying intellectual conversations with other people about vaccines.

Often, when trying to share information that is critical of vaccines, participants received highly negative feedback from others. A participant described the response they received when they shared a vaccine safety post on Facebook. “Everything that came back at me from the other side was this vitriol with no facts. It was all shaming, put down, name calling, no scientific facts behind their side of the issue at all.” Participants stated that most of the time people would attack them through emotional means and not through factual means. Participants wished that vaccine advocates would take the time to have a conversation with them instead of resorting to insults about them. One participant recalled a time she was able to sit down and chat with a medical student and address each one of these arguments. The participant stated that it was a calm, levelheaded, adult conversation in which they were able to talk about each of their concerns.

Another participant said “...you know what I actually really, really enjoy is an intelligent person who is for vaccination and challenges me with their understanding of what's going on because then I almost invariably have an interesting discussion and we often come out with a lot of common ground and they start to realize that the ‘anti-vaccine’ community isn't as crazy as they think it is because there's a lot of rational argument a lot of scientific understanding in the community.” There is a concurrent theme that participants want to engage in an intellectual conversation based on their own intellectual curiosity and exploration of the topic. They want to push and continue the conversation in a scientific way.

Skepticism toward Scientific Elites

When participants were asked how they evaluate sources of information, a theme that emerged is the idea of challenging scientific elites. To clarify, the use of the term *scientific elites* does not mean that the community distrusts all researchers and scientists, but instead pushes against the idea of accepting a scientific claim, entity or institution based solely on the prestige of the title.

In evaluating peer reviewed journal articles about vaccines, they often question financial conflicts of interest (FCOI). While the concept of FCOIs in research is often addressed by an acknowledgment at the end of papers, participants go beyond that. They investigate how the study was funded and if

the authors have any ties that would be of concern. As one participant described their process, “I trust *Lancet*, mostly. I trust the *New England Journal of Medicine*, but the advertisers make a difference. I trust some journals, but I also know most of the research is funded by drug companies, by agriculture companies, corporations, and it's funneled through universities. So it's unbelievable, the bad research that gets out there.”

Participants are conscious about considering if a pharmaceutical company is responsible for funding a study on vaccines, and if so, they consider it an FCOI. FCOIs have been an issue in the past. Cigarettes, now known to be carcinogenic, used to have scientific research backing claims of their safety. Participants have brought up this connection in their interviews. “...the thing that really can get my ire is fraud in research because that's where you lose the public trust. And I feel like there's been so much fraud in this area. I've read the studies. It's like tobacco science. I mean like they want to convince us just like they tried to convince us that smoking cigarettes was just fine and dandy for your health. They're trying to convince us through that same kinds of data manipulation and science that they used in tobacco studies. It's appalling what I've seen.” Participants are very wary of work supported by CDC, the Federal Drug Administration (FDA) or other like organizations. Participants are conscious of the fallibility of these groups from previous events like drug recalls. As one participant described, “The FDA makes mistakes. All of those medicines taken off the market were first approved.”

Participants are highly concerned with how the FCOI of these large organizations, both private and government, potentially affect scientific findings by these organizations. And similar to vaccines, participants did not always hold these attitudes about these organizations. “I used to be one of those people who believed the CDC had our back and the FDA had our back and they wouldn't recommend something unless...it made sense.” Organizations like the CDC and the FDA are often thought to be trustworthy and a source of accurate information. The CDC is a commonly recommended source for information about disease prevention and health concerns. Participants challenge this assumption by holding skeptical views about these organizations and the research that is connected with them. This is not to say that participants think that these organizations are out to intentionally harm the public.

While certainly a few fringe people may think that the government and research organizations are out to intentionally cause harm, this is not the prevailing thought. As one participant stated, “I don't believe the government is out to kill us all. There are those conspiracy theorists out there. I mean, maybe they are, but choose not believe that. It doesn't help. You have to be open minded, but just have a little bit of brain. Does it make sense? Are there sources that corroborate it?” In a follow-up exchange that occurred during respondent validation, the participant later clarified, “So while I don't think that our government is into eugenics, I do believe they are certainly complicit in the ‘crime.’” Another participant also wanted to emphasize that “this is a movement because we believe that the government is in collusion with the vaccine industry to conduct a policy of ‘the greater good’ in public health which is unacceptable. We want to choose what vaccines our kids get. There is a disregard for the injured by our

government.” There is questioning of the assumptions of the government and the scientific institutions that they support, such as the CDC, the FDA and the NIH.

Many participants brought up the desire to be able to have a conversation about vaccines. As discussed in the previous section, participants want to be able to engage with people in a productive, not insult-based, discussion about vaccine safety. They expressed great frustration that indicating the slightest concern or doubt about vaccines results in them being labeled as “anti-vaccine.” As one participant lamented, “I consider myself pro-vaccine. Although I would like to say I think that some of those categories are completely misguided and that there really is no such thing as pro-vaccine/anti-vaccine but we push people who are vaccine hesitant so far into a corner that they’ve kind of tended to become very, sort of, you know, one sided in their thinking. And so now people embrace that as anti-vaccine but I’m not anti-vaccine. I’m pro-vaccine in the sense that I’m also pro-antibiotic.” This participant compared her views about vaccines with her views about antibiotics. She often expresses concerns that antibiotics, while useful, are often misused. This view does not cause her to be marginalized in any way; however, expressing similar concerns about the safety of how vaccines are currently used causes her to be ostracized by her peers. Participants, like this one, discussed the phenomenon they experience that they were immediately called “anti-vaccine” just because they had some questions and concerns. They wonder how science can tout itself in being rooted in asking questions and pushing the boundaries of what humans know, but when people begin to ask questions or doubt vaccines, they are called “anti-science.” One participant described the case of Dr. Stephanie Seneff, a senior research scientist at Massachusetts Institute of Technology (MIT). Dr. Seneff is a highly accomplished researcher who never had her work questioned until she began questioning vaccines and genetically modified organisms (GMOs). A participant described her story. “Because she suggested that vaccines are implicated they had to destroy her career as well. Even a high integrity researcher at NIH for years, and when she used the words ‘vaccine might have caused this,’ career destruction. And I’m seeing the same pattern with Andy Wakefield, with Dr. Mikovitz, with...researchers repeatedly where whenever they implicate vaccines the powers that be have to destroy their careers and discredit them. It’s really an amazing thing and it makes me sound like a conspiracy theorist.” Participants described case after case of educated, respected people whose standing in the scientific community changed drastically when they questioned vaccines. They wonder why scientists can question just about anything else except for vaccines. As a participant said, “My desire is that we can get back to scientific normalcy in this area.”

Respect for the Scientific Method

While these statements might indicate that these participants have a negative perception of science or the scientific community, they actually have a great deal of respect for science. Several of the participants come from an academic background in science. As discussed in the last section, they want to be able to question vaccines just like any other scientific issue. One participant described how, at least in the case of vaccines, science is losing its historical emphasis on questioning theories and traditional orthodoxy: “I think there’s

been so much just propaganda through the press, through doctors’ offices, and everything else. People really are brain-washed on this. It’s become a religion for people. It’s like I was attacking a religion when I said what I said. And so, I feel like on the vaccine issue anyway, science has become a religion to them and it’s not science so it’s actually not the science. If they actually worship science they would know what I know. You see what I’m saying? Yeah I was I was told I was ‘anti-science.’ Are you kidding me? I’m just pro-science person I’ve ever met in my life. You know, I want the science. They just haven’t done the studies yet... Vaccines has become just like politics and religion. Vaccines is one of the conversations we can’t have. Why? Is it because this whole area of science has become a religion and no questions are allowed? To contradict it because it’s heresy if you do. That’s what it feels like right now and so to me that’s not very scientific. That’s very theological.” This participant was frustrated by the “religion of science” around vaccines, the idea that scientific elites have determined that people cannot question scientific orthodoxy in any way, as in the case of organized religion, particularly vaccines. One participant described how the medical education process supports this ideology. They described how medical students are taught to accept the curriculum as-is without questioning the faculty about the content. The part of the message that seems to get lost in public perception of the vaccine safety movement is that these participants want more research into vaccines that is free of FCOI and done in a rigorous manner. They often refer to the striking lack of double blind placebo-control studies about vaccines, which are generally considered the gold standard for drug testing. While there are certainly people who may never trust another vaccine, some participants described a desire for better vaccines, or perhaps using vaccines only when they are appropriate. “I don’t think that vaccines are all bad and we should throw them out and never use them again. I don’t think that vaccines are all good and we should get every single one that’s ever been tested, you know, suggested to us necessarily unless we think it’s safe or effective and necessary. I think that vaccines have a place in public health. But in the United States are being grossly overused and inappropriately overused to the point where we are now all hurting so many children that I understand why people are vaccine hesitant to the point of not wanting to do any vaccine.” This participant describes the phenomenon of over vaccination and expresses a desire for more scientific scrutiny to be focused on vaccines. There are people within this community who hold a great deal of respect for science, vaccines and the health of people. They have adopted a way of being critical of science by scientific means and reasoning. For example, there is the notion that scientists should change and adapt theories and hypotheses if they are presented with new information. As one participant described, “I’m old enough that when I went to school I was taught to question everything. That is what science was.” Another participant also conveyed this same manner of thinking. “I want to say my views are not set in stone. I think that any time you have any medical intervention you should always be open minded about it and there’s always room for improvement. There’s always room for additional knowledge with always room for change.” This quote further supports the respect that vaccine safety advocates have for science. Perhaps one of the biggest misconceptions about people who question vaccines is that they are

'anti-science.' One participant who focuses on advocacy work said, "I have a standing statement to never use anything that cannot be backed up scientifically." While vaccine safety advocates are often written off as "anti-science," the interviews reveal that, to the contrary, vaccine safety advocates articulate strong admiration for and adherence to the scientific method.

DISCUSSION

To date, efforts to change of attitudes or behavior of vaccine safety advocates have been largely futile (Nyhan et al., 2014). Survey data indicates that the number of vaccine safety advocates is growing (Funk, Kennedy, & Hefferon, 2017). Our findings suggest that there is more to the vaccine safety movement than what current theories and models propose. We identified four emergent value-laden themes: benevolence toward children, intellectual curiosity about vaccines, skepticism toward scientific elites, and respect for the scientific method. These findings challenge what is currently understood about how people make decisions about vaccines and assumptions and stereotypes about the community. There is an assumption that the vaccine safety community is inherently anti-science and that they are selfish in caring only about their own children. These interviews indicate an evolutionary development to their beliefs that go against these assumptions. Our participants express deep care not only about their own children but also about children everywhere. Their desire to protect and improve the health of all children spurred their interest in exploring more about vaccines. This exploration and examination of vaccine information is done with a highly critical lens, particularly of scientific elites and financial conflicts of interest. Our participants expressed a high value and appreciation for science and the process of questioning and discussing scientific issues and concerns. These value laden themes seem to support previous work that indicate values play a larger role in vaccine decision making than once thought (Brunson & Sobo, 2017; Mitra et al., 2016; Moran et al., 2016; Wang et al., 2015).

The deficit model, which holds that these individuals do not have enough or accurate information about vaccines, is not supported by these findings. Participants were highly knowledgeable about vaccines, including their ingredients, legislation and scientific studies about their effectiveness and safety. Lack of information about vaccines does not seem to explain why these participants question vaccines. This suggests that this model is insufficient in understanding the movement. In addition, gaps in other models, like the GBM, highlight a deficiency in our understanding of how decisions about vaccines are made (van der Linden et al., 2015a, 2015b). While the GBM has been useful in increasing positive attitudes about vaccines this has not been effective for those who already hold some skepticism or negative attitudes about vaccines.

The results of this study support previous work highlighting the importance of values unique to the vaccine safety advocacy movement. This study improves upon previous work by providing a deeper understanding of those values through an ethnographic methodology as well as challenging assumptions about their perception of science. Research and literature about the vaccination debate have been heavily focused on content analysis of vaccine content online or through mass

surveys that are distributed to an entire geographic community. This study provides a qualitative field research-based approach to understanding their decision making. The values that emerged from this study also widen our understanding about how values influence the assessment and evaluation of scientific information. In addition, there is currently no proven intervention or theory that has proven to be effective in shifting opinions, attitudes and behaviors of vaccine safety advocates. While there are a variety of theories available from the health behavior literature, they have been applied primarily to addressing improving vaccine uptake across a whole community (e.g., a geographic area, school setting), not to the specific vaccine safety community. In a review of strategies to address vaccine hesitancy, tailoring to meet the needs of the group due to the complexity of the movement is identified to be a key area for future work (Jarrett et al., 2015). Our results suggest that current communication and public opinion theories about science need to be combined with health behavior theory to develop a model that addresses the gap in previous models.

In addition, the results of this study can help us to understand how values motivate individuals to take positions outside of the mainstream in public scientific controversies, such as climate change and genetically modified foods. Further, the findings help to demonstrate that enhanced understanding of the values that motivate individuals within the vaccine safety movement can help us to create shared dialogues that unite rather than divide factions within the vaccination debate.

LIMITATIONS AND FUTURE DIRECTIONS

There are several limitations with this study. First, there is a self-selection bias with these participants. This community tends to be cautious when participating in research studies. It can be difficult to convince people to trust that the research is not designed to mischaracterize their testimonies. The participants that agreed to be interviewed may be more familiar with research and therefore were more willing to participate. These participants may not be, and should not be considered, completely representative of the entire vaccine safety advocacy community. However, these individuals work and participate within those communities and their ideologies can be reflective of the community in some capacity. The second limitation is the sample size. This was an exploratory study. While there were only ten participants, the interviews indicate that there do seem to be values unique to the community that influence a switch from vaccine acceptance to questioning vaccines. Third, participants may be influenced by social desirability bias. The vaccine safety advocacy position is still taboo. Participants may have skewed their responses to seem more appealing or less extreme as they were aware they were being interviewed by an academic researcher. They may have had reservations still about divulging extreme opinions.

Future studies can include further exploration into the relationship values play in decision making about vaccines. Evidence from this study indicates there are unique values salient to the vaccine safety movement. Future studies can explore this concept with larger sample sizes, more embedded participant observation and deeper analysis.

IMPLICATIONS

The theoretical implications of this study challenge what is understood about the rationale of those who question vaccines. Often, the deficit model is considered a primary way to change people's opinions about vaccines; however, this study gives evidence that the lack of positive vaccine information does not seem to be the cause of why people question vaccines. While arguably misinformation or conflicting information about vaccines can decrease a person's certainty about vaccines, it does not explain the full evolutionary change from being in support of vaccines to questioning them. This research gives indication that values play a key role in decision making in this topic and potentially other controversial scientific issues.

Practical implications of this study can inform on how to develop interventions, craft messages, and support dialogue with those who question vaccines. Themes from this study suggest that the way this community interacts with healthcare professionals and others does not foster healthy or productive discussion for either side. By understanding the reasoning and the values of vaccine safety community, recommended guidelines for healthcare professionals and health information campaigns can be developed to reach a wider audience.

This study can also inform the "fake news" debate and how people develop belief systems based upon their values (Verma, Fleischmann, & Koltai, 2017). The information that a person is willing to ingest and trust in their everyday life can have major effects on their life choices and voting behavior. By understanding how values affect how people interpret information, particularly information related to controversial topics, we can gain insights into how information shapes decision making, and how values influence the interpretation of information and how exposure to the same information may lead different people with different values to make different decisions.

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