

Summer 2018

Values, Justifications, and Perspectives Connected to the Anti-Vaccination Movement

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Recommended Citation

Garzio, Gigi, "Values, Justifications, and Perspectives Connected to the Anti-Vaccination Movement" (2018). *Summer Research*. 309.
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Introduction

Throughout the 18th and 19th centuries, when the first smallpox outbreak began and the first vaccine was introduced, there has been vaccine skepticism (Offit, 2015). Smallpox outbreaks, and the fatalities that come with it, continued to spread around the world despite the development of the vaccine. However, between the 1940s and the early 1970s, anti-vaccine sentiment declined due to “three trends: a boom in vaccine science, discovery, and manufacture; public awareness of widespread outbreaks of infectious diseases (measles, mumps, rubella, pertussis, polio, and others) and the desire to protect children from these highly prevalent ills; and a baby boom, accompanied by increasing levels of education and wealth” (Poland et al, 2011). These factors led to general public acceptance of vaccines, which resulted in significant decreases in disease outbreaks. However, with less visible outbreaks of disease and more vaccines being added to the childhood vaccination schedule, the presence of the anti-vaccination movement returned in the 1970s (Wolfe, 2002). In April of 1982, a program called “DPT: Vaccine Roulette” aired on national television, packed with videos of screaming babies being poked with needles, images of severely mentally and physically disabled children, and inflammatory statements being presented as scientific facts (Offit, 2015). This program allowed for the widespread dissemination of poor science and anecdotal claims of harm from vaccines, sparking the beginning of the modern day anti-vaccination movement. Parents were motivated by the ideas put forward in the television program and, consequently, banded together in 1990 to form the largest anti-vaccination group in the U.S., the National Vaccine Information Center (NVIC). Certain countries began to halt routine pertussis vaccinations in the 1970s and 1980s, and then suffered 10 to 100 times the pertussis incidence of countries that maintained high immunization rates (Gangarosa et al, 1998).

In the face of the growth of the anti-vaccination movement in the U.S., there has been a threatening reemergence of previously stagnant or declining diseases, leading to many hospitalizations and deaths. Between 2009 and 2010, more than 3,500 cases of mumps were reported in New York. In 2010, California experienced an outbreak of whooping cough (pertussis) larger than any outbreak since 1947 (Poland et al, 2011). In 2012, Washington State suffered a 1,300 percent increase from the previous year in the number of pertussis cases, which was the largest outbreak in the state since 1942 (Poland et al, 2011). As of October 2014, more than six hundred cases of measles have been reported in the U.S., which is the biggest measles epidemic in the past twenty years (Offit, 2015). One of the most infamous examples of a measles outbreak in the United States was “believed to originate from the Disneyland Resort in Anaheim, California and resulted in an estimated 125 people contracting the disease” (Hussain et al, 2018). It was estimated that “MMR vaccination rates among the exposed population in which secondary cases have occurred might be as low as 50% and likely no higher than 86%. Physicians in the region were criticized for deviating from the CDC's (Center for Disease Control and Prevention) recommended vaccination schedule” and failing to secure herd immunity for the population (Hussain et al, 2018).

Because vaccine schedules are designed to be routine starting from a young age, they are also designed to be extremely safe for the majority of people. Safety testing “begins as soon as a new vaccine is contemplated, continues until it is approved by the FDA, and is monitored indefinitely after licensure. The American Academy of Pediatrics (AAP) works closely with the Centers for Disease Control and Prevention (CDC) to make recommendations for vaccine use” (American Academy of Pediatrics 2013). Health-care professionals indicate that a community needs at least 95% of its population to be immunized in order to ensure “herd immunity”, or the

idea that people who are not vaccinated, or cannot be vaccinated for a variety of other medical issues, will be protected when surrounded by a highly vaccinated population (Song 2013). However, the safety of everyone, even those who are vaccinated, relies on the vaccination rates of the community. For example, in June of 2009, an eleven-year-old boy from New York traveled to England and caught the mumps. When he returned to NY, he went to summer camp and began a massive epidemic. By October, 200 people were infected, by November 500 people, and by January of 2010, 1,500 people were infected with the mumps. This example displays that even vaccinated individuals are at risk of contracting a disease, which is why there is so much importance placed on the concept of herd immunity. The “fraction of the population that needs to be vaccinated to provide herd immunity depends on the contagiousness of the infection. For highly contagious infections- such as measles or pertussis- the immunization rate needs to be about 95 percent. For somewhat less contagious infections- like mumps and rubella- herd immunity can be achieved with immunization rates around 85 percent” (Offit, 2015). Recent overall vaccination rates in some communities do not even reach 80%, which is insufficient for guaranteeing herd immunity (Song 2013).

Today, the spectrum of individuals within the anti-vaccine movement ranges from those who are simply uneducated about science or “unable to understand and incorporate concepts of risk and probability into science-grounded decision making”, to highly educated people who continue to use mistruths, falsified data, and personal fear or concern as factors of their aversion towards the use of vaccines (Poland et al, 2011). In my research, I focus on the latter of these differing demographics; These individuals are of middle to upper class socioeconomic status and are college or above educated, yet still hold a deep distrust of medical institutions and manufacturers. They also often have flaws in their reasoning of their ideals, and a habit of

substituting personal anecdotes for empirical data. This research will explore how emotional appeal, personal anecdotes, and other reasons combine to form the current anti-vaccination mode of thought.

Literature Review

There are a variety of contexts to observe these differing viewpoints within. Existing literature regarding childhood vaccination discusses the dimensions of “perceived benefits and perceived risks”, in which perceptions of vaccination vary because of the “considerable disparities in individuals’ perceptions of vaccine benefits and risks” (Song 2013). There exists a relationship between disease prevalence and individual vaccinating behavior, which is dependent on the *perceived* vaccination costs and benefits rather than the actual ones (Feng et. al. 2017). There are many individuals who believe that the threat of disease is waning due to medical advances and decreased visibility of outbreaks, and that therefore, vaccination is much riskier than the disease itself. Whether someone has a high or low level of trust in their health-care professionals can also impact individual beliefs toward the benefits and risks of vaccinations. Additionally, individuals’ levels of concrete knowledge pertaining to vaccines can influence judgments about their safety, which demonstrates the importance of medical literacy and accessibility. Demographic characteristics of individuals also shape their risk perceptions, highlighting vaccine benefit-risk perception in particular (Allred 2005). The idea of “grid-group cultural theory of risk perception”, suggests that people form perceptions of societal danger in ways that will sustain their favored way of life (Hotez 2017). In addition, scholars attribute the Dunning-Kruger effect, or a bias in which people mistakenly assess their cognitive ability as greater than it is, to attitudes of overconfidence leading to anti-vaccine attitudes and non-expert involvement in policy making (Motta et. al 2018).

When contextualizing the ways in which individuals among the anti-vaccination movement justify their modes of thought, it is important to note the strong influence of Andrew Wakefield's 1998 publication in *The Lancet*. The paper stated that the "rubella virus is associated with autism and the combined measles, mumps, and rubella vaccine (rather than monovalent measles vaccine) has also been implicated [...] for 15 of 20 autistic children, the first symptoms developed within a week of vaccination" and that the "onset of behavioral symptoms was associated, by the parents, with measles, mumps, and rubella vaccination in eight of the 12 children [...] All 12 children had intestinal abnormalities, ranging from lymphoid nodular hyperplasia to aphthoid ulceration. Behavioral disorders included autism (nine), disintegrative psychosis (one), and possible post viral or vaccinal encephalitis (two)" (Wakefield et. al. 1998). The conclusion of the paper illustrated a "striking association between measles, mumps, and rubella vaccination and the onset of behavioral symptoms in all the children that [had been] investigated for regressive autism" (Wakefield et. al. 1998). Although the sample size was only 12 children, the study's research design was uncontrolled, and conclusions were drawn based on speculation, the paper gained extensive publicity and "MMR vaccination rates began to drop because parents were concerned about the risk of autism after vaccination" (Rao 2011). The *Lancet* completely retracted the paper in February 2010, acknowledging that numerous elements in the paper were inaccurate, contrary to the findings of the earlier examination (Rao 2011). Additionally, Wakefield was found guilty by the General Medical Council of "dishonesty and flouting ethics protocols", and they found that Wakefield "abused his position, subjected children to intrusive procedures such as lumbar puncture and colonoscopy that were not clinically indicated, carried out research that breached the conditions of ethics committee approval, and

brought the medical profession into disrepute” (Dyer 2010). However, in spite of the events that began to unfold post-publication, much of the general public remained focused on the false causal relationship that was propagated in the article, and ongoing discussions of vaccinations triggering the onset of autism continue to pervade across the U.S. This data currently remains one of the most pertinent points in arguments against the safety of vaccinations.

One of the largest and most influential modes through which individuals within the anti-vaccination movement gain information and evidence to support their ideals is on the Internet (Kata 2010), which is why a detailed content analysis of online forums is pertinent to this research. Because of how easily accessible medical information and research data has become, it has also been highly manipulated by non-scientific sources, which gain popularity, and in turn become part of normal and accepted conversation. As shown through Wakefield’s example, the types of mass ideologies spread by the anti-vaccination movement “spring up around an adverse event, perceived to be caused by a vaccination, although rarely confirmed to be causal”, and then remain in the public sphere as accepted explanations (Gander 2017). A common online theme “involves scientific debate about potential vaccine risks, which transmits a rhetoric of doubt; parents incorporate this with personal experiences and spread their views to their social groups. These social groups exert considerable pressure on parents and their vaccination decisions” (Kata 2010). In relation to vaccines, false or flawed information online is easy and accessible to find. A 2002 study discovered that out of 100 links resulting from a simple “vaccination” search, 43% of the websites, and all of the first 10 links that appear on Google, were anti-vaccination (Hussain, 2018). Main rhetorical appeals “[involved] themes of the scientific veracity of anti-vaccination argument; rapport with parents seeking to protect their children from harm; and alleged collusion between doctors, the pharmaceutical industry, and government to deny vaccine harm” (Davies

2002). Websites with ambiguous, but seemingly credible titles such as “National Vaccine Information Center”, “Mothering: The Home for Natural Family Living”, and “Vaccine Choice”, are actually all outlets for unregulated, misguided conversation, and for medically disproven theories to circulate and gain traction. In addition, research has also shown that “viewing an anti-vaccine website for merely 5-10 minutes increased perceptions of vaccination risks and decreased perceptions of the risks of vaccine omission, compared to visiting a control site” (Betsch et al, 2010). The study also found that “anti-vaccine sentiments obtained from viewing the websites still persisted five months later, causing the children of these parents to obtain fewer vaccinations than recommended” (Hussain, 2018). This research demonstrates how powerful the use of the internet actually is, especially when searching for and spreading information about medical information, and why it has been such a useful tool in the rise of the anti-vaccine movement. In order to understand the mechanisms by which individuals in the anti-vaccination movement think about and disseminate their beliefs, it is crucial to gather first hand accounts and information. This study explores these mechanisms using qualitative data in the form of interviews and content analysis of internet forum posts.

Methods

In order to collect data within the anti-vaccination community I joined many different anti-vaccination forums online. These online forums act as platforms for people across the country to share personal stories, information, and research articles with one another. After being accepted into 12 different groups¹, I posted a short description of my research and provided contact information to the members in order to set up interviews. From the online forums I was able to conduct interviews with 15 women, 13 of which were mothers. 14 of the interviews were done over the phone due to the location of the participants, and one was in person.

Interviews lasted approximately 30 minutes, and consisted of personal stories about experiences with vaccines, as well as findings from their own research. I asked the women the same range of questions, such as if there was a single event in the news, their own experience, a medical recommendation, or any research that influenced their opinion on vaccines. In addition, I asked them where they get most of their information about vaccines and how they decide what is or is not a legitimate source to consider in their medical decisions. All of the participants provided me with in depth answers about how they came to form their stance on vaccines, why they chose not to vaccinate their children, and many even provided potential solutions to the issues they see with mainstream medical guidance.

In addition to the interviews, I also conducted a content analysis of many of the discussion posts and comments on the forums, including an extended conversation that took place in the comments of my own post about my research. Individuals on these forums cite personal experience with their children, themselves, and their physicians as reasons for their aversion toward vaccines, as well as literature they have found online, documentaries they have watched, and books that they recommend to any new mothers thinking about vaccinating. The forums act as platforms to share information, ask questions, and get answers, however, they also

¹ Names of the online forums I joined: Holistic Action in the Vaccine Library, Vaccine Truth Movement, Stop Mandatory Vaccination, Positive and Vaccine Informed Parents, Anti-Vaccination for Non Religious Reasons, Anti-Vaccine and Natural Cures, Parents Against Vaccination, Vaccine Education Network, Vaccine Talk: A Discussion Forum for Pro-Choice and Education Support, Vaccine Talk: A Forum for Both Pro and Anti-Vaxxers, Safe Space for Anti-Vaccine Moms, Anti-Vaccination: Full Stop, and Mothering: A Discussion Forum.

act as a space online for those within the anti-vaccination movement to persuade others that vaccines are unsafe. Parents remain in the mindset that their children are born healthy, and chemicals like the ones in vaccines are the reason their children may end up sick, autistic, or even dead.

Analysis

After reviewing the data collected from the interviews and the online analysis, six main themes emerged as reasons behind the anti-vaccination mode of thought. These themes consist of: reference to vaccine injury- autism, paralysis, fever, and death; the belief that we have genetic immunity to the diseases we are vaccinating for; too much risk and not enough benefit to vaccines; skepticism or criticism of pro-vaccine theories (such as herd immunity); the use and strong value of anecdotal evidence; and the construction of credibility (around anecdotal evidence and parent intuition). The use of anecdotal evidence is interconnected among all of the other themes, and acts as a fundamental element in ensuring the credibility of the entire anti-vaccination movement.

Vaccine Injury

The most cited reason among all of the interviews for not vaccinating their children is the fear of vaccine injury, or the idea that the vaccine will cause some harm to their child's body after it is injected. All 15 of the respondents referenced a vaccine injury, either of their own child, someone they know personally, or someone they interact with on an online forum. The concerns about vaccine injury stem from the listed ingredients in the vaccines themselves. Many of the mothers I talked to expressed fears about ingredients such as “parasites and parasite eggs, [...] bovine serum, [...] formaldehyde, aluminum, mercury, aborted fetal cells” as well as “a lot

of other ingredients listed in the inserts that people aren't reading". When explaining the science behind how the vaccine ingredients lead to vaccine injury, one mother stated that "when a baby is born, they give them the vitamin K shot and most people think that it is harmless. But inside of the vitamin K shot, it has the complex Polysorbate-80 in it. And that complex crosses the blood brain barrier. So then with it, it's going to take any toxins that are pre-existing and it's going to cross the blood brain barrier. And this is part of how infants are getting injured". This narrative circulates online, and then many parents become worried about, which leads them to stop vaccinating. The narrative for vaccine injury is as follows: a healthy child goes in for a vaccine (at any age- birth, 2 months, 12 months, etc.), the child gets a fever and becomes ill hours or days after the shot, the child then loses the ability to speak or walk, then the child 'regresses'² into autism and remains autistic *or* regresses for a while and then gains back these abilities but still may have some more minor health issues. As one mother, who used to vaccinate her children but now strongly opposes it, states:

[My son] tolerated the first couple rounds, but then I started noticing he was acting very tired, just wanted to go to bed and didn't want to communicate. He lost all of [his speech], he couldn't remember his words, couldn't balance, very hyperactive, he couldn't sleep. And now this child is on the autism spectrum, even though he had no signs before that. So I guess it doesn't matter if you wait to vaccinate, if your child is susceptible to an injury, they're going to get a vaccine injury.

The details of the accounts given by the mothers interviewed did not stray far from this narrative; and these stories, coupled with media outbursts such as the Wakefield article, only fuel the

² The participants all commonly used the phrase "regressed into autism" to describe a child who was previously "normal" but then began to show autistic behavior (regardless of how severe) forums that I was able to join, there were extensive posts written detailing the deterioration of numerous children following vaccination.

passionately charged argument against vaccines. When asked about her decision to vaccinate her daughter, one mother expressed serious regret about the MMR vaccine, as well as anger at the perceived preventability of her daughter's autism. She explains that she "regret[s] it every day because a few days after [her daughter] got her [2 year-MMR] shots, she never spoke another word again; and she was completely normal and fine until that happened. No signs of autism, and now she's severely autistic, and that just reaffirmed that there's something wrong with the whole system". Explanations such as this one are common, and they continue fuel the vehement discourse surrounding vaccines. Stories of vaccine injury pervade the posts on the forums, and become impossible to ignore. One participant says:

You join these groups online and day after day, new moms are coming in saying 'my kid went in for their 2 month or 2 year vaccines and here's my child before and here's my child now'. And you just can't deny the volume of kids who have regressed into autism after being completely healthy. I just see those stories day after day and I'm convinced.

This mother's line of thinking demonstrates the effect that these accounts of injury have on the overall perception of vaccines. The sharing and spreading of different stories of infant injury and death adds a large component of fear into the decision to vaccinate or not. Parents who are on the fence about whether or not they should vaccinate their children may be exposed to something similar to the following account, and may quickly be scared out of any vaccines. One of the respondents perpetuates this narrative of fear by publically sharing this story:

My biggest thing is I see every single day, a kid that died- a baby just died two days ago 18 hours after getting vaccinations. I follow a guy on Facebook whose son was 20 months old, and every time the kid had had his vaccinations he had reactions, but of course the doctor said 'oh its fine blah blah blah'. So at 20 months old he got a DTAP vaccine and 17 days later he's dead. And they had money, so they had their own autopsy done and they proved that the DTAP vaccine killed his son.

The looming fear of vaccine injury is one that permeates the entirety of the anti-vaccination movement, and affects individuals who are on the peripheral. Circulating accounts of vaccine

injury such as autism, paralysis, and other disabilities are abundant both online and in conversation of anti-vaccination parents. These individuals have created a network in which more trust is placed in parents across the U.S. rather than their own pediatricians. This disparity in levels of trust is due to the idea that parents know their children better than anyone else, and that if a parent says their child was physically or mentally harmed from a vaccine, then they are not at liberty to argue with that sentiment (Offit, 2015).

Innate/Genetic Immunity

Apart from the idea that vaccines are dangerous, individuals in the anti-vaccination movement do not believe vaccines are even medically necessary due to their own family history of disease. Many of the mothers that were interviewed mention an “innate” or “genetic” immunity to the diseases that doctors want to vaccinate for, meaning that because their ancestors got the diseases decades or even centuries ago, their immune systems have the innate ability to fight off those same diseases. One respondent who is a practicing chiropractor, explained that “our bodies have an innate ability to be healthy and to ward off diseases, and our immune system is designed to develop immunity when it is exposed to diseases, and so I think that we should let our bodies naturally do that, rather than injecting them with poisons that actually weaken the immune systems.” She goes on to discuss the health benefits to getting a disease in relation to the immune system. She explains that “we don’t need to be making vaccines for every little thing that’s out there. Like when you get the chicken pox, you actually form a lifelong immunity. When you get the shot you might have immunity for a few years, but then you have to get some boosters. You might as well just get the disease and have immunity for life, and I think that’s what we were meant to do”. It is important to note that no one cited sources for how they discovered the science behind this theory of genetic immunity, yet the justification was repeated

among 87% of the participants, displaying the power of the Internet and the wide lengths that information can travel. Another respondent articulates the innate immunity explanation:

I think living in the place and location in the world that I live in, no I don't see any real benefit to any vaccine. Like if I moved to a place where the health care was poor or where it was non-endemic, like if I moved to Africa, and nobody in my lineage had ever been exposed to Ebola and there was an Ebola vaccine, then yea we'd probably get it because we don't have any genetic immunity to it, we've never had it anywhere in our past. But knowing that every single person above the age of 60 in my family has had and fully recovered from, with absolutely no side effects, the vast majority of these diseases- aside from polio- I think we're pretty safe.

These individuals are weighing the chances of surviving a disease against the chances of surviving the vaccine itself, and they are deciding that the vaccines are too risky, especially when considering their own genetic history. These narratives add to the fear and concern surrounding the vaccination discourse. The combination of the threat of vaccine injury and the idea of innate immunity creates a mindset of too much risk and not enough benefit for these parents.

Too Much Risk and Not Enough Benefit

The idea that children have the ability to survive through the diseases they are being vaccinated for, but not the chemicals in the vaccines themselves, is a belief that continues to circulate throughout the anti-vaccination community. The repeated explanation that vaccines contain mercury, formaldehyde, aluminum, and aborted fetal cells is one that deters parents from vaccinating their children, even if the CDC states that these ingredients are no longer in vaccines.

One of the participants states that:

There is too much risk involved in terms of the impact it could have to [my child's] health in doing it, and not enough benefit to take that risk. I've read a ton and feel like there's too much of a correlation with autism, immune disorders, digestive or stomach and allergy issues, and the ingredients – I'm actually not opposed to the concept of vaccinations meaning injecting a little bit of the illness in order for the immune system to fight it- my issue is with all of the other scary/questionable and toxic ingredients like the DNA, aborted fetal cells, heavy metals; there's just too much risk with those other ingredients.

It becomes clear through conversation with these mothers that they have done extensive research on the concept of vaccines, and even the science and immunology behind their development. However, the disconnect with biomedical medicine becomes clear when discussing vaccine ingredients and long-term impacts. There also exists a strong narrative that doctors are capable of aiding in the fight against these diseases if their children were to contract one, such as measles or mumps, because of how advanced medicine has become. One respondent has only vaccinated her children for tetanus alone. When asked why, she explains:

I'm definitely anti-vaccine, I don't like all of the risks they come with and I think that we live in a society where, if by some chance they got any of the diseases, that with modern medicine, we'd be able to cure it and they'd be fine. I'm more on the stance that if they get polio or whooping cough or chicken pox or measles, mumps, rubella, to handle it at the time and not put toxins in their body to try to prevent it. If they get the disease, let's let their body fight it and do what it needs to do.

Along the same lines, another participant has gotten her daughter vaccinated for a "handful" of things, and went on to explain why she regrets even these few. She states:

After all of the research I did and the documentaries I've watched and stuff, I just came to the conclusion that its just not safe enough to make the choice to do it. I just kept on researching and kept on researching, and it just doesn't make sense to me, the risks outweigh the benefits. Because I don't think the risks for childhood diseases are really that big, they're just not.

When it comes to treating their children *after* infection of a disease, these individuals' trust in mainstream medicine increases. However, because these mothers do not believe it is likely or very dangerous for their children to be exposed to the diseases doctors vaccinate for, they rely on natural or homeopathic medicine most of the time. The perceived risks of the ingredients in the vaccines outweigh any benefits for their children and for the security of herd immunity among their peers.

Criticism of Pro-Vax Ideology

A consistent theme throughout most of the interviews is the attempt to dismantle current pro-vaccine theories and ways of thinking. Two concepts that arise as points of contention with pro-vaccine individuals are vaccines for diseases that most children should not be contracting such as Hepatitis B and HPV, and the legitimacy of herd immunity. Most of the individuals argued that there is no way their child would contract a disease like Hepatitis B because they are not having sex or sharing needles in the time that the vaccine is effective. A mother I interviewed explains that “there are a couple [vaccines] that are pretty unnecessary and [she has] even had doctors tell [her] they’re unnecessary, like the hepatitis B. Hepatitis B is fine if they’re in an at risk group, but if they’re not then the chances of contracting the illness is next to none”. The perceived uselessness of vaccines such as this one cause these individuals to question the overall motives of physicians when administering any vaccine, leading to a distrust and rejection of modern medical intervention. Another mother states:

My kids got a hepatitis B shot for a disease that’s transmitted through sex and drugs and its going to wear off by the time they’re 10 years old. And unless something crazy happens, I don’t see anyone under 10 having sex or using needles. And so it kind of made me say why are we doing this? What’s the point? There’s something bigger to it.

In addition, these parents use recent outbreaks of diseases, such as measles and pertussis, as proof that vaccines are actually completely ineffective, but if more than 80% of the population where these outbreaks occurred were immunized, it most likely would not have happened. However, the parents look at these outbreaks in communities with higher vaccination rates, such as California and Washington, as an example of how vaccines do not work at all, because if they did then these epidemics never would have taken place. One woman I interviewed stated that “people talk about this ‘herd immunity’, well there is no herd immunity! In the movie silent epidemic, one of the doctors talks about herd immunity quite a bit [...] but there’s outbreaks, just

like the Disneyland thing”. This mother is referring to the measles epidemic in California, which went on to act as proof for many people in the anti-vaccination movement that herd immunity does not exist. Due to the perceived futility of these types of vaccines, parents begin to question the intentions behind mainstream medicine, such as profit, and subsequently begin to demolish the validity of overall vaccine effectiveness. One mom questioned this validity by saying, “something that did influence me was that earlier this year in Washington State there was a pertussis outbreak and Washington State has one of the highest vaccine rates. So that kind of made me think about it a little bit like how good are they?” Despite the theory that even vaccinated individuals are at risk of contracting a disease, which is *why* there is so much importance placed on the concept of herd immunity, the anti-vaccination movement uses this as a way to point out false inaccuracies in pro-vaccination data. Researchers have stated that the “fraction of the population that needs to be vaccinated to provide herd immunity depends on the contagiousness of the infection. For highly contagious infections- such as measles or pertussis- the immunization rate needs to be about 95 percent. For somewhat less contagious infections- like mumps and rubella- herd immunity can be achieved with immunization rates around 85 percent” (Offit, 2015). A different woman I interviewed also cited the Disneyland outbreak as a reason not to vaccinate her children. She says:

Just because you get a vaccine, doesn't mean it's going to work. And most of the time they don't work, I mean you can look at the Disneyland case out here. 32 of those people who got the measles had been vaccinated for it, yet we have these mandatory laws in California saying if you want your kid to go to school, they have to be vaccinated.

The percentage of immunized individuals in that area of California at the time was not at 95%, which may partially explain why the outbreak occurred, and actually places emphasis on how much we truly rely on one another to get vaccinated in order to prevent the spread of disease. However, the anti-vaccination movement continues to discredit the data put forth by pro-

vaccination doctors and researchers by propagating these inaccurate claims. By consuming so much anecdotal evidence in place of scientific research for medical decisions, a lot of information that is presented as empirical research becomes fabricated.

Anecdotal Evidence

Both online in parenting forums and in all of the interviews with mothers, the use of anecdotal evidence, or evidence that is relayed in the form of stories or personal testimonies, to back anti-vaccination claims is pervasive. Anecdotal evidence is used to support all of the themes that arose in this research, from vaccine injury to genetic immunity, to too much risk, and criticism of pro-vaccine ideas. There is a clear lack of empirical data when discussing the scientific proof that backs the claims of the anti-vaccination movement. Additionally, the larger theme of the abundant use of anecdotal evidence suggests a rejection of scientific evidence altogether. When asked about this type of evidence used to back the anti-vaccination stances, one mother went into a personal account:

I had a huge argument with my brother years ago [...] he had just gone on the CDC website, he was just so mainstream about it. He didn't look at anything else besides what the government is spoon feeding the public. And he would say to me 'all of this bullshit you're talking about its all anecdotal, there's no science'. And at the time that was probably true, you had to dig a lot harder on Google to find people who were addressing the science behind why you shouldn't vaccinate and there was a ton of anecdotal evidence. But now there's a ton of both. But I would say the anecdotal evidence is really what put me over the edge [...] there is such a massive volume of anecdotal evidence against the safety of vaccinations, and even if that was all there was, how could you deny it? I mean it's endless. And I totally completely trust what parents believe, they know their children; so after speaking with a few different parents directly, I was like 'yea I don't trust it'.

The idea that anecdotal evidence should be trusted above all else, especially when discussing something that involves complex science, is convoluting modern medical guidance. There is more trust placed in parents than in doctors; the suggestion that all of the children who have been 'vaccine injured' may have been showing signs of any abnormalities before being vaccinated is

insulting and unreasonable to anti-vaccination individuals. Another mother that was interviewed expressed:

When Facebook groups started to become a big thing, that's when I was just like 'case closed, done deal', there are so many phenomenal resources and so many well-read women in many many anti-vax groups that it just sealed the deal. And then when qualified scientists and physicians started to come out and say these are risky, it just confirmed what I had been thinking.

The immense value placed on anecdotal evidence in regards to all of the themes brought up in the interviews highlights the concept of credibility. While mainstream American parents are placing their trust in established medical systems, parents within the anti-vaccination movement create credibility and trust around anecdotal evidence and personal stories.

Credibility

The heavy use of anecdotal evidence brings up the question of credibility- why are individuals in this movement placing this type of evidence above empirical scientific data? It is clear that there is a significant lack of trust in the mainstream U.S. medical system among the anti-vaccination movement. This lack of trust appears to stem from negative experiences with the current medical system, such as contradictory information circulating among different physician groups, feeling ignored by physicians, not getting enough information from their doctors or not having their questions answered, a friend or family member falling ill while under the care of health care professionals, or a friend or family member dying due to a complication from medical care or disease.

The association between these negative experiences and biomedical practices leads to a shift away from mainstream medical guidance. This shift can be seen in the increased use of nutritionists or chiropractors in place of medical doctors, or searching outside of the U.S. or conventional informational sources (such as the CDC website) for research and data. Another

result of leaning away from mainstream medicine is the increased value placed on anecdotal evidence and ‘parent intuition’ when making medical decisions. Speaking to the credibility of pro vs. anti vaxxers, one participant states:

The pro vaxxers tend to spend a lot of time articulating why they should be believed, so they spend a lot of time saying like ‘I’m a doctor or I’m a scientist’, they spend more time focusing on their supposed qualifications. Whereas the anti-vaxxers tend to add the details of the studies, so its more of the quality of the writing and the depth to which they go that gives me more comfort in believing them, as opposed to saying ‘so and so is a doctor or the CDC is a government organization’ where you’re being asked to blindly believe, so anytime someone is picking apart studies or research and getting into the nitty gritty of the science, that gives me a lot more comfort.

This woman brings up a point that is echoed throughout many of the interviews, which is that pro-vaxxers, or those working within mainstream medicine, speak much more about their credentials, and not enough about evidence. This perception of the pro-vax stance is affected by all of the other factors that build up a strong distrust in mainstream medical guidance. Once an overwhelming amount of trust is lost between the patient and doctor, it makes sense that the patient will seek information and care elsewhere, which is what these parents are doing. 80% of the participants disclosed that they do not go to a pediatrician, but rather a nutritionist or chiropractor in place of a medical doctor.

One woman stated that a doctor is the “last person she would talk to” about her decision to vaccinate or not. A different mother said that “there’s a chiropractor that we go to, and she’s a nutritionist also, and she’s very anti vaccine and she kind of supports my decision, so that makes me feel better”, referring to her decision not to vaccinate her children. I had the opportunity to talk directly to a chiropractor that one of the other participants is a patient of, and this was her response when asked what she says to parents who are not sure if they should vaccinate their children:

I tell [my patients] that it's very important that they become educated, and so I have some videos in my office like the movie *Vaxxed*, and a series called *The Truth About Vaccines* that they can watch. And some parents still want to vaccinate, some people just don't like to go against the norm, and that's ok with me [...] I'm a chiropractor so I don't do any injections, but they may choose to have their doctor do that. But I'm totally against vaccinations, and some people say that anti-vax is not a good term to use, but I would call myself an anti vaxxer. My son is 37 and even when he was born I knew they were no good and even at that time we didn't do them. I just fed him right and kept him healthy. I was in chiropractic school when they were born- its very natural oriented- and so when I was in school I heard a lecturer talk about all of the ingredients that are in vaccines and I thought well 'I'm not going to inject all of those into my baby'.

It is important to note the sources she has on hand to inform her patients; *Vaxxed* is a documentary that includes extensive interviews with Andrew Wakefield, the physician who wrote the article linking MMR to autism, which has now been retracted by *The Lancet*. Because all of the participants referred to this documentary as a source of information, I watched it to gain a better perspective on what it says, and it was exceedingly fear oriented and convincing. All of the information in the documentary is based on anecdotal evidence, either from Wakefield himself or other parents of children who were vaccine injured. The wide acceptance of documentaries such as this one further highlight the creation of credibility around anecdotal evidence and the emphasis that is placed on parents' personal stories. One mother took it upon herself to provide medical care for her children, rather than take them to a medical doctor. When asked to elaborate further on this concept she stated:

I'm very hands on, so once I figure out what was going on, I figured I need to completely educate myself about homeopathic medicine, and anything that we need to do I do it myself. We don't have a general doctor or a pediatrician, there's really no need for it. My 4-year-old hasn't been to a doctor since he was 4-moths-old. I've watched pretty much every documentary you could think of, I don't think you can ever be too educated, the more educated you are the more prepared you are to face opposition or answer questions or even face people who think you're crazy. I probably spend 1-2 hours every morning going through new research, or upcoming studies, I'm pretty involved in the anti-vax community.

Another result of the lack of trust in mainstream medicine is searching outside of the U.S. for resources on vaccines. Many of the mothers explain that this is because U.S. research is too focused on pushing vaccines because of CDC and big pharma funding, and therefore it never is able to conduct legitimate research. These parents “want to see studies that are being done in Japan or Sweden, and look at scientific research that is being done without corruption from pharmaceutical companies who are paying them. Take the corruption out and look at research from other countries who use the same vaccines that we do”. Parents in the anti-vaccination movement quickly criticize the integrity and the agenda of organizations such as the CDC, however, they remain defensive of people such as Andrew Wakefield, who’s medical license was revoked due to the fraudulent research he published. Because Wakefield plays such a central role in the discrediting of the pro-vaccination side, it was important for me to ask participants directly what they think about his work being retracted and his license revoked. Responses were all similar, if not the same as the following:

I honestly haven’t paid too much attention, I mean I’ve heard about it a little bit, but I don’t know too much in detail, I know they said ‘he falsified all this information blah blah blah’, but I don’t believe that was true because I’ve read somewhere else that he’s been justified in everything that he did.

Along the same lines, another participant said:

They sort of took him down on a technicality, like one little thing, but there’s still this whole world of stuff that he revealed and made public that is still true, yet the CDC and big pharma are still focused on this one little thing, I don’t know if he like misrepresented something or left out some data, but there’s enough stuff that he’s published and revealed that I’m still comfortable listening to what he has to say and what he publishes.

Responses such as these imply that something suspicious happened with Andrew Wakefield, but nevertheless, his work is still credible in the minds of the anti-vaccination movement. Another participant refers to the bias within the CDC as a reason to look outside of the U.S. for vaccine information. She says:

You have to understand that all of these studies about vaccines are funded by the CDC which obviously has bias. I try to follow people that are reputable and have real information, because there's so much BS out there. And I think people get caught up in the BS and then they don't learn the truth. I just want to make the best decision for my kids, obviously- I love them. So, I definitely look online for studies done outside of the US, mostly because I can't find anything done by the CDC that's not paid for by big pharma.

Another way credibility is constructed around anecdotal evidence is the value placed in 'mother's intuition', or the idea that parents know their children more than anyone, even doctors, and that their word should be taken just as, if not more, seriously. Using this idea, different mothers explain how they decide what sources are credible to listen to, especially in the face of so much contradictory information circulating online. When asked how she decides what is credible and what is not, one mother references the online forums in saying that "the mothering forums bring up a lot of good topics and a lot of good stuff to think about [...] I don't listen to the doctors [...] I get all of my information, read through it, digest it, and make a decision on my own". Although the forums are helpful in leading parents to not vaccinate, the choice is ultimately left up to each individual parent. However, the anecdotal evidence is persuasive, and coupled with the pseudo-science that pervades the Internet, it can be difficult to decipher what is legitimate and what is not. Another mother comments on this process by stating:

Once you start to do your own research you can start to determine what's truth and what's not. And I guess I just use my own common sense, like I have a psychology degree so I guess that can help because there are just like crazy people online, but I guess just people's own personal experiences are really credible. Because moms just know, like if there was nothing wrong with their kid and then this event happened and now they're not the same anymore, I don't think people just make that kind of stuff up.

The idea that individuals can innately decipher what is true and what is false online is a concept that has been deeply analyzed. A study done in 2008 gauged how effectively users assessed the accuracy of medical information, specifically in relation to vaccines, online. The study demonstrated that 59% of the participants thought all of the sites were completely accurate.

However, out of the 40 sites they were given, only 18 were *actually* accurate, while 22 were *inaccurate*. The inaccurate sites claimed vaccines were inherently dangerous without any evidence-based proof. This resulted in 53% of the participants leaving the study with considerable fallacies about vaccines (Kortum et. al., 2008). Another study looks at the cognitive bias, Dunning-Kruger effect, to help explain the mode through which anti-vaccination individuals think about vaccines. Over a third of participants in the study “thought that they knew as much or more than doctors (36%) and scientists (34%) about the causes of autism [...] analysis indicates that this overconfidence is highest among those with low levels of knowledge about the causes of autism and those with high levels of misinformation endorsement” (Motta et. al., 2018). The combination of all of the factors convince people not to vaccinate, coupled with the difficulty and inability to decide what is credible online creates a large disparity between the trust placed in other parents’ accounts and the advice of medical professionals. The resulting mindset is what drives the anti-vaccination movement, and why anecdotal evidence is such a key component of this mode of thought. Due to the anti-vaccination movement’s success in creating such strong, unwavering credibility around anecdotal evidence, personal stories now hold equal weight and value as empirical data to many people online.

Discussion

The heavy use of anecdotal evidence is intertwined among all of the themes that arose in this research, from vaccine injury, to genetic immunity, to great risk, and criticism of pro-vaccine ideas. The larger, overarching theme of the abundant use of anecdotal evidence suggests a rejection of empirical evidence altogether, and introduces an approach to construct strong credibility around anti-vaccination sentiments. Through anecdotal evidence, this movement

grabs the attention of a vast range of parents, especially online, and becomes more credible than the recommendations of physicians and established medical organizations.

In order to discuss how the individuals in this movement come to see vaccines in a holistic sense, and rationalize their decisions, it is crucial to further examine some other factors that contribute to the results of this study. It is important to note that all of the participants in this research are women, and the majority of them are mothers. The explanation for this may be that the decisions about more serious areas of childcare, such as medical decisions, usually falls on the shoulders of the mothers because childcare has been a historically gendered responsibility. All of these women are employed in middle class or upper-middle class occupations, such as real estate agents, marketing managers, property managers, accountants, and more. In some cases, the women used to work and became stay at home mothers with a spouse to support them financially. Fourteen out of 15 of them are at least college educated, and some of them have master's degrees. The participants are from California, Washington, Oregon, Texas, New Jersey, Vermont, and Massachusetts. Additionally, it is important to note that although some of the participants were pulled from unbiased forums, most of them came from anti-vaccination online forums. This means that these people hold strong views about vaccinations, and they may be on the more extreme end of the anti-vaccination spectrum. Most of them are active in the anti-vaccination community, both online and in person. Despite this fact, they still represent a large portion of the anti-vaccination movement, and their line of thinking parallels numerous people in the U.S.

To answer the question of why people would choose anecdotal evidence over empirical evidence, further psychological research has looked at why certain people stray away from inarguable facts, such as the ones that come from scientific research. There is a large emotional

appeal to anecdotal evidence, but more specifically, and more recently, psychologists have been studying the acceptance and perpetuation of “alternative facts” to reality. “Alternative facts” can be characterized as rejections of certain truths of reality, and instead focusing on a different explanation as truth (Shtulman, 2017). Psychologists have been studying “how humans perceive and understand the natural world for several decades, and they have discovered that much of this knowledge is organized into coherent networks of cause-effect beliefs, or *intuitive theories*” (Pies, 2017). These are our first attempts to understand the occurrences around us, before we learn the scientific theories of those same phenomena. They also allow us to explain past events, intervene on current events and anticipate future events (Shtulman, 2017). Intuitive theories “allow us to make sense of phenomena we might otherwise find perplexing, [however], they prevent us from learning more accurate theories of the world, blinding us to counter-evidence and counter-instruction [and] also make us susceptible to scientific misconceptions — or, in today's parlance, alternative facts about science” (Shtulman, 2017). Pies (2017) explains, “the general public seems to have an appetite for falsehood [...] and when this magical transformation of reality occurs, whether in a political or scientific context, it becomes very difficult to reverse. As the writer Jonathan Swift put it, ‘Falsehood flies, and the Truth comes limping after it.’ (Pies, 2017). Using the insight from different psychiatrists’ and psychologists’ research, we are able to contextualize anti-vaccination mode of thought. The individuals in this movement are not disseminating information that they believe is false, however, they have a different mode of processing information in a way that results in the spread of scientifically inaccurate information.

A theme that arose from the interviews and analysis, that may be an area for future research, is the widening of potential negative effects of vaccines. The initial concerns about the effects of vaccines focused on the development of autism; but now mothers are referencing the

development of OCD, ADHD, learning disabilities, speech impediments, jaundice, restlessness, and more as results from vaccines. There may be a wide variety of reasons for this expansion; however, from the conversations I had in the interviews I would speculate that parents are trying to place reasoning for something wrong with their child onto vaccines. The way in which parents create a narrative of blame around something going wrong with their child medically could be another interesting mode of thought to examine in relation to the anti-vaccination movement.

Conclusion

Multiple themes for the justification of anti-mainstream modes of thought in relation to vaccines arose from this research. These themes consist of: reference to vaccine injury- autism, paralysis, fever, and death, the belief that we have genetic immunity to the diseases we are vaccinating for, too much risk and not enough benefit to vaccines, skepticism or criticism of pro-vaccine theories (such as herd immunity), the use and strong value of anecdotal evidence, and the construction of credibility (around anecdotal evidence and parent intuition).

Looking ahead, there is a call from parents, and all patients of medical establishments, for an increase in appeal to safety concerns by health care professionals as an attempt to bridge the gaps between perceptions of risk of vaccines, and actual possibility of harm. The “polarization of anti- and pro- sentiments is creating a war-like environment, fighting for ‘who is winning’ [which is] one of the most dangerous and counterproductive trends” (Gander 2017). Those who are anti-vaccine “feel ignored and victimized by mainstream science and media” and in response, the public health, science, and medical communities must be able to work at fostering a better relationship with opposing views that circulate among the general public, in order to be able to combat misinformation in an effective manner (Gander 2017). A recent research study “explored how parents respond to competing media messages about vaccine safety concluded that personal

experiences, value systems, and level of trust in health professionals are essential to parental decision making about immunization” (Hussain 2018). Therefore, health care professionals must be able to better establish a relationship of trust with their patients, as well as work to debunk myths about the dangers of vaccines put forth by the anti-vax movement. It is also important to correct the spread of inaccurate information, especially online. One of the worst possible outcomes of this disparity is people becoming seriously ill or even dying because they are not getting vaccines that have been effective for decades and could have protected them from diseases such as measles or diphtheria (Gander 2017). In order to protect the efficiency of herd immunity, and the well-being of the general U.S. public, there is a demand for an increased understanding of the conflicting viewpoints, in order to move forward and display effective public health improvement.

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