

Modern Vaccine Anxiety in America

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Introduction

Vaccination has been hailed as one of the most important medical interventions of the 20th century, preventing up to 3 million pediatric deaths every year (1). In addition to saving millions of lives from infectious diseases, they prevent certain cancers and save billions of dollars in healthcare costs (2). Yet despite their benefits, a small population of parents decline to have their children vaccinated out of the belief that some or all vaccines are unsafe, leading to outbreaks of diseases we have nearly eliminated in the U.S.

This essay looks at who the modern vaccine anxious parent is and how they have come into being. It illustrates that vaccine anxiety is an inevitable outcome of scientific debates that have left their roots in evidence-based reasoning and entered the public sphere of discussion, in which scientific evidence can be taken as mere opinion. It also focuses on how providers and parents perform different forms of “moral duty” regarding vaccination, and why it is important for providers to understand and empathize with vaccine anxious parents. Overall, this essay explores the perspective of parents who become vaccine anxious and how better science communication and healthcare provider interventions could lead to a resolution of their anxiety.

Parents That Refuse Vaccination

There is a drastic difference between the families of *undervaccinated* children and *unvaccinated* children. A study examining 2001 National Immunization Survey (NIS) data showed that families of undervaccinated children are more likely to be black, with an unmarried younger mother in a household near the poverty level with more than 4 children (3).

On the other hand, families of unvaccinated children are more likely to be white, with a married college-educated mother in a household exceeding an annual income of \$75,000 (no data on fathers were gathered in the NIS surveys). Unvaccinated children were also more likely to be male than female and even more likely than undervaccinated children to come from a family with more than 4 children. These unvaccinated children accounted for 0.3% (17,000) of US children between 19 and 35 months old in 2001.

According to the most recently published NIS data, unvaccinated children remain at less than 1% of US population and vaccine coverage on average is high, with over 90% vaccine coverage for MMR, DTaP, polio, and hepatitis B (4, 5). For new routine vaccines like rotavirus and hepatitis A, vaccine coverage has been steadily climbing upward.

That being said, because unvaccinated children tend to be geographically clustered, they are more likely to be the source of vaccine-preventable disease outbreaks. For instance, in Washington state, county-level nonmedical vaccine exemption levels ranged from 1.2% to 26.9% and similar clustering of exemptions has been found in other states (6). Clustering has been known to be associated with school policies favorable to exemptions and beliefs of school personnel responsible for ensuring vaccine compliance (7, 8).

As a result of unvaccinated children living in the same community, outbreaks of vaccine-preventable disease occur and spread rapidly. For example, the 2003 outbreak of pertussis (whooping cough) in New York was traced to four children whose parents decided against vaccination. The outbreak spread to a neighboring county in which five out of the first seven cases were of unvaccinated children (9). In total, 54 cases of pertussis were recorded. A high number of those cases were of vaccinated children whose conferred immunity for pertussis had

naturally waned over time and were more susceptible to acquiring the disease from unvaccinated children¹.

This small subset of unvaccinated children has increased since the 1990s. Between 1991 to 2004, mean state-level exemptions for personal beliefs have increased from 0.99% to 2.54% while religious exemptions have remained steady at about 1% (10). In a study of more than 2,000 parents, the most common reason reported for claiming vaccine exemption was concern that vaccines might cause harm (11). Physicians have also reported that many have had a parent refuse at least one vaccination for their child and once a parent decides to forego vaccination, they are unlikely to change their decision even after learning that the risks of disease versus the risks of vaccination (12, 13). As more parents claim personal belief exemptions, the clusters of unvaccinated children will continue to expand and increase the risk of vaccine-preventable disease outbreaks for both unvaccinated and vaccinated children whose immunity have waned, as seen in the case of the 2003 New York pertussis outbreak.

In summary, compared to parents of undervaccinated children who may have problems with healthcare access, parents who refuse vaccination on behalf of their children are well-educated and have the annual income to afford healthcare for their children, but ultimately decide not to vaccinate their children. Unvaccinated children are a small population (0.3%) compared to undervaccinated children (36.9%) but because they tend to live near one another, children without vaccinations become sites of potential outbreak that affect populations beyond themselves (3).

¹ It is now recommended that adults and adolescents receive a Tdap booster instead of a Td booster to protect against waning immunity to pertussis. [See here](#).

Provider Responsibility

Along with the increasing number of families opting out of vaccination, some physicians have begun to turn away families who decline vaccination. In a 2012 survey of 282 pediatricians, 21% stated that they often or always dismissed families who refused at least one vaccination (14). According to a national survey of members of the American Academy of Pediatrics, over 25% of physicians said they would choose to discontinue their provider relationship if parents refused permission for some vaccines (15).

The practice of turning away families due to their decision to forego vaccination for their children runs counter to academy's Committee on Bioethics official guidelines released in 2005 on responding to vaccine refusal for children:

“In general, pediatricians should endeavor not to discharge patients from their practices solely because a parent refuses to immunize a child...Such decisions should be unusual and generally made only after attempts have been made to work with the family.”

Despite reaffirmation of the guideline by the academy in 2013, this controversial practice continues and jeopardizes the health of the dismissed child and the community (1, 16). Douglas Diekema, the author of the Committee of Bioethics guidelines, pediatrician, and bioethicist, says that “while frustration over vaccine hesitancy is understandable”, dismissing families from care is not the solution. The children of these families will have limited health care options and cluster in the remaining clinics open to them or the emergency department. This clustering not only increases their risk of contracting a vaccine-preventable disease, but places the community at risk by creating epicenters for disease outbreaks.

The grounds on which providers adopt these clinical policies are shaky, Diekema argues. The main argument for restricting health care to vaccinated children is that providers have the

obligation to protect their other patients from vaccine-preventable diseases. However, the risk of contracting disease from an unvaccinated child “pales in comparison to the risk posed by other children in the clinic waiting room who may harbor...a host of other infectious diseases that result in far more hospitalizations and deaths”. Providers also argue that they have a right to choose not to care for unvaccinated or undervaccinated children, that they are a liability, and that spending time educating families are a source of lost revenue. In response, Diekema says this “strains the meaning of professionalism” and shifts the burden of care to providers who feel they have professional obligations to care for these undervaccinated families.

Parental attitude toward health experts promoting vaccination may be a major cause of providers’ frustrations with families who refuse vaccinations. Research has shown those who decline vaccination for their children tend to be firm in their decision (13). In a study in which vaccinators and nonvaccinators were given a table of the risks of pertussis versus the pertussis vaccine, nonvaccinators concluded that the disease was less dangerous and the vaccine was more dangerous. As a result, nonvaccinators stated they had increased resolve to avoid vaccinating their children against pertussis. In another study of nonvaccinators, 70.9% of nonvaccinating parents reported that their physician had little to no influence over their decision to not vaccinate their children (3).

Compound these attitudes with the provider perspective that it seems irrational for parents to deny their child one of the most effective ways of preventing disease, and perhaps it is not surprising that there are many providers that have difficulty interacting with these families, to the point at which dismissing them might seem more reasonable than caring for

them. At the same time, providers have the professional responsibility to care for all patients and must be able to set aside their frustration.

Alleviating providers' frustrations starts with providers understanding the historical events that led up to popularizing vaccine anxiety and the sense of duty parents feel when making a health decision for their child. By coming to understand the context behind modern vaccine anxiety, providers can begin to empathize with parents who forego or are hesitant about vaccinating their children. Informed providers thus may be more likely to continue providing care and to be able to communicate in a way that addresses parents underlying worries about vaccines.

While nonvaccinating parents may be firm in their decisions, all parents are vaccine hesitant before they are vaccine resistant (3, 13). By understanding some of the beliefs that lead parents to doubting vaccine safety, providers can mitigate vaccine anxiety before it turns into vaccine refusal. After all, providers are the front line for promoting vaccination coverage and the most trusted resource by parents for vaccine safety information (17).

Brief History Behind Modern Vaccine Anxiety

Anti-vaccination sentiment has been almost as old as vaccination itself (18). When the Vaccination Act of 1853 in the UK first made vaccination compulsory, many towns responded by throwing violent riots in protest. These first anti-vaccinators argued that vaccines caused illness, were ineffective, and that a 'natural' way of acquiring immunity was the better for the body. They also argued that imposing vaccination was a step toward totalitarianism, a government cover-up, and a result of medical profiteering.

These sentiments have continued unabated into the twentieth century. However, over time, they were relegated to individuals of the extreme left and right. Then, in the 1990s, certain events in US history fostered the spread of modern day anti-vaccination sentiment, specifically on vaccine safety, from its corners and into mainstream American thought².

In 1997, during the federal government's campaign against air pollution and environmental toxins like lead, the FDA launched a two-year inquiry into thimerosal, a mercury preservative used in vaccines (19). The final report showed that because several new vaccines had been added to the recommended immunization schedule, children within the first six months of life could be exposed to up to 187.5 milligrams of ethylmercury (a metabolite of thimerosal) (20). This exceeded the EPA limits for methylmercury exposure from fish consumption, which was set at 106 milligrams. While ethylmercury was known to be eliminated much faster than methylmercury, very high levels of ethylmercury exposure could still cause neurological damage. Because no guidelines for ethylmercury existed at that time, no one knew if the 187.5 milligrams of ethylmercury exposure from vaccination was significant (19, 20). Due to this uncertainty, the American Academy of Pediatrics and the U.S. Public Health Service announced in 1999 that manufacturers remove thimerosal from vaccines as a precautionary measure.

Around the same time thimerosal was being investigated, the leading british medical journal *The Lancet* published an article that suggested a relationship between the MMR vaccine and neurological disease. "Ileal-Lymphoid-Nodular Hyperplasia, Non-Specific Colitis, and Pervasive Developmental Disorder in Children" was published in 1998 by Andrew Wakefield

² For an interesting account of how antivaccination in American was developing in the twentieth century before the 1990s, see Mark Largent's *Vaccines*, pp. 37-67.

and his research group, the Inflammatory Bowel Disease Study Group (21). It was the first paper to link measles, gastrointestinal issues, and neurological regression together and to suggest that the measles vaccine might be the environmental trigger that lead to intestinal abnormality and ultimately developmental regression. While the paper stressed that there was only a correlation between the MMR vaccine and autistic syndromes, it sparked a flurry of articles rebuking the connection (22). Later on, the publication was formally retracted and Wakefield was found guilty of professional misconduct and conflicts of interest but by that time, speculation about the MMR vaccine safety had extended beyond the realm of scientific discourse and into public discussion.

The last key piece in understanding the rise of vaccine anxiety is that investigations of thimerosal and MMR vaccine safety appeared at a time when developed countries were experiencing an astronomical increase in autism cases *and* an increase in childhood vaccinations. Autism diagnoses rose from about 1-4 cases per 10,000 children to nearly 1 case per 150 children as the definitions for diagnosing autism expanded and Asperger's Disorder was added to the autism classification scheme in 1994 (19, 20). Because the increase in new routine vaccinations paralleled the rise in autism cases and because autistic symptoms can appear around the same time vaccinations are administered, there was a lot of speculation, both academic and nonacademic, about the true relationship between vaccines and autism (23, 24).

By the turn of the twenty-first century, there was an extensive library of material from both sides of the vaccination debate available to parents. Medical anthropologist Sharon Kaufmann has the following to say about the proliferation of vaccine information (20):

“...when one looked for or simply came across information in print or online about childhood vaccines, one also saw reference to autism and other childhood

development problems. Conversely, when one sought information, or came across material on autism or developmental disorders, one invariably noticed reference to vaccines.”

Because of pro-vaccination attempts to assuage parents about vaccine safety and anti-vaccination attempts to rouse fear about vaccination, vaccines and developmental disorders have become inextricably linked in the public sphere. By 1999, Kaufmann says, there was no way for well-educated parents of young children to avoid information, either negative or positive, on vaccine safety.

Vaccine Anxious Rhetoric Becomes Pervasive

Soon after Wakefield’s paper published and the FDA released its report on thimerosal exposure, the Institute of Medicine (IOM), a nonprofit organization part of the U.S. National Academy of Sciences, formed the Immunization Safety Review Committee (25). The goal of the committee was to provide an unbiased review of the epidemiological evidence surrounding vaccine safety. In their final report in 2004, citing over 200 papers, they had enough data to confidently say there was no causal relationship between the MMR vaccine and autism, no causal relationship between thimerosal and autism, and that there was no evidence for biological mechanisms for vaccine-induced autism (26).

This report should have laid to rest worries about vaccine safety but public figures like politicians and celebrities have continued to acknowledge a connection between vaccines and autism. During the 2008 presidential campaign, Senator John McCain said that there was strong evidence that the rise in autism was due to preservatives in vaccines (27). Months later, then-Senator Barack Obama said that the science between the link between vaccines and autism was

inconclusive and required more research. Statements like these reinforced public fears about vaccine safety by propagating the false notion that the scientific community still did not know the relationship between vaccines and autism.

Jenny McCarthy, celebrity and mother to an autistic boy, popularized the idea that children 'susceptible' to autism (for example, boys who are more often diagnosed with autism than girls), when exposed to multiple vaccines, were more likely to develop the condition (28). Through her narrative of her son's autistic regression that appeared after receiving multiple vaccinations, she presented an understandable answer for parents of autistic children who had no explanation for their child's condition. Her opinions combined with those of other public figures created the sense of a legitimate controversy surrounding vaccination safety even when science had concluded there was no real debate to be had and that vaccines were safe.

What keeps this controversy at the forefront is our own culture that promotes making informed consumer decisions about our life and our children's lives (20). Our modern notion of good parenting involves figuring out what among the advice books, the car seat options, and the educational materials is the best choice for a young child. Out of responsibility for their child's health, parents feel the need to research vaccine safety and form opinions on what choices hold the least risk and the most health benefits. Unfortunately, amongst the CDC pamphlets, there are hundreds of articles from authoritative-sounding anti-vaccination websites like the National Vaccine Information Center that stir doubts about vaccine safety and efficacy (29).

Because the current vaccine safety debate appears to offer two seemingly legitimate options for parents - one to vaccinate and one to not - vaccination becomes one of many

choices a parent must make regarding their child's health. Their final decision to vaccinate, delay vaccination, or refuse vaccination is formed by exposure to public discourse on vaccine safety and of weighing the risks and benefits of possibly skewed evidence.

The following two conversations are excerpted from Kaufmann's parent interviews (20). They illustrate the pervasive nature of vaccine safety talk and the resulting responsibility parents feel in making the 'right' choice about vaccines.

"It's hard to read about autism without coming across stuff on vaccines. My faith in mainstream medicine began to be significantly eroded when I started reading, and through the parent networks. Ninety percent of the information that is useful to me has come from parents....Again, I'm a very establishment person. Not on the left. So for me to be converted says something....So I'm mad at the pediatrician. I feel she didn't give me accurate information, based on my own research.

"....Parents are divided about vaccines. One view is that only thimerosal is bad. Once it's out of vaccines, they are okay. A second view is that nothing in vaccines is good for susceptible kids. Then there are the people in the middle, the confused people. I'm in this category. That's why I won't vaccinate my second child. We took a more conservative or, you could say paranoid, view. Right now I feel he's more at risk for vaccine adverse events than for the diseases." (mother of two boys, the oldest boy diagnosed with autism)

"I feel guilty that I didn't do more research on vaccines. You can't get away from the guilt, because you always need to do more reading, research. It goes on and on; it doesn't end. The pressure to interview the doctor, to ask the doctor questions and more questions is always there. Because you have the responsibility, not just of minimizing risk, but also of optimizing the physical, social, and cognitive development of your child." (mother of child without developmental problems)

Once a parent has decided not to vaccinate their child, social mechanisms can reinforce like-minded ideas about vaccine refusal (30). In a 2015 ethnography conducted of California Waldorf private school parents, anthropologist Elisa Sobo shows that increased post-enrollment vaccine refusal was likely linked to the school culture, which embraced alternative views of health and education. After interviewing the primary caregivers of 17 families, Sobo noticed

that some families with more than one child showed a drop-off in vaccination for each younger child. When questioned about vaccination, these parents and parents from her focus groups said that as they learned more about vaccines from the Waldorf community, they decided to stop vaccinating their children. Similar social networks like this particular school community may contribute to the geographic clustering of vaccine refusal, as these networks strengthen parents' opinions and ultimately their decisions about vaccine safety.

Lastly, it is important to acknowledge that high scientific literacy and being in a healthcare profession does not translate into adopting a pro-vaccination stance. In the AAP national survey of physicians, 4% of pediatricians reported back that they had refused vaccinations on behalf of their children (1). Mark Largent, a science historian on vaccines and a prior academic fellow at NSF, says that he felt conflicted giving permission for the hepatitis B vaccine for his daughter and later refused the influenza vaccine, believing it was not useful after his daughter already had a case of the H1N1 influenza (31). Furthermore, the original speculative paper linking thimerosal and autism was co-written by a nurse who also launched SafeMinds, a parent advocacy group against thimerosal (19).

What causes these well-educated parents, including some healthcare providers, to believe that vaccines are unsafe is an unavoidable rhetoric of vaccine anxiety. What sustains their opinions on vaccines may be the peer networks they become a part of and participate in. Their seemingly irrational belief that vaccines might cause harm to their children becomes more rational when one considers that these parents feel responsible for forming opinions on vaccinations based on a flood of contradicting information.

Vaccine Anxiety as a Parent's Duty

Vaccine refusal has become a prominent area of disconnect between what healthcare providers and vaccine hesitant parents consider responsible for a child's wellbeing. In the same guidelines endorsed by the AAP for continuing care despite vaccine refusal, the AAP states that parents who refuse vaccines are "individuals [that] place family interest ahead of civic responsibility...such parents do reject what many would consider to be a moral duty..." (1). At the same time, parents who are concerned about the safety of vaccines express that they are not doing enough to take responsibility for their child's health. Recall the above quote from a vaccine anxious parent (20):

"I feel guilty that I didn't do more research on vaccines....Because you have the responsibility, not just of minimizing risk, but also of optimizing the physical, social, and cognitive development of your child."

This disconnect between what healthcare providers and parents consider responsible and moral may be because providers and parents have come to weigh the risks and benefits of vaccines differently. As providers look at how many lives vaccination has saved on a population level, vaccine anxious parents look at their child and consider if any risk (whether or not it is a *real* risk) is worth taking. In historian Mark Largent's book *Vaccines: The Debate in Modern America*, as he traces the roots of modern vaccine anxiety, he himself becomes hesitant about vaccinating his daughter against some diseases. He says, "Like all children's health care decisions, decisions about vaccines are every parent's duty. In my view, ceding that responsibility to someone else—be it a highly qualified healthcare provider or a rabid anti-vaccinator—is an abdication of that duty." (32). Vaccine anxious parents act out of a sense of

moral duty for their child's protection, and as a result, may ultimately decide to forgo their secondary duty to public health.

Thus, the opinion the AAP holds of vaccine-refusing and hesitant parents does not do justice to the complex situation modern parents face and could potentially hinder the provider-family relationship. By viewing these parents as individuals that eschew civic responsibility, it obscures the fact that vaccine anxiety has become an inescapable public discussion that many parents face and that these parents respond by choosing what they believe to be the most moral choice.

Moreover, this vaccine anxiety is not just restricted to the population of parents who have already refused or vocally expressed hesitations about vaccines. In a study of common parental vaccine safety concerns, 90% of parents agreed that vaccines protected their children from disease but over 50% of the same surveyed population agreed that they were worried about serious adverse effects occurring and 25% agreed that some vaccines caused autism in healthy children (33). This shows that parents who agree to vaccinating their child are not necessarily pro-vaccination. Although most parents choose to vaccinate their children, they also appear to have underlying concerns about vaccines that have not been adequately addressed.

By neglecting the vaccine anxious perspective, providers may forget that well-educated parents are performing what they believe to be their civic responsibility to the most important figure in their lives, their own children. Whether their final decision is to vaccinate, delay vaccination, or refuse vaccination depends on the information and peer networks they are exposed to. As a result of their exposure, many parents seem to have underlying fears about

vaccine safety that could translate from vaccine compliance to vaccine resistance if these fears remain unaddressed.

A Path Toward Anxiety Resolution

While vaccination coverage can be strengthened by eliminating personal belief exemptions for school entry, it is certainly not the answer to soothing vaccine anxious parents (34, 35). Eliminating personal belief exemptions may in fact increase anti-vaccination fervor and further undermine provider relationships with vaccine hesitant parents.

To address the root problem of vaccine anxiety, Diekema says that public health officials and providers should ‘diagnose’ the specific reasons why parents are vaccine hesitant and employ strategies specific for those hesitations (34). For example, many parents have ethical dilemmas about the hepatitis B and human papillomavirus vaccines because, after researching them, parents find that these vaccines protect against sexually-transmitted diseases (33, 36, 37). Many parents do not understand why their child should receive such vaccinations at a young age or at all. These are worries should be addressed differently than worries about vaccines weakening the immune system or causing autism (34).

Regarding worries that are specific to vaccine safety and efficacy, Sobo suggests that public health organizations and providers adopt culturally-appropriate messaging that addresses the particular perspectives parents might adopt (30). Some parents have come to believe through research and through their peers that vaccines are not a ‘natural’ way of strengthening the immune system (scientists, after all, do call vaccinations a form of ‘artificially-acquired immunity’ (38)) and therefore, not effective. In response, public health and provider

communication can be tailored to say that vaccination is a natural form of prevention, as they “help children’s immune systems self-strengthen naturally” (30). Similar culturally-sensitive messaging has been successfully employed in other countries like West Africa (39)³.

Sobo along with others also argue that current public health communication strategies about vaccinations have not been effective (19, 30, 40). She cites a current CDC resource titled “If You Choose Not to Vaccinate Your Child” as an example of how vaccine hesitant parents can choose to view this pamphlet as suggesting vaccination refusal as a viable choice (41). In a randomized control trial of four common types of public health messaging, Nyhan and colleagues showed that none of the pro-vaccine messages were effective at increasing intent to vaccinate. In fact, some messages increased fear of vaccines. More remarkable are the instances that public health officials decided not to respond at all (19). When journalist David Kirby, who published a dramatized account of vaccine anxious parents, and when activist Robert F. Kennedy, Jr., who published an article on a vaccine-autism government ‘cover-up’, teamed up to vocally denounce vaccine safety, there was little response from major public health institutions. As a result of their media campaign, federal lawsuits for vaccine injury shot up to nearly 5,000.

In conclusion, a combination of effective public health communication, early and empathetic provider interventions, and restricted personal belief exemption policies may hold the answer to vaccine anxiety. Eliminating personal belief exemptions alone does not address the pervasive underlying vaccine anxiety that many parents have. Much of the work is on the provider to alleviate this anxiety and strengthen the provider-family relationship for future

³ For additional information and references using an anthropological approach toward addressing vaccine anxiety, see Sobó, 2015, pp. 393-395, section entitled *Implications for Practice*.

medical decisions. By understanding that vaccine anxious parents are making vaccination decisions based on conflicting information and that their decisions are likely reinforced by peer connections, providers can begin to see that a vaccine anxious parent's perspective is not unreasonable or illogical. Lastly, by diagnosing the specific worries parents have, providers can start the conversation toward viewing vaccination positively.

[~4,600 words]

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