Vaccine Hesitancy: Part 1

Well, when I talk about vaccines and particularly about vaccine hesitancy, I use a cartoon from the 18th century that depicts Jenner. And Jenner is giving injections of cow pox or smallpox vaccine to a number of people in the UK. And as he's giving the injections, these people are growing cow like parts. And so the first thing it reminds me of is that the whole controversy about the safety of vaccines and their benefits is really an old story. And, and it kind of helps me remember that this is not a new problem. It's a persistent problem.

This is the Antigen. I'm your host, Yasmeen Agosti.

In our last episode about global health, we heard about mothers who walk miles and wait in line for hours in order for their children to receive vaccines. And we also learned about this global health survey that showed that the majority of people view vaccines as important, safe and effective.

But there are some people who are unsure and others who completely oppose vaccination.

In today's episode, we'll look closely at vaccine hesitancy and anti-vaccination sentiments – their origins, how things have evolved over time and where we find ourselves now.

But first thing's first. What do we mean by vaccine hesitancy and how is it different from being antivaccination? Here's Dr. Todd Wolynn, a pediatrician and CEO of Kids Plus Pediatrics in Pittsburgh, Pennsylvania.

So when we look at the United States and this plays out fairly true across the world that there's the majority of people are considered the silent majority. In the US, we say it's about 75% of people who are vaccine accepting. You make a recommendation and they'll go ahead and accept the vaccine. We say about 23% are vaccine hesitant and the World Health Organization even subdivides that group down from hesitant being, yeah, they just need a little more information to hesitant, wow, they're really gonna need a lot of engagement because they're pretty, pretty concerned. Anti-vaccine really represents only one to 2% of the population. They're quite vocal, they're quite vaccine adverse or resistant or hostile. But again, they are the really vocal minority.

Professor Robert Field, a bioethics expert on faculty of both the law and public health schools at Drexel University, explains where this all started.

As long as there've been vaccines, there's been vaccine hesitancy. In fact, even before there were vaccines, there's vaccine hesitancy before the first smallpox vaccine, there was something called variolation, where people were inoculated by getting an active infection to get their antibodies going. And there was a hesitancy about that. Um, Benjamin Franklin famously was reluctant to have his son variolated during a smallpox epidemic and his son died in the epidemic and Ben Franklin never

forgave himself. When the smallpox vaccine was developed around 1800, there was an immediate pushback. And when you think about it, there's some intuitive logic to it. "I don't want some foreign substance put into my body. I'm healthy right now. I'd rather take my chances with the disease." And I think that has inspired a lot of the resistance for the 200 plus years since then.

While vaccine resistance is not new, it has changed shape over time.

Vaccine resistance, uh, sort of has peaks and valleys. It's almost like an epidemic that has flare ups at times and then it subsides at times. But there have been periods in history and I think we're seeing one right now, uh, where it's become more virulent, where more people have felt that "this is a foreign intrusion into my body and into my autonomy and I'm willing to take that risk."

In an effort to control smallpox outbreaks, mandatory vaccination laws began to appear in the early 1800's. Anti-vaccination sentiment began to organize thereafter, in the late 1800's.

There was the Anti-Vaccination Society of America, the New England Anti-Compulsory Vaccination League, and the Anti-Vaccination League of New York City, just to name a few.

Sara Novak, a science journalist and parenting columnist has written about the topic and explains in a bit more detail.

Pretty soon after in 1809, we started having mandatory vaccination laws starting in new England and then moving to other States like Minnesota, West Virginia and California. And then vaccination sentiment kind of sprung from there, but at the time, vaccinations were ripe for pushback because they weren't regulated until 1902.

And some vaccinations at that time were forced, especially amongst the African American population and amongst immigrants. So there was a little bit more of a reason for that anti-vaccination sentiment until the regulation of vaccinations in 1902 with the Biologics Control Act.

The Biologics Control Act of 1902 was the first federal legislation passed by U.S. Congress to control the quality of drugs. And it led to the development of Hygienic Laboratory of the U.S. Public Health Service. This Laboratory eventually became a part of National Institutes of Health or NIH – the nation's medical research agency.

Around the same time, we had one of the most important legal rulings on mandatory vaccination. The case of Jacobsen versus Massachusetts. Here's Professor Field again.

So the seminal case comes from 1905 after a period of intense vaccine resistance. There was a man named Henning Jacobson, who was a leader of the anti-vaccine movement. In the early 19 hundreds, there was a small pox epidemic in Eastern Massachusetts and smallpox, once you get it,

there's almost no treatment, especially back then. They had absolutely nothing. It's a deadly disease and those who survive are all often disfigured for life. The city of Cambridge instituted a policy that said that all adults had to receive the smallpox vaccine or pay a fine of \$5. Even 115 years ago that was not a lot of money, but Reverend Jacobson felt the principal was important and he was not going to pay the \$5 and he was certainly not going to get a vaccine. And he took his case all the way up to the Supreme Court.

The legal debate over how to balance the rights of an individual with the well-being of society was resolved here.

And this was the ultimate test of, of the balance. He argued his autonomy and the city of Cambridge argued, uh, the public good, uh, that, smallpox is very contagious. And if he got it, he could give it to other people, uh, even unwittingly. The Supreme Court came down very decisively on the side of public health. It said that the government could limit your liberty in the interests of the well-being of everyone else. And there were some famous phrases in that decision, uh, about there are limits to liberty. Uh, it is not unrestrained. Uh, you do not have the liberty to put your fellow citizen in danger. And that has to be recognized even in a society that values its liberty. That case, uh, for over a hundred years has been the precedent on which mandatory vaccination laws have rested and it has been settled law. It has not been revisited. In fact, it has been affirmed a few times in the context of religious exemptions and school requirements. Uh, so that today it is clear the government can mandate vaccines as a matter of settled constitutional law.

We'll be talking more about vaccine policies, politics and bioethics with Professor Field in Episode 6. After this Supreme Court ruling, anti-vaccination sentiments got quiet for a while.

The 20th century was a time of incredible advance for public health and control of infectious diseases. During this century, we saw a huge drop in infant and child mortality and almost 30 years added to the American lifespan.

There were improvements in sanitation and hygiene – things which helped to eliminate outbreaks of cholera, dysentery, typhoid, yellow fever, and malaria.

The first antibiotic, penicillin, was discovered in 1928 and then developed for medical use in the 1940's.

We developed ways of detecting, diagnosing and monitoring infectious diseases across the country – and this helped our ability to respond to public health threats because we could identify what they were, who they were affecting and when. And, most of our vaccines were developed in this time period. So that within just a few generations, people who either witnessed or experienced serious infectious diseases, like polio, diptheria, measles, they saw them disappear.

And then, towards the end of 20th century...vaccine hesitancy re-emerged.

Once we started not to see these diseases anymore and parents didn't see how sick kids could be come from these diseases, that's when the sentiments sort of flared up again, in the eighties and nineties. And one of the most important times for that was when the Lancet released a study in 1998 that connected MMR with autism.

This study falsely claimed that the MMR or measles, mumps, rubella vaccine was linked to the development of autism in children. The article was retracted from the journal in which it was published after it was discovered that the data used in the paper was falsified. As a result, the lead doctor who conducted the study lost his license to practice medicine.

More importantly, there have since been multiple studies proving that there is no link between autism and the MMR vaccine. But this still doesn't explain why the vaccine autism myth persists continues to cause concern among some parents.

Autism, which is also referred to as autism spectrum disorder, or ASD, is a neurodevelopmental disability, that affects a child's social skills, behaviours, and communication. It affects an estimated 1 in 59 children here in the U.S.

Dr. Steven Salzberg, Bloomberg Distinguished Professor of Biomedical Engineering and Computer Science and Biostatistics at Johns Hopkins University, explains how autism is ripe for controversy.

So autism is we now know, um, at least partly a genetic disease. We haven't identified any environmental factors that cause it, but it shows up or typically it's diagnosed in children around the ages of one or two, sometimes three. So very young children, but it's not diagnosed at birth because it affects their communication and social behavior, which they're, you know, too young to show as a newborn. And that's the same time that they're getting all their vaccines. So at the same time they're getting these shots. They, the children who are autistic will start showing signs of autism. So of course you'd expect that given that, you know, millions and millions of children are being vaccinated, that, um, some of them get their shots right around the time they first started showing signs of autism.

And the parents would then attribute that or worry at least that the shot somehow caused it because we're kind of programmed to, um, associate, you know, if two events occur close together in time, we think one caused the other. It's not true in this case, but it's, um, it makes autism a particularly ripe sort of diagnose category to blame vaccines for.

The American Academy of Pediatrics, or AAP, has a specific webpage dedicated to vaccine safety. Parents can learn more about this topic and vaccine safety in general by going to the AAP's healthychildren.org website.

The public discourse on vaccines today is about much more than just a single topic like autism, for many people it's about having questions that need reliable answers from experts.

An important part of solving vaccine hesitancy is about improving communication between science and those who benefit from it's work.

Dr. Kathryn Edwards at Vanderbuilt University describes how most questions fall into one of three themes. But before she even begins to answer them, her conversation always starts with listening.

First of all, you have to listen very carefully and you have to listen to what their question is and, and not try and, and just say, well, you know, vaccines are safe and need to get them, but just to listen what their questions are. And in general, the questions about vaccines fall into three big buckets. The first bucket is, um, I don't think that this disease is important because it's, it's really gone.

The second big pot is, um, are vaccines safe, you know, "how have you tested them?" And, and so in that situation, I often will go through how we do test them. And I think it gives some credibility because that's what I do and I've done for a long time.

The development of a single vaccine can take decades. Safety is evaluated each step of the way until it is licensed by the FDA and then it is continuously monitored thereafter, for as long it is in use.

And then thirdly there is the concern "well why does the government tell me what I have to do there? It's my child, why can't I decide?"

It's understandable that people should have questions about vaccines - what are they, why do they matter, how do they work, are they safe? But face to face communication is not always an accessible option depending on how often you go to the doctor.

Chad Herman, the communications director for Kids Plus Pediatrics in Pittsburgh, Pennsylvania, explains the challenge for both patients and providers.

But if you think about that, particularly once kids get beyond toddler stage and we're seeing them only once a year, we're seeing them once a year for well visits, maybe a couple of times a year for sick visits. So our opportunities to have face to face conversation and build on the trust and the relationships that we have as their primary care office are really pretty slim because again, there's a lot of things we have to do in those visits. There are boxes that we have to check. Oh, and we have to give them vaccines and answer all of their questions as well.

And that leaves around 364 days or so for people to find answers on their own.

Dr. Todd WoyInn describes what this looks like these days.

So the key here with the anti-vaccine movement in 2019 and beyond is that they become better funded, they're better organized, and they are leveraging social media platforms in a way that is effective and destructive in terms of eroding vaccine confidence. And the problem is that every other business sector, every other industry has gone to social media probably about a decade ago because they know that's where their customers are. And guess what? That's where our patients are. But somehow healthcare views, social media and going on and talking about your beliefs of science might be viewed as self-promotion. Hospital systems and residencies and medical schools have feared at like the plague. And by doing so have invited the birth and the flourishing of disinformation. And so all the things we've talked about, the fact that the most trusted influencer of vaccines is locked in an office with four walls and a door. And that seems to be the only place we think that this conversation can happen. They've just invited everybody else to take over, which is exactly what's been happening.

Part of the challenge that we now face, is in how healthcare providers approach communicating the benefit of vaccines. Here's Professor Field again:

Some of my colleagues at Drexel Public Health School recently published research, uh, looking at the messaging on social media of the anti-vaccine movement and much of it is based on images and on appeal to emotion. And they looked at the pro-vaccine, um, messaging and most of that was based on statistics. Um, and they felt that even though most people do accept vaccines, the small number who are susceptible to the hesitancy arguments are going to be swayed by the images. And their suggestion is for the pro-vaccine movement, more use of Instagram or use of images, more use of that emotional pull rather than the dry statistics.

One mother advocate whose story illustrates the power of emotions is Tara Hills. Tara has been sharing her personal experience with vaccine hesitancy in hopes of changing the tone of the discussion.

So the thought process that led to my vaccine hesitancy started about 15 years ago when I became a new parent. I wasn't hesitant at first, but over the next four years as I had four kids, I was hearing a lot of things from other moms just to hanging out at the park play dates and stuff. Just disconcerting and disturbing things like, you know, questionable ingredients or bad things that could happen, I don't know, ethics that were involved in the development.

And I also at the same time I opened my first Facebook account and social media started to become not just a trickle of information, but eventually a whole wave of all kinds of information. And by the time my fourth child was born, I was nervous and unsure. So I hesitated and chose not to vaccinate him because it didn't look like there was a real imminent threat. Like it was kind of out of sight, out of mind, all of these diseases and bad things that could happen. So I felt stuck between, damned if you do, damned if you don't. And I felt like I had to choose the lesser of two evils. So being afraid and nervous and unsure what to do, I assumed that all the stories were factual and correct and decided to protect my kids by not vaccinating them.

Vaccine hesitant parents are like every other parent – asking questions and trying to find answers so that they can make decisions for their children. As Tara explains, emotions can make it really difficult to sort fact from fiction.

It wasn't until 2015 and I was then the mother of seven that I started to revisit the topic mostly because the cultural conversation was getting pretty heated about people who didn't vaccinate. And at the time the term vaccine hesitancy didn't even exist. You are either anti-vax or pro-vax. And those were kind of two really polarize stereotypes, who almost didn't seem to be able to communicate with each other, at least online, which had become a really vicious forum for tearing people apart. So when I would read blog comments about people who didn't vaccinate, it was intimidating that people thought I was that kind of parent. And it was really upsetting because I didn't feel like, I just felt like there's was a stereotype and it was really an ugly conversation and really unhelpful.

While, vaccines and vaccinology are based on science – like almost everything else in life – there's a wide spectrum of emotions that can get involved. This has been the case since the very beginning of vaccination in America.

But fear and doubt are really powerful human emotions and they can mess with your head. I look back now and I see that the misinformation was just coming through conversations and coupled with the social media, which suddenly had like really gripping images of like crying moms holding a beautiful little baby and this emotionally gripping line, "if only I'd known."

We'll share more of Tara's story and insights – including a key turning point for her family – in the next episode. What's clear at this point is that stories resonate, even when they are not true.

I mean I think one of the things I always like to tell folks is that I think a lot of public health folks and, and academics and physicians, you know, we, we find it so hard to believe that, but that story is, is not true. So why is it changing so many people's behavior and mind? And, and the point of the matter is a well told story will change behavior and will change minds even if it's not true.

That's LJ Tan, the Chief Strategy Officer of the Immunization Action Coalition. He makes the case that when it comes to sharing the benefits of vaccines, we need to move beyond the black and white numbers and get creative.

For some reason the anti-vaccine folks, you know, they, they seem to have the pulse on creativity for, so we, that we don't yet. And, and maybe that's, you know, one of the things IC has been advocating for, and we've actually got some proposals out to do this is we need to get, we need to get someone or a group of experts together who are PR marketing people that have no knowledge of vaccines, sit them in a room and as a, as an, as a panel give them some background and then tell them, you know, what are we doing wrong? Because we've been saying the messages over and over again and we don't seem to get, you know, the traction is not great. Whereas the anti-vaccine voices seem to have some traction. You know, I did you know that, um, I said I'm a big flashmob fan. Do you know what flash mobs are?

Ok so, I'll admit it, I wasn't entirely sure what LJ was talking about when he brought up flash mobs. But soon, it became clear.

So a flash mob is kind of cool, you can go to a square, like you're in middle of Times Square. And a lot of them, people use it for wedding proposals, but you can do much more. So all of a sudden one person starts dancing and then two people start dancing. All of a sudden, a whole bunch of people are dancing and then the groom walks up and he proposes, right? So the anti-vaccine people are using flash mobs. So they're in public malls. They're in you know, in areas where the public are. And they will start a flashmob very catchy, great dancing.

And then all of a sudden they hold up signs that says things like, you know, vaccines kill. So, you know, they thought of it, we didn't. You know, again, it's this whole idea of revitalizing how we kind of communicate in the new environment, you know, and understanding where are we sending our messages to.

LJ's right – there are surely better and more creative ways to communicate. Flash mobs are certainly one option. But many people these days are seeking their information on their own, and online.

This calls for a certain level of digital health literacy – which the WHO defines as the ability to seek, find, understand and appraise health information online. Stories may resonate but they can be a double-edged sword.

Next time on The Antigen, we'll look more closely at the response we are seeing today to both vaccine hesitancy and anti-vaccination sentiments.

My name is Kim Schrier, I'm a pedatrician turned member of Congress, and believe me, if there was ever something that would hurt a child the pedatrician would be the first to stop doing it. Our goal is to have healthy children.

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